

Challenges of Implementing Augmentative Alternative Communication (AAC) Technology in Multiple Disabilities After School Graduation: A Parent's Experience

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Abstract

Augmentative alternative communication (AAC) is an important component for people with multiple disabilities who have communication barriers. Many studies have focused on the implementation of AAC in the classroom but limited outside of school. This study aims to describe parents' experiences of assisting their multiple disabilities with visual impairment (MDVI) children to use AAC at home after school. This study used a qualitative ethnographic approach involving 6 parents of MDVI children with complex communication needs. The researcher conducted in-depth interviews, observations, and documentation studies. Thematic analysis using the manual data analysis procedure (MDAP) was applied in this study. 5 central themes were found in this study including parents' paradigm, acceptance, challenges, concerns, and expectations on the use of AAC at home. Furthermore, this study recommends further studies on member involvement to support communication independence through AAC for multiple disabilities post-graduation.

Keywords: *Augmentative Alternative Communication (AAC), Multiple disabilities, School Graduation*

1. Introduction

The quality of human life is determined by one's ability to communicate and build meaningful relationships wherever one is. We all need to communicate and connect with each other - not just in one way, but in many. It is a basic human need, a human right and a basic human strength (Light & McNaughton, 2014). The challenge of post-graduation life for children with multiple disabilities with complex communication needs is communication independence. Often students can communicate with their teachers at school, but not with their parents when they go home. In their research, (Patton & Kim, 2016) emphasize that one of the important things in disability education is preparing children for post-graduation. Even (Petroff et al., 2019) findings reinforce that individuals with hearing and visual impairments tend to experience a decrease in life skills to support their independence.

For Multiple Disability with Visual Impairment (MDVI) individuals with complex communication

needs, they require communication aids or tools to facilitate interaction with others (Tukimin et al., 2019). Given that they are a heterogeneous group, with different ranges of speech, language, intellectual, motor and sensory abilities that require communication supports and services that are appropriate for the type of disability (ASHA, 2016). Communication independence can be determined by providing opportunities for children to connect with communication partners who can understand interactions with educators, caregivers, families, and even the surrounding environment.

Augmentative and alternative communication (AAC) is used for individuals who cannot effectively use their natural language and is used as an alternative to engage with their community and social environment. (Simmons-Mackie et al., 2013) highlighted several factors contributing to the increase in the number of individuals requiring Augmentative and Alternative Communication (AAC): individuals with autism spectrum disorder (ASD), Cerebral Palsy, Developmental Apraxia, Visual Impairment, Deafness have increased significantly in recent years. In fact, approximately 30-50% of children with developmental disabilities in the United States are functionally unable

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to speak and require AAC. The use of AAC has been advocated to provide opportunities for students with complex communication barriers as the use of technology can be utilized at the student's own pace (Johnston et al., 2012). This model is designed to overcome these potential barriers so that students can participate meaningfully, which is influenced by students' skills, capacities, and preferences, as well as external factors, including the environment, personnel, and external support (Simmons-Mackie et al., 2013).

In line with this, (Light & McNaughton, 2012) asserted that the development of mobile technology has forced some individuals to make changes in learning strategies through AAC technology, not by choice, but because the developmental needs of children are no longer supported through symbols and the school system puts pressure to choose cheaper and more commonly available technologies. Light & McNaughton (2012) added that this type of technological change forces everyone to adapt and needs to adapt new procedures (e.g., individuals with cognitive impairments, older individuals) or who do not have access to educators to teach them AAC. Technology should ensure that communication aids reduce, and not exacerbate, disability (Simmons-Mackie et al., 2013). One size does not fit all although the use of small, highly portable technologies is a boon for some, access to support is a challenge for many (Light & McNaughton, 2012).

