

Social Sciences

Caregivers' Perspectives on Service Provision in Augmentative and Alternative Communication: A Systematic Literature Review

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Alternative and augmentative communication (AAC) services are essential to improving communication skills in children with complex communication needs (CCN). Communication through whatever means necessary is essential for one to relate to the world and the people in it. By providing children with complex communication needs with alternative and augmentative communication services, they can communicate with caregivers, friends, and the public. Caregivers are key stakeholders in the process. As a result, a systematic literature review was conducted from 1985 to 2022 to determine caregivers' perspectives on AAC service provision and if there were differences during assessment or identification process (pre-service), during the implementation of services (during), and during the follow-up (post-service). A total of seven studies met the inclusion criteria. Studies were thematically coded into seven overarching themes based on the findings from each included study. Results are discussed based on the timing of the service provision. Implications and future practical and research directions are outlined. This literature review found that caregivers acknowledged challenges getting involved in the initial AAC process, finding an appropriate focus for their child's AAC interventions, promoting access and inclusion in educational settings and the community, overcoming barriers inhibiting service provision, and collaborating with service providers. These findings are particularly important for children with CCN because, to engage in the world effectively and appropriately, children and caregivers need to be equipped with all possible tools to successfully communicate.

INTRODUCTION

Communication is crucial in all educational settings and for all children so that they can share ideas and have needs met. Without communication, children cannot connect with others in their environment or get what they need. To engage in the world effectively and appropriately, children and caregivers need to be equipped with all possible tools to successfully communicate. To support communication for children with complex communication needs (CCN), alternative and augmentative communication (AAC) devices can help. AAC technologies increase meaningful participation in these children, who often have difficulties accessing written language and interpersonal communication (Beukelman & Mirenda, 2013; Newton et al., 2007). As the availability and research on AAC devices have increased during the last decade, the demand has increased for quality AAC services for children with CCN (Light et al., 2018).

However, providing an AAC device alone is not enough. Unlike most other teaching strategies, these services are needed because AAC is not just a piece of technology but an entire multisystem intervention (Moorcroft et al., 2019). In essence, AAC technologies increase meaningful participation in children with complex communication needs (Beukelman & Mirenda, 2013) by helping them access written language and interpersonal communication (Newton et al., 2007). Children with CCN, caregivers, and educators must all be taught how to use the device to facilitate interactions. In addition to the children themselves, all the stakeholders in the child's life, such as educators and caregivers, need to be trained in using AAC to increase meaningful communication for the child with CCN.

When considering AAC training, arguably the most important individuals are parents and other primary caregivers. Compared to others who

interact with children with complex communication needs, caregivers are the stakeholders that interact most frequently with the child and in the greatest number of contexts (Da Fonte, & Boesch, 2019). Thus, caregivers have the most opportunities to promote AAC usage and generalization. It is critical that caregivers be provided with AAC services to promote successful AAC usage (Newton et al., 2007).

So far, few studies have depicted caregivers' perceptions of AAC service delivery and instead focus more on experiences of service providers and the children with CCN themselves. The reviews focus on only smaller sub-issues. Saito and Turnbull (2007) identified issues of priority for families by using a specific family quality of life framework.

A few general reviews have been published concerning parental participation in AAC. Specifically, Moorcroft et al. (2019) addressed barriers and facilitators to the provision and implementation of AAC systems, particularly low-tech and unaided systems. While this article addressed barriers to AAC and discussed family members, it did not focus on caregiver perspectives. Additionally, this review focused only on low-tech and unaided systems. Furthermore, Moorcroft et al. (2019) primarily focused on the phase during service provision, or when a child is currently receiving services teaching them how to use an AAC system, and lacks explanation of pre-service and post-service phases.

Finally, Perfect et al. (2020) reviewed literature with the goal of classifying the outcomes of eye gaze assistive technology, as well as barriers and facilitators of the technology's successful uptake. This review specifically focused on children who were school-aged and looked at a range of disabilities that are associated with CCN, examined eye gaze assistive technology, and identified barriers for this type of technology. Perfect et al. (2020) recommended the importance of future research to clearly define approaches for integrating technology into the daily lives of users, as well as caregivers.

