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Profiles of Children With Cortical Visual Impairment Who Use Augmentative and Alternative Communication: A Retrospective Examination

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ABSTRACT

Purpose: Cortical visual impairment (CVI) is the most common cause of visual impairment in children today and can impact the outcomes of children who rely on augmentative and alternative communication (AAC). This study provides baseline data of 13 children with CVI who used AAC during their first year of participation in an integrated CVI program. One purpose was to describe similarities and differences in the student's demographic, functional vision, communication, and educational profiles. A second purpose was to examine differences in students described with different communicator profiles.
Method: Archived student records were de-identified and reviewed using a systematic coding scheme. Two researchers independently reviewed and coded all student records. Reliability was established. Measures included CVI Range scores; supports for positioning, mobility, vision, and writing; AAC systems, including modes, access methods, and language representation; communicative competence; self-determination; literacy; and mathematics.
Results: The study yielded a rich description of similarities and differences among students at baseline and led to careful consideration of differences among the participants with emergent communicator and context-dependent communicator profiles.
Conclusions: Currently, limited evidence exists that informs practice regarding AAC assessment and intervention for children with CVI. This article describes a small sample of children with CVI who use AAC. Results underscore the need for educators and practitioners to ensure that vision functioning in students with CVI is evaluated carefully and regularly when conducting AAC assessment and intervention and formulating communication or education goals.
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Vision affects all areas of development (Rainey et al., 2016). Today, cortical visual impairment (CVI) is the leading cause of visual impairment in children from developed countries (Good et al., 2001; Nielsen et al., 2007; Swaminathan, 2011; Williams et al., 2021). It is caused by damage to the brain rather than to the eye. For children with CVI, improvements in vision are not to be expected from interventions commonly used for children with ocular visual impairment, such as the use of prescriptive glasses, eye patching, surgery, and so forth. Rather, when improvement in a child's vision occurs, it is due to the neuroplasticity of the brain. Research has established that some level of improvement can nearly always be attained in the visual capabilities of children with CVI when they have access to appropriate visual experiences (Idil et al., 2021). Therefore, professionals working with children who may have CVI and may not yet be identified must be able to recognize the relevant symptomology of

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CVI and provide appropriate referrals, so these children receive a timely diagnosis and relevant interventions (Chang & Borchert, 2020; Swift et al., 2008).

According to recommended practice guidelines (American Speech-Language-Hearing Association [ASHA], 2004), the status of a child's hearing and vision needs to be addressed as part of the assessment process and then used to make decisions about intervention approaches. Referrals to professionals in audiology and/or ophthalmology are needed when hearing and/or vision problems are suspected. Therefore, it is of great importance that professionals, including speech-language pathologists, are able to recognize the visual and behavioral characteristics exhibited by children with CVI. In addition to visual difficulties, these children may have coexisting conditions (e.g., difficulty walking, reaching, sitting, talking, understanding, communicating), which can further impact their learning and development across sensory–motor, language, social, and emotional domains (Flanagan et al., 2003; Swetha et al., 2020). Children with complex needs, including those with CVI who use augmentative and alternative communication (AAC), require a family-centered, interprofessional collaborative practice (IPCP) model to address their unique and diverse needs (American Council of Academic Physical Therapy, 2021; American Occupational Therapy Association [AOTA], 2021; ASHA, 2021; Luo et al., 2022; Ogletree, 2022).

The literature on the assessment and intervention of children with CVI who rely on AAC to communicate is sparse. What does exist suggests that professionals who are involved in their assessment and intervention believe they do not know enough about CVI and/or AAC. In 2019, parents and professionals from school and community settings were surveyed (Blackstone et al., 2021; Luo et al., 2022). Professionals reported they lacked access to the knowledge and supports needed to treat children with CVI who require AAC. They also reported a lack of relevant training opportunities at the preservice and in-service levels and a lack of access to IPCP. Parents surveyed noted that services their children received were delivered in silos by speech-language pathologists, occupational therapists, and physical therapists, often on a weekly basis. They also reported that teachers of students with visual impairment and orientation and mobility specialists provided services less frequently than other professionals, and in some cases, no vision-related services were provided at all.

Most aided AAC systems rely on the visual channel and depend heavily upon a child's ability to recognize and use two-dimensional representations of language in the form of visual displays/graphic symbols (Beukelman & Light, 2020; Higginbotham et al., 2007; Wilkinson & Jagaroo, 2004). Although information about how to design visual displays for children with CVI is beginning to emerge (McCarty et al., 2021; Wilkinson & Wolf, 2021), findings do not yet support the development of specific assessment and intervention guidelines based on visual and behavioral characteristics displayed by children with CVI.

In an extensive scoping review, Boster et al. (2021) stated that although a few children with CVI were included in AAC research, their inclusion was more incidental rather than deliberate. The authors concluded that available evidence is insufficient to guide assessment and intervention planning for children with CVI who use AAC. Furthermore, they suggested that researchers in the field of AAC need to consider how vision may impact both the design of AAC systems and the nature of AAC assessment and interventions. They also indicated that studies should include a consistent description and characterization of children's visual and communication skills. The National Joint Committee for the Communication Needs of Persons with Severe Disabilities has also called for better documentation of the varied profiles of etiologies, skills, strengths, and weaknesses of children with complex communication needs (Sevcik & Romski, 2016). Research that informs practice regarding issues related to AAC assessment and intervention for children with CVI is needed.

The Bridge School and CVI

The Bridge School (TBS) is a small nonprofit organization in Hillsborough, California, with a mission to ensure that children with severe speech and physical impairments achieve full participation in school, home, and community settings, incorporating AAC and other assistive technologies. Founded in 1986 and located on a suburban, public elementary school campus in northern California, TBS is certified by the California Department of Education as a nonpublic school authorized to provide special education instruction to students identified as having multiple disabilities, orthopedic impairment, and other health impairment, aged 3–13 years. The school's curriculum adheres to California standards for public education. Students are referred to TBS by their home school districts or their families. The school provides a transitional educational placement with the goal to return the students to their home school districts when their Individualized Education Program teams determine they are ready. Most children attend TBS for at least 3 years.

