Am I Muted?!?
Effective Self-Advocacy in AAC Users

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Melonie and Heather are co-owners of a private practice, *Collaborative Speech Solutions, PLLC.*

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Terminology

We strive to use **neurodiversity affirming** language in our practice and in our presentations. We also attempt to learn as much as we can from AAC users and autistic individuals themselves about the terminology they prefer. This means we do not use "person first language". You may hear other terms you are not familiar with but know that we are intentional in our language and mean our words to be as respectful as possible to autistic people and to AAC users.

Learning Objectives

1. Define "psychosocial competence" and its role in self-determination and self-advocacy.

2. Discuss at least three strategies that can be put into place across the span of a school age population to promote self-determination and self-advocacy.

3. Describe the role of social-emotional development in promoting adequate self-determination and self-advocacy skills in AAC users.

Where do we work?

New Horizons Regional Education Centers

- Regional Public Day program
- Serves six surrounding school divisions
- Elementary, Middle and High school campuses
- Ages 5 to 22
- Center for Autism and ED/ID program
- All students use some form of AAC

Why are we talking about this?

Levels of self determination and self advocacy are evidence based indicators of post-secondary success.

Light & McNaughton, 2015

Why are we talking about this?

2006:
Individuals with developmental disabilities: 4-5x more likely to be victims of a crime
Sexual assault: 10.7x
Robbery: 12.7x
Women with developmental disabilities: 50% have been sexually assaulted at least 10x
2018:
Women with intellectual disabilities were 12x as likely to be victims of sexual assault as women without intellectual disabilities.

Huer, 2006; NPR, 2018

Why are AAC users more vulnerable??

- Power differential
- Physical isolation
- Smaller social network
- Reduced choice & control
- Reduced ability to report

Hartman & Sheldon

What part do we play in making AAC users more vulnerable?

We prioritize "compliance".
We often ignore or downplay opinions.

Communicative Competence is our ultimate goal!

Linguistic

Operational

<mark>**Psychosocial**</mark>

Social

Strategic

Light, 1989; Dorney & Erickson, 2019

Psychosocial competence targets self-determination and self-advocacy.

Confidence

Motivation

Attitude

Resilience

Light, Arnold, & Clark, 2003; Light & McNaughton, 2014

Components of Self-Advocacy and Self-Determination

Access to robust communication system
Student choices and opinions
Communication partner training
Connection to role models
Social emotional language development

Light & McNaughton, 2014

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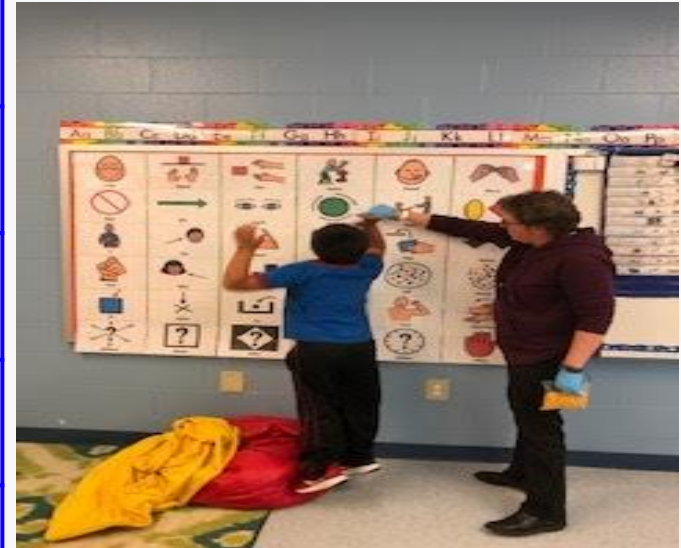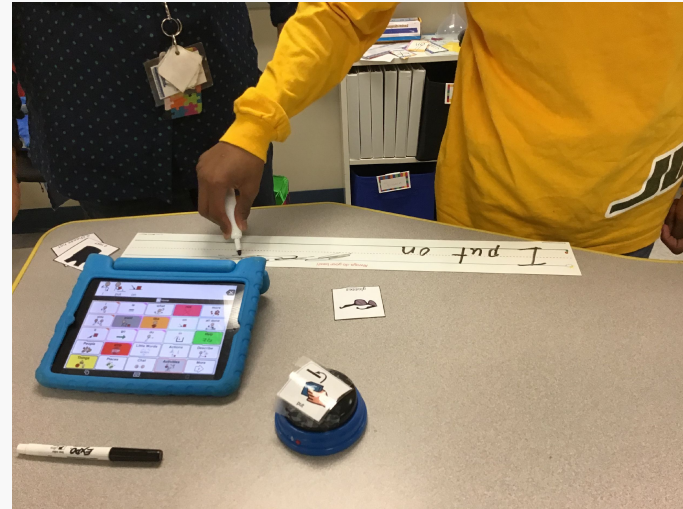
What makes a communication system robust?

