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## Research Article

# Parents' Perceptions of Eye-Gaze Technology Use by Children With Complex Communication Needs

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ABSTRACT

**Purpose:** Some preschool students with complex communication needs explore eye-gaze computer technology (EGCT) and adopt computer-based augmentative and alternative communication (AAC). The objective of this study was to follow preschool explorers of EGCT who are now school aged to describe the children's use of technology and parents' perceptions of its utility for communication, participation, or leisure.
**Method:** Ten parents completed survey questions by Internet and phone and reported their perceptions of nine children's effectiveness in the use and acceptance of AAC and the support they received in implementing technology. The results are reported as a descriptive study.
**Results:** All children in this research continue to use AAC technology in school and most at home. Many children who tried and obtained EGCT while in preschool continue to use that technology. Most parents agreed that the children understood how to use the devices, which enhanced the children's communication, and that the parents received sufficient support. Most children were limited in their use of the devices for leisure and control of their environments.
**Conclusions:** Computer-based AAC for school-aged children who trialed it when they were in preschool appears to be a powerful means for them to communicate and participate. However, the technology appears not to be used to its full capabilities to support the children's agency to control environments and to pursue leisure. Teams may want to consider how to support children in using their AAC devices to meet multiple needs. The study was limited by its small sample size and its descriptive nature. Additional research on this subject is needed.

Young children with multiple disabilities that significantly impede speaking and movement face many challenges in communicating, participating in daily activities, and playing. For some children, augmentative and alternative communication (AAC) in the form of eye-gaze technology can enable communication and participation by allowing them to use their eyes to select messages, play, or interact with the environment. Eye-gaze technology can range from simple (using objects) to complex (using a computer). A computer with eye-gaze technology utilizes a sensor that detects the location of the user's gaze. Users select a target picture, symbol, word, or message by directing their gaze and sustaining it on the target, blinking, or pressing a switch.

Despite the opportunities that eye-gaze computer technology (EGCT) offers to children with complex needs, there are many challenges to exploration and implementation. The eye-gaze equipment, seating, and mounting are expensive and may not be readily available, and a multidisciplinary team may be required to implement it. In addition, many children with cerebral palsy (CP) also have visual impairments (Ego et al., 2015; Lueck & Dutton, 2015), compounding the effort they must expend for engagement in intentional communication through AAC with use of their eyes.

Over the past 12 years, the authors have consulted with clinicians in exploring eye-gaze technology with children who have significant issues with communication and

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participation due to neuromotor conditions such as CP. The children were enrolled in early intervention or preschool through a nonprofit, nongovernmental agency. Interventionists introduced eye-gaze technology and expanded on children's interests through the playful, sequential use of objects (no tech), pictures and language boards (low tech), and computer technology (high tech). Some children ultimately received EGCT for communication and participation while in preschool or later.

Research on eye-gaze technology for young children with disabilities is lacking (Borgestig et al., 2021; Karlsson et al., 2018). Researchers (Borgestig et al., 2021; Hemmingsson & Borgestig, 2020; Karlsson et al., 2019) have noted difficulties with recruiting participants for EGCT studies. Karlsson et al. (2019) reported problems when attempting to use many published measures for evaluating children who use EGCT due to the particular challenges faced by the children. Emerging research suggests that children who use EGCT develop accuracy and increase time on task with practice (Borgestig et al., 2016, 2017; Hemmingsson et al., 2018), and that the children benefit from the technology by increasing communication, activity participation, and achieving individual goals (Borgestig et al., 2021; Hsieh et al., 2021, 2022; Karlsson et al., 2019). Parents seem to find that the EGCT allows the children to engage in activities that were previously impossible, and therefore, the parents could be hopeful for children's future opportunities for inclusion and participation (Rytterstrom et al., 2019).

## Objectives

The purpose of this descriptive study was to determine whether children who had tried eye-gaze technology while in early intervention or preschool are currently using EGCT or other AAC; to gather information about the current characteristics of the children; to probe the parents' perceptions of their children's use and acceptance of the technology; and to explore the parents' perceptions of the strengths and weaknesses of the support they received.

## Method

A descriptive survey study was approved by Easterseals Southeastern Pennsylvania Office of Human Research Institutional Review Board. All participants gave informed consent to participate in the study. The authors surveyed and interviewed the parents/guardians of the children regarding the children's characteristics and their use, understanding, acceptance, and independence of eye-gaze or other technology for communication, socialization, recreation, and environmental access. We used a convenience sample of parents of 26 children who tried eye-gaze technology over the past 12 years through the agency. The children's ages at the time of the first eye-gaze trials were 2.5–5 years of age. We could not locate nine families; eight did not respond to contacts; nine families participated in the survey and interview. Thus, from an $N$ of 17 contacted families, nine participated, yielding an $N$ of 9 responding families. The response rate was adequate to detect trends within our sample.

