

NATURE VS. NURTURE

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So, this is not going to be a “normal” case study but rather a combination of several cases. Why? Because I am still seeing 10-year-old kids come into my clinic in chairs that are too large, too heavy and poorly designed for their actual needs. So, this article is going to cover two kids who I was lucky enough to start working with when they were very young, and I’m still seeing to this day.

I’m hoping to highlight many of the worries that people seem to have about putting kids in minimal positioning and lightweight pediatric wheelchairs. Plot spoiler ... for the right kids, this is just what they need.

When I first started in pediatrics, I had previously worked with adults following spinal cord injuries, so I was already a bit biased toward rigid lightweight wheelchairs. Additionally, I had the opportunity to work with athletes who use wheelchairs. Many of these athletes had been using a manual wheelchair throughout their lives. These individuals were high functioning, very independent and many had the smallest hip widths I’d ever seen in an adult.

These athletes were the opposite of what I was seeing in my clinic. Older kids seen for the first time in my clinic were mostly overweight and had a low activity level. Was this the natural result of their disability or was it due to their equipment?

Most of these kids were in folding frame wheelchairs that, despite five years of use, were still at least an inch too wide. The center of gravity was often so far back that the child couldn’t effectively propel the wheelchair. Add on heavy positioning equipment that wasn’t really necessary, and the wheelchairs were difficult for these kids to propel. With a chair that hard to propel, it makes sense that these kids would prefer to be sedentary. I know I would have made that choice (everyone who knows me knows how true that is)!

Twenty-two years in my clinic have shown me that it is not likely to be nature leading to these sedentary tendencies. I work with a great cohort of kids who have been active and remained at an appropriate weight / body mass. Do all of these kids live in families with strong follow-through? Some do, others don’t. Do I spend a lot of time telling the families about future implications to current activity levels? Absolutely! I know that makes some difference, but my telling a family about the importance of wheelies and participating in sports can’t be the only reason these kids are at an appropriate weight and are more active.

So, could it be the wheelchair style and set-up? I think it could! Here are a few examples:

JOSH:

Josh is a great young man with a complex medical history including C6 quadriplegia secondary to transverse myelitis, diabetes, a mitochondrial disorder and seizures. I didn’t meet Josh until he was 5. At the time, he was in a wheelchair that was too large and too heavy for him, and he was having a hard time propelling. (Full disclosure, he was seeing a doctor next to my office, and I saw him. I told his mom that I needed to see him and help. Yes, I have been known to stalk kids in my clinic.)

Josh’s original wheelchair weighed well over 45 pounds, and he only weighed 37 pounds at the time. He had a heavy planar back and a head support that his head never touched. The wheels were set about 3 inches further back than they should have been. He had no seat slope at all, so he tended to slide forward in the chair (see Figure 1).



FIGURE 1 Josh in his first wheelchair when I met him. Note how far back the center of gravity is.

“HE DOES WHAT HE WANTS TO DO, AND HE IS GETTING READY TO GET HIS LEARNER’S PERMIT THIS YEAR. HE KNOWS THAT HE CAN LOAD HIS CHAIR INTO THE CAR BY HIMSELF ONCE HE IS DRIVING. NOTHING IS SLOWING HIM DOWN FROM ACHIEVING WHAT HE WANTS TO DO IN LIFE!”



FIGURE 2 Josh in his first new chair from my clinic. Note the center of gravity..

We took Josh out of that chair and got him into a lightweight rigid frame pediatric wheelchair with lighter seating components and no head support. This chair also had a much more appropriate center of gravity and seat slope. The seat width was much closer to his sitting width (see Figure 2). It was also almost 20 pounds lighter than his old chair!

Once in the new chair, Josh was much more active. He started propelling more and did not want others pushing him. Whenever he would come to our clinic to see his doctors, he’d spend a lot of time going up and coasting down the ramp to my office.

Over the years, Josh has had a couple of new chairs. All have been configured tightly to him. He had a hip width of 10.5” in 2013, and his new chair was set at 12” seat width. In 2018, his hip width had only increased to 12.5”, and we set his seat width at 14”. All have lasted the recommended five years with minimal growth and adjustment over that time. I just saw him a week ago, and he’s still got plenty of room in his seat width. Truthfully, most of the work done has been to fix his chairs as he is really active and a little hard on his equipment.

Josh likes tearing up chairs so much that he now plays wheelchair rugby (see Figure 3). He loves it, and he’s learning a lot from the guys on his team (some good, some bad, but what can you do?). He’s done martial arts from his chair over the years as well.

