Fluctuating Access: How Parents and Teachers Support Learning for Children with Cerebral Visual Impairment

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Abstract

Cerebral Visual Impairment (CVI) is the leading cause of childhood visual impairment, affecting approximately one in thirty children. Yet, CVI remains critically understudied, with limited accessibility research on understanding and designing technologies for CVI individuals. Given its prevalence among young children, investigating its impact on how children develop fundamental literacy and practical skills in increasingly technology-mediated educational settings is critical. Through interviews with eleven parents, three teachers, and one teenager with CVI, we contribute empirical evidence of how CVI-specific characteristics, co-occurring conditions, and resource constraints intersect in shaping children's accessibility challenges in educational settings, and how parents and teachers adopt, adapt, and create technologies and materials to address them. We surface how established assistive technologies cannot be repurposed through a simple retrofit for CVI children, given their unique constellation of fluctuating capacities and conflicting accessibility needs. Finally, we outline design implications for future CVI-friendly technologies.

CCS Concepts

• **Human-centered computing → Empirical studies in Accessibility**.

Keywords

Cortical/cerebral, visual impairment, CVI, children, accessible learning, parents, teachers

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1 Introduction

Cerebral/Cortical Visual Impairment (CVI) has emerged as a leading cause of childhood visual impairment [31, 34], affecting approximately one in thirty children [69]. Unlike ocular visual impairments (OVI), CVI is a neurological condition where individuals struggle to process visual information despite having pathologically intact eye structures [37]. CVI remains critically under-reported and underdiagnosed, largely due to limited awareness among parents, caregivers, and educators [10]. CVI's complexity is compounded by its frequent co-occurrence with other neurocognitive and developmental disabilities such as autism, cerebral palsy, and Down syndrome [16, 65].

Individuals with CVI[1] demonstrate fundamentally different visual and sensory processing behaviors compared to those with OVI [37, 43, 57]. These behaviors may include preference for bright color, visual attraction to moving objects, difficulty identifying objects in visually cluttered environments, and sensory perception abilities fluctuating based on fatigue, lighting, weather, and environmental familiarity. However, despite significant advances in Assistive/Accessible Technology (AT) design for various disability groups [40], HCI research has largely overlooked the needs of people with CVI [29]. While AT designed for OVI may alleviate *visual presentation barriers* by augmenting, substituting, or removing visual information, such approaches fall short of addressing the distinct *cognitive processing barriers* at the core of CVI [10, 29].

Given the prevalence of CVI among young children [69], it is of paramount importance to understand and design effective interventions during early childhood when children develop fundamental literacy and practical skills. Therefore, we investigated how CVI children navigate learning experiences, and how technologies are adopted and adapted by parents and teachers to support their accessible learning. Through interviews with ten parents, one parent-child dyad, and three teachers who worked with CVI children, we explored two key research questions: *1) How do CVI-specific characteristics shape the challenges CVI children encounter in their educational development?* and *2) How do parents and teachers support the needs of CVI children, with or without technology?*

Our analysis revealed the multifaceted burden parents bore to pursue CVI diagnosis for their children who often remained undiagnosed, misdiagnosed, or exposed to misaligned interventions for extended periods, leading to lasting developmental harm. We illustrate how parents and teachers observed and adapted to children's sensory behaviors and compensatory strategies. In particular, we document how they created adaptations to help children manage visual-spatial dysfunction, develop literacy and math skills, and mitigate sensory fatigue, all while continually reconfiguring AT setups to reconcile the competing demands placed by children's evolving skills, sensory capacity, co-occurring conditions, and technology access needs. We also elucidate how parents and teachers managed resource constraints in school and home settings.

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[1] We use person-first (e.g., children with CVI) and identity-first (e.g., CVI children) language interchangeably, noting that individuals' preferred language vary [61].

Overall, we make three key contributions. First, we provide a detailed empirical account of how parents and teachers adopt and adapt technologies to help CVI children navigate unique accessibility challenges in learning contexts. Prior research has informed understanding of CVI children's needs through building new tools [27, 28, 32, 35, 59], identifying gaps in Augmentative and Alternative Communication (AAC) device design [10, 44, 68], and critiquing existing accessible learning tools [63]. We extend this work by documenting the extensive challenges CVI children encounter in learning contexts as their CVI-specific characteristics, co-occurring conditions, and resource constraints intersect, and how parents and teachers continually adopt, configure, and often create from scratch the adaptations and materials to address them. Second, our analysis surfaces how established AT design principles fail to address the needs of CVI children, given they experience a unique constellation of co-occurring conditions that often fluctuate in severity and sometimes present contradictory access needs. Through this, we illustrate the complex interplay of factors that impact the design, adoption, and adaptation of ATs for CVI. Finally, we outline practical design implications for future technologies to enhance experiences of CVI children and reduce caregiver burden.

2 Related work

2.1 CVI-related Visual and Behavioral Characteristics

CVI is characterized by a complex set of visual behaviors that significantly impact individuals' sensory perception and interaction with the world [37, 57] (see Table 1). Researchers developed various assessment tools to evaluate the complex visual, motor, and cognitive functioning among individuals with CVI. For instance, Roman-Lantzy [57]'s CVI Range systematically assesses functional vision across ten distinctive characteristics and provides quantitative measures of visual functioning. Other assessment scales similarly combine parent interviews, teacher questionnaires, structured observations, and clinical examinations [15, 25, 50, 54]. Building on these assessment methods, researchers developed educational interventions to support CVI children [14, 26, 45, 65]. For example, Perkins CVI Protocol [43, 72] considers 16 visual behaviors and compensatory skills to help parents and teachers create CVI evaluation reports with actionable recommendations.

Compensatory skills—often developed inherently—refer to alternative sensory channels and cognitive processes individuals leverage to overcome visual challenges. For instance, CVI individuals may use verbal mediation strategies (constant silent narration of object characteristics) to perceive and interact with their surroundings [52]. Importantly, CVI children need personalized adaptations based on their unique profiles, as there is no "one-size-fits-all" approach to CVI [37]. Complementing these frameworks and assessment methods, adults have shared how CVI affects daily life [9], detailing how they access the world through sensory substitution and augmentation techniques [24].

2.2 Technologies Designed for People with CVI

The advancement of ATs has significantly improved access and function for people with OVI [33, 67], with a 2019 paper reporting that over 43% of CHI and ASSETS accessibility-related papers in the prior decade focused on OVI [40]. Yet, academic and public attention to building technologies for people with CVI remain remarkably sparse [29]. The limited existing work predominantly focuses on CVI diagnosis and assessment using eye tracking [3, 5], virtual reality [6], and tablet applications [17, 19, 46], which ask children to complete playful activities while assessing their visual attention, response time, and performance metrics. Beyond diagnosis, some apps and games support CVI children in learning cause-and-effect [66], object identification [49], visuoperceptual skills like visual discrimination and motion perception [35], and combining physical manipulation with visual feedback using tangible toys [27, 28, 32, 59]. More recently, Gamage et al. [30] studied how smart glasses can assist CVI adults with object recognition, facial perception, and attention to complex environments. Others have specifically focused on CVI children who use AAC devices and found that the design of current AACs (primarily targeting people with limited or no verbal speech due to conditions like autism and cerebral palsy but with stable vision) are misaligned with the skills and needs of CVI children [10, 44, 68]. Closely related to our work, Smolansky et al. [63] investigated how teachers develop accommodations for CVI children and elicited their feedback on how an existing digital math learning tool, AI-learners that was designed for general visual impairments, can be improved for children with CVI.

Collectively, this prior work contributes important knowledge about supporting CVI children by building new technologies [27, 28, 32, 35, 59], identifying gaps in the design of existing AAC devices [10, 44, 68], and contributing design critiques of an existing digital learning tool [63]. We build on and extend this work by revealing previously unreported challenges CVI children face across learning situations where their CVI-specific characteristics, co-occurring conditions, and resource constraints compound in ways that complicate technology access, and by documenting the ever-ongoing work parents and teachers put into piecing together and refining the adaptations to address them.

3 Method

3.1 Participants

With the approval from our university's Institutional Review Board, we recruited participants for interviews using an online survey circulated through a CVI-related community organization, Facebook groups operated by that organization, and snowball sampling. Out of 46 respondents, we interviewed ten parents who have a child with CVI, one parent-child dyad (P1-CP1), and three certified Teachers of the Visually Impaired (TVIs) who regularly taught CVI children. Participants were selected based on their availability and after screening out potential fraudulent responses from the survey [42, 53]. Parents and teachers interviewed are denoted as P# and T#, while CP# refers to P#'s child with CVI. All but one participant lived in the US. All participants were women, which likely happened due to gender roles in childcare and women-dominance in special education workforce [23]. Tables 2 and 3 in the Appendix respectively show parents' self-reported information about their children and teachers' experience with CVI children.