The parents completed the following instruments contained in an online survey: "Functional Outcomes of Children's Uses of Their Single Most Advanced AAC Device" (Calculator, 2014); Gross Motor Function Classification System–Expanded and Revised (Palisano et al., 2007); Manual Abilities Classification System for children with cerebral palsy (MACS, 2010); and Communication Function Classification System (CFCS, 2010), with additional questions posed by the authors. Calculator's questionnaire and the additional questions are included in Appendix A. The Functional Classification Systems are available online at no cost and were not modified except to insert the phrase "My child . . . " After completing the online survey, the parents were interviewed using a script (see Appendix B) that included the Visual Function Classification System (VFCS; Baranello et al., 2019; SMILE Lab, 2020).

The online survey probed demographics and activity participation and contained a questionnaire adapted with the permission of Stephen Calculator (Calculator, 2014). Because the Likert scale of Calculator's questionnaire contained seven response categories, we dichotomized the responses into "agree" and "disagree" in order to detect trends in the small sample size. "Agree" includes responses of all levels of agreement from somewhat to strongly agree, and "disagree" includes responses from neutral to strongly disagree. The children's functional levels in mobility, fine motor skills, communication, and vision were documented by parents completing the CP classification systems instruments that are designed to grade functional performance.

All respondents completed the survey independently on their computers, except for one who completed it independently on paper. One parent did not complete questions regarding computer-based AAC because the child does not use computer-based AAC. Therefore, in the results report, some findings were based on eight children and some on nine. The surveys, completed anonymously, took 10–15 min. The respondents finished the online survey before the phone interview so that their responses would not be influenced by their previous interactions with the authors.

The interview portion included questions about the respondent's background, the child's current educational placement, the kind of technology used currently, the VFCS (SMILE Lab, 2020), and open-ended questions about the parent's perception of the support needed and received to acquire and use the technology. Interviews ranged from 20 to 60 min. Please see Appendix B for the interview script.

## Results

### *Characteristics of the Respondents*

Ten parents/guardians participated in the investigation. In one case, a child's mother completed the survey and the father completed the interview, yielding 10 respondents for nine children. Most parents have college-level educations. All spoke English at home; two families also used other languages at home. In all cases, the language on the AAC device was English; one child also has access to another language on the device. All respondents reported living in a home with no difficulty moving the child and AAC device into and out of the home.

### *Characteristics of the Children*

At the time of the interviews, the five boys and four girls in the study ranged in ages from 7 to 16 years. Table 1 displays the children's characteristics. The children comprise a diverse group with complex medical conditions. All have movement disorders; most have seizure disorders; and some have sensory issues. The medical diagnoses of eight of the children include CP, with one child also having arthrogryposis, and one having a genetically related ataxia. Two children have mild hearing loss; according to the parents, their audiologists did not recommend hearing aids.

**Table 1.** Children's characteristics.

| Gender | *N* = 9 | % |
|---|---|---|
| Boys | 5/9 | 56% |
| Girls | 4/9 | 44% |
| Age mean | 10.2 years | |
| Age range | 7.3–16.7 years | |
| **Diagnoses** | | |
| Cerebral palsy (1 with arthrogryposis also) | 8/9 | 89% |
| Genetic disorder with ataxia | 1/9 | 11% |
| Seizure disorder | 6/9 | 67% |
| Cortical visual impairment | 2/9 | 22% |
| Hearing impairment (not aided) | 3/9 | 33% |
| **Ethnicities of children** | | |
| Asian | 1/9 | 11% |
| Black | 3/9 | 33% |
| Latino | 1/9 | 11% |
| White | 4/9 | 44% |

Table 2 summarizes the children's functional classifications. Referring to the CP functional classification systems, all of the children have significant limitations in mobility and fine motor skills. The children vary widely in their communication abilities. Some are efficient communicators and some are inconsistent or seldom effective in sending and receiving messages. Although most of the children do not have functional visual impairment, two children need environmental adaptations or adapted equipment for vision (such as high contrast, increased size, or magnification systems) as reported on the VFCS.

### *Educational Placements*

All children receive some level of special education support, with education being delivered in a variety of settings ranging from inclusive classrooms in local schools to state-approved private special education schools. About half of the children are educated in programs for students with multiple disabilities or life skills programs.

**Table 2.** Cerebral palsy functional classifications of the children.

| Gross Motor Function Classification System | *N* = 9 | % |
|---|---|---|
| Level IV Self-mobility with limitations; may use powered mobility | 3/9 | 33% |
| Level V Transported in manual wheelchair (pushed by another person) | 6/9 | 67% |
| **Manual Ability Classification System** | | |
| Level III Handles objects with difficulty; needs help to prepare and/or modify activities | 3/9 | 33% |
| Level IV Handles a limited number of easily managed objects in adapted situations | 2/9 | 22% |
| Level V Does not handle objects and has severely limited ability to perform even simple actions | 4/9 | 44% |
| **Communication Function Classification System** | | |
| Level I Effective Sender and Receiver with unfamiliar and familiar partners | 2/9 | 22% |
| Level II Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners | 2/9 | 22% |
| Level III Effective Sender and Receiver with familiar partners | 1/9 | 11% |
| Level IV Inconsistent Sender and/or Receiver with familiar partners | 1/9 | 11% |
| Level V Seldom Effective Sender and Receiver even with familiar partners | 3/9 | 33% |
| **Visual Function Classification System** | | |
| Level I Uses visual function easily and successfully in vision-related activities | 7/9 | 78% |
| Level III Uses visual function but needs some adaptations | 2/9 | 22% |

