

Addressing **MULTIPLE NEEDS** for a Child with *Cerebral Palsy*

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MANY ASSISTIVE TECHNOLOGY ARTICLES cover a specific area or application of assistive technology. I believe it is helpful to step back and look at everything in context periodically and to “put a face on it.” In this article, I would like to introduce you to Mackenzie.

Mackenzie is a 5-year-old girl with the diagnosis of cerebral palsy. She is non-ambulatory, non-verbal and her gross and fine motor skills are significantly impaired. She also has a very strong will and a killer smile. I first met Mackenzie when she was 4. Her speech language pathologist, Jill, had referred Mackenzie to me to evaluate her positioning and access. Jill was working with Mackenzie to determine the most appropriate speech generating device (SGD) to provide independent communication, but Mackenzie was positioned poorly, greatly impacting her ability to use her body to access the device. So, I took the long drive out to the house and met Mackenzie, her mom, her physical therapist and Jill.

The home was full of equipment—therapy balls, mats, a stander and a few different adapted chairs. Mackenzie was on the floor, her usual spot, showing off her extension and trying very hard to see everyone standing around her. I introduced myself to everyone, got some consensus on the team goals and went to work.

POSITIONING

I started with positioning. Without stability, Mackenzie was going to have quite a bit of difficulty accessing an SGD or anything else. I placed Mackenzie in each of her seating systems and evaluated the results. None of these adaptive seats provided the level of support and stability she required to do more than maintain sitting without falling over. She tended to extend her pelvis and rotate forward on the left. Her arms and legs were extended, scapulas protracted, and her head was typically flexed forward.

With Mackenzie seated in one of these bases, I placed her pelvis in neutral and held her in this position with my hands. With her pelvis in a neutral alignment and stable, her extension in her legs was greatly improved. Next, I moved onto her trunk. While holding onto her pelvis (being an OT, I really have four arms), I also pulled back on the anterior

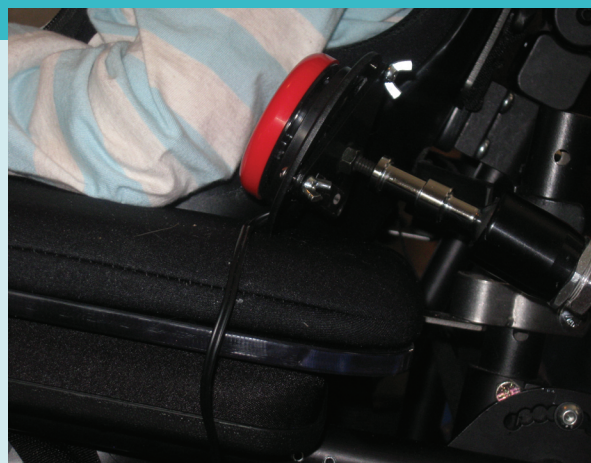
shoulders, providing scapular retraction and upper trunk extension. Now, Mackenzie was able to hold her head upright and her arms were no longer in extension. She required a seating system that could maintain her pelvis in neutral and provide trunk extension and scapular retraction.

The seating system needed to prevent the posterior upper pelvis from moving back and also keep the pelvis from sliding forward anteriorly. A custom molded seating system (Aspen Seating Orthosis or ASO) was fabricated to hold the pelvis snugly posteriorly and laterally. A pelvic positioning belt placed at 60 degrees helped to maintain the pelvis in this pelvic well. A build up in front of the ischial tuberosities (sometimes referred to as an anti-thrust) helped to prevent forward sliding/thrusting. A build up between the knees also minimized hip adduction—a component of extension.

Aggressive pelvic positioning was required as Mackenzie would not tolerate any restraint of her feet. Allowing those feet to move around makes sustaining a neutral pelvis very challenging. She was able to tolerate a dynamic anterior lower leg strap to minimize knee extension and keep the feet on the footplates. She uses this intermittently. The back of the ASO positioned the chest just posterior to the pelvis, which promotes trunk extension and also wrapped around the sides of her chest for lateral support. A chest harness supported the trunk and

Mackenzie < minimized her tendency
requires more < to pull forward, which
practice to learn < had led to head flexion
how to sustain < and upper extremity
contact with < extension. The last
her elbow, as < component to be decided
she is so used < upon was the head
to activating < support. Although a
this only < neutral pelvis, trunk
momentarily in < extension and scapular
scanning. < retraction greatly
< assisted an upright head
< position, Mackenzie
< tended to hyperextend
< her neck. In combination
< with her reflux, this
< placed Mackenzie at risk

MACKENZIE USES A SWITCH MOUNTED
BEHIND HER LEFT ELBOW. >



for aspiration. A Stealth i2i head support was recommended. This uniquely shaped head support provides support under the occiput to encourage a neutral head position.

WHEELCHAIR

A tilt-in-space manual wheelchair was recommended as a dependent mobility base. Mackenzie required a tilt to assist with her positioning, minimize reflux and manage fatigue. The base folds, as the family does not yet own an accessible vehicle. The ASO is removed, the base folded and everything fits in the trunk of the car. Mackenzie is delighted with the shiny purple frame color.

ACCESS

I was anxious to look at access at the initial evaluation, despite not yet having an adequate seating system. Enlisting several members of the team to literally hold Mackenzie at the hips and shoulders, I started looking for a switch site. Even with optimal positioning, Mackenzie did not have adequate motor skills for direct (finger to display) access of the SGD. She was going to need a switch to activate the SGD through scanning. One switch activation would begin the scan (the SGD was set up for row column scanning). The rows were scanned first. When the correct row was highlighted, Mackenzie needed to activate the switch again to begin a scan of the columns within that row. When the desired choice was highlighted, final switch activation selected and spoke that choice. Mackenzie needed to access a switch numerous times throughout her day to communicate with others. We needed to identify an optimal switch site and type. An ideal switch site uses a small, isolated, non-reflexive, repeatable movement.