Letter access

Multimodal (gestures, facial expressions, pictures, writing, etc.)
Vocabulary (core, fringe and pre-stored messages)

Word forms (grammatical markers)

Organized in a systematic way

Ability to grow with the user

Beukelman & Mirenda, 2013; Praactical AAC, December 2021
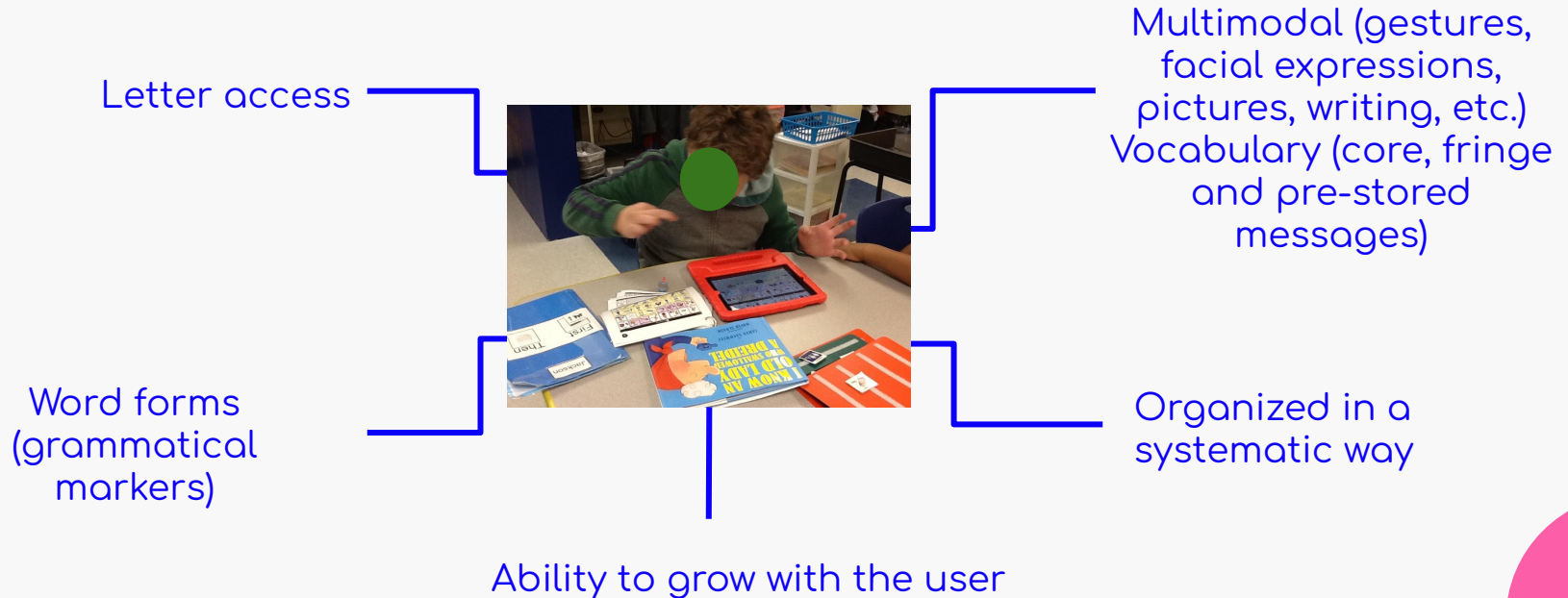
The Role of Literacy

Literacy includes writing!

Literacy can be incorporated into all instruction.

Educate stakeholders that our students with complex communication needs can "write"-there are NO prerequisites!

Remind stakeholders that writing is a part of literacy.

