

Seating to Maximize Participation and **OTHER** Related Information:

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A CASE STUDY

IMAGINE THAT YOU HAD TO DO EVERYTHING

you love sitting in one chair. Not one chair at a time...just one chair. Maybe it's not even a comfortable chair. Many families face challenges like this as they try to include children with disabilities in many activities that we take for granted. The Plasters are one of those families. They live near the coast of Southern California. With their three kids, they enjoy the lifestyle that the area offers — regular visits to the beach, as well as camping trips to the mountains and desert. These outings include their teenage daughter, Robyn, who has Type II Spinal Muscular Atrophy. Robyn has never been ambulatory. The weakness that limits her movement doesn't dampen Robyn's enthusiasm for outdoor fun and other activities with her family.

A MOVE TO CUSTOM MOLDED SEATING.

Seating was a difficult challenge in all of Robyn's mobility systems, including her everyday chair. Robyn had "growable" rods incorporated into a spinal fusion at a young age. While the fusion stabilized her spine through the fused area, the upper and lower ends of spinal alignment were left at the mercy of gravity and positioning devices. Robyn had a variety of wheelchair mounted seating over the years, including planar, air flotation and off-the-shelf contoured systems. All of those systems allowed enough movement of her body away from midline for the development of deviations away from alignment in her spine at her lower spine and pelvis and neutral at her neck. [See photo at top right on page 29.]

In 2008, at the age of 15, Robyn reluctantly agreed to consider a full contact orthotic seating system. It was difficult to find the 'right spot' using off-the-shelf seating, and progressive deviation in the curvature at her neck was causing problems with function and fatigue. She had been leaning to the left through her trunk for years and compensating to the right with her head for balance. Those of us experienced in working with high functioning clients with a severe physical impairment know any change in equipment is traumatic even when the benefits are clear. We struggled for a year with refinements, such as how the system mounted to her Permobil C500 with tilt and full recline, the shape and firmness of the back and seat cushion, and how to preserve full recline with a custom orthotic system. It was a big learning curve for both of us.

It seems to be a widespread belief that kids with MD generally won't tolerate custom molded systems. They often prefer little or no contact and to use whatever they have for independent

balance and function. Frequently, they will find balance by leaning on one elbow or balancing forward in an anterior pelvic tilt. The unfortunate result of little or no support for kids with low tone is the progressive collapse into destructive postures that ultimately limit or altogether prevent healthy posture and function. So many of those kids present as adults with more than 90 degrees of lateral flexion, or such a hyperlordosis they can no longer rest back on a back rest, and must either rest their ribcage on their thighs, or hang off a chest strap. The earlier we can encourage these kids to learn to rest with a healthy posterior tendency into seating that promotes upright, neutral spinal extension, the greater the likelihood they will maintain healthy spinal alignment throughout their lifespan. One therapist who specializes in children with Duchene's MD recommends full contact orthotic systems as soon as the child needs a power chair. Only time will tell if this strategy can help avoid some of the spinal misalignment that is so common at present.

In Robyn's case, she has a wonderful and persistent physical therapist by the name of Christy Malonzo at Precision Rehabilitation. Robyn and I had both tried to give up on the Ride system several times, but Christy knew what she wanted for an outcome and just wouldn't let it go. After almost an entire year, the kinks had been worked out and the seating system was comfortable. Once Robyn was able to develop new strategies to participate in the activities she enjoys, she was an immediate fan. With the increased core stability she gains from the seating, she has been able to improve her upper extremity function, as well as head alignment and control.

