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The eyes have it: a visual-vestibular rehabilitation program for pediatric oncology and neuro-rehabilitation

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THE EYES HAVE IT:

A VISUAL-VESTIBULAR REHABILITATION PROGRAM

FOR PEDIATRIC ONCOLOGY AND NEURO-REHABILITATION

by

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DEDICATION

For Maks, Riley and Lindsey…and all the children that change my life as they fight for theirs.

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ABSTRACT

The Marianjoy Rehabilitation Hospital (MRH) Occupational Therapy (OT) Pediatric Visual-Vestibular Dysfunction (PVVD) program is a clinical education and training program that aims to teach OT clinicians to better assess and treat PVVD in children with CNS cancer and/or other neurologic conditions. With a growing number of children surviving and participating in daily life with chronic and disabling health conditions, it is imperative that OTs stay informed on how to best support these children to live their best lives. Through education and training efforts of OTs at MRH, and by providing clinicians with tools to implement assessment and intervention techniques aimed to address PVVD, the program intends to expand OT practice and improve care for children with PVVD. In turn, this program will impact short and long-term health outcomes for these children. In addition to these training and clinical support efforts, the program will examine how effective these interventions are and publish results in order to advance OT practice and rehabilitation science as a whole. In combination with the outlined dissemination plan, the MRH OT PVVD program has the potential to significantly and positively influence OT practice and the lives of children with and at-risk for PVVD.

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LIST OF ABBREVIATIONS

ADL .....Activity of Daily Living

ASD..... Autism Spectrum Disorder

BU ..... Boston University

CDH .....Central DuPage Hospital

CNS..... Central Nervous System

CP..... Cerebral Palsy

FOR.....Frame of Reference

IADL ..... Instrumental Activity of Daily Living

MLMC .....Motor Learning/Motor Control

MPTD ..... Marianjoy Pediatric Therapy Department

MRH .....Marianjoy Rehabilitation Hospital

NM .....Northwestern Medicine

NMCPC..... Northwestern Medicine Chicago Proton Center

N/TBI .....Non-Traumatic/Traumatic Brain Injury

OT .....Occupational Therapy

PVVD..... Pediatric Visual-Vestibular Dysfunction

SI ..... Sensory Integration

SPV .....Subjective Postural Vertical

SVV..... Subjective Visual Vertical

VOR ..... Vestibular-Ocular Reflex

VVD..... Visual-Vestibular Dysfunction

CHAPTER ONE

INTRODUCTION

As medicine advances, more children are surviving and participating in everyday life with neurologic injuries, neurodevelopmental challenges and cancer (American Cancer Society, 2016; Hirtz et al., 2007). Clinically, occupational therapy (OT) practitioners see many pediatric clients with varying diagnoses and medical histories that present with dizziness, balance, motor planning, strength, and functional vision deficits that impact their ability to participate in everyday activities (Alghadir, Iqbal, & Whitney, 2013; Medeiros et al., 2005; Rine & Wiener-Vacher, 2013). It is imperative that OT practitioners stay at the forefront of rehabilitation services that will maximize the rehabilitation potential for these clients in order to facilitate their return to or prolonged participation in daily activities.

In recent years, Marianjoy Rehabilitation Hospital (MRH) – part of Northwestern Medicine (NM) – has experienced a significant increase in referrals to the Marianjoy Pediatric Therapy Department (MPTD) for OT services for children neurologic and neurodevelopmental challenges (G. Girten, personal communication, June 27, 2017). With the merger of MRH into the NM network and the development and growth of the NM Chicago Proton Center, the MPTD has had growing demands placed on therapy practitioners to provide intensive, high quality care to children with central nervous system (CNS) cancers and children with cerebral palsy (CP) or other cerebellar based neurologic conditions. These children are overwhelmingly at risk for having significant pediatric visual-vestibular dysfunction (PVVD) that impacts occupational performance

and participation, especially in ADL and IADL activities (Alghadir et al., 2013; Cohen, 1994; Konczak et al., 2005; Mori, 2015; Rine, Dannenbaum & Szabo, 2016; Toto, 2012). Despite awareness of risk factors leading to PVVD, OT practitioners within the MPTD remain limited in their ability and confidence to comprehensively affect change in these performance deficits. As a result, the MRH OT PVVD Program will be developed to guide clinicians in the MPTD in evidence based PVVD rehabilitation. The program will focus on expanding the current clinic-based model of care in the MPTD to increase clinician knowledge and expertise in the area of PVVD rehabilitation, development of assessment and intervention tools in alignment with current practice evidence, and to develop a standard of care within this specialized area of practice that can be utilized across the NM network and beyond.

RATIONALE FOR A PVVD REHABILITATION PROGRAM

According to reports by the Vestibular Disorders Association (Christy & Rine, 2016; Cronin & Rine, 2016; Rine & Christy, 2016), 1 in 5 US children ages 3-17 complain of vestibular related impairments. Of these children, only 29.9% receive treatment. Vestibular related impairments include dizziness, poor balance, delay in motor development, difficulty with stability of vision, and headaches. Vestibular dysfunction can be related to a variety of medical diagnoses including sensorineural hearing loss, migraine, chronic otitis media, congenital cytomegalovirus, meningitis, enlarged vestibular aqueduct syndrome, traumatic brain injury and ototoxicity (Christy & Rine, 2016; Rine & Christy, 2016).

As documented in the Occupational Therapy Practice Framework: Domain &

Process 3rd edition (AOTA, 2014), occupational therapy's domain and process focus on occupational therapy practitioners enabling clients toward "achieving health, well-being and participation in life through engagement in occupation" (p. 54). As such, occupational therapists have a vested interest in providing intervention to maximize participation in everyday activities for those with visual-vestibular dysfunction. Additionally, it is well within the scope of practice for occupational therapy practitioners to directly address visual-vestibular dysfunction in children. As documented by AOTA, occupational therapy practitioners have a strong role in intervention for rehabilitation of children and youth, persons recovering from a brain injury, those with cancer diagnoses and people with limitations in overall health and wellness (AOTA, 2014; AOTA, 2016; Gupta, Chandler, & Toto, 2012; Longpre & Newman, 2011; More, 2011; Mori, 2015; Toto, 2012).

"Occupational therapy practitioners work with children, youth and their families, caregivers and teachers to promote active participation in activities or occupations that are meaningful to them" (More, 2011, p. 1). Occupational therapy practitioners are also able to provide interventions for children with sensory integration deficits, such as those related to visual-vestibular dysfunction, which can target the underlying neurobiological processes involved. Occupational therapy practitioners can also help persons with brain injury to remediate skills or learn compensatory strategies to maximize return to occupations. In addition, occupational therapy practitioners can work within the scope of oncology by "facilitating and enabling an individual patient to achieve maximum functional performance both physically and psychologically, in everyday living skills

regardless of his or her life expectancy" (Longpre & Newman, 2011, p. 1). Children make up a portion of each of these populations. In order to serve these children well, occupational therapy practitioners must identify and meet their needs to solve environmental, physical, social and developmental barriers to participation.

Visual-vestibular function is a client factor (including body structures, sensory functions, mental functions, neuro-musculoskeletal functions and movement-related functions) that significantly impacts participation patterns and performance skills (i.e., motor skills, process skills and social interaction skills) needed to participate in daily occupations (Christy & Rine, 2016; Rine & Christy, 2016). Vestibular dysfunction can negatively impact daily occupations including bathing/showering, dressing, feeding, functional mobility, community mobility, meal preparation and cleanup, shopping, rest, sleep preparation, sleep participation, school participation, play exploration and participation, leisure exploration and participation, and social participation within the community, within one's family and between peers and friends. All of these activities are occupations of children and adolescents and can be drastically impacted if the child faces challenges with visual-vestibular function.

CONTRIBUTING FACTORS JUSTIFYING THE NEED FOR THE MRH OT PVVD PROGRAM

1. Increased survivorship of children with neurologic impairment

- Medical treatments are advancing and there are higher incidence and longer survivorship of people with neurodevelopmental impairments and childhood cancers (American Cancer Society, 2016). As a result, there are more children being seen in

Marianjoy clinics for rehabilitation services to maximize independence, participation and meaningful life fulfillment.

2. **Limited evidence to guide rehabilitation of children in acute phases of cancer treatment**

- Many research studies looking at rehabilitation needs and interventions for children surviving childhood cancers focus on long term effects of medical treatments (Chan, Xiong, & Colantonio, 2015; Demers, Gelinas, & Carret, 2016; Hwang, Lokietz, Lozano, & Parke, 2015; Khan, Amatya, Ng, Drummond, & Galea, 2015). Few identify the challenges children face in the acute phases of diagnosis and treatment and related effective interventions. The MPTD has had an unanticipated rise in clientele falling within this population, and has to find ways to best serve this population with limited evidence to support this phase of recovery.

3. **High incidence of visual-vestibular dysfunction with low rates of identification for rehabilitation treatment and different causes of vestibular dysfunction as compared to adult populations**

- Only 29.9% of children with symptoms of vestibular dysfunction currently receive treatment, even though 1 in 5 children present with possible vestibular related impairments (Christy & Rine, 2016).
- Significant populations of children with brain tumors have visual and balance deficits after surgery and medical treatment of the cancer/tumor (American Cancer Society, 2016; Chen, Bach, Shoup, & Winick, 2013; Demers et al., 2016; Haybach, 2002; Hwang et al., 2015; Khan et al., 2015; Nevin, 2014; Toto, 2012).

4. Limited client/family knowledge of visual-vestibular function and its impact on daily occupation

- Few families receive treatment for children with vestibular dysfunction (Christy & Rine, 2016; Cronin & Rine, 2016; NM, 2016).
- A high incidence of children who participate in therapy at Marianjoy for other concerns also exhibit visual-vestibular dysfunction.

5. Limited treatment knowledge of pediatric therapy practitioners on rehabilitation of vestibular dysfunction outside of the sensory integration framework

- Many pediatric occupational therapists that I work with currently have knowledge of sensory dysfunction within the Ayres SI framework, but few OTs and PTs have direct education and understanding of more complicated visual/vestibular dysfunction.

OUTLINE OF NEEDS ASSESSMENT AND PROGRAM DEVELOPMENT ACTIVITIES

1. Critical analysis and synthesis of current evidence for best-practice within PVVD rehabilitation

- Search, read, review and synthesize multidisciplinary evidence including peer-reviewed research articles and systemic reviews.
- Compile information to determine best-practice protocol for assessing, identifying, and treating visual-vestibular dysfunction in children.

2. Development of a PVVD rehabilitation program within the MPTD

- Development of clinician training and resources to support implementation and utilization of best-practice standards.

- Creation of client education materials and home programming guides that clinicians can use to supplement their current practice.
- Planning and implementation of program outcome measures in anticipation of ongoing quality assurance and sustainability evaluations of the proposed program.

3. Knowledge translation of the proposed program and outcomes to advance practice outside the MPTD

- Provision of MRH/NM educational seminars to disseminate knowledge within the NM network.
- Presentation of the MRH OT PVVD Program and outcomes of the program at local, state and national conferences to disseminate knowledge to OT practitioners outside the NM network.

4. Contribute to growing evidence base for PVVD rehabilitation to advance OT and rehabilitation science

- Initiate planning and development of quality assurance and IRB approved clinical research to evaluate program design and outcomes with intention to publish results for macro-level dissemination to advance OT and rehabilitation practice.

CHAPTER TWO

THEORETICAL AND EVIDENCE BASE FOR THE MARIANJOY OCCUPATIONAL THERAPY PEDIATRIC VISUAL-VESTIBULAR DYSFUNCTION PROGRAM

INTRODUCTION

As stated in chapter one, a critical analysis and synthesis of current evidence for best-practice standards in the area of PVVD rehabilitation is necessary in order to develop a PVVD rehabilitation program within the MPTD. To guide such a review, it is necessary to explain further the nature of the current service gap to ensure that the methods utilized in the critical appraisal of current evidence is in alignment with the theoretical basis of the problem. This chapter will provide an overview of the focus and methods utilized to critically appraise current evidence pertaining to PVVD rehabilitation.

EXPLANATION OF THE CURRENT SERVICE GAP

With ongoing medical advances and increased survivorship of children with neurodevelopmental diagnoses and central nervous system tumors and cancers, there are an increasing number of children living each day with vestibular-visual dysfunction that impacts their daily lives. With the increasing population of children facing challenges associated with vestibular-visual dysfunction, it is imperative for rehabilitation programs and services to adapt to best serve this clientele. Currently, there is a gap in service at Marianjoy Rehabilitation Hospital (MRH) in the pediatric program to meet the needs of this population: we continue to grow and have an increased number of children

presenting for rehabilitation services as a result of a neurodevelopmental condition or central nervous system cancer (Appendix A). This gap in service is impacted by the limited clinical knowledge among our therapy department in PVVD rehabilitation outside of the sensory integration framework. Similarly, the causes and subsequent presentation of PVVD varies substantially from the more well-known and identified causes of VVD in the adult population. In addition, MRH is in a unique situation of serving a large population of children undergoing acute medical treatment for central nervous system cancers, though there is limited evidence to guide best practice therapy to children at this acute level of care.

Currently, MRH serves clients in need of VVD and impairment through an adult focused physical therapy clinic. At present there is no clinic model or protocol for more comprehensively identifying, assessing, and providing intervention for children with PVVD due to neurodevelopmental/neurologic impairments. In order to best serve our growing population of children and to support them in achieving their maximum potential for independence, participation and performance in daily activities, Marianjoy must develop a program to supplement our current clinical model to directly address vestibular-visual dysfunction in this population of children.

THEORETICAL EXPLANATION OF THE CURRENT SERVICE GAP

MRH pediatric therapists need to better understand, assess, and treat PVVD in children with neurodevelopmental disorders and CNS cancers. In order to further explore the current gap in service and to identify solutions to the current problem, use of the Motor Learning/Motor Control (MLMC) theory, the Sensory Integration framework and

the Stetler Model for Research Utilization are being employed to frame the current issue and guide solution-based problem solving.

The Sensory Integration (SI) model was chosen as a model to understand the connection between the neurologic impairment present in the population at hand and how that relates to the observed movement, vision and occupational deficits therapists are already identifying. The SI framework is a commonly utilized framework among MRH pediatric therapists, though application of the model to more explicitly neurologically impacted children is limited. However, the model does offer a useful "lens" to comprehend the body/brain connection at play in these children. The SI model offers a way of understanding the complexities of sensory and motor integration using a familiar framework. The SI model explains the process of sensory intake, sensory integration and organization, adaptive occupational behavior, and the impact these have on development. This familiar model can be reexamined within an uncommon population to understand how therapists can translate their current knowledge to impact functioning within these children (Kielhofner, 2009b). Therapists may also determine, through this analysis, the weaknesses of the model in application to this uncommon population and to better understand why therapists remain challenged when developing intervention to address functioning within this population (Kielhofner, 2009b).

To supplement the SI model, the MLMC theory has been chosen to better understand how environmental factors and cognitive factors also impact effectiveness of current intervention strategies with this population of children, and what knowledge gap may be present that limits therapists' ability to identify and address the visual-vestibular

function that impacts the child's functioning. The MLMC states that with a change in environmental conditions, the task, or the person, there may be a shift or disintegration of the preferred pattern of movement (Kielhofner, 2009a). This component of the model will help to frame how these children function in their day to day lives, and why their performance often varies between environments, with changing dynamics of the task. Additionally, the MLMC theory helps explain why the motor patterns and behaviors of children with CNS cancers may change as they progress through their medical treatments and especially after their tumor resection (Kielhofner, 2009a). To understand this further, the model offers the concepts that motor control is a self-organizing behavior based on the context of the occupation, and that damage to the CNS results in challenges to previous motor behaviors, resulting in the person's attempts to compensate for those challenges (Kielhofner, 2009a). In children with CP and CNS tumors, this framework offers significant insight into why and how these children move and behave in their daily lives in a way that the SI model lacks, as many of the challenges present in these populations does not follow expected developmental sequences (Kielhofner, 2009a).

To frame the problem further, the Stetler Model of Research Utilization (SMRU) has been chosen to guide the process of identifying, validating, evaluating and applying current literature and other evidence to integrate principles of evidence-based practice (EBP) into the work being done with children in the MRH pediatric therapy program. The SMRU is a practitioner-oriented knowledge translation model that provides a procedural and conceptual guide for applying research into clinical practice (NCCMT, 2011; Sudsawad, 2007). It provides a formal process involving 5 phases (purpose,

validation, evaluation, implementation and evaluation of use) to facilitate change in a practitioner's or group's EBP (NCCMT, 2011; Sudsawad, 2007). This model is important for understanding the factors related to increased survivorship in this population, incidence of visual-vestibular dysfunction within this population, low identification of visual-vestibular dysfunction and its impact on daily life, and what evidence or lack of evidence there is to guide treatment in these unique populations. This is critical in determining and developing the appropriate solution that will bring about individual and departmental change in order to best serve the needs of these clients.

The final stage of the Stetler model involves evaluation of the developed program and translation of knowledge (NCCMT, 2011; Sudsawad, 2007). In regards to this project, it is anticipated that phase 5 will be broached after completion of the BU doctoral project. The evaluation phase will involve gathering data, tracking health outcomes of the children impacted by this program, and evaluation of quantity and quality of utilization of program resources by therapists at MRH. This phase of program development will likely entail ongoing formal and informal evaluation of the program itself as well as research to determine the clinical effectiveness of the program on health outcomes of children receiving services. This will be integral in expanding the reach of the program from within the MRH community to influence EBP within the OT community as a whole. A visual model of how the Stetler model has been integrated into the overall process of this dissertation can be found in Appendix B.

EVIDENCE APPRAISAL TO EXPLAIN THE CURRENT SERVICE GAP

To research the connections between medical advancement, increased survivorship, rehabilitation needs and barriers to service for children with visual-vestibular dysfunction, I conducted a literature review across several databases and resources directed by 8 guiding questions.

1. Is there evidence that children with neurodevelopmental conditions, N/TBI and CNS cancers have an increased rate of survivorship since prior to 2000?
2. Is there evidence that children with neurodevelopmental diagnoses (cerebral palsy, ASD, genetic syndromes) and central nervous system tumors/cancers are more likely to have vestibular-visual dysfunction?
3. Is there evidence that the presentation of vestibular-visual dysfunction in children differs from that in adults?
4. Is there evidence guiding intervention addressing vestibular-visual dysfunction during acute stages of medical treatment in children with central nervous system tumors and cancers?
5. Is there evidence that occupational therapists have limited clinical knowledge of the vestibular-visual system outside of the SI framework?
6. Is there evidence that there is low identification by parents and families of vestibular-visual dysfunction impacting the daily life of children with central nervous system tumors and cancers?

7. Is there evidence that there is low identification by clinicians of vestibular-visual dysfunction impacting the daily life of children with central nervous system tumors and cancers?
8. Is there evidence that vestibular-visual dysfunction in children impacts daily occupations?

Various evidence and literature sources were utilized to answer these questions in order to substantiate the hypothesized causal pathway (see Appendices C & D) explaining the need for additional occupational therapy intervention for children with visual-vestibular dysfunction. The searches completed focused on locating data to determine the accuracy and completeness of the initial explanatory model. In addition to literature and evidence searches, organizational information was gathered through sources within Northwestern Medicine and Marianjoy Rehabilitation Hospital to target program specific data and informational evidence.

To locate data related to the theory that survivorship rates of children with neurodevelopment conditions, N/TBI and CNS cancers are increasing, PubMed and the U.S. Census Bureau website were utilized to gather national statistics of childhood disability and survivorship rates. Subsequent searches for information related to incidence and etiology of visual-vestibular dysfunction of children was completed using PubMed, the Boston University Library search engine, Vestibular.org, the American Journal of Occupational Therapy (AJOT), and CINAHL databases. Searches included combinations of the following search terms: “vestibular”, “vestibular rehabilitation”, “children”, “childhood”, and “symptoms”. To focus searches on diagnosis specific

evidence related to CNS tumors/cancer and cerebral palsy and visual-vestibular dysfunction, additional search keywords of "CNS tumor", "CNS cancer", "cerebral palsy", "medulloblastoma", "posterior fossa", and "childhood cancer" were utilized.

In exploring the limitations of clinical and family-centered identification of visual-vestibular dysfunction in children (theoretical frames of reference used, evidence guiding rehabilitation intervention during acute phases of cancer treatment, and etiology/presentation of symptoms), Pub Med, CINAHL, AJOT, Canadian Journal of Occupational Therapy (CJOT), the British Journal of Occupational Therapy (BJOT), the BU library search engine, and Web of Science were utilized to explore the multifactorial influences at play. Further research was done focused on the justification for and role of occupational therapy services with these populations utilizing AJOT, CJOT and BJOT archives. During initial searches, approximately 500 research articles were considered for more in-depth review. Searches were restricted to recent publications (most often within the past 10-20 years), studies published in peer-reviewed journals (when not coming from government and organizational resources) and through brief reviews of article titles and condensed abstracts to assess for relevance to the current project.

From the original 500 considered, 36 articles and sources were determined to provide relevant, informative evidence to be reviewed to determine the validity of the proposed hypotheses. After reviewing and determining the content of literature that informs the postulated problem and need to expand current practice offerings to children with visual-vestibular dysfunction by occupational therapists, the primary pathway proposed in the initial model was substantiated. However, through extensive information

gathering it became apparent that the causal pathway involves a complex array of factors. While the primary factors leading to the need for expanded OT intervention continues to include increased survivorship of children with CNS cancers and cerebral palsy, their subsequent high rates of visual-vestibular dysfunction and limitations in current knowledge guiding intervention and referrals to occupational therapists, a complete explanatory model must include a more complex array of influencing factors (Appendix D).

Medical Advancements Impact Survivorship in Childhood Disability

Current evidence shows increasing trends of survivorship of children with neurologic conditions and/or CNS cancers; this can be attributed to recent, fast-paced advances in medical research and medical interventions as well as improved methods of identification and treatment of childhood disabilities (Norberg & Steneby, 2009; Smith, Altekruse, Adamson, Reaman, & Seibel, 2014). Between 2002 and 2010; there was an annual decline of childhood cancer mortality of 2.4%, including CNS cancers and brain tumors (Smith et al., 2014). Overall, survival rates after 1 year of diagnosis of a brain tumor is 78% and 52% at 5 years post-diagnosis as of 2011 (Norberg & Steneby, 2009). In addition, overall rates of childhood disability have been steadily rising (Houtrow, Larson, Olson, Newacheck, & Halfon, 2014; US Census Bureau, 2003; US Census Bureau, 2011). Between 2001 and 2011 childhood disability prevalence increased by 15.6% with disability cases related to neurodevelopmental or mental health conditions increased by 20.9% (Houtrow et al., 2014). While these statistics are not specified by individual disabilities, it does include neurologic impairments including brain tumors.

When considered in combination with US Census Bureau (US Census Bureau, 2003; US Census Bureau, 2011) reports from the 2000 and 2010 US Census, nationwide trends of increased childhood disability rates further support the hypothesis that greater numbers of children are surviving and living with disabilities than in the recent past.

Medical Advancements Impact the Service Population at MRH

Medical advancement to treat pediatric brain tumors and cerebral palsy has directly impacted therapy referrals at MRH, especially in the pediatric therapy program. More specifically, medical advancements in treatment of pediatric nervous system tumors led to the opening of a proton radiation treatment facility within miles of MRH. Current research from the NMCPC indicates upwards of an 80% cure/success rate with pediatric head and neck cancers treated with proton radiation (NM, 2016). Opening in 2010, the NMCPC is the first, and currently the only, proton radiation center in Illinois. It is one of only 25 in the country and 55 in the world as of 2016 (NM, 2016). The center treats national and international populations of adults and children: up to 90 adult and pediatric patients each day, 600 per year and 2,700 overall to date (NM, 2016).

Development of the NMCPC has resulted in a significant increase in referrals for children with neurologic-based diagnoses to the MPTD for occupational, physical and speech therapy services (G. Girten, personal communication, June 27, 2017). During fiscal years (FY) 2014 and 2015; the MPTD treated a total of 56 and 51 patients respectively on the inpatient (IP) unit, 13 and 7 of which were categorized as having a NTBI and 6 and 5 with diagnosis of CP (G. Girten, personal communication, June 27, 2017).

By FY2016; significant growth occurred with inpatient referrals with the MPTD treating a total of 79 patients, 13 of which were categorized as having a NTBI with an additional 5 with CP (G. Girten, personal communication, June 27, 2017). Further growth in referrals is noted with 3rd quarter statistics from FY2017 indicating a total of 54 patients treated on the IP unit of the MPTD, with 14 categorized as NTBI and 15 with CP, more than doubling the total served in FY2014 and 2015 (G. Girten, personal communication, June 27, 2017). For outpatient services, including the day rehabilitation and single service programs, similar growth was observed with total served in FY2015 being 480 patients and FY2016 at 528 patients; FY2017 statistics were unavailable at the time of this report (G. Girten, personal communication, June 27, 2017). This growth indicates a 41% increase in patients served by the MPTD between FY2014 and FY2016; with 3rd quarter FY2017 statistics indicating anticipated totals for the year meeting or exceeding FY2016 levels.

Although these growth trends of the MPTD cannot be concretely attributed to growth of the cancer treatment program at NMCPC without more intensive chart review and case listings, they have subjectively been correlated to the growth of this program by long-standing employees familiar with the trends in services offered by the MPTD (G. Girten, personal communication, June 27, 2017). This correlation is further supported by program reports that no pediatric patients served by MPTD prior to 2013 were receiving proton radiation therapy and program trends indicating children receiving proton radiation therapy for brain tumors is approaching 30% of the total population served categorized as having diagnosis of a NTBI (G. Girten, personal communication, June 27,

2017). This data along with reports from the NMCPC as well as the facility's association with our partner medical facilities can confidently be attributed to the significant increase in referrals for rehabilitation services.

Incidence and Etiology of PVVD in Children with Neurologic Conditions

Evidence strongly indicates children with cerebellar-based motor disabilities have impairments of visual, vestibular and multisensory processing that are more pronounced than their typically developing peers; these impairments may be linked to structural deficits of the occipital region and thalamocortical projections (Pavao & Rocha, 2017). This hypothesis is consistent with findings that have identified balance and motor deficits in children with confirmed cerebellar lesions or structural damage (Archer, Faldon, Daview, & Bronstein, 2012; Konczak et al., 2005; Syczewska, Dembowska-Baqinska, Perek-Polnik, & Perek, 2006). Similarly, many sensory processing based studies looking at populations with genetic disorders, ASD, and other developmental delays present strong evidence of vestibular and sensorimotor deficits in children with neurologic impairment (Dannenbaum et al., 2016; Roley et al., 2015; Walz & Baranek, 2006).

Current literature further supports the observations made in the MPTD that children with central nervous system tumors present with visual-vestibular dysfunction. While medical advancements to diagnose and treat pediatric tumors have increased survivorship rates, they also come with significant risk factors and side effects that are overwhelmingly linked to greater risk for peripheral and centrally-based visual-vestibular dysfunction (Archer et al., 2012; Dannenbaum et al., 2016; Konczak et al., 2005; Pavao & Rocha, 2017; Syczewska et al., 2006). In long-term survivors of cerebellar tumors

diagnosed in childhood, Konczak et al. (2005) found that over 64% of children had ongoing balance and postural control as well as impaired eye/hand coordination skills. Likewise, Syczewska et al. (2006) identified that more than half of their subjects had impaired balance that was not compensated for by increased visual feedback. This study also found that despite treatment occurring at a young age, neither the length of time since surgery, nor the medical treatment, nor the age of the child at time of surgery were good predictors of motor and cognitive recovery (Syczewska et al., 2006).

Overwhelmingly, current research has shown that children with compromised cerebellar functioning have high rates of visual-vestibular dysfunction (Archer et al., 2012; Dannenbaum et al., 2016; Konczak et al., 2005; Pavao & Rocha, 2017; Roley et al., 2015; Syczewska et al., 2006; Walz & Baranek, 2006). Further, it indicates that children with cerebellar lesions are not able to better compensate for the motor and cognitive deficits despite injury occurring during a critical motor development period (Konczak et al., 2005).

ADL/IADL Deficits Confirm the Need for OT Intervention in PVVD

Within the available literature there is a high correlation of visual-vestibular dysfunction with impaired performance and independence in activities of daily living (ADLs). Adult focused studies have found that those with diagnosed vestibulopathy also present with decreased strength, endurance and ADL activity performance (Alghwiri et al., 2012; Cohen, Kimball & Adams, 2000; Ward, Agrawal, Hoffman, Carey, & Della Santina, 2013). Ward et al. (2013) found that of adults with vestibular impairment, 44% had changes in driving habits, 56% had a negative impact on participation in social

activities, 58% had difficulties with ADLs, and that there was a 31-fold increase in fall risk. In pediatric populations, many of the often under-acknowledged symptoms of visual-vestibular dysfunction are related to performance and participation deficits in ADLs (Cohen, 1994; Mehta & Stakiw, 2004; Rine & Christy, 2016; Rine & Wiener-Vacher, 2013). Further, children with neurologic conditions have been noted to have similar levels of ADL dysfunction upon admission to an inpatient rehabilitation unit, with children with CNS cancer having higher levels of retained impairment at discharge (Tsao, Bjornson, Christensen, & Apkon, 2016).

Barriers to Identification and Intervention of PVVD

Historically, advocacy, awareness and practice efforts relating to vestibular rehabilitation have focused on adult populations, especially in occupational therapy (Alghwiri et al., 2012; Cohen, 1994; Cohen, Miller, Kane-Wineland, & Hatfield, 1995; Cohen et al., 2000; Cohen, Burkhardt, Cronin, & McGuire, 2006; Rine & Wiener-Vacher, 2013; Ward et al., 2013). More recently, researchers have made efforts to expand knowledge about rehabilitation needs of children related to visual-vestibular dysfunction (Dannenbaum et al., 2016; Pavao & Rocha, 2017; Rine, 2009; Roley et al., 2015; Weiss & Phillips, 2006). Therapy practice has further spurred research to explore the need for rehabilitation for children following diagnosis of nervous system cancers (Ilg et al., 2009; Konczak et al., 2005; Piscione, Bouffet, Mabbott, Shams, & Kulkarni, 2014; Syczewska et al., 2006; Turner, Gagnon, Lagace, & Gagnon, 2013). However, much of the available literature to date has focused on clarifying and identifying incidence of PVVD, as opposed to identifying and evaluating effective intervention strategies, especially in

regards to centrally based dysfunction.

PVVD Presents Differently Than in Adults

Research revelations over the past two decades have improved our understanding of visual-vestibular dysfunction in children, though clinical identification of these impairments remains low. One factor contributing to this problem is variability of symptom presentation and difficulties related to symptom reports by children (Mehta & Stakiw, 2004; Rine & Christy, 2016; Rine & Wiener-Vacher, 2013). Researchers have acknowledged that children often have difficulty describing symptoms related to vision and vestibular dysfunction, validating what is frequently observed in the pediatric therapy setting (Rine & Christy, 2016). For instance, with vertigo or dizziness, adults often have the vocabulary to describe the sensations to a medical professional while children may lack such vocabulary or self-awareness (Mehta & Stakiw, 2004; Rine & Christy, 2016). Instead of verbally reporting sensations, children often demonstrate challenges behaviorally; these behaviors may include refusing to stand, excessive sleepiness, clinginess to caregivers, avoidance or fear of certain playground equipment, outbursts of anger or anxiety, or difficulty focusing or attending (Mehta & Stakiw, 2004; Rine & Christy, 2016; Rine & Wiener-Vacher, 2013).

Another factor influencing clinical identification rates is the lived experience of a child with visual-vestibular dysfunction. In adults, onset of impairment often coincides with a distinct change in balance, gait, or sensory experiences (Mehta & Stakiw, 2004; Rine & Christy, 2016). However, children often acquire impairments early in life or are born with neurologic deficits and subsequent visual-vestibular dysfunction (Rine &

Wiener-Vacher, 2013). As a result, children often will not have typical foundational visual-vestibular experiences and may not have typical experiences to help them identify that what they experience and how they feel is abnormal (Rine & Christy, 2016; Rine & Wiener-Vacher, 2013).