Familiarize stakeholders with alternative methods for "writing."

How to make writing accessible

- Predictable Chart Writing
- Device keyboards with word prediction
- Adapted keyboards
- Alternative pencils
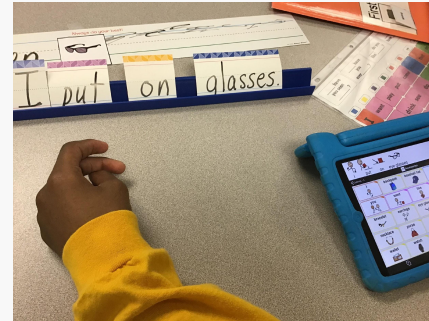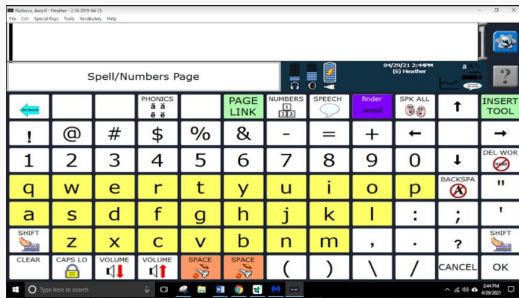
Project-core.com

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EVERYONE SEEMS TO HAVE QUITE AN OPINION.

Light & McNaughton, 2014

Communication Bill of Rights

I have the right...

To be given real choices

To say no, refuse and reject choices

To ask for what I want

To share my feelings

To be heard and responded to (even if the answer is no)

To ask for and get attention and interaction

To have and use my speech system all the time

To ask and know about my schedule and my world

To be taught how to communicate

To have my speech system in working order & to have a backup

To be a full and equal member of my community

To be treated with respect and dignity

To be spoken with, not about

To be communicated with in a sensitive way

From the National Joint Committee for the Communicative Needs of Persons with Severe Disabilities. (1992). http://www.asha.org/NJC/bill_of_rights.htm For information regarding the graphic symbols contact DART (www.dart-gbg.org).

Zangari, 2017

How do we make it work?!?

Self-acceptance

Self-regulation

Advocacy for the Students

Zangari, 2018

Questions to consider...

How are you helping students know their goals and actively meet their goals?

Are you a team player? How is the team working together toward development of self-advocacy?

Are you using tools, such as the Communication Bill of Rights, to assess and develop self-advocacy for students?

Are peers an active part of therapy? Are you pushing in and shaping group behavior?

Dann, 2019

Acknowledge and Honor

We do not always have to comply, but we always need to acknowledge.

Try to understand the "why."

Shows that we respect him/her.

Villegas, 2021; Zangari, 2018

Think about times you need to tell people what's wrong. Practice saying these messages.

I don't want to.

I can't stand this.

Please don't talk about me without me.

Tell me what to expect.

It's too loud!

Stop. I don't like that.

I can do it myself.

Don't touch me.

The Language Lady, 2020

"People with intellectual disabilities are generally taught from childhood up to be compliant, to obey, to go along with people. Because of the intellectual disability, people tend not to believe them, to think that they are not credible or that what they are saying, they are making up or imagining…And so for all these reasons, a perpetrator sees an opportunity, a safe opportunity to victimize people."

-Nancy Thaler

Restraint and Seclusion Litigation– Fairfax County Schools

1

Requires ALL students who use AAC to have their AAC available and have hands free to use it where feasible.

2

Requires that communication be addressed in plan to reduce restraint and seclusion.

Communication First, 2021

Honoring Multimodal Communication

Multimodal Communication
Value all forms of communication!

Speech & Vocalizations

Robust AAC Systems

Pictures & Choice Boards

Mid-Tech Devices

Respect how your learner chooses to communicate. Acknowledge what they have expressed and model the mode you want to teach.

Hand Writing

Typing

Gestures

Body Language

Facial Expression

Sign Language

Texting

@the.aac.coach

Model how to use together, in different contexts and with different communication partners.

Ensure student is aware of his/hers modes of communication.

