

Proposal to RFP BD-20-1065-MCB1-1-50100

Implications of Increased Incidence that Cortical/Cerebral Vision Impairments (CVIs) could Have on VR Outcomes

Original RFP (excerpt)

“MCB’s Vocational Rehabilitation counselors (VRCs) have noticed an increase of VR clients who experience vision loss as a result of Cortical/Cerebral Vision Impairments (CVI). MCB seeks a vendor to conduct a study to provide information relative to CVI. MCB seeks a deeper understanding of; how CVI impacts VR outcomes. This will include a data-driven analysis of consumers experiencing CVI. Both consumers with successful and unsuccessful VR outcomes should be considered. Further, the successful bidder will also ascertain if there are any common denominators amongst this specific set of conditions that could aid VR outcomes.”

A group of investigators with interest in CVI formed a consortium to respond to the RFP. This is their report.

BACKGROUND

Cortical/cerebral visual impairment (CVI) is defined by Sakki et al. (Br J Ophthalmol. 2018 Apr;102(4):424-432. doi: 10.1136/bjophthalmol-2017-310694. Epub 2017 Nov 16.PMID: 29146757) as a verifiable visual dysfunction that cannot be attributed to disorders of the anterior visual pathway or any potential co-occurring ocular impairment. In short, the diagnosis of CVI is considered when the level of observed vision or use of vision cannot be explained by an ocular disorder, ocular motor deficit (such as an eye turn or nystagmus), the need for glasses, or constriction of peripheral vision.

CVI is a brain-based visual impairment that can impact not only areas of the brain responsible for commonly assessed visual functions (such as acuity, visual field, contrast) but also higher areas of processing that impact color vision, the ability to apply labels to what is seen (such as recognition of faces), and visually guided activities, such as accurate placing of a letter in a mail slot. Any particular deficit may vary in severity. Deficits may cluster in some individuals. Thus there is potential for a broad range of deficits even within one individual with CVI. The diverse manifestations of vision based difficulties are frequently complicated by comorbidities that affect mobility, such as cerebral palsy. Deficits in expressive and receptive language deficits and intellectual impairment may co-exist in those with CVI.

These deficits in function impact attention, social behaviors, ability to travel independently, communication, and performance on specific tasks. Some of the impact may be attributable to the vision based deficits, and some to the motor and intellectual difficulties caused by the comorbidities. Or it may be some combination of the two.

A multidisciplinary provider team is needed by an individual with CVI including for those with pediatric CVI. Team members include the family and a squad of professionals. Our consortium of investigators endorses across the board collaboration and integrated care to satisfy the extended needs of the individual with CVI. The eye care professional contributes an accurate diagnosis of CVI in collaboration with families and vision professionals. Early, accurate diagnosis of the comorbidities by other professionals enables appropriate guidance along the pathway of care, education and preparation for rehabilitation or further education. Comprehensive, dynamic, longitudinal assessments aim to maximize the capacity of the individual with CVI.

STUDY PURPOSE

MCB sought deeper understanding of how CVI impacts vocational rehabilitation (VR) through a data driven analysis of MCB consumers experiencing CVI. What distinguishes individuals who are successful in VR, from those who are unsuccessful in VR? What of these distinguishing features are pertinent to CVI?

The number of individuals with CVI is increasing rapidly. CVI is unambiguously the #1 cause of pediatric visual impairment in the United States.

In response to the RFP, we set out to determine the current population of MCB clients with CVI. As indicated in the RFP, MCB's Vocational Rehabilitation counselors (VRCs) have noticed an increase of VR clients who experience vision loss as a result of Cortical/Cerebral Vision Impairments (CVI). The members of the consortium anticipate that the numbers of individuals with CVI will continue to increase as CVI becomes better diagnosed and more clients are registered.

ORIGINAL PROPOSAL

In collaboration with MCB, a consortium of researchers, clinicians, and educators from Boston Children's Hospital Ophthalmology Department, New England College of Optometry Low-Vision Service, Perkins School for the Blind, and University of Massachusetts proposed to gather and analyze data on vocational rehabilitation (VR) outcomes for MCB consumers with and without CVI. The histories of those with CVI and without CVI were to be compared. The expertise of the consortium in delivery of care to individuals with CVI would be brought to bear on interpreting and analyzing any differences between VR outcomes in CVI compared to those outcomes in non-CVI clients. Surveys were proposed as a means of gathering this information.

Based on their experience in providing for individuals with CVI manifesting diverse features, the consortium approached this project with the strong conviction that much more could be done in the way of VR for MCB-CVI consumers while recognizing the enormous challenge that brain-based visual impairment, CVI, plus comorbidities place on all parties involved in the CVI client's navigation of a pathway to successful employment. The consortium envisioned that MCB-CVI clients would ideally be matched to suitable job opportunities. And that those job placements would ensure visual accessibility. If only they could use their abilities to attain and maintain jobs! Visual accessibility would allow individuals to operate at their optimal level of

employment even in consideration of recognized characteristics and behaviors that have been considered, historically, to preclude successful employment.

Successful employment would permit MCB-CVI consumers to make contributions to their communities. The consortium anticipated remediation would come about through identification of consumers' needs in care, rehabilitation, and vocational services at every step along the pathway from family to employer.

The plan was to do the following.