As a result of communication barriers and self-awareness of visual-vestibular challenges, presenting symptoms can often be misdiagnosed or missed completely by the physician or therapy clinician (Mehta & Stakiw, 2004; Rine & Christy, 2016; Rine & Wiener-Vacher, 2013; Weiss & Phillips, 2006). Often, the manifestation of visual-vestibular dysfunction in children is misidentified as purely behavioral or developmental in etiology (Mehta & Stakiw, 2004; Rine & Christy, 2016; Rine & Wiener-Vacher, 2013).

Limitations of Client/Family Acknowledgement and Understanding

As communication and awareness factors limit clinical identification of visual-vestibular dysfunction, research also supports the notion that these challenges impair parent/caregiver identification, minimizing the likelihood of a caregiver to seek out medical intervention for visual-vestibular impairments (Rine, 2009). Furthermore, current evidence supports the notion that children and their families/caregivers also have restricted understanding and identification of vision and vestibular functioning as factors influencing the child's performance levels, possibly as a result of limited understanding and retention of medical education provided to them (Norberg & Steneby, 2009; Smith et al., 2014). Retention of education is further limited during acute phases of medical diagnosis and treatment when the diagnosed condition is life threatening, as is seen in

childhood cancers (Norberg & Steneby, 2009; Smith et al., 2014).

Current literature indicates that families dealing with a cancer diagnosis for their child often experience emotional trauma that influences the caregivers' ability to learn and retain medical information (Norberg & Steneby, 2009; Smith et al., 2014). While parents and caregivers in these situations identify strong desires to address physical and cognitive functions and maximize their child's ability to participate in daily family, school and social life, they also face a variety of stressors that impact their learning (Norberg & Steneby, 2009). Additionally, these caregivers often interact with many medical providers and healthcare professionals, resulting in a kind of "information overload" that further challenges their learning and ability to identify functional signs/symptoms of visual-vestibular dysfunction (Smith et al., 2014).

Limitations of Clinical Identification by Occupational Therapy Practitioners

Within the MPTD, many therapists have identified visual-vestibular dysfunction impacting occupational performance of children with neurodevelopmental, N/TBI and/or CNS cancers (Stone & Salentine, 2017). More than 50% of these children have diagnosed visual acuity, visual field, ocular motor and/or visual perceptual dysfunction (Stone & Salentine, 2017). However, roughly 80% of these children have no medical diagnosis of a vestibular disorder or previously identified vestibular dysfunction despite having seen or been referred to a physiatrist, neurologist/neuro-oncologist, ophthalmologist and/or optometrist (Stone & Salentine, 2017). Still, 100% of OT practitioners in the MPTD report directly addressing visual and vestibular dysfunction with most of the children on their caseload with these diagnoses (Stone & Salentine, 2017).

Given the frequency of which OT practitioners within the MPTD are addressing visual-vestibular dysfunction without or with limited guidance of a medical diagnosis, it is important to consider how OTs are guided in their intervention. Within occupational therapy practice, many clinicians in pediatric practice consider and identify performance deficits related to sensory processing and the sensory integration frame of reference (FOR) (Berry & Ryan, 2002; Reid, 1987; Roley et al., 2015; Walz & Baranek, 2006). However, research has also suggested that OT practitioners may have restricted use of various FORs within their practice and/or may be misguided in their use of certain FOR (Berry & Ryan, 2002; Reid, 1987). These suggestions were supported by OT practitioner reports within the MPTD (Stone & Salentine, 2017). Among OTs in the MPTD, 80% report utilization of the SI and MLMC FORs to address vision deficits in children with a neurodevelopmental, N/TBI and/or CNS cancer diagnosis, while 100% of therapists report use of the SI FOR to address vestibular dysfunction (Stone & Salentine, 2017). However, less than half of therapists report use of any other FOR in their practice when addressing vestibular dysfunction (Stone & Salentine, 2017).

Based on the clinical and literature-based evidence gathered as well as personal professional experience, it can be deducted that OT practitioners regularly consider and identify visual-vestibular dysfunction in children with neurologic conditions. However, it is possible, and even likely, that clinicians utilize a limited clinical perspective of visual-vestibular dysfunction through use of primarily the SI FOR in their practice. As a result, precision of identification and understanding of the etiology of a child's visual-vestibular dysfunction, and the subsequent influences this has on clinical decision making may be

limiting the efficacy of OT interventions for children with neurologic conditions.

Evidence-Based Practice Guiding Occupational Therapy

As stated above, most current research has focused on etiology and presentation of visual-vestibular dysfunction in pediatric clients. Though research has confirmed pediatric visual-vestibular dysfunction varies from adults in etiology and symptom presentation (Mehta & Stakiw, 2004; Rine & Christy, 2016; Rine & Wiener-Vacher, 2013), very few peer-reviewed reports have been found to provide adequate guidance for assessment and intervention with children with cerebellar based diagnoses like cerebral palsy and CNS cancer. None have been found to provide focused and effective strategies for occupational therapy practitioners to utilize with pediatric clients. This further contributes to the reported bewilderment of practitioners in the MPTD attempting to identify and intervene in these cases.

Despite the limited availability of pediatric specific research guiding treatment, current literature does promote multidisciplinary rehabilitation intervention for children who have been diagnosed with CNS cancer (Ilg et al., 2009; Miyai et al., 2012; Scheinberg, 2015). Many medical interventions for childhood CNS cancer have associated side effects and risk factors including increased rates of physical, cognitive and neurologic dysfunction related to these conditions, comorbidities and standard medical interventions (Archer et al., 2012; Konczak et al., 2005; Scheinberg, 2015). In cases of tumor resections that involve the cerebellum, immediate therapeutic intervention has been shown to have positive impacts on functioning, especially when ataxia is present immediately after resection (Ilg et al., 2009; Mitoma & Manto, 2016; Miyai et al., 2012).

Specifically, a 2016 study found that early, high-intensity treatment was correlated with long-term benefits (up to 1 year) for children with posterior fossa tumors (Mitoma & Manto, 2016). The authors also acknowledged that unlike adult populations, gains achieved through intensive rehabilitation may not be sustained following intervention due to natural disease process associated with pediatric brain tumors. Nevertheless, repeated intensive rehabilitation once the child is further into recovery can effect similar improvements (Mitoma & Manto, 2016).

While there is support for early rehabilitation intervention, these sources recognize significant limitations in current evidence to guide specific intervention protocols. Of the evidence that is available currently to guide practice, much of it comes from international studies focusing on adult populations. In Japan, adults with cerebellar degeneration who immediately entered into an intensive rehabilitation program including OT and PT services showed significantly greater functional gains in regards to ADLs, ataxia-based impairment and gait even at 24 weeks post treatment as compared to those who were delayed entry into the program by 4 weeks (Miyai et al., 2012). Similarly, a study from Germany identified significant improvements in motor performance and ataxia-based impairment up to 8 weeks after an intensive rehabilitation program in adults with degenerative cerebellar disease (Ilg et al., 2009).

Need for Evidence-Based Practice Guidelines for Pediatric Occupational Therapists

As explained above, recent advancements in medical diagnosis and interventions has resulted in increased identification of childhood disability and a growing population of children living with neurologic conditions (Brandes & Franceschi, 2011; Houtrow et

al., 2014; Lee, Robinson, Chi, Gururangan, & Kieran, 2011; Smith et al., 2014; US Census Bureau, 2003; US Census Bureau, 2011). With these advancements, MRH has experienced significant increases in occupational therapy referrals for children with CP and CNS cancers within the MPTDNM, 2016 (G. Girten, personal communication, June 27, 2017). These children are overwhelmingly at risk for having significant visual-vestibular dysfunction that impacts occupational performance and participation, especially in ADL and IADL activities (Alghwiri et al., 2012; Archer et al., 2012; Cohen, 1994; Cohen et al., 2000; Dannenbaum et al., 2016; Konczak et al., 2005; Mehta & Stakiw, 2004; Pavao & Rocha, 2017; Rine & Christy, 2016; Rine & Wiener-Vacher, 2013; Roley et al., 2015; Sudsawad, 2007; Tsao et al., 2016; Walz & Baranek, 2006; Ward et al., 2013). Despite awareness of risk factors leading to pediatric visual-vestibular dysfunction, OT practitioners remain limited in their ability to comprehensively affect change in these performance deficits.

While vestibular rehabilitation has been shown to improve functional performance of ADLs when a central lesion or TBI was the cause of vestibular impairment (Cohen, 1994; Rine, 2009; Rine & Christy, 2016), OT practitioners continue to lack confidence in their ability to maximize their client's potential for recovery. Current evidence confirms several factors limiting the ability of OT practitioners' ability to enhance client's performance of daily occupations (Berry & Ryan, 2002; Mehta & Stakiw, 2004; Norberg & Steneby, 2009; Reid, 1987; Rine & Christy, 2016; Rine & Wiener-Vacher, 2013; Roley et al., 2015; Soanes, Hargrave, Smith, & Gibson, 2009; Stone & Salentine, 2017; Walz & Baranek, 2006). These factors include limited

identification, diagnosis and misdiagnosis of impairment by medical professionals referring children for OT services as a result of the varied etiology and presentation of PVVD, limited caregiver awareness and understanding of symptoms that are consistent with PVVD, limitations and misguided use of clinical FORs in OT practice, and limited evidence-based knowledge to guide OT assessment and intervention (Berry & Ryan, 2002; Mehta & Stakiw, 2004; Norberg & Steneby, 2009; Reid, 1987; Rine & Christy, 2016; Rine & Wiener-Vacher, 2013; Roley et al., 2015; Soanes et al., 2009; Stone & Salentine, 2017; Walz & Baranek, 2006).

In a survey of OT practitioners in the MPTD, reports indicate that the majority of children with neurologic conditions treated within the program have been identified as having impaired visual/vestibular processing, gravitational insecurity, dyspraxia, and/or sensory-based movement deficits (Stone & Salentine, 2017). However, therapists report addressing vestibular dysfunction less than 50% of the time with these children (Stone & Salentine, 2017). Based on the gathered evidence, this service gap is presumably stems from a lack of clinical guidance on how and when to intervene. Thus, it is imperative that evidence-based practice guidelines be developed in order to better steer OT practitioners as they work to support children with neurologic conditions achieve their full-potential in every day occupations.

APPRAISAL OF CURRENT EVIDENCE AND PRACTICE STANDARDS TO ADDRESS THE SERVICE GAP

Recent advancements in medical diagnosis and interventions have resulted in increased identification of childhood disability and a growing population of children living with neurologic conditions (Brandes & Franceschi, 2011; Houtrow et al., 2014; Lee et al., 2011; Smith et al., 2014; US Census Bureau, 2003; US Census Bureau, 2011). With these advancements, MRH has experienced significant increases in occupational therapy referrals for children with CP and CNS cancers within the MPTD (G. Girten, personal communication, June 27, 2017; NM, 2016). These children are overwhelmingly at risk for having significant PVVD that impacts occupational performance and participation, especially in ADL and IADL activities (Alghwiri et al., 2012; Archer et al., 2012; Cohen, 1994; Cohen et al., 2000; Dannenbaum et al., 2016; Konczak et al., 2005; Mehta & Stakiw, 2004; Pavao & Rocha, 2017; Rine & Wiener-Vacher, 2013; Roley et al., 2015; Syczewska et al., 2006; Tsao et al., 2016; Walz & Baranek, 2006; Ward et al., 2013). Despite awareness of risk factors leading to PVVD, OT practitioners remain limited in their ability to comprehensively affect change in these performance deficits.

While vestibular rehabilitation has been shown to improve functional performance of ADLs when a central lesion or TBI was the cause of vestibular impairment, OT practitioners at MRH continue to lack confidence in their ability to maximize their client's potential for recovery. Current evidence confirms several factors limiting the ability of OT practitioners' ability to enhance client's performance of daily occupations (Berry & Ryan, 2002; Cohen, 1994; Mehta & Stakiw, 2004; Norberg &

Steneby, 2009; Rine & Wiener-Vacher, 2013; Roley et al., 2015; Soanes et al., 2009; Stone & Salentine, 2017; Walz & Baranek, 2006). These factors include limited identification, diagnosis and misdiagnosis of impairment by medical professionals referring children for OT services as a result of the varied etiology and presentation of PVVD, limited caregiver awareness and understanding of symptoms that are consistent with PVVD, limitations and misguided use of clinical frames of reference in OT practice, and limited evidence-based knowledge to guide OT assessment and intervention (Berry & Ryan, 2002; Mehta & Stakiw, 2004; Norberg & Steneby, 2009; Rine & Wiener-Vacher, 2013; Roley et al., 2015; Soanes et al., 2009; Stone & Salentine, 2017; Walz & Baranek, 2006).

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Theoretical Foundations

Review of the Evidence

Throughout this literature search, many of the articles reviewed revealed trends in the theoretical foundations and frames of reference (FOR) utilized for evaluation and intervention with children with PVVD. In all, 11 articles were chosen for inclusion from a selection of approximately 20 articles based on the relevance of the subject matter of the article and inclusion of detailed theoretical background information, foundational explanation and/or considerations in the results of the article (Arbesman & Lieberman, 2010; Berry & Ryan, 2002; Case-Smith, Frolek-Clark & Schlabach, 2013; Cohen, 1994; Koester et al., 2014; Lane & Schaaf, 2010; McLean et al., 2017; Nilsen et al., 2014; Rine et al., 2004; Rine & Wiener-Vacher, 2013; Silva, Schalock, Garberg, & Smith, 2012). Overwhelmingly, evidence is supportive of the use of a MLMC approach to neurorehabilitation in adults and children who have experienced neurologic injuries (Arbesman & Lieberman, 2010; Case-Smith et al., 2013; Lane & Schaaf, 2010; McLean et al., 2017; Rine et al., 2004; Rine & Wiener-Vacher, 2013; Silva et al., 2012). Use of MLMC approaches have been shown to affect long term positive health outcomes and facilitate improved ADL/IADL participation and performance (Arbesman & Lieberman, 2010; Caldwell, Fleming, Purcell, Whitehead, & Cox, 2011; Cohen, 1994; Lane & Schaaf, 2010; Mehta & Stakiw, 2004; Nilsen et al., 2014). Similarly, there is a growing evidence base to support the use of a SI FOR in pediatric neurodevelopmental rehabilitation (Arbesman & Lieberman, 2010; Lane & Schaaf, 2010; Nilsen et al., 2014; Rine et al., 2004; Rine & Wiener-Vacher, 2013; Silva et al., 2012).

In pediatric studies specifically, there is a growing number of researchers that are exploring the possible applications of SI theory and sensory based interventions and the impact these strategies have on neuroplasticity and motor learning in areas outside of traditionally represented SI populations (Arbesman & Lieberman, 2010; Koester et al., 2014; Lane & Schaaf, 2010; Rine et al., 2004; Rine & Wiener-Vacher, 2013; Silva et al., 2012). Much of the evidence demonstrates correlations and parallels between traditional Ayres SI theory (and more contemporary perspectives based on Ayres foundational theory) and MLMC theory (Arbesman & Lieberman, 2010; Case-Smith et al., 2013; Lane & Schaaf, 2010; McLean et al., 2017). A substantial number of studies demonstrate sustained neuroplastic changes in subjects with a combined intervention approach using both FORs (Berry & Ryan, 2002; Case-Smith et al., 2013; Koester et al., 2014; Lane & Schaaf, 2010; Silva et al., 2012). Several articles that studied children with CP specifically found prolonged changes in motor function even months after SI based intervention, including changes in ataxia, gross and fine motor coordination, balance and visual motor skills - of which are associated with PVVD (Arbesman & Lieberman, 2010; Case-Smith et al., 2013; Koester et al., 2014; Lane & Schaaf, 2010; Nilsen et al., 2014; Rine et al., 2004; Silva et al., 2012).

While there are consistently supportive trends in the evidence regarding the use of SI and MLMC FORs in pediatric neurorehabilitation practice, much of the evidence that considers SI based evaluation and interventions, even those that compare and consider it in relation to MLMC theory, focus primarily on children with autism spectrum disorders and/or sensory processing and sensory modulation disorders (Arbesman & Lieberman,

2010; Lane & Schaaf, 2010). Historically, the SI FOR has been primarily used in practice by pediatric clinicians working with children with sensory processing, sensory integrative, and/or sensory-based motor dysfunction with a large proportion of those identified in the literature being children with ASD (Arbesman & Lieberman, 2010; Case-Smith et al., 2013; Lane & Schaaf, 2010). While parallels can be drawn from this evidence in regards to children with other neurologically based conditions that impact sensory integration and sensorimotor abilities, little evidence can be found considering the SI FOR in pediatric neurorehabilitation populations, including pediatric neuro-oncology populations. Similar limitations can be found in the evidence surrounding the use of MLMC FOR in neurorehabilitation, with the strongest evidence and most extensive studies being conducted on adult populations explicitly (Berry & Ryan, 2002; Cohen, 1994; Nilsen et al., 2014). While valuable information can be drawn from these studies, questions remain about the effectiveness of the use of these theoretical approaches to neurorehabilitation with the pediatric neuro-oncology population, and in regards to pediatric visual-vestibular rehabilitation more broadly.

Implications & Conclusions

Within the current evidence base, there is a significant foundational basis for the use of SI and MLMC FORs in combination when considering evaluation of and intervention for PVVD in pediatric populations including pediatric neuro-oncology and other cerebellar based conditions (Arbesman & Lieberman, 2010; Berry & Ryan, 2002; Case-Smith et al., 2013; Koester et al., 2014; Lane & Schaaf, 2010; McLean et al., 2017; Silva et al., 2012). However, the limited reach of SI evidence-based literature to more

conventional populations reduces the overall strength of the available literature to support expanded use within pediatric rehabilitation. Still, evidence indicates there is a benefit of using a combined FOR approach to intervention, with findings implying potential underuse of the SI FOR in OT practice when considering the possible broad reaching applications of the theory (Arbesman & Lieberman, 2010; Berry & Ryan, 2002; Case-Smith et al., 2013; Cohen, 1994; Koester et al., 2014; Lane & Schaaf, 2010; McLean et al., 2017; Nilsen et al., 2014; Rine et al., 2004; Rine & Wiener-Vacher, 2013; Silva et al., 2012). Further, current gaps in the evidence indicate a need for additional evidence-based treatment practices with pediatric populations, especially those with neurologic conditions that impede occupational participation and performance (Arbesman & Lieberman, 2010; Berry & Ryan, 2002; Case-Smith et al., 2013; Cohen, 1994; Koester et al., 2014; Lane & Schaaf, 2010; McLean et al., 2017; Nilsen et al., 2014; Rine et al., 2004; Rine & Wiener-Vacher, 2013; Silva et al., 2012).

Thus, while the proposed program is supported foundationally in the evidence to be guided by the SI and MLMC FORs, there is a need to measure and assess the outcomes of this program as the outputs will be a new and somewhat unique approach to pediatric neurorehabilitation evaluation and intervention. Additionally, with the ongoing movement for OT practice (and multidisciplinary rehabilitation practices in general) to become more stably rooted in scientifically driven evidence, objective program and intervention evaluations need to be conducted. If published, these evaluations and the outcomes data generated through these assessments would be highly beneficial for the advancement of the OT profession, pediatric rehabilitation science, pediatric

neurorehabilitation, and pediatric oncology rehabilitation. As a result, it will be prudent to continue to objectively explore the effectiveness of the program through scientific studies, not only to ensure efficacy of the program as it applies to MRH clientele, but also to fulfill a professional responsibility to contribute to the literature that will support and advance therapeutic practice.

Evaluation

To contribute to the current needs assessment, review and assessment of current practices in clinical evaluation of PVVD in occupational therapy at MRH, it was necessary to specify what solutions exist to mitigate current gaps in evaluative practice. This extensive literature review of occupational therapy research identified and evaluated the evidence for use of many assessment tools when working with children with PVVDs with central nervous system etiologies. Evidence reviewed was found through the American Journal of Occupational Therapy, the Canadian Journal of Occupational Therapy and the British Journal of Occupational Therapy, and drew from multidisciplinary studies including physical therapy, occupational therapy, optometry, neurology, audiology and otolaryngology. Keyword searches in the American, Canadian and British Journals of Occupational Therapy, OTJR and PubMed were done utilizing a combination of terms including “assessment”, “evaluation”, “visual”, and “vestibular.” These searches were limited to research articles published between 2000-2017, with high priority given to review articles. In all, 412 articles were briefly reviewed based on the above noted search results. Of these, 60 articles were reviewed for consideration based on title and description offered on each database search. The final outcome included 21

articles that were deemed relevant and appropriate for consideration of this report following more in depth review (Berry & Ryan, 2002; Blanche, Bodison, Change, & Reinoso, 2012; Brodsky, Cusick, Kenna, & Zhou, 2015; Choi et al., 2015; Colver, Fairhurst & Pharoah, 2014; Davidson & Williams, 2000; Gal, Dyck & Passmore, 2010; Hamilton, Zhou & Brodsky, 2015; Ivey, Lane & May-Benson, 2014; Konczak et al., 2005; Lawerman, Brandsma, Burger, Burgerhof, & Sival, 2017; Li, Beaumont, Rine, Slotkin, & Schubert, 2014; Liao, Mao & Hwang, 2001; Mailloux et al., 2014; Mailloux et al., 2011; Nilsen et al., 2014; Norberg & Steneby, 2009; Ross & Helminski, 2016; Schupak, Parasher, & Zipp, 2016; Toupet, Van Nechel & Grayeli, 2016; Zwergal et al., 2009).

Review of the Evidence

Of the available research, many studies utilized similar screening and assessment tools and offered repeated validation of each tool's use as an outcome measure (Blanche et al., 2012; Brodsky et al., 2015; Choi et al., 2015; Cohen et al., 2000; Colver et al., 2014; Fisher, Mixon & Herman, 1986; Gal et al., 2010; Hamilton et al., 2015; Ivey et al., 2014; Konczak et al., 2005; Lawerman et al., 2017; Li et al., 2014; Liao et al., 2001; Mailloux et al., 2014; Mailloux et al., 2011; Nilsen et al., 2014; Norberg & Steneby, 2009; Ross & Helminski, 2016; Schupak et al., 2016; Toupet et al., 2016; Zwergal et al., 2009). However, there was a large variability across these studies of study design, population being studied, and outcomes being measured (Blanche et al., 2012; Brodsky et al., 2015; Choi et al., 2015; Cohen et al., 2000; Colver et al., 2014; Fisher et al., 1986; Gal et al., 2010; Hamilton et al., 2015; Ivey et al., 2014; Konczak et al., 2005; Lawerman

et al., 2017; Li et al., 2014; Liao et al., 2001; Mailloux et al., 2014; Mailloux et al., 2011; Nilsen et al., 2014; Norberg & Steneby, 2009; Ross & Helminski, 2016; Schupak et al., 2016; Toupet et al., 2016; Zwergal et al., 2009). Nevertheless, despite such variability, there is an overwhelming evidence base recommending that clinicians perform battery assessments consisting of multiple evaluation and screening tools in order to identify and determine the plan of care for people dealing with visual-vestibular dysfunction review (Berry & Ryan, 2002; Blanche et al., 2012; Brodsky et al., 2015; Choi et al., 2015; Colver et al., 2014; Davidson & Williams, 2000; Gal et al., 2010; Hamilton et al., 2015; Ivey et al., 2014; Konczak et al., 2005; Lawerman et al., 2017; Li et al., 2014; Liao et al., 2001; Mailloux et al., 2014; Mailloux et al., 2011; Nilsen et al., 2014; Norberg & Steneby, 2009; Ross & Helminski, 2016; Schupak et al., 2016; Toupet et al., 2016; Zwergal et al., 2009).

The use of assessment batteries made up of several screening tools and quickly administered standardized assessments is preferred over the use of a single evaluation tool (Blanche et al., 2012; Colver et al., 2014; Konczak et al., 2005; Mailloux et al., 2014; Mailloux et al., 2011; Nilsen et al., 2014; Norberg & Steneby, 2009; Ross & Helminski, 2016; Schupak et al., 2016). The use of multiple measures has been found to be effective in distinguishing between dysfunction stemming from peripheral lesions or disease as compared to deficits related to centrally based conditions (Berry & Ryan, 2002; Blanche et al., 2012; Cohen et al., 2000; Ivey et al., 2014; Konczak et al., 2005; Mailloux et al., 2014; Mailloux et al., 2011; Nilsen et al., 2014; Norberg & Steneby, 2009; Ross & Helminski, 2016; Schupak et al., 2016). Though much of the literature seeking to

specifically identify centrally based dysfunction has somewhat inconclusive evidence for specific tools that identify central dysfunction, many tools have been identified as picking up on peripheral dysfunction at much higher rates than central nervous system dysfunction (Berry & Ryan, 2002; Blanche et al., 2012; Cohen et al., 2000; Ivey et al., 2014; Konczak et al., 2005; Mailloux et al., 2014; Mailloux et al., 2011; Nilsen et al., 2014; Norberg & Steneby, 2009; Ross & Helminski, 2016; Schupak et al., 2016).

Many research studies utilize non-functional evaluation tools that may be inaccessible to therapists at MRH including rotational chair testing, caloric testing, and more involved tests of the vestibular-ocular reflex (Berry & Ryan, 2002; Cohen et al., 2000; Fisher et al., 1986; Ivey et al., 2014; Konczak et al., 2005; Mailloux et al., 2014; Mailloux et al., 2011; Norberg & Steneby, 2009). Although many non-functional, inaccessible, highly expensive and bulky evaluation tools and equipment were used throughout the evidence reviewed, many more accessible and easy to use screenings and evaluation tools were also shown to have significantly positive evidence base for their use, with many of them being studied in children or potentially being easily adapted for use with children (Blanche et al., 2012; Brodsky et al., 2015; Choi et al., 2015; Colver et al., 2014; Gal et al., 2010; Hamilton et al., 2015; Lawerman et al., 2017; Li et al., 2014; Liao et al., 2001; Nilsen et al., 2014; Ross & Helminski, 2016; Schupak et al., 2016; Toupet et al., 2016; Zwergal et al., 2009). Further review of the evidence on the use of these more accessible and easy-to-use tools was completed to explore them as potential solutions for the clinical evaluation of PVVD for children with CP and CNS cancers in

the occupational therapy department at MRH. This evidence is synthesized and described next.

Evaluation of Specific Evaluation Tools

Within the articles reviewed, several evaluation and screening tools were identified as potentially beneficial ways to assess children with centrally based PVVD in order to determine an appropriate plan of care (Berry & Ryan, 2002; Blanche et al., 2012; Brodsky et al., 2015; Choi et al., 2015; Cohen et al., 2000; Colver et al., 2014; Fisher et al., 1986; Gal et al., 2010; Hamilton et al., 2015; Ivey et al., 2014; Konczak et al., 2005; Lawerman et al., 2017; Li et al., 2014; Liao et al., 2001; Mailloux et al., 2014; Mailloux et al., 2011; Nilsen et al., 2014; Ross & Helminski, 2016; Schupak et al., 2016; et al., 2016; Zwergal et al., 2009). Quickly administered assessment tools that were identified include tests of subjective visual vertical (SVV) such as the bucket test (Blanche et al., 2012; Brodsky et al., 2015; Choi et al., 2015; Toupet et al., 2016; Zwergal et al., 2009), tests of vestibular ocular reflexes (VOR) including head impulse testing (HIT) (Hamilton et al., 2015; Ross & Helminski, 2016), and assessment of dynamic visual acuity (DVA) (Li et al., 2014; Nilsen et al., 2014; Ross & Helminski, 2016). Of the more extensive standardized assessments reviewed, the Scale for Assessment and Rating of Ataxia (SARA) was identified as a potential new addition for use in the MPTD (Lawerman et al., 2017; Liao et al., 2001).

Tests of subjective visual vertical (SVV), including the bucket test, have been tested extensively in children and reliable and valid age and developmental norms have been determined (Blanche et al., 2012; Brodsky et al., 2015; Toupet et al., 2016), though

many research articles reviewed were restricted to adult populations (Choi et al., 2015; Zwergal et al., 2009). In these tests, a child's perspective of what and where vertical is can be determined with a visual line orientation test within specific positioning and environmental parameters (Blanche et al., 2012; Brodsky et al., 2015; Choi et al., 2015; Toupet et al., 2016; Zwergal et al., 2009). Positive responses (perception of vertical being significantly off of true vertical) have been more strongly associated with peripherally based vestibular dysfunctions than centrally based dysfunctions, partially due to the fact that the research being done in most studies was focused solely on those with peripherally based visual/vestibular dysfunction (Blanche et al., 2012; Brodsky et al., 2015; Choi et al., 2015; Toupet et al., 2016; Zwergal et al., 2009). However, this test can be administered quickly (within minutes), so the use of a SVV test within an assessment battery in the clinic could help rule out peripherally based dysfunction. This is important because peripherally based dysfunction can also be prominent in children going through cancer treatment and with other neurologic conditions (Brodsky et al., 2015; Toupet et al., 2016).

Similarly, research on head impulse testing (HIT) tools have been done with children many times, though often in studies with small sample sizes or in studies focused solely on adult populations (Hamilton et al., 2015; Ross & Helminski, 2016; Schupak et al., 2016). HIT (and related tests) have been found to be effective in ruling out peripheral based dysfunction when a centrally based impairment is suspected (Berry & Ryan, 2002; Blanche et al., 2012; Cohen et al., 2000; Ivey et al., 2014; Konczak et al., 2005; Mailloux et al., 2014; Mailloux et al., 2011; Nilsen et al., 2014; Norberg &

Steneby, 2009; Ross & Helminski, 2016; Schupak et al., 2016). There are several variations of HIT that are done clinically; one such means of testing involves use of videonystagmography (VNG) or videotaping VOR responses through the use of goggles worn by the subject (Hamilton et al., 2015; Ivey et al., 2014; Nilsen et al., 2014; Ross & Helminski, 2016). Video goggle testing often takes significantly longer time than other battery assessment tools and may not be easily utilized in the current program model at MRH. Though VNG is available at MRH, staff trained in the use of the equipment is limited, with the primary user being trained to assess only adult populations, which significantly restricts access of such testing in pediatrics. Alternative tests include rotary chair testing (RCT) and modified rotary chair testing (mRCT) (Fisher et al., 1986). Like VNG testing, RCT involves large, highly expensive equipment and technology (Fisher et al., 1986), making it unreasonable to consider for use at MRH. While more accessible and low-tech, mRCT is often medically contraindicated for use in the population considered for this project (children actively receiving cancer related medical treatments, children with seizure disorders, and symptomology that would be highly exacerbated by spinning in any form). Manual HIT, however, can be done with minimal gross motor rotation of the child limiting risk for overstimulation and subsequent adverse reactions and eliminating the need for specialized equipment or extended time (Hamilton et al., 2015; Ross & Helminski, 2016; Schupak et al., 2016). Still, given the clarity of which medical imaging and diagnostic tests are in identifying central nervous system lesions as being the primary source of motor, visual and vestibular changes, and the high risk of inducing symptom exacerbation that could cause prolonged discomfort for the child, this

evidence review indicates HIT may not be a priority assessment tool to be used upon initial evaluation of children considered in this project.