The successful use of AAC in the communication of children with complex communication needs is highly dependent on dynamic interactions and communication partners (Beukelman & C.Light, 2020; Simmons-Mackie et al., 2013). Communication partners in children with complex needs such as children with multiple disabilities have a vital role (Beukelman & C.Light, 2020). However, communication skills to achieve learning mastery often focus only on the child without preparing communication partners outside of school (Argyropoulos et al., 2020). If only focused on the child, it will result in cooperation between schools and parents that encourage the communication needs of students with multiple visual impairments to be not maximized. Influencing factors are not only the competence of teachers and other professionals (Tönsing & Dada, 2016), but support from family and neighborhood ((Argyropoulos et al., 2020) . Light & McNaughton (2014) assert that the achievement of children's communication competence is not only influenced by linguistic, operational, and social competence but must consider factors that hinder and support the child's surrounding environment such as family and living environment. Limited speech means conventional symbolic images or objects are very important to

facilitate communication, especially with other people with different environments (Chung & Stoner, 2016). However, poor school-parent partnerships mean that efforts are needed to prepare parents for their role in building post-school independence (Goldman & Burke, 2017). Therefore, Andzik et al.'s (2019) findings highlight the importance of preparing families as communication partners to maintain continuity of communication skills in out-of-school settings.

Previous research has highlighted disability interventions to meet alternative communication needs to support communication independence, but has been limited in addressing post-graduation life. Optimizing communication independence through learning strategies developed through AAC requires consistent personnel support in both schools and families, namely teachers and parents ((Johnston et al., 2012) . The absence of training or mentoring by schools for family members is also a challenge for families ((Hanley et al., 2022). Therefore, building a shared commitment with communication partners in the family is essential for the effective and efficient use of AAC especially for students with severe intellectual disabilities ((Dodd et al., 2015; Hanley et al., 2022; Park, 2020). The difficult part is when children leave school and return to their families. Family partners are an important part of influencing children's independence (Pacia et al., 2022) . This is challenging given that the focus of AAC interventions is not only assessed individually but is influenced by the environment and support of the family who are together every day. So this study wanted to examine the challenges of parents in the implementation of AAC technology used by post-school children at home.

2. Method

A qualitative ethnographic approach (Creswell, 2012) was applied to this study. A purposive sample was used to ensure the selection of informants was in line with the purpose of this study, which was to focus on parents who have MDVI children who have graduated from high school and use AAC at home. This study involved 5 parents living in an urban area. The researcher spent 6 weeks on the data collection process. The first stage was the field study. The researcher collected data related to the characteristics of the child, the location of the house, the tools and materials to be prepared, and choosing the right time. The second stage was data collection. Observation, in-depth interviews and documentation studies were conducted with 5 parents.

The main focus of the researcher's observations was the parents' experience of involvement with their

children when using AAC at home. There were 4 activities observed by the researcher namely; 1) social area; 2) working area; 3) eating area; 4) drinking area. Observations were made using an android camera version 13 with 64Gb storage capacity to document video, photo, gesture data. Observation results are stored in a locked file on the software and only the researcher can access. In-depth interviews referred to the guidelines that had been developed centered on the experience of parental involvement and support in the four areas under study. The third stage was data analysis. Data analysis was conducted using the manual data analysis procedure (MDAP) (Bungin & Irwanti, 2022) with reflexive thematic analysis from (Braun & Clarke, 2006, 2023). MDAP was used to analyze the interview transcripts, initial identification, coding, theme development and analysis. This procedure was also

Table 1. Overview of The Family and The MDVI Child

Informant	Child		Diagnose	Family Situation
	Gender	Age		
Parent_ 1 (FMA)	Mother_40 Sibling_17 Caregiver_50	Female/A 21	Totally Blind, Autism Spectrum Disorder, Global development delay, Hearing Disorder.	FMA is single mother, her husband passed way since Covid. Caregiver help A for daily routine.
Parent_ 2 (FMB)	Father_65 Sibling_30 Caregiver_25 Grandmother_78	Male/B 21	Visual Impairment, Hearing disorder, Autism Spectrum Disorder	FMB have divorce since B 8 old. Middle up economy. Caregiver and grand mother help B for daily routine
Parent_ 3 (FMC)	Father_45 Mother_39 Grandmother_24	Male/C 22	Totally Blind, Autism Spectrum Disorder, Global development delay, Hearing Disorder.	FMC are blind family and live with grandmother. They work as massager by call.
Parent_ 4 (FMD)	Father_47 Mother_47 Sibling_22 Without caregiver	Female /D 22	Visual impairment, Autism Spectrum Disorder, Global development delay, Hearing Disorder.	Complete family. They haven't caregiver. Father as a driver online.
Parent_ 5 (FME)	Father_39 Mother_41 Sibling_15 Without caregiver	Male/E 21	Visual Impairment, Autism Spectrum Disorder, Global development delay, Hearing Disorder.	Complete family. They haven't caregiver . Father as a cleaning service

