Supplemental Material S2. Codebook.

THEME 1: INTEGRATING AAC INTO LIFE: Describes the challenges/realities or supports/success stories of using AAC (unaided or aided) either within the family (at home, with family members) or outside the family (in school or community, with partners who are not family members).

<u>Subtheme 1.1: Integrating AAC into family life</u>: Describes the challenges/realities and supports/success stories of how AAC fits into relationships within the immediate family (e.g., with parents, siblings, extended family) AND how AAC fits into family routines that occur at home.

Code	Definition	Example data
Integrating AAC	Describes the supports and success	He [brother] learned quite early on
family supports	stories of using AAC in	how to use the book as a
(and success	relationships within the immediate	communication partner, and things
stories)	family and within family routines	like that
Storres)	at home. This includes people	tine their
	coming into the home to care for	
	the child (e.g., sitters, home care	
	aides, nurses). For example:	
	• successful use of AAC with	
	family members	
	• successful use of AAC within	
	various routines at home	
	• Use of multiple modalities (e.g.,	
	low tech symbols around home)	
	• Supports for family functioning,	
	such as other families, online	
	forums, and respite care	
Integrating AAC	Describes the challenges and	So some activities that we do, I
family challenges	realities of using AAC in	don't incorporate AAC. For the
(and realities)	relationships within the immediate	simple fact of, if we're doing
	family and within family routines	something really physical, I can't
	at home. This includes people	do it. On the bike, I try to do things,
	coming into the home to care for	because she has to hold on, and she
	the child (e.g., sitters, home care	really grips it. And so I will use it
	aides, nurses). For example:	just for modeling, or I'll have the
	• Little use of AAC with some	taking bricks where she can say
	family members	stop and go.
	• AAC not available within all	
	family routines at home (e.g.,	
	morning care routines, bedtime,	
	when out of wheelchair)	
Integrating AAC	Description of important people in	
family description	family or family routines, that does	
	not include a discussion of AAC or	
	the barriers/supports.	

<u>Subtheme 1.2: Integrating AAC into school and community</u>: Describes the challenges/realities and supports/success stories of how AAC fits into relationships with individuals outside of the immediate family members (e.g., paraprofessionals, medical professionals, peers, friends, instructors, teachers), and in settings/contexts outside of the family context (e.g., school, community).

Integrating AAC outside supports (and success stories)

Describes the supports and success stories of using AAC with individuals outside of the immediate family members (e.g., paraprofessionals, medical professionals, peers, friends, instructors, teachers), and in settings/contexts outside of the family context (e.g., school, community). This includes:

- Successful use of AAC with various partners (e.g., care aides, paraprofessionals, teachers, peers)
- Using multiple modalities (e.g., low tech board during swimming, unaided AAC, backup system)
- Partners use interaction strategies (e.g., modelling)

They hook the nova chat up to a big tv now that's in the classroom.
They'll have conversations with him and they'll say, "where do you want to go?" The therapist will hit it, and then he'll have to respond back, so they are modeling, and he responds. And I guess that's like amazing and that's working really well.

Integrating AAC outside challenges (and realities)

Describes the challenges and realities of using AAC with individuals outside of the immediate family members (e.g., paraprofessionals, medical professionals, peers, friends, instructors, teachers), and in settings/contexts outside of the family context (e.g., school, community). This includes:

Challenges/realities related to using AAC with multiple partners such as:

- Knowledge and training needed for partners
- Communication partner responses and attitudes (negative, unsure of how to respond)
- Wait time needed (especially hard for peers)

You have to make a conscious effort to be patient and wait and that's hard. And imagine what it's like for children? Um and whether they're going to stick around to engage with that you know?

But if we're in direct sunlight she can't see the screen. And you know we just go and if there's bright sun on it, she will get frustrated.