The more extensively researched and validated assessment for use with children with visual and vestibular impairments is the test of dynamic visual acuity (DVA) (Li et al., 2014; Nilsen et al., 2014; Ross & Helminski, 2016). The DVA combines a simple reading or visual identification task with repetitive, specific and controlled head movements to explore the status of vestibular and visual function in terms of gaze stabilization and strength of the vestibular-ocular reflex (VOR) (Li et al., 2014; Nilsen et al., 2014; Ross & Helminski, 2016). The DVA has normative scores for children age 3 through adults up to age 85, and has been found to be valid and reliable as a way to identify visual-vestibular dysfunction across the lifespan based on high quality, nation-wide research through the National Institute of Health (NIH) (Li et al., 2014; Nilsen et al., 2014; Ross & Helminski, 2016). There is also a computerized version of the test (cDVA) that can be used with a low-tech head strap and laptop to more objectively measure and interpret results of the test (Li et al., 2014; Nilsen et al., 2014; Ross & Helminski, 2016). The DVA/cDVA is available with an extensive evaluation toolbox developed by the NIH for clinicians to support and guide their use of this quick and easy to administer assessment (Li et al., 2014). The strength of evidence validating the DVA/cDVA, extensive use of the tool clinically within occupational therapy and other disciplines, low cost, and low-tech needs to administer the assessment, combined with the ease of administering and scoring the test, makes the DVA a well-rounded assessment that would fit well in a pediatric focused clinically used visual-vestibular assessment

battery (Li et al., 2014; Nilsen et al., 2014; Ross & Helminski, 2016).

A more time-intensive and detailed evaluation tool that measures motor outcomes associated with central nervous system dysfunction that can be associated with PVVD is the Scale for Assessment and Rating of Ataxia (SARA) (Lawerman et al., 2017; Liao et al., 2001). The SARA was initially developed and used in adult populations, but has been standardized and found to be a reliable and valid measure of ataxia in children over age 8 (Lawerman et al., 2017; Liao et al., 2001). The SARA assesses cerebellar ataxia specifically, can be used as an index of gait and ADL status, and is made up of 8 performance items (Lawerman et al., 2017; Liao et al., 2001). It takes approximately 20-30 minutes to administer, is available free of cost, and can easily be conducted in a pediatric therapy setting (Lawerman et al., 2017; Liao et al., 2001). While the SARA does have solid research to support its use with pediatric populations, it may be limited in its use within this project given the advanced age a child must be at in order to use the test reliably, as well as there being a lack of evidence of its use within the pediatric oncology population (Lawerman et al., 2017; Liao et al., 2001). However, it is well supported in its use with children with CP and may be beneficial as a more long term measure of motor outcomes, especially motor outcomes as they related to SI based dysfunction and interventions, within both the pediatric oncology and CP populations seen at MRH (Lawerman et al., 2017; Liao et al., 2001).

Implications & Conclusions

In reviewing current evidence on assessment strategies and commonly used evaluation tools for children with centrally based PVVD, there are several implications

that can be drawn from the currently available literature to address current gaps in service. These include:

- Based on a needs assessment at MRH and this review of current evidence, a more extensive and revised assessment battery needs to be created for use at MRH. A comprehensive assessment battery is essential to ensure an evidence-based approach to evaluation and treatment of children with PVVD, regardless of the etiology. Current assessment and evaluation procedures at MRH that are used with children suspected of having PVVD need to be revised and expanded. Adaptation of the current MRH Vision Screening battery covers some activities recommended in the literature, omits activities that are essential in discriminating vestibular function from purely vision or motor-based impairment, and includes performance items that provide information that may not be valid or reliable measures of visual-vestibular functional status and outcomes.
- While there is detailed and highly accurate means of assessing peripheral and centrally based PVVD, many gold standard tests are not feasible for the current clinical model at MRH. However, grouping easily administered screening tools and assessments are recommended for use in the clinic. These include the SVV, HIT, and DVA. Use of the SARA is recommended for use in cases where more extensive testing and follow up is warranted and feasible. These assessment tools need to be included in an updated MRH assessment battery in order to ensure clinicians are gathering comprehensive and informative data that will support intervention planning and positive health outcomes of our clients.

- While not feasible for the current model of OT practice, the more extensive tests (i.e., VNG or RCT, SARA) may be beneficial for use in multidisciplinary program and department outcome evaluations in future clinical endeavors at MRH. Collaboration among therapy disciplines, especially physical and occupational therapists, should be done in order to provide a comprehensive rehabilitation approach for children with PVVD. For instance, many children working with an OT practitioner at MRH also work with a physical therapist (PT). In PT, these children may undergo sensory organization testing and balance assessments using objective and reliable measures that may be essential in helping OT clinicians supplement their observations and in-clinic assessments of the child.
- The current evidence draws on multidisciplinary research that supports use of evaluation methods with pediatric oncology and neurologically impacted populations. However, limited data specific to these populations indicates need for collection and analysis of such data stemming. Thus, data collection for the purpose of outcomes measurement and contribution to the current research base should be prioritized in the proposed project.

With the need for revision and expansion of current evaluation practices as well as the need to supplement current efforts with additional assessments, there will also be a significant need for clinician education and training to ensure true knowledge translation (Appendix B). In-service educational and training sessions, written and visual self-directed learning tools and direct mentorship will likely be needed in order to fully

translate this newly acquired knowledge throughout the MPTD. In considering the development of clinical guidelines for practitioners working with children at MRH, an extensive list of evaluation tools and guidance on what to include in an assessment battery will need to take into consideration the unique and varied needs of children with cerebellar based impairments due to varied tolerance of activities based on medical and functional status. Use of flow-charts, decision trees or sample/example cases may need to be developed to guide clinicians to ensure reliable and comprehensive assessment is completed before conclusions about a child's needs and plan of care are made.

Intervention

To explore what evidence is available for the use of intervention strategies and protocols to address centrally based PVVD, a multidisciplinary and multi-database search was completed. Evidence reviewed was found through the American Journal of Occupational Therapy and the PubMed database with literature from occupational therapy, physical therapy, optometry, neurology, audiology and otolaryngology. Keyword searches utilizing a combination of terms including "intervention", "vision", "visual", "vestibular", "vestibular diseases", "central vestibular diseases", "children", "rehabilitation", and "treatment" were used. The PubMed search was limited to a timeline of 10 years (2007 – 2017), and AJOT searches were limited to "neurologic conditions", "pediatric evaluation & intervention", "evidence based practice", and/or "sensory integration" to focus the searches on relevant evidence. In all, 263 search results were narrowed down by title review with 23 articles undergoing an abstract review and 13 included in this report following a full review (Anoh-Tanon, Bremond-Gignac & Wiener-

Vacher, 2000; Arbesman & Lieberman, 2010; Bucci, Kapoula, Yang, Bremond-Gignac, & Wiener-Vacher, 2004; Case-Smith et al., 2013; Jainta, Bucci, Wiener-Vacher, & Kapoula, 2011; Lane & Schaaf, 2010; McLean et al., 2017; Nilsen et al., 2014; Rine & Braswell, 2006; Rine et al., 2004; Rine & Wiener-Vacher, 2013; Ruiz et al., 2010; Silva et al., 2012). These articles were chosen for inclusion based on the population of the study (pediatric studies were preferred over adult focused studies; subjects with centrally based dysfunction were preferred over peripheral), if the article focused on intervention as opposed to diagnosis or evaluation, and the details that the study offered about the intervention protocol in order to gather information needed for the development of clinical practice guidelines. Five of 13 articles were evidence reviews (Arbesman & Lieberman, 2010; Case-Smith et al., 2013; Lane & Schaaf, 2010; Nilsen et al., 2014; Rine & Wiener-Vacher, 2013), while 8 were experimental studies (Anoh-Tanon et al., 2000; Bucci et al., 2004; Jainta et al., 2011; McLean et al., 2017; Rine & Braswell, 2006; Rine et al., 2004; Ruiz et al., 2010; Silva et al., 2012) including one small randomized control trial (Silva et al., 2012).

Review of the Evidence

Results of review articles and experimental trials consistently demonstrate positive health outcomes for children with visual and motor impairments related to neurologic conditions, including cerebellar based conditions, following rehabilitation intervention (Arbesman & Lieberman, 2010; Case-Smith et al., 2013; Lane & Schaaf, 2010; Nilsen et al., 2014; Rine & Wiener-Vacher, 2013). In children with identified vestibular symptoms and dysfunction, outcomes across studies are consistent in reducing

symptoms and improving functional outcomes in motor skills and performance and participation and independence with ADL and IADL activities (Anoh-Tanon et al., 2000; Arbesman & Lieberman, 2010; Bucci et al., 2004; Case-Smith et al., 2013; Jainta et al., 2011; Lane & Schaaf, 2010; McLean et al., 2017; Nilsen et al., 2014; Rine & Braswell, 2006; Rine et al., 2004; Rine & Wiener-Vacher, 2013; Silva et al., 2012). Interestingly, in several experimental trials, children who presented with mixed symptomology including vertigo, dizziness, and ocular motor deficits, but had no findings on peripheral vestibular dysfunction assessments and no known neurologic conditions, also showed significant improvement in symptoms and motor and visual motor skills following intervention focusing on ocular motor and visual motor skills and optometric interventions (Anoh-Tanon et al., 2000; Bucci et al., 2004; Jainta et al., 2011; Rine & Braswell, 2006). Though these studies did not explicitly attempt to identify if the vestibular symptoms experienced by the children were associated with cerebellar dysfunction instead of peripheral vestibular impairment, the outcome measures used in each study and the identified symptomology of the subjects has been highly correlated to cerebellar based visual-vestibular impairment in other studies (Berry & Ryan, 2002; Blanche et al., 2012; Cohen et al., 2000; Ivey et al., 2014; Konczak et al., 2005; Mailloux et al., 2014; Mailloux et al., 2011; Nilsen et al., 2014; Norberg & Steneby, 2009; Ross & Helminski, 2016; Schupak et al., 2016).

Additional exploration of the literature revealed strong support for expanded use of SI interventions with children who present with centrally based PVVD (Arbesman & Lieberman, 2010; Case-Smith et al., 2013; Lane & Schaaf, 2010; McLean et al., 2017;

Nilsen et al., 2014; Rine et al., 2004; Rine & Wiener-Vacher, 2013; Silva et al., 2012). Of the 5 review articles included in this evidence search, 4 focused on the state of the evidence for SI interventions as it relates to motor, balance and visual skills and its impact on ADL/IADL functioning (Arbesman & Lieberman, 2010; Case-Smith et al., 2013; Lane & Schaaf, 2010; Nilsen et al., 2014). Overwhelmingly, the evidence shows that SI interventions are theoretically paralleled with concepts of neuroplasticity, that SI interventions do facilitate neurologic changes in both structure and function, and that focused, consistent and repetitive sensory based rehabilitation approaches impact motor output, behavior, learning and participation in ADL/IADL activities (Arbesman & Lieberman, 2010; Case-Smith et al., 2013; Lane & Schaaf, 2010; McLean et al., 2017; Nilsen et al., 2014; Rine & Braswell, 2006; Rine et al., 2004; Rine & Wiener-Vacher, 2013; Silva et al., 2012). The outcomes elicited through SI intervention signify lasting neuroplastic changes especially when provided in combination with stimulus pairing and interventions consistent with motor control theory (Anoh-Tanon et al., 2000; Arbesman & Lieberman, 2010; Case-Smith et al., 2013; Lane & Schaaf, 2010; McLean et al., 2017; Nilsen et al., 2014; Rine & Braswell, 2006; Rine et al., 2004; Rine & Wiener-Vacher, 2013; Silva et al., 2012). Though current SI research has not explored the role of these interventions with pediatric oncology rehabilitation, several studies do explicitly investigate the impacts SI interventions have on children with CP as it relates directly to the impairments of sensory organization, sensorimotor development, motor control and vision and vestibular processing due to damage to the cerebellum, indicating an SI/MC approach to intervention with children with other cerebellar lesions may be effective to

produce positive and meaningful neurologic change (Arbesman & Lieberman, 2010; Case-Smith et al., 2013; Jainta et al., 2011).

While the evidence reviewed shows consistent findings across studies, there are limitations of the current literature. Among the research covered in review studies and additional experimental trials included in this report, all pull data from small sample groups and have moderate strength in study design (Anoh-Tanon et al., 2000; Bucci et al., 2004; Case-Smith et al., 2013; Jainta et al., 2011; McLean et al., 2017; Rine & Braswell, 2006; Rine et al., 2004; Silva et al., 2012). However, while individual studies do not provide strong evidence in and of themselves, the consistent outcomes found across all of the studies significantly strengthens the reliability and generalizability of the findings (Anoh-Tanon et al., 2000; Arbesman & Lieberman, 2010; Bucci et al., 2004; Case-Smith et al., 2013; Jainta et al., 2011; Lane & Schaaf, 2010; McLean et al., 2017; Nilsen et al., 2014; Rine & Braswell, 2006; Rine et al., 2004; Rine & Wiener-Vacher, 2013; Ruiz et al., 2010; Silva et al., 2012). Further limitations of the evidence for this project is the lack of research exploring specific interventions and their impact on function with oncology rehabilitation practice of people of all ages, and especially with children. While this restricts the confidence clinicians may have in applying the intervention principles outlined in the evidence within this population, the evidence does strongly support trialing SI and vestibular focused interventions within pediatric oncology rehabilitation and with children with known cerebellar and central nervous system lesions (Anoh-Tanon et al., 2000; Arbesman & Lieberman, 2010; Bucci et al., 2004; Case-Smith et al., 2013; Jainta et al., 2011; Lane & Schaaf, 2010; McLean et al., 2017; Nilsen et al., 2014;

Rine & Braswell, 2006; Rine et al., 2004; Rine & Wiener-Vacher, 2013; Ruiz et al., 2010; Silva et al., 2012).

Implications & Conclusions

In reviewing current evidence for intervention plans and strategies to impact functional outcomes of children with centrally based PVVD, there are several implications for the proposed program that can be drawn from the currently available literature. These include:

- Currently available evidence consistently shows that visual, vestibular and SI focused interventions facilitate positive health outcomes for children with PVVD.
- Current evidence lacks details and guidelines for intervention protocols and strategies, which may impact execution of treatment approaches, especially with less experienced clinicians.
- The limitations of the current evidence base for intervention with central PVVD in children with cancer and other cerebellar and posterior neurologic conditions provide a lower clinical confidence in the application of these interventions in these populations.

Based on the current state of evidence for rehabilitative interventions for centrally based PVVD, significant considerations need to be made in the development of the proposed program. In developing intervention guidelines, the evidence does not provide specific protocols or highly reliable progressions of activities to promote change. Thus, substantial clinical reasoning, collaboration, and intervention tracking must be done to continually assess the efficacy of each intervention strategy. Further, the current evidence

does not explore how SI, motor and visual interventions are executed within pediatric oncology. While the evidence does support trialing these intervention strategies within this population, special care must be taken in considering the unique needs and clinical presentation of pediatric clients undergoing cancer related medical interventions while receiving rehabilitative care. Additionally, the restrictions and limitations of the application of the knowledge gained through this evidence review indicate that the proposed clinical program and clinical guidelines that will be developed as a part of this project may have a unique and substantial role in contributing to the development and expansion of the current state of evidence in this practice area. Not only will this program need to continually assess outcomes and program efficacy in order to best serve current and future clientele, evaluation of the program should be completed and published to contribute to the growing body of evidence related to pediatric oncology rehabilitation, pediatric vestibular rehabilitation, and the advancement of occupational therapy practice as a whole. Research of the program intervention guidelines and protocols is essential not only for the success of the program, but will also be integral in the advancement of rehabilitation science in order to impact the lives of children with cancer and other neurologic conditions on a much larger scale.

Summary Discussion

Upon extensive review of the current body of evidence and research-based literature related to theoretical foundations, evaluation of, and intervention for PVVD, consistent trends and guidelines for OT practice have been synthesized. Consistently, the use of SI and MLMC FORs in neurorehabilitation have been shown to be effective in

facilitating improved postural and motor outcomes in adults and children including balance, ataxia, coordination, and visual motor skills – all of which are known to be impacted by centrally based PVVD (Anoh-Tanon et al., 2000; Arbesman & Lieberman, 2010; Bucci et al., 2004; Case-Smith et al., 2013; Jainta et al., 2011; Lane & Schaaf, 2010; McLean et al., 2017; Nilsen et al., 2014; Rine & Braswell, 2006; Rine et al., 2004; Rine & Wiener-Vacher, 2013; Ruiz et al., 2010; Silva et al., 2012). While the evidence does not explicitly examine the use of these FORs for neurorehabilitation of children with CNS cancers, many studies do explicitly study children with CP with findings supportive of short term and long-term positive health outcomes with a combined theoretical approach to intervention including both SI and MLMC FORs. Based on the evidence review, expanding the use of the SI FOR within MPTD when working with children with CNS cancers, CP and other cerebellar based neurologic conditions and combining this approach with MLMC strategies supported by the current literature, OT practitioners may be able to more comprehensively, confidently and effectively address PVVD that challenges ADL/IADL participation and performance in this population.

To expand current practice, modification and additions to current evaluation and screening processes at MRH should be done to ensure comprehensive assessment that aligns with current evidence. Care will need to be taken in customizing assessment batteries to each child based on their age, cancer-related symptoms, activity tolerance, and medical status. While extensive balance and vestibular testing may be warranted and/or completed on a multidisciplinary level, initial, in-clinic assessments will need to be quickly administered, be valid and provide clarifying evaluation data, and be

reasonable to administer with children who may or may not have cognitive, behavioral, and/or significant physical limitations. Assessment batteries should be combined with functional and task-based ADL/IADL assessment and integrated into client-centered goal setting and treatment planning procedures.

When developing intervention protocols, plans and goals, this project will need to prioritize translation of theoretical and vaguely described research strategies into utilitarian, clinically relevant and explicit treatment activities, strategies and guidelines. In developing these guidelines, specific attention should be paid to the combination of SI and MLMC based strategies, as well as multivariable gradations and modifications of activities that will allow them to meet the "just-right" fit for children with a variety of functional levels and activity tolerances. Additionally, intervention activities and strategies will need to not just replicate the evidence but instead build on current evidence in order to maximally integrate the needs of the client and address the cerebrally based nature of the child's neurologic impairment in order to effectively facilitate functional improvements. In identifying these practice needs, translation of this knowledge in the form of therapist education and training will be essential in applying these principles in order to best serve this population of clients (Appendix B).

In summary, current evidence does support the need to expand the abilities of OT practitioners at MRH to support children with centrally based PVVD. However, gaps in the current body of evidence, including limited scope of the current research, also call for additional explorations of and sharing of knowledge in this area of practice. Thus, it will be imperative to extend the current program proposal to include scientifically rigorous

evaluative studies to ensure current and future practice at MRH remains based in the most up-to-date practice standards possible as well as to contribute to the growth and advancement of rehabilitation medicine.

CHAPTER THREE

DESCRIPTION OF THE PROPOSED PROGRAM:

The Marianjoy Rehabilitation Hospital Pediatric Therapy Department Occupational Therapy Pediatric Visual-Vestibular Program (MPTD OT PVVD Program)

DESCRIPTION OF THE INTERVENTION PROGRAM

The Marianjoy Rehabilitation Hospital (MRH) OT PVVD Program will be a combination of evidence-based practice resources, clinical education activities and materials, and intervention and program outcomes processes that will expand and drive pediatric rehabilitation services for children with CNS cancer/tumors and other cerebellar and centrally-based causes of visual-vestibular dysfunction impacting occupational performance and participation. Recent advancements in medical diagnosis and interventions have resulted in increased identification of childhood disability and a growing population of children living with neurologic conditions (Brandes & Franceschi, 2011; Houtrow et al., 2014; Lee et al., 2011; Smith et al., 2014; U.S. Census Bureau, 2003; U.S. Census Bureau, 2011). With these advancements, MRH has experienced significant increases in occupational therapy referrals for children with CP and CNS cancers within the MPTD (G. Girten, personal communication, June 27, 2017; NM, 2016). These children are overwhelmingly at risk for having significant PVVD that impacts occupational performance and participation, especially in ADL and IADL activities (Alghwiri et al., 2012; Archer et al., 2012; Cohen, 1994; Cohen et al., 2000; Dannenbaum et al., 2016; Konczak et al., 2005; Mehta & Stakiw, 2004; Pavao & Rocha, 2017; Rine & Wiener-Vacher, 2013; Roley et al., 2015; Syczewska et al., 2006; Tsao et

al., 2016; Walz & Baranek, 2006; Ward et al., 2013). Despite awareness of risk factors leading to PVVD, OT practitioners remain limited in their ability to comprehensively affect change in these performance deficits.

The MRH OT PVVD Program will target OT practitioners at MRH and the pediatric clients they work with to facilitate clinical excellence to impact positive health outcomes of the children served by the MPTD. The MRH OT PVVD Program will expand on current practice standards, modify and add to current evaluation and screening processes at MRH, and drive implementation of evidence-guided intervention strategies to facilitate improved occupational performance and participation, health-related quality of life (HRQoL), and positive health outcomes for children in the target population. The following will describe the proposed program, planned intervention and intended outcomes of the MRH OT PVVD Program based on a comprehensive synthesis of current evidence for practice in this field.

INTENDED RECIPIENTS AND RECRUITMENT METHODS

Clinical Intervention Recipients:

In a survey of OT practitioners in the MPTD, reports indicate that the majority of children with neurologic conditions treated within the program have been identified as having impaired visual/vestibular processing, gravitational insecurity, dyspraxia, and/or sensory-based movement deficits (Stone & Salentine, 2017). However, therapists report addressing vestibular dysfunction less than 50% of the time with these children (Stone & Salentine, 2017). However, there is significant evidence to support rehabilitation services to reduce symptoms, improve functional motor skills and improve performance,

participation and independence with ADL and IADL activities (Anoh-Tanon et al., 2000; Arbesman & Lieberman, 2010; Bucci et al., 2004; Case-Smith et al., 2013; Jainta et al., 2011; Lane & Schaaf, 2010; McLean et al., 2017; Nilsen et al., 2014; Rine & Wiener-Vacher, 2013; Silva et al., 2012).

1. Children with diagnoses of CNS cancer/tumors at all stages of cancer-related medical treatment who are referred to the MPTD for OT evaluations and treatments and are identified by the evaluating/treating OT practitioner as demonstrating signs/symptoms of PVVD or are at high risk for PVVD based on current and past medical history.

   Recruitment Methods: Preliminarily, internal recruitment will occur via education and collaboration with MRH physiatrists that write/make client referrals to the MPTD to increase awareness of PVVD, risk factors, signs and symptoms, and assessment and intervention resources and outcomes developed through the MRH OT PVVD Program. Current clients will also be recruited via clinical identification by their evaluating and/or treating OT practitioner following education, training and mentorship of those practitioners through the MRH OT PVVD Program. Anticipation of expanded recruitment efforts may include external sources including the NM Proton Center, Lurie Children's Hospital, Central DuPage Hospital, Loyola University Medical Center and other local pediatricians and medical practices that serve the target population. However, currently the MPTD has limited availability to accept external referrals as the program continues to grow and develop within the NM network.

2. Children with diagnoses of CP and/or other neurological, neurodevelopmental or neuromuscular conditions who are receiving or referred to the MPTD for OT evaluation and intervention and are identified by their evaluating/treating OT practitioner as demonstrating signs/symptoms of PVVD or are at high risk for PVVD based on current and past medical history.

   Recruitment Methods: Internal recruitment will occur via education and collaboration with MRH physiatrists that write/make client referrals to the MPTD to increase awareness of PVVD, risk factors, signs and symptoms, and assessment and intervention resources and outcomes developed through the MRH OT PVVD Program. Current clients will also be recruited via clinical identification by their evaluating and/or treating OT practitioner following education, training and mentorship of those practitioners through the MRH OT PVVD Program.

Educational and Clinical Training Recipients at MRH:

1. Current and future OT practitioners practicing in the MPTD will be the primary recipients of specific clinical education and training for use of the program developed tools to address PVVD in the target clinical intervention population. While vestibular rehabilitation has been shown to improve functional performance of ADLs when a central lesion or TBI was the cause of vestibular impairment, OT practitioners at MRH continue to lack confidence in their ability to maximize their client's potential for recovery. Current evidence confirms several factors limiting the ability of OT practitioners' ability to enhance client's performance of daily occupations (Berry & Ryan, 2002; Cohen, 1994; Mehta &

Stakiw, 2004; Norberg & Steneby, 2009; Rine & Wiener-Vacher, 2013; Roley et al., 2015; Soanes et al., 2009; Stone & Salentine, 2017; Walz & Baranek, 2006). Thus, it is imperative that OT practitioners in the MPTD be targeted to expand practice knowledge to facilitate implementation of optimal standards of care. Recruitment Methods**:** Current OT practitioners will be informed and provided with educational training during monthly MPTD meetings, via in-person recruitment and mentorship by the leading clinician of the MRH OT PVVD Program, and with support of MRH administrative staff responsible for clinic scheduling to allocate time to complete educational training and mentorship. Future practitioners will be identified at time of hiring and will have education/training via the MRH OT PVVD Program integrated into their new-hire orientation and mentorship period.

2. Current and future PT and SLP practitioners practicing in the MPTD will be secondary recipients of clinical education/training on PVVD and the proposed/developing program within the OT department to address this area of functioning for the target clinical intervention population. Overwhelmingly an interdisciplinary approach to rehabilitation for children with neurologic impairment has been shown to have the greatest impact on functional and health outcomes (Brandes & Franceschi, 2011; Konczak et al., 2005; Lee et al., 2011; Piscione et al., 2014; Rine & Wiener-Vacher, 2013; Scheinberg, 2015; Soanes et al., 2009; Syczewska et al., 2006; Tsao et al., 2016). As members of such a team in the MPTD, education and inclusion of PT and SLP practitioners is essential in

assuring optimal outcomes of the target client population.

Recruitment Methods**:** Current practitioners will be informed and provided with educational training during monthly MPTD meetings and/or via electronic communications. Future practitioners will be identified at time of hiring and will have education/training via the MRH OT PVVD Program integrated into their new-hire orientation and mentorship period.

3. Interdisciplinary team members of the MRH Pediatrics team will be secondary recipients of education and training efforts. This team is made up of medical and allied health practitioners and clinical administrators including: physiatrists and resident physicians, dietician/nutritionist, spiritual care team, psychologist, nurses, the MRH Pediatric Clinical Coordinator, Nurse Manager for the MRH inpatient pediatric unit, and pediatric case managers.

   Recruitment Methods**:** Current practitioners will be informed and provided with educational training during monthly MPTD meetings and/or via electronic communications.

Macro-level Educational and Clinical Training Recipients:

1. MRH and Northwestern Medicine administrators will be targeted in dissemination of clinical outcomes and research data to elicit ongoing support of the MRH OT PVVD program and the MRH Pediatric Therapy department as a whole.

   Recruitment Methods**:** Administrators will be identified for targeted knowledge dissemination through collaborative relationships with MRH physiatrists, MPTD leadership and the MRH Clinical Education team.

2. OT and other rehabilitative allied health practitioners will be the target audience for future published clinical research, dissemination of program design, outcomes and research findings at professional development events and conferences, and other professional publications to disseminate knowledge gained through the MRH OT PVVD program.

   Recruitment Methods**:** In-person and distance education opportunities will be identified (professional conferences, peer-reviewed journals and non-research publications, professional organizations, etc.) with presentation and evidence proposals submitted for publication/dissemination and to expand the reach of the MRH OT PVVD Program outside of MRH.

INTENDED PROGRAM OUTCOMES

The MRH OT PVVD Program aims to advance OT practice within pediatric oncology and neurologic rehabilitation through development of clinical skills of OT practitioners and implementation of evidence-supported interventions to promote optimal health outcomes for the target client population. Additionally, this program aims to more globally advance rehabilitation science and care for pediatric cancer survivors to facilitate improved quality of life (QoL) and improved participation and performance of daily occupations. The intended outcomes of the MRH OT PVVD Program are:

- Development and advancement of clinical competency and service provisions of the MRH oncology rehabilitation program

- Improved QoL, independence and participation in ADL, IADL, play and leisure activities, and reduction of functionally debilitating physical symptoms within the target population
- Increase research utilization by MRH OT practitioners in the area of PVVD rehabilitation and advance clinical skills of clinicians to maintain optimal standards of care within the MPTD
- Advancement of rehabilitation medicine and therapy practices to maximize survivorship outcomes of children with CNS cancer
- Advancement and expansion of OT practice within the area of pediatric oncology and neurologic rehabilitation and promotion of OT's unique role in these areas of rehabilitation

IMPORTANT FEATURES/ELEMENTS OF THE MRH OT PVVD PROGRAM

OT Practitioner resources for assessment and evaluation of PVVD

There is an overwhelming evidence base recommending that clinicians perform battery assessments consisting of multiple evaluation and screening tools in order to identify and determine the plan of care for children with PVVD (Choi et al., 2015; Hamilton et al., 2015; Konczak et al., 2005; Lawerman et al., 2017; Li et al., 2014; Liao et al., 2001; Mailloux et al., 2014; Mailloux et al., 2011; Nilsen et al., 2014; Norberg & Steneby, 2009; Ross & Helminski, 2016; Schupak et al., 2016; Toupet et al., 2016; Zwergal et al., 2009). Assessment batteries should include several screening tools and quick-to-administer standardized assessments and be supplemented with other formal standardized tests and clinical observations as appropriate (Bucci et al., 2004; Lane &

Schaaf, 2010; Nilsen et al., 2014; Norberg & Steneby, 2009; Ross & Helminski, 2016; Schupak et al., 2016; Silva et al., 2012; U.S. Census Bureau, 2003; U.S. Census Bureau, 2011). For PVVD, an assessment battery should include tools that assess subjective visual vertical (SVV), subjective postural vertical (SPV), dynamic visual acuity (DVA), vestibular ocular reflexes (VOR), balance, ocular motor control, motor coordination, symptom report questionnaires and quality of life measures (Berry & Ryan, 2002; Blanche et al., 2012; Choi et al., 2015; Cohen et al., 2000; Fisher et al., 1986; Hamilton et al., 2015; Konczak et al., 2005; Lawerman et al., 2017; Li et al., 2014; Liao et al., 2001; Mailloux et al., 2014; Mailloux et al., 2011; Nilsen et al., 2014; Ross & Helminski, 2016; Schupak et al., 2016; Toupet et al., 2016; Zwergal et al., 2009). As part of the MPTD OT PVVD Program, the tools and resources for clinical evaluation listed in table 3.1 will be created, revised, adapted or added to in order to ensure use of an optimal standard of care when working with the target client population.

Table 3.1 – Tools and Resources for Clinical Evaluation

Description	Details/Rationale

Revised OT Evaluation Kit to Assess PVVD	• One assessment battery kit per unit (outpatient/inpatient)
	• Kit will consist of brief overview of administration, scoring and score interpretation as able for each assessment/screening tool
	• Kit will include the following screening tools/assessments:
	  o MRH Vision Screen – Revised Pediatric Version
	  ▪ Optokinetic Screening
	  ▪ Revised ocular motor screening
	  ▪ Head Impulse Test (HIT)
	  ▪ Post-Rotary Nystagmus (PRN) screen
	  ▪ Subjective Visual Vertical screen (the Bucket Test) (Appendix H)
	  ▪ Subjective Postural Vertical screen (Appendix I)
	  ▪ Dynamic Visual Acuity Test
	  o Body Mapping screening
	  o Pediatric Vestibular Symptom Questionnaire (Appendix G)
	  o PedsQL Modules
	  ▪ Generic Core Scales
	  ▪ Pain Questionnaire
	  ▪ Brain Tumor Module
	  ▪ Cancer Module
	  ▪ CP Module
	  ▪ Neuromuscular Module
	  o SARA

Full-Form Assessment Resources	• On-site availability of the following for each screening tool/assessment listed above
	  o Full test administration and scoring manual
	  o Extra copies of test forms
	  o Additional reference/resource packet that may include case study examples

OT Practitioner resources for interventions to address PVVD

While vestibular rehabilitation has been shown to improve functional performance of ADLs when a central lesion or TBI was the cause of vestibular impairment (Cohen, 1994; Rine & Wiener-Vacher, 2013), OT practitioners continue to lack confidence in their ability to maximize their client's potential for recovery.