Though valuable, none of these articles singlehandedly review the multiple factors occurring during the many phases of pre-, during-,

and post-service provision of AAC devices that one needs to understand caregiver perceptions of AAC services. Based on limitations of previous studies, this literature review addresses more specific information on caregivers' perspectives on AAC service delivery. The authors hypothesize that this literature review can inform the development of services by creating a more collaborative approach with caregivers to strengthen realistic service delivery techniques. The research questions for this paper include (1) what are caregivers' experiences of AAC assessment (pre-service)? (2) what are caregivers' perspectives on AAC service delivery (during-service)? (3) what are caregivers' views of ongoing AAC supports (post-service)?

METHODS

To synthesize research on caregiver perceptions of AAC services, we conducted a systematic review of the literature using database keyword searches and a forward search of the accepted articles to identify and synthesize research evidence on caregiver perceptions of augmentative and alternative communication services. The research team examined articles of such services provided to a school-age child at the pre-service, during-service, and post-service time periods. Our review looks at relevant studies published from January 1985 through July 2022, covering 37 years. By assessing the relevant research, we were able to synthesize common themes from the perspectives of parents and caregivers of AAC users, which will be useful to the provision of services.

Inclusion and Exclusion Criteria

For an article to be included in this literature review, the article had to meet the following criteria. Specifically, the identified article had to be (1) peer reviewed; (2) an empirical study (i.e., based on observed/measured phenomena that contained new data); (3) in English; (4) published between January 1985 and July 2022; (5) focused on participants who were the primary caregivers of users of AAC (part-time caregivers were excluded). In addition, articles had to focus on school-aged children who used AAC (i.e., between 3-21 years), and the article had

to directly relate to services or service provision in the pre-, during-, or post-service stages.

Search Procedures

The search was performed in two phases. First, we conducted two database searches to cumulatively find articles published between January 1985 and July 2022 that met the inclusion criteria for this literature review. This search was conducted using ProQuest and included the key terms *augmentative and alternative communication*, or *augmentative communication*, or AAC; *family*, or *parent*, or *mother*, or *father*, or *caregiver*; *perspective*, or *outcome*, or *attitude*, or *experience*. The research team also examined each remaining article and proceeded to perform a forward-search. Thus, the team examined the initial 11 articles and examined all subsequent articles that cited these articles. From this examination, eight additional articles were produced, but none were accepted based on the inclusion criteria.

The initial database search yielded 69 articles for inclusion coding. Initially, the research team accepted 20 articles, but those articles were then narrowed down to seven articles accepted. The previously removed articles did not meet criteria because the study was not empirical, the study was not from the perspective of primary caregivers, children in the study did not use AAC as their primary mode of communication, and the AAC users in the study were not between the ages of 3 and 22 years old. Additionally, the results of the study were not about pre-, during-, and/or, post-services. Once articles were selected for inclusion in the study, they were divided into three categories for analysis of results: these categories were pre-service, post-service, and post-service. Articles could be placed in more than a single category.

Coding Protocol and Interobserver Agreement

To determine if an article met inclusion criteria, the research team first extracted data from the articles considered for inclusion. The articles were divided into three groups and each author coded one group of the articles. Later in the process, this same coding protocol was repeated with the 20 articles being considered for inclusion at the time. Following that

coding, seven articles were accepted for inclusion in the final paper.

More detailed coding was also completed to further determine the content of the accepted articles. This coding was done using the same protocol in which the articles were divided into three groups, one group for each author to code. The categories for this coding were (a) participants were caregivers, (b) child's type of disability (i.e., Rett syndrome, intellectual disability, Cortical Visual Impairment), and (c) child's type of communication system. These categories were chosen based on the characteristics of the participants in the articles.

To ensure the accuracy of these first two coding protocols, reliability was conducted multiple times using interobserver agreement. Interobserver agreement is repeated coding by multiple observers using the same coding protocols, or set of rules, to ensure that everyone agrees on how an article should be coded. Each of the three coders used for interobserver agreement reviewed a random selection of articles. First, for the inclusion coding, reliability was conducted on 30% of articles that were yielded from the original database search, reviewed by abstract, and then read in full to determine inclusion. Phase two then occurred, which involved conducting a thematic analysis on major themes of caregiver perspectives of AAC services. The research team then prepared a codebook for coding and analyzing included studies and operationally defining each theme. After this process, reliability was conducted on all articles included in the thematic coding. Interobserver agreement was determined for each subtheme that was coded. Percentage of agreement was calculated for each subtheme identified by dividing the number of agreements by the sum of the number of agreements and disagreements; that number was then multiplied by 100. Also, kappa was calculated to determine the significance of agreement. Kappa for the 16 subthemes ranged from .53 to 1.00 with a median value of .71. According to Cicchetti (1994), kappa values above .75 are considered excellent. Those between .60 and .74 are considered good, and those between .40 to .59 are adequate. Anything under .40 is poor. The large majority of subtheme

kappa values fell in the good range (Cicchetti, 1994).

