

Critical Research and Clinical Gaps in Neurorehabilitation After Pediatric Traumatic Brain Injury

While there have been tremendous advances in the field of neurorehabilitation, there are still many unanswered questions and areas of unmet medical need. It is critical for scientists, clinicians, and other neurorehabilitation professionals to understand and appreciate the lived experiences of patients and their caregivers to continue identifying and addressing key gaps in rehabilitation research and clinical practice. ASNR Member James Sulzer, PhD, provides his perspective on the process of recovery and rehabilitation after traumatic brain injury (TBI) in pediatric populations, based on his own experiences with his daughter Liviana (“Livie”). Dr. Sulzer is a mechanical engineer by training, and he is currently an Investigator studying sensorimotor recovery after brain injury at MetroHealth Medical Center and Case Western Reserve University.



In May of 2020, Livie sustained a severe TBI from a falling tree branch while playing with her siblings in their backyard. At the time, Livie was nearly four years old, and in that moment, the trajectory of her life changed dramatically. Dr. Sulzer and his wife Dr. Lindsay Karfeld-Sulzer shared their family’s story in an [open access article published in 2021 in the *Journal of NeuroEngineering and Rehabilitation*](#). The accident led Dr. Sulzer and his family down a long and winding path of recovery for Livie. In the course of navigating medical treatments and rehabilitation technologies for their daughter, insurance issues, time demands, emotional trauma, and also taking care of their two sons, Dr. Sulzer experienced firsthand the challenges surrounding the paucity of evidence-based treatment options, as well as major limitations with the medical system in the U.S.

Key Limitations in the Present State of Rehabilitation for Pediatric TBI

With a background in research, Dr. Sulzer went straight to the literature to try to identify the best treatments for his daughter. He quickly realized that there was very little research in young children with traumatic brain injury. Instead, he and Lindsay, also a PhD researcher in biomedicine, relied on cerebral palsy literature or literature on adults with TBI. With such limited evidence, it was impossible to determine what the most beneficial treatments might be, and with a limited number of hours in each day, there was a real opportunity cost to choosing one treatment over another.

In addition, when looking at the literature, many of the studies, reviews, and meta-analyses focused on identifying whether a group of heterogeneous participants, as a whole, benefited from a particular treatment. However, this isn’t really the kind of question that a caregiver trying to help their loved one wants answered. “All we really want to know is if it can work — if there’s a possibility. But that review just gives you the difference between means, and if it’s significant or not. And that’s not the language we’re speaking. We’re not speaking in statistics. We want to know if our kid can be a responder. So, it’s a different question than what the science is reporting,” explained Dr. Sulzer.

With his background in mechanical engineering and his neurorehabilitation research lab, Dr. Sulzer was in a fortunate position to have experience working with rehabilitation technology. Even with his considerable expertise, he encountered numerous challenges finding and adapting technology for Livie. Most rehabilitation technology is not developed for children, both in terms of the dimensions of products and other practical considerations, such as a child's tolerance for unengaging or uncomfortable therapy. There were multiple instances where Dr. Sulzer spent hours adjusting and personalizing technology that just didn't work for their situation or wasn't well-tolerated.

Another important consideration is ensuring that the research and clinical communities are adequately addressing the key areas that would provide the most meaningful improvements in people's lives. For instance, compared to research on the recovery of motor functions like walking, less research has focused on rehabilitation of speech and tongue function (which is important for both eating and talking). This pattern is also often seen in clinical rehabilitation programs, which may spend very little time focusing on evaluating and improving communication and tongue control.

These insights were somewhat surprising for Dr. Sulzer, and they really brought to light the difficult position that patients and their families are in after an accident like the one Livie went through. Decisions have to be made based on less relevant, incomplete, or anecdotal information because no one really knows the best course of treatments for optimal recovery in cases like Livie's. Further, many of the solutions, devices, and therapies available don't work well or are not feasible to implement in daily life.

