

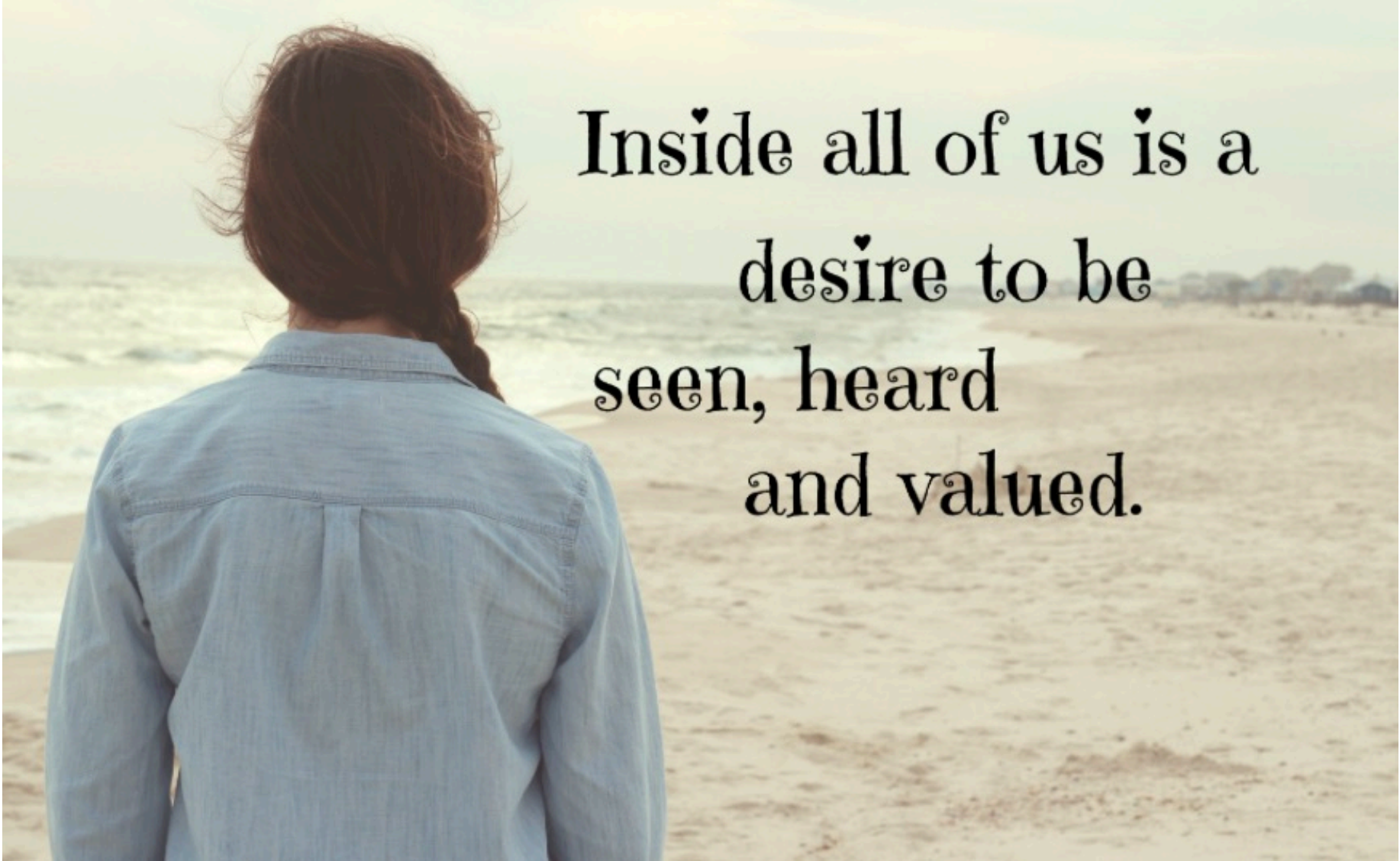
AAC Implementation: Parent Buy-In

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Inside all of us is a
desire to be
seen, heard
and valued.