Table 1: Similarities and differences in visual processing and sensorymotor challenges between people with Cerebral (CVI) and Ocular Visual Impairment (OVI) [29, 43].

Criteria	CVI	OVI
Eye movement	Repeated, uncontrolled eye movements (nystagmus). Difficulty shifting gaze or tracking moving objects.	Similar challenges.
Eye appearance	One eye points forward and the other goes in a different direction (strabismus).	Similar challenges.
Visual field	Reduced or heightened visual attention in specific visual fields; strong central but reduced peripheral vision, or vice versa.	Similar challenges.
Visual attention	Varies with sensory inputs (e.g., noise, movement, clutter, light) and fatigue.	Relatively stable.
Visual recognition	Depends on familiarity, environmental conditions, context clues, and sensory inputs; generalization i.e., recognizing unfamiliar versions of known objects may be challenging.	Relatively stable.
Hand-eye coordination	Difficulty maintaining gaze while reaching for items or exploring objects by hand; may over- or underestimate reach.	Occasional difficulty if poor depth perception, visual field loss, blurry vision, etc.
Foot-eye coordination	Navigation challenges, frequent tripping or falls, Over- or under-stepping when walking over uneven ground.	Occasional difficulty if lazy eye, nystagmus, etc.
Impact of clutter	Difficulty processing cluttered or crowded arrangements. May process only one item at a time (simultanagnosia) and prefer spaced-out items.	No impact.
Impact of color	Heightened attention to specific, highly saturated colors. Reliance on color to locate objects in clutter or at a distance.	Sensitivity to color contrasts.
Impact of light	May require light for visual attention. May be involuntarily drawn to target lighting (lamps), backlighting (iPad), or environmental lighting (from windows). May have light sensitivity (photophobia) and fatigue in bright environments.	Poor lighting or glares may affect perception, but does not *require* lighting for attention.
Impact of motion	May need motion to notice objects but be easily distracted by it. Difficulty tracking fast-moving items and judging speed, distance, or direction.	May have difficulty judging speed distance or direction if poor depth perception, etc.
Form accessibility	May be able to interpret 3D materials but struggle with 2D. Realistic materials may be more recognizable than cartoon-like or symbolic ones.	No impact.
Face recognition	Difficulty with eye contact, face recognition, and interpreting facial expressions and body language.	No particular difficulty.
Response interval	May take longer to notice and process objects. Response delay increases with inaccessible materials, clutter, noise, motion, fatigue, or overstimulation.	Relatively stable.
Visual curiosity	Difficulty noticing and recognizing surroundings near and far. Difficulty with visual inferences or incidental learning. Less interest in exploring unfamiliar surroundings.	No difficulty.
Sensory integration	Difficulty using vision simultaneously with other sensory inputs (sound, touch, motor actions, temperature, etc.). Preference towards single-modality information.	No difficulty. May prefer multimodal input for information access.
Other neurological conditions	Frequent co-occurrence with autism, cerebral palsy, Down syndrome, etc. May have complex communication needs requiring various assistive technologies (AAC and switches).	No particular association.

3.2 Procedure

We developed an interview guide in consultation with an expert TVI who had extensive experience with CVI children. We conducted semi-structured interviews over Zoom between February–March 2025. After obtaining participants' verbal consent, we asked them to share details of their children's CVI-specific visual behaviors, co-occurring health conditions, and how those impacted their experience in five broad categories: literacy (reading/writing), math/science learning, image exploration, communication, and daily living. We specifically asked about children's preferred learning media and any high-tech or low-tech adaptations they used, including assistive devices, digital apps/games, or physical tools. We requested participants to demonstrate these technologies via Zoom, either by screen sharing or bringing the physical devices within camera view. We then probed participants to describe how they created adaptations to support their children's needs, challenges they encountered, and workarounds to address those challenges. Before concluding, we probed for participants' satisfaction and dissatisfaction with the technologies used by their children or themselves, their rationales behind choosing certain technologies, and areas of improvement. After the session, teachers T1 and T3 shared example slide-decks they had created for their CVI students. Interviews lasted approximately 60-75 minutes. Participants were compensated with US$30 each via Amazon gift card. All interviews were video-recorded and transcribed for analysis.

3.3 Data Analysis

Following reflexive thematic analysis [12], the first author led open-coding of the entire corpus using a combined inductive-deductive approach. Our inductive coding attended to novel and nuanced aspects of participants accounts, e.g., unique compensatory strategies, challenges with advanced STEM learning, and interactions or breakdowns with technology. In parallel, a deductive lens informed by established CVI protocols and frameworks [20, 37, 43, 68] guided coding for recognized CVI-specific visual behaviors and compensatory strategies [43, 72]. The authors met regularly to review codes and implications of data. Through iterative comparison between data, codes, and initial themes, we constructed three overarching themes that capture core aspects of how children's experience with CVI shaped their learning and how parents and teachers adopted innovative practices to support their needs. Given our sample's skew toward parents, our analysis centered primarily around parent perspectives with complementary insights from teachers.

Our reflexive engagement shaped how we interpreted the data [12] and was informed by our epistemic positionality and background as sighted researchers with 9—10 years of experience working with disabled communities. The first author had 2 years of partnership with the CVI organization fostered through multiple on-site visits, connection with the members and staff, joining quarterly remote meetings targeted toward educators, membership in a CVI-related Facebook group, and attending a CVI conference hosted by this organization.

4 Findings

Our analysis revealed that parents and teachers invested extensive effort to support CVI children's educational development, from navigating complex diagnosis journey to creating individualized adaptations across literacy, sensory fatigue management, and assistive technology configuration. Throughout, they adopted, adapted, and cobbled together the technologies and materials their children needed, while navigating the competing demands of CVI-specific characteristics, co-occurring conditions, and resource constraints in school and home environments.

4.1 Navigating the Complex Maze of CVI (Mis)Diagnosis

Parents took on much of the observational work required to identify CVI, a process that spanned anywhere from age 4 to ages 12-17 in our sample before formal diagnosis arrived. This was because diagnosing CVI required sustained observation that short clinical visits could rarely achieve, as CVI's presentation shifted across contexts and over time. Children's own compensatory strategies further obscured what an outsider (e.g., teacher, medical professional) could capture in a single sitting.

Before any clinical consultation could happen, parents had to navigate the challenge of recognizing that their child's visual behaviors warranted medical attention. P7 noted, *"It's hard to know what he can and can't see,"* especially with younger minimally- or non-speaking children who *"didn't have the metacognitive skills to be able to tell you that that's a problem"* (P1). Moreover, the compensatory strategies these children developed (e.g., memorizing, imitating) to circumvent CVI-related dysfunctions could make them appear as using their vision typically, which further masked [13, 47] children's condition from parents without CVI-related knowledge. P5 reflected, *"Our kids fool us all the time... If you don't know all the compensatory skills, you can miss it all."* Consequently, some parents sought medical consultation only after noticing disparities between their children's and their peers' developmental milestones. P6 explained, *"We went to the doctor because we felt that he had difficulties with things he shouldn't have difficulties with as a 15-year-old."*

When parents did reach professionals and teachers familiar with CVI, short assessment sessions rarely surfaced enough of the condition for a clear diagnosis, given CVI's *"consistently inconsistent"* (P5) visual behaviors and the gap between a single session and everyday functioning. Doctors failed to detect P8' son's esotropia *"because it was intermittent."* P2 explained how her daughter's ability to detect seemingly small objects belied her broader CVI challenges: *"She trips over toys that she puts on the floor 'cause she just can't see in those areas. But then she'll see this tiny little speck of dust and she'll be able to pick that up."* Some children, despite generally struggling to navigate their broader environment, were able to complete specific visual recognition tasks during assessment. P1 recalled a TVI who, assuming CP1's 20/20 acuity meant intact vision, read CP1's passing fixation on a small object as evidence of sight: *"CP1 walks into an office and might say to the teacher, 'Ooh, a pink keyboard.' And instantly the educator is going to write down, 'Great, kid can see 40 feet away'... [They] saw no sign of CVI."* T1 acknowledged this knowledge gap among teachers: *"Even after 12 years [of teaching], I don't know what [CVI children] actually see."*

Participants also saw their children's CVI-related behaviors routinely misattributed to autism, ADHD, cerebral palsy, and Down Syndrome [16], better-known neurodevelopmental conditions that exhibit similar characteristics and sometimes co-occur with CVI. CVI alone was often misdiagnosed as one of these, while co-occurrence led clinicians to identify the more familiar conditions and overlook CVI. P6's son was tested for dyslexia due to handwriting difficulties and for Developmental Coordination Disorder due to motor coordination challenges. P8's son's CVI-related behaviors (e.g., looking away) were attributed to his autism. Certain compensatory strategies also contributed to misdiagnosis. P4's very gregarious son would *"talk [his] way through"* situations and offer a *"whole other story"* when he could not see, letting his behavior read as an attention or learning problem rather than a vision one. For outside observers, this *"looks like ADHD. So, it's hard for people to separate 'I can't see it' from 'I can't learn it'"* (P4).