A third coding protocol was used to code for the articles' themes. In this protocol, the articles were divided into two groups for two of the authors to code. The coders used observations to identify common themes and then coded the articles to identify which themes were in which articles. The coding was used to determine similarities between the results of the different articles. This assisted in determining overall results of the meta-analysis. The third author, who did not code any theme, then conducted reliability on 100% of the articles. 90.32% agreement was calculated by obtaining the kappa value. Upon initial calculations, the overall kappa for the entire coding was 0.62, meaning there was good agreement (Cicchetti, 1994). Kappa was also calculated for each individual subtheme using only the reliability coding for that specific subtheme. These individual scores ranged from 0.53 (fair agreement) to 1 (excellent agreement) (Cicchetti, 1994). Following these calculations, the three authors met to discuss disagreements and reach a conclusion. Following this meeting, the authors reached a kappa of 1 for all themes and subthemes, meaning there was perfect 100% agreement on the coding overall. Within the three stages of pre-service, during service, and post-service, there were 6 themes and 16 total subthemes. The distinction between pre-, during, and post- service was made because no article explicitly addressed service provision from the beginning to end of service. Additionally, the research team divided caregivers' perspectives into these groups to more precisely understand the parts of service to which the concerns apply.

RESULTS

Pre-Service

Four studies were included for the review of pre-service provision. Each of these studies gathered information on caregiver perspectives of pre-services for children who used AAC. Our research question focused on the caregiver perspectives of service provision, delivery, and success of AAC technology. Therefore, reviewing multiple studies

with interviews of caregivers gave us a holistic understanding of the benefits and drawbacks of communication technology. Analysis of these data resulted in the emergence of multiple important themes pertaining to pre-services. These included *caregiver stressors*, which referred to self-reported emotional challenges that influenced their acceptance of services; this could include having trouble accepting that the child had a diagnosis that involved CCN and required AAC intervention. "Parents took a leadership role in the AAC process by assuming various responsibilities such as researching and purchasing their children's technologies, using interaction strategies, educating other partners, advocating for their child's needs, and programming technologies" which means that caregivers experienced emotional discomfort and challenges with service provision pertaining to their child with CCN (O'Neill & Wilkinson, 2020, pp. 250, 13). This affects caregivers' care abilities because they are unable to best serve the child when they are unsure with what to do or are worried themselves.

This theme had subthemes *introducing AAC*, seen in Schladant & Dowling (2020), and *accepting diagnosis*, seen in Schladant & Dowling (2020) and Huer et al. (2001). Another theme was *initial AAC process*. This theme is defined as caregivers' self-reported experiences with the early stages of AAC services, including assessment and AAC system identification. The subthemes are *parental involvement* and *timescale*. *Parental involvement* was observed in O'Neill & Wilkinson (2020), Schladant & Dowling (2020), and Newton et al. (2007). *Timescale* was seen in Newton et al. (2007). These themes produced important information about caregivers' challenges with emotional struggles and access to AAC pre-service.

During-Service

There were seven studies in the during-service category of articles. The articles yielded multiple themes about during-services. They included *types of skills service address*, which refers to caregivers' self-reported views on the targeted skills through the services being provided to their child. The subthemes

are *conversational communication*, seen in O'Neill & Wilkinson (2020), and *specific communication*, which was included in O'Neill & Wilkinson (2020), Biggs & Hacker (2021), and Schladant & Dowling (2020). A second theme was *barriers to service provision*, which was defined as caregivers' self-reported perception of hurdles faced that negatively impact their child and caregivers' ability to use the AAC system or take part of the services being provided and included four subthemes. The first subtheme was *child characteristics* in O'Neill & Wilkinson (2020) and Larriba-Quest et al. (2020). These themes demonstrate that caregivers experienced multiple challenges with the different complexities and dimensions of service provision, such as types of communication and challenges with receiving services.

