Owen's AAC Story: Auditory + Visual Scanning to Communicate, Connect and Discover

Closing the Gap 2023

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Linda J. Burkhart - Financial Disclosure

- Self-Employed
- Paid Consultant and Trainer
- Small Home Business (books and software activities)
- Work with children, families and teams privately
- Volunteer consulting to AT Vendors and product developers

2

Ali Steers - Financial Disclosure

- Full time pediatric speech-language pathologist
- Self-employed at Steers AAC Language & Speech, Inc
- Caseload exclusively comprised of children with complex communication needs
- Performs AAC evaluations, direct therapy and consults/collaborates with schools and teams
- Paid trainer and AAC consultant

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Kristin Cooper - Financial Disclosure

- Mom of Owen
- Day job in tech
- Owen's 24/7 advocate for robust communication access and inclusive spaces

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Owen's Beginnings- Medical

- Emergency c-section due to reduced movement
- Seizures led to transfer to higher level NICU
- Discharged after 3 weeks with a feeding tube
- Diagnosed with infantile spasms in first year
- Spastic quadriplegic cerebral palsy (GMFCS V), cortical visual impairment, epilepsy, etc.

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Owen's Beginnings- Social

- Loves listening to and playing music
- Funny sense of humor
- Determined to do hard things
- Takes role as big brother very seriously
- Loves to win at board games
- Loves adventure, surfing, riding horses

"When practitioners only hear the medical model of Owen, they are often very surprised to meet him. They expect someone different."

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Family Priorities

- Early Priorities
  - I wanted to know him.
    - It always seemed false that I could guess what he was thinking.
  - I wanted him to be happy.
  - I wanted him to be safe.
    - Sickness, injury, risk of abuse
- Evolving Priorities
  - I wanted him to have friends and be known.
  - I wanted him to be fulfilled.
- Priorities that only felt possible after PODD
  - Inclusion, in the community and at school
  - Literacy, as in reading and writing print
  - Self-advocacy

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Research on Safety

"Children with disabilities are three to four times more likely to be sexually abused than other children."

-Rand & Harrell, 2009, as cited in Caldas and Bensy, 2014

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Realities

"If you push for AAC early on in life, people treat you as if you're giving up on your child."
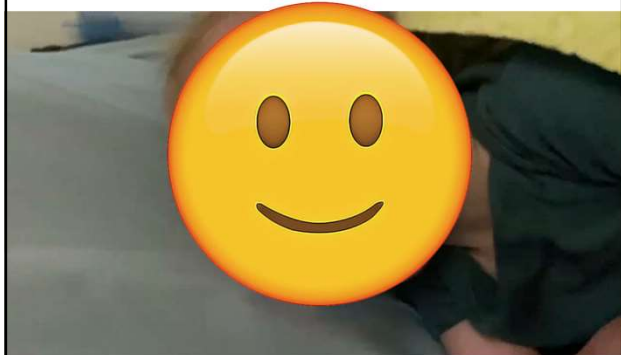- Kristin

But really, saying "we want AAC early in life" means we don't want to place limits on our child

Research shows AAC does not limit speech development and also encourages verbal output.

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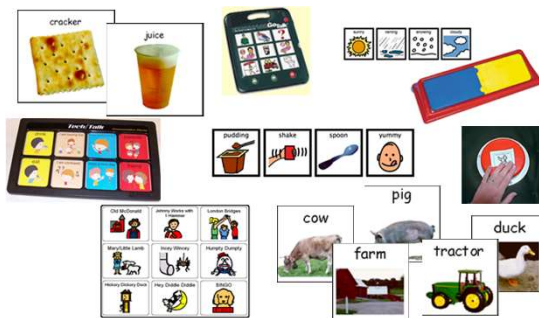## We need communication NOW

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He started to surprise us.

Once he learned yes/no, we thought we knew what he would choose but then he would choose something else and surprise us.

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Historical Strategies for Teaching Language: What were We Missing?