Parents shared that delayed diagnosis cost children *"all the building blocks"* (P8) of early intervention. Misdiagnosis added further harm. P8 described how Applied Behavioral Analysis (ABA), recommended because her son's autism was considered *"more significant"* than his CVI, was detrimental rather than helpful [36]. She explained, *"ABA was teaching him to look at something; he couldn't see it... He hadn't acquired a dictionary for these objects or verbs they were using... They were challenging him in ways that he wasn't able to participate in."* The therapy left him *"fearful,"* and without appropriate support he eventually *"regressed"* and *"lost the bank of words"* he had acquired as a child.

Across these challenges, participants described breakdowns at every turn of their pursuit of a complicated diagnosis. These breakdowns, together with CVI's unpredictable manifestations across contexts and moments, suggest a need for diagnostic and assessment approaches that support continued monitoring, a need we return to in Discussion Section 5.2.

4.2 Observing and Adapting to Children's Visual Behaviors and Compensatory Strategies

Parents and teachers reported that they thoroughly observed children's visual behaviors looking for *latent* compensatory strategies and developed adaptive resources to optimize their visual-spatial and multisensory demands across various learning and communication activities. Below we describe how participants created, curated, and shared adaptations *"to make it more visually accessible"* (P3) according to children's individual needs, abilities, and preferences.

4.2.1 ***Managing Visual-Spatial Dysfunction.*** Several participants described their CVI children experiencing significant visual-spatial processing challenges [8]. This manifested in children's

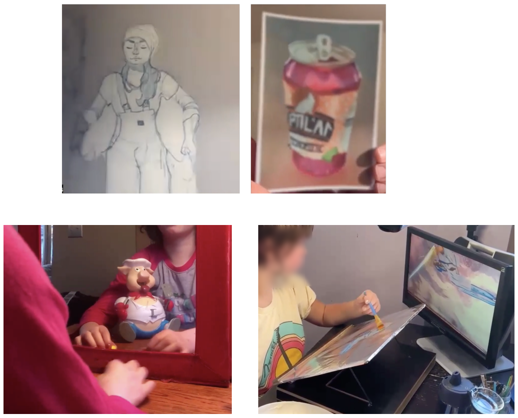

Figure 1: Two visual artworks created by CP1 (top). P9's daughter uses a mirror to place objects within her optimal visual field (bottom left) and paints on a slanted board while tracking hand movements in a CCTV screen (bottom right).

inability or difficulty to determine object locations in space, comprehend spatial relationships between objects, understand body positioning relative to the environment, and visualize maps, images, and scenes. Participants also reported a related visual phenomenon called simultanagnosia, i.e., difficulty processing simultaneous visual information. Consequently, children with CVI struggled to interpret visual scenes and images, whereby they might focus on individual elements while missing how these elements collectively formed the gestalt. P6 recalled her son's experience during CVI assessment: *"One of the pine trees on the picture didn't have a stem. It was hanging in the air, but he didn't see that... He understood it only when the psychologist pointed out."*

To help children recognize images with multiple objects, teachers sometimes *"sectioned it out and had her (child) go corner by corner to piece it together [so that] she was able to fully understand the scene"* (P5). While some children could conceptualize visual scenes through such part-to-whole processing, others continued to struggle due to fundamental difficulties with spatial processing. CP1 described how CVI affected their visual recall: *"I can't make visual-spatial memories in a way that I like... I can only see a small part of anything at once... but it's not useful because it doesn't have any relationship to anything else. "* Moreover, spatial processing difficulties often extended to the inability to form voluntary mental imagery (i.e., aphantasia) and caused a feeling of visual field shaking with head movement [8]. To address these challenges, CP1 developed a *"non-visual system of remembering visual things, like adding words and descriptors [to each small visual element they could process] and imagining feeling it and adding emotions to it."* P1 described this verbal consolidation as a habit CP1 deliberately developed, serving as a channel for encoding and recalling information in place of visual processing: *"Whether something is easy or hard, we'll make a point of like, 'tell your dad about it,' and now CP1 does that naturally. They had that support to increase their verbal capacity to such an extent that they could have an internal monologue about descriptors that were supporting their 'visual recall'."*

Furthermore, CP1 used art-making as a *"learning medium"* (Figure 1, top) to test and reinforce their non-visual memory strategies, as drawing required actively reconstructing visual characteristics from memory. Yet art-making itself was not free of CVI-related challenges, as they still faced difficulties with the significant visual field travel required to look back and forth between reference materials and canvas. CP1 addressed this by placing a phone screen close to the drawing surface, so that *"my eye muscle jumps from the reference to my art aren't as far and so I don't get lost as easily."* CP1 also leveraged their color vision proficiency, which made certain artistic styles more accessible to them: *"Painting is actually sometimes easier than sketching because... you're thinking about what's the color in what approximate shape and putting these blobs onto your canvas until it resembles it just enough."*

Likewise, P9's daughter intuitively developed compensatory strategies after discovering that mirrors could extend her functional vision to access lower visual fields when needed (Figure 1, bottom left), e.g., for viewing tabletop objects or monitoring herself strumming a guitar. She also instinctively placed an iPad on her *"propped-up knees to get that angled view."* Finding it *"fascinating that she did this on her own,"* P9 incorporated a CCTV (Closed-Circuit Television) and slanted boards (Figure 1, bottom right) so that CP9 could *"track [hand] movement"* in the CCTV screen while performing activities like *"writing, painting, anything that's tabletop that you have to look down and coordinate working."* These experiences illustrate how successful adaptations were not always explicitly taught but often emerged from children's own creative problem-solving. Such capacity for self-directed adaptations is an important, albeit under-recognized, dimension of how CVI children navigated visual-spatial challenges.

4.2.2 *Developing Literacy Skills.*

The visual-spatial processing challenges described earlier compounded significantly in the context of developing literacy for children with CVI, especially those with co-occurring conditions. For example, P3's child with optic ataxia had *"a hard time with looking and reaching for things at the same time."* Together, these compounding effects placed demands on reading and writing that far exceeded what visual augmentation (e.g., magnification, high color-contrast) alone could address. Unlike activities that permitted deliberate and paced engagement with visual content (e.g., art-making for CP1), reading required rapid recognition and fluency that left little margin for compensatory adaptation. P1 captured the compounded impact CP1's letter and word agnosia had: *"When we look at a word... we're seeing 11 to 13 letters at once. CP1 can never see more than 2-3 letters at once. So, no word could ever be recognized in its entirety, to be processed with all the letters at once visually."*

CVI children developed various compensatory strategies to address their reading difficulties. P4's son, for instance, had learned to use recognized patterns (e.g., images) from previously co-read books to guess the accompanying text rather than reading it (e.g., identifying an apple using the image versus deciphering the text A-P-P-L-E, which felt cluttered). Parents emphasized that this strategy, while adaptive in the short term, bypassed the development of literacy skills, as the child avoided engagement with the visual-cognitive processes that reading requires. Hence, to reduce her son's reliance on this strategy, P4 often *"covered up the picture"* during co-reading sessions.