In a survey of OT practitioners in the MPTD, reports indicate that the majority of children with neurologic conditions treated within the program have been identified as having impaired visual/vestibular processing, gravitational insecurity, dyspraxia, and/or sensory-based movement deficits (Stone & Salentine, 2017). However, therapists report addressing vestibular dysfunction less than 50% of the time with these children (Stone & Salentine, 2017). Based on the gathered evidence, this service gap presumably stems from a lack of clinical guidance on how and when to intervene. Thus, it is imperative that evidence-based practice guidelines be developed in order to better steer OT practitioners as they work to support children with neurologic conditions achieve their full-potential in every day occupations.

Table 3.2 – Planned Resources for OT Practitioners

Description	Details/Rationale
Activity Resource Book	• Print and electronic copies of intervention activities for reference by OT practitioners including (Appendix M): o Decision trees for selecting intervention activities based on contraindications/precautions, inclusion/exclusion criteria, etc. o Play-based intervention activity descriptions with examples of upgraded/downgraded challenges to individualize the activity for children of varying functional levels o Guide to writing functional goals when PVVD is a barrier to participation; samples/examples included o Compiled list of intervention resources (e.g., blogs, research articles, YouTube videos, etc.)
Case Study Examples	• Electronic resources available on the department network drive including: o Video case samples o Images with written activity description and suggestions for modifications/adaptations to fit child's needs o Active links to blog posts, internet videos, etc. that offer additional examples

OT Practitioner resources for home programming and client/caregiver education to address PVVD

PVVD is often associated with significant challenges with functional mobility, increased fall risk/rate of falls, and decreased independence and participation in ADL/IADLs (Brandes & Franceschi, 2011; Houtrow et al., 2014; Konczak et al., 2005; Mehta & Stakiw, 2004; Piscione et al., 2014; Rine & Wiener-Vacher, 2013; Scheinberg, 2015; Syczewska et al., 2006; Tsao et al., 2016), though medical identification of the presence of PVVD is low (Mehta & Stakiw, 2004; Rine & Wiener-Vacher, 2013). Parents and caregivers of children who have or are at risk for PVVD must manage complex childcare and healthcare schedules, needs and routines. These parents and caregivers also may be experiencing significant levels of stress and trauma, which may impact their understanding and retention of their child's complex medical status (Norberg & Steneby, 2009; Soanes et al., 2009). As part of the MPTD OT PVVD Program, resources will need to be developed in order to guide rehabilitation clinicians in providing comprehensive, efficient and sufficient education to parents and caregivers of children with CNS cancer who present with or are at risk for PVVD. In doing so, clinicians will be better equipped to meet their parents and caregivers' learning needs and to increase their knowledge and understanding of PVVD in order to promote improved health and wellness and support positive health outcomes in this population.

Table 3.3 – Planned Caregiver Resources

Description	Details/Rationale
Educational Brochure on PVVD	• Print and electronic copies of a general client/parent/caregiver brochure for use by OT practitioners to: o Increase ease of integrating education about PVVD into daily sessions/evaluations o Increase caregiver knowledge/understanding of PVVD to empower them in making decisions about their child's care o Improve collaboration between the OT practitioner and caregiver on developing and implementing a plan of care that is client-centered o Supplement verbal education in print/visual manner to support the learning needs of caregivers
Educational Resource Book	• Print and electronic copies of samples, suggestions and resources for developing home exercise programs (HEP) and facilitating client/parent/caregiver education on PVVD and its impact on daily functioning. Including: o Sample HEP handouts o Written descriptions of HEP activities with instructions, safety considerations, precautions/contraindications and activity dosage recommendations for reference by the OT practitioner o Picture examples of activities with written description/instruction written at optimal literacy level of general caregiver population o Compiled list of resources OT practitioners can issue to parents/caregivers (e.g. website links, book recommendations, etc.)

OT Practitioner training and mentorship on PVVD and use of assessment and intervention resources

A major factor in the MPTD OT PVVD Program involves facilitating a change in current practice among OT practitioners. If the program seeks to facilitate this change at a micro or macro level of practice to better serve the target population, then utilization of structured and purposeful education, training and mentorship of practitioners within the MPTD is necessary (NCCMT, 2011; Sudsawad, 2007). Table 3.4 is a description of the

activities that will be utilized in order to maximize knowledge translation and research utilization by OT practitioners in the MPTD through the proposed program.

Table 3.4 – Planned Knowledge Translation Activities

Description	Details/Rationale
Needs Assessments of OT Practitioner Learning Needs/Preferences	• Needs assessment survey and results for use by lead OT practitioner to guide implementation of education/training to maximize knowledge translation and research utilization by participating OT practitioners
In-Person Education/Training Activities	• In-service to MPTD to provide general overview of program rationale, proposal and status of program development. • Periodic updates on program during monthly MPTD department meetings • Seminar and/or lab-based professional development course offered to OT practitioners within the MRH network focused on assessment and intervention for PVVD including: hands-on practice lab and video case-studies • 1:1 and/or small group mentorship meetings and practice labs provided by the lead OT practitioner as requested by participating OT practitioners • Lead OT shadowing/co-treatment with participating OT practitioners as requested to provide direct clinical mentorship
Web/Electronic-Based Education/Training Activities	• Creation of a self-directed learning module focusing on basic clinical knowledge of PVVD to be completed by OT practitioners prior to participation in the in-person seminar and/or lab-based professional development course • Recording of live seminar course or recording of information provided in seminar course to be utilized as a job-aid and mentoring tool for future/newly hired OT practitioners in the MPTD • Periodic email communication generated by the lead OT to participating personnel regarding program development updates, development/availability of new resources, modifications/updates to program resource kits, and use of email for 1:1 mentorship on PVVD and use of program materials as needed

Program Sustainability and Macro-Level Knowledge Translation

A thorough appraisal of current evidence was completed to guide the development of the MPTD OT PVVD Program. Nevertheless, the literature lacks specifically described intervention methods and highly reliable progressions of activities to be used in therapy sessions with children. Thus, substantial clinical reasoning, collaboration, and intervention tracking must be done to continually assess the efficacy of each intervention strategy. While the evidence does support trialing these intervention strategies within this population, special care must be taken in considering the unique needs and clinical presentation of pediatric clients undergoing cancer related medical interventions while receiving rehabilitative care. Additionally, the restrictions and limitations of the current evidence indicate that the MPTD OT PVVD Program may have a unique and substantial role in contributing to the development and expansion of the current state of evidence in this practice area. Not only will this program need to continually assess outcomes and program efficacy in order to best serve current and future clientele, evaluation of the program should be completed and published to contribute to the growing body of evidence related to pediatric oncology rehabilitation, pediatric vestibular rehabilitation, and the advancement of occupational therapy practice as a whole. Research of the program intervention guidelines and protocols is essential not only for the success of the program, but will also be integral in the advancement of rehabilitation science in order to impact the lives of children with cancer and other neurologic conditions on a much larger scale. The activities in table 3.5 will be integrated into this program to ensure sustainability of the program and ensure meaningful

contributions to current medical practices.

Table 3.5 – Planned Sustainability Activities

Description	Details/Rationale

Evaluation of Education/Training	• Post-training surveys completed by practitioners who participate in the program education/training activities to assess the effectiveness of the training on clinician confidence and competence in addressing PVVD
	  ○ Will be completed ~3 months after completion of self-directed learning module and attendance at the in-person professional development course
	  ○ Survey will focus on clinician use of materials, effectiveness and recall of information presented during trainings
	• Periodic surveys of therapists regarding their use of and experiences using program resources as needs assessment of necessary updates/adjustments to program offerings and training
	• Periodic follow-up surveys of caregivers and therapists utilizing intervention and caregiver educational resources to track use and evaluate the effectiveness of these resources and to serve as potential needs assessment of program modifications
	• Regular evidence review completed by lead OT with subsequent updates to program resources as necessary to ensure ongoing alignment of the program with best-practice standards

Client Outcomes Measurement	• Ongoing tracking of client data with statistical analysis for quality assurance evaluation of client outcomes to ensure optimal standards of care. Exploration of outcomes and data pertaining to new assessment and intervention tools will be included to evaluate efficacy and feasibility of program activities. • Clinical outcomes and clinical research to assess validity/reliability of assessment procedures and effectiveness of intervention activities (pending IRB approval)

In-Network and Macro-Level Knowledge Translation Activities	• Dissemination of results of quality assurance and clinical research studies that may include:
	  ○ Submission to peer reviewed journals (e.g. AJOT)
	  ○ Submission to professional publications (e.g. OT Practice)
	  ○ Professional presentations at professional conferences (e.g. AOTA and ILOTA annual conferences)
	  ○ Written reports for publication within MRH/NM networks, blogs, websites and/or social media accounts
	  ○ Written and/or live presentations to MPTD and/or MRH/NM stakeholders on program outcomes
	• Periodic in-person updates on program status and outcomes during MPTD monthly meetings and during 1:1 mentorship opportunities
	• Presentation of this program proposal, status of implementation and outcomes at professional conferences (e.g. AOTA, ILOTA) to expand the reach of the program and empower other practitioners to adapt the program or create their own program at their facility

General Program Resources

In addition to the activities and resources already stated in this proposal, the activities in table 3.6 will be integrated into the MPTD OT PVVD Program to optimize knowledge translation and implementation of the intended interventions.

Table 3.6 – General Program Resources

Description	Details/Rationale
Full-text copy of MPTD OT PVVD Program manual	• Print copy to be available on-site for reference and guidance of program lead and participating practitioners to support implementation/execution of evidence-based program • Electronic version available on department network drive for remote access and quick reference on department computers by participating staff
Full-Text and/or citation list of evidence utilized in development, implementation and evaluation of the MPTD OT PVVD Program	• Electronic copies of research articles and other evidence sources as feasible/able for reference by participating staff available on department network drive

ROLE OF PERSONNEL

Lead OT Practitioner

The lead OT of the program will take on the primary leadership role for program development and sustainability. The program lead will be the primary investigator of program outcomes and potential research-based evaluation of the program as well as the primary practitioner to provide education, training and mentorship to the OT practitioners targeted by the program. Additionally, the lead OT will serve as liaison between the MPTD OT program and the MPTD interdisciplinary team, physiatrists, administrative staff and administration to support implementation and integration of the program into the overall standard of care across the continuum of pediatric care at MRH.

MPTD OT Practitioners

The MPTD OT practitioners will be recipients of this program, and will carry out program interventions with the target client population at MRH. Following training and with ongoing mentorship, these clinicians will be tasked with utilization of program resources to administer the assessments and interventions developed through this program including provision of client/family education and documentation of client outcomes. Additionally, the MPTD OT practitioners will be involved in data collection and feedback about program efficacy and feasibility to ensure sustainability and ongoing validity of the program. Revisions, updates and additions to resources and program execution will be implemented in collaboration with these clinicians via periodic needs assessments.

MRH Pediatric Physiatrists

As the primary referral source for the MPTD, the MRH pediatric physiatrists will play an essential role in the success of the MPTD OT PVVD Program. With ongoing collaboration and knowledge sharing, the physiatrists will be tasked with identifying potential clients seen in their clinic that may be at risk for or show signs/symptoms of PVVD and referring them for rehabilitative services including an OT evaluation. As the physiatrists often follow and manage many aspects of the medical care for the target client population, the program lead and participating OT practitioners will collaborate with these physicians on client education, external referrals for additional support services, and complementary medical and therapy interventions to maximize positive health outcomes for these children and their families.

MRH Contracted Behavioral-Optometrist

To maximize client outcomes, the MPTD OT PVVD Program will align itself with the MRH Vision Clinic in collaboration with the MRH Vision Team and contracted optometrist that leads the clinic. The optometrist will collaborate with the program lead in ongoing program improvement processes, collection and tracking of outcome data and quality assurance efforts to maintain effective knowledge sharing and collaboration between the vision clinic and OT practitioners providing intervention to the target client population. With referrals to the vision clinic, clients will see the optometrist to obtain comprehensive optometric exams and recommendations for orthoptic interventions, vision accommodations, and other sight and vision interventions. The optometrist will serve as an additional member of the program team to provide comprehensive client/family education on PVVD and recommended interventions and will collaborate with the client's treating OT to maximize positive health outcomes.

MPTD Interdisciplinary Allied Health Team

Members of the MPTD allied health team work closely with many clients and potential clients of the target population. With training/education on the MPTD OT PVVD Program, these clinicians will support the OT team in identifying clients that are at risk for or show signs/symptoms of PVVD and communicating concerns to the child's evaluating/treating OT practitioner and/or the program lead as part of the recruitment process for the target client intervention population. Collaboration between the OT practitioners and other team members will provide essential information to support the OT in individualizing interventions to maximize client health outcomes.

MRH Clinical Education Team and Administrators

The MRH Clinical Education team will be used to support the program lead and OT practitioners in maintaining the highest and most optimal standard of care provided under the MPTD OT PVVD Program. Clinical educators will provide practitioner support in endeavors including development of educational materials, planning and execution of research, program planning and process implementation.

MRH allied health administrators will also serve as support for the program lead in promoting the MPTD OT PVVD Program within MRH and across the NM network to increase referral sources to expand the impact of the program within the surrounding communities. Administrators will also play a role in budgetary and financial supports to enable the program lead to travel and participate in macro-level dissemination activities such as presenting at conferences and other professional events.

Potential Barriers/Challenges and Solutions

As with any new program or clinical endeavor, the MRH OT PVVD Program will need to account for potential challenges or barriers to implementation. The list in tables 3.7 and 3.8 outlines anticipated obstacles and potential solutions to address these challenges as they arise.

Table 3.7 – Anticipated Program Obstacles and Solutions

Barrier	Explanation	Solution(s)
Time availability of lead practitioner and participating practitioners to contribute to program development, implementation and evaluation	Productivity standards/expectations, complex care needs of pediatric clients and the resulting limitations in time allotted to therapists during the work day to complete indirect care and non-billable activities may impact personnel resources and the time practitioners can contribute to the many indirect care tasks associated with development and implementation of the program and the time needed to plan and execute program evaluations.	• Collaborate with administrative staff/supervisor to make periodic schedule accommodations for the lead practitioner to dedicate to program activities. This may be best utilized during low census periods • Utilization of time made available via late appointment cancellations by clients to contribute to program activities • Delegation of tasks by the lead practitioner among the program team members to reduce work load on lead practitioner as appropriate • Collaborate with team members to develop efficient plans of action to maximize time utilization for program activities • Keep consistent data tracking and utilize program outcomes to justify approval for additional non-billable time to support program development and outcomes to administration • Mentor and train other clinicians as identified through program mentoring activities to share leadership roles within the program with the lead practitioner • Utilize clinical education and administrative staff for completion of non-clinical program activity completion
Referral source of target client population	Disagreement among medical professionals and limited clinical evidence that clearly and concretely justifies the need for PVVD intervention in the target population may pose a challenge in recruiting said population of clients to the program, thus potentially impacting the feasibility and sustainability of the program.	• Develop and maintain rapport and interdisciplinary working relationship with MRH physiatrists, vision clinic optometrist and other medical staff encountered at MRH to maximize avenues of communication and collaboration to maintain the internal referral source • Provide periodic updates of evidence and program status to the interdisciplinary team in formal/informal communications to justify need for and maximize referral source potential • Offer to provide written, verbal and/or in-person education or participation in collaborative working meetings with providers to expand and maintain external referral source • Contribute to growing evidence base with written/published outcomes and research in medical /allied health evidence sources to strengthen justification for the program and interventions provisioned through the program

Table 3.8 – Anticipated Program Obstacles and Solutions Continued

Barrier	Explanation	Solution(s)
Ensuring **consistency of assessment and interventions** among participating practitioners	Newness of assessment and intervention activities, variations in clinical style and various skill/experience levels of OT practitioners at MRH poses a potential challenge in how to ensure standardization and consistent utilization and implementation of these activities when working with the target client population	• Integrate hands-on, lab-based learning activities into formal education/training sessions and mentoring interactions • Request occasional videotaped use of activities from clinicians to review and complete needs assessment for further training/accuracy of clinician carryover of learning • Provide intermittent refresher or re-training opportunities to current clients • Maintain mentorship relationships with all clinicians with periodic check-ins and observations to ensure consistency of carry-over of training • Utilize clinical education staff to supplement lead practitioner training/mentoring to develop and execute consistent feedback and learning opportunities for participating clinicians
Buy-in of MRH OT Practitioners to participate in professional development activities	Personal interests, past/current clinical experiences, and outlook/perspective on the scope of OT practice and the relevance/importance of the proposed program and interventions may limit clinician "buy-in" and motivation to actively participate in the programs educational, training, mentorship and implementation tasks, thus limiting the effectiveness and sustainability of the program	• Maintain daily working relationships with OT practitioners to collaborate and share clinical perspectives, knowledge and interests to maximize influence of lead practitioner and other participants to engage clinicians in necessary program activities • Focus training/education efforts on current staff based on their identified learning preferences/styles and interests based on needs assessment surveys and informal communications • Maintain consistent communication about program status, requests for feedback, and engaging therapists in conversations about the program to sustain awareness and engagement in program development and sustainability activities • Model clinical skills and follow-through with program plans to motivate and empower other clinicians to do the same • Utilize the clinical education team and administrative team members to develop the most effective and engaging education, training and mentorship opportunities to maximize clinician engagement

SUMMARY

Recent advancements in medical diagnosis and interventions have resulted in increased identification of childhood disability and a growing population of children living with neurologic conditions (Arbesman & Lieberman, 2010; Bucci et al., 2004; Fisher et al., 1986; NCCMT, 2011; Roley et al., 2015; Ross & Helminski, 2016). With these advancements, MRH has experienced significant increases in occupational therapy referrals for children with CP and CNS cancers. These children are overwhelmingly at risk for having significant visual-vestibular dysfunction that impacts occupational performance and participation, especially in ADL and IADL activities (Alghwiri et al., 2012; Allen & Casey, 2017; Baxstrom, 2009; Berry & Ryan, 2002; Choi et al., 2015; Dannenbaum et al., 2016; Houtrow et al., 2014; Konczak et al., 2005). Despite awareness of risk factors leading to pediatric visual-vestibular dysfunction, OT practitioners remain limited in their ability to comprehensively affect change in these performance deficits.

The MRH OT PVVD Program will address the current service gap and educational and training needs of MPTD OT practitioners. The program will focus on expanding clinician knowledge and practical clinical skills for assessment of and intervention for PVVD, advance current practice standards for care within pediatric oncology and neurorehabilitation in the area of visual-vestibular functioning, and contribute to the growing evidence base to promote OT's role within this area of practice while developing and continually improving the clinical program at MRH. The primary intended outcome of the program will be to expand services at MRH in an effort to facilitate improved QoL, occupational participation and performance, and overall

survivorship outcomes for children with CNS cancers/tumors and children with cerebellar based neurologic conditions through provision of new and modified clinical practice guidelines and provision of clinician education, training and mentorship.

CHAPTER FOUR

MRH OT PVVD PROGRAM EVALUATION AND SUSTAINABILITY PLAN

INTRODUCTION

Evaluation of the MRH OT PVVD Program will involve two separate program evaluation components: (1) evaluation of the knowledge translation process for educating/training OT practitioners within the MPTD and (2) evaluation of the developed clinical assessment and intervention procedures for direct clinical use with children being seen for OT services within the MPTD. Examination of the knowledge translation process with the practitioner participants of the program will utilize qualitative and quantitative evaluation strategies. These strategies will assess the value and effectiveness of instructional, educational and mentorship activities within the program as well as learning retention among the practitioner participants (Appendix E). Program evaluation of the clinical components will integrate quasi-experimental pre-/post-test procedures. These will be used to explore the effectiveness of the developed assessment and intervention protocols by comparing baseline and post-intervention changes in PVVD in the pediatric participants of the program (Appendix F).

EVALUATION OF EDUCATIONAL AND CLINICAL TRAINING COMPONENTS

Purpose

In order to assess the effectiveness of the planned staff education and training activities as part of the MRH OT PVVD Program, qualitative and quantitative evaluation strategies will be executed as part of the overall evaluation and sustainability plan for the

program. To ensure successful knowledge translation, it will be necessary to evaluate the application and evaluation of evidence as it is used as part of routine practice (NCCMT, 2011). The purpose of the evaluation activities will be (1) to determine if immediate and sustained learning has occurred among the practitioners that participate in the formal education and training activities on PVVD assessment and intervention, and (2) to measure clinical competence in this area of rehabilitation to ensure ongoing clinical excellence and sustainability of the program.

Evaluation Plan

Participants

OT practitioners within the MPTD who attend and participate in formal education, training and mentorship activities will be the participants in this portion of the program evaluation plan. During the initial roll-out of the MRH OT PVVD, the current primary OT staff of the MPTD will be recipients of the education and training components of the program; thus, they will be the primary participants of the program evaluation activities. However, as the program continues to develop and long-term education and training activities are developed and implemented, the participant pool will expand to include any additional registry and/or part-time OT practitioners at MRH that may provide services within the MPTD. Finally, this evaluation plan eventually may include practitioners who participate in educational and training activities offered to those who work outside of MRH.

Evaluation Design

Survey Evaluation

A cross-sectional descriptive survey study will be conducted following implementation of formal education, training and mentorship activities with OT practitioners within the MPTD to assess **learning retention** of the practitioners. Data will be collected on multiple occasions from participants:

1. At the conclusion of each formal education/training session to assess immediate recall of learned information covered in each session
2. Within 2 weeks of the completion of all formal education/training session to assess short-term recall of learned information covered in all the sessions.
3. At 3 months after the completion of all formal education/training sessions to assess long-term recall of learned information covered in all the sessions

At the end of each individual formal education/training session, an electronic or paper/pencil multiple choice and/or fill-in-the-answer survey will be conducted with each participant as is typically done at the conclusion of many formal continuing education courses. At the 2-week and 3-month follow-up points, an electronic multiple-choice survey will be emailed to all participants to assess short- and long-term learning retention. In-person and electronic follow-up done by the program lead will be utilized to maximize participant engagement in the survey within 10 days of receipt to ensure validity of survey responses as they pertain to this evaluation plan. The evaluation design is described in more detail in table 4.1.

Table 4.1 – Evaluation Design

<table>
<tr><th colspan="2">Dependent Variable</th><th>Independent Variable</th><th>Outcome Measure</th><th>Admini-stration</th><th>Measurement Procedure/ Data Analysis</th></tr>
<tr><td colspan="5">Effectiveness of knowledge translation:</td><td rowspan="4">Survey items will be developed by the lead practitioner providing training and cross-checked by a MRH clinical educator to ensure maximal validity/reliability of the measure. Surveys will be collected from each participant with learning measured by number of items answered correctly on the survey, with scores transformed to percentages. Adequate learning will be determined by a score of 75% or higher for each participant. Scores from all participants will be averaged with the same parameters to indicate adequate group learning</td></tr>
<tr><td>1.</td><td>Immediate recall learning of participant</td><td rowspan="3">Formal education/ training sessions</td><td>5-10 question multiple choice survey based on info presented during individual sessions</td><td>Immediately at conclusion of the session -paper/pencil assessment</td></tr>
<tr><td>2.</td><td>Short-term recall learning of participant</td><td>10-15 item multiple choice survey based on info presented during all sessions (questions from session surveys)</td><td>Electronic survey within 2 weeks of completion of all training sessions</td></tr>
<tr><td>3.</td><td>Long-term recall learning of participant</td><td>10-15 question multiple choice survey based on info presented during all sessions (questions from session surveys)</td><td>Electronic survey 3-4 months after completion of all training sessions</td></tr>
<tr><td colspan="2">Participant learning experience</td><td>Formal education/ training sessions</td><td>5-10 question multiple choice survey based on information presented during individual sessions</td><td>Paper/pencil or electronic survey within 72 hours of completion of each training session</td><td>Survey items will be developed by the lead practitioner providing training and cross-checked by an MRH clinical educator to ensure maximal validity/reliability of the measure. Questions will be scored on a 5-point Likert scale with adequate facilitation of positive learning experience determined if each item and average of all items scored at 3.5 or higher.</td></tr>
</table>

Clinical Competency

To assess clinical competency in the **application** of the knowledge translated through the educational, training and mentorship activities of the MRH OT PVVD Program, 1:1 clinical observation and assessment will be completed by the lead OT with each of the participants. An objective and standardized clinical competency tool will be created by the program lead for use in this stage of program evaluation to ensure consistent and objective evaluation of each participant's clinical competency. Use of the tool and assessment of clinical competency will be done after each participant completes all formal educational and training activities and has sufficiently completed the necessary formal clinical mentorship, as determined collaboratively between the participant and program lead. The competency check-off will occur no more than 1 month after the participant completes all education, training and mentorship activities.

To ensure sustained competence among OT practitioners in the MPTD, use of the developed competency tool and clinical check-offs may be implemented annually with clinicians if requested and/or deemed necessary or appropriate by the program lead and clinical education team at MRH. Additionally, use of the competency tool and clinical check-offs will occur with newly hired OT staff within 6 months of their hire date and/or after completion of formal educational and training activities as these become more standardly part of the MPTD OT orientation process. This evaluation design is described further in table 4.2.

Table 4.2 – Evaluation Design – Clinical Competency

Dependent Variable	Independent Variable	Outcome Measure	Administration	Measurement Procedure/ Data Analysis
Clinical competence in PVVD **Assessment**	Formal education/ training sessions	**Clinical competency tool** Practitioner performance of each assessment activity based on assessment and program protocols and adapted/modified appropriately for the child being assessed. Practitioner performs successfully with at least 2-5 children	Direct observation of practitioner within 6 months of completion of PVVD training	Competency tool will be made up of at least 5-10 objectively measured and observable performance measures related to PVVD assessment and 5-10 items related to PVVD intervention. The competency tool will be developed by the lead practitioner and cross checked by the clinical education department to ensure maximal validity/reliability. The lead practitioner will be tasked with evaluating each practitioner trained through the PVVD program to ensure clinical competence based on objective observational data. Competency will be determined when 100% of items on the competency tool are performed successfully by the practitioner. OT department competency will be determined when at least 80% of OT practitioners in the MPTD successfully complete the competency checkoff
Clinical competence in PVVD **Intervention**		**Clinical competency tool** Practitioner performance of at least 3-5 intervention activities based on activity and/or program protocols and adapted/modified appropriately for the child being treated. Practitioner performs successfully with at least 2-5 children		

Practical Considerations and Summary

While initial development of educational and training sessions and the program evaluation of the knowledge translation process will be the responsibility of the lead practitioner, much of these efforts will be done in collaboration with the clinical

education team at MRH. Still, in developing these activities and evaluation plan, the intention will be to develop sustainable processes that will be less time-consuming and allow additional trained practitioners to participate in executing the training and collection of outcomes data, thus sharing these responsibilities and lessening the burden on the lead practitioner. With successful implementation of the initial evaluation plan, repeat outcomes measures will be able to be gathered with minor editing/adjustments to the data collection plan and tangibles required to execute such a study.

EVALUATION OF CLINICAL INTERVENTION COMPONENTS

Purpose

The purpose of this program evaluation will be to examine the effectiveness of the newly developed assessment and intervention protocols for use by the MPTD OT practitioners as part of the MRH OT PVVD Program. Pediatric neurologic and oncology rehabilitation is a growing practice area, though evidence guiding therapy practitioners remains limited, especially when working with children actively receiving radiation therapy (RT) and chemotherapy for CNS cancers. Given the limited current evidence to guide current intervention procedures, this single-subject design will objectively assess the effectiveness of the developed program and guide future modifications and development of such intervention strategies to benefit the growing population of children being served through the MRH OT PVVD Program and beyond. The two primary research questions being addressed by this evaluation is:

1. Do the new/revised OT assessment protocols developed through the MRH OT PVVD Program objectively measure change in participant's PVVD?

2. Do the recommended OT intervention activities focused on PVVD rehabilitation improve health related quality of life (HRQoL), independence in self-care skills and decrease impact of debilitating symptoms?

While the primary evaluation plan will involve a quality assurance program evaluation, long term evaluation of the program and developed practice guidelines will include a more formal research study. This study will involve more rigorous evaluation and experimental standards, at which time pursuance of IRB approval for a clinical research study can be initiated. Initiation of this research study will have to be done in collaboration with my facility's quality assurance committee and/or IRB board and the physiatrist who manages rehabilitation referrals. Throughout the process, the lead practitioner will collaborate with the clinical education team and research coordinator at MRH to maintain compliance with legal and practice standards related to quality assurance and clinical research studies.

Evaluation Plan

Setting/Participants

The proposed program outcome evaluation will be completed within the outpatient/day rehabilitation programs in the MPTD. The participants will be individual clients between the ages of 6-18 years who present for OT rehabilitative intervention and have been identified as having or being at risk for PVVD. Inclusion criteria will include medical diagnosis(es) of standard, low or medium risk CNS cancer, CP and/or N/TBI, and a plan of care determined by the evaluating OT to be $\geq$ 3 months and able to participate in all or the majority of the designated outcome measures. Exclusion criteria

will include high-risk and/or diagnosed poor medical prognosis related to cancer diagnosis, unknown etiology of neurologic involvement, diagnosis of acute or chronic concussion, pre-morbid neurologic, neuromuscular, and/or developmental conditions (prior to diagnosis of CNS cancer or onset of BI), and inability to participate in outcome measures at baseline and the 3- and 6-month data collection points.

Additionally, a participant pool will be recruited from among the inpatient rehabilitation unit in the MPTD. Inclusion/exclusion criteria will be the same, though the data collection points will be at admission and discharge from the inpatient unit, with the client's plan of care determined to be >1 week on the inpatient unit to allow for adequate time to implement interventions. Recruitment and evaluation of two participant groups (outpatient/day rehabilitation and inpatient) is crucial. The MPTD serves both populations, so assessments and interventions developed through the MRH OT PVVD Program are relevant for children who are seen by OT practitioners at both levels of care. However, given the acuity of medical status of children who are seen on the inpatient unit at MRH, separate evaluation standards should be utilized to ensure validity of the outcome measurements.

Evaluation Design

To complete this program evaluation, a quasi-experimental pre-/post-test design will be utilized. Several factors were considered in developing the plan for this evaluation design including number of practitioners participating in the program, time allotted to practitioners for direct and indirect client services, client pool and overall size of the MPTD, factors influencing practical data collection, and the newness of the MRH OT

PVVD Program. Given these barriers/limitations a quasi-experimental design has been determined to be most beneficial to assess outcomes of the program related to direct client assessment and intervention. The program evaluation will occur across the outpatient and day rehabilitation program as well as in the MPTD inpatient program as outlined in table 4.3.

Table 4.3 – Program Evaluation Plan

	Outpatient/Day Rehabilitation	**Inpatient**
Practitioner Participants	5 OT practitioners in the MPTD carrying caseloads within the single service and/or day rehabilitation programs	2 lead inpatient OT practitioners in the MPTD
Child Participants	1-2 clients from each practitioners' caseload (total n $\geq$ 10)	2-3 clients practitioners' caseload (total n $\geq$ 5)
Data Collection Points	Evaluation or within 2 sessions from initial evaluation	Within 72 hours of admission
	3 months after initial evaluation	Within 72 hours of discharge
	6 months after initial evaluation	

Variables and Outcome Measures

Evidence has shown that PVVD negatively impacts a child's ability to be independent in age-level self-care skills and the child's ability and tolerance to participate in play-based activities for learning and social-emotional development (Archer et al., 2012; Konczak et al., 2005). Thus, the primary dependent variables for the evaluation of the program's clinical components will be health-related quality of life and level of independence and participation tolerance for self-care ADLs. Additional dependent variables that will be considered include physiological abilities and responses including balance, ataxia, ocular motor coordination, gross and fine motor coordination,

visuospatial perception, and vestibulo-ocular and vestibulo-spinal reflexes. These areas of physiological and neurological functioning have been highly correlated with centrally based visual and vestibular dysfunction in adult and pediatric populations (Valente, 2011).