1. Identify and characterize the population of MCB-CVI and non-CVI consumers
2. Explore the possibility of surveying everyone, including a subset of MCB CVI consumers and professionals they encounter along the pathway to a job including Vocational Rehabilitation Counselors (VRCs), Teachers of Students with Visual Impairments (TVIs), and Orientation & Mobility Specialists (O&Ms). The purpose would be to delineate their experience regarding education, training, vocational rehabilitation, and employment.
3. Analyze results of numbers 1 and 2 (above) to identify factors associated with VR-positive and VR-negative outcomes.

METHODS AND RESULTS

The MCB-CVI Project Manager directed a search of the files in MCB's central database and case management system, called AWARE (Accessible Web-Based Activity and Reporting Environment). AWARE holds a total of seven years of data. The search included both closed and open cases.

A diagnosis of CVI was indicated by the combination of codes (750, Other affection of optic pathway or visual center) and code (78, Other specified disease or disorder not elsewhere classified). A code specific for cortical/cerebral visual impairment was not available. Given the known complexity typical in individuals with CVI, we comment that the nature and severity of the visual impairment and of any comorbidities was not specified.

The tables and graphs (below) summarizing the results of the database search tell a remarkable story about MCB-CVI clients and vocational rehabilitation (VR).

KEY RESULTS OF THE SEARCH

In SRC (Table 1 and Table 2; Figure 1) there are 397 individuals with CVI among a total of 1,331 cases; a whopping 30%! Remarkably, the next most frequent diagnosis is only 7%; it is albinism.

SRC CVI Consumers by MA Area of Residence

The number of children (0-14 years) is shown by area of residence

Table 1	
AREA	SRC CVI
Cape Region	25
Western MA	50
Bristol	35
Middlesex	118
Norfolk	38
Worcester	56
Suffolk	28
Essex	47

- SRC= Social Rehabilitation-Children, 0–14 years
- AREA= Consumers by Massachusetts areas of residence

SRC Consumers With A Diagnosis of CVI vs. Those Without

Table 2	
CVI Diagnosis	30%
All Other Diagnosis	70%
397/1331 Cases in AWARE	
Closed and Open Cases	

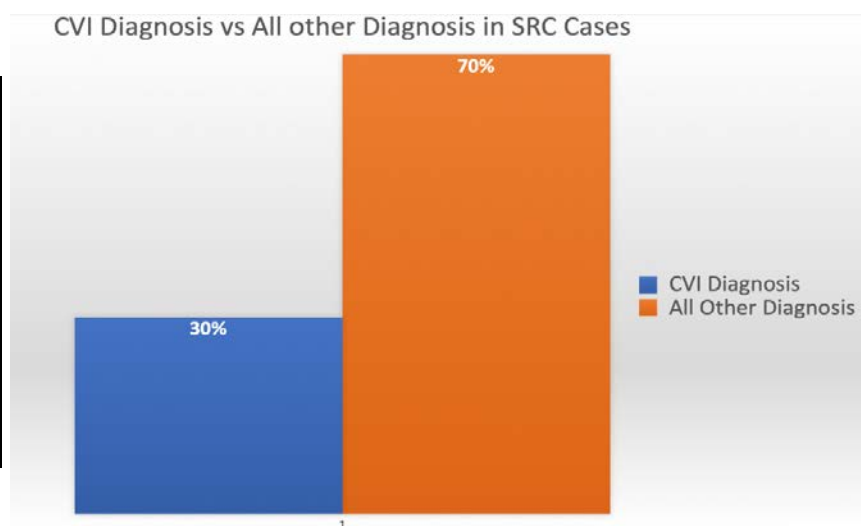


Figure 1.

All MCB CVI Consumers by Service Program

Table 3			
Total CVI Cases in AWARE by Category Open and Closed			
Category	CVI Cases	Total Cases	% of Cases
SRC	397	1,331	29.827%
VR	30	5,999	0.500%
SR	304	22,455	1.354%