	• Communication between school	
	and home needed (e.g., regarding	
	academic vocabulary)	
	Challenges/realities related to using	
	AAC in multiple settings/contexts,	
	such as:	
	• Eye gaze not available outside	
	• Device cannot be out in the rain	
	• AAC is not always available,	
	especially during available during	
	physical activates (e.g., riding	
	bike, swimming, horse riding)	
	• AAC not accessible out of	
	wheelchair	
	• Not used in community due to	
	uneven surfaces and fear of	
	falling	
Integrating AAC	Description of relationships with	
outside description	individuals outside of the	
	immediate family members and	
	activities outside the home, without	
	mention of AAC	
THEME 2. AACT	ECHNOLOCIES. Describes the limi	tations on arrangate of arristing AAC

<u>THEME 2: AAC TECHNOLOGIES:</u> Describes the limitations or supports of existing AAC technologies, or ideas for features that would characterize ideal technologies. This does not include features of low-tech AAC systems (e.g., communication boards).

<u>Subtheme 2.1: Limitations of existing technologies</u>: Describes features of existing technologies that present challenges for use, either for the child in successfully using the technology, or for parents or other partners in supporting the child to use the technology.

Code	Definition	Example
AAC limitation access	Describes access limitations, including inefficient (slow) rate of communication or effortful access that causes frustration for the child and/or partners. This could be due to: • the child's motor skills, • slow pace of scanning (partner assisted or auditory), • eye gaze access challenges	I mean it is exhausting for him to use the AAC, he would use it more if it wasn't so much work for him to get that arm up and get it directionally on the exact button.
AAC limitation reliability	Describes technologies as unreliable due to: • glitches, • having short battery life, • limited storage, • hardware issues	They can be prone to you know crashing or not working or whatever —and that's really bad when that happens. That's really frustrating for himSo that sort of reliance on it, that can be an issue I think.

AAC limitation lack of fit	Describes a mismatch between the needs and skills of the child (e.g., motor, cognitive, vision) and the design of the system. This could be due to: • poor organization, • too many symbols, • child not being able to perform operational functions, • visual complexity, • changes in organization upon addition of vocabulary, • trade-offs (e.g., adding vocab increases demands of use).	The extra actions and descriptions are alphabetized. "Actions A-Z" and like if you know if you wanna look for throw and you don't know that throw begins with a "T" how are you ever gonna find that? You're not, and so you're just gonna have to say something else. That's the big letdown about that.
AAC limitation physical design	Describes how the size, weight, or position of the device presents challenges such as: • interfering with the social channel (i.e., partners) • blocking things the child is trying to look at (e.g., TV). • challenges with mounting (e.g., large/heavy mounts, challenging to mount due to weight of device, expensive and limited options for mounting) • being breakable/fragile	Then also just the blocking of his face. Cause if I'm having a conversation with you, you can see me and I can see you and we can make eye contact but for him sometimes if the person is talking I'll notice he's looking at them and then his eyes are out of the field because he wants, he's very aware of how people are social so he'll look at the speaker and then he can't (voice cracks), you know, so that's hard
AAC limitation vocabulary	Describes vocabulary available on the device as limited for the child (e.g., lack of academic vocabulary, lack of interest related vocabulary such as toys)	There's a lot of specific vocabulary—and he doesn't need to have everything, but he needs enough to be able to participate
AAC limitation programming	Describes challenges in modifying technologies. For example: • adding vocabulary is not intuitive or slow, • no options to program offline, • changes on one page do not carry across pages, • additional technology needed for programming offline	I mean it's not it's not intuitive. You definitely have to learn how to do it. And, there are a lot of keys involved.
AAC limitation appeal	Describes technologies as unappealing, making children uninterested in using them. This includes voices that are not age	I mean I think it's hard for her to get excited about using it.