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Offered a Limited Set of Choices

cracker

juice

13

What would you like to eat right now?

14

Here are your choices:

banana   jello

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Choices Help Provide a Means of Active Participation
But

- Being able to say what you want – when you want
- Not the same as making choices!
- Just Indicating a Choice that Someone Else Selects - Isn't Enough to Develop Language

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Choice Making

"The dark mommy side of me wouldn't have offered the drum set as a choice."

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Remembering our Family's Priorities

- Early Priorities
  - I wanted to know him.
    - It always seemed false that I could guess what he was thinking.
  - I wanted him to be happy.
  - I wanted him to be safe.
    - Sickness, injury, risk of abuse
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When young children have significant physical and visual challenges, there is <u>no way to know</u> what they understand or are capable of learning (Porter & Iacono)

- Cannot assume cognitive challenge
- May lack early gestures and visual attention
- Need to be given appropriate opportunities to learn first

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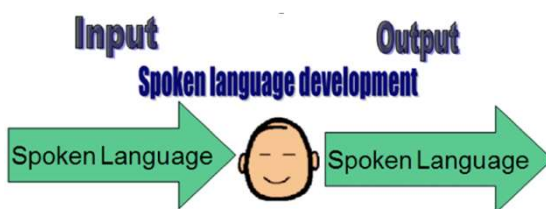**How Do Children Learn Language?**

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Typical children learn language by being <u>immersed</u> in a native language learning environment, where they can freely interact with, and <u>try out</u> their developing skills
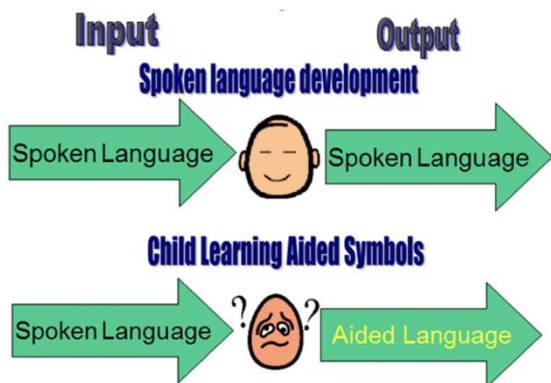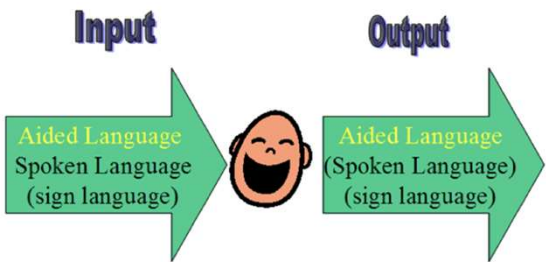

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Gayle Porter, 2004

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Gayle Porter, 2004

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Gayle Porter, 2004

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Learning is Connecting Intent with Movement/Action

Physical, Emotional and/or Cognitive Action

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Beginning development of an active sense of self (agency)

- I can make things happen
- I have some control
- I can advocate for my needs and preferences
- I can move toward or move away from interactions with other people
- I can have an impact on other people

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Learning is Enhanced by Attention to Relevant Components

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What Might Attention Look Like?

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Learning is Dependent upon Active Engagement

- Moving an individual's body through motor patterns multiple times is not as effective as the child having a reason to move
- Random visual stimulation done to the individual is not as effective as helping that individual develop visual curiosity
- Drilling or testing an individual on vocabulary or syntax is not as effective as modeling language with a full range of functions across the day in natural contexts
- Visual identification of letters and words is only one small part of robust literacy learning

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The Brain is not a Video Recorder

memory?

