

January 17, 2024

**Part Time AAC Use:
What Does It Mean and Why Does It Matter?**

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by January 31, 2024

Who am I?

Dr. Zisk has multiple relationships to AAC. They are the AAC research lead at AssistiveWare (disclosure!) and an Autistic part time AAC user. Dr. Zisk's AAC research addresses both topics which are not relevant to their own AAC use and topics which are relevant to their own AAC use. An example of Dr. Zisk's AAC research not related to their personal is their dissertation research on brain-computer interfaces for people with ALS. An example of Dr. Zisk's AAC research related to their own needs is the topic of today's webinar: part time AAC use.



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Defining AAC

“AAC means all of the ways that someone communicates besides talking.”

“Augmentative and alternative communication (AAC) is an area of clinical practice that supplements or compensates for impairments in speech-language production and/or comprehension, including spoken and written modes of communication.”

(ASHA, no date, public page & practice portal)

What if *there is no clinician involved?*

Defining part-time AAC use

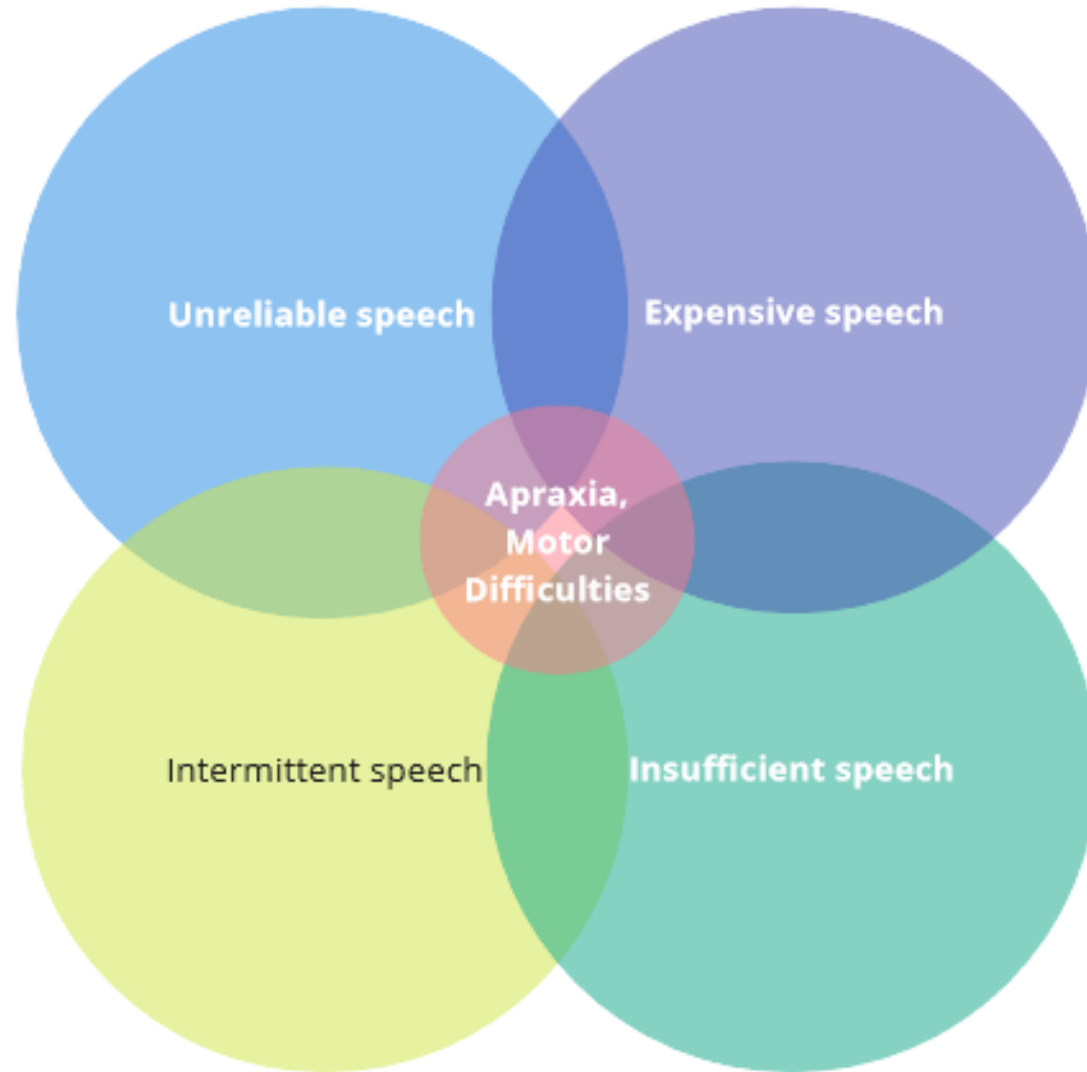
- Part time AAC users are people who use AAC sometimes, but not always. This can look like:
 - AAC use patterns which most closely resemble repeated temporary use
 - Using AAC both with and without speech at different times
 - Patterns of using both AAC and speech which do not fit nicely under augmentative, alternative, or temporary use due to dynamic disability
- Note: part time AAC user is an identity term and may not be used by everyone it *could* apply to.