	appropriate or symbols that are not	
	motivating.	
AAC limitation	Describes other limitations not	
other	included above such as: variability	
	between devices	
	ports of existing technologies: Descri	
	hild, or use by partners who are suppor	
Code	Definition	Example data
AAC support	Describes characteristics of the	If the words aren't in there, it
programming	technology that facilitate	recommends you can actually add
	programming, that is, adding	some of the words that don't
	vocabulary and making changes.	already show up.
	This includes:	
	• ability to easily add vocabulary	
	on the fly,	
	• the system recommends	
	vocabulary,	
	• search feature,	
	• capability to program offline, and	
	• changes made to one page that	
	carry across pages.	
AAC support	Describes the vocabulary on the	A couple times he's been screaming
vocabulary	technology as a support for	pissed off mad at me and I can't
		v —
	1	
	1 * '	•
	_	
	<u> </u>	
	• core vocabulary.	
AAC support	Describes how the AAC	· ·
-	_ = = = = =	
and reactives		v e
	·	
	<u> </u>	
	1 -	
	1	
AAC support multiple functions and features	communication about: • likes, interests, important people, • pain, • things not available in the immediate environment, • core vocabulary. Describes how the AAC technology supports multiple functions such as: • environmental control, • internet use, • access to a camera, • social media, etc. Also describes the features of the technology that promote use such as: • prediction (to increase efficiency), • access to multiple languages, and • access to various software programs (e.g., document readers, literacy software, etc.).	figure out what he wants. And I'll get his talker out. He'll want something, you know, out in the garage, that there's no way he would be able to tell me that he wants to go on his bike or something. The Tobii is programmed to contithe TV remote so that he can acceptal television himself and change the channel and record what he want

AAC support	Describes the physical design of	Yep. It's just like one of those rigid
physical design	the technology as a support for use	mounts and then it's a quick
	by child and partners. This	release mount 2, a QRM2. It kind of
	includes:	just, you pull that thing back and
	• portable or light	you snap it in there and it just
	• mounting	snaps in. (Inc 10:12) and it's
		flexible. It works pretty good
AAC support fit	Describes how the technology is	It has pretty much everything that
with child	well matched to the child's needs	he needs is on that setup—the 42. I
	in terms of the vocabulary	mean the layout of the device is
	available, selection technique,	pretty good, I feel. It was pretty
	organization of vocabulary, etc.	well thought out. I don't know that
	Also, describes fit with the child's	you could do that any differently.
	motor skills (e.g., via use of	Um, I think it is as good as it's
	keyguard)	gonna be for what he needs
AAC support other	Describes an AAC technology	
	support not encompassed in the	
	codes above.	
	l technologies: Parents describe featur	<u> </u>
	rogramming, efficiency, improved phy	
Code	Definition	Example data
AAC ideal reliable	Parents describe an ideal	
	technology as being:	
	• having adequate storage,	
	• working smoothly.	
AAC ideal	Describes the technology as	I wish that there were better icons.
appealing	appealing/easy for the child to use,	And a better selection of different
	for example by having better voices	icons.
A A C ' 1 1	or better representations.	
AAC ideal	Describes an ideal technology as	it would be nice to be able to—be
programming	easy to program, manage	able to download like a folder for
	vocabulary off of the device, edit	American history that was pre-
A A C : do al	across pages, etc.	built.
AAC ideal efficient	Described an ideal technology as quicker and easier to use/access.	But it would be really neat if he could use brain waves because
efficient	This includes features such as:	
		there's always going to be a motor
	• sentence prediction,	component to eye gaze, and he has a very severe motor impairment.
	• brain-computer interface, and	a very severe motor impairment.
A A C ideal	• facial recognition software.	I'd like it to be lighter and a light
AAC ideal	Describes the physical design of an	I'd like it to be lighter and a bit
physical design	ideal technology as being:	smaller if possible and the
	• lighter,	attachment system and mounting— that could all be much improved I
	• smaller,	think
	• wearable,	, iiiiik
	• easier to mount	

