Aided Language Stimulation: Giving Kids the Gift of Language

Meet the Owens Family

Karen Owens
Linda J. Burkhart

Madi
- Oldest
- Typical 11 year old
- Loves gymnastics and YouTube

Gavin
- Oldest son
- Mitochondrial Myopathy

Angela
- Happy
- Determined
- Social
- Spastic Quad CP, 1p36 deletion syndrome
- CVI - difficulty looking and listening at the same time
- She taught us that you never know what a child is capable of

Jayden
- Active / Vibrant
- Adventurous / curious
- Sensory seeking
- Traumatic brain injury
- Cortical Visual Impairment
- Moderate Bilateral Sensory Neural Hearing Loss

Harper
- Quiet and sweet
- Inward Focused
- Easily over stimulated
- 15Q duplication, fetal alcohol syndrome, drug exposure, meningitis, mild hearing loss
Siah

- An observer
- Social
- Chill
- 8 years of institutional living
- Spastic Quad CP, Lobar Holoproencephaly, NF type 2

Developing autonomy and a sense of self is facilitated by use of language

- Children start dependent - rely on others to figure out what they need
- As language develops roles shift
- Becomes 2-way
- negotiation and conversation
- development of autonomy

Children with multiple challenges often have trouble with typical skills that we classify as early communicative behaviors

- Early communicative gestures
- Directed or coordinated eye-gaze for joint attention
- Non-verbal signals

Children with multiple challenges often have trouble with typical skills that we classify as early communicative behaviors

- Lack of early communicative gestures often cue caretakers to continue treating the child as if a much younger child
- Child may not cue adults to begin treating them differently
- Roles remain more one-way - care-taker and cared for

Making Communication a Priority for Children with Complex Needs

- Parents are very focused on medical/physical needs.
- Always had been told that the kids couldn’t handle more than a few pictures at a time
- Saw a post on Facebook that kids with severe challenges were successfully using a larger set of vocabulary

Selection of AAC Systems

- NEEDS:
  - Multiple presentations for vision challenges
  - Multiple access strategies for vision and motor challenges
  - “light tech” and “high tech”
  - Organizational system that is able to be used across children
  - PODD (Pragmatic Organization Dynamic Display) met that needs after many trials with other systems and strategies
Features of PODD that reduce load on working memory

- Requires less sophisticated motor skill

- Systematizes presentation of vocabulary
- Reduces random presentation of symbols that have to be consciously processed as new, each time

- Uses recognition memory - reducing load on recall memory

- Natural branching - eliminates meta cognitive process of planning what link to follow

Has many scaffolds that support early language development

- Pragmatic branches before relying on syntax for intent
- Tense markers for early word forms
- Yes/no intonation marker for early questions
- Plus many others

- Patterns that continue and build across increasing levels of language and access methods
Getting Started

- Belief that every human has worth and purpose
- Belief “every child deserves a robust voice”
- Research, learning
- Acquire materials: Boardmaker, PODD CDs, iPad, Compass/PODD....
- Seek out support and mentors who will fuel your passion and encourage your journey

PODD Modifications

- High Tech vs. Light Tech
- Motor Challenges
  - Access (method)
  - Access (Operational Skills)
- Vision - CVI
- Durability (waterproof, tear-proof paper)

Sisters Chatting using PODD with Visual Plus Auditory scanning

https://www.youtube.com/watch?v=w99Og1b54vc

Angela

- Past experiences: Proloquo2go 4 grid, direct select, Picture symbols for choices, switch access pal pad switch with Accent Device
- High contrast symbols
- Auditory plus Visual partner-assisted scanning (mostly auditory)
- Expanded Functions 12 PODD

Jayden

- Proloquo2go - 8 items direct select, gotalk 9
- Recordable switches on the wall
- PODD started with iPad Compass
  - banging, slapping, stimming
- PODD book
  - High Contrast - 12 expanded
  - Direct Access
  - Flashlight modeling
- PODD Compass on brother’s Tobii then
- iPad Pro (no longer seen as a toy)

Angela using PODD with Visual Plus Auditory scanning

https://www.youtube.com/watch?v=uVNTw42Be5g&t=16s
Jayden Joking with Light Tech PODD: “Excuse me”

https://www.youtube.com/watch?v=PUpTAgaAGMk

Jayden using Light Tech PODD

https://www.youtube.com/watch?v=oRVB5Ry8gNc

Jayden using High Tech PODD for the First Time

https://www.youtube.com/watch?v=mS6N79htS28

Jayden Chatting with Dad

https://www.youtube.com/watch?v=3iPm2Jripso

Harper

- Sign language - input
- PODD - direct access
- Expressive Mini-PODD up to categories - too heavy to hold full book
- Full book is used Receptively - 12 Expanded Functions PODD
- Planning to add high tech iPad mini

https://www.youtube.com/watch?v=qylWwIAVmJQ

Harper Experiments with PODD with Direct Access
Siah

- 8 years of institutional living - no attempt to teach AAC
- 2.5 years ago - began teaching yes/no for answering questions
- PODD partner-assisted auditory plus visual scanning
- Tobii Eye-Gaze Compass PODD 15 added