Despite a few medical setbacks, Josh is now a 15 year old who is fully living his life (see Figure 4). He does what he wants to do, and he is getting ready to get his learner’s permit this year. He knows that he can load his chair into the car by himself once he is driving. Nothing is slowing him down from achieving what he wants to do in life!

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FIGURE 3 Josh in his rugby wheelchair.



FIGURE 4 Josh making breakfast for his family.



FIGURE 5 Front view of Lyla on delivery day for her first wheelchair.



FIGURE 6 Side view of Lyla on delivery of her first wheelchair.



FIGURE 7 A very happy Lyla on delivery day for her second chair.

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LYLA

“DURING OUR FIRST APPOINTMENT, I PUT HER INTO ONE OF MY CLINIC CHAIRS AND SHE JUST TOOK OFF. EVEN WITHOUT A PERFECT FIT, SHE WAS MOVING HERSELF AROUND AND LOVING THE INDEPENDENCE.”

I first met Lyla when she was 2 years old. She was a spunky young lady and that has not changed in the time that I’ve known her. Lyla has spina bifida and has very little lower extremity movement, so she will likely be a wheelchair user throughout her life.

During our first appointment, I put her into one of my clinic chairs, and she just took off. Even without a perfect fit, she was moving herself around and loving the independence. She was so sad when she left that day without a chair. However, a month later (yes, it only took a month to get the chair approved and ordered), she was back in my office getting her hot pink chair.

As you can see from the pictures, we did not put much extra seat width in the chair so that she felt stable and she could reach the wheels effectively (see Figures 5 and 6). She loved the color and the independence and hasn’t stayed still since then.

Many professionals look at her in the initial chair and panic.

“There is no room for her to grow without having to actually grow the frame.”

“She’s two and she’s going to have the chair until she’s 7; she’s going to grow out of the frame and you’re going to be stuck.”

Guess what? None of that happened. She came back to see me five years after getting the original frame, and it was a little small, but it was fine. She never totally grew out of it. At 2, she has a hip width of 8”, and at 8, she had a hip width of 10.5”. So, a chair that had a seat width of 9”-11” was just fine and never caused problems.

So, after five years we got her a new blue chair. This one took a month and a half from evaluation to delivery. As you can see, the new chair is also fitted tightly to her

(see Figure 7). And, if you look two years after getting the chair, she still fits just fine in the chair (see Figure 8).

During all this time Lyla has been an active young lady. She goes everywhere her family goes. It is very rare that she asks for or will allow others to push her chair. She dabbles in some wheelchair sports activities as long as they don't mess up her nails too much (see Figure 9).

What can be learned from Lyla? Configuring a wheelchair to facilitate function from the start has made her an active kid with very few limitations. In five years, she grew 12 inches taller and gained 16 pounds. She has remained at an appropriate weight because she has stayed active.

CONCLUSION

I could bore you with stories about Charlie, Theo, Rynon, Natalie, Dahlia, Jazlynn and many other kids who have similar stories to the two above. Unfortunately, I have a word limit so I can't share all of them here.

The thing that all these kids have in common is that I started with them early (some at just over 1 year of age). All went into the lightest weight rigid manual wheelchair available at the time they received their first, second and, in some cases, third chairs. Some have solid backs and lateral supports while others have basic upholstery backs. All had a seat width no more than 1.5" wider than their hip width, an appropriate seat slope and as forward of a center of gravity as the child could safely propel. Each child was individually evaluated sitting on my mat table to decide what they truly needed to be successful operating their wheelchair. No one has equipment on their chair that was not medically needed, yet all were allowed on the school bus without head supports or anterior trunk supports (that's a much longer conversation than we can have here, but just know I've convinced many school bus drivers that these chairs are safe).



FIGURE 8 Lyla, 2 years after receiving her second wheelchair.



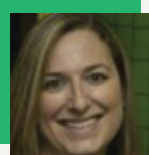
FIGURE 9 Lyla living her life getting her nails done.

By providing this kind of wheelchair with the proper set-up, all of these children have viewed their chairs as enabling devices and have been very active in them. Not all participate in sports but they all play with friends, go to the mall, get their nails done and do what makes them happy without feeling limited. While living their lives and being active, they have all maintained a low body fat percentage (BMI) and no one has needed a chair replaced before a five year time frame.

So, please look at the kids you work with and make sure you are setting them up for success. An "OK" chair is not good enough. We can achieve a longterm impact by teaching children and their families that the chair is not a pain or limitation. Properly designed pediatric lightweight wheelchairs teach kids that they have no limits. At the end of the day, isn't that what we want to see?

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