SRC = Social Rehabilitation-Children, pertains to MCB consumers of 0–14 years

VR = Vocational Rehabilitation, consumers >14 years–adults

SR = Social Rehabilitation, consumers >14 years–adults

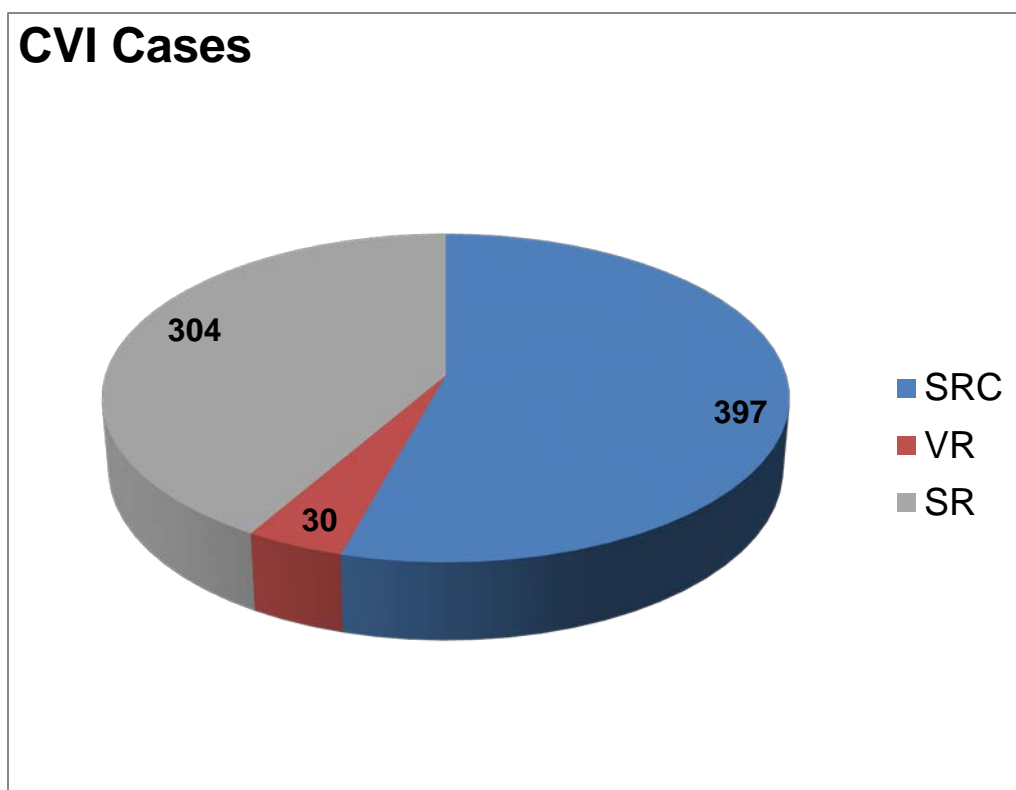


Figure 2.

Social Rehabilitation–Children (SRC) nearly 400 (397) have a diagnosis of CVI. As the investigators discussed these results, the possibility of under-reporting of CVI was recognized but judged to be a non-fatal flaw, and some errors in data entry were acknowledged.

By comparison, in SR (adults), numbering ~23,000 there are many fewer with CVI; barely over 1% of that group had a diagnosis of CVI, reflecting the higher prevalence of other causes of blindness in adulthood including age-related macula degeneration and diabetic retinopathy. As the consortium discussed this, the prevailing perspective was given the increased understanding of brain-based vision impairment resulting in a more encompassing definition, it is very likely that the adults with CVI are under-represented in the MCB data. Further, without a precise code for CVI and with varying understanding of CVI on the part of eye care providers, it is possible that both the pediatric and adult census for CVI is lower than it should be.

As shown in Table 3 and Figure 2, the VR group yielded 30 CVI cases, only 0.5% of the total of 5,999 cases. The MCB-CVI Project Manager reported that, of the 30 CVI cases in VR, 25 are now closed—closed unsuccessfully. This is a BIG wakeup call!! Of the remaining 5 cases, 4 are reported to be making poor progress and 1 was misdiagnosed (not CVI).

The leading, non-mutually exclusive explanations for the low VR success among MCB-CVI clients considered by the consortium were:

1. CVI is underdiagnosed, and individuals with CVI are in fact receiving vocational rehabilitation
2. The comorbidities associated with CVI preclude participation in the vocational rehabilitation program as it is currently construed.

This led the MCB-CVI Project Manager and the consortium to consider approaches to improve the success of MCB-CVI consumers in VR.

PHASE TWO OF STUDY

Once the information from the database was received and assessed (above), the consortium recognized that, given the low representation of MCB-CVIs in VR and the high prevalence of CVI among children registered with MCB something needed to be done. The SRC-CVI cohort was moving unrelentingly forward, approaching the threshold for taking their next steps on a pathway to possible employment. The vocational rehabilitation counselors (VRCs) were recognized as crucial to the final common step of an MCB client to employment. The consortium decided to focus on surveying the 15 vocational rehabilitation counselors (VRCs) employed by MCB. The consortium created a survey with the purpose of capturing the VRCs' cumulative experiences interacting with MCB consumers deemed appropriate for rehabilitation. (See survey, below)

Design and Rationale for the Survey of Vocational Rehabilitation Counselors (VRCs):

The service provider at MCB who guides a client's final pathway to employment is typically a Vision Rehabilitation Counselor (VRC). VRCs work with adults with blindness and visual impairments. They provide information, resources, and support so that adults with visual impairments, including CVI, can lead their fullest, most successful, and most productive lives. They provide specialized methodologies or adaptations for optimal success. This includes support in the client's workplace.

Our survey was designed to gather information from MCB VRCs about their own experience, training, and work; their consumers' characteristics, and their judgment as to whether behaviors typically associated with CVI were likely to impact the client workplace interaction and therefore successful employment.

There are three sections in this survey:

1. Because CVI is admittedly less well understood by medical professionals and vision professionals alike and is often underdiagnosed, we sought to gather information about the VRCs comfort level and knowledge about CVI, and their work. Information about their caseload and composition, both for ocular and brain-based vision loss, how they would rate their own knowledge of CVI, where they learned about CVI, how they understood the impact of the CVI visual behaviors in environmental adaptations, and the rehabilitation methods used.
2. It is recognized that individuals with brain-based visual impairment (CVI) struggle with specific areas of functioning. We designed 10 questions about the widely-recognized behaviors of individuals with CVI and the potential impact of these behaviors in the workplace: impact of motion, clutter, visual field difficulties, visual motor skills, visual recognition, sensory integration, color supports for recognition, social skills, environmental lighting, and elements of the client's safe, independent navigation.
3. We included an open-ended, free-text comment section. We asked the VCR to list the three most impactful factors that might impede a client's success and the client/VCR relationship.

Next is the actual survey below:

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Impact of CVI on VR Outcomes Survey

Please complete the survey below.

Please complete the survey in a single window in your web browser. If you receive an error message while completing the survey please refresh your screen.

For any questions or concerns, please email Dr. Nicole Ross at rossn@neco.edu

Thank you!

Dear Vocational Rehabilitation Counselor,

We seek your help in considering a possible path of MCB consumers with cortical/cerebral visual impairment (CVI) to participation in VR and towards successful employment. Your input from the VR perspective is critical.