When assessing a client for an ideal switch site, I tend to follow a hierarchy. I typically start at the hands. Mackenzie's upper extremity movements were mostly in a large pattern of bilateral extension and adduction. This pattern also pulled her head forward. Although she was able to press a switch placed distally and midline on a tray, the movement was large and pulled in a lot of overflow. This takes too much time and effort. Patterns of movement tend to worsen when utilized repeatedly as well. Release of the switch can also be more difficult when using a pattern of movement. Finally, Mackenzie needed to see the SGD

display and this pattern tended to pull her head, and eyes, down. Next on the hierarchy of switch sites is the head. During the initial evaluation, Mackenzie did not yet have adequate head support. She was also not used to keeping her head up very much and so head control was only fair. She was unable to activate switches with her head at the time.

Next on the hierarchy are the lower extremities. As with the upper extremities, Mackenzie did not show isolated control in her legs, but rather moved these in large patterns of extension and adduction. After the lower extremities come the upper extremities. We had looked at the hands, but I wanted to go back to other arm movements. With some effort, Mackenzie was able to overcome the strong extension pattern of movement and pull her left arm back into elbow flexion. A switch was placed behind her left elbow (see photo), and she began to pull back and access this. The movement was difficult, as her tone tended to pull her forward, but the movement was small, isolated and accurate. She began scanning through choices on the speech language pathologist's SGD. Mackenzie was very excited! Of course, we were, too.

It was going to take some time to get funding approval for a new seating system and speech generating device. In the meantime, we modified one of her adaptive seats as much as possible and Mackenzie started practicing with a switch on a universal switch mount accessing a loaner SGD. She also practiced with switch toys to provide independent play and a variety of motivating practice opportunities.

EQUIPMENT DELIVERY

Finally, funding approval was obtained, the seat was fabricated and secured to the manual wheelchair, and the SGD and mount arrived! I returned to Mackenzie's home to ensure her access was still optimal after months of practice and in her new seating system. She was tolerating the new seating system well. Minor adjustments had been made and I made a few more to optimize her positioning and function. Mackenzie's team stated they

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would like the switch placed in front of her, distal and midline on the tray again. This site was re-evaluated, but this position continues to lead to upper extremity extension and adduction patterns of movement as well as neck flexion. The site behind the left elbow continues to work well for her. Mackenzie can activate this repeatedly, accurately and with a small, isolated movement. She can also keep her head upright during access. She is using an AbleNet Jellybean switch on a universal switch mounting system and a permanent mount is being ordered (ASL armrest mount). She is able to use her SGD very well and is expanding her vocabulary. One of her favorite activities is to control her Buzz Lightyear remote controlled toy through the Prentke Romich Vantage Lite SGD. This toy is controlled by infrared commands that can be “learned” by this SGD. She can make him move forward, backward, spin and even dance!

FUTURE NEEDS

Now that positioning, access to the SGD and play were addressed, we had one more major area to explore: mobility. Mackenzie does not have the motor control to use any type of manual wheelchair. She uses a gait trainer with very limited mobility. For functional and independent mobility, Mackenzie was going to need a power wheelchair. Mackenzie is using an SGD with multiple pages of vocabulary, so she certainly has the cognitive skills to understand how to use a power wheelchair (a typical 24-month-old child can drive a power wheelchair).

I told Mackenzie I was going to be her motor and the switch behind her elbow was now “forward.” When she activated the switch, I pushed her manual wheelchair forward. When she let go of the switch, I stopped. We added a switch at either side of her head for directional control using universal switch mounts. Mackenzie was able to activate these switches fairly well while positioned in her new seating system and with the new head support. When she pressed the switch by the left side of her head, I moved the chair to the left, and moved the chair to the right when she activated the switch by the right side of her head. Mackenzie requires more practice to learn how to sustain contact with her elbow, as she is so used to activating this only momentarily in scanning. The next step: I planned on seeing Mackenzie again soon with the equipment supplier and a loaner

power wheelchair (placing the ASO into this base) for a more formal power wheelchair evaluation. Given her age, we would record her driving and send in a DVD with the report to help with funding. However, I don’t accept her funding source, so she went to a local seating and mobility clinic which does. They completed this last step.

She will require a power wheelchair that can support driving with three switches, has a power tilt (for the same reasons she requires a manual tilt) and that has the required electronics for her to control the SGD through the power wheelchair access method. This will require one more switch (a reset or mode switch) that will allow Mackenzie to choose which mode the wheelchair is in. In drive mode, the three driving switches will control forward, left and right. The power wheelchair can be programmed so when the mode switch is activated, the chair enters power seating mode. Now those driving switches will control the power tilt. For example, the left switch may tilt the chair back, and the right switch may tilt the chair forward. When the mode switch is activated a second time, the chair will enter an auxiliary mode. Now, the forward switch will send a signal to the SGD for communication. Another mode switch activation will return the chair to drive mode. The mode switch can also be used to access reverse and speeds if these features are enabled.

Mackenzie still has a long way to go. Although she has had a formal mobility evaluation, funding will probably be a battle and she will require some mobility training for optimal use. The family will need to explore an accessible vehicle once a power wheelchair is obtained. Years of speech therapy will be required to continue to develop Mackenzie’s language skills and expressive vocabulary. Eventually, she will be able to use the SGD to control a variety of devices in the home, such as audiovisual equipment and even a power door opener. The SGD can also be used as an alternative computer access method for schoolwork and other tasks. Identifying an optimal positioning system and a means to access assistive technology are only the first steps, but very important steps indeed.

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