TBS serves up to 14 students per school year. There are two classrooms (i.e., preschool and elementary) with four to seven students per classroom. Each classroom is co-taught by a full-time special education teacher and a full-time speech-language pathologist with expertise in AAC and is staffed by instructional assistants and a shared assistive technology specialist. The curricula include content at the preschool, kindergarten, and elementary school levels. Consultant services (e.g., occupational therapy and vision) are also provided, as needed. Professional staff members who work in the educational program are credentialed and hold advanced degrees and relevant licenses and certifications in their respective fields. After students return to their home school districts, TBS's transition team continues to follow them, providing ongoing support to the school district teams and their families.

Each student who attends TBS has an individualized program that considers both strengths and challenges. Because the school is located on the campus of a public elementary school, TBS students have opportunities to interact with their typically developing peers. Teachers/therapists also have ready access to the standard curriculum and other classroom teachers. Family involvement is an integral part of the TBS program, and family members are actively engaged in the students' educational programs, developing advocacy skills and participating in meetings, field trips, and special school events. TBS model differs from models commonly used in schools, in which professionals (e.g., speech-language pathologists, occupational therapists) tend to provide separate services once or twice per week outside the classroom (Bolton & Plattner, 2020; Brandel, 2020; Green & Johnson, 2015). Students at TBS receive their education and specialized services within an integrated classroom environment.

Vision problems have been documented among students attending TBS. In a 15-year follow-up study of 16 students who had attended TBS, Hunt-Berg (2005) reported that seven (43%) students had "unspecified vision problems"; however, none had received a diagnosis of CVI. Recommendations from ophthalmologists and teachers of students with visual impairment had encouraged staff to focus on supporting the use of other modalities (e.g., auditory, tactile).

In the 2012–2013 school year, staff members were introduced to the CVI Range (Roman-Lantzy, 2007, 2018), a direct assessment of the visual and behavioral characteristics associated with CVI that enables professionals to determine if, and to what extent, those characteristics might impact a student's learning, communication, and participation in differing educational environments. Subsequently, TBS staff implemented a systematic approach to CVI assessment and intervention using the CVI Range. Their integrated CVI program incorporated vision accommodations with educational curricula and AAC interventions.

Purpose

The purpose of this article is to characterize the demographic, functional vision, communication, and educational profiles of 13 students with CVI who attended TBS during their first year participating in the integrated CVI program, that is, the baseline year (Sevcik & Romski, 2016). There are two specific objectives of this study. The first was to provide a rich description of the similarities and differences among a small group of children with CVI who use AAC at baseline, in terms of their medical and vision diagnoses, scores on the CVI Range, supports they needed to participate (i.e., positioning, mobility, vision, and writing), AAC systems (i.e., modes, access, and language representation), communicative competence, and academic performance. Second, using a communicator profile framework (Dowden, 1999), we examined differences between the profiles of students described as emergent communicators and students described as context-dependent communicators. We hypothesized that students with the context-dependent communicator profile will have significantly higher CVI Range scores, have significantly fewer medical and vision diagnoses, and require and/or use significantly fewer supports for participation. They will also score significantly higher on measures of communication competence and self-determination, AAC modes, measures of literacy skills, and measures of mathematics skills.

Method

Research Design

The study used a systematic review of archival records to examine demographic information and performance in areas related to functional vision, supports needed for participation, communication, and academics at the baseline year. Ethical approval was obtained from an independent institutional review board before reviewing the records.

Participants

From a pool of 27 children (17 boys and 10 girls) who enrolled in TBS between the 2012–2013 and 2018–2019 school years, 13 children with CVI, or 48% of those enrolled, were selected to participate in this study. At the baseline year, the median age for participants was 71 months (5;11 [years;months]) with a range of 37 months (3;1) to 139 months (11;7). Seven participants were female (median age = 45 months, range: 37–79 months), and six participants were male (median age = 79.5 months, range: 51–139 months). All 13 participants were diagnosed with CVI. All had severe speech and physical impairments and were classified at a Level V on the Gross Motor Function Classification System; that is, all areas of motor function were limited (Palisano et al., 1997). Their hearing was reported to be within normal limits. All had complex communication needs, relied on AAC to communicate, and used a variety of assistive technologies and equipment to access communication, most activities, and the educational curriculum. Based on Dowden's framework (Dowden, 1999) as described in Table 1, participants were identified as having one of the three communicator profiles, namely, an emergent communicator, a context-dependent communicator, and an independent communicator. Among the 13 participants, four (31%) were identified as emergent communicators, and nine (69%) were context-dependent communicators. None were independent communicators.

As shown in Table 2, participants presented with a variety of medical and vision diagnoses. Eleven participants (85%) had cerebral palsy. The next most common diagnoses were hypoxic–ischemic encephalopathy (n = 3) and seizure disorder (n = 3). In addition, two participants were diagnosed with chromosomal disorders, and two were diagnosed with microencephaly. One participant was diagnosed with a metabolic disorder, one was diagnosed with periventricular leukomalacia, and one was diagnosed with traumatic brain injury as the result of asphyxia at the age of 14 months. Finally, three participants were diagnosed with intellectual disability. In addition to CVI, participants also had ocular visual impairments including refractive errors such as myopia, hyperopia, or astigmatism (n = 12); strabismus including exotropia or esotropia (n = 12); retinal disorder (n = 2); optic nerve disorder (n = 4); mobility or movement disorder (n = 3); and ptosis (n = 1).

Procedure

Records Preparation

Existing records from each participating student's baseline year were collected and de-identified, including annual enrollment documents, individualized educational plans, and evaluation and progress reports from both TBS and outside agencies (e.g., physicians, school districts, clinics). Reports from TBS consisted of information obtained from established evaluation protocols appropriate to each child, which included checklists, published assessment tools, and structured observations (see Supplemental Material S1). Documents from outside agencies included reports from ophthalmologists, pediatricians, occupational therapists, physical therapists, and psychologists.