Consequently, the adaptations participants employed to support CVI children's literacy development worked by restructuring the

Figure 2: The Sound Slider feature on Reading.com app showed by P4 (left). Word bubbling (middle) and image outlining (right) techniques showed by T3.

literacy tasks to operate within children's available visual capacities and sensory channels rather than attempting to improve their visual processing of text. Some adaptations reduced the visual units being processed at a time, others transformed letter-by-letter decoding into word-shape recognition, while others added non-visual channels to guide reading and writing. P4 used Reading.com [56], especially its 'sound slider' feature (Figure 2, left), which *"helps with [visual] scanning and seeing what a word sounds"* by underlying the word being spoken. Many participants also incorporated the Bubbling technique [58] of outlining words with bright colors to create distinct word shapes (Figure 2, middle), as *"learning word shapes takes a layer of visual clutter out"* for children with CVI (P4). P2's daughter used Writing Wizard [1], where letter tracing demonstrated with animated stickers *"helped her learn to write."* For some children, however, the literacy barriers were not at the level of visual presentation but at visual recognition itself, a distinction that visual augmentation tools, however well-designed, could not address. P1 recounted: *"I tried for many years making modified materials using color coding, large graph paper, high contrast, low contrast, CP1's preferred color paper, tinted overlays, different spacing of text, different fonts... but that wasn't gonna help them approach third-grade level, much less middle school."* Instead, tactile means (e.g., braille, wikki-stix) helped them *"build foundational knowledge"* (P1) of literacy. Similarly, P5's son relied on sound rather than visual recognition alone. For him, Clicker's [18] text read-aloud and word suggestion features provided *"the auditory feedback [after typing] that showed him he's on the right track."*

4.2.3 ***Facilitating Math and Science Learning.*** To help CVI children understand basic concepts of numbers and counting, participants turned to tactile manipulatives [63], e.g., Numicons [51], 3D models, tactile graphics, and braille (Figure 3). More advanced mathematical operations, however, required *"mental imagery and visualization"* (P5), such as mentally picturing relative positioning of positive and negative numbers across a number line or visualizing geometric relationships. Unlike children with OVI who can develop mental models of such spatial and mathematical relationships using tactile or auditory channels, children with CVI face a more fundamental barrier, as visuospatial processing dysfunction means such models are difficult to conceptualize, regardless of sensory channel. P1 illustrated this through CP1's difficulty with number lines: *"You have to—in your mind's eye—be able to zoom in and zoom out of portions of the number line, which CP1 didn't understand... They didn't have a sense of how positives and negatives were related with a central point."* P1 employed an embodied technique to help CP1 *"spatially conceptualize"* equation terms, physically placing hands on either side of the equation sign; yet this remained error-prone. P6 noted her son struggled with multi-step equations, since memorization, the primary compensatory strategy available to these children, proved inadequate in this regard. Consequently, her son required *"5-10 times"* longer than peers, all while still losing track when problem formats varied even slightly. P1 lamented the scarcity of CVI-specific resources in advanced math learning:


[redacted]

Figure 3: Various tactile adaptations. Top left: P2 shows Numicons for learning numbers. Top right: P8 shows a tangible calendar board with 3D representations of personally meaningful real-life objects. Bottom left: P5's son uses muffin tins and colorful tactile materials for learning braille. Bottom Right: P5 created a story box using tangible materials and a switch device for playing pre-recorded audio stories.

> *"Math is just a void of helplessness and hopelessness for most people with CVI... These kids are drowning. They're barely keeping up till third or fourth grade, and then their peers are just plowing past them. And it's not for a lack of intellectual strength... But we have no idea of how to move forward because... they can't spatially line it up on paper."*

Beyond these neurocognitive challenges, inaccessible visual presentations of math workbooks and scientific diagrams created additional difficulties. Worksheets from mainstream schools were often *"over-cluttered and overwhelming"* (P2). To address this, participants digitized paper worksheets using tools like SnapType [64] and added enhancements like larger fonts, highlighting, and text-to-speech. They also *"sectioned out"* complex diagrams into separate slides to reduce visual clutter, though this introduced its own friction. P3 broke down the water cycle diagram into separate slides but noted that *"you need to see the whole thing together to get the full idea,"* a challenge related to her son's visual recall limitations.

For children who relied on AAC and switch devices, the barrier extended beyond visual presentation to input itself. P3's son could not type answers with switch-scanning, requiring conversion to multiple-choice format, which introduced its own cognitive cost: *"you have to remember what [choice] each letter stands for and that adds a layer of complexity."* Excessive verbiage in questions created additional barriers to succeed in exams. P6 explained that her son could not *"sort it out logically"* when math problems included extraneous information to *"confuse"* students. He also struggled to understand questions with multiple sub-parts and often missed later parts. To remedy this, P6 broke down the questions into individual sub-questions for him. Additionally, with P6's guidance, he sometimes utilized generative AI tools like Copilot and ChatGPT to receive step-by-step problem-solving assistance.

4.2.4 ***Mitigating Fatigue from Visual and Multisensory Processing.***

Since CVI impacts not the eye's ability to receive visual signals but the brain's capacity to process them, navigating complex visual scenes involving moving, unfamiliar, or cluttered objects demanded significant cognitive effort and rapidly depleted sensory resources for children. Participants developed a variety of strategies in response, such as carefully scheduling visually intensive tasks, facilitating regular breaks, reducing visual overstimulation, and supplementing visual information through other sensory channels. However, many of these strategies carried their own risks, as multisensory approaches could themselves compound into overload.

Signs of visual fatigue among CVI children manifested even in everyday activities like writing. P6 explained, *"Writing takes a lot of energy for him. Even though he writes on a computer, his shoulders go up and the whole neck is very tense. And when he writes with a pen, it's even worse."* Relatedly, light and movement could be both a boon or bane for CVI children, depending on their inclination or sensitivity. While many CVI children benefited from lightboxes (translucent, illuminated surface [4]), finger light, or flashlight that stimulated their visual curiosity, others with photophobia or seizure struggled with lighting effects. Similarly, mild visual motion (e.g., animation effects) helped some children identify where to focus their visual attention, but those with dyskinetopsia found it hard to process moving things. To mitigate visual overload, especially for younger children, parents and teachers monitored their bodily response to detect when they were *"falling apart"* (P4) and scheduled visually intensive tasks during periods of peak alertness. P4 shared an example of deliberate scheduling: *"He really enjoys going to the movies. But we have to do that early in the morning, and we can have zero demands afterwards, or only extremely familiar demands. So, if we were gonna go to lunch, it'd have to be a restaurant he knows and not very busy."* Children must also learn to strategically manage visual demands throughout the day to preserve energy for activities they enjoyed. CP1 detailed their approach to allocating visual energy: *"I've set up my life so that I have the visual spoons [48] and energy to be able to [make art], because when I'm asked to do other things visually, like read or navigate, it wears me out so quickly and then I don't have energy for this thing that I love."* Considering such visual fatigue, participants advocated against building CVI interventions solely focused on enhancing visual attention, recognition, and recall, and emphasized non-visual approaches instead. CP1 said, *"Our culture loves to use vision because that's what the majority of the people depend on... But it's really important [for] a professional not to be scared to offer a non-visual tool just because [CVI children] have 20/20 acuities or similar."*

Yet non-visual approaches were hardly a panacea, as many children's struggle with sensory integration exacerbated when responding to simultaneous stimuli across multiple sensory channels. P3 noted, *"Sometimes looking and listening can be a challenge for him. So, he might need to wait until someone stops talking in order to look at something that you're showing him."* As such, multisensory adaptations intended to support learning sometimes yielded counterproductive effects. P1 explained this paradox: *"We can throw more [techniques]. Unfortunately, the opposite happens where it's like, we've added the highlighter, now we're gonna add verbal cuing, and tap you on the shoulder. And then the poor brain of a CVI kid, that's like, one thing at a time please. It's melting down from multisensory processing."* For example, although P4's son benefited from moving the 'sound slider' while listening to read-aloud text on Reading.com (Figure 2, left), P4 observed, *"when he gets really tired, he can't do the motor [function] and vision at the same time."* In such cases, P4 would control the slider herself, freeing up her son's energy to attend to the visual and auditory feedback only. Moreover, fatigue level (and consequently sensory abilities) could fluctuate throughout the day, depending on environmental factors (e.g., precipitation, excessive heat, noise, light, or movement) and bodily experiences (e.g., headache, growth spurt, etc.). As such, participants carefully organized children's physical surroundings (e.g., closing windows, creating enclosed spaces with dark tri-fold boards) to limit factors that could exacerbate burnout, both at school or home [63].