Table 1 provides an overview of families who have children with MDVI. All of them are families living in urban areas in the capital city of Indonesia with a minimum standard income. 4 out of 5 children with MDVI are the first of 2 siblings, and the other is an only child. Interestingly, the researcher also found that both parents were totally blind to the challenges of caring for their children. All children who have graduated from school have spent 10-15 years in school. This is due to the limited choice of schools that cater for their children's education.

a. Parent Paradigm

In the opening question, the researcher asked all parents about their views when their children had graduated and returned to their families. Parents mostly

applied in (Doak, 2021). Finally, triangulation was applied to family members who live with the child, including siblings, grandparents, and caregivers.

3. Results and Discussion

Creswell (2012, p. 464) reflects the attitude taken by the researcher towards the individuals being studied. Realist ethnography is also interpreted as an objective view of the situation, usually written in the third person, reporting objectively on the information learnt from the research objects in the location. In this realist ethnographic view, the researcher reports the results of the study from the parents' perspective in assisting the use of AAC for their MDVI child who has graduated from school according to the perceptions and facts in the field when the researcher collected the data.

gave their opinions about their concerns over their children's future. Parents also painted a bleak picture of the activities their children would spend all day at home. However, all parents stated that their child is a blessing to be grateful for as a creature of God.

"...even though he is not perfect, he is here by the power of God, so we can only give the best for him" (Mother_A).

" honestly S's presence has brought fortune to our family..." (Father_C).

The concept of pity and compassion also emerged in parents. The meaning of pity is very close to the form of providing help and assistance. Parents explained that as their children grew older, their health began to decline,

so they provided more assistance in the activities their children did, including using AAC at home.

"We are not willing for our child to suffer, we are sorry to see his future. So we make every effort to provide the best service for him" (Mother_D).

"Actually, we understand that the child is smart. He understands the concept of school and at home. That's why at home children tend to want to be served and pampered" (Mother_A)

Post-graduation life is a difficult phase for both children and parents. Almost all parents expressed pity and were willing to provide assistance or care according to their ability. Even for the use of AAC for communication at home, parents also admitted that they still ignore a lot because they can't bear to see their child's condition.

"All families, both small families and large families, are very loving, although it requires extra patience." (Father_C)

My mother (grandmother) ended up staying with us, because she wanted to accompany and serve my son, because she could not bear to leave him alone while I worked outside the home (Father_B).

"We have explained to the caregiver to stimulate AAC when he eats, but the child refuses..." (Mother_D)

Factors underlying parental paradigms include past experiences, childhood caregiving experiences, birth trauma, medical trauma, and also perceptions formed due to parents' spiritual experiences.

b. Parent Challenge

AAC is designed to reduce communication barriers between parents and children during graduation. The use of this tool has been provided in schools and customized according to the child's ability. The technique of using AAC requires specialized knowledge, skills and assistance to support communication independence. The gap in knowledge and skills of using AAC tools between school teachers and parents poses many challenges for implementation outside of school. For parents in economically disadvantaged families who have to work outside the home, assisting their children requires special challenges and is not easy to do. Parents' financial limitations do not allow them the option to hire a caregiver to accompany their child at home.

".....we have to leave the house, when the child is still sleeping and return home when the child is fast asleep at night..." (Father_D)

"Honestly, it's not easy for us to be an ideal communication partner for our children nowadays, because we work and have to leave them only with their grandmother..." (Mother_C)

The involvement of family members who live in the same house is something that cannot be ignored. The task of mentoring and being the child's communication partner is not solely child-centered. Often other family members such as siblings, grandmothers/grandparents or caregivers are not given full information regarding the use of AAC.