A second theme was *service providers*, which included O'Neill & Wilkinson (2020), Schladant & Dowling (2020), Larriba-Quest et al. (2020), Mandak & Light (2018), and Newton et al. (2007). The third subtheme was *family*, which appeared in Schladant & Dowling (2020) and Mandak & Light (2018). Lastly, *device* was the final subtheme observed in O'Neill & Wilkinson (2020), Schladant & Dowling (2020), Huer et al. (2001), and Larriba-Quest et al. (2020). This theme is exemplified by "...the mothers [who] reported challenges related to the cost, programming, and maintenance of the devices" (Schladant & Dowling, 2020, pp. 415, 7).

A third major theme included *access and inclusion* with two subthemes. This theme is defined as caregivers' self-report on the impact the AAC system may have on the child's ability to increase equal opportunities so that they have the same opportunities as their typically developing peers. The subthemes were *education* in Biggs & Hacker (2021) and Newton et al. (2007), which focuses on the school setting, and *community* in Biggs & Hacker (2021) and Huer et al. (2001), which focuses on public places other than school. These themes produced important results for during-services, including that AAC during-service can have multiple different focuses, that there are multiple different barriers to accessing during-services, and that during-services can promote access and

inclusion in education and the community. Access means that children with CCN have the same options for involvement as all their peers. Inclusion means that children with CCN will be involved with their peers socially and academically in a communicative manner. Inclusion can be increased in education systems by giving more opportunities for children with CCN to experience time with their typically communicating peers to develop friendships and overall acceptance between the children. This theme demonstrates that caregivers have concerns with the big picture impacts on inclusion that AAC is having for their children with CCN.

Post-Service

Two studies were selected for analysis within the post-service category, which analyzes caregiver perspectives of AAC services once these services are completed for their child. One major theme emerged from post-service results, and this theme was *attitude towards the future*, which was defined as the stage in which a child with CCN has received training on the AAC system from professionals and is no longer receiving AAC related services. The studies had two subthemes, the first being *independence* and the second being *belonging*. *Independence* was observed in Biggs & Hacker (2021) and Huer et al. (2001) and *belonging* was observed in Biggs & Hacker (2021). Huer et al. (2001) exemplified *independence* well by stating, "a mother noted, 'It's been helpful because before I would always have to check him ... But now that he has this little button, he can push to say, 'I need to go to the bathroom,' I don't need, have to worry'" (Huer et al., 2001, p. 202). This thematic analysis portrays caregivers concerns with long term impacts of AAC on the quality of life for children with CCN. The conclusion from these results was that AAC services work to increase a child's independence and belonging during the post-service provision stage. Operational definitions and examples from caregivers during all stages of service explain caregiver perspectives on AAC provision and its role in communication, as illustrated in Table 1.

DISCUSSION

All the studies included in this literature review analyzed caregiver perspectives of AAC, specifically regarding barriers to service provision and the importance of service provision. However, the studies failed to thoroughly investigate the holistic perspective of service provision spanning the pre-, during-, and post-service provision phases. While these themes were prevalent across the different articles, there was not one article with every theme present. Therefore, the research team cannot come to one conclusion about service provision because no article provided a full overview of the entire timeline caregiver perspectives of AAC service provision. Through this literature review, the research team discovered that by collaborating with caregivers during all phases of service provision, AAC service providers can increase caregiver confidence in all phases of the AAC process. All included articles provided comprehensive analysis of caregiver perspectives that were in line with our hypothesis. All the articles used and themes found in each article can be found in Table 1. This literature review combines all of these to provide a more complete overview of caregiver perspectives, illustrating that caregivers experience difficulty with service assessment, delivery, and supports available.

The pre-service section of the review demonstrated that parents struggled to initiate the AAC process and to receive initial AAC services in a timely manner. They also experienced challenges with active involvement in collaborating with service providers. Caregivers expressed feeling a lack of support during diagnosis of their child with CCN and when first seeking out AAC services. It is essential that caregivers have supportive collaboration with service providers so that the child with CCN can receive the most effective AAC technology quickly.

