“You just want to be able to communicate with your child”

Experiences of Parents of Beginning Communicators on the Autism Spectrum Who Use AAC

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Background

- Approximately 25-30% of young children on the autism spectrum are unable to rely on speech to meet all their communication needs (Kasari et al., 2014)

- Augmentative and alternative communication (AAC) such as pictures, manual signs, and apps with voice output can provide a means of communication for children with limited speech (Beukelman & Light, 2020)

- Evidence has shown that AAC supports communication skills in young children on the autism spectrum without negatively impacting speech (Ganz, 2015)
  - Requesting
  - Protesting
  - Vocabulary
  - Social interaction
Background

- Supporting AAC implementation within daily life can help maximize opportunities for learning and for successful interactions (e.g., Parette, Huer, & Brotherson, 2001)

- Parents are often key communication partners for young children on the autism spectrum

- To date, we know little about their experiences and needs relative to their child’s communication and use of AAC.
Research Question

What are the experiences of parents of children on the autism spectrum who are beginning communicators relative to communication and AAC? What are the challenges and supports?
Design

- Phenomenological qualitative design (Creswell, 2013)
  - Understand and describe the essence of a phenomenon (e.g., parents' lived experiences)

- Data collection:
  - Virtual interviews conducted via Zoom (7 participants)
  - Asynchronous online focus group and virtual interview (1 participant)
Participants: Parents

- Recruited via informational flyer

- 8 respondents met inclusion criteria and consented to participate
  - Gender
    - 6 female; 1 male; 1 did not report
  - Relationship to child
    - 6 parents; 2 grandparents (interviewed together)
  - Education
    - 2 had some college; 2 had a college degree; 2 had an advanced degree; 2 did not report
  - All spoke English
Children

- Diagnosis of ASD (parent report)
- Age range: 3-8 years
- Not yet using a variety of phrases or sentences generatively
- Use some form of AAC
Materials, Procedures, and Data analysis

- Semi-structured interview guide (Brinkmann & Kvale, 2015)
  - 14 questions about child, communication, and AAC

- Interviews transcribed by the first author (Vaughn, Schumm, & Sinagub, 1996)

- Thematic analysis conducted to identify themes and patterns (Braun & Clarke, 2006)
Note: Some parent quotes have been edited for clarity
Daily life, family, and community

Communication:
Description, challenges, and impacting factors

Implementing AAC to Support Communication

3 Themes
Theme 1: Daily life, family, and community

Parents described making enormous efforts and personal sacrifices to ensure the best life and outcomes for their child and their family, including taking on roles above and beyond those required of most parents.
"I was at one point teaching and have left that to take care of my family and my kids, and I now work through the state to take care of my son, in keeping him out of homes or having caregivers from the state come in and take care of him because of the demand of how much care he needs."

“We’re doing all the training instructions and overseeing, and making sure that they’re doing what they’re supposed to be doing, and if they’re not then, you know, we’re...we’re stepping in and re-training or re-teaching something or telling them no, you cannot do that with him.”

“I had to teach myself and husband sign language to then be able to teach our son.”

“Um, so I literally moved to (state) for services.”
Theme 1: Daily life, family, and community

Despite these efforts, parents worried about their child's future.

“We are their voice. You know, we need to be able to help them now so they can help themselves in their own future. And I freak out when I start thinking about it too much but I’m like, you know, what happens if something were to happen to me tomorrow, you know, what would happen to my son?”
Theme 2: Communication

Parents uniformly described communication as a priority.

They described communicative interactions that included use of multiple modalities on the part of both child (expressively) and parent (input). Children often used innovative and sometimes unconventional strategies to get their message across.
Theme 2: Communication

“(Child) does have an abbreviated sign and it’s because he’s abbreviated it as his own way of saying “please,” and he goes like this (demonstrates).”

“Or if we tell him something and we’re sitting here and he says, you know, we tell him oh good job. We’ll sign good job. As we tell him good job. We will sign it. So we’re constantly doing one of two things to see whatever he’s gonna pick up on.”

“…but he’ll take scripting that he hears elsewhere and he uses it…Sometimes it’s just random but there are times where he’ll answer you or something, or ask you something appropriately based on something you’ve seen.”
Theme 2: Communication

In spite of these inventive solutions, parents also described substantial child communication difficulties that have a negative impact on the child, the parent, and communicative interactions.
Theme 2: Communication

“Um, and so that is most of (child)’s communication, is rote memorization. Very little spontaneous. It has no meaning, it serves no purpose, so there’s no wants, needs, requests, anything like that.”

“...and then we kind of go through the laundry list of ok, what do you want? Do you want this, do you want that, you know, trying to guess and figure out what she wants.”

“Lack of communication leads to behaviors and behaviors are then a form of communication for my lil man who has no other way of expressing what he means.”

“You know, it’s just constant just, worry and frustration. I don’t know what’s wrong with my kid, to help him.”
Theme 3: Implementing AAC

AAC holds promise and supports communication in many ways, but it is often difficult to access, learn, and implement.

Parents expressed a need for help and guidance to be able to support implementation of AAC with their child.
“And a lot of it’s coming down to insurance. And insurance not wanting to pay for it...it’s almost like that disconnect between insurance companies...not understanding what all the experts say about early childhood. Start them young. Get them in there learning young. Get them in there, you know, learning to love to read and love to write, and everything in preschool. Preschool, preschool, preschool. The first five years are so valuable. And they say the same thing about autism, the earlier you get them in, the earlier you get them therapies, the better off they are throughout life. But yet, we’re not gonna allow you to have an iPad. To speak. We’re not gonna give it to you cause I don’t want to spend the ten grand, but at the same time I’m willing to spend how much in psychiatry, and medication, and therapy bills for family and everybody else because - or even hospital bills for when he’s so aggressive because he can’t talk.”
Theme 3: Implementing AAC

“PECS was such a struggle for our little man as he thought of the pictures as an object and not a visual representation of something he wanted/needed.”

“And, you know, getting up and getting the PECS book at 3 in the morning is not happening. You know. It’s not gonna work.”

“And then it needs - so you go from basic, there needs to be basic, intermediate, and advanced using. That all comes with a lesson! That you’re not learning on your own. Yeah. Like I don’t need to learn this on my own. It’s too hard.”
Researchers, AAC manufacturers, healthcare professionals, and educators need to be aware of parents’ lived experiences.

AAC system design and communication/AAC instruction must consider the context in which communication is occurring and the challenges and needs of children as well as their parents, who are key communication partners.