Baseline measurements for the outpatient/day rehabilitation group will be taken during the OT evaluation or within 2 sessions from the initial evaluation; follow-up measurements will occur at 3 and 6 months after the initial evaluation. For the inpatient group, measurements will be taken within 72 hours of admission and discharge from the unit. All measurement and interventions will be carried out by an occupational therapist with a minimum 2 years of experience working with pediatric clients and who has completed all the education/training activities and competency checkoff as part of the MRH OT PVVD Program. A description of the assessments that will be used are outlined in tables 4.4 through 4.8

Table 4.4 - Self-Care ADLs

Assessment	Description/Rationale	Group	Data Collection Points	Measurement
WeeFIM	Based on clinical observation, parent and child report/interview to objectively measure participation/performance of self-care ADLs (AbilityLab, 2017*c*)	Inpatient	Admission Discharge	Total *0-56 when adding scores for 8 domains*
		Outpatient/ Day Rehab	Evaluation 3 month 6 month	

Table 4.5 - Health-Related Quality of Life (HRQoL) and Symptom Impact

Assessment	Description/Rationale	Group	Data Collection Points	Measurement
PedsQL™	The child and/or parent will complete the General Full-Form and the Brain Tumor, Cancer or Cerebral Palsy modules as appropriate based on age, cognitive status, and diagnosis as well as the Pediatric Pain Questionnaire to assess HRQoL (Varni, 2017)	Inpatient	Admission Discharge	Total Scores *0-100 with higher score = higher HRQoL*
		Outpatient/ Day Rehab	Evaluation 3 month 6 month	
The Pediatric Vestibular Symptom Questionnaire	The child will complete this 10-item symptom questionnaire to assess the impact symptoms are having on daily function (Pavlou et al., 2016; Appendix G)	Inpatient	Admission Discharge	Normed score *0-3 with higher score = greater symptom severity*
		Outpatient/ Day Rehab	Evaluation 3 month 6 month	

Table 4.6 - Gross and Fine Motor Coordination, Balance and Ataxia

At least one of the following:				
Assessment	**Description/Rationale**	**Group**	**Data Collection Points**	**Measurement**
BOT-2	This tool will be used to assess fine motor, gross motor, and bilateral coordination by using the subtests for Manual Dexterity and Upper-Limb Coordination (Manual Coordination) and for Bilateral Coordination and Balance (Body Coordination) at baseline and post-intervention points (AbilityLab, 2017*a*).	Outpatient/ Day Rehab	Evaluation 6-month	Composite Standard Scores *Average = 50+/- 10*
Scale for the Assessment and Rating of Ataxia (SARA)	This semi-quantitative measurement for ataxia can be used to measure gross motor function when ataxia is a significant symptom/side effect of the child's diagnosis (AbilityLab, 2017*e*)	Outpatient/ Day Rehab	Evaluation 6-month	SARA Ataxia Rating *0-40*
Pediatric Balance Scale	This criterion referenced measure can be a quick and easy to administer test of functional balance (AbilityLab, 2017*d*; Chen et al., 2013)	Inpatient	Admission Discharge	Sum of item scores *0-56 with higher score = better balance*
		Outpatient/ Day Rehabili-tation	Evaluation 6 month	

AND at least two of the following:

Table 4.7 - Gross and Fine Motor Coordination, Balance and Ataxia Continued

Assessment	Description/Rationale	Group	Data Collection Points	Measurement
Standardized Grip and Pinch Strength Testing	Standardized, age-normed testing of grip and pinch strength with a dynamometer and pinch gauge will be utilized to measure changes in functional strength. (Mathiowetz, Weimer & Federman, 1986)	Inpatient	Admission Discharge	Average for RUE and LUE in pounds *Gross grasp, tip, lateral and 3-point pinch*
		Outpatient/ Day Rehab	Evaluation 3 month 6 month	
Nine Hole Peg Test	This standardized age-normed test will be utilized to measure changes in fine motor coordination in response to intervention. (Mathiowetz, Weber, Kashman, & Volland, 1985)	Inpatient	Admission Discharge	Time to complete for RUE and LUE in seconds
		Outpatient/ Day Rehab	Evaluation 3 month 6 month	
Manual Muscle Testing (MMT)	MMT of bilateral upper extremities (BUE) will measure changes in functional strength along with clinical observations of posture and balance during testing. (Wadsworth Krishnan, Sear, Harrold, & Nielson, 1987)	Inpatient	Admission Discharge	0-5 Scale
		Outpatient/ Day Rehab	Evaluation 3 month 6 month	

Table 4.8 - Neurologic Functioning of Visual-Vestibular Systems

At least two of the following:				
Assessment	**Description/Rationale**	**Group**	**Data Collection Points**	**Measurement**
Subjective Visual Vertical – The Bucket Test	This performance measure will assess the child's visuospatial perception of verticality (AbilityLab, 2017*f*; Appendix H)	Inpatient	Admission Discharge	**Positive =** dysfunction/ abnormal response **Negative =** if no deficits/ abnormal responses present
		Outpatient/ Day Rehab	Evaluation 3 month 6 month	
The Dynamic Visual Acuity Test (DVA)	This performance measure assesses VOR function and gaze stability (AbilityLab, 2017*b*)	Inpatient	Admission Discharge	**Positive =** dysfunction/ abnormal response **Negative =** if no deficits/ abnormal responses present
		Outpatient/ Day Rehab	Evaluation 3 month 6 month	
Revised MPTD Vision Screen	This group of clinical observations will assess vestibular and ocular motor impairments. It will be administered at each measurement point and will include the following domains: ocular alignment, horizontal and vertical smooth pursuits and saccades, gaze holding, optokinetic reflex, teaming/binocularity and accommodation	Inpatient	Admission Discharge	**Positive =** dysfunction/ abnormal response **Negative =** if no deficits/ abnormal responses present
		Outpatient/ Day Rehab	Evaluation 3 month 6 month	

Measurement Procedure & Data Analysis Plan

OT practitioners in the MPTD will be trained on the evaluation procedures and data collection plan as indicated for each outcome measure described above. Individual

practitioners will be tasked with executing the assessment plan for each child participant as part of their routine plan of care. Data from each of the outcome measures will be retrospectively pulled from the electronic medical chart for data analysis purposes. Data will be graphed and visual analysis and Z statistic analysis will be completed using the data collected for each participant. Analysis may include celebration line analysis, binomial test, and C and Z statistic tests.

Practical Considerations

Given the medical complexity of the participants, the severity of symptomology present in this population, and potential ethical concerns if intervention were to be withdrawn, the quasi-experimental design with retrospective data collection will offer the greatest objectivity while maintaining the integrity and benefit of OT intervention for each participant. Additionally, due to the medical complexity and variability in presentation associated with cancer-related treatment and side effects, attendance may be a factor that limits potential data collection. However, given that currently there is no research or literature that explores this type of intervention in this population at this stage of medical treatment, any results obtained through this program evaluation will be beneficial in guiding practice and future research.

Summary

Through this program evaluation, practical, meaningful and useful data and outcomes will be collected to support the ongoing development and growth of the MRH OT PVVD Program. This evaluation design will also lend itself to ongoing data collection following initial data analysis and any necessary adaptations/adjustments are

made to variables and outcome measures utilized within the program. With continuous data collection, this quasi-experimental approach to program evaluation will lend itself easily to the exploration of additional evaluation endeavors that will support the MRH OT PVVD Program and contribute valuable information to OT practice and rehabilitation science at MRH and beyond.

In summary, evaluation of the MRH OT PVVD program will involve program evaluation of the staff training and education activities as well as evaluation of the effectiveness of the developed practice guidelines for assessment and intervention for PVVD in the target population. Evaluation of both aspects will be crucial to ensure successful knowledge translation from the lead practitioner to MPTD OT staff to facilitate consistent carryover of program assessment and intervention activities. Additionally, given the limitations in the current evidence to guide OT practitioners in assessment and intervention of PVVD, evaluation of the effectiveness of the developed practice guidelines is essential to facilitate optimal care and improved health outcomes in the target population and to maintain alignment with optimal standards of care.

CHAPTER FIVE

FUNDING PLAN

INTRODUCTION

As medicine advances and more children survive with neurologic injuries, impairments and challenges and participate meaningfully in daily life, OT practitioners must stay up to date on current evidence to guide their practice in order to optimize functional outcomes for their clients. The Marianjoy Rehabilitation Hospital (MRH) OT PVVD Program aims to develop, educate and train OT practitioners on the use of evidence guided principles to address PVVD in children with neurologic impairment in order to facilitate improved health and wellness outcomes for this population of survivors. A combination of in-person, print, electronic/online education and training modalities will be utilized to expand OT practice in the area of oncology and neuro-rehabilitation at MRH and beyond.

PROGRAM BUDGET

In order to develop and execute essential clinical and non-clinical activities to realize the MRH OT PVVD program's potential, significant cost consideration must be undertaken. The largest expense for the implementation of this program is non-billable time spent by the lead practitioner, MPTD OT practitioners and other MRH staff in program development and participation in education and training sessions. The largest portion of this will come from time spent by the lead practitioner in the initial 1-2 years of program development and outcome evaluation, with significant cost associated with MPTD OT practitioner time spent in education and training sessions during year 1 of the

program. As the program becomes more established, there will be a significant decrease in non-billable time spent by all participants in order to sustain the program. Table 5.1 lists program budget items related to the activities the lead practitioner will be responsible for.

Table 5.1 – Program Budget Items for Lead Practitioner

Activities	Cost
Planning/Development non-billable time • Development of OT practitioner education/training sessions and learning modules • Evidence reviews and development of intervention activities • Organization and operational planning of program activities and resources • Planning meetings with clinical educator and MPTD administrators • Planning and collaborative meetings with MRH IT services for development of documentation/data tracking methods • Planning and collaborative meetings with MRH research director on outcomes measures and data analysis • Planning and collaborative meetings with behavioral/neuro-optometrist • Data analysis and writing outcomes reports and publications • Networking meetings to facilitate avenues for dissemination • Attendance at CE courses/seminars/activities to expand evidence/knowledge base on PVVD Educational/Training non-billable time • Instructional time for classroom/formal education/training sessions • Data collection and analysis of surveys/quizzes as part of evaluation plan Clinical mentorship and assessment non-billable time • 1:1 mentorship of MPTD OT practitioners • Clinical competency check-off assessment administration Administrative time/in-house dissemination efforts • In-services/presentations to administrators, physicians, and MPTD stakeholders • In-services/presentations to NM facilities and administration • Seminars and CEU course preparation and presentation to MRH staff	**$40/ hour**
Dissemination Activities • Non-billable time to write reports, publication manuscripts, research/IRB proposals, conference proposals, and internal memos/dissemination reports • Presentation at local, regional and national professional conferences	

Additional personnel costs will need to be considered in the development of the program budget. Table 5.2 outlines the costs associated with these personnel needs.

Table 5.2 - Program Budget Items for Other Personnel

Personnel	Activities	Cost
OT Practitioners	Non-billable time • 1:1 non-clinical mentorship • Classroom/formal educational/training sessions • Self-directed learning modules Reimbursed clinical time • 1:1 clinical mentorship/shadow/co-treat • Clinical competency check-off assessment	**$30-45/hour individually** **$175-225/hour with all 5 participating**
Clinical Educator	• Development of OT practitioner education/training sessions and learning modules in partnership with lead practitioner • Planning meetings with lead practitioner and MPTD administrators • Data analysis and writing outcomes reports and publications in partnership with lead practitioner • Setup/cleanup and assistance with OT practitioner education/training sessions	***services built into position's salary**
Research Director	Planning and collaborative meetings with lead practitioner on outcomes measures and data analysis	***services built into position's salary**
Pediatric Rehab Technician	Obtaining, organizing and managing program equipment, storage and resources as directed by lead practitioner	**$20/hour**
Volunteers	Obtaining, organizing and managing program equipment, storage and resources as directed by lead practitioner and pediatric rehab technician	**$0/hour**

PROGRAM EXPENSES

In addition to staff related budget items for the program, there will be some upfront costs associated with implementation of the MRH OT PVVD Program. Integration of assessment and intervention activities new to the MPTD will need to be funded as well as consideration of costs associated with print, electronic and in-person

education and training sessions for MPTD OT practitioners. However, with current resources available through NM and MRH for MPTD staff, and availability of low to no-cost assessment materials, these costs will be negligible. The most significant cost involved with the program activities likely will involve costs associated with providing printed materials for education/training sessions, outcomes surveys, and print resources/guidelines available for in-clinic use. Table 5.3 includes the program expense items.

Table 5.3 – Program Expense Items

Expense Item	Description/Cost
Assessment Materials/ Supplies	• **Scale for Assessment Rating of Ataxia (SARA)** – $0; available as free download • **Subjective Visual Vertical – Bucket Test** - $20 bucket and parts; score guidelines and score sheet available as free download • **Vision Screen** - $0; modified from current MRH vision screen using items available free within evidence sources • **Optokinetic screening** - $1-5 iPad app and guidelines available in evidence sources • **Dynamic Visual Acuity Test** - $0; available as part of NIH ToolKit iPad app with optional $499 subscription fee for access to data saving, score reports, and data exports • **Head Impulse Test (HIT)** - $0; guidelines available in evidence sources • **Post-rotary Nystagmus (PRN) screen** - $0; guidelines available in evidence sources • **Subjective Postural Vertical screen** - $0; based on clinical observation; guidelines available in evidence sources • **Pediatric Vestibular Symptoms Questionnaire** – $0; questionnaire and guidelines available in evidence sources • **PedsQL Modules** - $0; free for use in individual practice – up to ~$6k for annual license fee if for unlimited use for 1 year with studies with <200 patients
Intervention Materials/ Supplies	• ~$50-$75 for assortment of light and vision related toys • $0.03 - $0.05/page printed for paper/pencil activities and home exercise programs • $0.99 - $4.99/ iPad app download • $0 – current equipment and toys available within the MPTD
Educational/ Training Sessions	• Available at no cost for MRH staff o Educational/instructional classrooms o AV/IT equipment and resources needed for presentation o Personal computer and network drive for development and saving of educational materials and session preparation o iPad for photo and video recording for case study examples • Printed Materials - $0.03 - $0.05/page printed • Manipulatives and hands-on training equipment (most available for use already within MPTD equipment/intervention materials) - $50-100 for duplicates/extra materials
Print resources	$0.03 - $0.05/page printed $5-10/binder for storage of printed materials

OVERALL BUDGET

Combined, the personnel costs and materials expenses for this program will be the primary items taken into consideration when budgeting for this program. Tables 5.4 and 5.5 provide the initial program budget estimate.

Table 5.4– Initial Program Budget Estimate – Personnel Costs

Budget Item	Cost Summary	Program Year 1	Program Year 2
Personnel Costs			
Lead Practitioner	~$40/hour non-billable time	(5 hours/wk x 52 Wks) x $40/hr = $10,400	(3 hrs/wk x 52 wks) x $40/hr = $6,240
OT Practitioners	$30-45/hour individually $175-225/hour with all 5 participating	*Individual time:* (1-3 hrs/mo x 12 mo) x $30-45/hr = $360 - $1620/therapist x 4 additional OT practitioners = **$1,440 - $6,480** *Group time:* (3-6 hrs/quarter x 4 quarters) x $175 - $225/hr = **$2,100 - $5,400**	*Individual time:* (2-3 hrs/quarter x 4 quarters) x $30-45/hr = $240 - $540/therapist x 4 additional OT practitioners = **$960 - $2,160** *Group time:* (1-3 hours/quarter x 4 quarters) x $175 - $225/hr = **$700 - $2,700**
Clinical Educator	$0 – cost built into job salary	**$0**	**$0**
Research Director	$0 – cost built into job salary	**$0**	**$0**
Pediatric Rehab Technician	$20/hr	(10 hrs/mo x 12 mos) x$20/hr = **$2,400**	(10 hrs/mo x 12 months) x$20/hr = **$2,400**
Volunteers	$0	**$0**	**$0**

Table 5.5 – Initial Program Budget Estimate - Expenses

Program Expenses			
Assessment Materials/ Supplies	Varies	*Initial startup – creation/purchase of all assessments (NOT including DVA subscription or PedsQL license fee)* $25 + ($0.03 - $0.05/page printed x 9 assessments x 2-3 pages/copy x 100-200 copies) = **$80 - $300**	***Program Sustainability*** Cost of printed assessment pages ($80 - $300) + potential DVA subscription + possible PedsQL license fee = **$300 - $6,500**
Intervention Materials & Supplies	Varies	(Assorted vision/light toys $50-$75) + ($0.99 - $4.99/iPad app x 5-10 apps) + ($0.03 - $0.05/page printed for HEP/intervention materials x 500-1000 pages) = **$70 - $175**	(Assorted vision/light toys $50-$75) + ($0.99 - $4.99/iPad app x 5-10 apps) + ($0.03 - $0.05/page printed for HEP/intervention materials x 500-1000 pages) = **$70 - $175**
Educational and Training Sessions	$0 AV equipment/ space rental Varied cost for manipulatives and hands on training materials $0.03 - $0.05/page for printed materials	$0 AV/Space cost + ($10-$25/item x 3-5 activities x 5-7 participants) + ($0.03 - $0.05/page x 100 – 500 pages) = **$155 - $900**	$0 AV/Space cost + ($10-$25/item x 3-5 activities x 2-5 participants) + ($0.03 - $0.05/page x 50 – 250 pages) **= $65 - $650**
Print Resources	$0.03 - $0.05/page	$0.03 - $0.05/page x 500-1000 pages = **$15 - $50**	$0.03 - $0.05/page x 250-500 pages = **$10 - $25**
TOTAL BUDGET		**$16,660 - $26,105**	**$10,750 – $20,850**

POTENTIAL FUNDING SOURCES

With the primary cost associated with development and implementation of the MRH OT PVVD Program being non-reimbursable staff time, initial funding of the program will likely depend on petitioning MPTD supervisors and MRH administrators to allocate within the MRH operational budget the wages associated with the hours needed

for program activities. Secondarily, internal and external resources may be explored to fund additional expenses associated with program implementation and dissemination of the information, data and outcomes gathered through program development and evaluation efforts. A primary source of such funding may come from the NM and MRH Foundations department – an internal department focused on fundraising and searching for and writing for grant funding. Secondarily, outside funding sources may be considered including government funded grants, the American Occupational Therapy Foundation, and private not-for-profits and/or grant databases. Table 5.6 lists the internal and external funding sources that may be utilized to obtain supplemental funding for this program.

Table 5.6 – Internal and External Funding Sources

Funding Source	Description
Northwestern Memorial Foundation	http://foundation.nm.org/ NM and MRH department tasked with fundraising, grant writing and donor recruitment. Collaborating with the MRH foundations department may provide grant and/or private funding sources for part or the entirety of the funding needs
MPTD/NM Budget	Collaboration with MPTD and NM administrators to allocate funds from operational budget for the MPTD to go towards budget/expenses
NM Program Development Grants/Awards	Monetary awards/grants for program development, innovative practice awards/grants and development of clinical centers of excellence through corporate funds/budgets – monetary award varies
Government funded grants	Research, program/clinical intervention development and needs based grants and funding sources for studies and programs related to pediatric health, wellness, disability and oncology care - available through government agencies including the NIH, NCI, HRSA, and NCIHD. https://www.grants.gov
AOTF	Scholarships/grants for efforts to advance OT practice http://www.aotf.org/scholarshipsgrants
Patient Centered Outcomes Research Institute	Not-for-profit funding grants for programs and research that advance medical and allied health practice https://www.pcori.org/funding-opportunities
Fundsnet Services	Searchable database for funding/grant opportunities and resources. http://www.fundsnetservices.com/searchresult.php?sbcat_id=3

SUMMARY AND CONCLUSION

The primary cost to execute the MRH OT PVVD Program in years 1 and 2 are non-billable personnel costs, with the addition of potentially costly licensure and subscription costs associated with the selected assessment materials. While these personnel costs remain high, in comparison to the potential added income from an increase in referrals and billable time contributed by OT practitioners performing assessments and providing interventions for the target populations, these costs are relatively low. Similarly, many of the personnel costs for this program can be absorbed

by current budgeted dollars dedicated to non-billable education and administrative time for practitioners within the MPTD. Still, to maximize the success and outcomes of this program, exploration of supplemental funding sources will be highly beneficial to maintain fiscal responsibility and ensure ongoing justification of the non-reimbursable time needed from MPTD practitioners to facilitate success of this program.

CHAPTER SIX

POST-PROGRAM IMPLEMENTATION DISSEMINATION PLAN

INTRODUCTION

While the Marianjoy Rehabilitation Hospital (MRH) OT PVVD program will focus heavily in years 1 and 2 on staff training and outcomes measurement of the developed practice guidelines, the long-term objectives of the program will be to influence United States (US) OT practice to better serve children who face challenges related to PVVD. In order to achieve this macro-level objective to advance OT practice, in the years following the initial program implementation much care and effort will be focused on disseminating the acquired knowledge the MRH OT PVVD program produces to practitioners and influential stakeholders outside of the MPTD. This chapter will explain in detail the proposed plan for dissemination of the results of this program implementation.

GOALS AND OBJECTIVES OF THIS DISSEMINATION PLAN

After initial implementation of the MRH OT PVVD Program, ongoing consideration will be given to dissemination of the acquired information to share knowledge and expand OT practice in the area of PVVD rehabilitation outside of MRH. The goals and objectives of this plan are described in Table 6.1.

Table 6.1 – Long-term goal and short-term objectives

Long-Term Goal	The MRH OT PVVD Program will promote the unique role of OT in pediatric oncology and neuro-rehabilitation to expand OT practice and increase access to services that can facilitate meaningful and positive health and wellness outcomes for children across the U.S.
Short-Term Objectives	Within 1-3 years of program implementation, the lead practitioner will facilitate knowledge translation of assessment and intervention for centrally-based PVVD to OT practitioners through professional presentations at local, state and national professional conferences
	Within 2-5 years of program implementation, the lead practitioner will contribute to the current evidence base with professional publications in reputable OT practice mediums in order to guide OT practice in assessment and intervention of centrally-based PVVD.

KEY MESSAGES AND TARGET AUDIENCE

The primary target audience that this dissemination plan will focus on will be US OT practitioners practicing in pediatric rehabilitation who may work with children at risk for or have PVVD. With the development of clinical guides for assessment and intervention of PVVD, it is essential that the transference of this clinical knowledge occur across the U.S. in order to expand the clinical reach of the developed program. Secondarily, medical professionals involved in managing the care of and parents/caregivers of children at-risk for or have PVVD will also be targeted in this dissemination plan. Since clinical and parental identification of PVVD have been identified as a contributory factor in the justification for the MRH OT PVVD Program, dissemination of the information acquired through the development and implementation of this program is essential to share with these populations to sustainably facilitate children's access to PVVD rehabilitation services. For each of the target audiences, directed key messages regarding the results of this doctoral project will be conveyed to engage these groups in ongoing efforts to expand OT practice in the area of PVVD

rehabilitation. Table 6.2 lists the key messages for the primary and secondary target audiences.

Table 6.2 – Key messages for the primary and secondary target audiences

Message	Target Audience
Children with CNS cancer and/or other cerebellar-based neurologic conditions are at high risk for PVVD that can negatively impact participation and performance of daily occupations. These children can benefit greatly from rehabilitation services to address symptoms and barriers to participation presented by PVVD.	Primary Secondary – Medical & Parents/ Caregivers
Current medical and therapeutic methods do not adequately identify PVVD, and improved screening and assessments need to be done in order to facilitate access to appropriate services in order to optimize health and wellness outcomes for these children.	Primary Secondary - Medical
OT has a meaningful, impactful and unique role in facilitating improved short and long-term health, wellness and quality of life outcomes for children with or at-risk for PVVD.	Primary Secondary – Medical & Parents/ Caregivers
Parents, caregivers, pediatricians, neurologists, oncologists, physiatrists and others responsible for the care of children with CNS cancer and/or other cerebellar-based neurologic conditions need to consider OT services as an essential and medically necessary service for children who present with or are at risk for PVVD and should make appropriate referrals for OT services when symptoms or risk factors are present.	Secondary – Medical & Parents/ Caregivers
OT practitioners should assess for PVVD in children with CNS cancer and/or other cerebellar-based neurologic conditions and collaborate with parents/caregivers and the child's interdisciplinary health care team to provide comprehensive intervention services to facilitate improved occupational participation and performance.	Primary

In order to effectively communicate these key messages to the targeted primary and secondary audiences, reputable and influential messengers will need to be employed to engage the target audiences. The identified messengers and why they have been chosen

as credible spokespersons for sharing the key messages of this program are described in Tables 6.3 – 6.5.

Table 6.3 – Spokespersons to spread the key messages – Primary Audience

Primary Audience	Messengers	Rationale	Key Messages
OT Practitioners Across the US	Lead Practitioner	The lead practitioner of the MRH OT PVVD Program can and will serve as the expert clinician in the area of PVVD rehabilitation. As such, the lead practitioner can serve as a most effective promoter of the program and speak professionally and clinically to the needs of the target population and the services and outcomes the program can offer in order to most effectively translate knowledge to practitioners in a variety of geographic and practice settings in order to empower practitioners to expand their skills and services to include children with needs related to PVVD.	1, 2, 3, 5
	American Occupational Therapy Association (AOTA)	As the leading professional organization in the U.S. for OT practitioners, AOTA has an influential and powerful impact on OT practice and dissemination of practice guidelines, educational materials and professional development activities in all areas of OT practice. In collaboration with the lead practitioner, AOTA will enable a much broader audience for dissemination of PVVD rehabilitation and can be a champion for establishing OT as a routine standard of care in neuro- and oncology rehabilitation, especially when there is a risk or presence of PVVD.	

Table 6.4 – Spokespersons to Spread Key Messages – Secondary Audiences Medical

	Messengers	Rationale	Key Messages
Medical - Referring Physicians within MRH Referral Area	MRH Pediatric Physiatrists	These physicians have established professional relationships and referral sources from several local hospitals, private medical offices and medical treatment centers that serve children at high risk for PVVD. MRH pediatric physiatrists also has an established consultative clinic biweekly in the NM Chicago Proton Center collaboration with Central DuPage Hospital (CDH) and Lurie Children's Hospital through which they screen and follow many children receiving medical treatment for CNS cancer who may benefit from the services provided through the MRH OT PVVD Program. In collaboration with the lead practitioner, these physicians can encourage their peers to consider and screen for PVVD and PVVD risk and establish referral relationships between those physicians and the MPTD to support their efforts in caring for children in the target population.	1, 2, 3, 4
	Lead Practitioner	The lead practitioner of the MRH OT PVVD Program can and will serve as the expert clinician in the area of PVVD rehabilitation. As such, the lead practitioner can serve as a most effective promoter of the program and speak professionally and clinically to the needs of the target population and the services and outcomes the program can offer in order to facilitate an increase in referrals to the MPTD OT program.	

Table 6.5 - Spokespersons to Spread Key Messages – Secondary Audiences Family

Parents/ Caregivers of Children with or At-Risk of PVVD	MPTD Program Coordinator	The MPTD Program Coordinator serves as a liaison between the MPTD program and practitioners and the parents/caregivers of children receiving services at MRH. Additional roles of the coordinator include leading the therapy team in collaborative and interdisciplinary care efforts with physiatrists and other care providers to ensure optimal care provision to all children served at MRH. The Program Coordinator will be a valuable champion of the MRH OT PVVD Program in reinforcing its importance, clinical merit and impact on functional outcomes to support buy-in and engagement of parents and caregivers as they work with the MPTD practitioners.	1, 3, 4
	MRH Pediatric Physiatrists	As the primary lead of many children's rehabilitation care while they are seen at MRH, the pediatric physiatrists have established, trustworthy relationships with the parents and caregivers of the children in the program's target population. The physicians are often viewed as experts and an authority in collaborating with families to make medical and health related decisions that impact their child. In collaboration with the practitioners providing direct care to program participants, the physiatrists can reinforce program objectives, processes and outcomes with parents and caregivers that may strengthen the rapport between the client and the care team that can enable more positive outcomes for the child and the family as a unit.	

DISSEMINATION ACTIVITIES, MECHANISMS FOR DISSEMINATION AND BUDGET

In order to reach each of the identified target audiences of this dissemination plan, several tasks will be completed to translate knowledge acquired through the implementation of the MRH OT PVVD Program to the target audiences. These activities will include person-to-person contact activities (conference presentations, collaborative program planning, educational presentations, etc.), written information (educational

brochures, written dissemination articles, etc.), and electronic media (social media posts, electronic organizational reports, etc.). These activities will be executed over the span of approximately 5 years post program implementation, with initial priority placed on activities targeting audiences within the MRH and NM organizations then expanded to include target audiences outside of the NM network. A breakdown of the proposed activities, timeline, cost of each activity and personnel that will be responsible for executing each task are listed in Tables 6.6 and 6.7.

Table 6.6 – Dissemination Activities – Person-to-Person Contact

Activity	Target Audience	Timeline	Responsible Party	Cost
Professional Conference presentations (i.e. AOTA, ILOTA, etc.)	• Primary	Year 1+	• Lead Practitioner with support from clinical educator	~$1000/ conference *(registration, travel, presentation costs)*
Collaborative planning meetings and in-services with MRH staff, medical and administrative leadership	• Secondary – Medical	Year 1+	• Lead Practitioner • MRH Pediatric Physiatrist • MPTD Program Coordinator	Cost of non-billable wages of involved parties
Educational Presentation to physicians and care teams at partner healthcare facilities (i.e. CDH, NMCPC)	• Secondary -Medical	Year 1-2	• Lead Practitioner • MRH Pediatric Physiatrist • MPTD Program Coordinator	Cost of non-billable wages of involved parties
Guest lectures and in-service presentations at local, regional and national OT practitioner educational programs	• Primary	Year 2-5	• Lead Practitioner	Cost of non-billable wages Travel expenses (varies)

Table 6.7 - Dissemination Activities – Written Information and Electronic Media

Written Information				
Professional reports and articles submitted to reputable OT practice sources (i.e. AJOT, OT Practice, etc.)	• Primary	Year 2-5	• Lead Practitioner in collaboration with clinical educator, physiatrists, MPTD program coordinator and other MPTD OT practitioners	Cost of non-billable wages of involved parties
Educational brochure on PVVD and the MRH OT PVVD Program (Appendix J)	• Secondary – Family	Year 1-2	• Lead Practitioner • MPTD Program Coordinator • MPTD OT Practitioners	Cost of non-billable wages of involved parties Cost of printing ($0.03 - $0.05/pg.)
Electronic Media				
Memos, briefs and outcomes reports distributed within MRH and the NM system	• Primary • Secondary – Medical	Year 1-3	• Lead Practitioner in collaboration with the clinical educator, physiatrists, and MPTD program coordinator	Cost of non-billable wages of involved parties
Self-directed professional development module and/or webinar/YouTube video	• Primary	Year 2-5	• Lead Practitioner in collaboration with the clinical educator	Cost of non-billable wages of involved parties

The implementation of this dissemination plan will rely heavily on expert and trained personnel time, thus the majority of the budget to execute this plan will be largely to cover the non-billable/non-reimbursable time of these team members. A breakdown of the anticipated budget over the expected five-year dissemination period is in Table 6.8.