1. You need to hear our story

Meet Camden



Camden's Story

- Mom almost died during childbirth
- Camden was premature
- At first, all delays were attributed to prematurity
- Deaf?
- Dual Sensory Impairment?
- Solution: DSI – Therapy to “remove prematurity right out of him”

Diagnosis and Prognosis

What the doctors (and the internet) reports:

- Pelizaeus–Merzbacher Disease (form of leukodystrophy)
- There is no cure for PMD, nor is there a standard course of treatment.
- It is caused by an inability to form myelin due to mutations in the [PLP1](#) gene.
- Individuals affected with the severe (connatal) type may die during infancy or childhood, usually of aspiration.

Mom's thoughts

- I will bury my child

It's time to bring Camden home

- This is my new reality
- I have several Masters Degrees and work with children for a living but I don't know how to “do” my kid
- DSI was one of my first lifelines
- How do I wrap my brain around progress in the face of decline?

Meet Nani



Nanie's Story

- Nanie was born typical

At six months old, she had an accident

Medical Perspective

- Fell off of bed? Call CPS
- Hypoxic Endoischemia resulting in cerebral palsy
- Simplify the language and describe her as “a noodle”
- “It’s time it ‘pull the plug’.”
- Let’s be sure mom is “mentally stable”

Mom’s Perspective

- They are judging me as a parent
- I can tell they are “dumbing down the information”
- Dad doesn’t speak English so I am mom and translator
 - Or would be just one more person dumbing it down?
- I have so many questions but if I ask them they will think I’m dumber – trach, vent, NG tube
- I’m working on my GED – I am not trained in this

She woke up.....

She squeezed my finger....

She knew mom.....

It's time to bring her home

- Nursing because she had a trach
 - Stranger in my home
- Prognosis for improvement
 - Still talking about “noodles”
- I don't know anyone with a disability
- If you don't walk in these shoes, you don't know anything

- Then I met my support coordinator. I LOVED HER!
 - She talked to me like a friend
 - She checked in on me here and there
 - She saw me....she heard me....

Meet Bella



Bella's story

- Bella was born with:
 - "low tone"
 - Needed oxygen
 - NG tube
 - Apnea Monitor
- It was two weeks before we had a diagnosis
- I was alone among millions

Diagnosis and Prognosis

Medical

- She will:
 - Always struggle with weight
 - Cognition will be low
 - She will not attend college
 - You will have to lock up food
 - She will need a group home later in life
- No one said
 - She can do....
 - She will learn to....

Mom

- Is this my fault
- Y-linked
 - now my husband is falling
- I don't know about "special needs"
- I don't know about NG tubes and O2 machines
- I have a business degree

It's time to come home

- Home Nurse
 - “Every kid has issues, the difference is you know hers now”
- Therapists
 - Good: looking at what she can do and building on it
 - Bad: showing up late, leaving early, interviewing me so they can write the note, not actually working with Bella
- Thoughts: Show me how to play with my kid

1. You need to hear our story...when we are ready to tell it

Bella -AAC Evaluation –AGE 3

- Trusted OT made the recommendation
 - What if she doesn't understand?
 - What if you tell me she isn't smart enough?
 - What if the device is too advanced?
 - Do they know she is “intellectually disabled”?
- I feared there was nothing going on in there
- Her only communication was clapping – which meant everything

Bella - AAC Evaluation Con't

- The evaluator assumed potential and ability
- Bella pointed to the picture of me and then looked at me
 - “She knew who I was”
- Somebody else sees her
- Bella is human
- They see the whole person – not the body
- “We have help now”
- One word: HOPE

“She (Bella) is in there!”

Camden: AAC Evaluation –AGE 2

- A trusted DSI recommended the evaluation
- He cries at the sight of a switch
- Direct select with his hand is possible from a field of two but skill is likely to decline
- Let's look at eye gaze
- This was a process – 5 visits
- He could find the “horse” and the “dog”
- One Word: SHOCK

“He’s (Camden) is in there.”