	• durable	
AAC ideal other	Described other features of ideal	
	technologies not described above.	
THEME 3: CHILD	NEEDS AND SKILLS: Describes the	e developmental, communication, or
	and skills of the child.	· · · · · · · · · · · · · · · · · · ·
	elopmental needs and skills: Describes	s the motor, cognitive, sensory-
perceptual, or psycho	osocial skills and needs of the child.	
Code	Definition	Example data
Child	Describes the child's fine or gross	We're just getting to the point
developmental	motor skills including:	where she can isolate her pointer
motor	• ambulation,	finger. And so we do a lot of
	• finger isolation,	activities with that because that's
	• use of a wheelchair to achieve	how she's going to be able to
	mobility,	progress to more squares.
	• motor control	
	• spasticity.	
Child	Describes the child's cognitive skills	He is such a bright person. The
developmental	including:	school district assessed him and
cognition	• attention,	he is definitely age- appropriate
	• memory, and/or	cognitively
	• intelligence	
Child	Describes the child's vision or	Some of the issues that we didn't
developmental	hearing including:	realize we were going to have
sensory-perception	• vision loss/limitations	was the vision issue. So the CVI
	• cortical visual impairment.	so she wasn't totally blind. They
	• hearing loss	called her technically blind at one
	• hearing aids	point.
Child	Describes the child's attitude,	And he'll tug on my arm and
developmental	motivation, self-advocacy, or	point to the talker and, that's how
psychosocial	personality, including:	I'll know he wants me to add the
	• the child's feelings about	characters from this movie or he
	communication or another task that	wants to be able to talk about this
	are charged with emotion. (attitude)	TV show.
	• the child's drive to communicate or	
	complete other tasks (motivation)	
	• how the child makes his/her needs	
	know to others (self-advocacy)	
	• the child's demeanor, such as being	
	witty, funny, likes to make people	
	laugh (personality)	

Subtheme 3.2: Communication needs and skills: Describes the child's operational, linguistic,		
social, or operational skills.		
Code	Definition	Example data
Child communication operational	Describes the child using skills that are required to use technically operate the AAC system. This includes: • turning on/off device • changing languages or volume • navigating between pages/displays	It has groups, so he can hit groups and then he's had to learn, like, the farm animals are under this button.
	 use of selection technique (e.g., eye gaze) use of other programs and communication tools (e.g., email, internet, camera, social media) 	
Child communication linguistic	Describes the child's receptive and expressive language skills in the native language of community and in language code of AAC system. This includes: • combining symbols on the AAC technology (syntax)	He's able to whip out four to six words without any trouble. But her spelling, because she's never been able to sound out her phonics, her spelling is not great.
	 Using vocabulary concepts on the AAC system (semantics) Comprehension of spoken language Literacy (writing, typing, reading) 	She's fully aware of what's going on and understands just as much as anyone else her age would
Child communication social	Describes the child's pragmatics (skills in initiating, maintaining, and terminating interactions) and interpersonal skills. This includes: • Conversational skills (e.g., taking turns, asking questions, initiating topics) • Using a variety of communicative functions (e.g., requesting, commenting, etc.)	And he's actually come a long way, he knows that if he starts with, "Hi, what's up?" then that tells people a lot about you. Like oh ok, you communicate age appropriately and that sort of thing
Child communication strategic	Describes the child using compensatory strategies to maximize the effectiveness and efficiency of their communication. This includes: • Using multiple modalities (e.g., unaided first because faster) • Using telegraphic utterances to increase rate	If he wants to say something, you know, 90% of the time, he's going to try first with a gesture or his voice. Because it's the fastest way, and we understand him for a lot of basic things.

• Using "sounds like" strategies (e.g.,	Well she didn't have the word
"brown knees" for brownies)	brownies on her device. So she
 Dealing with communication 	used the color brown and then
breakdowns	the body part knees

THEME 4: PARENT RESPONSIBILITIES AND PRIORITIES: Describes the parents' roles related to supporting their child and his/her communication, as well as their goals and priorities for their child.

<u>Subtheme 4.1 Parent roles</u>: Describes the parents' role in supporting their child, that includes: advocacy, leadership, educating, preparing for the future, performing device related roles, using various partner interaction strategies, and everyday parenting responsibilities.

