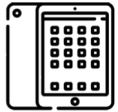


## Objectives



What are the experiences of parents of young children with complex communication needs related to supporting their child's communication with a speech-generating device (SGD)?

## Method

Semi-structured interviews ranging from 25-118 minutes ( $M= 58$  minutes)

Descriptive qualitative design strongly influenced by phenomenology to focus on lived experiences



## Participants

The full sample includes 14 mothers of children with complex communication needs ages 3-6 years old who use or are learning to use an SGD. **The presented sample includes 5 of those mothers.**

## Experiences of Families

### Getting the device

#### Initiating the process

*Related to who was involved in starting the process to acquire an SGD*

- Having an AAC<sup>1</sup> 'finder' (e.g., speech therapist, device consultant)
- Parent/family

#### Navigating the process

*Related to the challenges and facilitators associated with families' experiences when acquiring an SGD for their child*

- Starting 'early'
- Being told to wait
- Encountering delays
- Facing others' perceptions of the child's ability
- Finding the right device

### Supporting communication

#### Knowing how to support communication

*Related to the ways parents have learned or have been trained how to support their child's communication, including the ways in which this comes naturally*

- "The instinct of being a mom"
- Training/learning
  - Operating the device
  - Interaction strategies
  - AAC intervention techniques
- Utilizing field-related, professional knowledge

#### Trying to use the device

*Related to parents' description of how they communicate with their child and extent to which they use the device for a variety of purposes*

- Not using the device at first
- Using more speech and gestures than the device
- Using the device
  - For learning, play & exploration
  - In different routines and activities
  - Outside of the immediate family
  - To clarify meaning

#### Confronting device challenges

*Related to the various challenges parents have come up against while using the device*

- Breaking
- Technology & operational
- Stimming

#### Advocating

*Related to parents' role in advocating for their child*

- Initiating AAC-related supports with professionals

#### Making progress

*Related to parents' perception of their child's progress in several areas after learning how to use an SGD*

- Words/language (speech & AAC)
- Intentional communication
- Social engagement
- Frustration and behavior

<sup>1</sup>Augmentative and Alternative Communication

## Attitudes of Parents



### Sarah

White, married, mother of a 4 year old child with global developmental delay and childhood apraxia of speech  
Works part time as an allied health professional  
Average annual income \$100,000+

"[He] has three speech therapists, two OTs, and two teachers at school, but he only has one mom or one dad...I try to like take the pressure off myself that way"



### Amira

Black, divorced, mother of a 5 year old child with autism  
Works part time as a caregiver  
Average annual income <\$10,000

"Whatever will help my son...whatever will improve his life, I'm ready for it. / I just want what's best for him"



### Lorraine

White, divorced, mother of a 5 year old child with autism and a genetic disorder  
Works full time in the food industry  
Average annual income \$40,000-49,999

"I wouldn't say I'm stepping back...I'm always trying to do the things the therapists recommend. I just can't be as intense about it as they are, I just can't"



### Ynez

Latinx/Hispanic, married, mother of a 6 year old child with Down syndrome, developmental delay, and mild hearing loss  
Works full time as an educator  
Average annual income \$100,000+

"I am a special education teacher...and it was overwhelming. I still get stressed about his device, that we're not doing it right, that we're not good enough"



### Carolyn

White, married, mother of a 4 year old child with Down syndrome and autism  
Works full time as an allied health professional  
Average annual income \$100,000+

"I'm always the one that's asking for new things...I was the one to bring up the device in the first place. / I feel like I do everything in my kids' lives. / It's just exhausting. But that's parenting, right?"

## Emerging Findings

- 1 Though there were some common themes, families had widely diverse experiences in obtaining an SGD.
- 2 Parents described feeling overwhelmed by all that comes with learning how to use the device and implementing it into their daily lives.
- 3 Several parents explained the difficulties of navigating their role in their child's learning and emphasized not wanting to be their child's therapist.
- 4 Despite challenges, parents highlight the positive impact the device has had in their child's life.

