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 delayed were attributed to prematurity
• Deaf?
• Dual Sensory Impairment?
• Solution: DSI – Therapy the “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 \textit{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
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 > it’s 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 of
  • She was safe
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 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 him .....I 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