Table 6.8 – Preliminary budget for dissemination activities

Dissemination Activities	Expenses	Activity Budget
Professional conference presentations	$1000/conference	$1000 x 2 conferences/year x 5 years = **$10,000**
Collaborative planning meetings and educational presentations	Non-billable wages • Lead Practitioner = $40/hour • MRH Pediatric Physiatrist = $150/hour • MPTD Program Coordinator = $50/hour	($40 x 6 hours/month) + ($50 x 3 hours/month) + ($150 x 3 hours/month) = $840/month x 12 months x 2-4 years = **$1,680 - $3,360**
Guest Lecturing	Non-billable wages of Lead Practitioner = $40/hour	$40/hour x 3 hours per quarter x 4 quarters = $480/year x 3 years = **$1,440**
Written dissemination materials	Non-billable wages • Lead Practitioner and MPTD OT practitioners = $40/hour • MRH Pediatric Physiatrist = $150/hour • MPTD Program Coordinator = $50/hour Cost of printing = $0.03 - $0.05/page	($40/hour x 3 hours/month) + ($150/hour x 0.5 hours/month) + ($50/hour x 1 hour/month) = $245/month x 12 months = $2,940/year x 3 years = $8,820 $0.03- $0.05/page x 500 pages/year = $25 $8,820 + $25 = **$8,845**
Development of electronic media reports and dissemination materials	Non-billable wages • Lead Practitioner = $40/hour • MRH Pediatric Physiatrist = $150/hour • MPTD Program Coordinator = $50/hour • MRH Clinical Educator = $50/hour	($40/hour x 10 hours/quarter) + ($150/hour x 2 hours/quarter) + ($50/hour x 10 hours/quarter) = $1,200 x 4 quarters = $4,800/year x 3 years = **$14,400**
Total Budget		**$7,200 - $7,600/year x 5 years = $36,365 - $38,045**

EVALUATION PLAN

The dissemination of the information acquired through implementation of the MRH OT PVVD program aims to influence knowledge of PVVD rehabilitation through inter-organizational knowledge sharing, practitioner training and infusion of this knowledge into the current evidence base that guides rehabilitation practice. Thus, in order to measure the success of this plan, three factors need to be considered: the type and amount of written information added to the current practice evidence, the level of competence of practitioners who have been targeted by the dissemination of this information, and the impact the dissemination of this knowledge has on program outcomes for within the MPTD. Measurement criteria for evaluation of this plan will be as follows:

Evaluation Criteria - Contribution to current evidence base

- The lead practitioner will give professional presentations on PVVD rehabilitation at relevant professional conferences at least two times per year over five years (dissemination plan period)
- The lead practitioner will provide in-services and/or guest lectures on PVVD rehabilitation to at least five OT educational organizations/institutions within 5 years.
- Within five years, the MRH OT PVVD Program in collaboration with the MPTD will publish at least five reports, memos, articles, and/or studies within the Northwestern Medicine network, professional OT publications and/or peer-reviewed journal articles.

Evaluation Criteria – Practitioner competence

- Within 5 years, 80% of MPTD OT Practitioners will meet competency standards on PVVD rehabilitation.
- At least 75% of participants/practitioners targeted at professional conference presentations will be able to recall at least three main principles of PVVD rehabilitation based on a short, written survey completed at the conclusion of each presentation.

Evaluation Criteria – MPTD Outcomes

- Through person-to-person contact activities and written and electronic dissemination efforts, the MPTD will have an increase of referrals for OT evaluation/intervention of 10-15% within five years (dissemination plan period)

CONCLUSION

The long-term objective of the MRH OT PVVD program is to influence U.S. OT practice to better serve children who face challenges related to PVVD. To achieve this goal, efforts will be made to translate the knowledge gathered through this program implementation to practitioners, healthcare providers and parents/caregivers outside of the MPTD to revolutionize the care provided and health outcomes of children with and at-risk for PVVD. Through efforts to disseminate this knowledge at professional conferences, networking and educational events, in collaboration with a team of multidisciplinary experts in pediatric rehabilitation and medical care, and with activities targeting the education and awareness of parents/caregivers on PVVD and the available intervention options, the MRH OT PVVD program will aim to expand OT practice and

facilitate more comprehensive care for children with neurologic medical conditions and rehabilitation needs.

CHAPTER 7

CONCLUSION

As medical science advances, more children with serious illnesses and conditions are living longer and participating in meaningful lives (American Cancer Society, 2016; Brandes & Fraceschi, 2011; Houtrow et al., 2014; Smith et al., 2014; U.S. Census Bureau, 2003; U.S. Census Bureau, 2011). Childhood cancer survival rates and pediatric disability rates for children with neurologic conditions are rising as a result of these improvements in medical care (American Cancer Society, 2016; Brandes & Fraceschi, 2011; Houtrow et al., 2014; Smith et al., 2014; U.S. Census Bureau, 2003; U.S. Census Bureau, 2011). These children are at high risk for functional complications, including PVVD, in the acute stages of their diagnosis as well as long-term (Alghadir, Iqbal & Whitney, 2013; Archer et al., 2012; Dannenbaum et al., 2016; Konczak et al., 2005; Medeiros et al., 2005; Pavao & Rocha, 2017; Rine & Wiener-Vacher, 2013; Roley et al., 2015; Syczewska et al., 2006; Walz & Baranek, 2006). However, many medical providers, therapy practitioners and caregivers do not accurately identify PVVD (Mehta & Stakiw, 2004; Rine & Christy, 2016; Rine & Wiener-Vacher, 2013; Weiss & Phillips, 2006). Still, many clinicians work with children with symptoms of PVVD, though they do not have the confidence and understanding of PVVD to assess for and provide the most effective and impactful interventions to support improved participation and performance in daily life activities (Stone & Salentine, 2017).

The MRH OT PVVD Program will aim to fill the current service gap for children with CNS cancer and/or other neurologic conditions who present with or are at risk for

PVVD. Currently, all OTs in the MPTD serve a large number of children who fall into the target population of this program. Most of these OTs report limited knowledge of how to best assess for and treat PVVD, which impedes occupational participation and performance of the children on their caseload (Stone & Salentine, 2017). To address this gap in current practice knowledge and skills, this program will primarily focus on developing and implementing clinical education and training activities to expand practitioner knowledge and confidence in PVVD rehabilitation. Given the limited evidence and clinical practice guidelines available for PVVD rehabilitation currently, the MRH OT PVVD program will also conduct program evaluations of the developed assessment and intervention activities. These evaluation results will be shared with occupational therapists at conferences and in publications to add to the developing OT practice pool of evidence.

Through the development of new assessment and intervention guidelines, a didactic clinical training program, and execution of objective outcomes measurements of each of these program components, the MRH OT PVVD will be a pioneering influence on current OT practice in the area of pediatric oncology and neuro-rehabilitation. As oncology- and neuro-rehabilitation becomes a more prominent practice area for many pediatric focused OT practitioners, this program will contribute new, meaningful and substantial evidence to the growing body of literature that guides OT practice. Additionally, through development of the educational and training programs and with execution of the planned dissemination activities, this program will be able to influence rehabilitation science and OT practice at MRH, and also facilitate knowledge translation

to practitioners across the country. In doing so, this program will strengthen the current state of OT pediatric oncology and neuro-rehabilitation through the provision of evidence-based and evidence-guided assessment and intervention practice resources that can be applied to clinical practice throughout the U.S.

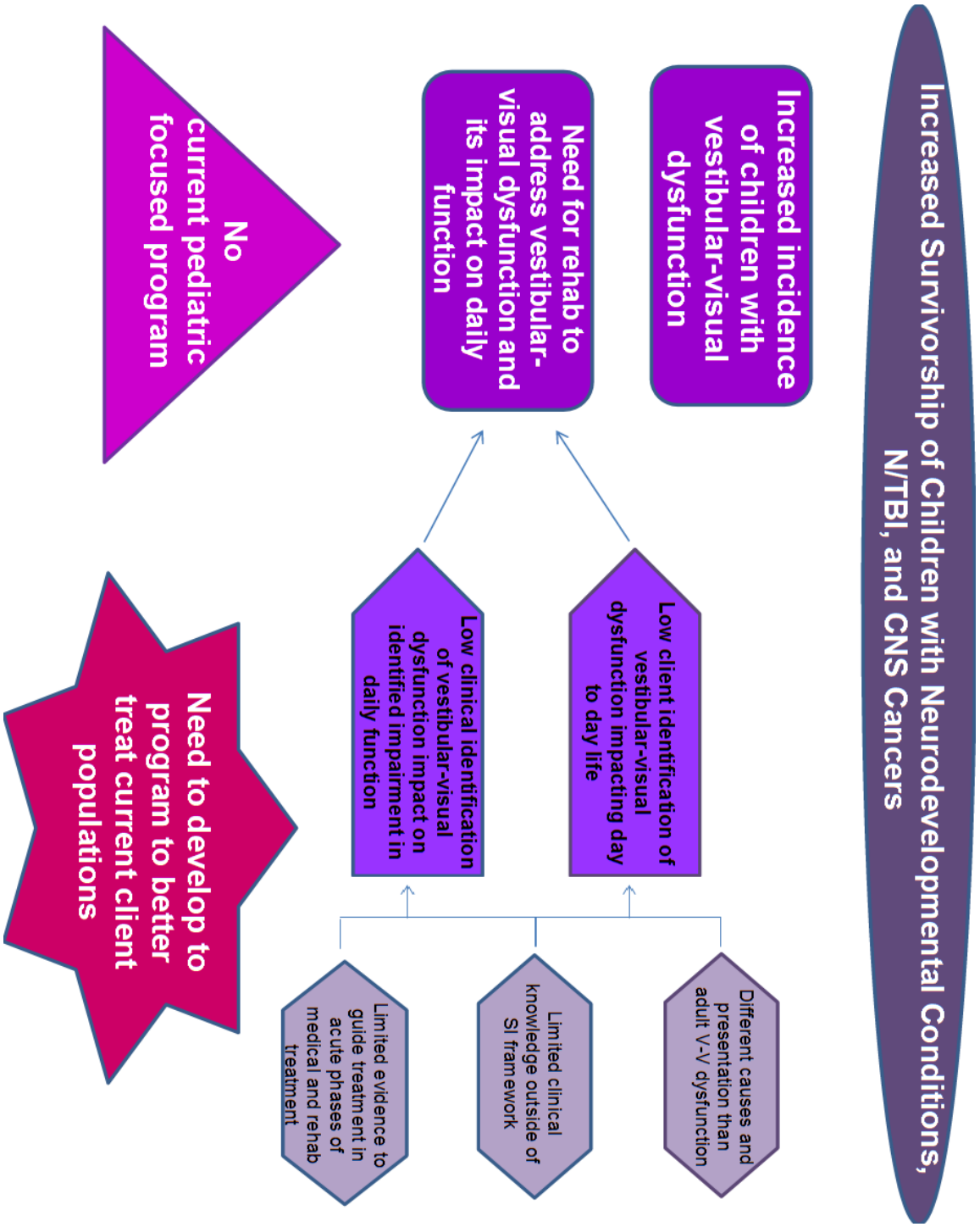
While innovation and expansion of current OT practice is a major by-product of this program, the ultimate goal of the MRH OT PVVD program is to facilitate improved health and wellness outcomes for children with CNS cancer and/or other neurologic conditions. It is the purpose of this program to facilitate these outcomes through (1) empowerment of the clinical practitioners that provide rehabilitative services to these children; (2) expansion of knowledge and understanding of PVVD and PVVD rehabilitation for caregivers, medical providers and therapy practitioners; and (3) collaborative advocacy and promotion of the unique role OT has in enabling improved quality of life of children with CNS cancer and/or other neurologic conditions. By addressing the clinical service and practice gaps regarding PVVD rehabilitation, this program will enable practitioners to collaborate with their pediatric clients and their caregivers to effect positive changes in their daily functioning and well-being by better addressing the barriers to occupational performance and participation as a result of PVVD.

Broadly, the MRH OT PVV program is a clinical education and training program that aims to train OT clinicians to better assess and treat PVVD in children with CNS cancer and/or other neurologic conditions. With a growing number of children surviving and participating in daily life with chronic and disabling health conditions, it is

imperative that OTs stay informed on how to best support these children to live their best lives. Through education and training efforts of OTs at MRH, and by providing clinicians with tools to implement assessment and intervention techniques aimed to address PVVD, the program intends to expand OT practice and improve care for children with PVVD. In turn, this program will impact short and long-term health outcomes for these children. In addition to these training and clinical support efforts, the program will examine how effective these interventions are and publish results in order to advance OT practice and rehabilitation science as a whole. In combination with the outlined dissemination plan, the MRH OT PVVD program has the potential to significantly and positively influence OT practice and the lives of children with and at-risk for PVVD.

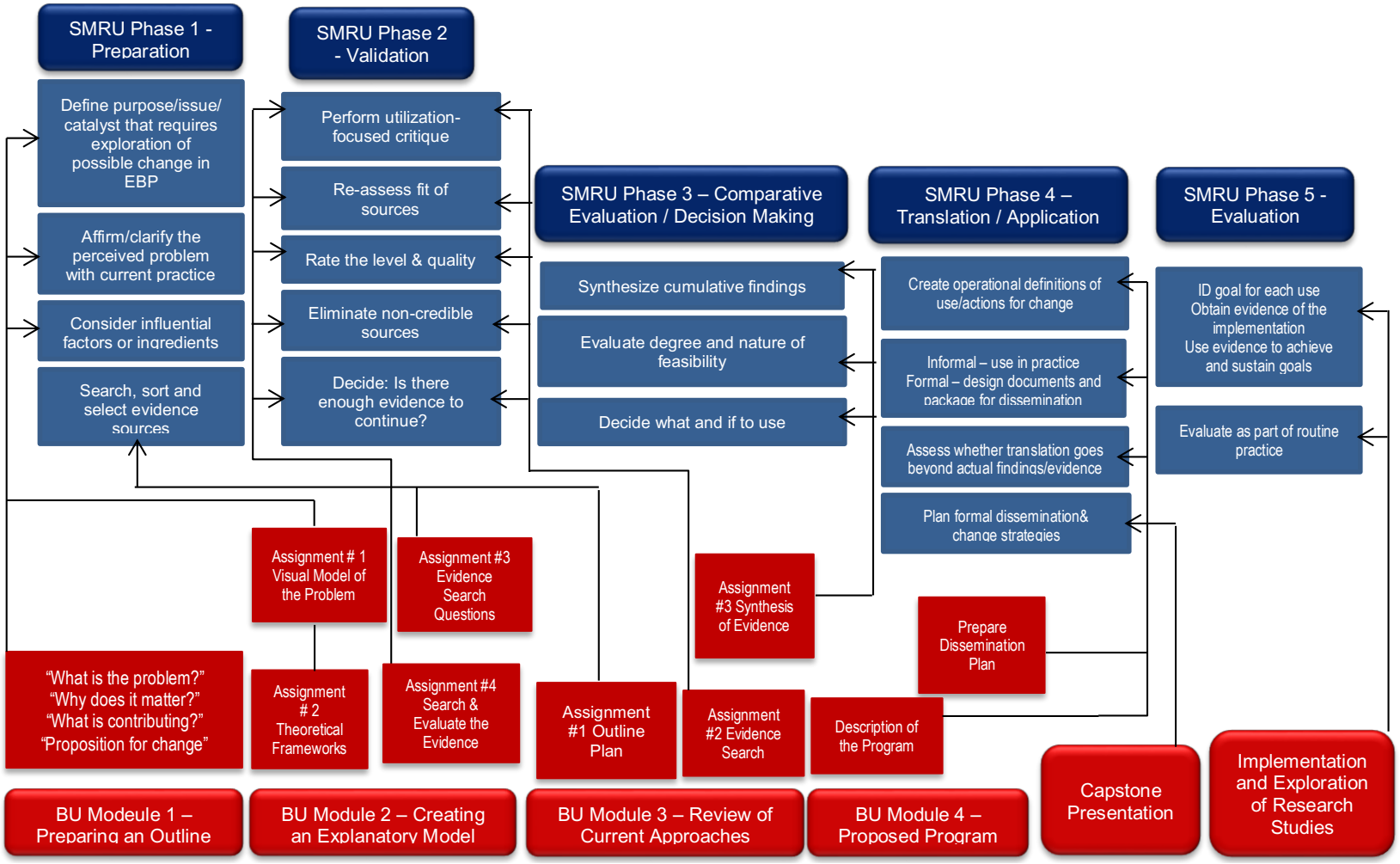
Appendix A

Initial Explanatory Model of the Clinical Service Gap



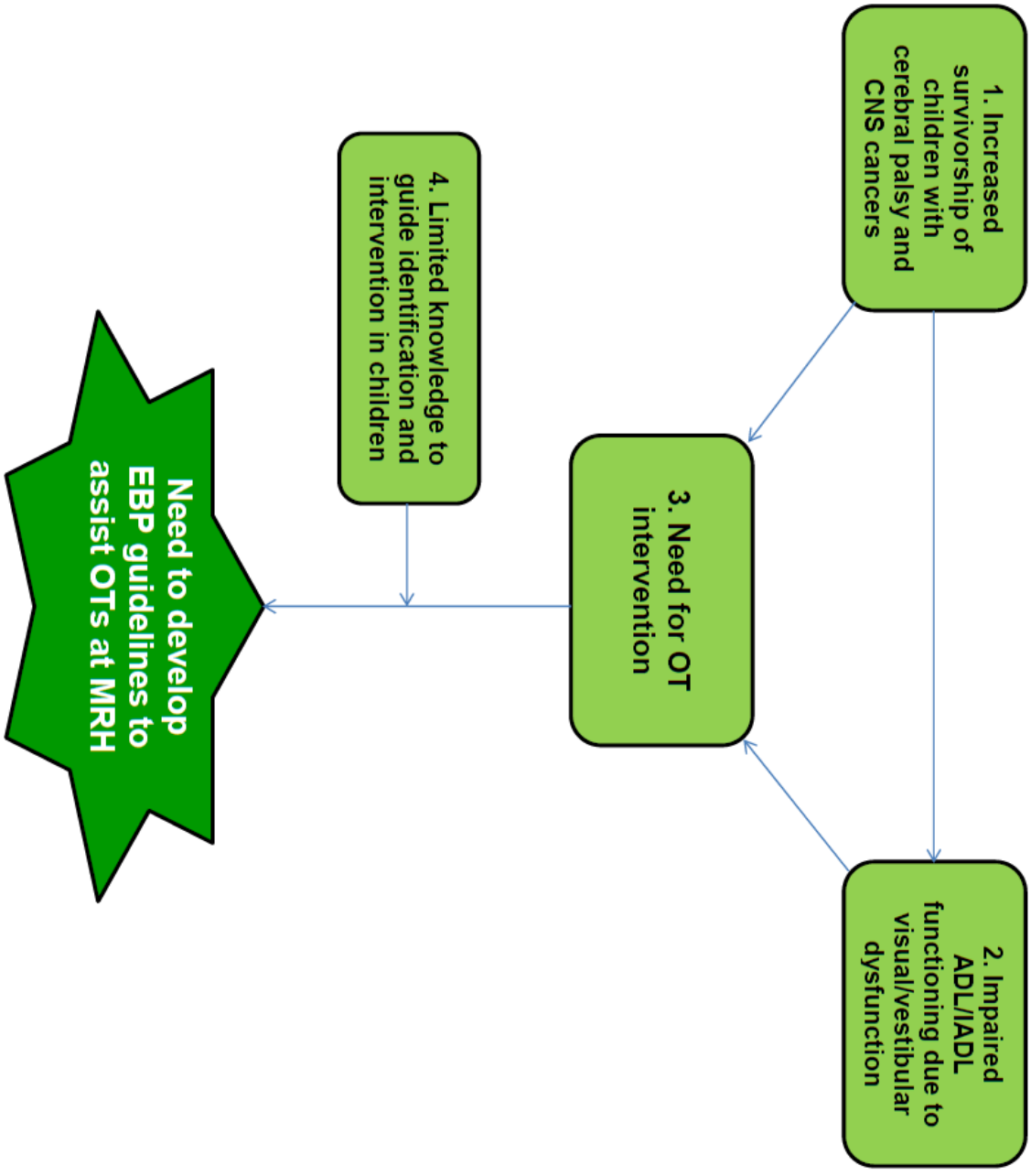
Appendix B

How the Stetler Model of Research Utilization is Integrated into This Dissertation



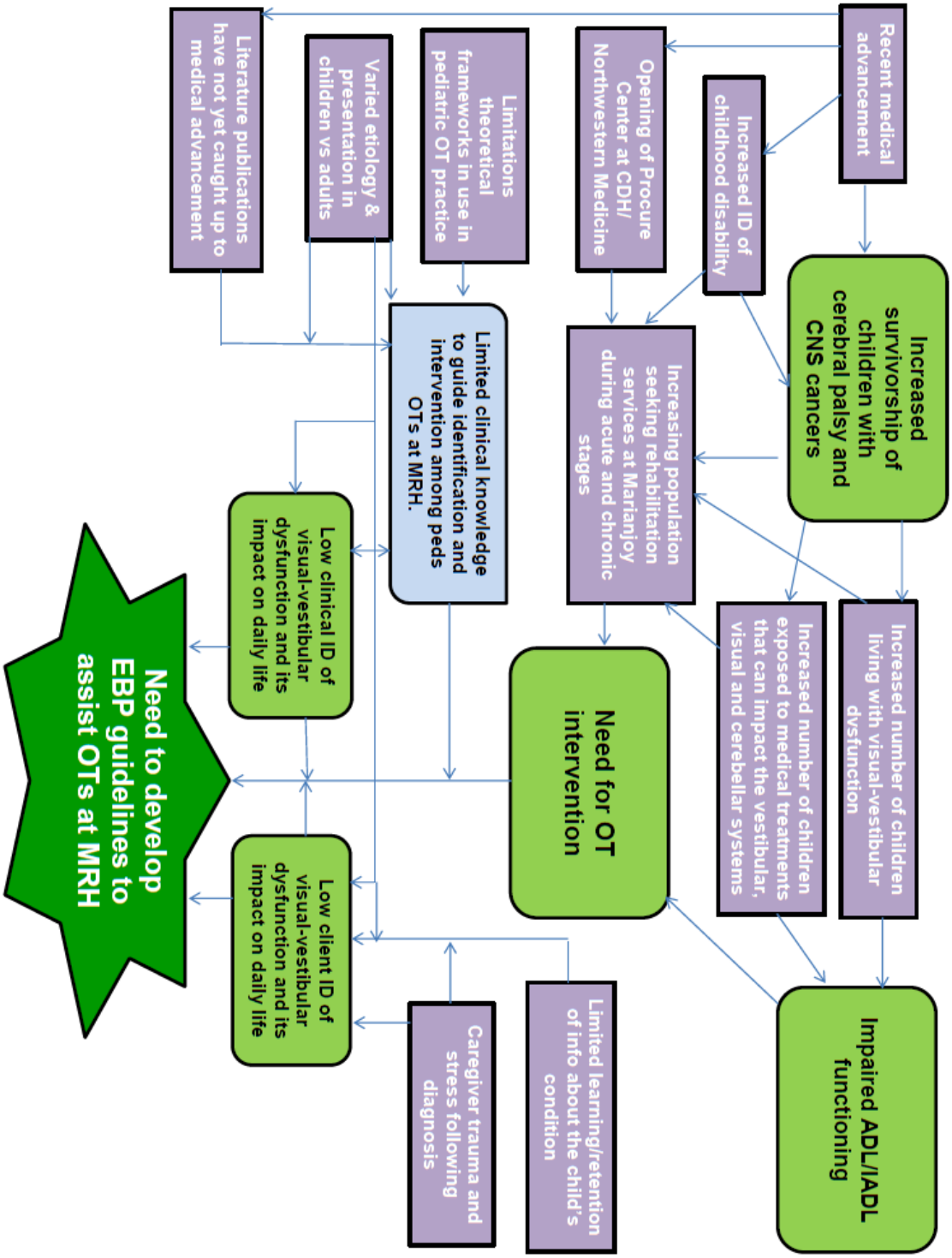
Appendix C

Revised Explanatory Model of the Clinical Service Gap – Simplified



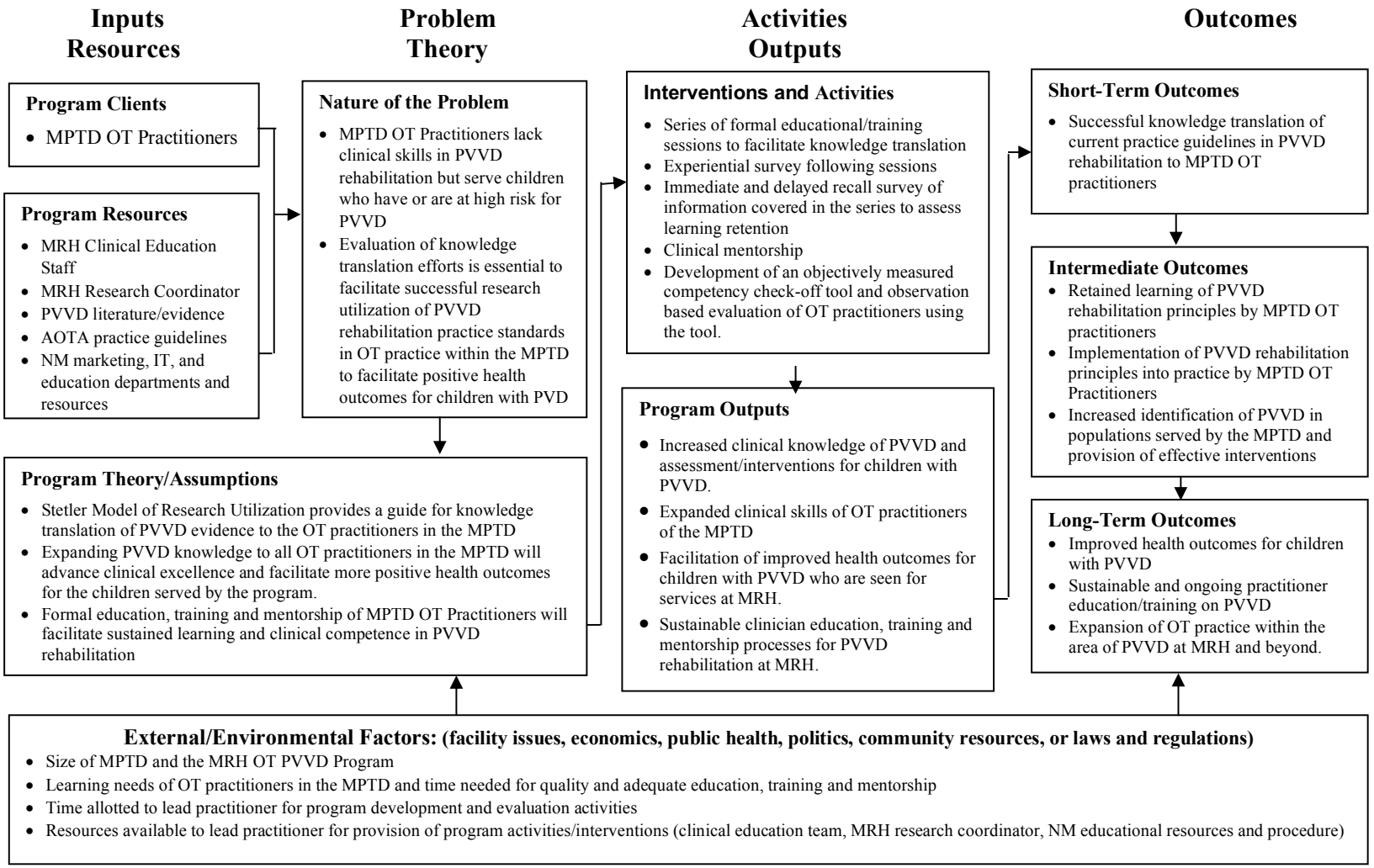
Appendix D

Revised Explanatory Model of the Clinical Service Gap – Detailed

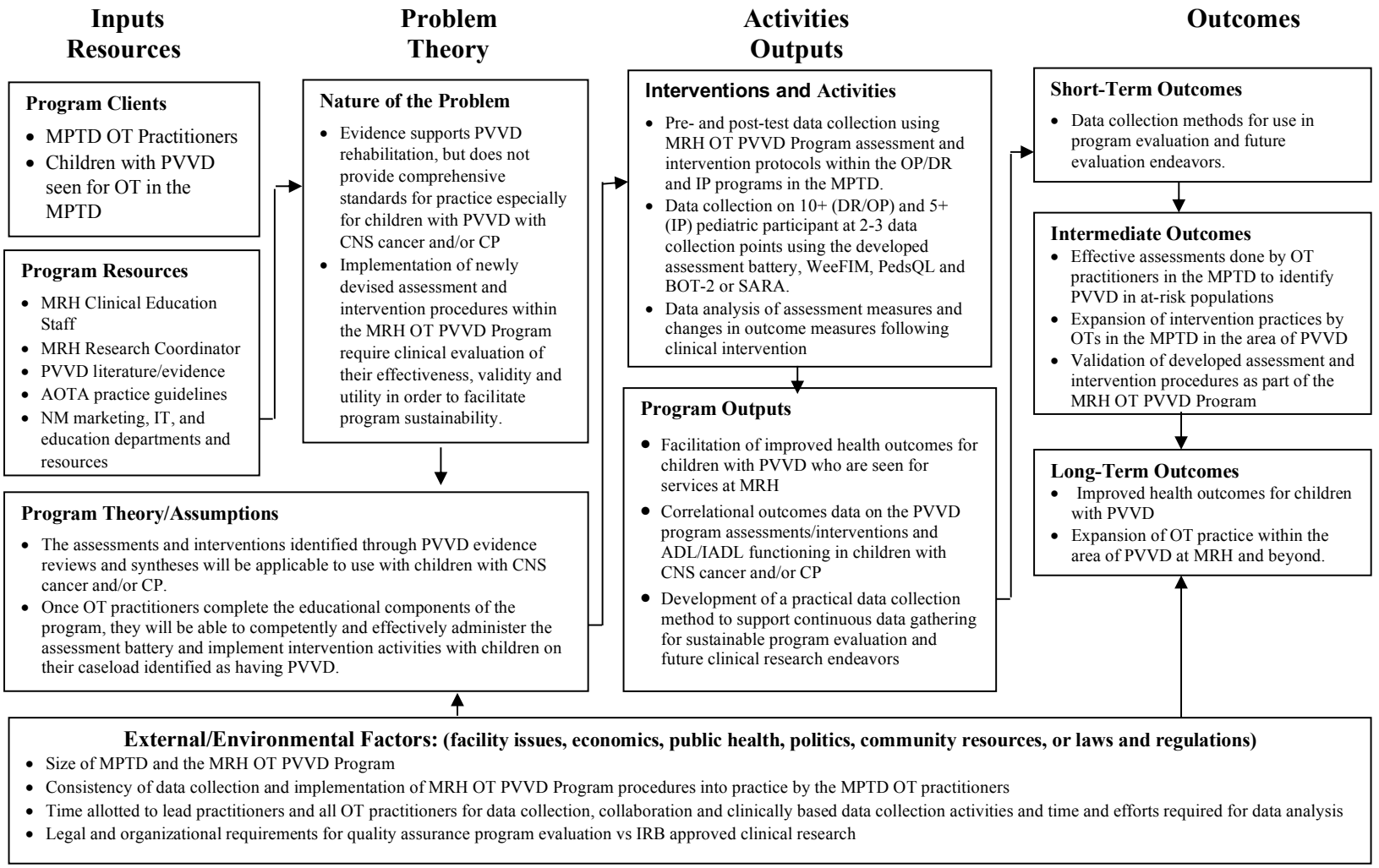


Appendix E

Logic Model – Evaluation of Educational and Clinical Training Program Components



Appendix F
Logic Model – Evaluation of Clinical Program Components



Appendix G - Example of an Assessment Kit Resource
Pediatric Vestibular Symptom Questionnaire (Pavlou et al., 2016)

The following questions ask about how often you feel dizziness and unsteadiness. Please circle the best answer for you. How often in the past month have you felt the following?