"Post-graduation is the hardest thing for us, because family members also have to be involved for a very long time..."

"In the end, the sibling is our hope to be the child's conversation partner at home, although the sibling also has to learn a lot for that" (Father_E)

'To be honest, we have not been able to consistently implement the ideal mentoring. Sometimes I still have to fully help with activities and occasionally assisted by caregivers" (Father_B)

"Sometimes it's done, sometimes it's not. Often I am reminded to use the device /AAC that invites interaction, but sometimes I am impatient..." (Mother_C)

c. Parent Hope

The presence of AAC in the home should provide opportunities for parents and family members to avoid communication barriers with their children. However, many parents admitted that they do not have enough time to implement AAC at home. In eating or drinking activities, initiating the child to use AAC tools takes a long time until the child responds. Parents' expectations are generally the same: they want their children to be able to perform activities on their own with minimal assistance. Reports from schools informed to parents indicated that their children could do some activities independently e.g. drinking, washing dishes and bathing. However, parents indicated that this often did not happen at home. The utilization of alternative communication/AAC to support children's communication skills in the family, in fact, leads to many dilemmas.

"I don't really expect much from my child's progress, because I don't have any expectations except that he stays healthy" (Mother_A).

"We hear a lot that after graduating from school, children like this have a lot of setbacks because of their health." (Father_E)

Through the Parent Support Group many parents gave testimonies of successes and failures in the consistent use of AAC devices. However, it was stated by parents that it depends on the ability of the child who has different conditions of impairment.

"..... So I just want my child to be healthy other than that I don't expect anything. ..." (Father_C)

"Caregivers often tell me that if the child is not helped immediately, they often have tantrums..." (Mother_D)

d. Parent Concern

Talking about death was a recurring statement and a concern for all parents in this theme. Most parents are concerned about the issue of parenting. If they die first, then no one can provide care for their children, not even close family. Adult parenting is certainly not easy. For some families, they cannot hire a caregiver to help with their child's activities. They admit to providing limited information on the main activities such as eating, drinking, bathing, while the use of AAC is not informed to the caregiver.

"We don't want to burden the caregiver with many things, because finding a caregiver who is willing to help MDVI children is not easy." (Father_B)

"I often fight with my husband. I want to be strict in the use of AAC at home, but my husband says, don't trouble the child. Let the children decide for themselves" (Father_E)

Parent Recognition

In this theme, many parents expressed feelings of doubt about long-term parenting. Doubts about consistently implementing the learning outcomes during school to home including the use of AAC. Long-term care without meaningful activities outside the home is not easy to do. But in the end, parents understand that whether they are ready or not, they have to accept the fact that their children will be with them in the long term.

"I don't know where to start, it's very difficult for us to start the same thing as what we were taught in school. (Mother_A)

"Children know the school programme and activities at home. The concept at home is to rest and play. So it's difficult for us to teach the child consistently. He thinks AAC is part of learning at school not at home..." (Father, E)

Parents are often confused when it comes to choosing leisure activities. Whether they realize it or not, most parents choose to stay in their comfort zone by not providing many activities to avoid tantrums. The use of ACC in key activities such as eating, drinking, working and leisure is often neglected because parents are confused about how to do the same things as they do at school.

"I once forced it, but the child rebelled, eventually the tool was thrown and broke during a tantrum" (Mother_A).

"Honestly, I still doubt my child's ability, so I sometimes reflexively help..." (Mother D)

The first important finding of this study is that parents need to prepare their children to graduate from school. Learning cannot only prepare the child, but also the parents. Preparing parents for their child's transition to graduation is important so that the AAC learning can be done consistently by the child and family when they graduate. This preparation takes time, as parents must be involved by the school in planning the transition programmed. For example, in the AAC programmed, parents need to be involved in all stages of preparation, namely assessment of children's abilities, building expectations, developing programmers, evaluation, monitoring AAC implementation activities both at home and at school.