Coding Setup and Procedure

A systematic coding scheme, based on accepted practices, was developed to code student records (Yoder et al., 2018). Coding categories and items within each category were developed through a multistep, collaborative, iterative process that involved a literature review and consultation with school/project staff and with experts in CVI and AAC. Specifically, the first and second authors (a) identified targeted areas of focus for students with CVI who use AAC at TBS, (b) drafted categories and items within categories that reflected program goals with input from school staff, (c) met with key staff to determine items most likely to be found in student records, and (d) developed a coding manual with operational definitions as well as instructions and examples on how to code records using the coding scheme for each specific area.

The first and second authors then reviewed and coded sample records from students who were not part of the current study using the coding scheme and revised the coding scheme when needed. The final coding scheme was also reviewed by experts in speech-language pathology, psychology, special education, occupational therapy, visual impairment, and statistics. The final coding scheme

Table 1. Communicator profiles (Dowden, 1999).

Continuum	Characteristics	Intervention focus
Emergent communicator	• Use body-based (facial expressions, gestures, vocalizations)/nonsymbolic modes • Mostly communicate with familiar partners • Topics primarily relate to "here and now."	• Increase use of reliable communication behaviors • Move toward symbolic modes • Expand interactions with more partners about a broader range of topics
Context-dependent communicator	• Able to use reliable symbolic communication modes • Communication often facilitated by a familiar partner • Often lack access to vocabulary and literacy skills	• Increase access to vocabulary • Build literacy skills • Broaden a person's ability to communicate with multiple communication partners and across contexts • Build a repertoire of communication strategies
Independent communicator	• Are literate and able to generate novel messages • Can communicate with familiar/unfamiliar partners about any topic and across contexts • May rely on communication supports, including familiar partners and recorded messages in some situations	• Rate enhancement strategies • Increase operational and strategic competencies • Develop use of new technologies and communication formats

Table 2. Basic demographics for individual participants.

Student	Sex	Age (months)	Grade	CP type	Med diagnoses	Vision diagnoses
A	M	139	Elem	Mixed	HIE	RE, Str
B	M	92	Elem	Mixed	None	RE, Str
C	F	71	Pre-K	Spastic	MIC	RE, Str, OND
D	F	74	K	Spastic	None	RE, Str
E	M	51	Pre-K	Spastic	TBI, ID	RE, Str
F	M	81	K	Spastic	PVL, SD	Str, RD
G	M	56	Pre-K	Spastic	HIE	RE, Ptosis
H	F	79	K	Spastic	HIE, SD	RE, Str
I	M	78	K	Mixed	SD	RE, Str, OND
J	F	45	Pre-K	NA	MetS, ID	RE, Str
K	F	37	Pre-K	Athetoid	CD, ID	RE, Str, OND, MD
L	F	40	Pre-K	Mixed	None	RE, Str, MD
M	F	41	Pre-K	NA	CD, MIC	RE, Str, RD, OND, MD

Note. Age is reported in months. CP = cerebral palsy; Med = medical; M = male; Elem = elementary; HIE = hypoxic ischemic encephalopathy; RE = refractive errors; Str = strabismus; F = female; Pre-K = prekindergarten; MIC = microcephaly; OND = optic nerve disorder; K = kindergarten; TBI = traumatic brain injury; ID = intellectual disability; PVL = periventricular leukomalacia; SD = seizure disorder; RD = retinal disorder; NA = not applicable; MetS = metabolic syndrome; CD = chromosomal disorder; MD = mobility/movement disorder.

included 10 data collection instruments (see Supplemental Material S1). Each instrument enabled researchers to code participating student information in different areas, such as demographic information, medical diagnoses, CVI Range scores, AAC systems (modes, access methods, and language representation), use of positioning, mobility and vision supports, communicative competence, self-determination, literacy, math, and so forth.

Student records were then coded using the final coding scheme in REDCap, an electronic data capture tool hosted at the Vanderbilt University Data Core Services. REDCap is a secure, web-based application designed to support data capture for research studies by allowing research teams to create and define a study-specific database (Harris et al., 2009, 2019).

The coding was conducted in two phases. During Phase 1, the first and second authors each independently coded 3 years of records for a single student who was not a participant of the study. The codes were compared for agreement. The disagreements were discussed and resolved, and the coding manual was revised accordingly. Phase 2 of coding began when the researchers reached a level of 80% agreement. During Phase 2, the first and second authors each independently coded one half of the available records, which were randomly assigned.

Intercoder Agreement

A third researcher from TBS served as an independent agreement/reliability coder. After being trained in the same manner as the primary coders, the researcher independently coded a randomly selected 20% of all available records. Half of the reliability records were randomly selected from each of the two primary coders' assignments. The reliability coder's responses were then compared, at the item level, with the corresponding main coder's responses for each domain evaluated by the coding scheme. Percent agreement ranged from 81.4% to 98.8%, with an average overall agreement of 90.4%. Additionally, Cohen's kappas were calculated on these same agreement data for each of the domains. Kappas ranged from .61 to .95, with an average overall κ of .76. Landis and Koch (1977) characterized κs of .61–.80 as representing substantial agreement and κs of .81–1.00 as representing perfect agreement. Taken together, agreement was well within the acceptable range, with all instruments having substantial or perfect agreement.

Measures

This section describes the measures used to describe each student's profile. All measures were generated from either specific items coded or the operational definitions provided in the coding manual. Table 3 summarizes the number of items included and how summary scores were calculated. Measures that used overall counts were not included in Table 3.

CVI Range

The CVI Range (Roman-Lantzy, 2007, 2018) is a direct assessment of functional vision for individuals with a diagnosis of CVI. It was used to investigate the degree of impact of visual and behavioral characteristics associated with CVI across 10 different vision domains. Those domains are color preference, the need for movement to elicit attention, visual latency, visual field preferences, difficulties with visual complexities, light-gazing and nonpurposeful gaze, difficulty with distance viewing, atypical

Table 3. Calculation of summary scores for measures.