## Acquisition and Use of Technology

All parents knew that their children explored eye-gaze technology while in the agency's program. Eight of the children explored EGCT, and one child explored only low-tech eye-gaze technology in preparation for a trial with EGCT, which she acquired after leaving the agency. Of the nine children, five received their initial AAC when at the preschool agency. The speech generating technology that the children acquired included EGCT for seven children; touch-activated computer-based AAC for one child; and a non–computer-based, three-message switch, activated by hand for one child. Eight children have now used computer-based AAC for 2–12 years, with most using it for 2–6 years ($M$ = 3.3 years). Table 3 lists the children's current AAC.

Parents estimated a generally high number of hours of use of computer-based AAC per day, ranging from 5 to 16 hr per day for seven children. One parent could not estimate because the child does not use the device at home. The duration of use reported by the parents in this study is much higher than the reported use averaging 2 hr per day in the studies by Hemmingsson and Borgestig (2020) and Borgestig et al. (2021). A limitation of our inquiry is that we did not define "use" of the AAC device, and we asked the parents to estimate. All eight of the children use computer-based AAC in school, and the majority of children use the device at both home and school.

All the children are multimodal communicators. In addition to technology, all children vocalize nonspeech sounds for communication. Most use gestures, pictures, and eye pointing. About half use language boards; one uses a three-message device occasionally. About a third of the children use some speech (single words or two-word phrases). Table 4 presents the hours of use, location, and additional communication used.

Most parents agreed that they received sufficient help to implement the AAC. Parents indicated that several people helped them implement the AAC device, with speech-language pathologists named most often (77%), followed by assistive technology provider (33%), then occupational and physical therapists (22% each), or other personnel (11%). (Note that the parents could name more than one person who assisted; therefore, percentages do not total 100%). See Table 5 for details.

**Table 3.** Current augmentative and alternative communication (AAC) use of nine school-aged children who trialed eye-gaze technology in preschool.

| Total current users of AAC | *N* = 9 | 100% |
|---|---|---|
| (Users of computer-based AAC) | (*n* = 8) | (89%) |
| Eye-gaze control only | 5/9 | 56% |
| Touch activation only | 1/9 | 11% |
| Eye-gaze & touch with keyguard | 1/9 | 11% |
| Eye-gaze & switch | 1/9 | 11% |
| (Users of non–computer-based AAC) | (*n* = 1) | (11%) |
| Three-message switch, activated by hand | 1/9 | 11% |

**Table 4.** Use of augmentative and alternative communication (AAC) and multimodal communication.

| Parents' report of hours of use of computer-based AAC | *N* = 8 | % |
|---|---|---|
| 5–6 hr/day | 3/8 | 38% |
| 7–8 hr/day | 1/8 | 13% |
| 8–10 hr/day | 2/8 | 25% |
| 16 hr/day | 1/8 | 13% |
| Unknown | 1/8 | 13% |
| **Where computer-based AAC is used** | ***N* = 8** | |
| Home and school | 7/8 | 88% |
| School only | 1/8 | 13% |
| **Communication methods in addition to AAC** | ***N* = 9** | |
| Nonspeech vocalizations | 9/9 | 100% |
| Gestures | 8/9 | 89% |
| Pictures | 7/9 | 78% |
| Eye pointing (staring at something) | 7/9 | 78% |
| Language boards | 5/9 | 56% |
| Speech (single words or 2 words) | 3/9 | 33% |

## Parents' Reports on Children's Uses of Technology

All parents of children using computer-based AAC devices agreed that their child understands the device's purpose, and all reported that their child uses the computer-based AAC for educational activities. A large

**Table 5.** Implementation of augmentative and alternative communication (AAC) technology.

| Did parent have sufficient support to implement AAC? | *N* = 9 | % |
|---|---|---|
| Yes | 7/9 | 78% |
| Probably | 1/9 | 11% |
| No | 1/9 | 11% |
| **Who helped implement use of the device? (Note that parents could name more than one person who assisted; therefore, percentages do not total 100%.)** | **Responders *N* = 9** | **% who named this helper** |
| Speech-language pathologist | 7/9 | 77% |
| AT specialist | 3/9 | 33% |
| Occupational therapist | 2/9 | 22% |
| Physical therapist | 2/9 | 22% |
| Others (social worker, IT, IEP coordinator) | 1/9 each | 11% |

*Note.* AT = assistive technology; IT = Information Technology; IEP = Individualized Education Program.

majority (88%) agreed that their child values the device, seems satisfied with it, has figured out how to operate it, and uses it effectively with many people. This majority also agreed that the device enables the child to make and maintain friendships, and that it contributes significantly to overall effective communication. Appendix A presents the 23-question survey and the results.