Alternative use	Augmentative use	Temporary use	Who doesn't fit nicely?
Instead of speech	Supplements existing speech	Limited duration (e.g. post-op)	Moving between categories Repeated temporary use
Simion, E. (2014). Augmentative and alternative communication—support for people with severe speech disorders. <i>Procedia-Social and Behavioral Sciences</i> , 128, 77-81.			Today's topic

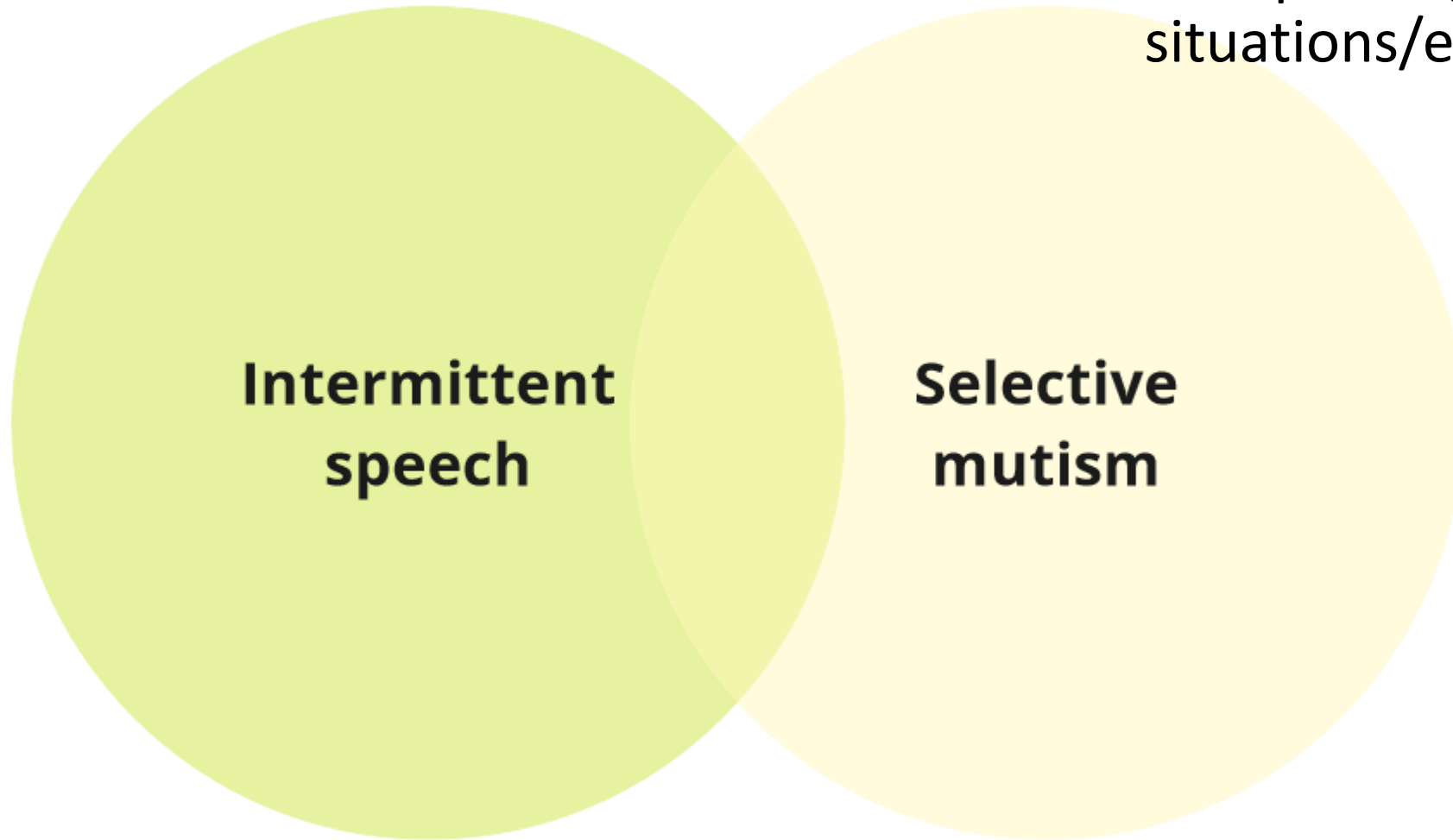
Why might someone use AAC (part time)?