Measures	Total items	Summary method	Possible range
CVI Range	10	Sum of points	0–10
Communicative competence			
Social	17	Observed points/total	.00–1
Linguistic	12	Observed points/total	.00–1
Strategic	10	Observed points/total	.00–1
Operational	12	Observed points/total	.00–1
Total	51	Observed points/total	.00–1
Self-determination total	20	Observed points/total	.00–1
Literacy			
Early emergent	7	Observed points/total	.00–1
Emergent	9	Observed points/total	.00–1
Alphabet knowledge	3	Observed points/total	.00–1
Phonics	5	Observed points/total	.00–1
Word reading	5	Observed points/total	.00–1
Writing	7	Observed points/total	.00–1
Comprehension	5	Observed points/total	.00–1
Total	41	Observed points/total	.00–1
Mathematics			
Premathematics skills	4	Observed points/total	.00–1
Emerging skills	4	Observed points/total	.00–1
Preschool-level skills	3	Observed points/total	.00–1
Kindergarten-level skills	6	Observed points/total	.00–1
Higher grade–level skills	4	Observed points/total	.00–1
Total	21	Observed points/total	.00–1

Note. CVI = cortical visual impairment.

visual reflexes, difficulty with visual novelty, and absence of visually guided reach.

The CVI Range is administered by a trained evaluator and scored using information gathered from observation of the student, parent interview, and direct assessment. These data are then used to score two ratings, which ultimately results in a "range" of functional vision. The CVI Range is used to describe essential behaviors of individuals with CVI that are observable and provide a snapshot across all CVI characteristics in a progression from the lowest score of 1–2 to the highest levels of CVI behaviors at a score of 9–10. Higher scores indicate visual functioning that is more like the typical visual functioning of same-age peers. A threshold or ceiling is established to obtain the Rating I score. Rating II is used to examine the impact of each individual characteristic on a continuum. CVI Range Rating II scores further categorize data into three "phases" (i.e., Phase I, II, III), indicating broad levels of functioning, which have implications for intervention approaches. As shown in Table 3, scores of the CVI Range were summed. Summary scores could range from 0 to 10.

Supports for Positioning, Mobility, Vision, and Writing

This measure included items coded to show the different equipment or assistive technologies that a student needed to participate in activities and access the environment, instruction, and materials. Four areas of supports were included, namely, positioning, mobility, vision, and writing (see Supplemental Material S2).

AAC Systems

Several characteristics of AAC systems were measured, specifically, the modes a student used to communicate, methods used to access AAC, and ways a student used to represent language.

Modes. This measure included items coded related to the AAC modes used by a participant, that is, body based, low tech (nonelectronic), mid tech (electronic systems with recorded messages), and high tech (speech-generating devices [SGDs]; see Supplemental Material S3). There were 28 different modes coded across these four categories. To summarize these data, the number of different modes found was summed to produce an overall count of modes a student used.

Access methods. This measure included items coded related to different methods that a participant used to access low-tech systems, mid-tech systems, and high-tech SGDs (see Supplemental Material S4). There were 11 different access methods that were evaluated, with higher scores indicating a greater number of AAC access methods.

Language representation. This measure included items coded related to different ways a participant represented language when using AAC systems. There were 10 possible methods coded, including tangible and auditory symbols, photos, pictographic symbols, and letters/words (see Supplemental Material S5).

Communicative Competence

Communicative competence is a widely used framework for describing communication in individuals who use AAC, encompassing four areas: social competence, linguistic competence, operational competence, and strategic competence (Light, 1989; Light & McNaughton, 2014). As used in the study, social competence indicated the extent to which a student was able to participate in social interactions. Linguistic competence indicated a student's ability to use language skills, including the use of a variety of increasingly complex linguistic forms and functions. Operational competence indicated the extent to which a student was able to operate and use body-based, low-tech, mid-tech, and high-tech modes of communication. Strategic competence indicated the extent to which a student used strategies to support effective communication. This measure included coded items related to skills in all four areas mentioned previously (also see Supplemental Material S6). Proportions were calculated for analysis and to facilitate comparison across measures. Table 3 describes this process for each competence area (i.e., social, linguistic, operational, and strategic) and a communicative competence total score.

Self-Determination

This measure included coded items related to a participant's self-determination skills (Weymeyer, 2005). Self-determination was defined as "a combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behaviors" (Field et al., 1998, p. 2). Items coded as self-determination were relevant items in communicative competence and were bolded/italicized in Supplemental Material S6. A proportion was calculated for analysis and to facilitate comparison across measures. Table 3 describes this process.

Literacy

This measure included items coded related to skills from seven different broad categories of literacy development, including early emergent, emergent, alphabet knowledge, phonics, word reading, writing, and comprehension (see Supplemental Material S7). Proportions were calculated for analysis and to facilitate comparison across measures. Table 3 describes this process for each of the categories and the method for calculating scores for each category and the literacy total score.

Mathematics

This measure included items coded related to the mathematics skills from different levels, including pre-mathematical, emerging mathematical, preschool-level mathematics, kindergarten-level mathematics, and higher grade-level mathematics (see Supplemental Material S8). Proportions were calculated for analysis and to facilitate comparison across measures. Table 3 describes this process for each of these levels and the method for calculating the mathematics total score.

Data Analyses

Data analyses were conducted to address the two objectives of the current study. To demonstrate the similarities and differences among the participants, descriptive data were reported in the following areas: the CVI Range; supports needed for positioning, mobility, vision, and writing; AAC systems (modes, access methods, and language representation methods); areas of communication competence and self-determination; literacy; and math.

To address the second objective of this study—that is, were there differences between students on variables of interest related to their communicator profiles—we conducted a series of 15 analyses of variance (ANOVAs), each of which used communicator profile as an independent variable with two levels (i.e., emergent vs. context dependent). Note that the ANOVAs that evaluated communication and academic achievement as outcomes included age in months as a covariate.

Analyses were conducted using RStudio Version 2021.09.1.372 (RStudio Team, 2021) and R Version 4.1.2 (R Core Team, 2021). The infer package Version 1.0.1 (Bray et al., 2021) was used to estimate the ANOVAs. The car package Version 3.0-12 (Fox & Weisberg, 2019) was used to estimate model standard errors (*SE*s). Finally, the emmeans package Version 1.7.1-1 (Lenth, 2021) was used to estimate marginal means, effect sizes, *SE*s, and confidence intervals (CIs) around the estimates.