Parents of six children (75%) reported that their child uses the AAC device for recreation or leisure. Of those children, four (or 50% of all computer-based AAC users) use the device for games. Fewer children use the device for art, music, or TV. Only two children use their AAC to access the Internet, and only one uses EGCT for social media. Table 6 lists the children's recreational uses of their devices. The responses suggest a lower use of the devices by this group for games than reported by Hemmingsson and Borgestig (2020) for a similar population, and about the same low level of Internet use as reported by Hemmingsson. In addition, most parents reported that the children in our group were not able to get to their device and turn it on independently, and they did not use their devices to control environments by using smart home technology or digital assistants.

During open-ended interviews, the parents shared what aspects of the eye-gaze trials and implementation were helpful, and which could be improved. The parents most frequently mentioned these aspects as helpful: technology support and expertise; general support for educational implementation and insurance requests; transition support by having trials with technology before entering school; and exploring options by starting when the child was young. The mother of a 9-year-old girl shared how early education paved the way for communication: "At the preschool they did an amazing job. They figured out how to understand her and to help her communicate with eye-gaze technology. She will tell us if she wants to take a shower, is hungry, wants to go to the floor or to play."

Some parents indicated that some aspects were problematic, such as communication with staff about what was happening during the trial process; length of time to complete the trial and acquisition process; and academic integration. The complexity of integrating all the aspects was reflected by the parent of an 11-year-old student: "It is all very time consuming. The time to migrate technologies, to learn technology and use it. . . . There are lots of people to coordinate; the logistics; difficulty to understand the device, and then to engage the device to carry out academic tasks. . . . " Table 7 summarizes emerging trends in parents' perceptions of helpful and challenging aspects of acquisition and implementation of EGCT. Appendix C provides samples of parental statements. This topic would benefit from further research.

**Table 6.** Recreational uses of computer-based augmentative and alternative communication devices by eight students.

| Activity | Participants, *N* = 8 | % |
|---|---|---|
| Games | 4/8 | 50% |
| Music | 3/8 | 38% |
| Art | 3/8 | 38% |
| TV, movies | 2/8 | 25% |
| Social media | 1/8 | 13% |

## Discussion

The responses by parents of children in our sample indicate that children who explore eye-gaze technology in preschool continue to need AAC when they enter school, and that most who adopt EGCT will continue to use eye gaze to access communication devices. A few children may develop fine motor skills that enable them to use touch activation through a keyguard or switch in addition to or in place of eye gaze. In our group, one child who trialed EGCT preferred to use his hands and never obtained EGCT; two others now use their hands as well as eyes. Based on our small sample, about a third of the potential eye-gaze AAC users are using their hands to some extent or exclusively to access AAC. Our sample was much smaller than that of Hemmingsson and Borgestig (2020), which found that 14% of the EGCT users used their hands in addition to their eyes, but our figures suggest that hands can be important in activation of the AAC system for some. The findings suggest that young children with complex communication needs may continue to develop physical abilities after they enter school programs. Periodic evaluation, as described by Beukelman and Light (2020), is essential to support and expand the child's current level of functional use of AAC and to revise the student's implementation plan. The Participation Model of Beukelman and Mirenda (2013) is a resource to support a systematic analysis of an AAC

**Table 7.** Emerging themes of helpful and challenging aspects of eye-gaze computer technology trials and implementation as reported by parents.

| **Helpful aspects of implementation. Respondents, *N* = 9** | **# citing** | **%** |
|---|---|---|
| Receiving technology support | 7/9 | 78% |
| General support (education, decision making, insurance) | 6/9 | 67% |
| Transition support | 3/9 | 33% |
| Starting young | 3/9 | 33% |
| **Challenging aspects of implementation. Respondents, *N* = 9** | **# citing** | **%** |
| Communication with teams | 3/9 | 33% |
| Academic integration | 3/9 | 33% |
| Time consuming, complicated process | 2/9 | 22% |

user's participation patterns and communication needs. In addition, Clinical Guidelines are available to assist teams specifically with evaluating and implementing EGCT (AusACPDM, 2021).

The use of vision in relation to EGCT is complicated for children with neuromotor conditions. Two children in the group have diagnoses of cortical visual impairment (CVI). One of these children never adopted EGCT, and the other child uses a hand-activated switch as well as eye gaze to activate EGCT. The latter child's parent reported frustration with EGCT and with the child's use of the system. The findings suggest that additional support may be needed for the child, team, and family when exploring EGCT with a child with diagnosis of CVI. Visual issues should not preclude the opportunities for trials, but teams may benefit from the support of vision specialists to identify strategies to improve the child's ability to visually access materials. Children's efforts to visually attend, discriminate, and select screen images may increase burdens to their struggles with motor control and communication. Virtually, no research has been published regarding CVI and its implications for implementation of AAC (Blackstone et al., 2021). Wilkinson and Wolf (2021) suggest that teams carefully consider complexity and number of presented symbols for children with CVI.