Co-occurring conditions introduced additional layers of complexity, which at times limited children's access to the very sensory channels they preferred or relied upon as alternatives to visual processing. P5's son enjoyed activities with tactile manipulatives (e.g., organizing red balls in a 6-cup muffin tin; Figure 3) for learning braille fundamentals but found braille *"hard to learn"* due to cognitive disabilities. CP1, who preferred auditory and tactile learning methods, faced challenges with screen readers due to their auditory processing disorder. They said, *"It's really hard for me to set my screen reader to start reading a long piece of text, especially because I have my screen readers at a higher talking speed."* To mitigate these challenges, these children required carefully calibrated auditory enhancements. For example, CP1 needed brief pauses between paragraphs and preferred voices with more inflection, while P5's son required a *"clear even tone, slower rate of speech, no distracting audio around him."* These calibrations highlight how co-occurring conditions complicated CVI children's technology use and required additional optimization of assistive devices.

4.2.5 ***Optimizing Technology Access Across Complex and Competing Needs.***

Participants emphasized the *"heterogeneous"* nature of CVI due to its co-occurrence with other complex conditions [16]. Many CVI children in our study were minimally- or non-speaking and relied on AAC devices for both communication and access to digital materials. Navigating these devices required children to reconcile AAC interface demands alongside their CVI-related visual needs [68]. For instance, AAC apps typically present arrays of buttons and icons on a single page, which creates visual clutter that directly conflicts with CVI visual processing. P2 addressed this for her daughter by *"blacking out the buttons that we don't use."* P7's son struggled with the sensory integration demands of visually tracking selections while simultaneously practicing fine motor control by pushing buttons: *"It's hard for him to push a button and look at what he's selecting."* Consequently, since P7's son *"has to look at it (screen) to select it"* anyway, P7 shifted him to eye gaze as an alternative input mechanism.

Yet, children's eye gaze proficiency was contingent on their attention and accuracy—visual characteristics that were themselves disrupted by CVI and therefore required careful management of stimuli and fatigue. P7 explained, *"To calibrate the eye gaze device, you have to follow so many points and his attention, speed, and accuracy with calibrating the device ... depended on the environment, lighting, his mood, attention and how tired he is."* As such, P7 collaborated with teachers to customize her son's AAC interface with simple, high-contrast images and larger buttons with borders on a black background. For additional support, she incorporated tactile cues, e.g., *"shiny red or blue pipe cleaners or fuzzy ones made into a circle, or brightly colored wikki-stix made into certain designs, to try to get his attention on a specific button."* Teachers also positioned the device in his preferred visual field by mounting it *"on his wheelchair in the upper left-hand corner."* Moreover, when visual fatigue set in, P7 shifted her son to switch devices to avoid reliance on eye gaze, using two adapted switches *"so that he can use his hands and he knows where [the switches are] placed, because they're placed in the same order as the two large buttons on the AAC screen."*

Furthermore, participants continually incorporated adaptations to AAC devices to accommodate children's evolving visual and motor skills. P3 adopted an extensive trial and error process involving various AAC devices and input mechanisms (e.g., hand operation, eye gaze, head mouse, and single-switch automatic scanning [60]) to help her son develop mastery with double-switch scanning (i.e., using one switch to move the cursor and another to select an option). She also customized his AAC software to align with his navigation skills and communication needs (Figure 4, left): *"His communication vocabulary is VOCO-chat [62]. It's normally a smaller grid. I've expanded it into a larger grid and more robust vocabulary for him, so he doesn't have to navigate quite as many pages to get to all the language he needs to access."* However, using a single AAC for both communication and other purposes prevented him from multitasking. P3 addressed this by teaching him to operate two AAC devices simultaneously so that he could *"use one to keep talking and the other to watch Netflix or something if he wanted to."*

Sometimes CVI children repurposed AAC devices into *"stim tools"* to meet self-regulation needs, albeit at the expense of the devices' learning goals, and parents had to redesign interactions to balance both. For example, some children resorted to clicking or swiping repetitively for sensory comfort rather than engaging with the presented tasks. P2 addressed this by replacing click-based interactions with drag-and-drop that required focused attention: *"We've started changing how some of her stuff is built on Boom cards [11] where she has to drag the answer to the spot. It slows her down, rather than just having stuff to click."*

Participants also identified CVI-specific needs that current AAC devices did not support. For example, T3 explained that to attract visual attention, some AAC devices provided a moving red dot on an icon/image, but *"that doesn't help with visual recognition of the icon itself, because the dot is also obscuring the image. And then kids are just looking at moving dots and not the image itself."* Instead, she suggested that *"the icon itself move to work on visual targeting... wiggle, pulse, or bounce around in the space."* Similarly, many CVI children benefited from learning visual targeting using *"low- or mid-tech AAC"* devices with placeholders for 3D objects (Figure 4, right) before moving to *"more high-tech dynamic systems."* However, T3 wanted these devices to include visual scanning feature that *"could light one [object] at a time in a left-to-right pattern to highlight what choices are before they select."*

Figure 4: Left: P3 shows adapted vocabulary on her child's AAC app. Right: T3 shows a low/mid-tech AAC with placeholders for 3D objects but no support for visual scanning.

Importantly, accessibility requirements of CVI children are not simply the sum of needs related to CVI and those stemming from co-occurring motor/cognitive disabilities. These conditions interact to produce barriers that would not exist under either condition alone, and that technologies designed for individual conditions independently cannot anticipate. Yet, existing technologies address CVI and AAC-related needs in isolation and leave children at the intersection severely underserved. T1 referenced a collection of 72 iPad apps suitable for learners with complex support needs, but only 26 had built-in switch access, three were CVI-friendly, and only one featured both characteristics. Likewise, P3 shared frustration with the Read2Go [2] app, which supported screen reader and magnification but lacked switch accessibility and visual customization support for her son's complex needs: *"I'd want him to be able to isolate text, where he's only seeing a portion of the text at a time and the rest is black around it, or just moving the text along with using switches. But it's difficult to make it switch accessible."* P3 also reported that navigating search engines like Google was *"extremely difficult"* using switch-scanning due to the excessive links that must be scrolled through.

Although parents and teachers helped children operate technologies that were not fully accessible, they emphasized the importance of facilitating children's *"independent access."* P5 explained: *"I keep thinking about how can he become more self-initiated with these [technologies], especially now as he's getting older. He loves watching YouTube videos, but it's hard when the interface is not set up for his needs."* Cookie consent popups and excessive navigation links on websites hindered independent access for switch users with CVI. *"As soon as he gets to that [popup], he's stuck, and he can't do anything. And then someone has to help him... That's a big problem, 'cause you can't really be independent if you keep getting stuck every five minutes,"* reported P3. To support her son's agency, P5 recorded audio stories in chunks and created a *"low-tech"* switch device (Figure 3, bottom right) that allowed him to *"go through different chunks of the story on his own... and drive the learning"* instead of following *"adult-driven"* learning routines.

4.3 Addressing the Challenges of Enabling Accessibility at School and Home

Parents and teachers faced significant challenges while adapting environments, materials, and technologies to meet CVI children's unique sensory processing needs, which required them to invest substantial time, expertise, and resources.

4.3.1 *Challenges in Adaptation Creation.*

Nearly all participants created customized slide-decks with adaptive learning materials for their children using various digital tools e.g., PowerPoint, Google Slides, and Canva [63]. While preparing slides, participants attempted to children's CVI-specific needs. For example, these children experienced challenges with form interpretation [7], which manifested in children visually recognizing some forms (e.g., 3D, realistic) better than others (e.g., 2D, cartoon-like or symbolic). To help children conceptually associate 2D-3D counterparts, participants incorporated personalized materials meaningful to the children and created boards with tangible symbols representing real-life objects children could refer to for communication (Figure 3, top right). Alternatively, they captured images of children's favorite toys, characters, or persons, removed clutter from these images, and placed them against plain, high-contrast backgrounds for a *"pop out effect"* (P5). Furthermore, to enhance children's visual attention and recognition, they adjusted typography (e.g., font size, spacing, style), applied color coding and word bubbling [58] with children's preferred colors, and outlined salient features of objects (Figure 2). For children who enjoyed videos for their multimodal output and repeated watchability, participants created individualized videos or curated CVI-friendly videos from platforms like Brainpop, Flocabulary, and YouTube.

Participants emphasized the substantial time investment required to create these adaptations. P2 explained, *"Sometimes it takes me 3–4 hours to build everything. Because if it's a book and you have to take pictures of every image you want, and edit the pictures and put them in... For videos, the setup part takes longer than actually doing the video."* P5 underscored the highly individualized nature of this work: *"It's hard to do a mass production of this for CVI when it's highly based on what they have the most experiential memory with, what they can easily recognize and use that to learn something new."* Participants expressed a desire for tools that would, at least partially, automate their workflow for creating adaptive materials. P3 said, *"If there were easier ways to import something, like a math workbook or social studies text, and it could create slides based on that automatically. Then you could edit it a little bit to make sure it's right."* Additionally, they desired *"easier to find materials"* and *"easily customizable"* learning tools with greater flexibility in controlling visual and auditory output.

