

TIME FOR A CHANGE: A CASE STUDY ILLUSTRATING A COMPLEX CHILD WHO HAS PLATEAUED IN AT USE

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What we will be covering today:

- A detailed case study of a child with significant visual and cognitive impairments, as well as significant sensory needs.

Case Study

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Rachel

- Rachel
- Age: 19 years
- Diagnoses: cerebral palsy, hydrocephalus, seizures, optical nerve atrophy



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Initial Evaluation

- Rachel was referred for evaluation by her speech language pathologist for positioning and access for communication
- Rachel was 12 years old



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Current Positioning

- Wheelchair Seating
 - Quickie IRIS tilt in space manual wheelchair
- Freedom Designs linear seating system
 - Generically contoured seat and back
 - Full length hip guides
 - Anterior trunk vest
 - Lateral chest pads
 - Foot straps
 - Large contoured head support



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Current Positioning

- In this seating system, Rachel sits with the following concerns:
 - Hips abducted
 - Feet turned outward
 - Upper trunk flexed
 - Neck flexed
- She tends to tuck her left arm under the vest style anterior trunk support, under her bandana, and prop her head on her left hand
 - Sometimes sucking the bandana or her hand



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Current Positioning

- Alternative Positioning
 - Rachel also spent time
 - on her tummy or side on the floor
 - Sitting cross legged on the floor
 - Sitting on the couch
 - Sitting in a rocking chair



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Positioning Assessment

- Support needs
 - She actually needed **very little** support in sitting
 - She reportedly leans into whatever support is provided
 - She reportedly sat in the worst posture in her wheelchair! As a result, she spent little time in it at home.



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Positioning Assessment

- Why was Rachel sitting in this flexed position?
 1. She has no functional vision
 - Visual input activates certain righting responses to keep the head upright
 2. Rachel was withdrawing in this seating system with a lack of stimulation
 - She was seeking some sensory input by sucking on her bandana or hand



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Positioning Assessment

- Sensory Needs
 - When provided with sensory input, Rachel often lifted her head and was more engaged
 - In her rocking chair, she actively rocks with upright head and increased alertness and interaction with others



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Positioning Assessment

- Sensory Needs
 - Recommendation:
 - Dynamic Seating!
 - Kids Rock Dynamic Manual Wheelchair to encourage rocking



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Positioning Recommendations

- Recommendations
 - Rachel trialed a Kids Rock for 2 weeks
 - She clearly enjoyed the movement
 - Demonstrated increased alertness
 - Improved posture



She is playing with an iPad, so her head isn't up in this picture!

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Access

- Access for Communication
 - Rachel had been using her left hand to activate a switch placed on the left side of the tray or on her left leg
 - She perseverated on this switch, hitting it repeatedly
 - Rachel was using the Dynavox Maestro at this time
 - She subsequently changed to a PRC Accent 800.



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Access

- Access for Communication
 - Prior to my initial evaluation, her Speech Language Pathologist, Jill Tullman, moved the switch to the right side of Rachel's head to encourage a more upright head position and Rachel was doing well
 - Question – should we relocate a switch solely to improve head position?
 - Not if switch access is compromised
 - In this case, switch access was good



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Access

- Access for Communication
 - Recommended a head support which could support an AbleNet Spec switch by the right side of the head and a speaker embedded in a pad by the left side for auditory scanning



Stealth
Products
Comfort Plus



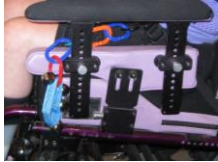
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Sensory Needs

- Rachel seeks out sensory input and is much more alert and engaged with this stimulation
- Sensory choices were already on the communication device – yeah!
- Encouraged to continue to provide these choices

Bells on MWC



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Results

- Rachel received a new seating system and a new Dynamic Manual Wheelchair
- She continued augmentative speech therapy to develop language and communication using her new switch by the right side of her head



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Rachel

- Rachel loves Hippotherapy and the sensory input is great!




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Second Evaluation

- Rachel was now 17 years old
- Positioning
 - Seating needed to be replaced
 - Mobility base had been discontinued
- Access
 - Rachel was having difficulty with switch access at the current location




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Time for a Change

- Rachel had been well supported by her seating system
- Rachel had done well with the dynamic movement in the wheelchair
- Switch access had become more difficult over time and, as a result, Rachel was not communicating to her potential
 - Her communication had plateaued
 - Did she have more potential?