30

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The Brain Builds Understanding Based Upon Patterns

The Brain Craves Patterns

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Our Memory is Stored as Patterns

Get the "Gist"

Not All the Details

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Our Memories are Stored as Patterns - not isolated details

Memories are retrieved by associations

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Language is built upon patterns of interaction

- Without connection, interaction and relationships with other people, language/words have no meaning
- Interaction and contact comes first

Second Language Infant Studies
(Patricia Kuhl 2003)

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Patterns Can be Visual, Spacial, Auditory, Tactile, Kinesthetic, Temporal, Procedural, Cognitive, Linguistic, Multi-Modal, etc.

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Language is a Pattern

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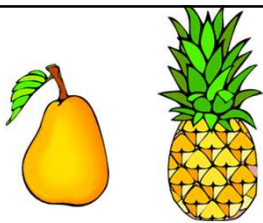
Neurologically, the brain needs a **large** enough set of experiences with **meaningful use of language** to recognize patterns and create meaning

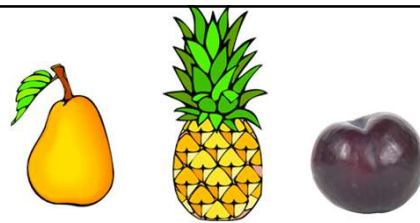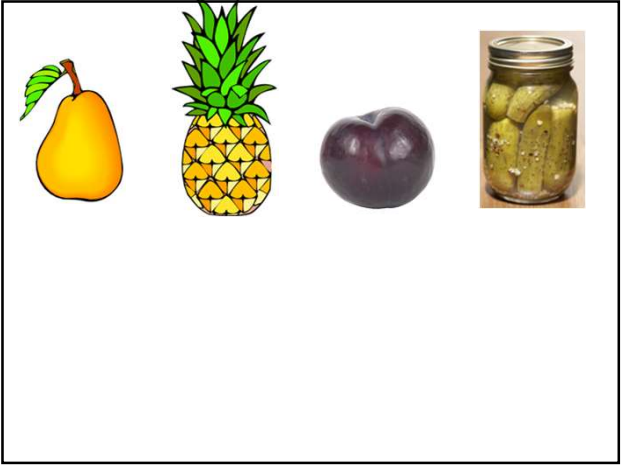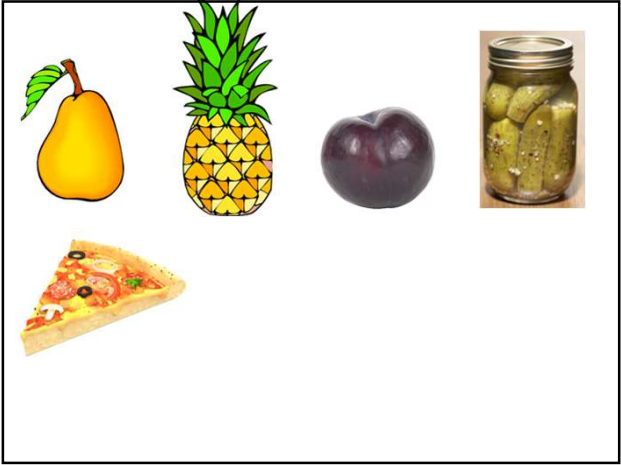**Patterns are harder to recognize from a limited set**

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Clinician Created vs. Longitudinal Robust Language

"What if he wants to say this sucks?"

49

Children begin using language based upon their own agendas, long before they can talk about what we want them to talk about, so others providing options is not how language is learned

Try to maintain topic control when chatting with a typical two year old

50

We need to Provide Enough Vocabulary for the Child to Say What he Wants to Say
When he Wants to Say it!

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Forward Thinking Planning

"Owen needs to learn the language now that he is going to use in the future."

52

Does the individual actually have a language disability or an access to language disability? Accessible language must be used in the environment to be learned

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Cortical Visual Impairment (CVI)

- 60-70% of children with cerebral palsy also have cortical visual impairment (Sandoval, Castlebury & Rice, 2020).