- Intermittent speech: A person with intermittent speech can speak sometimes, but not always.
- Unreliable speech: A person with unreliable speech may say things that do not match their preferences or intended meaning.
- Insufficient speech: In insufficient speech, a person's oral speech agrees with their knowledge and beliefs, but does not fully meet their communication needs. That is, the person can speak orally and accurately, but not completely.
- Bonus: expensive speech: Speech is effective but has a significant cost in terms of energy, cognitive resources, or other internal resources, affecting what is available for other or later skills or tasks.

Apraxia: problems in sending messages from the brain to the body (e.g. to the mouth & vocal folds)



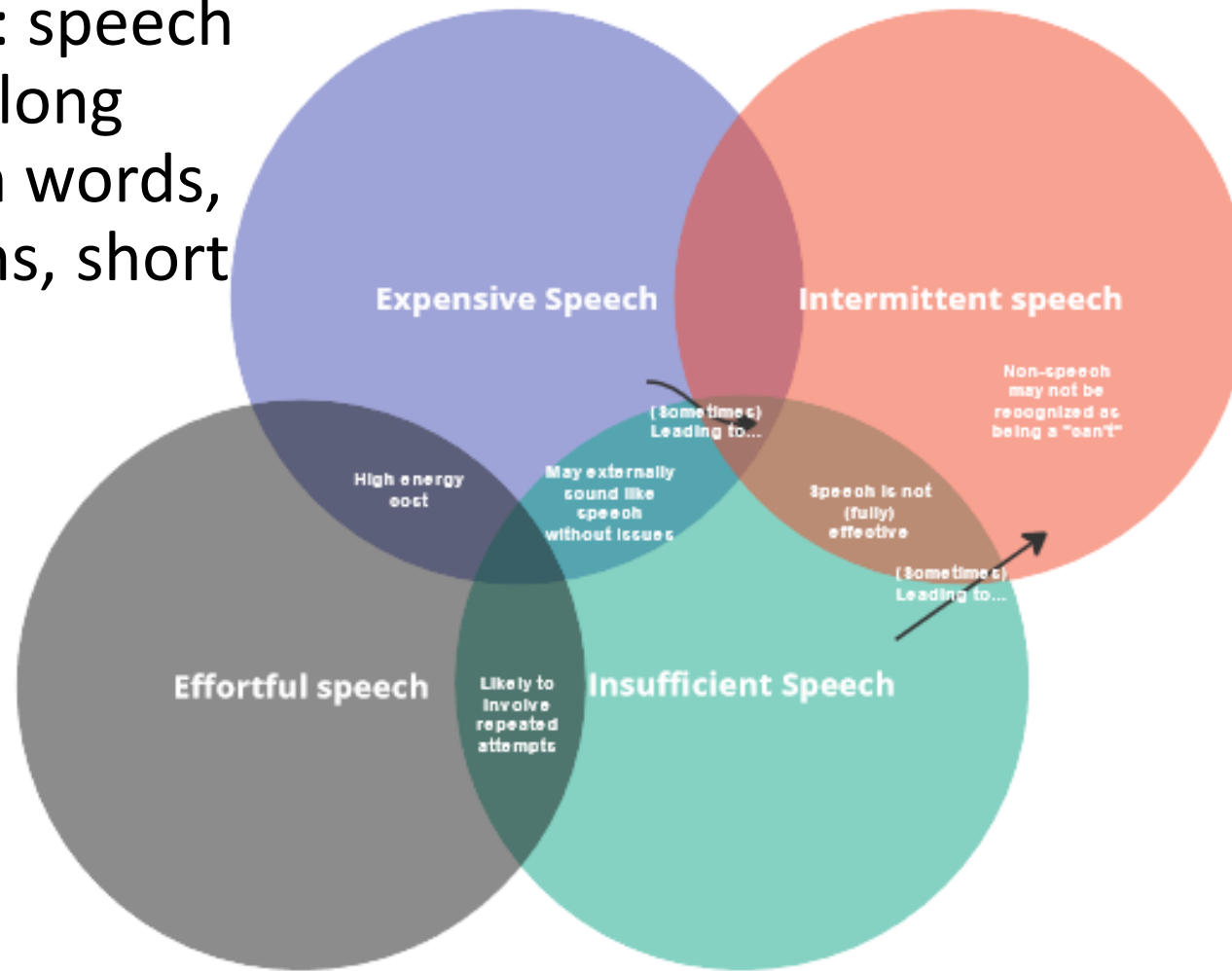
Selective mutism: anxiety diagnosis in the DSM about not speaking in certain situations/environments