various partner interaction strategies, and everyday parenting responsibilities.		
Code	Definition	Example data
Parent role	Parents describe playing a big role in	I think I have a big role and I
leadership	supporting their child and their	actually sometimes have to
	child's communication. This could	remind myself to have less of a
	involve:	role because you know I was the
	 managing multiple responsibilities, 	one who did the research and
	• taking the lead on organizing	found the device
	services, etc.	
	• being an expert on the child and	
	his/her needs (e.g., interpreting	
	nonverbal communication.	
Parent role	Parents describe their role as being	We were fighting for a long time
advocacy	"pushy" or demanding by:	to try and get the school district
	• standing up for their child's needs	to do what we wanted
	and	
	• making their child's needs known	
	to other communication partners	
Parent role	Describes the parents' role of	I went in and kind of trained them
educating	educating:	[school professionals] how to use
	• themselves on AAC (e.g., reading, researching),	it and what worked at home.
	• educating others (e.g., showing care	
	aides how to setup device) and	
	• educating society.	
Parent role	Describes parents as supporting the	I'm his mom and I know where I
preparing (for	independence/autonomy of their	want him to be as an adult and I
future)	child and reinforcing the value of	feel like, it's kind of my
	communication.	responsibility to get him there.
Parent role device	Describes specific technology related	It's always me that gets to do all
(related)	roles such as:	the tech stuff with it. So when she
	• programming and adding	wants vocabulary added or if we
	vocabulary,	need to reprogram something or
	• technical upkeep (e.g., finding	check out some new software for
	software to use, running updates),	her to paint with or play music
	• providing access to AAC, and	with, or anything like that.

	• supporting the child's navigation on the device	
Parent role	Describes the use of various partner	As soon as the talker goes on if
interaction	interaction strategies to support the	we want to encourage him, if he's
(strategies)	child's communication including:	not jumping right into saying
(strategres)	• modeling/aided input,	something, we start with like an
	• prompting,	open-ended phrase. So, my
	• providing wait time,	husband will say, "Dad is"
		musouna wiii say, Daa is
	• contingent responding,	
	• providing choices,	
D . 1	• asking questions	
Parent role	Describes caregiving responsibilities	Another aspect of our day that
parenting	related to everyday care such as:	really consumes our time is, since
	• feeding,	she's on blenderized diet, it takes
	• dressing,	me 15 minutes to give waterAnd then 45 minutes
	• toileting, etc.	later, so everything is cleared,
		then I can feed her.
Parent role other	Describes other roles not described	men i can jeeu ner.
1 arent role other	above.	
Subtheme 4.2. Pare	ent goals: Describes the goals and priori	ties parents identify for their
	nguistic, social, fluency, independence,	
Code	Definition	Example
Parent goal	Parents describe goal for the child to	Literacy is something that I would
linguistic	improve his/her morphosyntax,	like to see her achieve because I
	semantics, or literacy skills. This	think it would be a great gift to
	could include:	her and it's you know so very
	• use of a wider range of vocabulary	enjoyable.
	concepts,	
	• formation of more complex or	
	longer sentences, or	
	• various literacy skills (writing,	
	typing, reading, distinction between	
	written and spoken communication)	
Parent goal social	Parents describe goal for child to	I would like to see him being able
	improve his/her pragmatics (skills in	to respond to conversation with
	initiating, maintaining, and	some kind of wit or some kind of,
	terminating interactions) and	other than, "that's funny"
	interpersonal skills. This could	because he says that a lot".
	include:	
	• social communication with peers,	
	• looking at partners,	
	• conversational skills,	
		1
	• having a greater number and variety	

Parent goal fluent (communication)	Parents describe a goal for their child's communication to be faster and more efficient.	I think the next thing which we're working on with speech and language therapy and experts that support them are faster—programs to make it faster.
Parent goal independence	Parents describe a goal for their child to achieve greater autonomy. This could be by using environmental controls on device and/or using AAC across various settings.	I can foresee him being able to be more independent if he can use his communication device to control the lights in his house or the locks on the doors. I think that would be really great for him
Parent goal inclusion	Parents describe a goal for their child to be included, for example, in: • a mainstream school, • with typically developing peers, • in society, • by a variety of partners	We feel really strongly about inclusion, and being around typical children. And so to me it's really important for him to stay with, you know, the peers that we live near and that his brother is friends with
Parent goal motor	Parents describe a goal related to motor skills (e.g., being able to help more with mobility such as standing and transferring)	Right now he's really heavy. So my big things for him—I need him to either stand or help more with transfers—like he's just really getting heavy, so we've been kind of working on having him help a little bit with that.
Parent goal other	Parents describe a goal not encompassed in the codes above.	

THEME 5: AAC PROCESS AND DECISION MAKING: Describes the process of acquiring and learning technologies, collaborating with professionals, and the changes that occur over time. It also includes the feelings and emotional responses of parents to this process.