In this survey, CVI is defined as visual impairment due to difficulties with the brain's processing of visual information rather than due to eye disease. CVI is associated with numerous vision mediated behaviors. None of these behaviors is unique to CVI. For instance, for CVI individuals a common behavior is tripping or bumping into things, but individuals with field loss due to eye disease may also bump into things.

Thank you for your expertise in identifying factors that may impact the client-workplace interaction and success in employment (regardless of the cause of visual impairment).

If you have questions or concerns in completing this survey, please contact Dr. Nicole Ross at rossn@neco.edu.

Please know that responses are kept anonymous, no identifying information is recorded.

Thank you!

**Massachusetts Commission for the Blind/CVI Project Team
(members include MCB staff, eye care specialists and educators)**

1) I. Your Work Experience with CVI:

Total number of clients on your case load

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From your current caseload, please provide an approximate percentage for each of the following primary causes of visual impairment.

2) Albinism

3) Corneal disease

4) Keratoconus

5) Cortical/cerebral visual impairment

6) Glaucoma (primary or secondary)

7) Glioma (or other cancer affecting the visual system)

8) Injury/non-accidental trauma

9) Optic atrophy/hypoplasia (including Leber's)

10) Retinopathy of prematurity

11) Retinal degeneration/dystrophy (e.g. RP, Usher, Bardett-Beidel...)

12) Others

CVI Knowledge and Training

13) My knowledge regarding CVI is:

- ☐ Building
☐ Moderate
☐ Extensive

14) I first learned about CVI:

- ☐ On the Job
☐ In College/Graduate School
☐ At a Conference/ Workshop
☐ Webinar/Internet
☐ Other

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Please rate your understanding about the following CVI concepts:

	Building	Moderate	Extensive
15) How CVI is diagnosed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16) CVI Education/Rehabilitation Methods	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17) Common CVI Behaviors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18) Environmental modifications for CVI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

II. Vision mediated difficulties associated with CVI

For those of you who have CVI clients, please estimate the frequency with which they struggle with the following:

- 19) First please confirm, Do you have CVI clients? ☐ Yes
☐ No
 If No, Survey will skip to Section III.

For those of you who have CVI clients, please estimate the frequency with which they struggle with the following:

	Not At All	Rarely	Sometimes	Often	Very Frequently
20) Tripping or bumping into things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21) Avoid using their vision?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22) Look away when reaching?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23) Seeing materials around them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24) Finding things in clutter?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

III. Clients' interaction with environment and with other people

For each of the following factors, please rank the importance for successful employment of a client with visual impairment, no matter the cause of the visual impairment.

	Not Important	Important	Very Important
25) Ability to work in busy environments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26) Visual recognition of objects and people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27) Social skills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28) Recognition of new objects and new environments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29) Ability to tolerate clutter	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30) Ability to tolerate noise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31) Independent mobility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32)			

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- | | | | |
|---|-----------------------|-----------------------|-----------------------|
| Ability to maintain attention to task in various lighting conditions | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 33) Accurate eye/hand coordination (reaching and placing items) and eye/body coordination | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

V. Additional Comments

- 34) Please share with us comments about your experience in working with clients with CVI.

- 35) What would you say are the 3 most important factors determining success on the path to employment?

- 36) What are the most important features of a VR-client relationship?

- 37) Other Comments

The survey was composed in REDcap, a secure, web-based survey tool. Pilot testing of the survey was conducted to be sure the survey questions were well written and understood. Additional pilot testing with MCB's technology office explored accessibility of the survey with screen reader programs and also explored the utility of additional accessibility options to modify print size or allow for text-to-speech. This protocol was reviewed by the Institutional Review Board at the New England College of Optometry. The board deemed the survey to pose minimal risk. An exemption letter was provided for the study.

Again, our overall goals were to understand professional development needs, recognize functional difficulties in the workplace, and define factors that determine success in obtaining and retaining employment. Understanding this more fully will inform possible solutions.

The survey was disseminated by the MCB project manager

Survey Results

A total of 5/15 (33%) of VRC's responded and completed the survey.

The median case load for each respondent was 11 VR clients, but one had as many as 100 cases. As for clients with CVI, a median of 5 (range 0 – 20) clients with CVI were included in the case mix. The most common diagnosis was glaucoma (median 19; range 4 – 40)

Regarding their knowledge of CVI, Figure 3 shows that 40% of VRCs responded that their overall knowledge of CVI was building, and 60% reported it was moderate. As to where respondents had learned about CVI, only 20% had learned about CVI in their graduate educational programs, most reported learning on the job (40%) or, at conference (40%). The VRCs reported their knowledge of how CVI is diagnosed as building (40%) or moderate (60%). No VR reported extensive in overall knowledge of CVI, understanding of how CVI is diagnosed, knowledge of CVI educational strategies, and knowledge of environmental modifications for CVI.

These responses highlight an opportunity for growth, mentorship and training programs. The consortium discussed the possibility that the very nature of a VRCs work, which may be largely home-based, may limit opportunity for collaborative and the forward propulsion of the cycle of knowledge about CVI. Similarly the majority of VRCs reported their knowledge of educational strategies, behaviors associated with CVI, and environmental modifications for CVI as either building or moderate and many gained in other venues that their own training program. Only one VRC reported having extensive knowledge of CVI associated behaviors (green bar).