4.3.2 Challenges in the School Setting.

Although teachers often *"controlled"* (T2) classroom environments to declutter CVI children's visual field and reduce environmental distractions, these still presented significant barriers to maintaining visual attention. P7's son, for example, *"likes to people-watch and there's a lot of busy preschoolers in the classroom. He just has a hard time focusing."* Parents also confronted continued resistance to individualized accommodations at mainstream schools. P4 lamented that getting the school to adapt anything had been *"a real fight,"* with the district *"not making anything individualized"* for her son. P9 described how a school district transition systematically dismantled her daughter's carefully developed CVI accommodations, made rapid changes to her AT setups without proper assessment, and *"put her on the device that everybody in the class uses."* Such institutional decisions undermined years of individualized adaptations and forced CVI children to repeatedly *"be put at ground zero"* and restart learning new technologies. Moreover, timely provision of specialized accessible materials remained a point of failure at many schools. The propensity to serve sighted students first in ability-diverse classrooms yielded *"tech-heavy"* pedagogical practices that caused visual exhaustion for CVI children, as illustrated by P4: *"They're always using the Promethean board [55]... Teachers are probably cuing in that classroom to say, 'Look up here.' That is oftentimes a real detriment to him."*

Lack of awareness about CVI within mainstream schools further limited accommodations. P6 said, *"CVI, for the school is totally new. They've never heard about it before... So, we're still finding our way, because the teachers haven't learned how they need to adapt the questions for him."* Though the school permitted using computers for written tests, oral exams—the most accessible format for P6's son—were not allowed, and he had to accept the compromise knowing he *"might not get exactly the same grade."* T1 acknowledged this concern : *"It's a very complex field and irrespective of all the resources that we already have, it's a lot more confusion [about] what to do with these kids."*

Furthermore, the responsibility for creating adaptations fell unevenly across the support team (e.g., parents, school teachers, TVIs, occupational therapists, O&M trainers, physiotherapists, speech and language therapists), with some people shouldering a disproportionate share. P2 reported, *"It's basically me and her TVI creating all the materials for the whole team... If more people on her team did their own content creating, that would help."* Parents also carried the burden of ensuring home-school consistency by having to get materials *"generalized so that parents are carrying over the same things as in school"* (P8). Chronic resource scarcity made broader distribution of this work difficult, as P7, a former preschool speech therapist, recognized: *"Resources are spread thin and so are the teachers and the support staff. So, my expectations are low at this stage."* P4 highlighted how the work of creating CVI-accessible materials lacked any legitimate institutional owner, leaving parents to absorb it by default: *"It's not fair to ask the general-ed teacher to do it... It would be more fair to ask the TVI. However, we have 87,000 kids in one school district and three TVIs ... They are very willing for me to be the material specialist. But I'm not a TVI... It should not be the role of every parent."*

Advocating for CVI-specific accommodations also strained parents' relationships with school personnel, as requests for individualized support could be construed as excessive or challenging to institutional practices. P9 said, *"I'm often perceived as a difficult parent to work with because I have a lot of questions and requests."* Thus, parents paid a relational cost with the very personnel they collaborated with for their children's access.

4.3.3 Homeschooling as an Accommodation Strategy.

In response to these challenges in school environments, several parents opted for homeschooling as an accommodation for their children. For some families, this approach emerged not as a preference but a necessity, as P1 called school environments *"literally a destroyer of CP1's brain."* CP1 elaborated: *"I can't go into a school building because it exhausts my minimal energy so quickly but also destroys my sensory processing abilities... Homeschool allows me to pace my day a lot better."*

However, with homeschooling's greater flexibility and sensory control came substantial additional responsibilities for parents, including self-directed training in specialized adaptation. P1 explained that she lacked *"experience of how to use tangible ways of teaching"* and began receiving TVI training herself. In her professional capacity, P5 shared training materials with parents lacking CVI-specific support to help them *"learn how to observe their kids, what they're seeing, what they're doing, and what learning looks like."*

Besides knowledge development, homeschooling families were also strained by financial constraints. P3 found the image background removal feature and picture library on Canva to be *"super helpful"* for creating adaptations for her child, but *"wished the pro version was free to homeschooling parents,"* like it was for formal K-12 teachers. Access to tactile materials was similarly limited. Tactile graphics printers cost *"several hundred dollars,"* and alternatives like Draftsman tactile drawing boards, though cheaper, involved a *"time consuming"* process.

To address resource constraints, some parents developed creative workarounds to deliver specialized instruction themselves. For instance, to create custom practice materials for CP1's braille challenge, P1 prompted ChatGPT to generate an interest-based paragraph at CP1's grade level (e.g., *"Dungeons and Dragons"*) that embedded the specific braille contractions CP1 needed to practice (e.g., -ount endings), and gave the output to CP1 for dictation. Although *"ChatGPT doesn't know that they have anything to do with braille,"* P1 combined her own *"pedagogy ideas"* with ChatGPT's output to circumvent the absence of specialized TVI support.

Collectively, these findings highlight the considerable effort participants expended to create accessible and adaptive materials for CVI children, while negotiating institutional support, specialized expertise, and accessible resources that place disproportionate burdens on homeschooling parents.

5 Discussion

Drawing on the findings, we discuss how traditional AT paradigms fall short for complex, fluctuating disabilities like CVI and outline practical considerations for designing CVI-friendly technologies.

5.1 Rethinking Technology Design, Adoption, and Adaptation for CVI

Widely-adopted ATs thus far have largely operated under paradigms designed for relatively stable, single sensory impairments [40], such as screen readers and magnifiers for OVI, hearing aids for hearing loss, or mobility devices for physical disabilities. However, CVI represents a fundamentally different category of disability that challenge established AT design principles. Developing CVI-friendly technologies requires navigating a complex interplay of factors across multiple dimensions: children's individual abilities, support team's expertise, infrastructural constraints, and the specific contexts in which they will be used, as illustrated in Figure 5.

Sensorimotor Challenges and Co-occurring Conditions Create Contradictory Needs (Figure 5C). While OVI primarily affects low-level functional vision (e.g., visual acuity, contrast sensitivity, visual field loss), CVI encompasses both low-level and high-level visual processing difficulties [29], leading to a complex constellation of sensorimotor challenges including visual-spatial dysfunction, visual fatigue, and sensory integration difficulties [72] (see Table 1). OVI-specific ATs thus cannot be simply retrofitted for CVI [29]. Co-occurring neurological conditions (e.g., autism, Down syndrome, cerebral palsy) further complicate this situation by creating contradictory access needs, where solutions for one challenge may conflict with another. A CVI child might benefit from visual enhancements (high contrast, color coding) for some tasks while requiring nonvisual approaches (tactile manipulatives, auditory feedback) for others; yet co-occurring motor or cognitive disabilities may constrain these alternatives. For instance, a child with CVI and cerebral palsy may prefer tactile media but struggle with braille due to poor hand dexterity. CP1 navigated this challenge by strategically allocating sensory energy across modalities—visual approaches for personally meaningful tasks (e.g., art) and nonvisual techniques for reading and writing (Section 4.2.4). This represents a departure from traditional disability categories where competing access needs arise only during collaboration across people with different disabilities [21, 22, 38], not within one's own self.

Interoperable ATs are Needed for Intersectional Disabilities (Figure 5D). Most ATs are designed with single-disability assumptions to operate in isolation, with digital access provided through a single primary interface. Children with CVI, however, navigate complex technological ecosystems involving multiple ATs (e.g., AAC devices, switches, eye gaze technologies, screen readers) to address various co-occurring conditions [44, 68] (Section 4.2.5). For instance, P3's son used multiple AAC devices simultaneously—one for communication, another for entertainment—because no single system could accommodate both. P2's daughter needed her unused AAC buttons *"blacked out"* to reduce visual clutter, while P7 cycled through eye gaze, switches, and tactile cues to help her son navigate his evolving AAC needs. P3's frustration with the Read2Go app (functional with screen readers and magnifiers but inaccessible via switches) exemplifies how single-disability design assumptions exclude CVI children requiring interoperable ATs.