**Intermittent
speech**

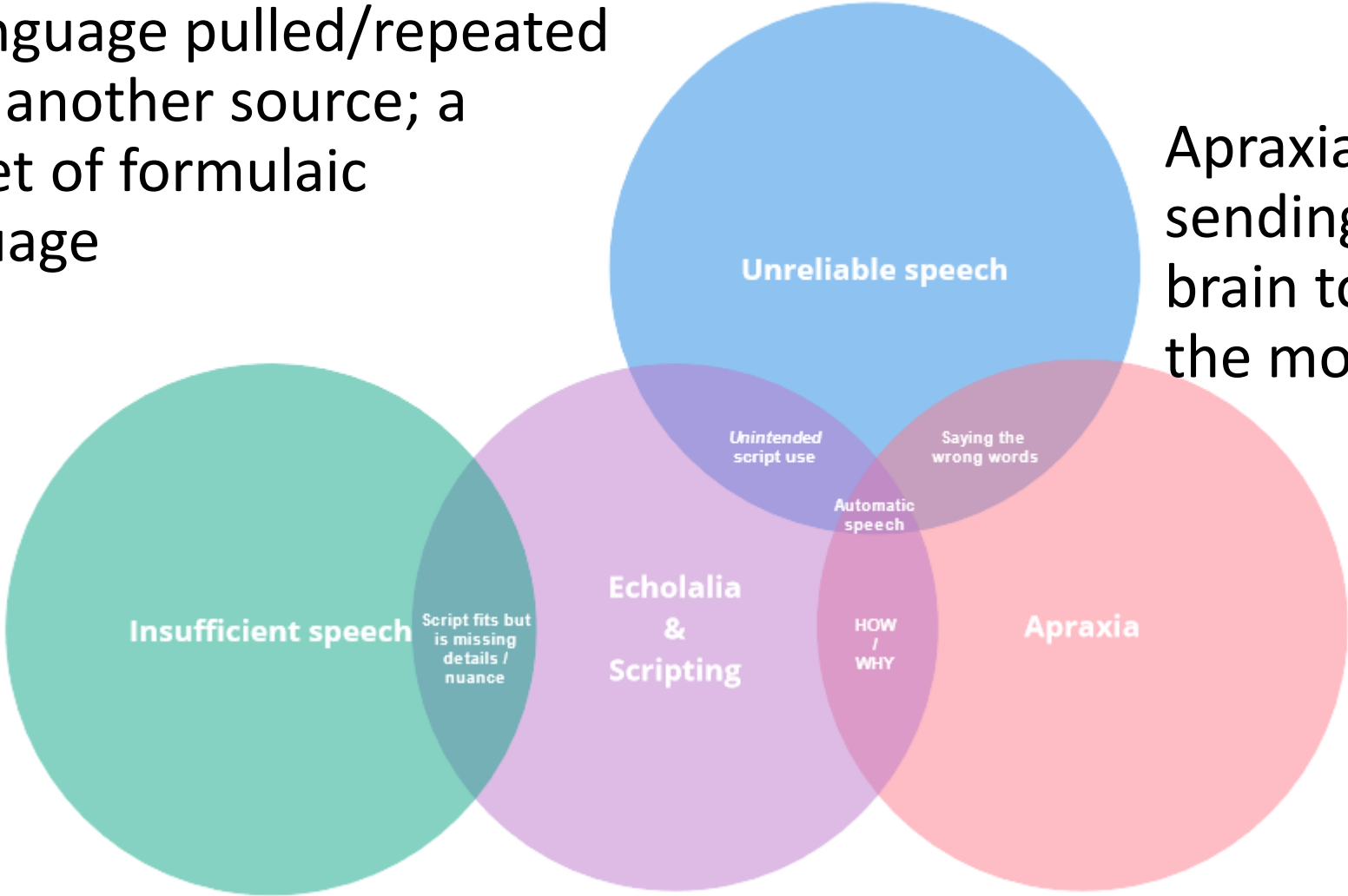
**Selective
mutism**

Effortful speech: speech may be halting, long pauses between words, sound distortions, short utterances,



Echolalia/scripting: chunks of language pulled/repeated from another source; a subset of formulaic language

Apraxia: problems in sending messages from the brain to the body (e.g. to the mouth & vocal folds)