The AAC Coach

TEACHING CORE VOCABULARY

ATTRIBUTE

MEANING

MODEL AN ALTERNATIVE WITH SYMBOLS

WWW.PROJECT-CORE.COM
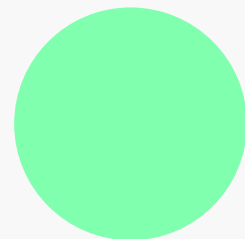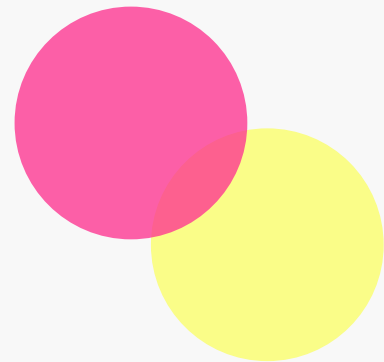
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Consider Equity

EQUALITY   EQUITY
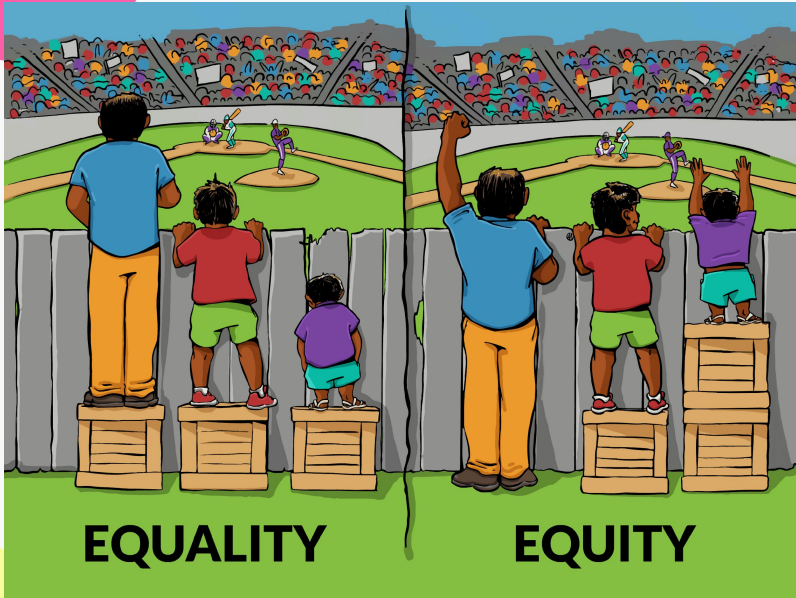
Ensure competence of an individual is NOT doubted due to his/her modes of communication.

Corbin, 2021; IISC, 2016

NEURODIVERSITY

Self-awareness

Preferences and what is hard may differ across his/her peers and staff (sensory inputs, such as lights, touch and sound)

Being comfortable with the word autism-what that means to him/her

Self-Advocacy Expressions

You are triggering...	I am autistic	I need space	I am nonverbal	Not what I meant	I made a mistake	Don't read my screen	I need to charge my device	Don't touch my device	It's too loud
It's too bright	It's too hot	It's too cold	You are too close to me	Don't touch me	Don't touch my hair	Let me stim	I am an adult	I am not a child	I can do that myself
Leave me alone	I'm not hurting anyone	Please	Wait	Now	Stop	I need you to take me seriously			

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Light & McNaughton, 2014

How?

S'MoRRES

| S | 🐢 | **Slow Down** (use a slow rate of speech) |
Mo		**Model** (point while doing self and parallel talk)
R		**Respect & Reflect** (respect *how* student initially communicated and model on AAC/verbally)
R		**Repeat** (frequently repeat their utterances)
E		**Expand (build up)** (repeat, rephrase, and build upon what student said)
S	STOP	**Stop** (pause to allow student to respond)

S'MoRRES © Jill Senner & Matthew Baud   Visual created by Carolyn O'Hearn

Communicative Functions
We communicate so we can...