Dynamically Adaptive Technologies Could Address Fluctuating Abilities (Figure 5B). CVI's fluctuating nature presents unique challenges to existing AT paradigms that assume relatively stable user needs, e.g., a screen reader user consistently needs auditory output, or a mobility device user consistently needs physical support. CVI children, however, experience *"consistently inconsistent"* (P5) sensory abilities that change based on both external (e.g., noise, light, clutter, movement) and internal factors (e.g., fatigue, stress, familiarity). P4's observation that her son could use visual scanning in the morning but required complete auditory support later when tired exemplifies this dynamic variability (Section 4.2.4). Current ATs are not designed to accommodate such fluctuations where *one size does not fit one* throughout the day [39, 41]. Applying ability-based design principles [71] could help to automatically adjust interface parameters based on real-time performance and physiological signals (e.g., eye tracking data indicating a visual fatigue onset and triggering a shift to auditory-focused interfaces). However, these principles typically track user capabilities along a single modality. Complex disabilities like CVI require capturing fluctuating abilities holistically and in a context-aware manner, tracking not only interactions within a single interface but also environmental factors, task demands, and co-occurring conditions.

Technologies Should Leverage Children's Compensatory Strategies (Figure 5A). To navigate their fluctuating abilities and sensorimotor challenges, CVI children develop sophisticated compensatory strategies including memorization, imitation, repetition,

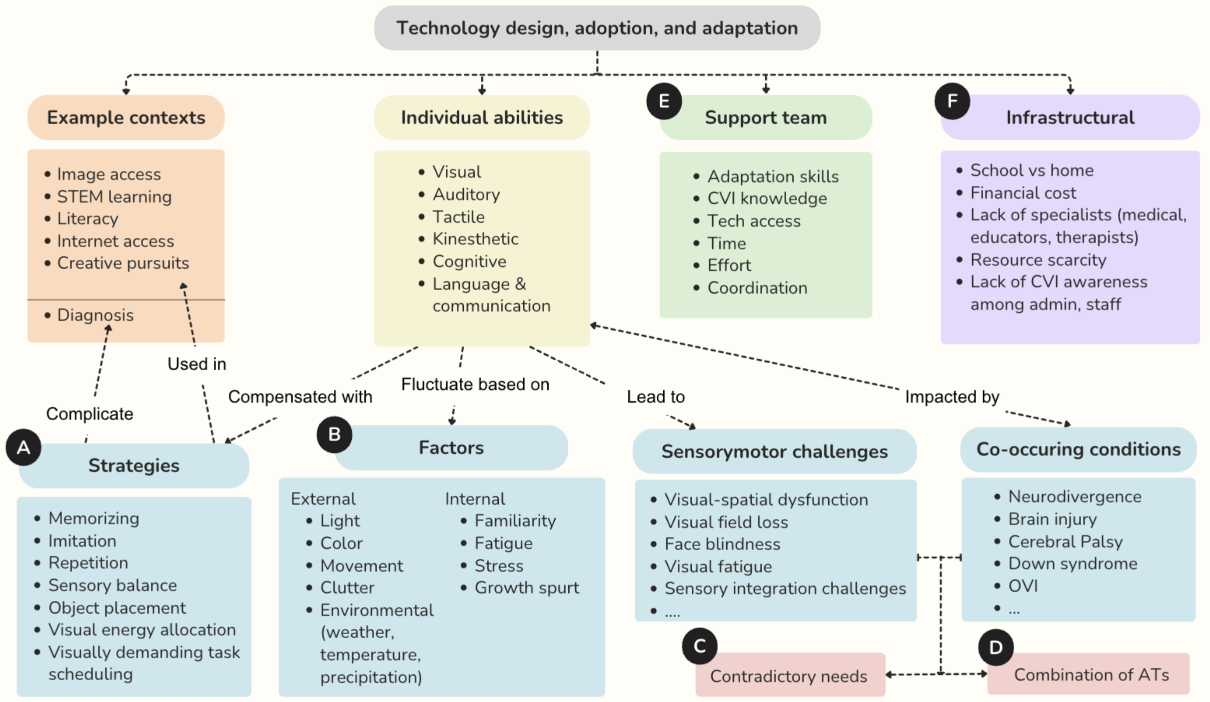

Figure 5: A framework detailing the factors that impact the design, adoption, and adaptation of technologies for CVI. These include (1) example contexts where the technology will be used, (2) children's individual abilities, (3) support team, and (4) infrastructural resources. Individual abilities 'fluctuate based on' various internal and external factors, 'lead to' different sensorimotor challenges, are 'impacted by' co-occurring conditions, and are 'compensated with' different strategies. The compensatory strategies are 'used in' different contexts but also 'complicate' CVI diagnosis. Sensorimotor challenges and co-occurring conditions create contradictory needs and require using a combination of interoperable ATs.

sensory balance across modalities, strategic object placement within optimal vision fields, and scheduling visually demanding activities when capacity allows. We observed examples of this when P9's daughter used a mirror to expand her usable visual field (Section 4.2.1) or when P4's son memorized images in books to compensate for reading difficulties (Section 4.2.2). There is an opportunity to design technologies that leverage these strategies to support CVI children across diverse contexts, from image access and STEM learning to literacy development and creative pursuits. Simultaneously, diagnostic technologies should take into account compensatory strategies as these strategies can hide visual-spatial challenges and complicate CVI diagnosis (Section 4.1).

Support Teams' Expertise Determine Adaptation Success (Figure 5E). Even well-designed adaptations can fail without adequate support team capacity involving parents, teachers, therapists, and medical professionals. Participants revealed that adaptation effectiveness depended heavily on educators' and parents' CVI knowledge, content creation skills, available time, and support team coordination (Section 4.3.1). This places unsustainable burden on parents and teachers who must constantly adjust settings, switch between tools, and create new adaptations as children's needs change throughout the day or across developmental stages.

Infrastructural Barriers Compound Technology Adoption Challenges (Figure 5F). Beyond individual abilities and social support, systemic factors shape whether technological adaptations can be implemented effectively. Children may have access to specialized equipment at school but lack equivalent resources at home, or conversely face greater noise and distraction in school settings (Section 4.3.2). Financial costs restrict which technologies families can afford (Section 4.3.3), while scarcity of specialists limits both diagnosis and adaptation quality (Section 4.1). Resource scarcity extends further to CVI-appropriate educational materials and assistive devices. Perhaps most critically, limited CVI awareness among school administrators and staff means that even when resources exist, they may not be allocated appropriately or used correctly.

5.2 Design Opportunities for CVI-Friendly Technologies

Below we outline design considerations for future technologies to enhance experiences of CVI children—from early detection through educational support, independent technology access, and creative expression—by leveraging their compensatory strategies and enabling intelligent, adaptive interfaces that reduce caregiver burden.

5.2.1 Longitudinal Diagnostic Support Systems. The complex diagnostic journey parents described foregrounds opportunities for new technologies to support timely and accurate CVI identification [44]. Current diagnostic approaches rely heavily on clinical visits and teacher assessments [15, 25, 50, 54, 57] that may miss the fluctuating and context-dependent nature of CVI symptoms, as when P8's son performed well during appointments yet struggled significantly in daily life. Future technologies could help parents systematically record children's visual behaviors and compensatory strategies across diverse contexts and timeframes, aggregating data over weeks or months to reveal behavioral patterns that brief clinical visits miss. Computer vision algorithms could analyze parent-recorded videos to detect visual attention patterns, gaze aversion, or visual preferences, while wearable smart glasses [30] adapted for children could passively collect data during naturalistic activities. However, these technologies must supplement rather than replace professional evaluation to avoid misdiagnosis.

5.2.2 Intelligent Content Adaptation Tools to Reduce Caregiver Burden. Parents and teachers spent hours creating personalized slides, adapting worksheets, and modifying digital content to meet their children's specific visual processing needs, which reveals a critical gap between CVI children's highly individualized needs and limited customization capabilities of existing tools. The learning curve for caregivers remains prohibitively steep, as they must develop expertise in CVI-specific visual behaviors, color theory, typography, and sophisticated tools (e.g., background removal, adapting AAC devices). Expecting parents and teachers to become amateur AT developers is neither sustainable nor equitable. Future tools could offer intuitive, template-based approaches while maintaining flexibility for personalized adaptations. AI-powered tools could automatically generate educational materials by applying CVI-friendly design principles (e.g., outlining salient objects). Browser extensions could offer one-click transformation of web content and digital textbooks. Collaborative repositories where caregivers share successful adaptations could be paired with recommendation systems that match materials to specific CVI profiles, reducing redundant effort while building collective knowledge.

