

BENTLEY: ON TIME-POWERED MOBILITY BECOMES PART OF EVERYDAY FAMILY LIFE

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The cumulative experiences of our clients are one of the most valuable resources we have. A case study should be a story. A story we can listen to, read, learn from and share with our clients. This is the story (so far) of Bentley. Bentley is a 4-year-old boy with the diagnosis of arthrogryposis. He lives on a ranch with his parents and older brother outside of Colorado Springs, Colorado. The first part of this story is told by his mom in Bentley's voice.

THE CHILD – BENTLEY AND MOM

Hello! My name is Bentley. I was born in January 2018, but my story starts before that. When my mom was pregnant with me, they found out that I would be born with a condition called arthrogryposis multiplex congenita (AMC). This meant my joints would be contracted at birth, and there would be little to no development of the surrounding tendons, ligaments and muscles from lack of movement in the womb. I am affected in all four limbs including my shoulders, elbows, wrists, fingers, hips, knees, ankles and toes. Before I was born, the doctors were also worried about my lung and jaw development as I would have had trouble breathing if the related muscles were affected. Although these were not affected, my mom had to be monitored every week until I was born.

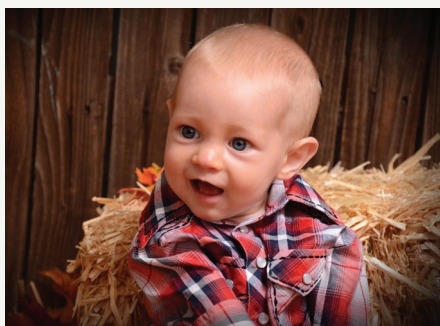


FIGURE 1 Bentley as a baby.

When my mom was 37 weeks pregnant, the doctors told my parents it was time for me to be born. The next day they went to the hospital, and I was delivered by cesarean section. I came out longer and weighing more than they thought I would! From the minute I was born I have been proving doctors wrong and making progress!! When I was just a few hours old, I met all my specialty doctors and some therapists, and they started on my care plan. When I was only a few days old, I started physical and occupational therapy. My therapists worked together for an entire year and got more movement in my limbs, got me into clothes and into a regular car seat instead of a modified one!! I still go to therapy one to two times a week with each therapist to work on my range of motion, mobility and independence goals (see Figure 1).



FIGURE 2 Early chair trial

When I was 6 months old, my therapists started working with me on how to drive a power wheelchair and figuring out what modifications I would need (see Figure 2). With my condition, I was unable to crawl, but I could scoot around the floor on my bottom using the backs of my hands for

support. The doctors and therapists hope someday I can walk, and we are working toward that goal. I will only be able to walk short distances before getting worn out and will have to have mobile support of some kind, hence the wheelchair. This started a long process that took my parents, the therapists, doctors and Numotion team more than a year to complete. Everyone took notes, did a lot of research, took lots and lots of pictures, and wrote a bunch of letters to the insurance company. The power wheelchair was denied, because I was too young and would grow too fast. The reasons for denial were endless and repetitive, and we proved every reason they gave wrong, yet they still denied the chair.

Over the course of that same year, I had two corrective surgeries on my feet and ankles. I spent months in full leg casts and then boots and bar braces. My only mode of getting myself around was



FIGURE 3 Bentley in his post-op bracing

scooting on the floor, and I could not do that in a cast or braces. My parents had to carry me around and when they set me down, I was stuck. Boy, Let me tell you, I was MISERABLE (see Figure 3)!

Finally, at the end of 2019, we put in an appeal to go to court with the insurance



FIGURE 4 Helping dad around the yard

SINCE I GOT MY CHAIR, MY LIFE HAS CHANGED SO MUCH! I CAN MOVE AROUND SO MUCH EASIER, AND I CAN MOVE AROUND BY MYSELF AND KEEP UP WITH MY FAMILY AND BE MORE INDEPENDENT!

company. The court date was set for January 7, 2020, and the day after Christmas we got the call that my power chair had been approved!! So finally, after fighting for a year and a half, I got my power chair – just before my second birthday!!!

