Parent Approaches and Recommendations for Supporting Adolescents and Young Adults who use AAC

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Disclosures

Relevant financial Relationship

Dr. Hajjar is a salaried full time employee of Ithaca College
Dr. Sanders is a salaried full- time employee of Moravian University
Dr. Seale is a salaried full time employee of the University of Wisconsin/Waisman Center

Non-Financial Relationship
Dr.Hajjar, Dr.Sanders, and Dr. Seale do not have any non-financial relationships relevant to the content of the presentation.

Introduction/Literature Review
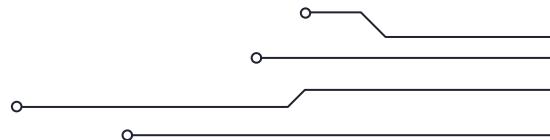
Importance of Parents and Caregivers (Beukelman & Light, 2020)

Parents and caregivers of individuals who use AAC have a significant, long-term role in a variety of aspects related to communication, participation and engagement in the lives of their children.

Research: Kim & Soto, 2023

- Scoping review; found 27 qualitative studies that focused on the experiences and perceptions of families supporting AAC implementation
- 3/27 studies involves AAC users 18+; 13/27 studies involved adolescent AAC users
- Key findings:
  - Disjointed AAC service provisions
  - Parents & caregivers are primary partners
  - Parent input during assessment & selection process is critical for full AAC adoption
  - Caregivers: closest and most important

Research: McNaughton et al., 2008

- 7 parents of individuals with cerebral palsy who use AAC, ages 6-30.
- Focus group online for 9 weeks
- 6 primary themes:
    - Selection of AAC technology
    - Knowledge and skills to use AAC technology
    - Barriers to learning AAC
    - Teaching the individual
    - Educating society
    - Recommendations to others
- Parents reported:
    - frustration when obtaining AAC services
    - engaging with professionals who were unfamiliar with AAC
    - missed opportunities for learning and communication
    - a need for improved training for professionals

Aim of the Research Study

To gather the lived experiences from parents of adolescents or young adults who use AAC with particular focus in how they approach participation, communication and finding support.

This presentation will focus specifically on how parents approach supporting their children through life transitions

Methods
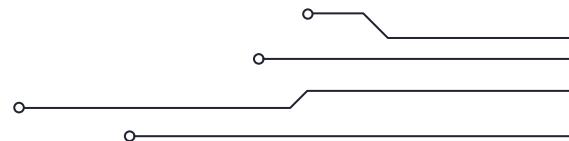
Procedures

Parent recruitment via invitations to participate in research posted on web-based forums and listservs (e.g., ASHA SIG 12).

Screening and intake questionnaire sent to participants who consented to participate

Semi-structured interviews via Zoom later analyzed with Applied Thematic Analysis (Guest, McQueen, & Namey, 2011)

Parents

Parent Initials	Role	State	Race	Education	Income*	Job Status
B&N M	Parents	NY	White/Caucasian	Associate's Degree	Low	Employed
DJ	Parent	NY	Multi/Biracial	Doctoral Degree	High	Employed
GA	Parent	WA	Asian	Master's Degree	High	Unemployed
MK & SC	Parents	NY	White/Caucasian	Bachelor's Degree	High	Employed & Unemployed
RB	Parent	FL	White/Caucasian	Bachelor's Degree	-	Unemployed
TC	Parent	PA	White/Caucasian	Master's Degree	Middle	Employed
CL	Parent	FL	Asian/Pacific Islander	Associate's Degree	Low	Employed
CJ	Parent	PA	White/Caucasian	-	Low	Employed

*Annual household income is based off of the following: High ($100,000+), Middle ($50,000-$100,000), Low (<$50,000)

AAC User

| AAC User	Gender	Age	Medical Diagnosis	School or Work	SGD	Funding for Device
Leo	Male	16	Autism	School	iPad	Private Pay
Nate	Male	15	Chromosonal Abnormality, Autism, Developmental Delays	School	Accent	Private Insurance
Sarah	Female	14	Autism, Intellectual Disability	School	iPad	Private Insurance
Owen	Male	14	Cerebral Palsy	School	iPad	School & Private Pay
Rita	Female	28	Schizencephaly	Unemployed	Accent 1400	Insurance
Mitch	Male	26	Cerebral Palsy	Work	Tobii Dynavox Maestro	Medicaid
Steph	Female	24	Cerebral Palsy	Unemployed	I-110 Tobbi Dynavox	Medicaid
Mike	Male	28	Partial 9q Trisomy	Unemployed	iPad	Medicaid Waiver

Data Analysis

Systematic and iterative analysis of 8 interview transcripts using the principles of Applied Thematic Analysis

- Data Familiarization
- Independent Coding to develop primary themes (3 coders)
- Iterative process: Generating, refining, reviewing, naming and defining themes (audit trail; consensus coding)

Descriptive data collected via intake/screening questionnaire.