Computer-based AAC has contributed significantly to children's abilities to communicate, in their parents' perceptions. The wide variation of responses on the CFCS suggests that some students, even with their EGCT, struggle to communicate consistently and efficiently. Despite the reported limitations in communication on the CFCS, the parents gave positive reports when answering specific questions about their child's AAC use when responding to Calculator's questionnaire. It appears that when questioned about specific aspects of a child's communication, the parents can provide important distinguishing characteristics of their children's communication. Calculator's questionnaire may be useful for further studies of children using EGCT.

These parental responses suggest that the AAC technology has helped the children to overcome some of the challenges that they face in communication and participation. All of the children use the device for education and understand the purpose of the device. A large majority appear to be satisfied with it, understand its operation, use the device to communicate with familiar and unfamiliar people, and use it to maintain friendships.

There is some evidence suggesting many children may be deprived of some of the benefits that EGCT has to offer. For example, most children cannot access their devices independently. Children's dependency in getting to and setting up the device is not surprising given the children's significant physical challenges. Therapists could consider whether access to a device could be adapted, perhaps through environmental modifications.

Interventionists may want to consider how children use devices beyond communication. Most children are not using their devices for environmental control or the Internet access. In addition, the children are using the devices in a limited way for recreation. Less than half the children are using their devices for art, music, or social media. Computer-based AAC devices can offer independence to children who are currently dependent for many of their personal, environmental, leisure, and cognitive needs. The devices can support development of agency (Borgestig et al., 2016) and enhance quality of life (Karlsson et al., 2018) in addition to providing a means for communication. Our findings suggest that there is potential to develop greater use of devices for access to recreation, and interventionists could consider this when evaluating how the children are engaging in self-directed activities or socialization. Without access to leisure opportunities, the children are missing opportunities for "fun, freedom, fulfilment, and friendship" (Powrie et al., 2015, p. 994).

Speech pathologists are most frequently the interventionists providing support for eye-gaze technology, as reported by parents. Due to the complexity of the children's conditions, a multidisciplinary team approach is appropriate to address the many aspects of the children's needs (AusACPDM, 2021; Morgan et al., 2021). Teams could periodically probe the uses of devices and revisit issues as technology evolves, the child develops, and the needs of the child and family change. As part of periodic review, team members can collaborate to address the broader use of computer-based AAC for environmental control and leisure to meet a child's current needs. Parents and teams may not be aware that AAC devices can have multiple functions that, and if funded by insurance, devices may be "unlocked" for other uses by payment of small fees.

Generally, parents seemed satisfied with the support they received. Starting eye-gaze technology trials when the child was in preschool, being given technological and educational support, and assistance with insurance proposals were cited by parents as valuable in acquiring and implementing this technology. Parents reported that communication from the teams about the trials is essential and that the amount of time to implement trials feels long. Integration of the technology to meet academic requirements is an area that the parents frequently reported was challenging that would benefit from improved teamwork.

Limitations of this study include low sample size and use of descriptive methods to analyze responses. Parents were not given guidelines to define what constituted "use" of technology; therefore, the estimates of amount of time that the children used the technology per day may have been skewed. Children were not interviewed to verify parents' statements. All children were former clients of the researching institution, which could have influenced the way parents responded.

## Conclusions

Parents' responses suggest that computer-based AAC has a profound impact on fostering communication, social engagement, and school participation by children who have complex disabilities. The multiple capabilities of these devices appear to have the potential to be utilized further by teams and families to help children meet their needs for leisure and environmental control. As EGCT evolves and offers increasing opportunities for social interactions, practitioners need research to make meaningful decisions. The logical next step is to determine if other parents perceive similar effects of eye-gaze technology. The responses of the AAC users themselves to the same questionnaires would be helpful in understanding the users' perspectives of the benefits and challenges of the technology. Additional exploration of the supports that parents and children find helpful is needed. Determining the easiest arrangement of vocabulary, phrases and symbols on a device through a systematic investigation would assist in planning intervention. Extensive research is required to gain a deeper understanding of the potential benefits and limitations of EGCT for preschool- and school-aged children.

## Data Availability Statement

Raw data are available from the authors. Data generated and analyzed during this study are included in this published article.

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## References

**AusACPDM.** (2021). *Eye-gaze control technology for people with cerebral palsy. 2021 clinical guidelines.* https://www.ausacpdm.org.au/resources/eye-gaze-control-technology-for-people-with-cerebral-palsy-2021-clinical-guidelines/

**Baranello, G., Signorini, S., Tinelli, F., Guzzetta, A., Pagliano, E., Rossi, A., Foscan, M., Tramacere, I., Romeo, D. M. M., & Ricci, D.** (2019). Visual Function Classification System for children with cerebral palsy: Development and validation. *Developmental Medicine and Child Neurology, 62*(1), 104–110. https://doi.org/10.1111/dmcn.14270

**Beukelman, D. R., & Light, J. C.** (2020). *Augmentative & alternative communication: Supporting children and adults with complex communication needs* (5th ed.). Brookes.