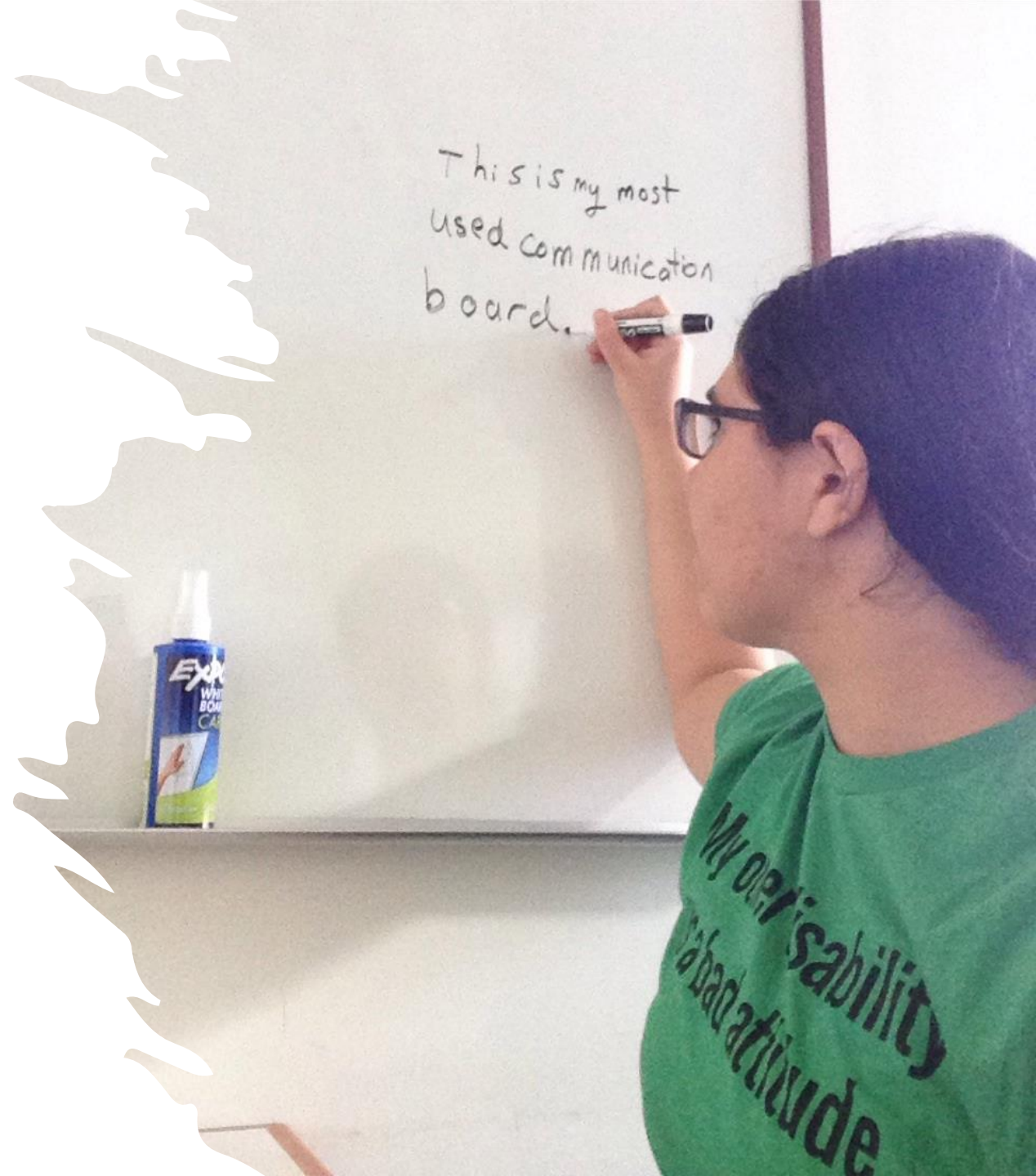


	Meant to tell the truth	Meant to lie
Told the truth	An accurate statement (no problems)	Unreliable speech
Did not tell the truth	Unreliable speech	Told the intended lie (no problems)
		Told a different lie than intended – unreliable speech

Discussing your examples

- Intermittent speech
- Unreliable speech
- Insufficient speech
- (Expensive speech)
- Selective mutism
- Echolalia/scripting
- Lying
- Effortful speech

Part time AAC use
and intermittent
(non)-speech



Case study: Alex

Alex participates actively in class, asking and answering questions in school. After he goes home, he struggles to answer what he did in school and experiences significant emotional distress while repeatedly trying (and failing) to clarify what happened in an incident at lunch. He soon stops speaking entirely for the rest of the evening.

- Intermittent speech
- Unreliable speech
- Insufficient speech
- (Expensive speech)
- Selective mutism
- Echolalia/scripting
- Lying
- Effortful speech

Case study: Sam

Sam was taught how to accept invitations. (“Yes, I would love to, thank you!”) A classmate invites her to go bowling after school. Sam hates the bowling alley because it is loud and bright. She *intends* to ask about an alternative activity, but what comes out of her mouth is “Yes, I would love to, thank you!”