Since I got my chair, my life has changed so much! I can move around so much easier, and I can move around by myself and keep up with my family and be more independent! I love to be outside, and now instead of sitting in one spot, I can move around and help out! I love having my own chores to do like helping around the house inside and out. Outside I love playing with my brother and chasing him and my cousins around, helping dad in the garage and playing with the tools he needs, helping mom with the gardening and watering the plants, helping take care of the animals and watering them, and just moving things and helping out around the property. Inside I love to help with vacuuming and cleaning, as well as helping mom and dad cook and helping mom bake — but most of all I love tasting everything!

Even now, out in public, I can have my chair instead of having to be carried around, and I can explore more and look at things myself — and maybe even add some things to the shopping cart when mom and dad aren't looking!!!

I love having my chair and the newfound freedom and independence it gives me, and I'm so thankful to my care team and parents for fighting for me and not giving up until we got my chair!! I'm so happy to have the amazing people in my life who care enough to fight!! I hope we can make it easier for other kids like me with limited mobility to get the equipment they need without as much of a battle one day (see Figures 4 through 7)! I also sometimes use my gait trainer (see Figure 8)!

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FIGURE 5 Hiking with his family



FIGURE 6 Bentley guiding his pig at a 4H event. His father made a special bracket that allows the guide for the pig to be mounted on the chair.



FIGURE 7 Giving big brother a ride!



FIGURE 8 Occasionally using the gait trainer

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THE EQUIPMENT — LINDSEY REA, BS, ATP

Bentley and his family have been amazing. I have learned a lot together with the clinical team, including Joanna Prosch, OTR/L, CHT, and Ellen Gaspar, MPT, from Children's Hospital of Colorado. As noted, Bentley was first exposed to a power wheelchair at 6 months old. After trialing the chair for five months, he was unable to accurately maneuver using a micro-light joystick or maintain contact with the joystick handle for more than a few seconds. He next tried a Stealth Products Eclipse tray and proximity switches mounted under the surface and showed significant improvement in moving the chair. Each driving experience provided more exposure to the idea of moving through space using the chair.

Bentley worked with the power chair again 10 months later, while the power wheelchair request for funding was in process and after multiple appeals. This trial was to show how Bentley's ability and cognition had continued to develop after the initial evaluation. After having not been in the power wheelchair in some time, Bentley did great. He was able to drive independently using the joystick and did not need assistance for hand placement. He struggled with some upper extremity movements secondary to his condition but compensated with elbow and trunk movement. Remember above when he talked about how awful it was to be immobile after surgeries? The chair allowed him to independently

access and explore his environment, as any kid his age should/would be able to. Additional delays in motor development, and social skills would occur without the ability to independently access his environment.

In January 2019, an order was submitted for Bentley's first power chair. The Permobil Koala Mini-Flex, a compact lite joystick (on a midline mount with tray cut-out to accommodate this position) and remote stop switch were recommended. The chair was first denied by insurance in March 2019 due to having "features the patient is not currently able to operate independently, and safety is a concern given the need for a power stop." Bentley had demonstrated the cognitive ability needed to learn, take direction and operate the chair appropriately within age-appropriate parameters.

Even though Bentley showed improved skills and greater need for powered mobility, his claim was once again denied in October 2019 due to "lack of documentation that lesser costly equipment had not been tried," even though self-propulsion had been ruled out. Clinical notes and pictures were provided

MOBILITY IS ESSENTIAL FOR KIDS TO GROW, EXPLORE, AND FIND INDEPENDENCE THAT WILL CARRY THEM THROUGHOUT LIFE



FIGURE 10 Lindsey and PT, getting his new chair

indicating that a manual wheelchair was tried and found unsuccessful. Additionally, the suppliers listed 16 dates the selected equipment was tried with increasing improvement in skills. A hearing was scheduled for January 2020, though the chair was finally approved in December 2019 after video documentation was provided.