**Beukelman, D. R., & Mirenda, P.** (2013). *The participation model for augmentative and alternative communication.* https://www.asha.org/siteassets/practice-portal/augmentative-and-alternative-communication/participation-model-for-augmentative-and-alternative-communication.pdf [PDF]

**Blackstone, S. W., Luo, F., Canchola, J., Wilkinson, K. M., & Roman-Lantzy, C.** (2021). Children with cortical visual impairment and complex communication needs: Identifying gaps between needs and current practice. *Language, Speech, and Hearing Services in Schools*, *52*(2), 612–629. https://doi.org/10.1044/2020_LSHSS-20-00088

**Borgestig, M., Al Khatib, I., Masayko, S., & Hemmingsson, H.** (2021). The impact of eye-gaze controlled computer on communication and functional independence in children and young people with complex needs—A multicenter intervention study. *Developmental Neurorehabilitation, 24*(8), 511–524. https://doi.org/10.1080/17518423.2021.1903603

**Borgestig, M., Rytterström, P., & Hemmingsson, H.** (2017). Gaze-based assistive technology used in daily life by children with severe physical impairments—Parents' experiences. *Developmental Neurorehabilitation, 20*(5), 301–308. https://doi.org/10.1080/17518423.2016.1211769

**Borgestig, M., Sandqvist, J., Parsons, R., Falkmer, T., & Hemmingsson, H.** (2016). Eye gaze performance for children with severe physical impairments using gaze-based assistive technology—A longitudinal study. *Assistive Technology, 28*(2), 93–102. https://doi.org/10.1080/10400435.2015.1092182

**Calculator, S. N.** (2014). Parents' perceptions of communication patterns and effectiveness of use of augmentative and alternative communication systems by their children with Angelman syndrome. *American Journal of Speech-Language Pathology, 23*(4), 562–573. https://doi.org/10.1044/2014_ajslp-13-0140

**Communication Function Classification System.** (2010). [Homepage]. http://cfcs.us/

**Ego, A., Lidzba, K., Brovedani, P., Belmonti, V., Gonzalez-Monge, S., Boudia, B., Ritz, A., & Cans, C.** (2015). Visual–perceptual impairment in children with cerebral palsy: A systematic review. *Developmental Medicine & Child Neurology, 57*(Suppl. 2), 46–51. https://doi.org/10.1111/dmcn.12687

**Hemmingsson, H., Ahlsten, G., Wandin, H., Rytterström, P., & Borgestig, M.** (2018). Eye-gaze control technology as early intervention for a non-verbal young child with high spinal cord injury: A case report. *Technologies, 6*(1), Article 12. https://doi.org/10.3390/technologies6010012

**Hemmingsson, H., & Borgestig, M.** (2020). Usability of eye-gaze controlled computers in Sweden: A total population survey. *International Journal of Environmental Research and Public Health, 17*(5), Article 1639. https://doi.org/10.3390/ijerph17051639

**Hsieh, Y.-H., Borgestig, M., Gopalarao, D., McGowan, J., Granlund, M., Hwang, A.-W., & Hemmingsson, H.** (2021). Communicative interaction with and without eye-gaze technology between children and youths with complex needs and their communication partners. *International Journal of*

*Environmental Research and Public Health, 18*(10), Article 5134. https://doi.org/10.3390/ijerph18105134

**Hsieh, Y.-H., Granlund, M., Odom, S. L., Hwang, A.-W., & Hemmingsson, H.** (2022). Increasing participation in computer activities using eye-gaze assistive technology for children with complex needs. *Disability and Rehabilitation: Assistive Technology*. Advance online publication. https://doi.org/10.1080/17483107.2022.2099988

**Karlsson, P., Allsop, A., Dee-Price, B.-J., & Wallen, M.** (2018). Eye-gaze control technology for children, adolescents and adults with cerebral palsy with significant physical disability: Findings from a systematic review. *Developmental Neurorehabilitation, 21*(8), 497–505. https://doi.org/10.1080/17518423.2017.1362057

**Karlsson, P., Bech, A., Stone, H., Vale, C., Griffin, S., Monbaliu, E., & Wallen, M.** (2019). Eyes on communication: Trialling eye-gaze control technology in young children with dyskinetic cerebral palsy. *Developmental Neurorehabilitation, 22*(2), 134–140. https://doi.org/10.1080/17518423.2018.1519609

**Lueck, A. H., & Dutton, G.** (2015). *Vision and the brain: Understanding cerebral visual impairment in children*. AFB Press.

**Manual Ability Classification System.** (2010). *Manual Ability Classification System for children with cerebral palsy: 4–18 years*. https://www.macs.nu/files/MACS_English_2010.pdf

**Morgan, C., Fetters, L., Adde, L., Badawi, N., Bancale, A., Boyd, R. N., Chorna, O., Cioni, G., Damiano, D. L., Darrah, J., de Vries, L. S., Dusing, S., Einspieler, C., Eliasson, A. C., Ferriero, D., Fehlings, D., Forssberg, H., Gordon, A. M., Greaves, S., . . . Novak, I.** (2021). Early intervention for children aged 0 to 2 years with or at high risk of cerebral palsy: International clinical practice guideline based on systematic reviews. *JAMA Pediatrics, 175*(8), 846–858. https://doi.org/10.1001/jamapediatrics.2021.0878

