The Gift of Play

By Jody Roberts

Christmas time has always presented a series of challenges for our family. But it also provides us with amazing opportunities to take many of our favorite family traditions and adapt them so that our daughter, Helena, can participate. Helena has severe cerebral palsy (CP) that leaves her in need of significant support. She also loves to bake, listen to and play music, and think about what gifts to get for her family – especially her cousins.

Choosing gifts for Helena, however, can be difficult. Almost anything will require some level of adaptation; most require direct (and constant) effort by an adult. As she gets older, we want to find activities and games that support Helena’s autonomy, but the quadriplegia manifested by her CP presents a significant hurdle.

Last year, based on her own stories from school and notes from her teachers, we discovered that Helena thoroughly enjoyed playing the Wii set up at her school – especially if the game was a dancing game. It made a lot of sense given her love of music and dancing, so we began exploring ways in which we might adapt the activity to allow her to participate at home (mostly) on her own. We knew that some of the more sophisticated motorically-centered games (driving games or other games requiring accuracy of motion) would not work. Could we make the dancing games, which require little motion of the controller to register activity or motion, more independent?

A few months before we got the Wii, we had an opportunity to visit the WREX team at Nemours, A.I. DuPont Hospital in Wilmington, to explore the exoskeleton system they have been developing. WREX (Wilmington Robotic EXoskeleton) is the brainchild and sweat of Tariq Rahman and Whitney Sample (and some collaborators) that takes a different approach to orthotic support. Rather than providing static, solid support, the system provides more fluid, dynamic support to allow movement within a specified range of motion (watch this amazing video to get a better sense of how WREX operates at www.youtube.com/watch?v=tvqZJkSNz0w). Looking at the setup, it reminded us of floating – a sense that the limbs were in water, untethered from the weight of gravity and free to move.
Helena has been working with an aquatic-based NDT therapist for almost her entire life. To watch her in the water is to forget just how difficult it is for her to move her body when she’s on dry land. Sitting in her chair, she struggles to coordinate gross and fine motor skills. But in the water, she kicks independently, flops like a whale, and throws her arms attempting to pull herself through the water. Her experiences in the water have largely guided our philosophy and approach on land.

- Give her just enough support to free her body to do its own work.
- Use our own bodies to help guide hers.
- Help her learn when to quiet her body as well as when to be active.
- Make the work fun.

Between our experiences with aquatic therapy (and land-based yoga and stretching) and the recent visit to the WREX laboratories, we dreamed up a contraption that might make independent play with the Wii possible. We started knowing that we would use Helena’s stander, which would create more space and opportunity for movement of her arms and hands. Firmly grounded and without her tray, she could theoretically move her arms in almost any direction. We also knew that we could secure the Wii remote to Helena’s hand using the vintage technology known variously as the rubber band or gum band, depending upon one’s geolinguistic roots. But even the weight of the Wii remote is too much for Helena to operate effectively in this position. This is where we integrated our experiences of the pool and the WREX program.

We wanted to simulate these two models to ensure Helena’s arm could hold the controller at a chest-level height that would allow her to focus on side-to-side motions and not worry about up and down. A few quick sketches in the notebook and a quick trip to a hardware store resulted in what follows.

Using some small diameter PVC piping, screws, and washers, we mounted supports to the back of the stander and then using elbows brought the structure up over Helena’s head. Using two metal hooks, we attached one extra-large rubber band to each hook and placed one end of the loop at Helena’s elbow and the other at the wrist. The result, as we hope you can see, was pretty amazing. We broke out the new dance games and watched as Helena worked (almost) independently to dance with her sister.
The set-up is in no way ideal (sometimes the horizontal arms launch!), but it worked just enough to provide Helena with some much needed autonomy and to inspire us to think about other uses for the contraption. Painting and, to a limited extent, baking are also possible. And we still find ways to dance together. Sitting on the edge of a bench sharing the control provides another opportunity to test out our ability to mimic some signature Michael Jackson moves (a current favorite, quite understandably). And we keep tinkering. What if we attached hair bands to our fingers so that we could grasp things together? How can we keep her head up better so she can see what she’s doing and feel more control of her body? How can we make the orthotic look more welcoming so friends and family don’t see a barrier but an invitation to play?

We know we’ll never land on a simple solution. But we also know Helena will keep working every day and so will we.

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