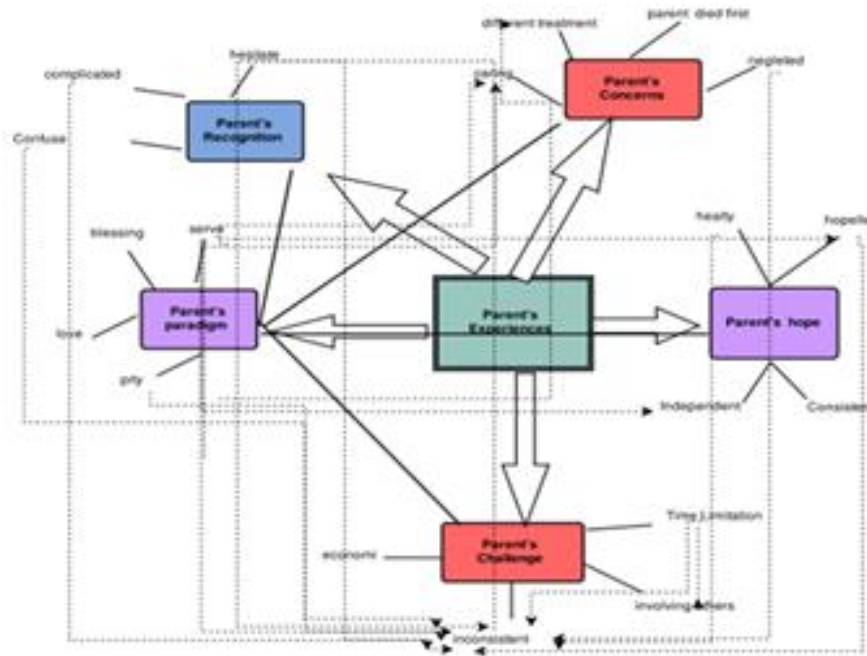


Figure 1. Diagram of Findings on Parents' Experiences of Using AAC After Graduation

Secondly, Figure 1 shows that the use of AAC in MDVI children after graduation is not just a technical issue, but it raises many issues for parents. Parents' paradigms of their children determine how they treat their children at home. Parental paradigms are closely related to parental challenges, concerns, acceptance and expectations. Inconsistent treatment in applying AAC to post-graduation children is strongly related to the paradigm that parents have built from the beginning. Table 2.1 shows the relationship between the absence of expectations, the desire to provide services, the confusion of parents, the complicated problems faced by the family, and the economy, which has a great influence on parents' inconsistency in applying AAC to their children. Thirdly, independence, which is the family's expectation for their children after graduation, is not explicitly shown in the consistent treatment of their children. For this reason, it is necessary to build a joint agreement from both the school and the family on the achievement of children's independence to be achieved when they graduate.

Fourth, the key to communication is consistency. The concept of continuity in the use of AAC as a communication aid for children must be understood as an effort to independent children's communication not only at school. Fifth, AAC is not just a communication aid, but should be understood as a means of strengthening the attachment of parents and other family members. Through AAC tools, emotional connections

between family members are built so that MDVI children will feel "accepted" and not excluded. Although it must be recognized, the implementation of AAC at home requires clear stages from the beginning of its use and communication partners who understand the characteristics of the child. Economic dilemmas, work routines outside the home, substitute caregivers need to be emphasized in this section.

4. Conclusion

The use of AAC as an alternative communication tool for MDVI children after graduation requires a long and gradual preparation. The preparation should involve parents as the main communication partner who will be with the child for a long period of time at home. Connectedness between family members to be involved from the beginning of the preparation for the use of AAC is needed at this stage. The success of AAC use does not depend on the amount of technology or the limitations of the child using it, but on the communication partners who consistently use it together with the child. A limitation of this study is that it did not explore the programmers that schools have prepared for parents to use AAC after school. The researcher recommends an in-depth study of strategies to encourage the involvement of family members for the use of AAC at home after graduation.

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