**Palisano, R., Rosenbaum, P., Bartlett, D., & Livingston, M.** (2007). *GMFCS–E & R: Gross Motor Function Classification System–Expanded and Revised*. CanChild. https://canchild.ca/system/tenon/assets/attachments/000/000/058/original/GMFCS-ER_English.pdf [PDF]

**Powrie, B., Kolehmainen, N., Turpin, M., Ziviani, J., & Copley, J.** (2015). The meaning of leisure for children and young people with physical disabilities: A systematic evidence synthesis. *Developmental Medicine & Child Neurology, 57*(11), 993–1010. https://doi.org/10.1111/dmcn.12788

**Rytterström, P., Borgestig, M., & Hemmingsson, H.** (2019). Hope and technology: Other-oriented hope related to eye gaze technology for children with severe disabilities. *International Journal of Environmental Research and Public Health, 16*(10), Article 1667. https://doi.org/10.3390/ijerph16101667

**SMILE Lab.** (2020). *Visual Function Classification System*. https://www.pisasmilelab.it/vfcs

**Wilkinson, K. M., & Wolf, S. J.** (2021). An in-depth case description of gaze patterns of an individual with cortical visual impairment to stimuli of varying complexity: Implications for augmentative and alternative communication design. *Perspectives of the ASHA Special Interest Groups, 6*(6), 1591–1602. https://doi.org/10.1044/2021_PERSP-21-00111

## Appendix A

Functional Outcomes of Children's Computer-Based AAC Systems

| Survey question number | Question | Parental agreement % | *N* = 8 |
|---|---|---|---|
| 1 | My child understands the purpose of this device. | 100% | 8/8 |
| 21 | My child uses device for educational purposes (math, reading, writing). | 100% | 8/8 |
| 2 | Overall, my child seems satisfied with this device. | 88% | 7/8 |
| 4 | My child is able to use the device effectively with people who are unfamiliar with him/her. | 88% | 7/8 |
| 9 | My child values the device. | 88% | 7/8 |
| 13 | My child has figured out how to operate the device. | 88% | 7/8 |
| 15 | My child uses this device to communicate with many different people. | 88% | 7/8 |
| 18 | This device has been helpful in enabling my child to make and maintain friendships with others. | 88% | 7/8 |
| 19 | When I consider the device in combination with his/her other methods of communication, it is clear the device has contributed significantly to the overall effectiveness with which my child communicates. | 88% | 7/8 |
| 3 | My child uses this device as his/her primary method of communication (vs. other methods such as natural gestures and vocalizations). | 75% | 6/8 |
| 5 | My child is more likely to be understood when he/she uses the device instead of other methods of communication. | 75% | 6/8 |
| 6 | My child is able to use device spontaneously, rather than always relying on others to prompt and encourage him/her to use it. | 75% | 6/8 |
| 14 | My child uses the device efficiently (i.e., he/she gets a point across in a reasonable amount of time). | 75% | 6/8 |
| 16 | This device has contributed positively to my child's overall quality of life. | 75% | 6/8 |
| 17 | The device has provided a means by which my child can express most basic wants, needs, and ideas. | 75% | 6/8 |
| 23 | My child uses device for recreation or leisure. | 75% | 6/8 |
| 7 | My child is usually more successful getting his/her point across with the device rather than his/her other methods of communication. | 63% | 5/8 |
| 8 | My child uses device in many different settings/ places at school, home and out in the community. | 63% | 5/8 |
| 10 | When my child uses the device, he/she is less likely to become frustrated than when he/ she uses other methods of communication. | 63% | 5/8 |
| 11 | I believe my child would be upset if device was taken away and was no longer available to him/her. | 63% | 5/8 |
| 20 | My child uses device for Internet access. | 25% | 2/8 |
| 12 | My child accesses the device on his/her own and is not dependent on others to make it available. | 13% | 1/8 |
| 22 | My child uses device for environmental control (TV, lights, Alexa). | 13% | 1/8 |

*Note.* Survey questions 1–19 adapted from Table 2 of S. N. Calculator, "Parent's perceptions of communication patterns and effectiveness of use of Augmentative and Alternative Communication systems by their children with Angelman syndrome," *AJSLP*, 2014. Used with the permission of the American Speech-Language-Hearing Association (ASHA). Copyright ASHA. Questions 20–23 added by authors.