- CVI is often underidentified in children with CP

- Even when CVI is identified, it can be difficult to find appropriate services/professionals

Sandoval, M. A., Castleberry, K, & Rice M. L.; An analysis of the correlation between cerebral visual impairment and cerebral palsy severity at Cincinnati Children's Hospital Medical Center. Invest. Ophthalmol. Vis. Sci. 2020;61(7):2151

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When designing a communication system, some things are non-negotiable, and communication must be the priority, with vision taking a back seat during the communication exchange. Vision skills can be worked on at other times.

A communication system must support <u>autonomous</u> <u>communication</u> at the appropriate language level for that individual!

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The Symbols Were Speech

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Strengths

Very good listener/attends auditorily

Can produce a head shake for "no"

Vocalization for "yes"

Visually regards familiar three dimensional objects in his preferred color

Visual abilities improving with targeted intervention

Social/emotional skills were well developed

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The Symbols Were Speech

With auditory scanning, the symbol system (speech/spoken word) was familiar.

PODD gave him the organization.

"I'm telling you something + it's about now + turn the page + body parts + head + nose + nose + cheeks + cheeks"

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Early ROBUST language

Express genuine messages:

Initiate novel topics/thoughts

Request assistance, actions and activities

Request information

Reject, protest, complain

Draw attention to something

Comment on action/object

Ask questions

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What is PODD?

<u>Pragmatic Organization Dynamic Display</u>

Created by: Gayle Porter - Melbourne, Australia over 30 years of working directly with children and adults

PODD is a <u>language organization system</u>: designed to support communication all day long in any context and is designed to be used receptively as well as expressively

Focus of PODD is on:
<u>Pragmatics</u> -- how language is used (pragmatics)
<u>Discourse</u> (conversation) across all aspects of the individual's life

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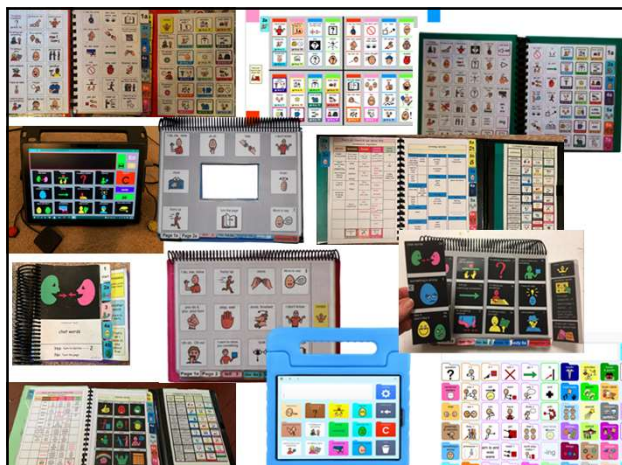
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What is PODD?

Begins at early language development with robustness, but not complexity

PODD continues to build on learned early language patterns through communication books and electronic page sets that systematically move to expanded language functions, to keyword phrases, expanded keywords and then complex syntax

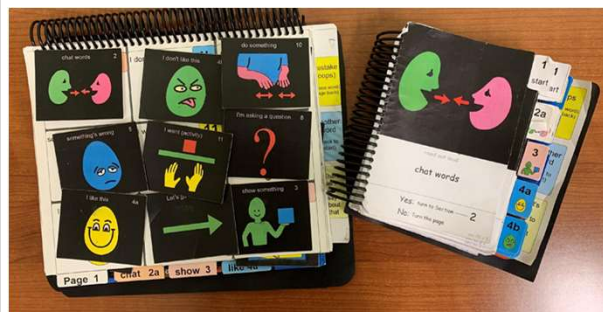**Can be electronic - "high tech" SGD or non-electronic "light tech"**

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What is PODD?

Owning a PODD is not enough, PODD is also how it is used to promote autonomous communication

Designed to be used to support the intervention strategy of aided language stimulation - learning language through natural and genuine interactions

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Owen's first PODD books

Early Functions: One-at-a-time + Companion (PAAVS) PODD

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There are No Prerequisites

From day 1, the primary intervention strategy was "speak PODD."