During-service analysis showed that caregivers struggled to find service providers that adequately overcame barriers and addressed important focuses to intervention to promote full access and inclusion for the children with CCN. Some barriers that caregivers faced during service provision were child characteristics, service providers, family barriers, and device barriers. Each of these

subthemes illustrates a different area where AAC service provision can be improved for caregivers and children with CCN. By collaborating with service providers that understand the individual child's needs, these barriers can be lessened. With support from AAC professionals who understand family relationships, services can be provided with a greater understanding of what is most beneficial for the children and caregivers.

Post-service analysis portrayed that caregiver expressed concerns over barriers to independent living and belonging for their children's complex communication needs in the community after the conclusion of services for AAC interventions. In other words, the focus on the post-service period is the staying power, generalization, and independent use of the AAC system once consistent intervention services conclude. The main findings for post-service include caregivers' perspectives of how services impacted their children's long-term outcomes throughout their adult lives.

Implications for Practice

Pre-Service Implications

The results indicate that caregivers may need more support than they are currently receiving during the early stages of AAC because they report personal struggles, high levels of involvement in pre-service, and a long timescale for access to AAC for their children (O'Neill & Wilkinson, 2020). Pre-service implications are significant because caregivers' first experiences with AAC services will be during the pre-service stage, and that can set the tone for how dedicated caregivers are to pursue the rest of the AAC service process for their children with CCN. Therefore, there are multiple needs that should be addressed pertaining to pre-services. Service-providers should provide emotional support for caregivers as they learn about their child's diagnosis and AAC needs (O'Neill & Wilkinson, 2020). There should also be additional advocates for children with CCN in early stages of pre-services and a more efficient pre-service process that will have shorter waits time for AAC. Overall, pre-service providers should offer more support to caregivers during the pre-service stage of the AAC process. Pre-service

Table 1. Operational Definitions of Themes Identified During Coding Based on Findings Included Studies

Theme	Operational Definition	Examples
Pre-services	The stage in which the child is being assessed for eligibility of AAC services or for an AAC system.	"Five of the seven parents frequently referred to the difficulty of having a child with special needs" (Huer, Parette Jr., & Saenz, 2001, pg. 202).
<i>Caregivers' stressors</i>	Caregivers' self-reported emotional challenges that influenced their acceptance of services.	
<i>System identification</i>	Caregivers' self-reported experiences with the early stages of AAC services, including assessment and AAC system identification.	
During services	The stage in which the child has been recommended for AAC services or has received an AAC system and is currently receiving training from a professional.	"...for David the process of receiving a VOCA took a year and during that year his parent had to 'chase up' information on the status of the delivery of the aid, receiving different—incorrect—information from people she telephoned" (Newton et al., 2007, p. 59).
<i>Type of skills</i>	Caregivers' self-reported views on the targeted skills through the services being provided to their child.	
<i>Barriers to service</i>	Caregivers' self-reported perception of hurdles faced that negatively impact their child and caregivers' ability to use the AAC system or take part of the services being provided.	
<i>Access and inclusion</i>	Caregivers' self-reported on the impact the AAC system may have on the child's ability to increase equal opportunities so that they have the same opportunities as their typically developing peers.	
Post-service	The stage in which a child has received professional training on the AAC system and is no longer receiving AAC-related services.	"For example, the values of social functioning (i.e., believing in the importance of students' having the communicative and social competence to interact with others across environments) and belonging (i.e., wanting students with complex communication needs to be known and accepted; to have valued contributions; and to be supported and befriended within communities and groups) were portrayed by all of the participants" (Biggs & Hacker, 2021, pg. 33)
<i>Outcomes</i>	Caregivers' self-reported perspectives of how AAC services may have impacted the child's outcomes.	
Collaboration	Caregivers' self-reported perception of the interaction between the family and the service providers on the provision of AAC services.	"Parents discussed positive collaborations with professionals who helped to program and modify technologies, provided training for school staff, and shared information to support family decision making" (O'Neill & Wilkinson, 2020, pg. 249)

implications are especially important for both practitioners and researchers so that each group can learn how to best support individuals with CCN. There has previously been very little research on this phase of the AAC process, so increasing knowledge about supporting caregivers in the early stages of the AAC process, specifically selecting devices, may lead to better outcomes for their children.