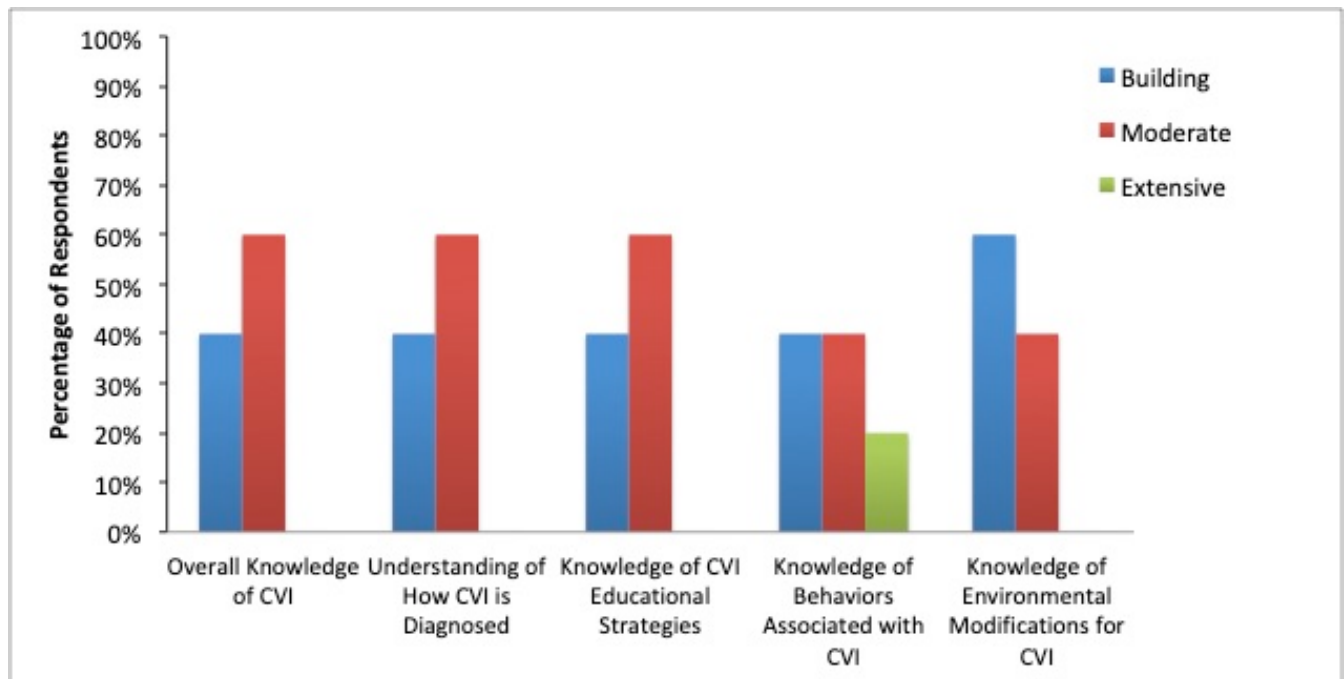


Figure 3. VRC-reported knowledge of CVI

Regarding the visual difficulties of their CVI clients, Figure 4 indicates that the majority of VRC's reported noting their CVI clients had mobility difficulties, tripping, and difficulties seeing materials around them sometimes (50%) or often (50%). Difficulties such as avoidance of use of vision, looking away when reaching, and difficulty finding things in clutter were noted to be observed rarely or sometimes.