Nanie: AAC Evaluation – AGE 3

- Trusted OT recommended an evaluation.
 - Agreed to it if it was at the clinic
 - Still don't trust people in my home
- First impressions: Eye Gaze was “WOW”
- So many questions but didn't ask any of them
- Feeling in one word: EXCITED
 - She can talk to me?!
 - Anything other than crying is a welcome relief

“She (Nanie) is in there”

2. At the evaluation, take your time and validate concerns and potential

3. We have the device – now what?
SHOW ME

Nanie -AAC Training

- Trainer came to the house
- What did the trainer do right?
 - Explained Everything
 - Provided a hotspot for downloading without judgement of no WIFI in the home
 - Talked about hard things – didn't lie and say it was going to be easy
 - The VERY FIRST DAY she could do it
 - Recommendations were to play and explore

Nanie Training (Continued)

- Honor her voice – she picks it she gets it
- Her choices were consistent with her facial expressions
- She cried when we rolled it out of the way
- We never doubted if she “meant to select that”

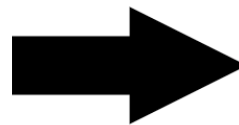
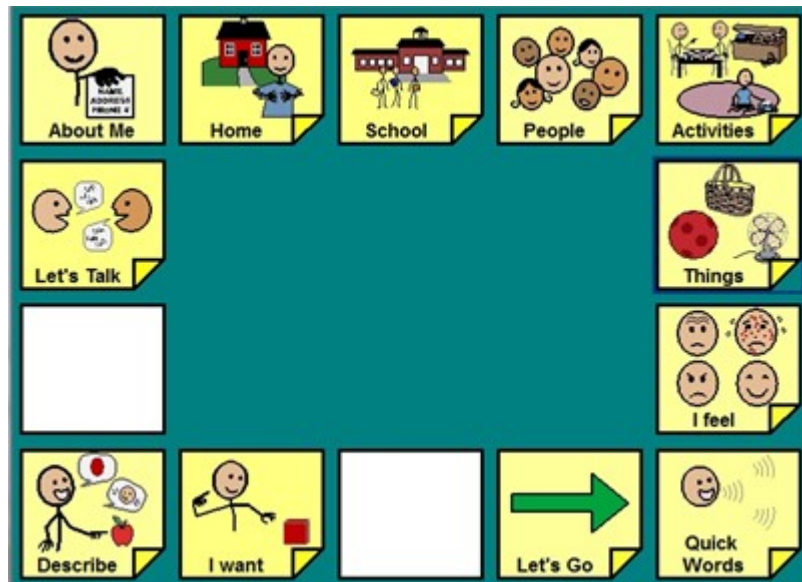
- We still needed a no-tech “yes” and “no”

Nanie: Addressing Access Over Time

- She was still ‘non-verbal’ around her family because her device was not bilingual
- Rolling floor mount was essential for seating and positioning
- Mounting is tricky with a power chair
 - School has a rolling floor mount
- Warm up games each session makes her more accurate
- Standing behind her talker, facing her makes her more accurate

4. Progress them to the highest level of language

- Moved from 12 button to 36 Bilingual



Bella - AAC Training

- My biggest question was “What does talking with a talker look like?”
- The trainer had a logical plan
- Explained every step of the way

- Programming was the furthest thing from my mind

- SHOW ME
 - What does “wait time” looked like
 - What does talking with “a talker” look like

Bella - Therapy with AAC

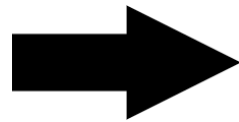
- Showed examples
- Mental shift
 - Expensive equipment → it's her voice
 - On the counter → on the floor
 - Testing → Teaching (hiding buttons)
 - Choice Making → Total Communication
- No tech yes and no

Bella - Addressing Access

- Learning about global apraxia
- Information created understanding and hope
- Turning red upon selection helped to slide to her desired button
- Attracted to recorded speech buttons

4. Progress them to the highest level of language

- 15 button layout with some hidden (4 choices) to 42 to 60



WordPower60 Basic

Camden: AAC Training

- All in – the tablet didn't have the right fit so we created our own
- What did the trainer do right?
 - In the beginning:
 - I needed data so we took data – right on the frig
 - I needed short term goals so she gave short term goals
 - I needed long range plans so she showed me what the device could do down the road
 - I needed homework so she gave be homework
 - We programmed language that his brothers use – he used those words
 - “You're a bugger”