- Intermittent speech
- Unreliable speech
- Insufficient speech
- (Expensive speech)
- Selective mutism
- Echolalia/scripting
- Lying
- Effortful speech

Case study: Dave

Dave usually speaks at full volume at home, but rarely speaks at all at school. When they do speak at school, they whisper. However, when Dave is tired or sick, or after they have spent a lot of time in a loud environment, Dave may not speak or whisper at home. At these times, Dave sends texts instead, or they use the text chat function when gaming online with friends.

- Intermittent speech
- Unreliable speech
- Insufficient speech
- (Expensive speech)
- Selective mutism
- Echolalia/scripting
- Lying
- Effortful speech

Part time AAC use and unreliable speech

Part time AAC use
and insufficient
speech

Participants



Share Screen

Rec

Part time AAC use
and expensive
speech



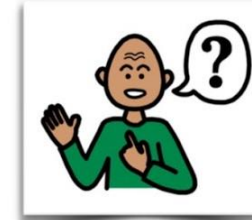
Getting AAC as/for a part time AAC user

- Many are self-funded
- Insurance funding is possible (see Koerner et al., 2023)
- Some requests for this as an accommodation in school
- “Classroom” AAC
- Communication Bill of Rights

My Communication Bill of Rights



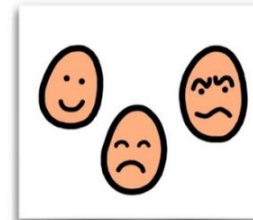
I have the right to my own friends and social life.



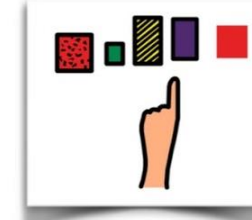
I have the right to ask for what and who I want and where to go.



I ALWAYS have the right to say, “no!”



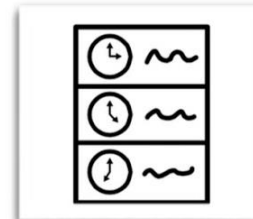
I have the right to say what I feel.



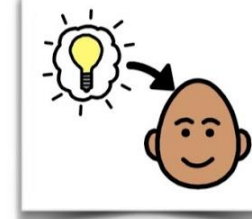
I have the right to make my own, real, choices.



I have the right to say what I think.



I have the right to ask for, get and give information.



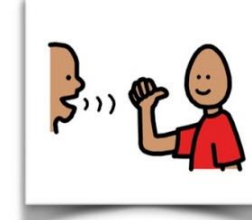
I have the right to know about the people in my life and everything happening to me.



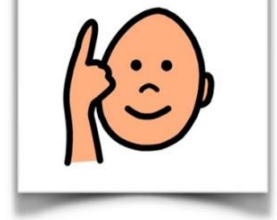
I have the right to be taught to communicate and have what I need.



I have the right to be treated with respect.



I have the right to be talked to and not about.



I have the right with be talked to in a way I understand.

AAC Research As Self-Advocacy

- Representation in research: are people “like me”
 - Different axes of “like me”
 - Autistic *adult*
 - AAC using *adult*
 - Use of both AAC & speech
 - Increased AAC/reduced speech use as an *actual goal*, not the thing we’re reassuring people is unlikely
 - Research participants?
 - Discussed via proxy? (parents, caregivers, teachers, therapists, aides)
 - Discussed *at all*?
 - Researchers?