Getting Started

- Mom created all the books
- Committed to using it all day in all types of environments
- Started with just using Quick Chat
- Focused on one pragmatic branch at a time
- Mom learned and then taught and supported the school
- School was onboard (inclusive learning environment)
- Eventually expanded to extended family members

Intervention strategy:

- Aided Language Stimulation
- Based upon how typical children learn speech
- Receptive input - modeling conversation and “kid talk” in natural contexts
- Step one is for the people around the child to learn and embrace the system
- No pressure for children to use the system or express anything in particular
- Goal: For the child to be able to say what she/he wants to say to whoever, whenever and however she/he wants

Siah Using High and Light Tech PODD

https://www.youtube.com/watch?v=rOFfMWkT9DU&t=33s

Siah Using High and Light Tech PODD

https://www.youtube.com/watch?v=ayKFSvwPzPw

Harper Calms with PODD

Modeling

https://www.facebook.com/wespeakpodd/videos/1093473044056492/
Facebook Group

- We Speak PODD
- Frustration in finding good videos of the process, so wanted to make sure that others can find videos
- Document our own journey
- Ongoing correspondence with families and professionals all over the world

Belief System to Keep Going

- Ok to know that you aren’t going to be fluent right away
- Being vulnerable, and understanding that mistakes and fumbling around are all part of the learning process and actually help children feel comfortable taking risks and making mistakes themselves.
- Not always being perfect, but not beating up on yourself, just getting back on track.
- Keeping in mind why you are actually doing this

Hard for us but Important not to Communicate to the kids that it is hard

- Introducing AAC is a lifestyle change — sacrifices will be made, extra work will be required.
- The work is on the adults, never the children.
- It’s through our sacrifices (time/energy) that we give our kids power and pride in themselves

The Rewards:

- Definitely worth it!
- Developing a more interactive, two-sided relationship with children
- Enjoying the children’s developing abilities and sense of self as an active members of the family
- The children’s pride and ownership of their language
- Impact on behavior challenges
- Change in perceptions of children’s potential by school and community
- Feels like an amazing gift to give to your children

Definitely worth it!

- Best things come when we have fought for it.
- The gift we give to our children, comes at a great cost — “blood, sweat and tears”.
- But unlike working to provide physical possessions, which fade away and lose interest, we are providing them with a tool for life — a tool which gives back to us in the form of reciprocal relationship.
- “The most important thing you will ever do will be within the walls of your own home.”

Developing a more interactive, two-sided relationship with children

- Parents work so hard to complete required tasks to serve their children.
- The relationship becomes one sided – that’s not connection.
- When we give them a voice we are telling them that they deserve and have enough worth to join the connection.
- Examples from our family: Teasing and bathroom talk from Angela, Excuse me - Jayden, Angela having a tool to show empathy “Are you ok?”
**Impact on behavior challenges**

- Our children thrive with routine and familiarity
- When things begin to change or become overwhelming, PODD has given them a constant and a way to find and seek comfort knowing that they can express what they need.
- Even when they may not be actively using PODD expressively, they still find comfort in being spoken to in their language.
- Examples:
  - Jayden: TBI and self regulation
  - Harper: Lack of expressive language, anxiety and social challenges

**Enjoying the children’s developing abilities and sense of self as an active members of the family**

- Ability to say no, and self advocate
- Giving them the opportunity to take family roles as individuals (mother type, funny guy, tattle tale.)
- They have become active participants, not spectators!

**The children’s pride and ownership of their language**

- This is their language and when they hear it spoken throughout their day, they begin to take ownership of it — even prior to expressive output
- Think of traveling to a foreign country. As soon as you hear English spoken, your attention is captured, you become curious and excited!

**Change in perceptions of children’s potential by school and community**

- Now that they communicate - Bar was raised for them - more opportunities
- People see them as individuals that they can form a relationship with
- Show their personalities, opinions and desires
- They are perceived as less vulnerable and become less of a target for abuse.

“Feels like an amazing gift to give to your children”

- We as parents and providers give many things to our kids. Most of those gifts meet very physical needs, especially for complex kids like mine.
- Even though we know in our hearts that our children are more than their diagnosis, our energy often gets focused there and gets stuck there.
- When you give children a voice, you are reaching their soul — the very thing that makes them human.
- You are giving a gift that allows a child to not just maintain life, but have quality of life and actually LIVE life.
- You give them a reason to transition from spectator to active participant.
"Adam and I work hard each and everyday to give all our children the tools they need to reach their full potential. We learned very early on that just because a child may appear a certain way on paper means nothing of what their true potential is.

Each child placed here on this Planet has purpose, and it is our job as humanity to embrace each other and push each other to live lives worth living. We are not spectators. We are participants in this beautiful thing called life.

So that’s what we do. We live life. We truly live life -- which includes communication, experience, connection, passion and risk.”

Additional Resources

- Introductory PODD training - 2 day, or 3 day that has more emphasis on alternative access
- We Speak PODD - Facebook page and Youtube
- PODD and Alternative Access - Facebook page (request to join and email me to let me know why you would like to join)

We Speak PODD on Facebook & YouTube

Handout will be at:
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