Get our needs met · Make requests · Get help · Ask & answer questions · Disagree or argue · Compliment · Gain attention · Negotiate · Direct others · Refuse or protest · Share opinions · Tell stories · Socialize · Comment · Share ideas · Express feelings · Greet others · Share experiences · Make choices · Label & describe · Share information

List is not exhaustive

the SLT signpost

ImPAACt

PrAACtical AAC

Project Core

like · want · not · go
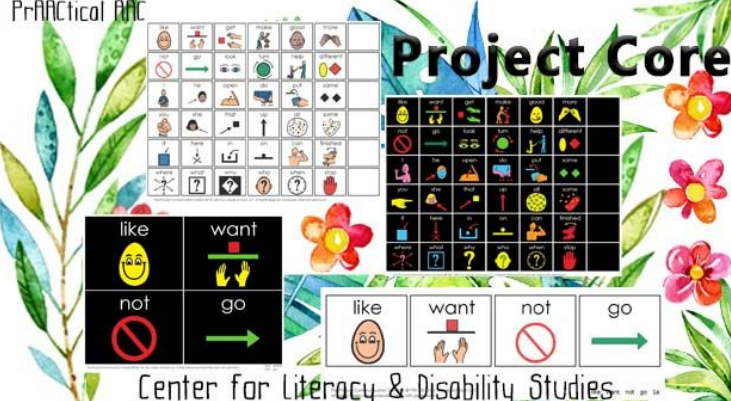
Center for Literacy & Disability Studies

What other approaches do you like?

What do we teach?

Art and value of arguing and negotiating

Let them argue!

What do we teach?

Behavior is the earliest form of advocacy!

What do we teach?

HEARING your students is an effective de-escalation strategy

How we do it during group therapy...

Zangari, 2017

How we do it in real time...

Communication Partner Accountability

Woodside Lane Communication Partner Agreement 2023-24
Please initial the following upon review of classroom and student communication systems.

- _____ I ensure systems of communication are easily accessible and positioned appropriately at all times for students in the classroom.
- _____ I ensure there are visual supports around the classroom to support expression for a variety of purposes.
- _____ I ensure each students' contributions are valued equally, no matter how it is expressed.
- _____ I provide extra time to process and form messages.
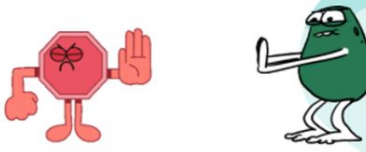- _____ I am willing/able to help my students repair communication breakdowns.
- _____ I use various communication systems to communicate my own messages-MODEL.
- _____ I support my students' autonomous communication (saying what he/she wants when he/she wants to say it).
- _____ My students can initiate their own messages, not only respond to others.
- _____ I provide opportunities for students' communication systems to be used in multiple environments.
- _____ I will ensure communication systems are never removed for disciplinary reasons.

  Back-up systems may be used, if warranted.

- _____ I will play an active role in my students' speech therapy sessions, learning ways I can incorporate communicative opportunities throughout their academic day.

- _____ I, as administrator, support staff to build students' communication skills.
- _____ I, as behavior specialist, support staff to build students' communication skills.
- _____ I, as speech therapist, support staff to build students' communication skills.
- _____ I, as reading specialist, support staff to ensure students' communication systems are integrated into literacy instruction.

Communication Environment Checklist, Authentic Expression, L.L.C.; The AAC Agreements Clearing House

Provide a variety of training opportunities.

Scenario Three

One individual in the group plays the role of a student who pushes their work away. Another plays the role of the staff who says "You are going to have to finish your work before you get the swing" without providing any other visuals or using the students communication system to talk to them.

What does communication between staff and student look like? What works and doesn't work?

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Light & McNaughton, 2014

Connection to Role Models

Connection important for student, staff and families

YouTube videos of first person account

Peer models in our classrooms

Television/streaming has provided access

this is **not** about me

"This is Not About Me" available through vimeo.com

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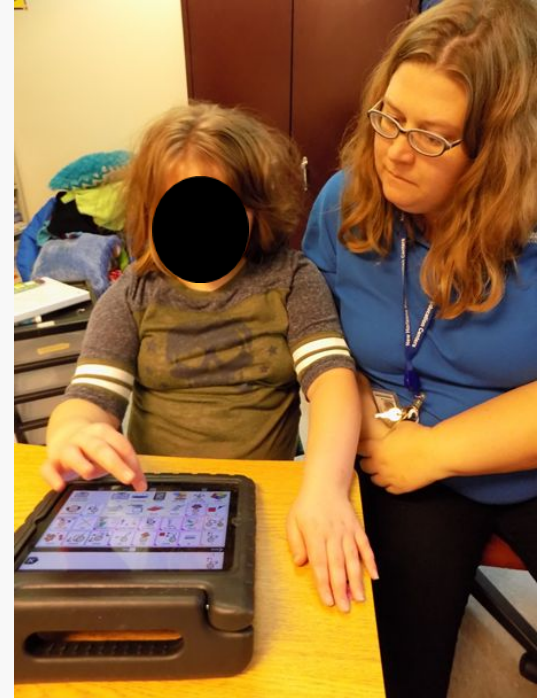
Social Emotional Development
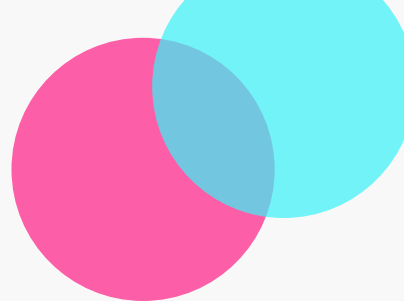
Kimochis