1. A feeling that things are spinning or moving around?

0	**1**	**2**	**3**	**?**
Never	Almost Never	Sometimes	Most of the Time	Don't Know

2. Unsteadiness so bad that you actually fall?

0	**1**	**2**	**3**	**?**
Never	Almost Never	Sometimes	Most of the Time	Don't Know

3. Feeling sick?

0	**1**	**2**	**3**	**?**
Never	Almost Never	Sometimes	Most of the Time	Don't Know

4. A light-headed or swimmy feeling in the head?

0	**1**	**2**	**3**	**?**
Never	Almost Never	Sometimes	Most of the Time	Don't Know

5. Feeling of pressure in the ear(s)?

0	**1**	**2**	**3**	**?**
Never	Almost Never	Sometimes	Most of the Time	Don't Know

6. Blurry vision, difficulty seeing things clearly, and/or spots before the eyes?

0	**1**	**2**	**3**	**?**
Never	Almost Never	Sometimes	Most of the Time	Don't Know

7. Headache or feeling of pressure in the head?

0	**1**	**2**	**3**	**?**
Never	Almost Never	Sometimes	Most of the Time	Don't Know

8. Unable to stand or walk without holding on to something or someone?

0	1	2	3	?
Never	Almost Never	Sometimes	Most of the Time	Don't Know

9. Feeling unsteady, about to lose balance?

0	1	2	3	?
Never	Almost Never	Sometimes	Most of the Time	Don't Know

10. A fuzzy or cotton wool feeling in the head?

0	1	2	3	?
Never	Almost Never	Sometimes	Most of the Time	Don't Know

11. **Do any of these symptoms stop you doing what you want to do? If yes, which ones?**

Appendix H - Example of an Assessment Kit Resource

Subjective Visual Vertical Test (bucket method)

Purpose:

- To assess the perception of verticality
- Test of vestibular tone imbalance
- Screening for postural imbalance due to brainstem lesions
- Test of spatial deficits
- Test to distinguish between peripheral and central vestibular dysfunction

Time: ~5 minutes ***Ages***: 6 years and up ***Materials Needed***: SVV Bucket

Directions:

- Child sits upright with the bucket held up to their face with both eyes open (binocular test) or with one eye covered (monocular left/right test) – the child's visual field should be completely covered by the rim of the bucket.
- The examiner randomly rotates the bucket to the right or left to varying degrees and slowly turns the bucket back towards the 0 degree position.
- The child should be instructed to signal when they think the inside line is truly vertical by saying "stop".
- The examiner then reads the distance from the 0 line in degrees.

Scoring and Interpretation:

- 2 degrees or more deviation from vertical = peripheral vestibular dysfunction (most likely utricle)
- Central lesions and other causes may have typical SVV; but:

○ Lesion in the upper pons may show as a tilt towards the side of the lesion

○ Upper brainstem lesions may show as a tilt away from the side of the lesion

Tips/Additional Information

- Monocular measurements may reveal greater degree of SVV deviation than binocular measurements
- Peripheral dysfunction tends to have spontaneous recovery in 1-6 weeks, though central based dysfunction may be present more chronically

Appendix I - Example of an Assessment Kit Resource

Subjective Postural Vertical (upright body orientation)

Purpose:

- To test for impaired verticality perception
- Test for verticality impairments due to cerebral/central lesions

Directions: Child's posture is observed in static sitting and standing. Ask child to sit/stand up straight, and observe if posture tilts, leans or pushes in any direction.

Scoring and Interpretation: If SPV tilt is present, child may have contraversive pushing, pushing or leaning towards side of hemiparesis/hemi-sensory loss to compensate for tilt of SPV.

Appendix J - Example of an Educational Program Activity

Caregiver Brochure

Visual-Vestibular Impairment

Risk Factors, Symptoms, and Rehabilitation Options For Your Child

WHAT IS VISUAL-VESTIBULAR IMPAIRMENT?

Vestibular
The vestibular system controls balance and stabilization of vision when a person is moving or is moving his/her head. Vestibular impairment can be due to issues with the inner ear and/or the nerve that connects the ear to the brain stem (peripheral nervous system) or because of issues in the brain and spinal cord (central nervous system).

Vision
Using vision involves processing information with the eye (focal pathway) and using that information to orient to time and space to support balance, movement, coordination and posture (ambient pathway).

Central Nervous System Vestibular Impairment and Ambient Pathway Vision Impairment
After a neurologic event or injury to the brain, the vestibular and visual systems can be damaged. If there is an impairment of the central nervous system area of vestibular system and the ambient pathway of vision, a child may have a variety of symptoms and

SIGNS & SYMPTOMS

Vestibular-Related Signs and Symptoms
Dizziness
Loss of balance/falls
Poor motor coordination
Spinning sensation
Nausea & vomiting
Headache
Clumsiness
Changes in behavior
Changes in vision

Vision-Related Signs & Symptoms
Difficulty moving the eyes
Nystagmus (rhythmic uncontrollable movement of the eyes)
Poor balance/falls
Poor motor coordination
Blurry vision or double vision
Turning/tilting of the head to see
Misalignment of the eyes
Clumsiness
Squinting or covering one eye
Excessive blinking/squinting
Nausea & vomiting
Headache
Dizziness
Poor attention
Difficulty when reading
Poor handwriting

IN THIS ISSUE

The Pediatric Therapy program offers a multitude of resources for you and your child when dealing with visual-vestibular impairment. Our team of physiatrists, occupational, physical and speech-language therapists, and neuro-optometrist work together to support your child's health and wellness.

WHO IS AT RISK?

If your child has one of the following medical diagnoses, they may be at higher risk for visual-vestibular impairment

Cerebral palsy
Central nervous system cancer or tumor
Traumatic brain injury
Cerebral vascular accident or stroke
Meningitis
Concussion and Post-Concussion Syndrome
Congenital cytomegalovirus
Developmental Delay
Autism Spectrum Disorder
Migraines
Congenital malformations
Genetic conditions that impact neurologic functioning
Sensory processing disorder
Hydrocephalus
Sensorineural hearing loss
Late or preterm birth
Learning disabilities

If your child has taken or is receiving any of the following medications or medical treatments, they may be at higher risk for visual-vestibular impairment

Surgery to remove a brain tumor
Other surgeries involving the brain
Chemotherapy
Radiation targeting areas of the brain
Aminoglycoside antibiotics
Anti-neoplastic medications (e.g. cisplatin, carboplatin)

CARE OPTIONS

Visual-vestibular impairment because of issues with the central nervous system can make every day activities very difficult for children. Thankfully there are many ways to treat visual-vestibular impairment and help children get back to doing the things they enjoy. Children who complain of the related symptoms and/or have medical conditions or have undergone medical treatments that put them at high risk for impairment should be tested so that the proper treatment can be given.

Many rehabilitation services can help treat visual-vestibular impairment. Many of these services are available at Marianjoy including:

Medical management by a Marianjoy physiatrist
Occupational, Physical and Speech Therapy
Neuro-optometric Rehabilitation in collaboration with the Marianjoy Vision Clinic

Talk to your physician and/or therapist if you have concerns about your child's visual-vestibular functioning

PEDIATRIC CARE TEAM

Pediatric Physiatrists and Nurse Practitioners can help guide you through the rehabilitation process, manage and monitor your child's medical needs and coordinate with your child's therapists to provide comprehensive medical care

PEDIATRIC REHABILITATION

Pediatric Rehabilitation programs and services are available at our facility. A prescription is required to receive Pediatric Rehabilitation. A prescription may also be obtained through one of our physicians. To make an appointment with one of our physicians, please call. For more information, or to make an appointment with our Pediatric Department, please call.

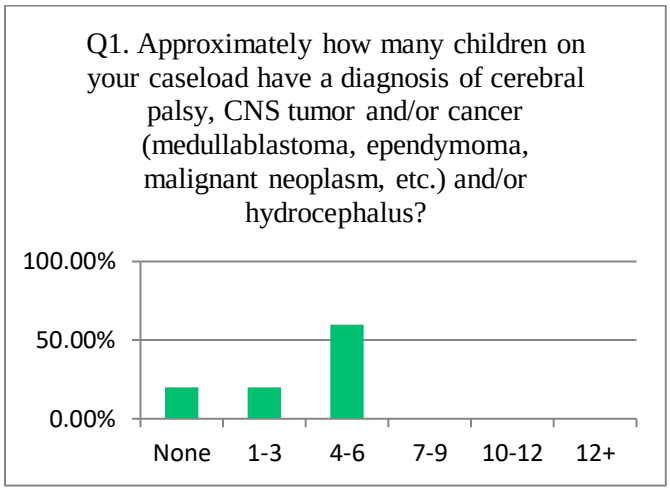
VISION CLINIC

A vision clinic at our facility is lead by a behavioral optometrist in collaboration with our physicians and team of occupational therapy practitioners. Talk to your therapist for more information about services available through the clinic.

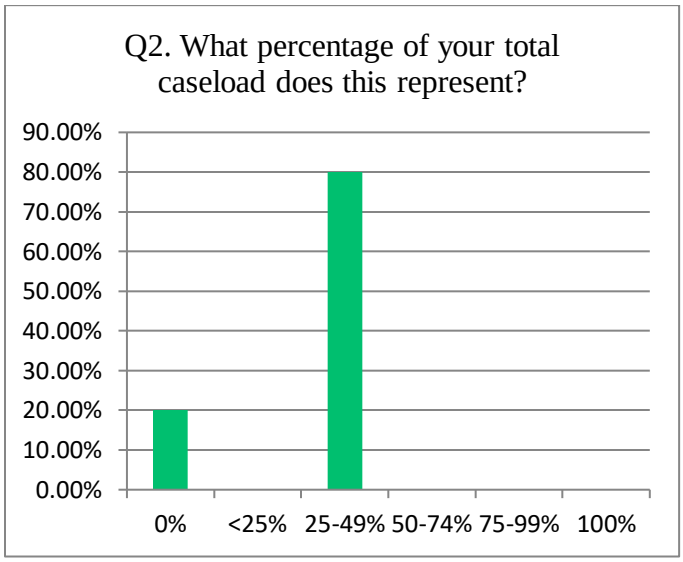
Appendix K – Example of Educational Program Activity

MRH OT PVVD Program Needs Assessment Survey

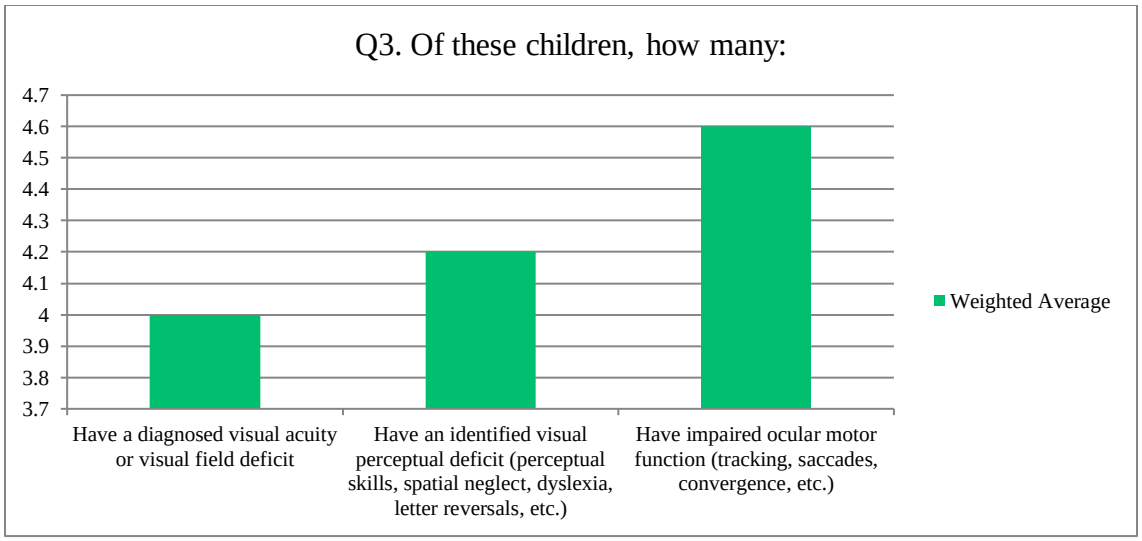
(Stone & Salentine, 2017)



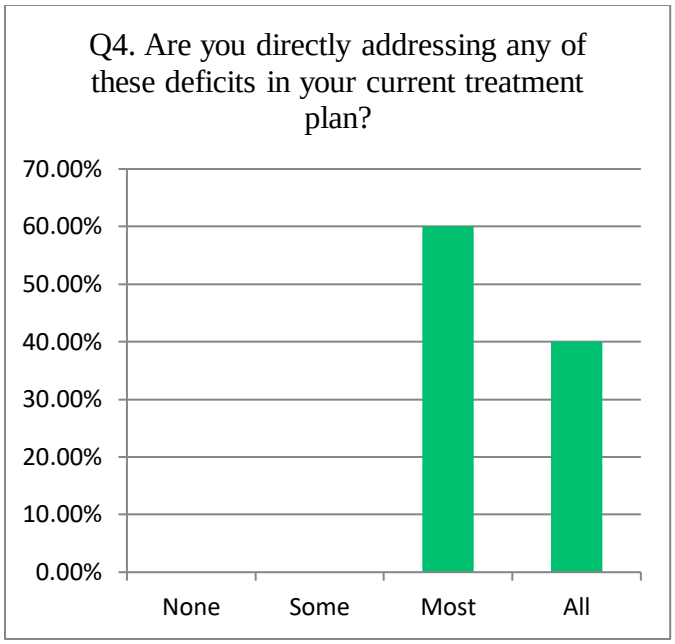
Answer Choice:	Responses	
None	20.00%	1
1-3	20.00%	1
4-6	60.00%	3
7-9	0.00%	0
10-12	0.00%	0
12+	0.00%	0
	Answered	**5**
	Skipped	**0**



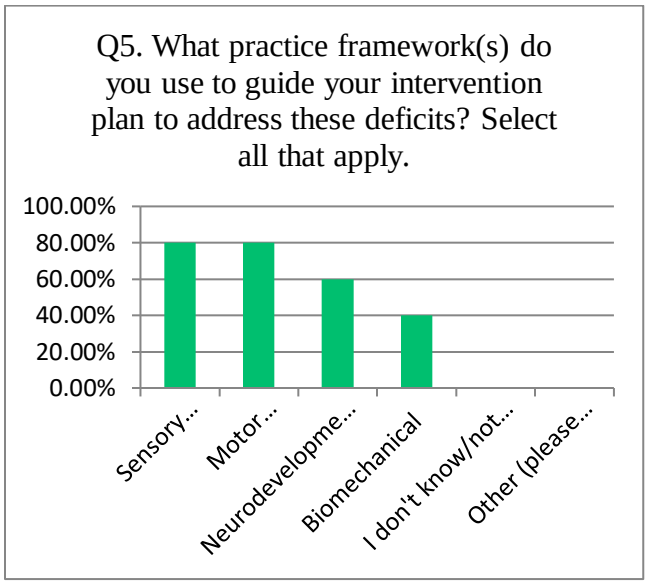
Answer Choice:	Responses	
0%	20.00%	1
<25%	0.00%	0
25-49%	80.00%	4
50-74%	0.00%	0
75-99%	0.00%	0
100%	0.00%	0
	Answered	**5**
	Skipped	**0**



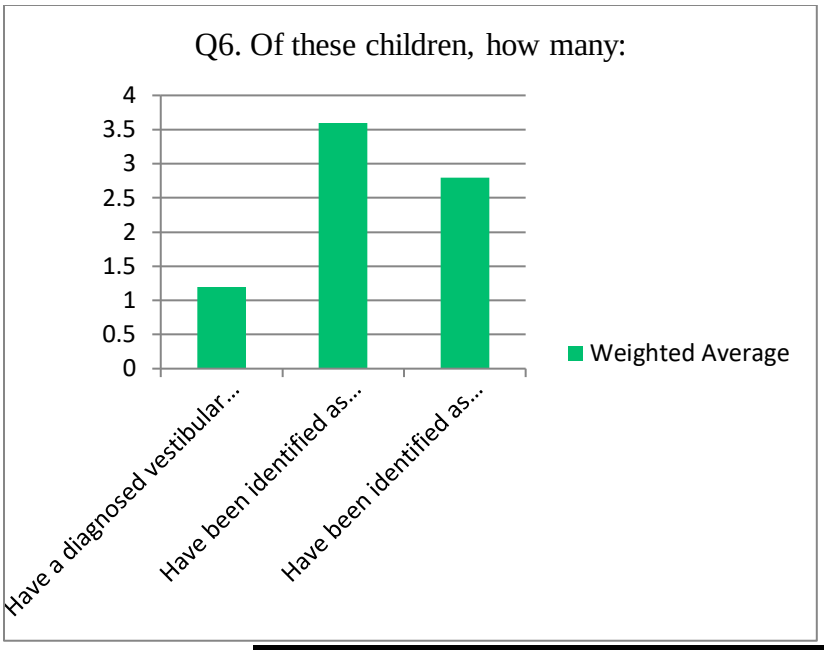
	0%		<25%		25-49%		50-74%		75-99%		100%		Total	Weighted Average
Have a diagnosed visual acuity or visual field deficit	0.00%	0	0.00%	0	40.0%	2	40.0%	2	0.00%	0	20.0%	1	5	4
Have an identified visual perceptual deficit (perceptual skills, spatial neglect, dyslexia, letter reversals, etc.)	0.00%	0	0.00%	0	40.0%	2	20.0%	1	20.0%	1	20.0%	1	5	4.2
Have impaired ocular motor function (tracking, saccades, convergence, etc.)	0.00%	0	0.00%	0	40.0%	2	0.00%	0	20.0%	1	40.0%	2	5	4.6
											Answered			**5**
											Skipped			**0**



Answer Choices	Responses	
None	0.00%	0
Some	0.00%	0
Most	60.00%	3
All	40.00%	2
	Answered	**5**
	Skipped	**0**

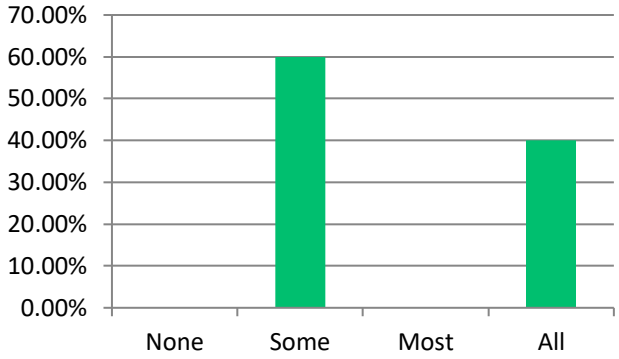


Answer Choices	Responses	
Sensory Integration	0.00%	0
Motor Control/ Motor Learning	0.00%	0
Neurodevelopmental	60.00%	3
Biomechanical	40.00%	2
I don't know/not sure	0.00%	0
Other	0	0
	Answered	**5**
	Skipped	**0**



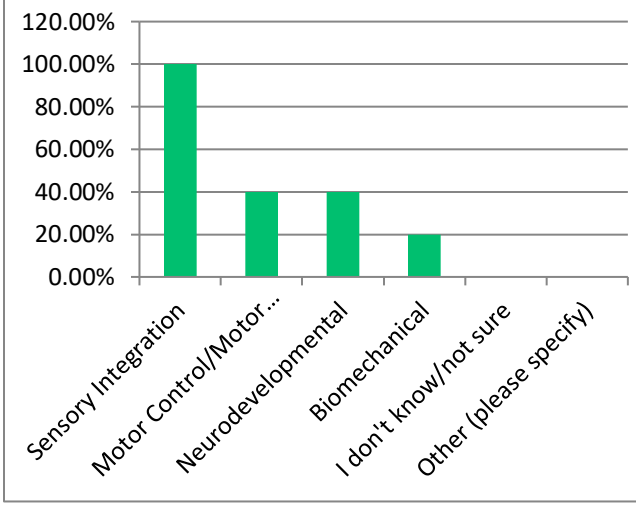
	0%		<25%		25-49%		50-74%		75-99%		100%		Total	Weighted Average
Have a diagnosed vestibular disorder? (BPPV, Meniere's disease, labyrinthitis, other peripheral vestibular disorders)	80.00%	4	20.00%	1	0.0%	0	0.0%	0	0.00%	0	0.0%	0	5	1.2
Have been identified as having vestibular related dysfunction (impaired vestibular processing, gravitational insecurity, seeks/avoids vestibular stimulation) May be formal dx or therapist identified	20.00%	1	20.00%	1	0.0%	0	20.0%	1	20.0%	1	20.0%	1	5	3.6
Have been identified as having sensory-based movement deficits (SPD/SMD/SDD/SBMD involving vestibular functioning, dyspraxia, postural deficits) May be formal dx or therapist identified	20.00%	1	20.00%	1	40.0%	2	0.0%	0	20.0%	1	0.0%	0	5	2.8
											Answered			**5**
											Skipped			**0**

Q7. Are you directly addressing any of these deficits in your current treatment plan?

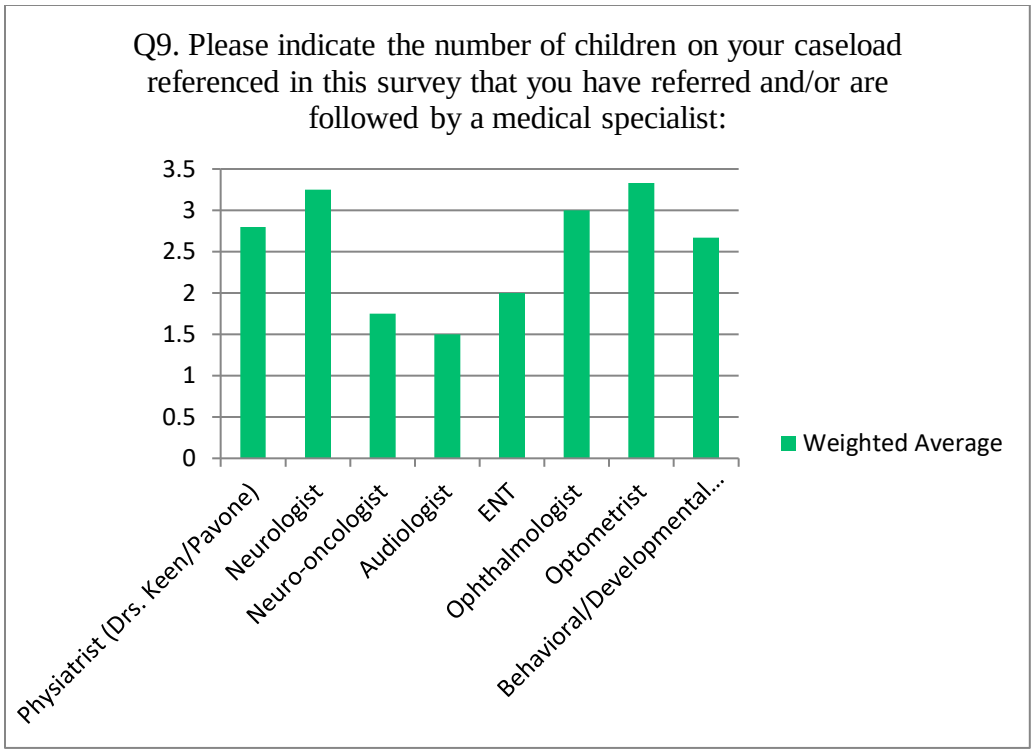


Answer Choices	Responses	
None	0.00%	0
Some	60.00%	3
Most	0.00%	0
All	40.00%	2
	Answered	**5**
	Skipped	**0**

Q8. What practice framework(s) do you use to guide your intervention plan to address these deficits? Select all that apply.



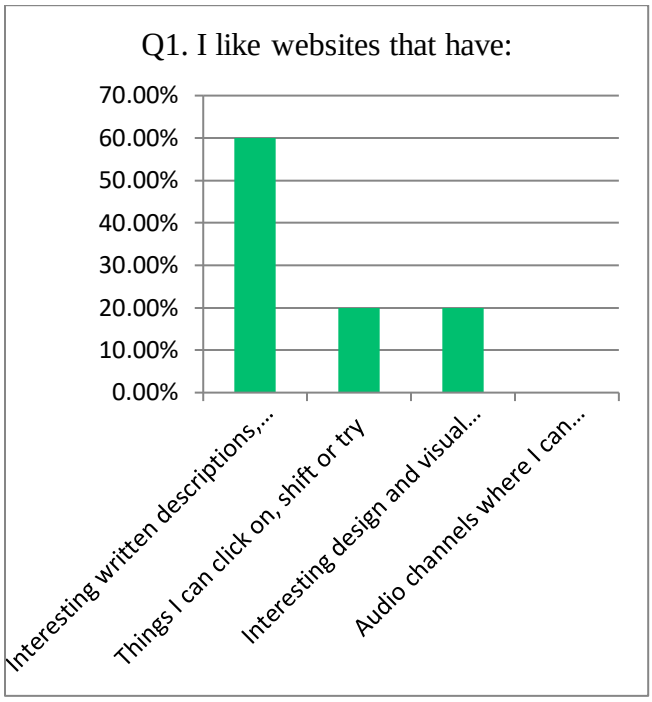
Answer Choices	Responses	
Sensory Integration	100.00%	5
Motor Control/ Motor Learning	40.00%	2
Neurodevelopmental	40.00%	2
Biomechanical	20.00%	1
I don't know/not sure	0.00%	0
Other	0	0
	Answered	**5**
	Skipped	**0**



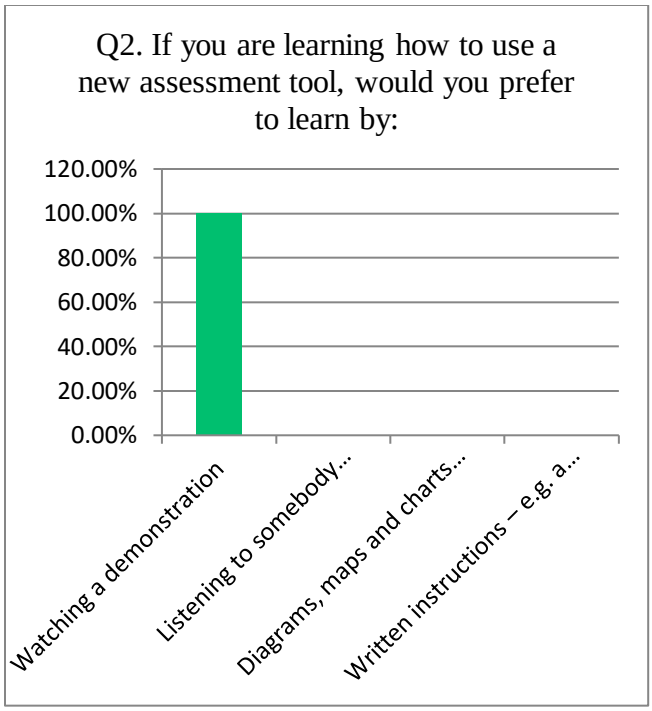
	NONE		SOME		MOST		ALL		Total	Weighted Average
Physiatrists	0.00%	0	40.00%	2	40.00%	2	20.00%	1	5	2.8
Neurologist	0.00%	0	25.00%	1	25.00%	1	50.00%	2	4	3.25
Neuro-oncologist	25.00%	1	75.00%	3	0.0%	0	0.0%	0	4	1.75
Audiologist	50.00%	1	50.00%	1	0.0%	0	0.0%	0	2	1.5
ENT	0.00%	0	100%	2	0.0%	0	0.0%	0	2	2
Ophthalmologist	0.00%	0	50.00%	2	0.0%	0	50.00%	2	4	3
Optometrist	0.00%	0	33.33%	1	0.0%	0	66.67%	2	3	3.33
Behavioral/ Developmental Optometrist	0.00%	0	33.33%	1	66.67%	2	0.0%	0	3	2.67
Other									0	
							Answered			**5**
							Skipped			**0**

Appendix L – Example of Educational Program Activity

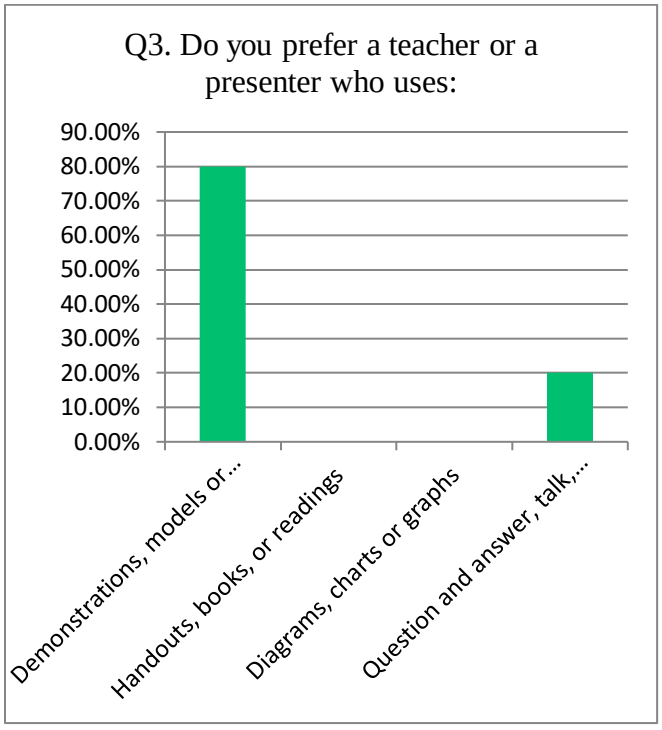
MRH OT PVVD Program OT Learning Preferences Survey



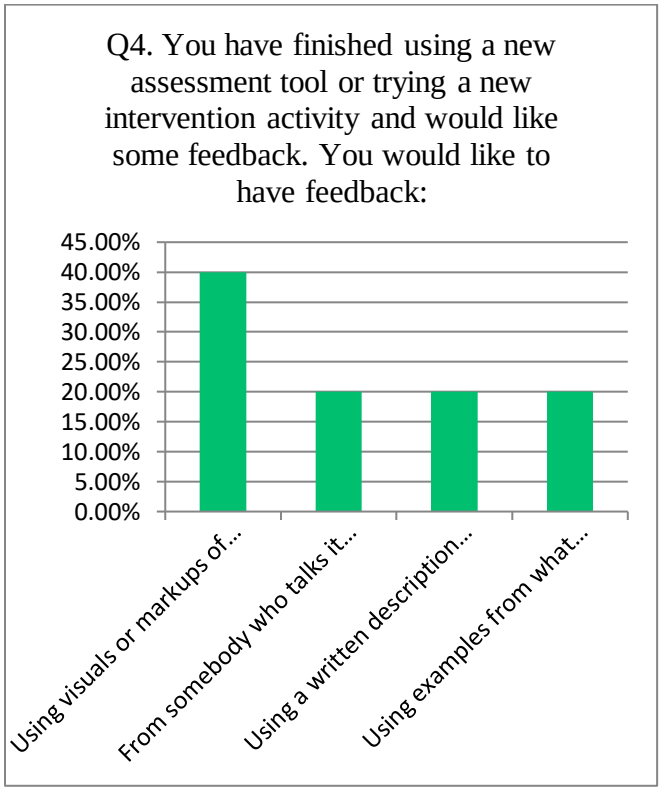
Answer Choices	Responses	
Interesting written descriptions, lists and explanations	60.00%	3
Things I can click on, shift or try	20.00%	1
Interesting design and visual features	20.00%	1
Audio channels where I can hear music, radio programs or interviews	0.00%	0
	Answered	**5**
	Skipped	**0**



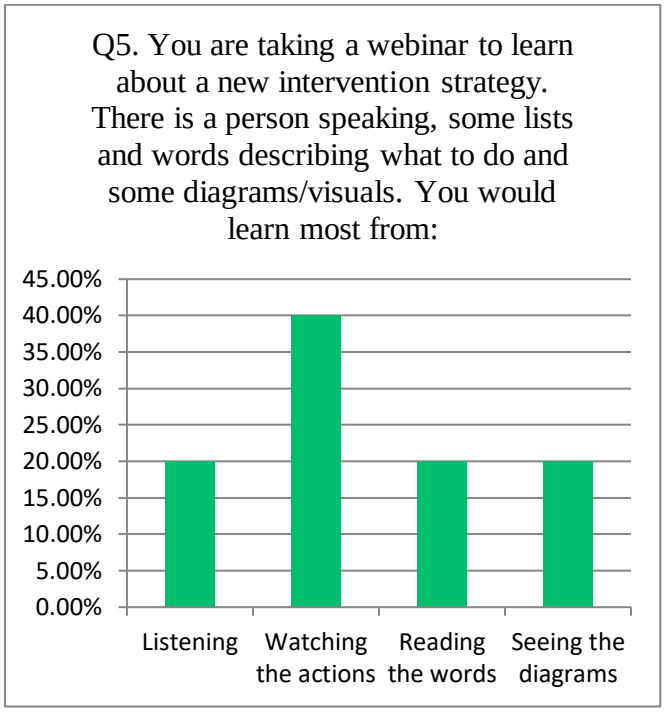
Answer Choices	Responses	
Watching a demonstration	100.00%	5
Listening to somebody explaining it and asking questions	0.00%	0
Diagrams, maps and charts – visual clues	0.00%	0
Written instructions – e.g. a manual or book	0.00%	0
	Answered	**5**
	Skipped	**0**