Considering the small sample size in the current study, we focused not only on the presence or absence of conventional levels of statistical significance (i.e., $p < .05$) but also on estimates of effect size. To detect differences, we used Cohen's d, estimated directly from the model results. In doing so, estimated population standard deviations were used to calculate the magnitude of the observed mean differences between the emergent and context-dependent groups, standardized using the estimated population standard deviation.

Results

First, we provide a description of the similarities and differences among the participants. Next, we describe the differences among the participants with two communicator profiles (i.e., emergent and context-dependent communicators). Measures included CVI Range scores; number of supports used for positioning, mobility, vision, and writing; AAC modes, access methods, and language representation; communicative competence total scores; self-determination scores; literacy total scores; and mathematics total scores.

Similarities and Differences

In the following sections we described, in detail, the similarities and differences between the participants. Table 4 presents estimates of central tendency, variability, and 95% CIs for many of these variables, where appropriate.

CVI Range

The mean CVI Range score was 4.60 (SD = 2.30), and scores ranged from 0.25 to 8.25 (see Table 4). On the CVI Range, three (23%) students scored in Phase I (scores from 0 to 3); eight (62%), in Phase II (scores from 3.25 to 7); and two (15%), in Phase III (scores from 7.25 to 10).

Supports for Positioning, Mobility, Vision, and Writing

Participants used different equipment and assistive technologies to support positioning, mobility, vision, and writing so they could communicate and participate in various school activities. Table 4 presents descriptive statistics of the number of supports the participants used in each area.

Participants used a variety of supports for positioning. Ten participants (77%) used custom seating and/or a lap tray. Nine participants (69%) used a headrest. Hand splints and Subasis Bars were used by eight participants (62%). High/low chairs were used by five participants (38%). Standers and keyguards were used by three participants (23%). Two participants (15%) used chin and neck supports and/or arm/elbow immobilizers. All participants used additional positioning supports not explicitly coded in this study, such as straps for holding limbs and trunk.

Participants also used a variety of equipment to assist with mobility. All used a hands-free walker; none

Table 4. Sample descriptive statistics.

Variable of interest	*M*	*SD*	95% CI	*Mdn*	Min	Max
CVI Range	4.60	2.30	[3.21, 5.99]	4.75	0.25	8.25
Medical diagnoses	2.23	0.83	[1.73, 2.73]	2	1	3
Vision diagnoses	2.62	0.96	[2.03, 3.20]	2	2	5
Positioning supports	4.54	2.22	[3.20, 5.88]	5	1	8
Mobility supports	2.69	0.85	[2.18, 3.21]	3	1	4
Vision supports	2.08	1.04	[1.45, 2.70]	2	1	4
Writing supports	4.62	0.65	[4.22, 5.01]	5	4	6
AAC modes						
Body based	4.77	1.30	[3.98, 5.56]	5	2	7
Low tech	1.62	0.77	[1.15, 2.08]	1	1	3
Mid tech	1.69	0.95	[1.12, 2.26]	1	1	4
High tech	0.69	0.85	[0.18, 1.21]	0	0	2
Communicative competence						
Social	.59	.24	[.45, .74]	.65	.18	.88
Linguistic	.41	.23	[.27, .55]	.42	.08	.75
Operational	.33	.17	[.23, .43]	.33	.08	.58
Strategic	.18	.17	[.08, .29]	.10	.00	.50
Total	.41	.18	[.30, .52]	.39	.12	.69
Self-determination	.17	.11	[.11, .24]	.15	.00	.38
Literacy						
Early emergent	.45	.19	[.33, .57]	.43	.14	.86
Emergent	.21	.21	[.09, .34]	.22	.00	.56
Alphabet knowledge	.33	.45	[.06, .61]	.00	.00	1.00
Phonics	.15	.25	[.00, .30]	.00	.00	.80
Word reading	.03	.08	[−.01, .08]	.00	.00	.20
Writing	.16	.22	[.03, .30]	.00	.00	.71
Comprehension	.00	.00	[.00, .00]	.00	.00	.00
Total	.20	.13	[.12, .28]	.20	.02	.44
Mathematics						
Premath skills	.69	.11	[.63, .76]	.75	.50	.75
Emerging skills	.37	.17	[.27, .47]	.25	.25	.75
Preschool-level skills	.18	.29	[.00, .36]	.00	.00	.67
Kindergarten-level skills	.05	.11	[−.01, .11]	.00	.00	.33
Higher-level skills	.00	.00	[−.00, .00]	.00	.00	.00
Total	.24	.08	[.19, .29]	.24	.14	.43

Note. CI = confidence interval; *Mdn* = median; Min = minimum; Max = maximum; CVI = cortical visual impairment; AAC = augmentative and alternative communication.

used a handheld walker. In addition, 11 participants (85%) used a manual wheelchair, and four (31%) used a stroller. Seven participants (54%) used a power wheelchair. In terms of vision supports, 10 participants (77%) wore glasses, three (23%) used a lightbox, and five (38%) used a tablet computer. Different computer software were used to participate in writing activities, including IntelliKeys (69%), IntelliTools CS (92%), Microsoft Office (46%), and Clicker (46%).

AAC Systems: Modes, Access Methods, and Language Representation

Participants used different AAC modes to communicate. All participants used at least two body-based modes. Six participants (46%) used more than one low-tech mode or mid-tech mode. Six participants (46%) also used a high-tech device (e.g., Tobii Dynavox), with three of them using one device and three of them using two devices.

Participants also used a variety of methods to access low-tech AAC systems. Nine (69%) used partner-assisted auditory scanning (PAAS); one (8%) used direct selection; and four (31%) used a combination of PAAS, eye gaze, direct selection, and speech. To access mid-tech systems, 10 (77%) used a switch, four (31%) used direct selection, and one (8%) used both methods. Of the six students who used a high-tech device, two (15%) used direct selection, two (15%) used switches, and two (15%) used both access methods.