5.2.3 Adaptive Learning Platforms for Advanced STEM Education. CVI-focused educational apps largely target early childhood learning, leaving advanced STEM subjects underserved. Standard accessibility approaches translate visual content into tactile or auditory form, but this is only a partial support for CVI children. Tools can intervene in two ways. First, they can communicate each transformation in multi-step problems through channels CVI children can reliably follow rather than leaving them to infer change by comparing visually different layouts. For example, each operation in math equations could be narrated through stable verbal form ("subtract three from both sides"), paired with distinct tonal motifs per operation or directional haptic sweeps, so children can follow how problems change step-by-step. Second, tools can surface integration failures when parts fail to cohere into wholes (e.g., P3 breaking down water cycle stages into separate slides to manage clutter but losing the cyclical relation). Future designs could animate transitions so the relation itself becomes the object of attention rather than something the child must assemble internally. Such tools should offer dynamic scaffolding adapted to individual CVI profiles, switching between tactile, verbal, and simplified visual representations based on fatigue level or environmental context.

5.2.4 Enable Independent Access to Technologies. Current CVI technologies overwhelmingly focus on children requiring parental guidance, leaving critical gaps in supporting autonomy for adolescents and adults. For instance, P3's and P5's teenage children struggled with independent web browsing due to complex layouts, rapid content changes, and switch incompatibility. CVI-friendly browser extensions could automatically detect and highlight relevant content areas, provide streamlined page layouts, isolate foreground-background elements, minimize visual clutter, and offer navigation support for AAC and switch users. Intelligent filtering could suppress auto-playing videos and dynamic advertisements that overwhelm visual processing.

5.2.5 Leverage Compensatory Strategies to Support Creative Pursuits. Our analysis showed that CVI children enjoyed consuming media and some actively participated in creative activities. Although some CVI-friendly educational games exist [27, 28, 35, 59, 66], age-appropriate technologies supporting recreational and creative activities remain sparse. Future technologies could elevate artistic expression and playfulness, recognizing CVI children as individuals with diverse interests, talents, and aspirations. These technologies could draw on compensatory strategies to enhance art creation. Digital art applications could incorporate picture-in-picture displays or split-screen reference windows positioning source materials within optimal visual fields, mirroring how CP1 placed reference images on a phone close to her drawing board, or provide multi-view interfaces at different angles and distances, similar to how CP9 used mirrors to monitor her guitar strumming.

5.3 Limitations and Future Work

An important limitation of our study is that only one child with CVI participated in the interview. Future work should prioritize involving more CVI children to center their perspectives directly. The limited teacher representation also warrants expansion to capture broader educational contexts and strategies. Additionally, remote interviewing, while providing rich verbal accounts, may not have fully captured the embodied interactions and physical adaptations that occur between CVI children and their parents or teachers. Future work would benefit from on-site observations to document children's interaction with their peers, teachers, therapists, and technologies. Importantly, future studies must be adapted for minimally- or non-speaking children [70], who are common in CVI population but poorly served by verbal interview-based studies.

6 Conclusion

Through interviews with parents, teachers, and one teenager with CVI, we explored how CVI-specific characteristics shape children's literacy development barriers and how parents and teachers implemented adaptations to facilitate accessible learning. Our findings reveal the ever-ongoing effort parents and teachers invested in supporting CVI children across literacy, sensory fatigue management, and assistive technology configuration, often developing customized adaptations and materials from scratch. Through this, we demonstrate how CVI fundamentally challenges established AT paradigms built for single-disability contexts, as CVI-specific needs and co-occurring conditions compound into challenges that existing technologies, designed for independent conditions, cannot address. Researchers and designers must develop adaptive technologies that accommodate fluctuating and intersecting needs of CVI children while lowering the barrier to customization for the parents and teachers who currently shoulder this work.

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A Appendix

Table 2: Parents' self-reported information about their children. * denotes that the child is non-speaking; ** denotes minimally-speaking; † denotes some speech issues. AAC: Alternative and Augmentative Communication device.

Parent ID	Age (gender)	CVI diagnosis	Co-occuring conditions	Educational details	Technologies used
P1	15 (preferred pronouns they/them)	At age 12	Central Auditory Processing Disorder, Dysautonomia, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), CVI conditions (oscillopsia, prosopagnosia, letter, form and object agnosia, accommodative insufficiency, optic ataxia)	9th grade, homeschooled	Screen readers (JAWS, VoiceOver); Desmos math studio, Equation Editor; BARD, Bookshare; iPad, Apple Watch, iPhone; noise canceling headphones and earbuds; braille input on iPhone; Perkins Brailler
P2	* 8 (F)	Phase 2, range score 6	Chronic lung disease, Retinopathy of prematurity (ROP), myopia, developmental delay, mild to moderate hearing loss, astigmatism, Intrauterine Growth Restriction (IUGR)	3rd grade, homeschooled, remote school	AAC; screen magnifiers; Writing Wizard app; Boom Cards; TouchChat; BrailleBuzz device
P3	**14 (M)	Phase 2, range score around 4.5	Ocular impairments (optic nerve atrophy, strabismus, nystagmus, myopia, low vision), cerebral palsy (mixed, spastic dystonic and quadriplegic), chronic lung disease, trached, ventilator-dependent	7th grade, homeschooled through a charter school	AAC (Grid 3 on Gridpad 12 or Surface Pro tablet); switch devices; audio-visual description; screen magnifiers; voice command
P4	8 (M)	High Phase 2, at age 4	Non-accidental trauma with multiple subdural hematomas	2nd grade, general education	Screen magnifier; voice command; iPad; Snaptype Pro; Bookshare; Bubbly, Writing Wizard app
P5	† 12 (M)	At age 5.5	Rare variant of ASTN1 gene, low muscle tone, vertical nystagmus, optic nerve hypoplasia, myopia, intermittent esotropia, intellectual disabilities, autism, ADHD, anxiety, severe chronic migraines, orthopedic conditions	6th grade, public school but separate special education class	Screen magnifiers, CCTV; Smart Brailler; Clicker writing software, voice command, audio description, text-to-speech, adaptive keyboard
P6	18 (M)	Mild, at age 17	Tested for Developmental Coordination Disorder	11th grade, regular high school	Larger font and spacing; mobile camera and photos instead of note taking; audio version of books
P7	* 4 (M)	Formally diagnosed	L1CAM syndrome, cerebral palsy, wheelchair user	Preschool	AAC with eye gaze and switches, TD Snap; talking books
P8	* 22 (M)	At age 17	Autism with full support need, profound intellectual disability, intermittent esotropia, severe osteoporosis, digestive issues	Tried three public and private schools (two autism-centric, one CVI-centric), currently in a residential group home	AAC; iPad; TouchChat
P9	** 17 (F)	At around 4th grade	Severely multiply impaired, global delay, autism level 3, severe cognitive disability, multiple brain anomalies (e.g., Corpus Callosum), rare genetic anomaly, seizure (Lennox-Gastaut syndrome), organ challenges (e.g., horseshoe shaped kidney, hole in the heart), skin condition (lichen sclerosis)	11th grade; public school in life skills classroom	AAC; CCTV; Selfie camera on iPad
P10	** 13 (M)	At age 12	Intellectual disability, global coordination disorder, ADHD, ocular conditions (amblyopia of his right eye)	7th grade, regular school but separate class	iPad to magnify printed worksheets, Light table, audiobooks
P11	* 13 (F)	At eight months old	Rare genetic condition (Ogden Syndrome), cerebral palsy, seizure (Lennox-Gastaut syndrome), heart condition	Goes to a CVI-friendly school, not academic learner	Voice output switches, Cosmo switches

Table 3: Teachers' teaching background and information about CVI children they support

Teacher ID	Case load	# of CVI children	Age range	Support format	Other information
T1	Currently 20 students; teaching for 12 years	13	–	In-person, training educational assistants and teachers	Most children have multiple disabilities with significant support needs, traumatic brain injury etc. Most are non-speaking, AAC and switch users
T2	Currently 14 students at a CVI-centric school	12	3–14	In-person, direct consultation with children	Most have co-occurring genetic issues, seizure disorders, cerebral palsy, learning disorders, autism, Angelman's Syndrome, etc.
T3	Teaching at a school for children with cerebral palsy for 7 years	All	K–21	Direct consultation with children	Most are non-ambulatory, predominantly non-speaking, AAC and switch users