RECLINE AND CUSTOM MOLDED SEATING

It seems to be a widespread belief that kids with MD generally won't tolerate custom molded systems. Too many kids with progressive neuromuscular conditions who are seated from an early age emerge into their teens or early 20s with severe contractures in their hips and knees from a lack of regular change of body position. A 2005 review of the available research on ergonomics for seating in the office environment for able



TOP: POSTURAL EVALUATION AT PRECISION REHAB
 (NOTE: LEFT LEAN AND CORRECTION THROUGH NECK)
 BOTTOM: ROBYN WITH HER NEW RIDE SEATING ORTHOSIS

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abled individuals came to this conclusion, “The only truly effective way to maintain a seated posture for extended durations is to continuously cycle through a range of natural, centered and healthful positions,” (review by Rani Lueder, 2005). That statement is no less true for a person with a disability. “The concept of “dynamic sitting” is endorsed in the ergonomic field for individuals who use office furniture and workstations (Kroemer, 1994) and should undoubtedly be applied to wheelchairs as well, since many wheelchair users may not have the extent of dynamic movement as able-bodied office workers,” (RESNA position paper on Tilt and Recline).

Robyn has been fortunate to have power seating that includes tilt, recline and power legs for most of her life. Through the regular use of recline and power legs in combination with a regular stretching program, Robyn has full range at her hips, knees, shoulders, elbows and wrists. The question was how would custom molded orthotic seating affect her ability to continue to move?

Since the advent of powered seating, problems associated with recline, shear and movement of the back support in relation to the user’s torso have been recognized as a cause of potential risk of injury to users. In a 1997 article on the application of powered seating, the use of power recline with custom molded seating was given a “Not Recommended” indication with the comment, “The use of an aggressively contoured back in combination with power recline systems presents a problem. The offset of the axis of rotation of the seating system is not the same as the person’s, therefore, when the person reclines, the backrest shears or moves relative to the person. This causes the back to no longer fit appropriately.” (David Kreutz).

In the years that have passed, power seating technology has come a long way. The shear reduction mechanisms are more effective, and the custom molded back supports don’t have to be so bulky, keeping the client closer to the pivot points on the seat mechanism. However, in current seating products, even with great improvement in the technology, the perception persists that a custom molded system with an intimate fit is not

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...Other Random Information

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advisable when used in combination with power recline. A recent article on recline included the statement, "For someone who has a molded seating system, recline is not generally advisable [...]. As you recline, the contact with the mold does change. So it no longer matches the individual's body shape because you're changing the position it's being used in," (Aug 2010, *Mobility Management*).

The research based evidence available shows us that the health and functional benefits of dynamic positioning make it worthwhile to take another look at the combination of custom seating and recline. There is no question that caution must be used when an aggressive positioning interface is combined with dynamic positioning like power recline. For most clients, we teach them to limit the back travel to 20 degrees of recline to reposition their upper body for different functional tasks when the seat base is horizontal. When the seat is fully tilted first, then more recline can be used without shear or misalignment problems. The final fit, backrest travel and fit on the client's torso through the range of movement to be used must be reviewed carefully before the final system is released to the client. The safe use of the system must be combined with a diligent skin check and conservative 'break in' program, starting out with short sitting times that increase over the next few days. Over the last three years in our program, we have provided nearly 100 custom molded seat systems on power and manual tilt/recline combination systems with no skin trauma or shape misalignment issues related to the dynamic movement. It can be done.

Robyn's situation was unique in that she is very sensitive to the firmness of the seating interface, and also was adamant that she be able to recline all the way to the 150 degree limit on her seat system. The support system on the Ride custom seat includes a raised 'candle' on the back of the cushion to provide enhanced posterior-

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TOP: DRESSED FOR HALLOWEEN

MIDDLE TOP: IMPROVED CORE SUPPORT MAKES PAINTING EASIER

MIDDLE BOTTOM: BOWLING WITH HER SISTER

BOTTOM: FIRST TIME IN THE SAND



IN HER POWER BEACH CHAIR



READY TO HIT THE DUNES

lateral pelvic support, taking the load off the bony prominences. This shape effectively prevents more than a few degrees of recline. To overcome this limitation, Joe Bieganek, the founder of Aspen/Ride, made a hybrid Ride Cushion with a soft cantle by using the firm proximal thigh support from the custom Ride and the soft cantle from a Ride Forward, and then put a layer of reticulated foam over the entire base to give it a softer feel. The end result is that Robyn can safely use the full range of powered seating on her chair, and still benefit from the aggressive positioning that comes from the orthotic seating.