kimochis.com

Zones of Regulation

What Zone Are You In?

Blue	Green	Yellow	Red
Sick	Happy	Frustrated	Mad/Angry
Sad	Calm	Worried	Mean
Tired	Feeling Okay	Silly/Wiggly	Yelling/Hitting
Bored	Focused	Excited	Disgusted
Moving Slowly	Ready to Learn	Loss of Some Control	Out of Control

believe

Considerations...

Alexithymia: lack of awareness of internal emotional states

AAC devices: Program a button for "because" and/or "I need" on the *feelings* page.

Because

I need
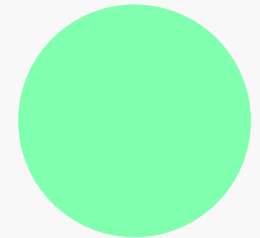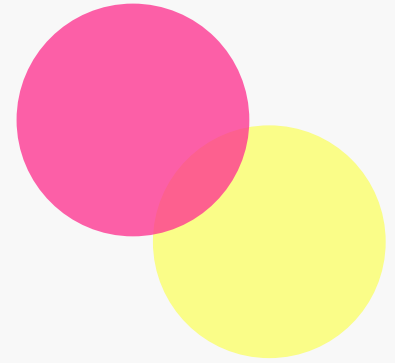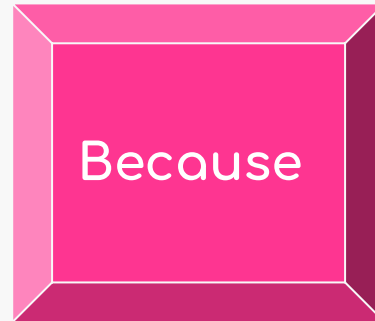
Considerations...

Our work on _narrative skills_ is critical for all of our students!

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Questions?

Light & McNaughton, 2014

Thank you for joining us today!

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References

Beukelman, D. R., & Mirenda, P. (2013). Augmentative and Alternative Communication: Supporting Children and Adults with Complex Communication Needs. Baltimore, MD: Brookes.

Communication First (November 24, 2021) *Restraint & Seclusion Litigation Against Fairfax County Public Schools Is Resolved;* available at https://communicationfirst.org/restraint-and-seclusion-litigation-against-fairfax-county-public-schools-is-resolved/

Corbin, E. (2021, November 19). Guest Blog: Communication Barriers Faced by AAC Users in Accessing Health Care. Communication FIRST. https://communicationfirst.org/guest-blog-communication-barriers-faced-by-aac-users-in-accessing-health-care/

Dann, Jordan, "The perspectives of speech-language pathologists on the development of self-advocacy in high school learners with autism" (2019). Master's Theses and Doctoral Dissertations. 966. https://commons.emich.edu/theses/966

Dorney, K. E., & Erickson, K. (2019) Transactions Within a Classroom-Based AAC Intervention Targeting Preschool Students with Autism Spectrum Disorders: A Mixed-Methods Investigation.*Exceptionality Education International*,29, 42-58. Retrieved from https://ir.lib.uwo.ca/eei/vol29/iss2/3

Griffin, R. (May 17, 2017) 10 Collaboration Tips for SLPs and Behavior Analysts Treating Students with Autism; ASHA Leader Live; available at https://leader.pubs.asha.org/do/10.1044/10-collaboration-tips-for-slps-and-behavior-analysts-treating-students-with-autism/full/

References

Hartman, Amanda & Sheldon, Erin. Assistiveware Blog. Reducing Vulnerability for Nonspeaking People. Available at
https://www.assistiveware.com/learn-aac/reduce-vulnerability-for-nonspeaking-people

Huer, M. (2006). AAC: Awareness of risk of victimization. ISAAC Biennial Conference, Dusseldorf, Germany.