Camden: AAC Training Con't

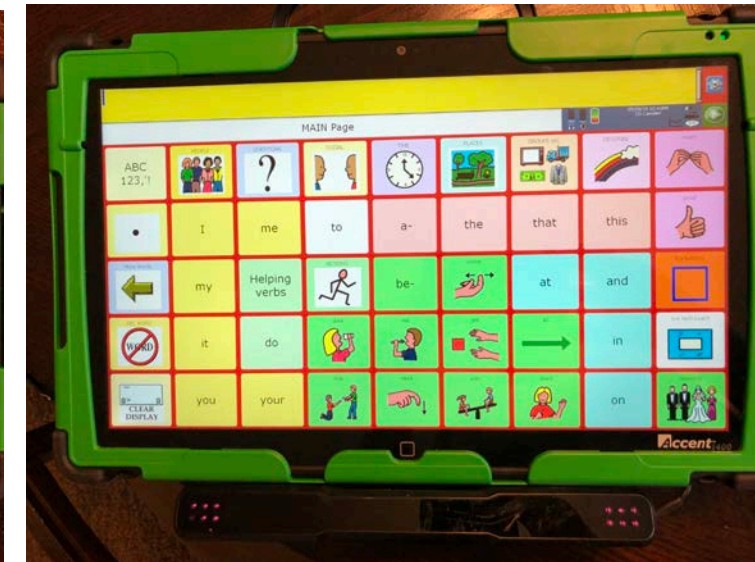
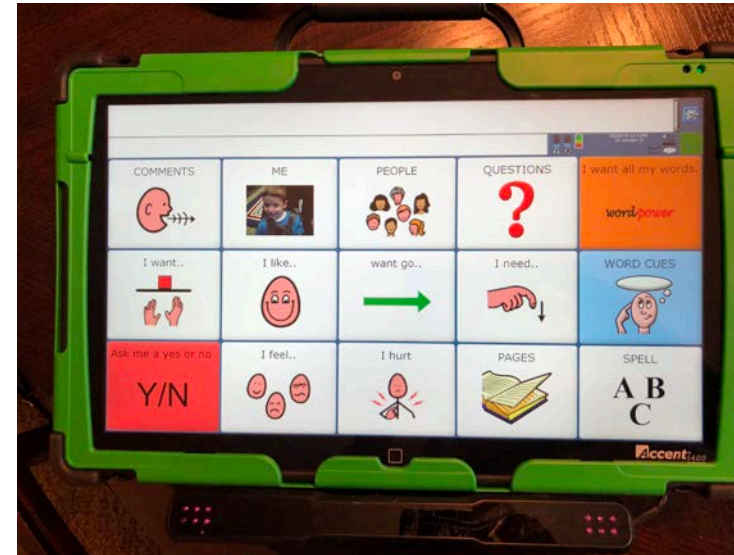
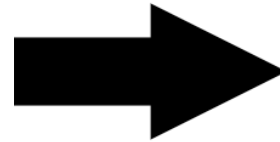
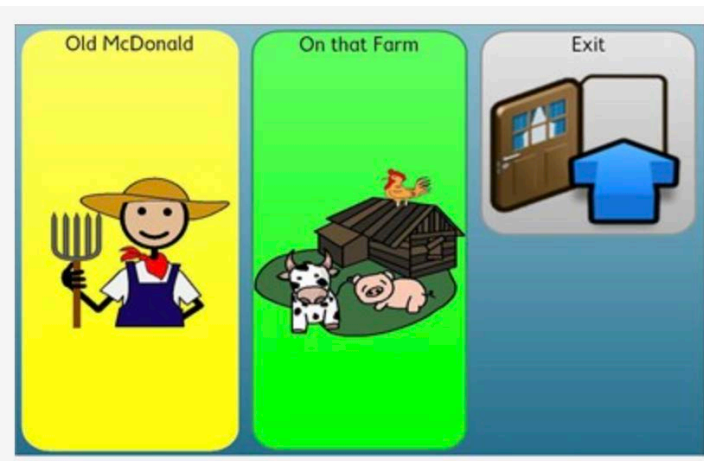
- We programmed buttons for him to control his environment and even rejection –he used them
 - “I > don’t > like > you”
 - ”I don’t like it when you touch my talker”
- We then had to program “I’m sorry”
- Something hurts > its my > foot – AFOs too tight
- It doesn’t look like complete sentences - and that’s okay
- Low tech used in the hospital

Camden – Individualized Approach

- Out of the chair is better for his body
- Eye gaze is still viable even with spasticity
- No tech yes and no
- Switch access is never off the table because there are limitations to eye gaze
- Always have low tech eye gaze available
- Step by Step helps helps to school connection

4. Progress them to the highest level of language

- 4 button layout to 12 to 45 with a 15 option



Camden: What happens at school?