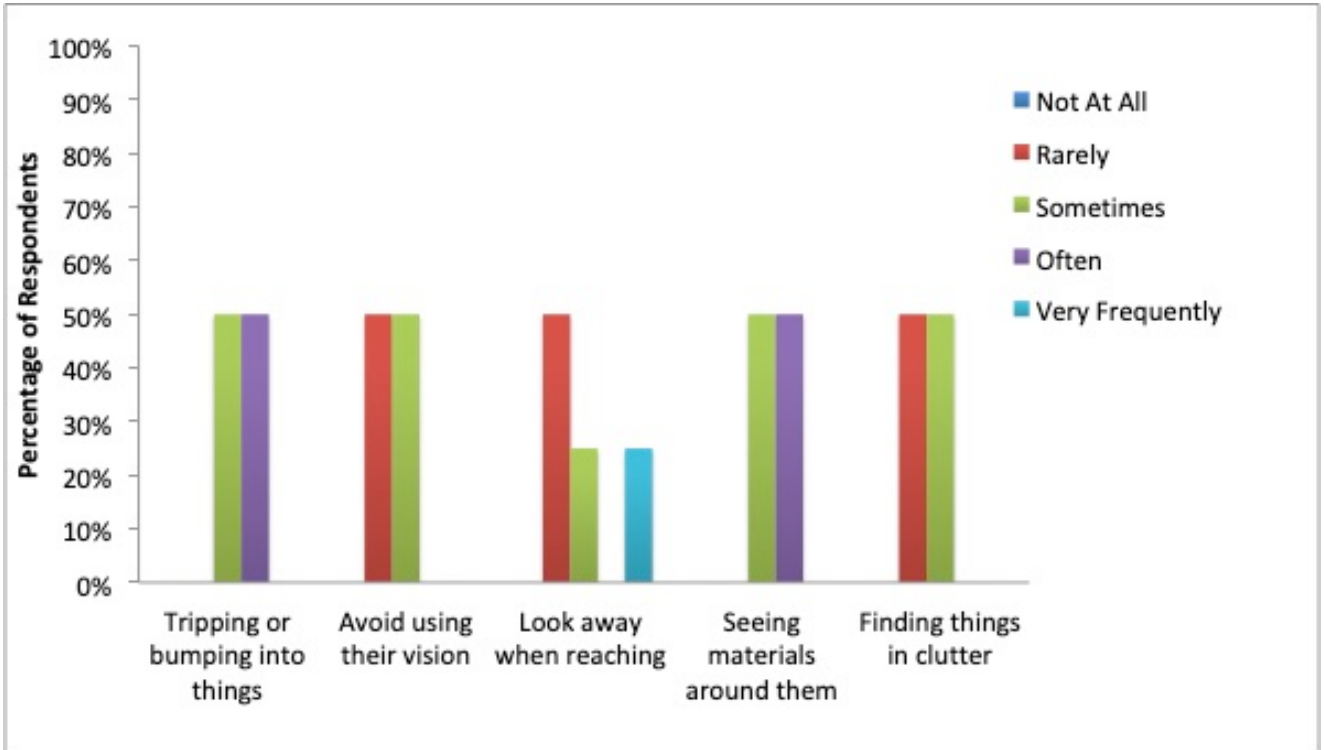


Figure 4. Frequency of visual difficulties in their clients. Each of these difficulties is common among individuals with CVI.

We asked VRCs to rank the importance of a variety of skills in successful employment. In Figure 5, the majority of respondents reported that the following skills were important or very important: ability to work in busy environments (80% ranked as important), social skills (80% ranked as very important), recognition of objects and new environments (80% ranked as important), ability to tolerate visual clutter (100% ranked as important), ability to tolerate noise (100% ranked as important), independent mobility (80% as very important, 20% ranked as important), ability to maintain attention in various lighting conditions (100% ranked as important), and accurate eye-hand and eye-body coordination (100% ranked as important). All of these skills are known to be difficult for patients with CVI. Additionally, 60% responded that visual recognition of objects and people would be important in a workplace environment. These represent skill areas for future rehabilitation interventions for patients with CVI including selection of type of job and also possible necessary workplace adaptations needed for clients with CVI.

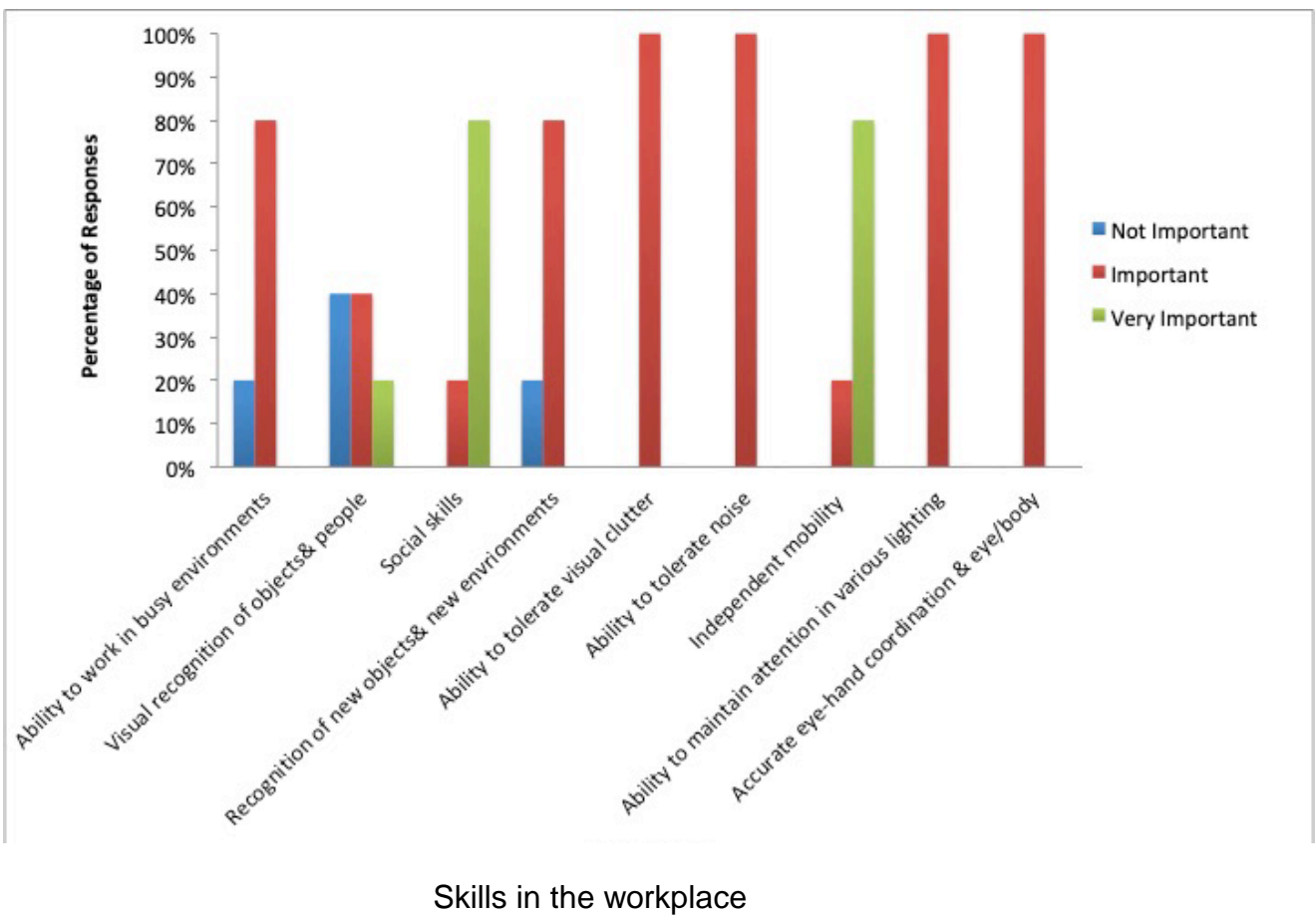


Figure 5. We asked VRCs to judge the importance of these skills in the workplace.