All participants also used multiple ways to represent language. Twelve (92%) used gestures, nine (69%) used photos, nine (69%) used pictographic symbols, nine (69%) used PAAS, and seven (54%) used their speech. Five students (39%) utilized letters and numbers, and four (31%) used written words/phrases. Two participants (15%) used tangible symbols, and one (8%) used manual signs. None used visual scene displays.

Communicative Competence and Self-Determination

The mean total communicative competence score was .41 (*SD* = .18; see Table 4). Participants scored highest in social communicative competence (*M* = .59, *SD* = .24), followed by linguistic communicative competence (*M* = .41, *SD* = .23), operational communicative competence (*M* = .33, *SD* = .17), and strategic communicative competence (*M* = .18, *SD* = .17). Self-determination scores were similar to strategic competence scores (*M* = .17, *SD* = .11).

Literacy

The mean total literacy score was .20 (*SD* = .13; see Table 4). Early emergent literacy and alphabet knowledge were relative strengths for the participants (*M*s = .45 and .33, and *SD*s = .19 and .45, respectively). Means for emergent literacy skills, phonics skills, and writing were similar to the total mean (*M* = .21, *SD* = .21; *M* = .15, *SD* = .25; and *M* = .16, *SD* = .22, respectively). Relative weaknesses for the group were word reading (*M* = .03, *SD* = .08) and comprehension (*M* = .00, *SD* = .00).

Mathematics

The mean total mathematics score was .24 (*SD* = .08; see Table 4). Premath skills and emergent math skills were relative strengths of the participants (*M*s = .69 and .37, and *SD*s = .11 and .17, respectively). Means were considerably lower, however, for preschool-, kindergarten-, and higher-level math skills (*M* = .18, *SD* = .29; *M* = .05, *SD* = .11; and *M* = .00, *SD* = .00, respectively).

Comparison of Emergent and Context-Dependent Communicator Profiles

Results of the 15 ANOVAs are presented in Table 5. The *p* values for these conventional statistical tests demonstrated only one significant difference on the math total score comparison, $F(1, 10) = 7.72$, $p < .05$. Considering the underpowered nature of the analyses, it is more informative, however, to examine the Cohen's *d*s associated with the differences between the groups. As a rule of thumb, Cohen's *d*s of approximately 0.2, 0.5, and 0.8 are considered small, medium, and large effects, respectively (Cohen, 1988). The estimated Cohen's *d*s for the profile comparisons are presented in Table 5, along with their associated *SE*s and CIs.

In total, differences between the context-dependent and emergent groups reached a medium (i.e., 0.5) or greater effect for seven of the 15 measures that were examined (see Table 5). Consistent with the hypotheses, the context-dependent group had fewer vision diagnoses than the emergent group (d = 0.64), used a higher number of mid-tech AAC devices (d = 0.77), used a higher number of SGDs (d = 0.89), and had higher communication competence total scores (d = 1.74), higher self-determination scores (d = 1.29), higher literacy total scores (d = 0.67), and higher math total scores (d = 2.26).

Differences between the context-dependent and emergent groups were small to medium (i.e., 0.2–0.49) for five of the 15 measures (see Table 5). Consistent with the hypotheses, the context-dependent group had higher CVI Range scores than the emergent group (d = 0.33), had fewer medical diagnoses (d = 0.46), used fewer vision supports (d = 0.23), and used a greater number of body-based AAC systems (d = 0.39). Contrary to our hypothesis, the context-dependent group used a greater number of writing supports (d = 0.25).

The differences between the context-dependent and emergent groups were small (i.e., d was less than 0.2) for three of the 15 outcomes: the number of mobility supports

Table 5. Means and standard errors (*SE*s) of outcomes for emergent and context-dependent (context-dep) communication profiles.

Variable	Emergent		Context-dep						
	M	*SE*	*M*	*SE*	*d*	*SE*	95% CI of *d*	*F*(1, 11)	*p*
CVI Range	4.06	1.19	4.83	0.79	−0.33	0.60	[−1.66, 1.01]	0.29	.60
Medical diag	2.50	0.42	2.11	0.28	0.46	0.61	[−0.88, 1.80]	0.58	.46
Vision diag	3.25	0.45	2.33	0.30	1.03	0.64	[−0.38, 2.44]	2.93	.12
Mobility sup	2.75	0.45	2.67	0.30	0.09	0.60	[−1.23, 1.42]	0.02	.88
Vision sup	2.25	0.54	2.00	0.36	0.23	0.60	[−1.09, 1.56]	0.15	.71
Positioning sup	4.25	1.16	4.67	0.77	−0.18	0.60	[−1.51, 1.15]	0.09	.77
Writing sup	4.50	0.34	4.67	0.22	−0.25	0.60	[−1.57, 1.08]	0.17	.69
Body based[a]	4.41	0.83	4.93	0.49	−0.39	0.82	[−2.21, 1.43]	0.23	.64
Low tech[a]	1.53	0.51	1.65	0.30	−0.15	0.81	[−1.96, 1.66]	0.03	.86
Mid tech[a]	1.20	0.58	1.91	0.35	−0.77	0.83	[−2.61, 1.08]	0.89	.37
SGD[a]	0.23	0.47	0.90	0.28	−0.89	0.84	[−2.75, 0.97]	1.20	.30
Com total[a]	.28	.07	.46	.04	−1.74	0.90	[−3.74, 0.27]	4.58	.06
Self-det total[a]	.10	.05	.21	.03	−1.29	0.86	[−3.21, 0.63]	2.51	.14
Literacy total[a]	.15	.07	.22	.04	−0.67	0.83	[−2.51, 1.17]	0.69	.43
Math total[a]	.14	.04	.28	.02	−2.26	0.96	[−4.39, −0.13]	7.72	.02

Note. $n = 4$ for emergent communicators; $n = 9$ for context-dependent communicators. Cohen's *d* was calculated using population standard deviation from the corresponding analysis for each variable. CIs and *SE*s for Cohen's *d* represent uncertainty in the Cohen's *d* estimate. CI = confidence interval; CVI = cortical visual impairment; diag = diagnoses; sup = supports; SGD = speech-generating device; Com = communication; Self-det = self-determination.