IISC. (2016, January 13). Illustrating Equality VS Equity. Interaction Institute for Social Change.
https://interactioninstitute.org/illustrating-equality-vs-equity/

Lanier, H. (2018, January 8). We Need to Talk About These #MeToos. Star In Her Eye.
https://starinhereye.wordpress.com/2018/01/08/we-need-to-talk-about-these-metoos/

Light, J. (1989) Toward a definition of communicative competence for individuals using augmentative and alternative communication systems, *Augmentative and Alternative Communication*, 5:2, 137-144, doi: 10.1080/07434618912331275126

Light, J. C., Arnold, K. B., & Clark, E. A. (2003). Finding a place in the "social circle of life". In J.C. Light, D.R. Beukelman, & J. Reichle (Eds.) Communicative competence for individuals who use AAC: From research to effective practice (pp. 361–397). Baltimore, MD: Brookes

Light, J. & McNaughton, D (2014). Communicative competence for individuals who require augmentative and alternative communication: A new definition for a new era of communication? *Augmentative and Alternative Communication,* 30.1.18. doi:10.3109/07434618.2014.885080.

References

Light, J. & McNaughton, D (2014). Communicative competence for individuals who require augmentative and alternative communication: A new definition for a new era of communication? *Augmentative and Alternative Communication,* 30.1.18. doi:10.3109/07434618.2014.885080.

Light, J. & McNaughton, D. (2015) Designing AAC Research and Intervention to Improve Outcomes for Individuals with Complex Communication Needs, *Augmentative and Alternative Communication*, 31:2, 85-96, doi: 10.3109/07434618.2015.1036458

Ponce, K.(May 8, 2018) "Communication is not Compliance"; AAC to the Core available at https://aactothecore.com/?s=Communication+is+not+Compliance

Shapiro, (2018). Special Series: Abused & Betrayed, National Public Radio. Available at https://www.npr.org/series/575502633/abused-and-betrayed

Stafford, C. (2018, November 23). AAC and Self-Advocacy. Northwest Augmentative Communication Society. https://www.nwacs.info/blog/2018/11/aac-and-self-advocacy

Villegas, T. (2021, March 17). Students With Limited Verbal Capabilities Can Thrive in Inclusive Classrooms. Edutopia. https://www.edutopia.org/article/students-limited-verbal-capabilities-can-thrive-inclusive-classrooms

Zangari, C. (2017, November 6). "AAC Site of the Month: Centre for AAC (CAAC)". PrAACtical AAC. available at www.praacticalaac.org/praactical/aac-site-of-the-month-centre-for-aac-caac/

References

Zangari, C. (2018, July 30). "5 Ways to Support Self-Advocacy in AAC Learners". PrAACtical AAC. available at www.praacticalaac.org/praactical/5-ways-to-support-self-advocacy-in-aac-learners/

Zangari, C. (2021, December 13) "PrAACtical Questions: What Does a Robust AAC System Look Like?" Praactical AAC; available at https://praacticalaac.org/praactical/praactical-questions-what-does-a-robust-aac-system-look-like/

Resources

The AAC Coach: Speech Therapy, Kate McLaughlin, M.S.,CCC/SLP; AAC resources including free resources and graphics about AAC; available at theaaccoach.com

Kimochis: A program addressing social emotional development; available at
https://www.kimochisway.com

The Language Lady (2020) "Self Advocacy Scenarios and Scripts With Audio"; available at
https://wow.boomlearning.com/deck/self-advocacy-scenarios-and-scripts-with-audio-aac-or-speech-2eXZsYbzjpPzsMXQR

Neimijer, Marco *This Is Not About Me* (September 1, 2021); available to rent at vimeo.com.

Project Core: A Stepping-Up Technology Implementation Grant Directed by the Center for Literacy and Disability Studies, available at http://www.project-core.com/

Zones of Regulation: A programmed approach to addressing sensory needs and emotional regulation; available at
https:www.zonesofregulation.com