The assumption- an "access to communication" disorder

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The Juggling Act Working Memory

- **Many things to juggle for both the student and team working with the student**
  - **motor**
  - **vision**
  - **communication**
  - **interaction**
  - **academic learning**
- **Developing automaticity takes time!**

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Children with Significant Motor Challenges - May Require a Great Deal of Cognitive Effort to Move and Stabilize themselves
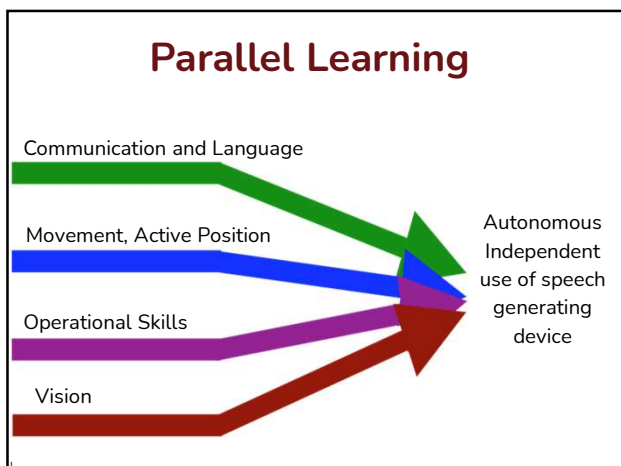
When a child needs to focus on movement and stabilizing, then there is very little working memory left for attention to the play, language or cognitive task

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Juggling Explains Inconsistency of Performance

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Parallel Learning

Communication and Language

Movement, Active Position

Operational Skills

Vision

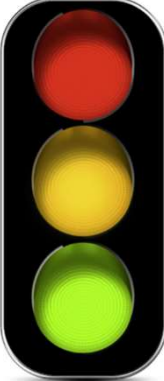Autonomous Independent use of speech generating device

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Focus on one component or skill within each activity, or part of activity

- Reduce motor load for difficult cognitive or language tasks
- Reduce cognitive load for motor learning tasks
- Reduce motor and cognitive load for vision tasks
- Teach access as a separate but parallel skill to language learning
- Only one "hard" at a time

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Hard	language
Easy	vision motor academic

Only one "hard" at a time

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Develop Motor Control and Active Positions

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Teaching Accept/Reject Signals for Auditory Scanning

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Language and Communication Development

"Light Tech" Non-Electronic Communication Book

- Reduce vision load
- Reduce motor load

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Yes/no for partner-assisted scanning

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Vision Development

Functional Vision Assessment: CVI Range, etc.
Appropriate adaptations throughout the day
Reduce motor, cognitive, and language demands

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Switch Play to Develop Motor Skills for Switch Access

- Reduce communication load
- Reduce vision load

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Eventually: Combine Motor and Language Skills to Operate a Communication Device

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Verbal Referencing

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Practice Verbal Referencing

"I like it, it's fun!"

chat words	No
Something's wrong	No
Like it	YES

good	No
great	No
funny	No
fun	YES

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Early Functions: One-at-a-time + Companion (PAAVS) PODD

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12 Expanded Functions (PAAVS) PODD

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12+ Expanded Functions (PAAS) PODD with Sentence Starters

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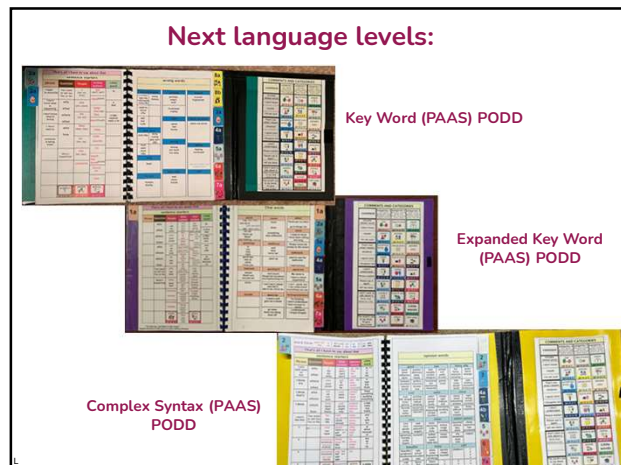## Next language levels:

Key Word (PAAS) PODD

Expanded Key Word (PAAS) PODD

Complex Syntax (PAAS) PODD
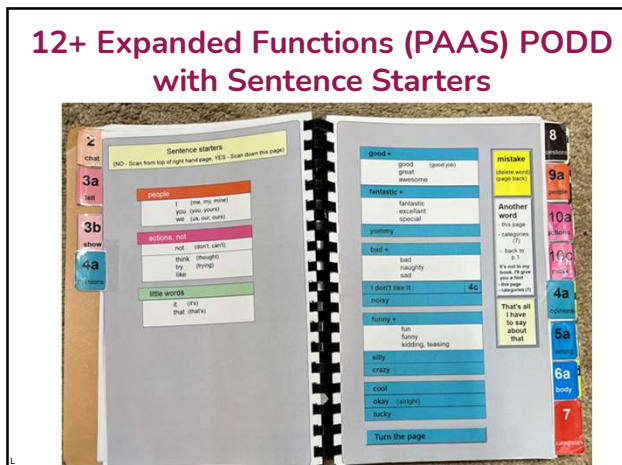
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The Important Stuff

"Everybody wants to know what device/symbol set/switch/etc we are using. What they don't ask is how many times per day am I modeling. How many times do I make sure Owen knows the book is by him."

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Immersion

"It's absurd that we expect a child to hear spoken language for two years before they are expected to speak it and yet we give children who use AAC a two week trial."

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Aided Language Stimulation in Natural Contexts

"Modeling is 90% of the battle. Learning to scan for your child is easy, but modeling is uncomfortable. Pretending it isn't only gets in the way. So embracing that pinch and diving in is so critical. Modeling says so much, your book is available, a communication partner is available, it's a gentle reminder that you can use PODD, it's language acquisition, it shows the missing words in your kids life, it's really the work." - Adam

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Mistakes, Fatigue, Bad Days are Part of the Process

"Sometimes you have to be willing to get it wrong and know that he will correct you."

Oops Mistake!

91

Time

"I actually don't think it takes that much longer to scan for Owen than it does to listen to typically developing four-year-old talk."

The alternative to not taking the time to hear what Owen has to say is...

It takes less time to scan for Owen and hear what he wants to say than it does for me to scroll social media.

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We are an "AAC Family."
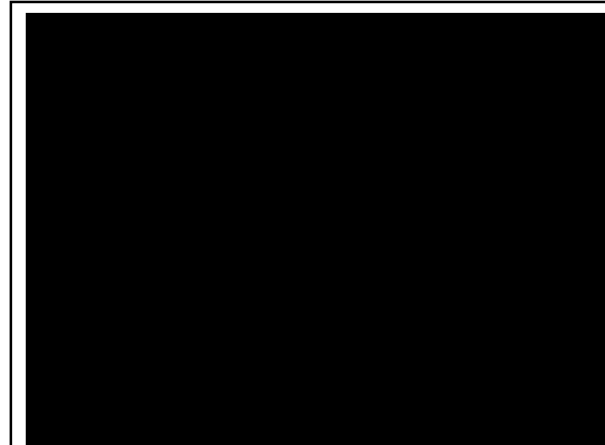
"I feel like I don't have to protect him from his sister."

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"Just being heard can be enough."

"Let's go + home"

"I want + something to eat + taste + water"

"I don't like this + boring"

95

Your Voice is Important

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Medical Team

Doctors have to wait and have to take what he says seriously.

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Be Proud

"I have no social anxiety about modeling for Owen in public. Having our book is a point of pride."
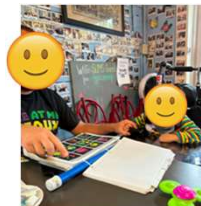
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People Think It's Awesome

"I love being out in the world and people see Owen talking and think it's awesome."