Results
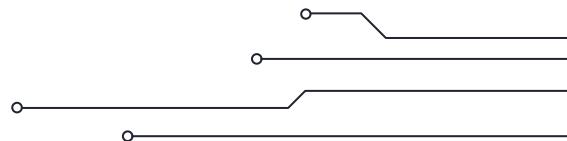
Results: Primary Themes From the Data

- AAC User
- **Parent Approach**
- Challenges & Barriers
- **Supports**
- Aided AAC
- Participation

Primary Theme: Parent Approach
7 Subthemes

- Communication
- Participation (independent living, vocation, recreation)
- Continuing education & resources
- AAC systems
- Professionals
- Advice & recommendations
- Parent characteristics

Quotes: Subtheme #1
Communication

Sometimes people will ask a quick question and he won't have any idea so we will repeat the question somebody asked… do you want this or something else you know, to try to get him to the understanding part. So he can function more by himself. (parent NM)

We put together sentences and all of the sentences would be programmed into button, so that he could click on one button and it could do a whole sentence, which is obviously much more efficient than having to type them out letter-by-letter. (parent SK)

So after like she does her morning like brushing teeth and stuff, I find that I can spend about a few minutes, with her talking about the previous day and... So when I say talking about, I am talking verbally and modeling on low tech and high tech AAC. (parent GA)

Quotes: Subtheme #2
Participation

What we did is we figured out our own situation so that he could live independently, with support. So about 15 years ago we purchased another house and it's right here in our neighborhood. It's actually right next door to this one…so the plan is for us to move to that house when XXXX is ready to live independently and you know completely have us fade out as primary caregivers and have him have staff, that he's already directing a staff but we're always here so it's. But we have had a plan that we've been working on for two years." (parent TC)

Quotes: Subtheme #3
Training, Education, & Resources

Several times, we were able to go in and actually once a month. it was you know, I stand behind, I do not try to be in their way. Honestly I'm really there just to learn and so and it just helps you know again so I can work with him at home (parent BM)

Everything else we use at home, we have bought out of pocket. It's a lot of this infrastructure that we have at home that we've bought. And we've spent a lot of money trying different things. (parents MK & SK)

Quotes: Subtheme #4
AAC Systems

Not being discouraged…I think it's easy as a parent, home life is so busy that you feel like you are not integrating the device enough, or feeling like you know, you're just not adequate at what you're doing so any sort of little moment that you can integrate it is a win. (parent DJ)

That was one reason I was keen to move her to is like a high tech system, which is more universally understood by everybody. (parent GA)

Quotes: Subtheme #5
Professionals

So when we were in person, it was a lot easier. I'm from the South originally so we do this thing where we win them over with Southern charm, and I would always bring tons of food to IEP meetings, and you would not believe how well that goes over. (parent DJ)

I think from my experience, I feel like what I did with the connecting the private and school therapist that is one very important piece, I found that. It makes life easier for us, if the school team is willing to collaborate in that sense, but I feel I have always found them open to wanting to know about what else is going on at home or in private therapy. (parent GA)

Quotes: Subtheme #6
Advice & Recommendations

We need to educate the public that you know we as parents, we shouldn't answer those questions, especially if we know that our child's capable of answering. (parent CL)

Don't leave it up to other people to suggest it, or don't leave it to chance, insist upon it, help facilitate it. (parent TC)

Not being scared to reach out, you know you're not supposed to be an expert, and know everything, and so getting help from other people. There's no shame in that and just do it, and don't be scared to make mistakes, you know, like I realized now all the mistakes I made along our AAC journey. (parent DJ)

Quotes: Subtheme #7
Parent Characteristics

I know we're a little lucky with the technology and that SK is very techie. So he can.. glitches are a big problem for us, and he can do that. (parent MK)

I consider myself to be a pretty resourceful person in finding, you know, and finding, you know things (parent DJ)

My background is as a teacher, but II was very, very fortunate. I was able to be a stay at home parent. Not many people are able to do that. I was able to do that (parent CJ)

I have a research background, I did my masters in biotechnology and had to quit my job. I'm always surprised that they don't know as much as I do, I think it's more my interest that has, it has led to me knowing so much about and and trying to be current with what is going on. (parent GA)

Primary Theme: Supports
5 Subthemes (preliminary themes)

A. Professional services
B. Online groups & resources
C. In-person groups & resources
D. Perspectives from caregivers & AAC users
E. Funding: foundations, waivers, & private pay

Quotes: Subtheme #1
Professional Services

We're really lucky. We've had great SLPs along the way. We were really lucky to get an OT who is part of the school district who has just really been an incredible advocate for all of our communication, and she really gets his body and how like position him for his better head control (parent SK)