[a]$df = 1, 10$. Analyses of variances included a covariate that controlled for age of student in months at the time of data collection. Means are adjusted for age.

used, the number of positioning supports used, and the number of low-tech AAC systems used (see Table 5). These results did not support or refute our hypotheses.

Discussion

Baseline information for research participants with complex communication needs is often sparse or lacking in detail. This study offers to enhance the evidence base of communication interventions for children with severe disabilities by documenting their varied profiles of etiologies, skills, strengths, and weaknesses (Sevcik & Romski, 2016). We reported baseline demographic, functional vision, communication, and educational profiles of 13 children with a diagnosis of CVI and severe physical and speech disabilities who used AAC. The results demonstrated that participants had different levels of functional vision as shown by the CVI Range scores, ranging from 0.25 to 8.25. All had severe speech and motor challenges and required positioning and mobility supports. All used a variety of equipment and assistive technologies to support their communication and participation in educational and social activities. All used multiple AAC modes, including body-based, low-tech, and mid-tech AAC modes. Six participants also used SGDs. They also used multiple access methods and ways to represent language.

When examining different areas of communicative competence, participants scored highest in social communicative competence, followed by linguistic competence, operational competence, and strategic competence. Academically, participants demonstrated stronger early emergent literacy skills and alphabet knowledge. Their weaknesses on literacy measures included word reading and reading comprehension. In mathematics, participants were stronger in the areas of premath and emergent math than in more advanced math skills.

When comparing between participants with an emergent communicator profile and those with a context-dependent communicator profile, the context-dependent group had a higher average CVI Range score and fewer medical and vision diagnoses; used fewer vision supports; used more of the body-based, mid-tech, and high-tech AAC systems; had higher communication competence; demonstrated greater self-determination; and had higher literacy and math scores, relative to the emergent group. Participants in the context-dependent group also used a greater number of writing supports than the emergent group. However, the differences in the number of mobility supports, number of positioning supports, and number of low-tech AAC systems were small. It suggests that these factors might be independent of their communicator profile.

This study underscores the need to consider and document the unique and diverse characteristics and current performance of children with CVI who use AAC prior to embarking on AAC interventions and/or clinical research studies. In addition, results raised issues and questions that may benefit from further consideration, such as investigating correlations between improvement on CVI Range scores and the development of communication skills and educational performance over time.

Communicator Profiles and Vision

At baseline, participants in this study were identified either with an emergent communicator profile or a context-dependent communicator profile. Of the nine students with a context-dependent communicator profile, two scored on the CVI Range in Phase I, four scored in Phase II, and three scored in Phase III. For the four students with an emergent communicator profile, one scored in Phase I and three scored in Phase II. Of the four students (ages 3;1–3;9) who were identified as emergent communicators, all were enrolled in the preschool program. However, of the nine participants considered "context-dependent communicators" (ages between 4.5 and 11 years), three participated in the preschool curriculum, four participated in a kindergarten curriculum, and two participated in an elementary school–level curriculum. In short, at baseline, a student's vision functioning, as indexed by the CVI Range score, did not necessarily reflect their communicator profile, age, or grade level. This finding is consistent with Chokron et al. (2021) and Roman-Lantzy (2019), showing that the learning levels of children with CVI can be very different. These findings underscore the need for educators and practitioners to evaluate a student's vision functioning, carefully and regularly, using tools such as the CVI Range when CVI is suspected or confirmed. These evaluation results can then be used to guide the design and implementation of communication or education intervention plans.

Use of Multiple Modes and Language Representation

All participants used multiple types of AAC methods to communicate, including body-based AAC modes, as well as low-tech and mid-tech AAC modes. Six participants also used high-tech SGDs. The use of multiple modes is a widely accepted principle of AAC, recognizing that choice of modes is influenced by both intrinsic factors, such as age, ability (e.g., access to vision), individual preference, communication competence, and so forth, and extrinsic factors, such as a student's access to and ability to use specific AAC tools and technologies effectively to communicate across contexts, partners, and tasks (Beukelman & Light, 2020; Blackstone & Hunt-Berg, 2012; Blackstone et al., 2007; Light & Drager, 2007; Light & McNaughton, 2014). Of note was that nine participants (69%) used PAAS. PAAS is an AAC access method that does not require the use of vision. A partner (or SGD) may present spoken letters, words, or phrases, one at a time, and the individual who uses AAC indicates the choice. Vocabulary access can be arranged so that the child can select from large vocabularies, as appropriate to the individual. Because PAAS relies on auditory input with limited or no demands on vision or motor skills, PAAS can be an important and necessary method to access low-tech and/or high–tech AAC systems for children with CVI who have limited functional vision and children with severe physical impairments. It is also noteworthy that all participants also relied on multiple ways to represent language, underscoring the need for research that guides specific assessment and intervention decisions based on characteristics displayed by children with CVI.

Continuum of Communicative Competencies

Regarding communication competence (Light & McNaughton, 2014), participants scored highest in social communicative competence, followed by linguistic competence, operational competence, and strategic competence. This finding suggests there may be a developmental pattern to how children with CVI who use AAC acquire communication competencies. Currently, there are few, if any, empirical reports that provide information about how children who use AAC develop in these four areas over time, and no information considers the impact of the development of communicative competencies on these children. Even so, our results are consistent with informal observations reported by staff at TBS. Specifically, children with severe motor and complex communication needs (including those with a diagnosis of CVI) first acquire skills related to social interaction and engagement (social competence), often relying on body-based methods, which are most accessible to them. Gradually, as they are introduced to AAC tools, they gain access to increasingly large vocabularies. However, because children with CVI often have difficulty discerning meaning from pictographic symbols, they may appear delayed in their language development and their language abilities may go unrecognized (linguistic competency). In any case, increasing access to language necessitates that children who use AAC learn to use an increasing number of AAC tools and technologies, such as switches, multiple selection techniques, SGDs, and so forth (operational competency). In turn, these skills enable children to communicate more independently, across more partners and environments, necessitating a need to develop strategies to repair conversational breakdowns, prepare messages in advance, and so on (strategic competency).