Survey Comments Section from VRCs

A paraphrase of the text responses from the VRCs are below. These comments support the survey responses above (Figure 3) that most VRCs learned about CVI on the job with individual CVI clients rather than through a comprehensive curriculum.

Regarding their experience with CVI:

“In my role at MCB, there have been three clients with a diagnosis of CVI. Each client is an individual that helps me increase my knowledge of the impact of CVI.”

“Students with CVI are often not diagnosed early in their lives and the lack of diagnosis limits the correct CVI assessments and limits effective implementation of CVI teaching strategies known to be effective for them. Lack of awareness of CVI and/or lack of training about the profile of individuals with CVI and lack of understanding of the correct educational programming for students with CVI is evident even when the child is being served in the school systems. Lack of understanding of the causes of CVI or the co-existing diagnosis (ROP, CP, brain bleeds in utero) means the children’s visual skills are not even screened for and

evaluated. There are too few qualified professionals to complete these functional vision evaluations. The later in life diagnosis loses valuable time in rehabilitation.”

“Clients with CVI often have other disabilities that seem to be a greater barrier to successful employment. That is my opinion.”

“I only have experience with one client with CVI that was a result of a traumatic brain injury.”

“I feel the challenges in the work place are common for all clients with visual impairment regardless of the cause whether eye based or brain based.”

Regarding factors associated with successful employment for CVIs:

The following comments from VRC’s with regard to successful employment for clients with CVI, point out gaps in VR readiness for individuals with CVI. This warrants further exploration and future study. The individual comments are reported below.

“1. independent mobility, 2. social skills, 3. recognition of objects/people”

“A student's motivation to work and work ethic is the most important trait for employment success. Another factor for employment success is whether they engaged in the Pre-employment Transition Services programs to learn the work related perquisite skills around work training and advocacy. Lastly, independent living skills such as self-care, social skills and mobility are highly impactful for workplace success.”

“Being ready to do the job and having the right adaptive technology to do that job effectively is important. Having a reliable way to get to work is also important.”

“Orientation and Mobility skills, access technology, communications, job completion and organization play a huge role in job success.”

“Being willing to problem solve, adapt and be resourceful are important as is being able to network.”

Regarding their relationship with CVI clients:

In regards to asking VRC’s about the important aspects in working with clients with CVI, most reported the importance of communication and relationship building. Paraphrased versions of the comments are posted below.

“Being able to develop a trusting relationship with open communication.”

“My work is with clients that are 14-22 years old. Building a trusting relationship with clients and families is the first place to start. That is the best way to collaborate with parents and clients. Appreciating the level of understanding by the family and client helps to get a starting point for the journey of successful employment with careful delivery of resources. This needs to be an individual approach since every client and family is different.”

“Strong and clear communication skills foster trust and foster the ability to learn.”

“Communication and carry through are vital. Good listening to the client and family helps us understand the capabilities of clients.”

“Clear and truthful communication and collaboration with well-defined goals and objectives.”

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

This pilot study has contributed to further understanding of CVI with respect to vocational training and aptitude. Table 1 identified that 30% of children registered with MCB have a diagnosis of CVI. Habilitation programs for children and teens with CVI have become an increasing priority. For those individuals with CVI who have reached VR age, no successful case closures have occurred. The increasing pediatric CVI population, and the lack of VR success calls for immediate action.

The expected tsunami of pediatric patients with CVI and the data showing that few with CVI enter VR (Table 3)—along with the reported lack of success of those who do enter VR calls for immediate action.

There is much that is unknown about the entire identification, educational and training processes, including initial diagnosis of CVI, appropriate identification, and best-practice habilitation programs. Once more information and action is taken around the steps outlined below, it would be anticipated that employment outcomes and perhaps educational and vocational outcomes would improve. The following proposals may also have applications for other pediatric causes of VI/blindness. The recommendations below may be explored through the development of further RFPs, collaborative grant seeking (including considering a joint NEI/OSEP grant) and the establishment of various task forces and/or ad hoc committees.

1. Initial diagnosis of CVI

- a. Through a survey, explore the potential for the need of additional education on the part of eye care providers, pediatricians, and pediatric neurologists on CVI
- b. As it is likely that additional education will be needed to support the development of a program to do so perhaps in consultation with a collaboration of area medical and optometric institutions.
- c. Nations such as Scotland have a mandatory registration system, regarding CVI, which integrates data collection with registration. They also have a system of collaborative assessments at various critical ages (entering school, between primary and secondary and one by approximately age 15) of the individual which include not only eye care but some level of educational assessment. An integrated report from these assessments is provided to the team and to the family.