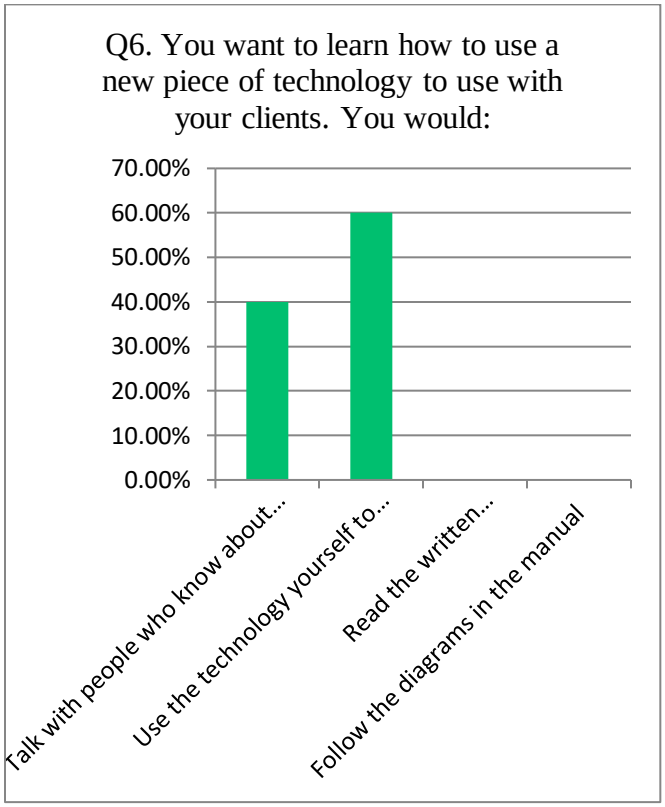
Answer Choices	Responses	
Demonstrations, models or practical sessions	80.00%	4
Handouts, books, or readings	0.00%	0
Diagrams, charts or graphs	0.00%	0
Question and answer, talk, group discussion, or guest speakers	20.00%	1
	Answered	**5**
	Skipped	**0**



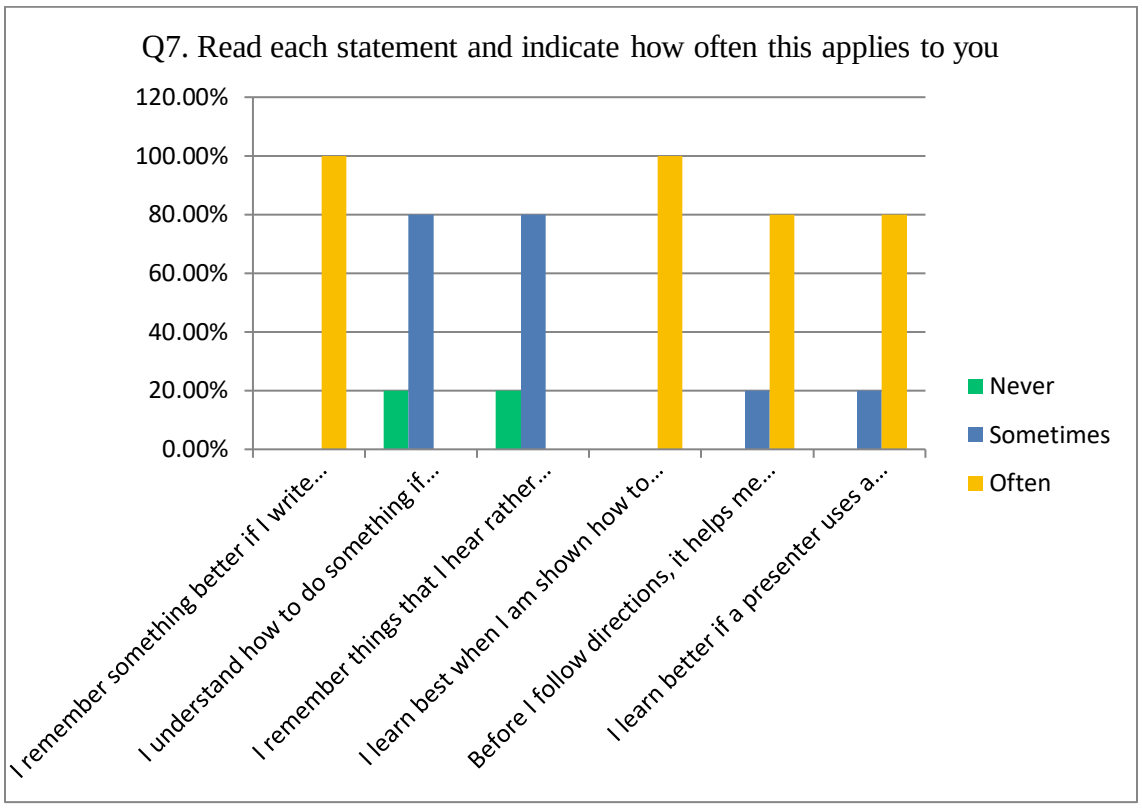
Answer Choices	Responses	
Using visuals or markups of your assessment form showing what went well and what improvements could be made	40.00%	2
From somebody who talks it through with you	20.00%	1
Using a written description of your performance and feedback	20.00%	1
Using examples from what you have done	20.00%	1
	Answered	**5**
	Skipped	**0**



Answer Choices	Responses	
Listening	20.00%	1
Watching the actions	40.00%	2
Reading the words	20.00%	1
Seeing the diagrams	20.00%	1
	Answered	**5**
	Skipped	**0**

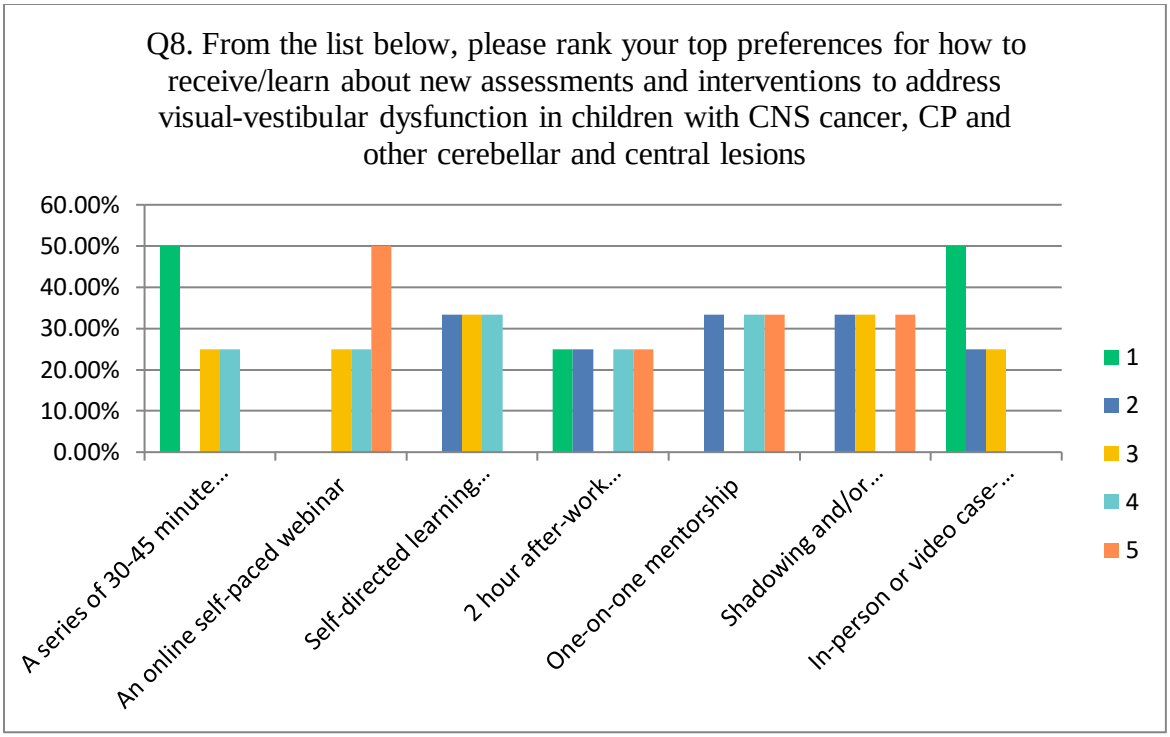


Answer Choices	Responses	
Talk with people who know about the technology	40.00%	2
Use the technology yourself to learn ways you can use it with your clients	60.00%	3
Read the written instructions/manual	0.00%	0
Follow the diagrams in the manual	0.00%	0
	Answered	**5**
	Skipped	**0**



	NEVER		SOMETIMES		OFTEN		Total
I remember something better if I write it down	0.00%	0	0.00%	0	100.00%	5	5
I understand how to do something if someone tells me rather than having to read the same thing to myself	20.00%	1	80.00%	4	0.00%	0	5
I remember things that I hear rather than things that I see or read	20.00%	1	80.00%	4	0.00%	0	5
I learn best when I am shown how to do something and I have the opportunity to try it	0.00%	0	0.00%	0	100.00%	5	5
Before I follow directions, it helps me to see someone else do it first	0.00%	0	20.00%	1	80.00%	4	5
I learn better if a presenter uses a PowerPoint, diagrams and/or handouts	0.00%	0	20.00%	1	80.00%	4	5

Answered	**5**
Skipped	**0**



	1		2		3		4		5		
A series of 30-45 minute sessions over the lunch hour	50.00%	2	0.00%	0	25.00%	1	25.00%	1	0.00%	0	4
An online self-paced webinar	0.00%	0	0.00%	0	25.00%	1	25.00%	1	50.00%	2	4
Self-directed learning (print/reading materials, online modules)	0.00%	0	33.33%	1	33.33%	1	33.33%	1	0.00%	0	3
2 hour after-work seminar/course	25.00%	1	25.00%	1	0.00%	0	25.00%	1	25.00%	1	4
One-on-one mentorship	0.00%	0	33.33%	1	0.00%	0	33.33%	1	33.33%	1	3
Shadowing and/or co-treating a client with a mentor therapist	0.00%	0	33.33%	1	33.33%	1	0.00%	0	33.33%	1	3
In-person or video case-studies	50.00%	2	25.00%	1	25.00%	1	0.00%	0	0.00%	0	4
									Answered		5
									Skipped		0

Q9. Please list 1-2 expectations or desired outcomes you have for a presentation or continuing education opportunity to learn more about assessment and intervention for pediatric visual-vestibular dysfunction?	
Answered	**5**
Skipped	**0**
Respondents	**Responses**
1	1. acute and long-term effects 2. research to support use of it
2	Home exercise programs that are sorted by type of difficulty (convergence, nystagmus, etc.)
3	Astronaut Training Program
4	actual treatment strategies, guidance, assistance, feedback on correct implementation of the assessment
5	Hands-on treatment strategies

Appendix M – Example of a Clinical Intervention Activity

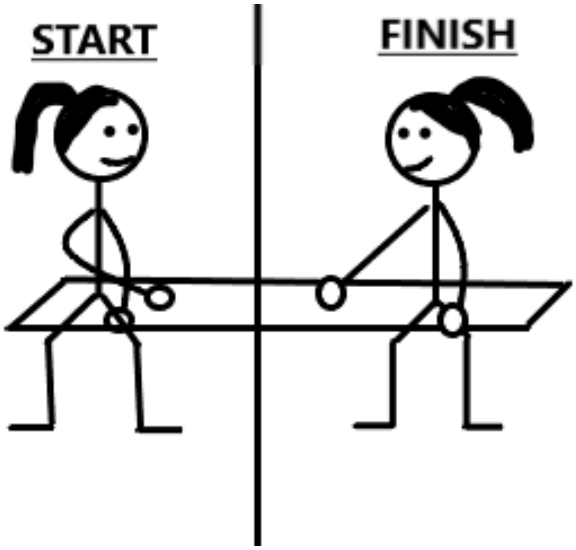
Intervention Resources Activity

Activity: Midline crossing with head turn and eye gaze

Aim of activity:

- Improve gaze stabilization
- Stimulate vestibular processing with dynamic vision challenge
- Motor reflex integration (ATNR)
- Postural control and strength
- Right/left discrimination
- Eye/hand coordination and targeted reaching for item retrieval
- Motor coordination, motor planning and improving ataxia

Basics Version of Activity: Have child reach across the middle of their body with elbow extension as much as possible and cervical rotation to look to target object. Child should retrieve object then bring it back to the other side without switching hands and rotate their head to the other side while placing the object in a targeted spot



Child should *NOT*:

- lean to the side they are reaching
- shift their body to avoid reaching across middle
- laterally flex head/neck to avoid true cervical rotation past midline
- lean into their non-reaching hand to avoid crossing midline with their reaching hand

Child should:

- obtain visual gaze on target before retrieving item preferably with eye turn past midline to side they are reaching.
- Rotate in their trunk/core to turn their shoulders while reaching
- Keep their non-reaching arm at their side without changing the position during the entire task
- Keep their legs/lower body in the same position

Modifications to Activity – Downgrades

- Perform sitting in supportive chair to stabilize trunk and provide extra postural control
- Perform in supine to reduce challenge on postural control, sitting balance and fatigue
- Have child reach to their opposite leg then bring object to set beside them, reaching within their base of support
- Keep object in visual midline in the vertical plane so they don't have to look up or down while also turning their head
- Make targets button activations, tapping, etc. to eliminate grasp challenge
- Make target objects and retrieval/placement targets larger so they are easier to see and easier to reach/be successful with motor coordination
- Provide hand over hand support, physical assist or behavior reinforcements to maintain positioning and engage in activity
- Use preferred toys, food, or other games to keep child engaged
- Give frequent rest breaks or rest in midline between repetitions
- Complete repeatedly with the same arm reaching before switching to the other side

Modifications to Activity – Upgrades

- Perform in unsupported sitting positions
- Perform in standing on solid surface
- Perform standing on uneven surface (foam, balance ball, tilt board)
- Perform standing on one leg
- Perform while sitting, kneeling, standing or supine on a swing while in motion
- Perform while seated on a ball, tilt board or unbalanced surface
- Have the child reach with rotating the trunk as much as possible
- Have the child reach to varying heights that require capital flexion/extension and eye gaze up/down while also rotating head
- Have the child reach outside his/her base of support
- Have child reach to a moving target or while moving on a swing or ball
- Use smaller objects/targets that require more fine-tuned movement and targeted reaching

- Integrate an activity that requires manual manipulation of the object or has language/cognitive components the child must complete while performing the task (color naming, matching, object identification, math problems, counting, puzzles, memory recall, problem solving, etc.)
- Have child complete more repetitions or hold the positions for longer
- Have child alternate reaching with right then left arm to shift motor plan with each repetition

Toy/Game Ideas to Use With This Activity:

- Peeling/placing stickers
- Retrieving paint dotters and making marks on paper on opposite side
- Drawing a card from a pile and placing in a discard pile on the opposite side during game play (i.e. Candy Land, Uno, Go Fish, etc.)
- Sorting puzzle pieces before assembling an interlocking puzzle
- Counting money/putting money into a coin bank
- Coloring with crayon/marker retrieval on one side and coloring page on the other
- Throwing games with ball/bean bag retrieval on side opposite of throwing target
- Crafts with child retrieving supplies/pieces from one side and assembling on the other
- Retrieving squigz and attaching to a surface on the opposite side
- Getting out clothes or putting away laundry; sorting laundry
- Cleaning up toys after playing with toys on one side and container on the other side

EXECUTIVE SUMMARY

As medical care improves, more children are surviving with brain injuries, neurodevelopmental challenges and cancer and are able to participate in everyday life at higher rates than before (American Cancer Society, 2016; Brandes & Fraceschi, 2011; Houtrow et al., 2014; Smith et al., 2014; U.S. Census Bureau, 2003; U.S. Census Bureau, 2011). Clinically, OT practitioners see many children with these diagnoses who have dizziness, balance, coordination, strength, and vision deficits that make daily life difficult (Alghadir, Iqbal & Whitney, 2013; Medeiros et al., 2005; Rine & Wiener-Vacher, 2013). It is very important that OT practitioners stay up-to-date on how best to help these children so they can return to or continue to participate in daily activities that are important to them.

What is PVVD?

Explanations of vestibular and visual functioning and what visual-vestibular dysfunction involves is in Table E.1.

Table E.1 – Explanation of PVVD

Vestibular	The vestibular system controls balance and stabilization of vision when a person is moving or is moving his/her head. Vestibular impairment can be caused by issues with the inner ear and/or the nerve that connects the ear to the brain stem (peripheral nervous system) or because of issues in the brain and spinal cord (central nervous system).
Vision	Vision is more than your ability to see. Vision involves processing information with the eye (focal pathway) and using that information to orient to time and space to support balance, movement, coordination and posture (ambient pathway). Vision also involves using the brain to make sense of what we see. This involves using language, emotion and knowledge to put meaning to what we see. Challenges with vision can occur if there are issues with the structures of the eye, the optic nerve, and damage to the muscles that control eye movements making it difficult to line up the information taken in by each eye or if there are issues with any part of the brain that helps to process vision information.
PVVD	After a neurologic event or injury to the brain, the vestibular and visual systems can be damaged. If there is impairment of the central nervous system area of vestibular system and/or and the ambient pathway of vision, a child may have a variety of symptoms and challenges that make every day activities difficult.

There are a variety of different symptoms, signs and risk factors for PVVD. These are outlined in Table E.2.

Table E.2 – Signs, symptoms and risk factors of PVVD

Signs & Symptoms of PVVD - Children with PVVD may not be able to report their symptoms well, but they may show the following signs of challenges with visual-vestibular functioning		
Vestibular-Related Signs & Symptoms	Dizziness Loss of balance/falls Poor motor coordination Spinning sensation Nausea & vomiting	Headache Clumsiness Changes in behavior Changes in vision
Vision-Related Signs & Symptoms	Difficulty moving the eyes Nystagmus (rhythmic uncontrollable movement of the eyes) Poor balance/falls Poor motor coordination Blurry vision or double vision Turning/tilting of the head to see Misalignment of the eyes Clumsiness	Squinting or covering one eye Excessive blinking/squinting Nausea & vomiting Headache Dizziness Poor attention Difficulty or worsened symptoms when reading Poor handwriting
Risk Factors Children with the following conditions or who receive the following treatments may be at higher risk for PVVD (Christy & Rine, 2016; Rine & Christy, 2016)		
Medical Diagnoses	Cerebral palsy Central nervous system cancer or tumor Traumatic brain injury Cerebral vascular accident or stroke Meningitis Concussion and Post-Concussion Syndrome Congenital cytomegalovirus Developmental Delay Migraines	Autism Spectrum Disorder Congenital malformations Genetic conditions impacting neurologic function Sensory processing disorder Hydrocephalus Sensorineural hearing loss Late or preterm birth Learning disabilities
Medications and Medical Treatments	Surgery to remove a brain tumor Other surgeries involving the brain Chemotherapy Radiation targeting areas of the brain Aminoglycoside antibiotics	Anti-neoplastic medications (e.g., cisplatin, carboplatin) Exposure to environmental chemicals (e.g. lead, carbon monoxide, mercury, carbon)

Description of the Proposed Program - The (MRH) OT PVVD program will be a combination of research-based practice resources, practitioner education, and

development of treatment guidelines that will expand rehabilitation services for children with CNS cancer/tumors and other cerebellar and brain-based causes of PVVD. With medical advancements, MRH has had many more referrals for OT services for children with CP and CNS cancers (G. Girten, personal communication, June 27, 2017; NM, 2016). These children are at very high risk for PVVD, which makes it difficult for them to participate and perform daily activities (Alghwiri et al., 2012; Archer et al., 2012; Dannenbaum et al., 2016; Konczak et al., 2005; Pavao & Rocha, 2017; Rine & Wiener-Vacher, 2013; Roley et al., 2015; Syczewska et al., 2006; Tsao et al., 2016; Ward et al., 2013). Despite awareness of the risk factors leading to PVVD, OT practitioners remain limited in their ability to assess and treat PVVD. The MRH OT PVVD Program will target OT practitioners at MRH and the children they work with to support the ability of these children to participate in meaningful daily activities.

Why the MRH OT PVVD Program is needed?

Many factors have been considered in development of this program. Five main factors that justify the need for this program are highlighted in Table E.3.

Table E.3 – Justification for the PVVD program

Contributing Factor	Explanation
More children are living with neurologic impairment	More children are surviving/living longer with neurodevelopmental impairments and childhood cancers (American Cancer Society, 2016). So more of these children are being seen at MRH for rehabilitation services.
There is limited research to guide OTs in how to treat PVVD in children who are still going through treatment for CNS cancer	Much of the research for the rehabilitation of children who survive childhood cancer focuses on long-term effects of their medical treatment and does not address the early needs these children face because of life-saving medical treatments (Chan, Xiong & Colantonio, 2015; Demers, Gelinas & Carret, 2016; Hwang et al., 2015; Khan et al., 2015).
Many children have or are at-risk for PVVD, not many are diagnosed or treated	Only 29.9% of children with symptoms of vestibular dysfunction receive treatment, even though 1 in 5 children present with possible PVVD including children with BI (American Cancer Society, 2016; Chen et al., 2013; Christy & Rine, 2016; Demers, Gelinas & Carret, 2016; Haybach, 2002; Hwang et al., 2015; Khan et al., 2015; Nevin, 2014; Toto, 2012).
Many caregivers do not know about PVVD and do not seek medical services	Few families know about PVVD even though many children show signs/symptoms (Christy & Rine, 2016; Cronin & Rine, 2016; NM, 2016).
Many OTs do not know how to assess and treat PVVD	Many OTs understand sensory dysfunction with the Ayres SI framework, but few have advanced understanding/training to address more complicated PVVD

Objectives of the Program

1. To ensure that all MPTD OT practitioners are competent and confident in PVVD assessment and intervention so they can use best practice with children on their caseloads
2. To improve the quality of life for children with PVVD by helping them to participate and be more independent in everyday activities
3. To disseminate information about PVVD so children across the country who have or are at-risk for PVVD can achieve better health outcomes

Why is OT needed for PVVD?

OT practitioners have a vested interest in PVVD because they play a big role in the rehabilitation of children recovering from brain injury, cancer, and other challenges that limit their overall health and wellness (AOTA, 2014; AOTA, 2016; Longpre & Newman, 2011; More, 2011; Mori, 2015). OT practitioners are able to provide interventions for children with sensory integration deficits related to PVVD and can help children recover skills or learn compensatory strategies in everyday living skills to help them do the things they want to do regardless of life expectancy (Longpre & Newman, 2011). Despite awareness of risk factors leading to PVVD and the clear role OT has in treating PVVD, OT practitioners within the MPTD are limited in their ability and confidence to assess and provide intervention for PVVD. As a result, the focus of the MRH OT PVVD Program will be to improve clinician knowledge and expertise in the area of PVVD rehabilitation and to develop a standard of care within this specialized area of OT practice that can be used at MRH and other healthcare facilities that serve children with PVVD.

Program Details

To train MPTD OT practitioners in PVVD rehabilitation, the following activities will be completed as part of the program as described in Table E.4.

Table E.4 – Training activities

Description	Details
Learning Preferences Needs Assessment	Conduct a needs assessment survey to understand how MPTD OTs learn best
In-Person formal education/training	In-services, seminars, lab-based training, individual and small group mentoring, practice labs, and job shadowing opportunities.
Web/electronic-based education/training	Creation of self-directed learning modules, video recordings of presentations/lectures/professional development courses, email communications, and access to electronic versions of all training information provided to each practitioner.

As part of the MPTD OT PVVD Program, Table E.5 lists clinical resources for OT practitioners that will be created, revised, adapted or added to in order to support OTs working with the target client population.

Table E.5 – Clinical Resources

Description	Details
Revised OT Evaluation Kit	One assessment kit for outpatient and inpatient departments including reviews and instructions for assessments/screening tools • Revised MRH Vision Screen • Body Mapping screening • Pediatric Vestibular Symptom Questionnaire • PedsQL Modules • Scale for Assessment Rating of Ataxia (SARA)
Assessment Resources	Full test administration and scoring manuals, extra copies of test forms, and additional references/training materials for each assessment above
Activity Resource Book	Print/electronic copies of treatment activities for use during therapy sessions including: decision trees for selecting and grading activities, play-based activity descriptions and examples of how to increase or decrease the challenge of the activity for each child, goal-writing guide, and list of intervention resources (i.e., blogs, research articles, demonstration videos)
Case Study Examples	Videos, images with written descriptions/suggestions, and active links to blog posts, internet videos, etc. as examples of how to use the PVVD resources in therapy sessions
Educational Brochure & Resource Book	Educational materials (informational brochure, exercise instructions and handouts) that OT practitioners can use and provide to parents/caregivers of children with PVVD to use as part of a home exercise program

To sustain this program, the evaluation of the activities and outcomes of the program will be needed. To assess its effectiveness, Table E.6. describes the evaluation activities that will be completed.

Table E.6 – Evaluation Activities.

Description	Details
Evaluation of Education/ Training	• Immediate and delayed post-training surveys will assess how effective the training was in teaching therapists about PVVD • Periodic surveys will assess department needs for additional training/education sessions • Development and use of a clinical competency will measure how well practitioners understand and can use PVVD principles in their practice • Regular evidence reviews will be completed to make sure the program stays in alignment with current practice standards
Evaluation of Client Outcomes	Tracking of clinical data and analysis of that data will be done to make sure the interventions being provided are actually helping children with PVVD participate more/better in daily activities

Budget

The budget for this program will be heavily based on the time costs of staff to carry out the program activities. Non-billable time to run the program will cost about $16,000-$22,000 in year one and $10,000 - $14,000 in year two of the program. Since most of the program development will be completed in year one, the cost to sustain the program is anticipated to be much less. Expenses to run the program include assessment and treatment materials, printing and costs to run the formal education/training sessions. For year one, expenses are expected to be about $300 - $1,500, and in year two are expected to be $400 - $7,000. Overall, the cost for materials is expected to be about the same over year one and two, though growth of the program might make costs rise including possible licensing fees for use of some assessments. Funding for the MRH OT PVVD Program

will mostly come from the MPTD and NM budget, though external funding sources (i.e., donations and grants) will be explored to add to the department budget.

Dissemination Plan

After the MRH OT PVVD Program is running, efforts will be made to share information gained through this program to improve care provided for children with PVVD across the country. Dissemination efforts will focus on targeting OT practitioners across the US (primary audience), physicians who make referrals for PVVD rehabilitation (secondary medical audience) and parents/caregivers of children with PVVD (secondary family audience). To disseminate this information to these groups, Table E.7 lists the activities that will be completed.

Table E.7 – Dissemination Activities

Activity	Target Audience
Person-to-Person Activities	
Presentations at professional conferences	Primary
In-services and meetings with MRH staff and leadership	Secondary -medical
Educational presentations to physicians and care teams at other healthcare facilities	Secondary – medical
Guest lectures and in-services at local, regional and national OT practitioner education programs	Primary
Written Information	
Professional publications in OT practice sources	Primary
Educational brochure on PVVD & MRH OT PVVD Program	Secondary-medical Secondary - family
Electronic Media	
Memos, briefs and outcomes reports distributed within the MRH/NM system	Primary Secondary – medical
Self-directed professional development modules and/or training webinar or YouTube video	Primary

The goal of the MRH OT PVVD Program is to train OT clinicians to better assess and treat PVVD in children with CNS cancer and/or other neurologic conditions. With a growing number of children surviving and participating in daily life with chronic and disabling health conditions, it is imperative that OTs stay informed on how to best support these children to live their best lives. Through education and training efforts of OTs at MRH, and by providing clinicians with tools to implement assessment and intervention techniques aimed to address PVVD, the program intends to expand OT practice and, improve care for children with PVVD. In turn, this program will impact short and long-term health outcomes for these children. In addition to these training and clinical support efforts, the program will examine how effective these interventions are and publish results in order to advance OT practice and rehabilitation science as a whole. In combination with the outlined dissemination plan, the MRH OT PVVD program has the potential to significantly and positively influence OT practice and the lives of children with and at-risk for PVVD.

FACT SHEET

The Eyes Have It:

A Visual-Vestibular Program for Pediatric Oncology and Neuro-Rehabilitation

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IDENTIFIED PROBLEM

- More children are living with serious health conditions = more need for rehab services for these [1, 2]
- OT practitioners need be involved in developing practice for pediatric oncology and neurologic and pediatric visual-vestibular dysfunction (PVVD) rehabilitation [3, 4]
- OT Practitioners in the Marianjoy Rehabilitation Hospital (MRH) see many children with central nervous system (CNS) cancer but are not confident on how to address PVVD with these children [5]

WHY SHOULD OT BE MORE INVOLVED?

- PVVD impacts ADL/IADL participation and lowers QoL [4, 5]
- PVVD is an under-identified barrier to participation [3, 4]
- Pediatric oncology and neuro-rehabilitation are growing areas of OT practice and these children are at high risk for PVVD [1, 2, 3, 4, 5]
- OTs have a unique skill set to address the sensory processing/integration, motor control and sensorimotor needs of children with PVVD

HOW THIS PROGRAM IMPACTS OT

- *Provide clinical guidelines on how to assess and intervene with PVVD*
- *Translate knowledge that will empower OTs to be more involved in PVVD rehabilitation.*

WHO

Children with CNS cancer and/or other neurologic conditions and the OTs that work with them.

WHAT

- Education/training on PVVD rehab for OTs
- Develop clinical resources for assessment and intervention of PVVD
- Evaluation of interventions and disseminating results to expand OT practice

WHERE

Marianjoy Rehabilitation Hospital, part of Northwestern Medicine
Wheaton, Illinois

LONG-TERM OBJECTIVE

Promote the unique role of OT in pediatric oncology and neuro-rehabilitation to expand OT practice and increase access to services to promote meaningful and positive health and wellness outcomes for children across the U.S.

PRIMARY PROGRAM ACTIVITIES

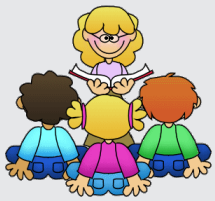
- **Create clinical resources for daily practice**
  - Assessment kits and guides
  - Intervention activity guides and case study examples
  - HEP and client/caregiver educational resources
- **MRH needs assessment and learning preferences survey**
- **In-person education and training**
  - In-services/seminars & formal training sessions\
  - 1:1 and small group mentorship, co-treatments & job shadowing
  - Self-directed learning modules & instructional videos
  - Video recording and/or live streaming seminars
  - Electronic and print evidence resources

EVALUATION/SUSTAINABILITY PLAN

- **Evaluation of Educational/Training Activities**
  - Post-training surveys & periodic experiential surveys
  - Periodic caregiver surveys to assess effectiveness/use of education resources
  - Clinical Competency tool
- **Evaluation of Client Outcomes**
  - **Primary** - Quality assurance study: track assessment data with pre/post-test measurements
  - **Secondary** – more rigorous clinical research to measure effectiveness of intervention strategies

DISSEMINATION

- **Professional conferences**
- **In-services**
- **Presentations to external stakeholders**
- **Professional**



FUNDING

- **High personnel costs**
- **Support at MRH**
  - Clinical Educator
  - Research Director
  - Rehab Technician
  - Program Coordinator
- **Internal Funding**
  - Department budget
  - Operations budget
  - NM Foundations / grant program
- **External Funding**
  - Government funded grants
  - AOTF grants
  - Private research and grant programs

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