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Time for a Change

- It is common for needs to change when working with complex clients, particularly children. Growth, medical changes and interventions and more require us to follow-up on clients regular and reassess, as needed



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Positioning Assessment

- Current Positioning:
 - The Kids Rock dynamic wheelchair was over 5 years old
 - Foam was compressed and worn and needed to be replaced
 - This base had been discontinued and we needed another solution
 - Rachel continues to seek out sensory input and frequently rocks in this base



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Positioning Assessment

- Recommendations:
 - new tilt in space manual wheelchair with a Dynamic Back and Dynamic Footrests
 - new linear seating with contoured cushion, linear back, lateral trunk supports, lateral pelvic supports, head support, and anterior trunk support



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Access for Communication

- Current Access
 - Exact switch placement by the head had been difficult as her resting head position varied
 - Her head remained forward much of the time due to lack of vision
 - Slight switch placement adjustments were made at this location



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Access for Communication

- Current Access
 - Rachel had been actively reaching out to touch the communication device display
 - She was not accurate as she cannot see the display and the icons are small
 - We set-up the communication device to respond to Rachel touching the screen as a switch activation. Rachel could use either her switch by the right side of her head or touch the screen to make selections.



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Results

- Rachel received her new seating system and manual tilt in space wheelchair with dynamic seating
 - This worked well for her
- Rachel continued to use both the repositioned switch at the right side of her head and touching the display for access

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Rachel

- High School Graduation!



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Third Evaluation

- Rachel is now 19 years old and uses an Ablenet Specs switch at her right side, using her left hand
 - She crosses over midline
- However, she tends to perseverate on the switch, activating this numerous times in a row.
 - Much of this is a self-stimulation behavior
 - Reduces ability to communicate
- She had less perseveration by her head, but is more motivated to use the switch by her hand
- What to do???



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Repeated Switch Activations

- Rachel was so focused on hitting the switch repeatedly that she wasn't listening to her choices and making intentional selections
- She liked hearing the clicking noise of the switch
- She liked hearing the communication device begin speaking and then be interrupted by a switch hit
 - She was rapping!
- And it is kinda fun to annoy everyone around you!



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Repeated Switch Activations

- Rachel had used a communication device for many years
- She knows how it works
- How do we convince her to stop perseverating and use the switch intentionally?
- This behavior was significantly impacting her ability to communicate
- She had **plateaued**

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Third Evaluation

- I set up a Switch Latch and Timer (SLAT) between the switch and the communication device
- A slight delay was set on the SLAT so that repeated switch activations were ignored
- This worked! At least during the evaluation... we loaned the SLAT to the family to try for a period of time
- This continued to work, and Mom came up with a great set-up for Rachel!



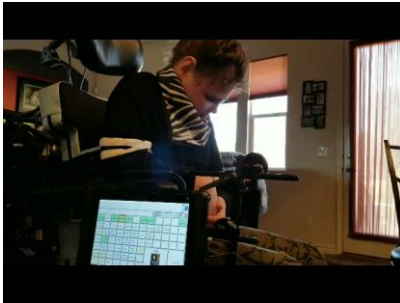
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Video

This video shows Rachel rocking in her new wheelchair, moving the Dynamic Back.

Mom points out when the SLAT is mounted



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Video

- Here, Rachel is reaching across her body and activating the switch appropriately, without repeated switch activations
- She is listening to the auditory cues
- Turn your volume up!



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Video

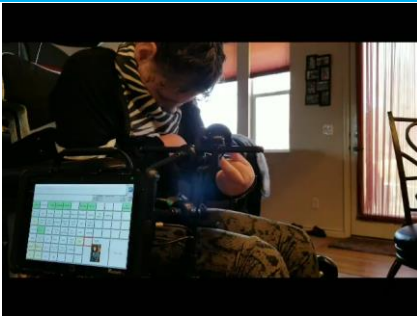


- Here we can see that Rachel still has a tendency to activate the switch multiple times, but the SLAT is allowing the communication device to ignore most of the extraneous switch hits.
- Also, this is not reinforcing the behavior, so Rachel does not perseverate all the time

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Video

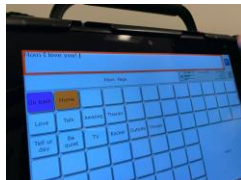


- Most of the time, her access is very appropriate
- This has allowed her to communicate more functionally and continue to progress

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- Rachel is a great communicator!

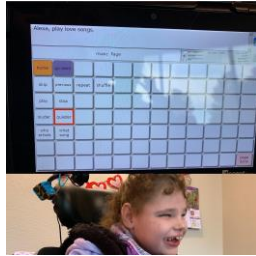


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More than Communication

- And she loves to tell Alexa what to do!
- Control of devices in the environment is critical for independence and participation!



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Take Home Message:

- The clients we work with have one thing in common – CHANGE
- Changing needs can sometimes lead to a client plateauing or even regressing in functional abilities
- We need to reassess as a team to help our clients continue to progress

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Thanks!

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Questions?

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