Although Light and McNaughton (2014) did not discuss a developmental sequence related to communication competence, they did note that the development of communicative competence is influenced not only by linguistic, operational, social, and strategic competencies but also by a variety of psychosocial factors (e.g., motivation, attitude, confidence, resilience) acknowledging the importance of addressing barriers and providing environmental supports. Our results suggest that practitioners might take a closer look at the communicative competence framework for children who have CVI and use AAC. Perhaps consideration of communication competencies at baseline from a developmental perspective might provide additional ideas about how to set priorities and establish intervention goals.

Communicator Profiles

Using Dowden's (1999) communicator profile framework as an independent variable, we examined the profiles of students described as emergent communicators and students described as context-dependent communicators, testing two hypotheses. Consistent with our hypotheses, the context-dependent group had a higher average CVI Range score and fewer medical and vision diagnoses; used fewer vision supports; used more of the body-based, mid-tech, and high-tech AAC systems; had higher communicative competence; demonstrated greater self-determination; and had higher literacy and math scores, relative to the emergent group. In fact, only one finding was contrary to our hypotheses; students with the context-dependent communicator profile used a greater number of writing supports than the emergent group. The results suggested that higher communication skills appeared to be related to higher vision functioning, greater ability to self-advocate, and better academic performance, suggesting the importance of improving communication skills and vision functioning. Also, the results showed that students with context-dependent communicator profiles used more writing supports, which may suggest they had more developed communication skills.

Limitations

There are a few limitations that impact the interpretation of our findings. First, the retrospective analysis permitted us to examine the children's profiles at the onset of their participation in the study. However, it meant that we relied on what reports were available for each child. An additional limitation was the small sample size, which limited the generalizability of our findings. Future research with a larger sample is necessary to confirm our findings.

Clinical Implications

CVI is caused by damage to the visual cortex of the brain, which means a child's functional use of vision can, and should, be expected to improve over time due to brain plasticity (Chang & Borchert, 2020; Roman-Lantzy, 2018). This fact has significant implications for children with CVI and their families, as well as for early intervention programs, service providers, and preservice education. Because vision affects all aspects of development and AAC approaches are highly dependent on vision, the quality of assessment and intervention programs need to take vision into account (Blackstone & Roman-Lantzy, 2019).

Unfortunately, a gap currently exists between the needs of children with CVI who use AAC and current practice. Providers from multiple disciplines, as well as parents, report facing multiple barriers in both school and community settings (Blackstone et al., 2021; Boster et al., 2021; Luo et al., 2022). Although professional organizations (e.g., AOTA, 2021; ASHA, 2021) now recommend IPCP models of service delivery for children with complex needs and advocate for interprofessional education training at preprofessional and professional levels, few school districts, community clinics, or preservice/in-service programs currently implement these approaches.[1]

The study demonstrates the importance of documenting a detailed description of children with CVI who also have severe speech and motor impairments and use AAC. Baseline data highlighted both their similarities and differences, clearly demonstrating that a "one-size-fits-all" approach to intervention is not appropriate. Rather, each child requires an interprofessional collaborative, individualized approach. Baseline data do raise interesting questions about the relationship between vision, as scored on the CVI Range, communicator profiles, communicative competencies, the use of AAC methods, and academic performance. In a subsequent report, we plan to explore children's change over time and the role of vision.

Conclusions

This article provides a rich description of 13 children with CVI who used AAC at baseline, focusing on variables related to functioning across multiple areas. These children vary within the same communication profile, same age, or same grade level and underscore the importance of documenting similarities and differences among participants with CVI who use AAC and how vision may impact both the design of AAC systems and the nature of AAC intervention over time. This article is the first in a series that will report results from a longitudinal, archival

[1]A university module entitled *Introducing Children with CVI: An Interprofessional Education Module for Preservice and Inservice Educators* is now available at https://cvi.bridgeschool.org/university-module. The module includes (a) a 1-minute introductory video; (b) videotaped stories of three children with CVI—each is told from a different perspective: educator, speech-language pathologist, and parent; (c) a PowerPoint slide deck with basic information about vision and children with CVI, which is easy for instructors to personalize to fit the needs of the course; (d) a video of the slide deck narrated by Dr. Christine Roman Lantzy; and an (e) instructor's manual with learning objectives, discussion questions, and additional resources and references.

record review of students with CVI who use AAC over time.

Author Contributions

Sarah W. Blackstone: Conceptualization (Lead), Data curation (Equal), Formal analysis (Supporting), Funding acquisition (Lead), Methodology (Supporting), Writing – original draft (Equal), Writing – review & editing (Equal), Visualization (Equal), Project administration (Lead), Supervision (Lead). **Fei Luo:** Conceptualization (Lead), Data curation (Equal), Formal analysis (Supporting), Methodology (Equal), Writing – original draft (Equal), Writing – review & editing (Equal), Visualization (Equal), Project administration (Equal). **R. Michael Barker:** Conceptualization (Supporting), Data curation (Equal), Formal analysis (Lead), Methodology (Equal), Supervision (Supporting), Visualization (Equal), Writing – original draft (Equal), Writing – review & editing (Supporting). **Rose A. Sevcik:** Conceptualization (Supporting), Methodology (Equal), Writing – original draft (Supporting), Writing – review & editing (Equal), Visualization (Supporting). **Mary Ann Romski:** Conceptualization (Supporting), Methodology (Equal), Writing – original draft (Supporting), Writing – review & editing (Equal), Visualization (Supporting). **Vicki Casella:** Conceptualization (Supporting), Methodology (Supporting), Funding acquisition (Equal), Writing – original draft (Supporting), Project administration (Equal). **Christine Roman-Lantzy:** Conceptualization (Supporting), Methodology (Supporting), Writing – original draft (Supporting), Visualization (Supporting).

Data Availability Statement

The data generated and/or analyzed during the current study are available from the corresponding author upon reasonable request.

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