SEATING FOR ACTIVITIES OUT OF THE WHEELCHAIR

The improvement in the seating on her wheelchair had made a dramatic improvement for Robyn, but a big seating problem remained. There are many activities that Robyn enjoys participating in that cannot be performed in her everyday wheelchair. The Ride system was now working great in her everyday wheelchair, but it must be mounted permanently to the wheelchair and can't be used in other activities outside of her wheelchair. When on outings, Robyn uses a power beach chair, an Omegatrac power chair for off-road camping use, an adaptive bicycle pedaled by family, and is the passenger in a Razor 4x4 off road ATV. Besides those devices, there are a range of activities that do not include a "chair," such as sitting on the sand at the beach, during which she needs to sit to enjoy. For Robyn to be comfortable, safe and functional in all of these activities, she really needed a transportable solution that could replicate the orthotic seating that could easily be moved to a variety of

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surfaces. A year ago Robyn was provided with an Aspen Seating Orthosis (ASO), a fully-integrated portable version of the Ride Custom Seat and Ride Custom Back. The ASO is not wheelchair dependent, and makes it possible for Robyn to sit wherever and on whatever she wants.

The first picture her mom sent me came with the note, "We went to the beach on Sunday even though Robyn had no wheels. Her seat was her chair in the sand and she built sand castles with her cousins." Since then, the family has sent several pictures of Robyn enjoying lots of activities that are facilitated by her portable seating orthosis, which are included here. The norm for custom seating has been, for the most part, produced and funded for attachment only to a wheelchair. As awareness of the possibilities for adapted participation in more activities of normal daily living with portable custom seating becomes widespread, wouldn't it be nice if every kid had access to this kind of technology and participation for the experiences that facilitate physical, social and cognitive growth and development?

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...Other Random Information

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OUTCOME MEASURE SURVEY

I thought the outcome was great, but it doesn't really matter what I think. What did Robyn think? Robyn was one of the first participants in a pilot run of a Custom Seating Outcome Measure Survey that was developed as a collaborative project by Lori Knott, OT, and Jen Birt, OT, of Manitoba, Canada, and myself. The survey asks questions about customer satisfaction across a range of seating factors, such as skin integrity, pain, effect on posture, heat, moisture, function, etc. The questions are answered on a six-point scale from "completely agree" to "completely disagree" (similar to the FEW), with six being the most positive response to the factor.

Robyn reported gains in many areas, with no loss of function, no skin issues and no decrease in outcome scores in any area. She reported an incremental one point improvement in stability and comfort, and larger gains in the areas of posture, fatigue and positioning. The problems with swallowing due to poor neck positioning went away with the new seating. She reported a gain from a two in her old system (mostly disagree) to a six (completely agree) in her new system on the question. "I am able to stay in the right spot in my seating equipment." Her mother noted that the number of times she needs to reposition Robyn in the seat decreased from 15 times a day to twice. Her score for the question on fatigue ("Sitting up in my seating equipment does not cause me to feel fatigued") for the old seating was four (slightly agree) due to the constant loss of position, and is now a six (completely agree) in the new seating.

At present time, about 20 sites across the United States and Canada have volunteered to participate in the Custom Seating Survey in an effort to gather further objective data on the value and outcomes of custom seating. Two of those sites are supplier business. The remaining sites are clinical settings such as rehab clinics, hospitals, etc. There will be great value to all suppliers to have objective outcome data. The act of measuring outcomes helps to justify funding, improve our practice standards and internal process and validates the quality of work we are doing. If any of you are currently a Ride custom seating provider, and wish to participate in the survey, please contact me by e-mail. ➔

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TOP: DESERT DOGGY TRANSPORT SERVICE
MIDDLE: CHILLIN' AT THE CAMPSITE
BOTTOM: BIKING WITH THE FAMILY