The Importance of Incorporating Lived Experience in Neurorehabilitation

Over the past few years, Dr. Sulzer has really come to appreciate the importance of lived experience in every aspect of neurorehabilitation research and clinical practice. "Lived experience should be considered a credential or qualification. Before Livie's injury, I thought that clinicians had the best insight into their patients' experiences. Now I see that while clinicians' perspectives are vitally important, lived experience is something entirely different. It seems crazy that we would spend billions of dollars on rehabilitation research without giving the lived experience perspective a significant role," Dr. Sulzer remarked. "It's important that it's integrated throughout the entire research process, from setting the agenda all the way down to being a participant in the experiment," he continued.

When researchers are balancing all of the responsibilities of academic science, it can be easy to lose track of what is most important to the patients who are living with the conditions they are studying. Further, in taking a reductionist approach to research, important aspects of the context of daily life are often overlooked. "I think that's one of the things with lived experience that you can't substitute — you get to understand the whole picture of all the problems and how they interact with each other. And it's really difficult because of how the scientific enterprise is. The way it's set up doesn't really treat lived experience with the gravity that it should," Dr. Sulzer explained. He urges researchers and clinicians to keep the perspectives of people with lived experience at the forefront to ensure the field is optimally prioritizing limited research resources and making meaningful advances.

For Dr. Sulzer, seeing the shortcomings and limitations of current systems and solutions firsthand has sparked his determination to drive positive change. Not every neurorehabilitation professional will be able to tap into wisdom from these kinds of experiences in their own lives, but everyone can take the time to learn from people who do have these experiences. This could start with something as small as

having conversations with patients, research participants, and their caregivers, and incorporating their perspectives into your own research or clinical practice. These relationships could grow into partnerships. Neurorehabilitation professionals should also connect with local support groups, work on educating people about the research process and how they can get involved, and encourage people with lived experience to pursue careers in neurorehabilitation. In these interactions, it is critical to consider how the neurorehabilitation community can make it easy and accessible for diverse groups of people with lived experience to meaningfully participate, including offering options for remote connection or meeting people where they are. These approaches can also help illuminate the context of how people are living and the challenges they face in their everyday lives outside of the lab or clinic.

Updates and Advice for the Future of Neurorehabilitation

Since the article was published in the *Journal of NeuroEngineering and Rehabilitation*, Livie has continued to recover. Though not able to walk independently, she can move around and explore with support. She is also eating more solid foods independent of her gastrostomy tube (G-Tube). Despite limited verbal communication abilities, Livie has been communicating more using an alternative augmentative communication (AAC) device in the form of a tablet that she uses to select desired words. While the device has been useful, Dr. Sulzer highlighted that this approach to communication is not without limitations. "Who's going to carry a five pound tablet around with them wherever they go when you're seven years old, right?" he pointed out. The logistics and practicality of interventions and devices will ultimately determine the extent to which people are able to use them in their everyday lives.

After an exhaustive evaluation of a wide variety of products, therapies, and approaches, Dr. Sulzer and his family have found a number of things that work well in terms of positive outcomes for Livie and the ability to fit them into their busy lives. Any therapies that can be combined allow them to do more in less time. For example, Livie can complete music therapy that trains cognitive and motor abilities with a home therapist while in her standing frame, receiving her g-tube supplied water, and wearing her therapeutic eye patch, and this is more efficient than completing each activity separately. In addition, Dr. Sulzer created a modified ride-on car that makes grasp therapy more fun and engaging for Livie and enables her to play with her brothers. Efficiency and engagement are critical considerations that should be kept in mind when developing future therapies for pediatric TBI and other conditions.

Beyond the improvements in Livie's function and benefits from using particular devices, Dr. Sulzer's family has been able to get regular caregiving help, and this has helped enormously. Getting regular nursing help has been a challenge due to the nursing shortage and level of physical effort required. However, the Sulzers have employed numerous physical, occupational, and speech therapy students to fill those gaps. Dr. Sulzer noted that good care is difficult to find, and these caregivers are often not well compensated for the important work that they do. Thinking about and developing comprehensive care systems and accessible resources, with input from people with lived experience, is important for achieving the best outcomes for patients and their families.

Livie has faced and will continue to face many challenges, but overall, she is a happy, playful, and social child. "She's just this bright ray of sunshine," Dr. Sulzer noted. He continued, "I think it's important to understand that, as human beings, if we have enough time, support and love, we can adapt to a whole lot of situations that we never thought we could before."