Subtheme 5.1: Device selection/acquisition and customization: Describes the process of acquiring and customizing the device, as well as trialing various low-tech and unaided communication modes and determining the most appropriate ones. Also describes the process of learning technologies for parents (families) and their children.

Code	Definition	Example data
Process selection	Describes the process of acquiring	We bought the device, we haven't
and learning	the AAC technology and	even, you know, gone through any
	customizing it. This also includes	sort of AAC trialing with the
	the process of trialing various low-	school.
	tech and unaided methods of	
	communication. Specific	
	examples/descriptions included are:	
	• trailing different devices and	
	selection techniques,	
	• AAC assessment,	
	• funding,	

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	 time for acquisition, cost of technology, parents taking a leadership role in device acquisition (i.e., purchasing device) changing the number of symbols Describes the process of learning technologies and various forms of AAC for children and their families. This includes a description of: the child's history of AAC use 	I didn't really know what I was doing, I was trying to figure it out on my own for a while, probably about a year.		
	 (e.g., when started using AAC); cost of learning (e.g., steep learning curve); trial and error (e.g., "learning as we go"); 			
	 lack of training for parents/families; independent exploration for the child having a separate tablet for "fun" 			
	for the child			
<u>Subtheme 5.2: Feelings and emotional responses</u> : Describes the feelings and emotional responses of parents and family members throughout the process of supporting their child to use AAC.				
Process feelings	Describes feelings and emotional responses of parents including: • accepting diagnosis and lack of speech/communication • feelings about the future (e.g., hopeful, unsure)	You know, we can handle her struggling to eat, we can handle the mobility issues, but its's the speechor-in any form. You know we would take any kind of form.		
	• managing competing demands of			
G 141 F3 C	parenthood and AAC			
<u>Subtheme 5.3: Changes over time:</u> Describes transitions, progress or technology changes that occur over time for the child and parents.				
Process transitions	Describes transitions, for example:	We're going to have to start over.		
1100035 transitions	• starting a new school	It's a whole new group of		
	• new therapists/professionals	professionals all new people, we		
	• new AAC system	have to make our case again for		
	Thew Are system	what we want.		
Process progress	Describes progress of the child or	His MLU has grown pretty		
	parents over time. This could	tremendously in the past year and a		
	include:	half it's up from one to maybe 3, 4.		

Process technology changes	 improved communication skills for the child fewer behavioral issues more use of device in community by parents etc. Describes changes in technologies over time, for example: new software released more vocabulary available different voices released 	Amazing. and he's starting to use core a lot more frequently. The devices have already changed so much since she was two. I can't imagine that by the time she is an adult, they won't be you know things that – things I can't even
	• etc.	think of or something astounding.
	aboration with professionals: Descri	
	ional-professional relationship, or char	
Code	Definition	Example data
Process collaboration positive	Describes positive relationships that parents have with professionals. This includes: • supportive professionals • getting professional "buy-in" • professionals are well educated and informed about AAC, OR are willing to learn • professionals help parents to set up device • professionals provide training, recommendations, information to parents • professionals provide training to school staff	I think a lot of what she does is give me information. You know, educate me and I then can help navigate.
Process collaboration negative	Describes negative relationships with professionals. This includes: • uneducated professionals • professional lack of time or large caseloads • professionals disinterested in learning about AAC • mistrusting professionals (don't believe what parents tell them child can do) • professionals disagree with parents about what child is capable of	The biggest stumbling block that we have is that teachers and SLPs are not familiar with AAC. They don't know anything about or, or what they do know is wrong.

Supplemental material, O'Neill & Wilkinson, "Preliminary Investigation of the Perspectives of Parents of Children With Cerebral Palsy on the Supports, Challenges, and Realities of Integrating Augmentative and Alternative Communication Into Everyday Life," *AJSLP*, https://doi.org/10.1044/2019_AJSLP-19-00103

Theme 6: Description and Uncoded: Used for comments that describe the child, but are unrelated to developmental, psychosocial, or communication. Also used for descriptions of the parent/family unrelated to roles and responsibilities. Uncoded comments include interviewer questions, participant questions, and comments unrelated to child, parent or AAC