- Preschool: Camden is a lot.
 - Most kids are in a variety of seating systems
 - Camden requires exact positioning to access his high tech
 - Low tech is acceptable
 - He was safe.

Camden: What happens at school?

- Elementary School:
- Camden is exceptional.
- His device use showed High Cognition.
 - Amazing teacher – Mrs. Marsh
 - She sets a high bar and my kid works for her
 - She is not afraid – of him, his diagnosis, his device or his access method
 - She doesn't have all the answers – she is going to give it a try
- Camden meets his IEP goals
- Camden is still safe

Bella: What happens at school?

- Preschool:
 - Lowest functioning classroom
 - Only child who moved
 - Placed due to her being “non-verbal”
 - Playing with toys she had grown out off
 - She was safe

Bella: What Happens at School Con't?

- Elementary School:
 - Amazing teacher – Mrs. Marsh
 - She sets a high bar and my kid works for her
- Accommodations are made for her distractibility
- Communication with my home based SLP helps the teacher understand her skill level
- Bella is challenged every day and meets her IEP goals
- Bella is still safe.

Nanie: What does school look like?

- Preschool: Nanie is a lot.
- We don't do (high tech) eye gaze
- Nanie is happy.
- Nanie is safe.
- Nanie already knows her her colors, shapes, animals, etc – the school staff just doesn't know that

Nanie: What does school look like con't?

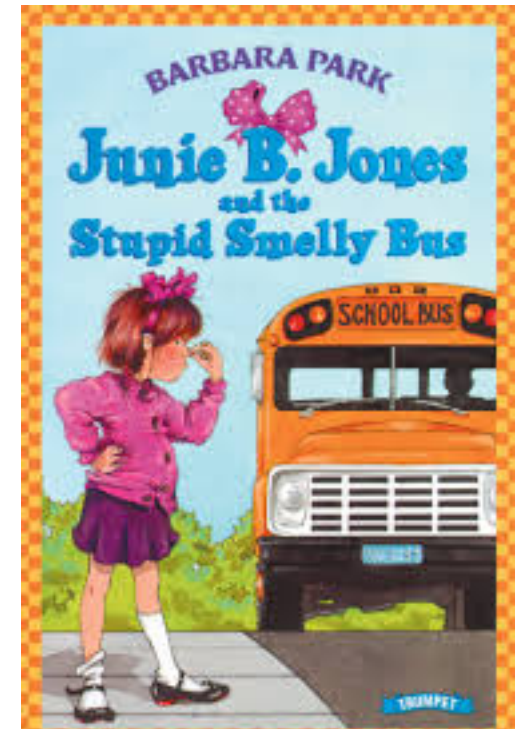
- Elementary: Training, Training, Training was required for teacher buy-in
- Vocabulary was added and pathways were emailed before each unit so the device wasn't hard
- Nanie was extremely accurate so cognition was undeniable
- Nanie meets her IEP goals
- Nanie is happier
- Nanie is still safe

5.It's time to learn to read!

- Letter sound correspondence
- Sight words
- Spelling Patterns
- Reading comprehension

SLP:

- I expected resistance.
- I got TOTAL trust.



Bella: Result of AAC

- No more clapping for everything
- No more buzzer – “ah”
- Reduced tantrums – face smacking
- Responds to “Use your talker”
- Uses alphabet page and word prediction
- Controls her environment
- Bella is a happy girl.....Bella is a healthy girl.....and if she isn't, she will tell me about it!

Nanie: Result of AAC

- Re-evaluation – bilingual device
- She speaks Spanish and home and English at school – like all bilingual children -INDEPENDENTLY
- Everyone knows she's smart
- She know her letters, the sounds they make and has sight words
- She navigates on a 36 button page with EYE GAZE
- No tech yes and no works for everyone
- People talk to her and not about her

Camden: Result of AAC

- True to his diagnosis, it is always changing
- He has options to have 45 buttons or 15 buttons – INDEPENDENTLY
- He can ask for his low tech board
- His yes and no is subtle but consistent
- People talk to him and not about himI hear:
 - Camden told me....
 - I (teacher or nurse) asked Camden and he said...
- My one word about AAC has changed over time
 - First it was shock, then sad, now.....flexible.

6. Recognize you are an important part of this story

...and give grace when we don't do all the things