Results of Doing AAC Research as Self-Advocacy

- Specific:
 - When I got AAC as a formal accommodation in grad school, I couldn't find any research about AAC for people like me!
 - High standards: all progress is progress, but...
- General:
 - Puts AAC user perspectives & priorities into academic & professional spaces without (or with less) filtering through (unrecognized) professional assumptions
 - ATIA survey on Assistive Technology needs:
 - Asks about pre-service mentoring by experienced AAC professionals, does not seem to ask about pre-service mentoring by experienced AAC *users*
 - Puts AT users and our families in the same category for continuing ed sources
 - Directly combines lived experience & academic/professional learning
 - Differing intuitions related to lived experience
 - Community connections

Academic sources addressing AAC use by speaking autistic people

Donaldson, A. L., Zisk, A. H., Eddy, B., corbin, E., Ugianskis, M., Ford, E., & Strickland, O. (2023). Autistic Communication: A Survey of School-Based Professionals. *Perspectives of the ASHA Special Interest Groups*, 8(6), 1248-1264. *

Donaldson, A. L., corbin, E., Zisk, A. H., & Eddy, B. (2023). Promotion of communication access, choice, and agency for autistic students. *Language, Speech, and Hearing Services in Schools*, 54(1), 140-155. *

Donaldson, A. L., corbin, E., & McCoy, J. (2021). "Everyone deserves AAC": Preliminary study of the experiences of speaking autistic adults who use augmentative and alternative communication. *Perspectives of the ASHA Special Interest Groups*, 6(2), 315-326.

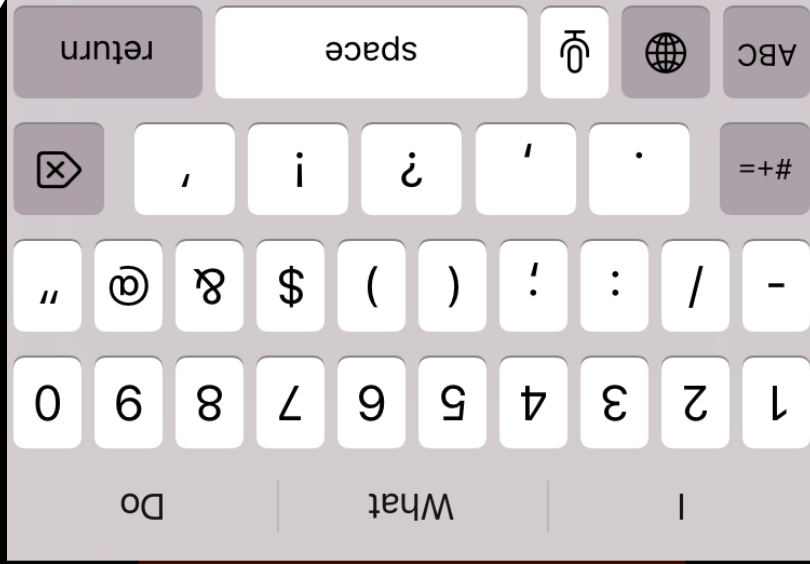
Hillary, A. (2019). Am I the curriculum?. *Curriculum Inquiry*, 49(4), 373-386.

Hillary, A., & Harvey, S. (2018). Teaching with Augmentative and Alternative Communication. *International perspectives on teaching with disability: Overcoming obstacles and enriching lives*, 219-234.

Koerner, S. M., Glaser, S., & Kropkowski, K. (2023). Perspectives of Part-Time Augmentative and Alternative Communication Use in Adults and Implications for Pediatric Service Delivery. *Perspectives of the ASHA Special Interest Groups*, 1-14.

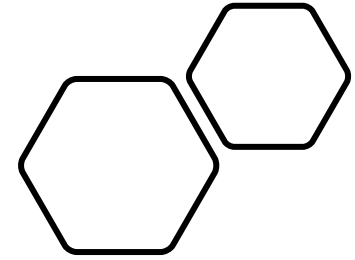
Kudryashov, L. (2021). *Participatory design of augmentative and alternative communication (AAC) technology with autistic adults* (Doctoral dissertation).

Zisk, A. H., & Dalton, E. (2019). Augmentative and alternative communication for speaking autistic adults: Overview and recommendations. *Autism in Adulthood*, 1(2), 93-100.



Thank you! What questions do you have?

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