99

It's a Superpower

"Talking PODD is a superpower. I feel really cool when I talk PODD."

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Communication makes the caregiving part of the relationship, not the whole relationship

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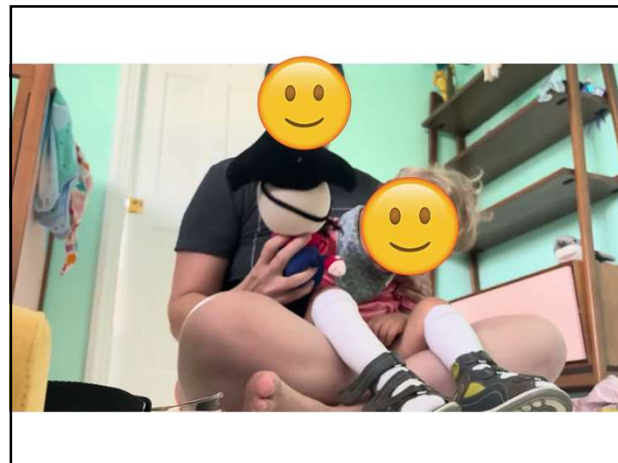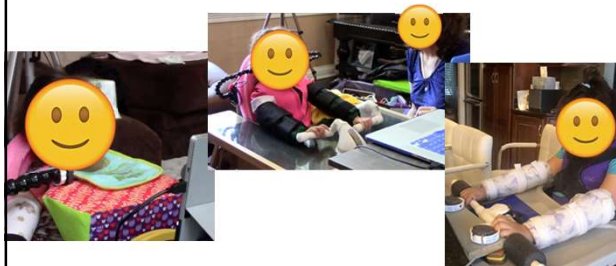## Electronic vs. Non-Electronic

"It doesn't matter if it's electronic or not. What matters is that it should be robust."

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"Catch-22"

Motor skills may need to be developed or refined over many years

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Owen's Launcher?

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Electronic vs. Non-Electronic, Robust vs. Not

"Electronic vs. Non-Electronic and Robust vs Not Robust are entirely different questions and ways of evaluating AAC which have nothing to do with each other. One of the biggest misconceptions I come across is that electronic = robust and non-electronic = not robust. "

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"You're off the hook, parents." - Karen Owens

Have fun.
Play.
Have a relationship.
Connect.
Explore.
Laugh.
All you need to do is speak th
same language.

107

We always have it with us.

"When he was heading to the hospital, we ran the book out to the ambulance."

108

"AAC is language, not isolated tasks."

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Parallel Learning

"Owen had to learn how to use switches."

"I never wanted switch access to an AAC system to be a reason why Owen would be forced to stay in a wheelchair because it's the only way he could talk."

"He shouldn't have to wait to develop the motor skills for switch access before he was permitted to talk."

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"Why would you ever not have both?"

Owen loves to swim. Ride horses. We go to the beach. He loves to swing.

"The technology is not easy to consistently set up and get reliably working well. If we started with the device that we were also just trying to learn PODD ourselves, I don't know that we would have persisted through the challenges and seen the progress that's necessary to keep the momentum going. It takes times, it takes discomfort and if you have to add troubleshooting technology on top of that you're running a very real risk of the whole project not getting off the ground."

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Educational and Social Inclusion

Communication is foundational to inclusion

"Having communication is the only thing that makes the literacy piece seem possible"

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Owen Believes He Lives in a World that Listens to Him

He's always thought of himself as a communicator.

We always knew he was his own person with his own thoughts.

We never "tried to get him to use it." We spoke it around him. We spoke it to each other.

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A Note for Professionals

"Don't make praise comparative. We don't want to know that we are better than other parents because that just lets us know you're judging us all."- Kristin

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Thanks For Joining Us

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References

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