2. Registration process with MCB

- a. Along with increasing the ability to diagnose this condition, MCB needs to work with eye care providers to improve and streamline the registration process. This would include ease of form completion and provision of appropriate primary and secondary diagnoses as well as identification of etiology and other comorbidities. Use of

- standardized medical diagnostic codes should be considered. Additionally, CVI may be a secondary diagnosis occurring in the setting of other eye conditions, this should be considered during the registration process. (Exploration of a way to securely and easily export information from the EHR to MCB would save time, improve registration accuracy and provide additional data points for future studies. Interactive steps such as the use of drop-down boxes or check lists could also be considered.)
- b. The current MCB database should be reviewed and a plan developed to ensure that those currently listed with other reported etiologies and combinations of codes do not also have CVI. Some of combination of the following etiological and diagnosis codes might also reflect the presence of CVI: prematurity, prenatal codes, numerous infectious causes, some diseases or disorders not elsewhere classified along with other affection of the optic nerve, optic nerve atrophy. Further, if ICD10 codes were adopted, other diagnoses and comorbidities could be added such as cerebral palsy and periventricular leukomalacia.
3. Appropriate identification of individuals with CVI in the home and educational setting
 - a. Determine if additional training or implementation of best practices around the academic assessment of CVI needs to be enhanced and provide such support in collaboration with in-state leaders.
 - b. Attention to key transition points is critical. These would include early intervention to preschool, elementary school to middle school and again in time for the beginning of the transition process at age 14 and as frequently as needed until transition to the community.
 4. Identification of best practices for habilitation at both home and in the school
Role of the parent in this process is critical and education and additional resources must be provided. An example of a parent led site regarding CVI is cviscotland.org. Another resource is a newly reorganized site at Perkins called CVI NOW (perkins.org/cvi-now).
 5. Assessment of how and when VCRs interact with students, team members and caregivers in the transition process and identification of ways to improve and or support their work
One VRC noted the following: "For me, because I work with 14–22 year olds, building trust with the client and families is first. Once that trust is built, I can create buy-in by the parents and then usually the clients. Meeting a client and family where they are and bringing them along the employment journey can be slow, but giving them what they need when they need it is at the core of my work. There is no "one size fits all" approach."
 6. Address how CVI is managed in elementary /middle school to promote development of basic skills to assist future employment. Establish a protocol to address the best-practice strategies for educational assessment of a child with CVI to identify early on the strengths and weaknesses of their individual profile. Research which are the best current educational practices to promote development of skills required for the workplace, including:
Core learning areas such as:
 - a. Reading
 - b. Mathematics

- c. English and Language Arts
 - d. Communication
 - e. Science
 - f. Social Sciences
7. With the passage of Senate Bill 39 in 2013 (Texas 83rd Legislative Session), evaluation in all areas of the Expanded Core Curriculum is required for students with visual impairments. Priority needs must be identified by the IEP team and instruction provided in these areas. Expanded Core Curriculum areas such as:
- a. Independence
 - b. Self-help/skills of daily living
 - c. Assistive Technology
 - d. Orientation and Mobility
 - e. Effective use of compensatory skills
 - f. Effective use of visual skills if any
 - g. Recreation and Leisure skills
 - h. Social skills
 - i. Self-determination and Advocacy
8. Identify corporate entities in Massachusetts willing to cultivate program opportunities and job training sites for individuals with CVI

SUMMARY

Massachusetts Commission for the Blind's Vocational Rehabilitation Counselors (VRCs) are increasingly aware and concerned about the notable increase of clients who are visually impaired due to Cortical/Cerebral Vision Impairments (CVI). This concern is appropriate and prudent given that CVI is currently the major cause of visual impairments in the school age population with future need for MCB's services. This study topic was proposed by Massachusetts Commission for the Blind to address this growing concern, to understand the factors that influence employment success and to ensure every client under MCB's care was served effectively.

The study's central outcome was to gain a more in depth understanding of how this brain based visual impairment, CVI, impacts successful vocational rehabilitation and employment. This information was gained through Vocational Rehabilitation Counselors surveys. These VR counselors helped us to identify the current MCB population diagnosed with CVI and to help identify common functional vision difficulties in the workplace.

Using the most commonly known CVI visual access difficulties in our survey, VRCs provided strong data on the importance of these visual behaviors to job success. All of these visual skills are well established and

documented in research about CVI. Those highly impactful visual behaviors of CVI, scoring between 80%-100% as “important” or “very important” on the survey, include: the ability to work in busy environments (80% of VRCs ranked as very important), use of social skills (80% of VRCs ranked as very important), ability to recognize new objects and new environments (80% of VRCs ranked as important), ability to tolerate visual clutter (100% of VRCs ranked as important), ability to tolerate noise (100% of VRCs ranked as important), independent mobility (80% of VRCs ranked this as very important), ability to maintain attention in various lighting conditions (100% of VRCs ranked as important), and accurate eye-hand and eye-body coordination (100% of VRCs ranked as important).

The VR counselors shared information about their own education around the topic of CVI. Most reported learned “on the job” with individual clients (40%) or in presentations at conferences (40%). Only 20% learned about CVI in their more formal graduate level educational experience. Highlighting their own need for increased CVI training and understanding, VRCs reported their understanding of CVI as “building” (40%) or “moderate” (60%). No VRC reported their CVI understanding as being “extensive”. This brought to light the multiple opportunities needed to build a systematic awareness, education and understanding of CVI.

What this survey revealed is the need for CVI collaboration in diagnosis, education and rehabilitation of clients with CVI. It revealed the need for a more systematic and consistent diagnosis and coding for individuals with CVI. Because there are various causes of CVI, the cause of CVI is often coded in multiple different ways. This also confirmed the highly individual nature of the manifestation of CVI in MCB clients.

The implications of these reported CVI visual access difficulties should have a significant impact on job placement choices and should provide significant information to help ensure visual accessibility in the workplace. This important data will help drive the considerations for accessibility for various types of employment and will speak to the need for environmental adaptation for individual clients in order for them to operate as the most effective worker. These visual considerations for accessibility along with implementation of the above action items will foster favorable employment outcome for clients with CVI.