**Appendix B** (p. 1 of 2)

Interview for Follow-Up Study on Eye-Gaze Technology

| |
|---|
| Date: |
| Subject ID # |
| Completed by: |
| **Questions about interviewee** |
| 1. What is your relationship to the child? Parent/Legal Guardian |
| 2. What is the language used at home? |
| 3. Is the language used at home the same as is on the AAC system? |
| 4. What is your educational level? [completed some high school; HS grad; completed some college; completed bachelor's; completed graduate school] |
| 5. Do you have any difficulties moving your child, wheelchair and device in and out of the home? (define any issues) steps to get into house; narrow doorways; other? |
| **Information about the child** |
| 6. DOB: |
| 7. What is your child's gender? |
| 8. What is your child's diagnosis? [CP. SMA. Lesch Nyahn. Arthrogryposis. Rett. Genetic Disorder. Seizure Disorder. Other: __] |
| 9. Does your child have any vision issues? (such as acuity; wears glasses; needs but refuses to wear glasses; nystagmus; cortical visual impairment; visual attention). Would you say your child uses visual function easily & successfully? |
| 9A. We want to know if your child needs any visual adaptations. **(Administer VFCS; SMILE Lab, 2020)** |
| 10. Does your child have any hearing issues? Wear hearing aids? Cochlear implants? Auditory perceptual problem? |
| 11. What is your child's current grade? ___ or ungraded: |
| 12. What kind of educational program is your child attending? [Full inclusion. Partial inclusion. Special education classroom full time. Special education school. Home school. Approved private school. Other: Category: MDS. Life Skills. Learning Support. Emotional Support. Autistic Support.] |
| 13. Were you aware that your child had trials with eye-gaze technology at Easterseals? |
| 14. Did your child acquire any **computer-related technology** through Easterseals (such a speech-generating device recommended by a speech pathologist)? Do not include power chairs. |
| 15. Did your child acquire any computer-related technology through another agency? |
| 16. **If yes to either of the above questions**, what technology did your child acquire? |
| 17. Think about the most "high-tech" computer kind of device that your child has. We are going to ask questions about that device. Is it eye-gaze technology; touch-activated speech generation; a computer? If the child has a device but does not use it, continue to ask questions about type of device. **[If the child does not have a high-tech device, go to Question 28 below marked FOR ALL TO ANSWER.]** |
| 18. What was the payment source (or sources) for the device? Personal Medical Insurance; School; Community Resource; Personal payment by family |
| **If using eye-gaze technology:** |
| 19. Current eye-gaze equipment name: Dyanvox Tobii I12; I15; I12+; I 15+; EM-12 or other __; PRC Accent 1200; or 1400 or ___; other: |
| 20. How long has your child owned or been assigned an eye-gaze device for personal use? |
| 21. Is this your child's first eye-gaze device? |
| 22. If no, how many devices has the child owned? |
| **If using touch-activated augmentative communication:** |
| 23. Current AAC equipment name: Dyanvox Tobii I12; I15; I12+; I 15+; EM-12 or other __; PRC Accent 1200; or 1400 or ___; Nova Chat; Other___ |
| **If using a computer:** |
| 24. What is the computer that your child uses? |
| **For all high-tech users to answer:** |
| 25. In the past week, how much did your child typically use the HIGH-TECH device each day? (in hours and/or minutes) |
| 26. Was that use at home, at school, or both? |
| 27. What other devices has he/she owned? |

(*table continues*)

**Appendix B** (p. 2 of 2)

Interview for Follow-Up Study on Eye-Gaze Technology

| **For all to answer** |
| --- |
| 28. We are going to name some low-tech augmentative communication. Does your child use any of these low-tech or ADDITIONAL augmentative/alternative communication methods as well as the high tech item? |
| 28A. Pictures |
| 28B. Language boards |
| 28C. Speech-generating devices (e.g., single message) |
| 29. Does your child use any gestures? (including head nods, reaching toward what s/he wants) |
| 30. Does your child use eye pointing (looking intently at what he or he wants)? |
| 31. Does your child use speech? If yes, words, phrases, or sentences? |
| 32. If no, does your child vocalize for communication? To “vocalize” is to make sounds. |
| 33. Do you feel that you have had sufficient support to implement the use of the technology with your child in your home and community setting? |
| 34. Who has helped you? [SLP, TEACHER, OT, PT, AT Spec, SW, NURSE, MD?] |
| 35. What has been helpful and what could be improved in this process? |
| Any additional comments? |

## Appendix C

Selected Quotes From Parents Reflecting Emerging Themes

**Helpful aspect themes**
**Technology support**

- The most helpful recently has been that the person in position of programming the academics is technologically advanced. Prior to that we did not have anyone who understood the system and my child well enough. (Mother of 16-year-old girl)

**General support**

- What was helpful for me is understanding the whole device; it really helps give the child a voice. At one time she was silent . . . she would look at TV or do nothing. (Guardian of 7-year-old girl)

**Transitioning**

- [The AAC Specialist] came to the house before our child was in pre K and that helped us know about possibilities for communication. It was invaluable to have experience on the eye gaze and to know what the roadblocks were. (Mother of 7-year-old)

**Starting young**

- From starting so young at [preschool] he was getting used to the device and it took off. He can tell all about himself. We keep adding more and more vocabulary. At school he is the student most likely to demonstrate it to other students. (Mother of 12-year-old boy)

**Challenging aspect themes**
**Communication**

- We could have had better communication. We didn't know what we didn't know. We could have used more ideas for carryover from classroom to home. (Mother of 7-year-old girl)

**Academic integration**

- To engage the device to carry out academics puts an extra step into the learning process for him to do school work. (Father of 11-year-old)

**Time consuming, complicated process**

- At first, I was frustrated because I wanted him to get a device right away. I learned that it's important to get it right and why I had to wait. (Mother of 9-year-old boy)