During-Service Implications

Due to the barriers to during-service provision identified, many AAC users are likely experiencing these identified barriers to access services. There has been more research regarding barriers related to service providers and devices than there was about child characteristics and families. Discrepancies in research may lead to a biased barriers to service provision. Getting a clear understanding of all barriers can lead to effective changes in the AAC process. Furthermore, access and inclusion for students with AAC are likely impacted for many AAC users receiving during-services (Biggs & Hacker, 2021). Access and inclusion are high-stake issues for individuals with CCN, yet are often not focused on in research about during-service AAC interventions. Lack of intervention for access and inclusion may be because practitioners are focused solely on equipping individuals with CCN with functional communication using AAC but rarely focus on the impacts of this technology on the greater issues of access and inclusion. During-services positively impact those critical aspects of a child's life. Service-providers should work to reduce the barriers to during-service provision to increase access to services for children who use AAC. This increased access to services will promote access and inclusion for individuals who use AAC.

Post-Service Implications

Based on the conclusions from the articles included in post-service analysis, there are multiple important implications. These include that independence and belonging for all children who receive AAC services for CCN will be impacted in some way by these services during the post-service stage (Biggs & Hacker, 2021). These impacts will greatly change the outcomes for a child's life, so it

is important that AAC services positively influence these domains. However, researchers often do not follow up on children with CCN who are in the post-service stage, so there is little knowledge about long-term outcomes. Having information on how AAC influences access and belonging long-term will inform effective interventions. Overall, AAC service providers should work to promote independence and belonging during post-service provision for the children to whom they provide services.

Future Research Directions and Limitations

Future Research Directions

Research should focus on creating actionable steps for providing improved AAC services to children with CCN. Interventions should be researched to determine what strategies are the most effective for assisting not only children with CCN, but also their families. Caregivers' perspectives can be used to inform that research.

Limitations

This review only included empirical articles. As a result, other types of sources that could have had valuable information (e.g., dissertations, literature reviews) were not included. This limits the scope of the findings and future implications. Additionally, the inclusion criteria required that all participants were between the ages of 3 and 22, meaning that the post-service results are limited to school age children. Much of post-service research involves adults, and we have left that research out of this literature review. Overall, there were very few articles that met our inclusion criteria for this literature review because to fit inclusion criteria, articles had direct contact with caregivers and obtained new information from them about perspectives on AAC service provision. Because of this, the research team was provided only sparse findings that could restrict the holistic approach to caregiver perspectives of service provision.

CONCLUSION

This literature review found that caregivers acknowledged challenges getting involved in the

initial AAC process, finding an appropriate focus for their child's AAC interventions, promoting access and inclusion in educational settings and the community, overcoming barriers inhibiting service provision, and collaborating with service providers. These findings are particularly important for children with CCN because, to engage in the world effectively and appropriately, children and caregivers need to be equipped with all possible tools to successfully communicate. This begins with addressing the quality of service provision for the pre-, during, and post-service phases of AAC intervention to better address caregiver needs in service provision, delivery, and support.

AUTHOR CONTRIBUTIONS

SMVE contributed significantly to the writing and editing of this manuscript as the second author. TRS and AEL both contributed to research and the initial draft.

CONFLICTS OF INTEREST

The authors have not disclosed any conflicts of interest.

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About The Author

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As a special education major, Madeline studied the perspectives of families who have a child with low-incidence disabilities in her classes. It became clear from these studies that families play a vital role in children with disabilities' experiences within special education, because they spend the most time with the child. Additionally, Madeline also studied alternative and augmentative communication, which helps children with low-incidence disabilities overcome significant barriers to accessing communication. Communicating is a crucial part of life, especially within a school environment. Madeline felt that family perspectives and alternative and augmentative communication were both very central components of the field of special education today, yet there was little research on the overlap between these two topics. This led her to complete an independent study researching that overlap. From this independent

study, Madeline produced a literature review that synthesizes the overlap in research from both family/caregiver perspectives and alternative and augmentative communication to develop clear themes about how caregivers feel about alternative and augmentative communication. This research is useful to practitioners in the field of special education because it can inform strategies used for communicating with both children and their families. This is of personal interest to Madeline as she prepares to enter the workforce of special education in the future. Understanding that her students' communication requires not only her interventions, but also the collaborative cooperation between herself, her students, and their caregivers will allow her to better teach her students and make them more successful in all settings, not just school.