Yes, I have a private OT, a private speech therapist and private physical therapist. (parent GA)

He would have speech therapy at a, like it's called a children's institute here, it's like a very comprehensive therapy center plus he had early intervention publicly funded from the state, and he had like the full complement of therapies he had yes/no buttons (parent TC)

Quotes: Subtheme #2
Online/Remote Groups & Resources

There's a lot of stuff online. I see a lot of training online now. If you get a system and go to that device website, they have video training and things like that. (parent CJ)

It's so great because now there's all of these groups and resources that weren't there, when my fellow was kind of coming up. So you have all these Instagram and Facebook groups that didn't exist back then (parent DJ)

I am on the Facebook group for Proloquo2Go, on a telegram group for the Avaz app that I was talking about earlier. The comprehensive literacy for all book study group. (parent GA)

Quotes: Subtheme #3
In-Person Groups & Resources

Well, in the past I think they all were, I'm not sure about that, but they would come out and offer you would set up classes and the DynaVox rep would come out and teach classes. (parent CJ)

When we lived in the Phoenix area there was a lot more support groups and activities and things like that where you were able to connect more in person (parent DJ)

Quotes: Subtheme #4
Caregivers & AAC Users

I find myself always talking to other parents of children who use AAC (parent GA)

It's all AAC users, they can talk about anything they want. And it's young adults, and so they mentor each other and what they talk about (parent TC)

# Quotes: Subtheme #5
Funding

I got through a grant through the the Helen Keller Foundation. (parent DJ)

I consult with her through something called the DDA that gives funding, it's called the DDA, the developmental disabilities administration, they have services and they have funding for it's through the state. So they have funding for children with disabilities, children or adults with disabilities and through those services. (parent GA)

With an organization (adult waiver program) it's a big disability organization, but they have a home care component, they are going to run his home, this home that we're in right now (parent TC)

Let me add one more resource and that's VR, I forgot to mention, VR does pay for some things and would pay for more, if we choose to go there (parent TC)

Discussion
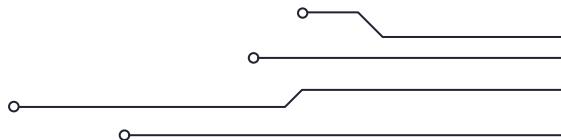
Parent Approach: Discussion

- **Communication:** creating opportunities, supporting literacy, letter by letter vs. whole phrase, educating partners(peers, teachers, etc.),

- **Participation**: independent living, vocational support, finding meaningful opportunities for social and leisure activities

- **Resources**: reaching out to experts, going to conferences, networking with other parents, being open to a range of sources

- **AAC Systems:** being open to multiple systems, flexible with different types of systems, having back up systems, holding on to older systems, troubleshooting

- **Professionals:** being mindful of professionals' time, prioritizing requests,

  creating a community with the AAC team

Parent Approach: Discussion

Advice & Recommendations: range of ideas and advice; promoting independence, focusing on team approach, transitions through school and post school

Parent characteristics: financial resources, being pro-active, highly educated, ability for one parent to stay home, interest and skill in using technology, living in resource rich communities

Supports: Discussion

Professional services: parents in this study frequently discussed skilled professional resources and institutions, supplementing with additional therapy via private pay, accessing clinics in higher education

Online & in-person resources: camps, specialty programs in higher education, SGD vendor company workshops, online groups for networking for parents and AAC user, increase in online learning & social opportunities

Perspectives: valuable to communicate with other parents & AAC users

Funding: a diverse stream of funding sources to support independent living, vocational paths, and AAC systems
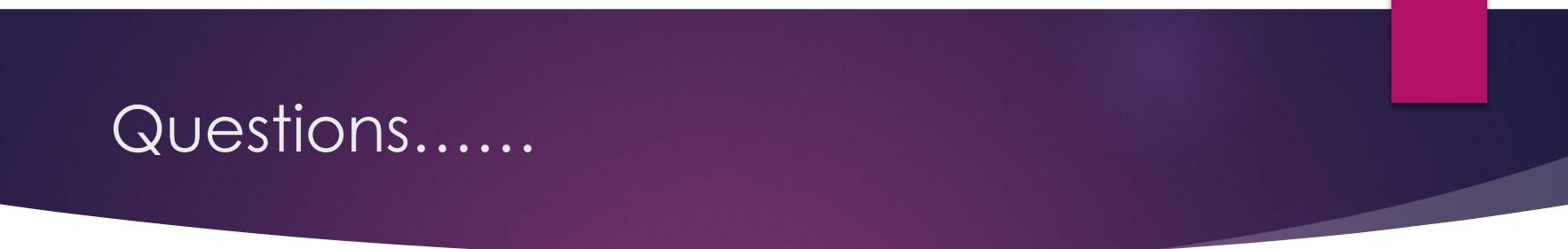
Questions……

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