Bentley's chair was finally approved and delivered in early 2020. Bentley's mom reported she is thrilled because "he can do things with his brother and keep up and play with him. He can also do activities with the family when we are outside, and we don't have to leave him behind." Bentley loves to help with chores around the house and ranch. His driving is extremely accurate. He can even back into small spaces without bumping into anything or needing assistance. His mom even jokingly added he is exploring so much they should put a cowbell on him to know where he has gone off to!

Bentley's dad stated "When we are in a store or out in the community, everyone is so amazed at Bentley in his chair. They are patient with him. People will compliment how well we are doing as parents with him and how his brother helps him and interacts with him. People show more patience with his driving and move for him. Everyone is so amazed at his abilities."

Mobility is essential for kids to grow, explore and find independence that will carry them throughout life (see Figures 9 & 10).

THOUGHTS – SUSAN JOHNSON TAYLOR, OTR/L

In helping to facilitate and compile this case study, I had heard so much about Bentley that I needed to meet him and his parents! I was less interested in the



FIGURE 9

Bentley LOVES to try to work with tools. Once out of the chair, he went immediately to Lindsey's tool kit so he could get started!

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THERE IS NO WAY FOR PARENTS TO SHEPHERD THEIR CHILD WITH MOBILITY LIMITATIONS THROUGH CHILDHOOD TO INDEPENDENCE, WITHOUT SELF-INITIATED MOBILITY.

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"medical and therapy" aspects and much more interested in the child/family aspects of this case. One day, I met Bentley and his parents at the Numotion branch for repairs. After talking with his parents, we made the decision to increase Bentley's speeds and provide him with access to powered seat elevation.

Dad said they have instilled in Bentley the notion if he wants to do something, there is a way. Sometimes he needs help getting there and sometimes he doesn't. He stated Bentley helps around the yard with the hitch on the back of the chair. This allows Bentley to pull brush and other things around the yard as it is collected, which Dad says is quite helpful! The family hunts, so the bracket that holds the guide for his pig, also holds a shotgun used for hunting under his dad's hands-on guidance (see Figure 6). Bentley's parents also incorporate his gait trainer as an additional way to get around. He may even use the gait trainer at the next 4-H event to show the family pig (see Figure 8)!

As I was commenting on Bentley's very independent attitude, Mom related a funny story to which many parents can relate. She said Bentley will sometimes refuse to follow through with a request. She asks, "Who is in charge?" Reluctantly Bentley will answer, "You are." "Then what do you need to do?" replies Mom. "What you said... ." Indeed.

This is a family, like so many we see, who make it happen for their child. There is no way for parents to shepherd their child with mobility limitations through childhood to independence, without self-initiated mobility.



Scan the QR code or go to <https://b.link/v2ags> to watch videos of Bentley using his chair.

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Lindsey Schubert Rea, BS, ATP, works for Numotion in Colorado Springs, Colorado. She has been in the Complex Rehab Technology industry since 2002 and a credentialed ATP since 2004. Rea served several terms on the Board of Directors for the Cerebral Palsy Association as board secretary during 2009-2010 and then for two terms as board president. In 2017, she received the Chuck Wilson Lifetime Achievement Award from Numotion. Rea co-wrote and presented the Numotion webinar "CRT in the Schools: Identification, Collaboration and Incorporation" in 2021. Rea is happily married to her husband, Scott, and they have three boys, Connor, Jackson and Aidan.



Susan Johnson Taylor, OTR/L, is an occupational therapist who has been practicing in the field of seating and wheeled mobility for over 40 years. She has worked primarily in the Chicago area at the Rehabilitation Institute of Chicago Wheelchair and Seating Center (now the Shirley Ryan Ability Lab), the Shepherd Center, and the University of Tennessee Rehab Engineering Center. Susan has published and presented nationally and internationally. Taylor is both a member and fellow with RESNA. She is currently a member of the Clinician Task Force and the RESNA/ANSI Wheelchair Standards Committee. She is a Certified member of the International Society of Wheelchair Professionals. Johnson joined Numotion in 2015 and is the Director of Training and Education. Taylor is also a Friend of NRRTS.