REHAB CASE STUDY

# Michael's Story:
## Three Years on a Couch

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I first met Michael in the winter of 2022, when he agreed to an interview to discuss his experiences in the wheelchair industry. Born with spinal muscular atrophy (SMA), Michael had used a power wheelchair for most of his life. I knew he would bring valuable experience and perspective to my study on person-centered care and Complex Rehab Technology provision. When I asked if he would participate, he immediately agreed and kindly invited me to his home one evening for the discussion.

As I sat with Michael, his wife, Desiree, and his sister, Alicia, I was struck by how seamlessly they worked together in his care. Alicia and Desiree often anticipated his needs before he even mentioned them. When Michael requested assistance, his voice was at times barely perceptible, yet they knew instinctively what to do — whether to clear his tracheostomy tube with a suction device or to move his right hand slightly so he could better activate the tilt switch on his power wheelchair.

Michael's needs are complex. In my 30 years as a CRT clinician, I've met many individuals like him, where small changes to seating or positioning can dramatically influence health and function for better or worse.

**"Michael on couch"**
Michael with his wife and son several years ago, when pain and ventilator transport issues limited his wheelchair use.

As we chatted, I asked Michael if he remembered any experiences where things either went well or poorly while working with professionals in the wheelchair industry. He quickly replied that he could share a good example of both. The story that follows summarizes that discussion. It underscores the critical role of service providers in the CRT industry and how the service provision process can profoundly impact a person's life. It also demonstrates why person-centered care must be an essential component of the service delivery model.

To understand why those experiences left such a lasting mark, it helps to know where Michael's journey began.

His story, like that of many long-term wheelchair users, started in childhood, shaped by both medical realities and the people who supported him along the way.

As part of our interview, Michael shared memories from early childhood through adulthood. Growing up with a disability, he learned early on the importance of a well-fitting wheelchair for his health, function and quality of life. He received his first power wheelchair in early childhood because muscle weakness prevented him from standing or walking. Spinal muscular atrophy, a progressive neuromuscular disorder, causes generalized weakness throughout the body, with greater strength in the distal muscles of the hands and feet and less in the proximal muscles near the torso and head. Progressive in nature, Michael's increasing muscle weakness means that the unpredictable nature of his condition, and future uncertainties, are a normal part of life.

Despite these challenges, Michael mastered his power wheelchair with remarkable skill as a young child. Using a joystick controlled by his hand, he maneuvered the chair independently throughout his home and community. Although he needed assistance with bathing, dressing and eating, his wheelchair gave him the ability to go where he wanted and needed to go each day.

As Michael grew up, his parents and siblings all chipped in to help him with self-care tasks, while also ensuring he was included in all family activities and outings, even carrying him to the top of the Statue of Liberty on one memorable vacation. A good student, Michael achieved many milestones typical of others his age. After high school, for example, he attended college where he met his future wife; shortly after their marriage, he and Desiree started a family. As a close-knit Hispanic family, the young couple moved in with his family, and they all shared in his

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**"Michael today"**
Today, Michael uses his power wheelchair for several hours each day. As his needs change, his Complex Rehab Technology team continues to identify technologies that support his health, comfort and participation.

care. While he needed help with daily tasks, this did not prevent Michael and Desiree from leading busy and active lives for many years. Their days were very full as they engaged in their work, community events and family activities.

But everything changed shortly after Michael turned 30. A planned surgical procedure led to unexpected complications. When Michael awoke, he could no longer see, breathe independently or move as before. Hospitalized for weeks, his life became a whirlwind of medical appointments as his care team worked to understand what had happened and to help him regain as much vision, movement and function as possible.

Although some of his vision eventually returned, the physical toll was immense. Before surgery, he could sit in his wheelchair for hours and drive it with a joystick. After discharge, he could do neither. His posture, strength and tolerance for sitting had all changed. His family propped him up with pillows and books to help him sit in the wheelchair, but he experienced severe discomfort. He now required a ventilator 24 hours a day, yet his power wheelchair could not safely carry the bulky machine.

After returning home, Michael and his family reached out to the wheelchair supply company that provided his power wheelchair and asked for their help, but unfortunately, the process of getting his power wheelchair fixed and appropriate for his changing body proved to be very frustrating and ultimately futile. The challenges that ensued would lead Michael to describe the next three years as some of the most trying in his life. Employees from the wheelchair supply company met with Michael and recommended a new power wheelchair that they assured him would accommodate all the changes to his body, but when it was approved by his insurance company and delivered to his home several months later, it was no better than the original. Without a mobility system that met his needs, Michael's life was restricted to the four walls of his living room. Using an arrangement of pillows for support, he spent nearly all his days sitting on the couch.

Desiree described this time of their life as one of extreme frustration as they repeatedly asked the wheelchair supply company for help, but each product solution they offered failed to address Michael's needs.

*"And that was the worst because, to be honest, it was a company that was like 'Okay here's what you need, we'll get it for you.' And they gave us a chair that he couldn't sit in. And so every time we'd go back and say, 'Hey, he's uncomfortable. He can't sit in the chair,' they would say 'Well, we can do this.' And they'd do something, and we'd say, 'Well, this doesn't work.' [...] And so, he couldn't get in the chair. It was so painful. And he sat on the couch for like three years."*

After multiple failed attempts, the company told Michael there was nothing more they could do. Feeling helpless, the family adapted their life around the couch. It became the center of their world — where they ate meals, watched movies, attended church services and even performed family skits so Michael could remain included in everything they did.

Three years later, a glimmer of hope arrived in the mail — a postcard advertising a wheelchair "tune-up" clinic hosted by another supplier. Intrigued, Michael and Desiree contacted the company, which sent a CRT supplier to their home. The representative asked detailed questions and

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evaluated Michael's remaining movements by placing a thumb under Michael's hand and asking him to pretend it was a joystick. Observing small but precise movements, the supplier suggested that Michael could operate a highly sensitive mini-proportional joystick. He recommended an evaluation with a CRT therapist at a local outpatient clinic to test equipment options and design a seating system suited to Michael's needs.

Desiree described that clinic visit as life-changing:

*"That appointment was the best. They simulated a seating system so Michael could sit in it. And they simulated a mini joystick and things like that. And Michael drove for like the first time in like four years. They said, 'We'd like you to drive to each of those cones,' and Michael did. He drove to each of the cones. And he was so excited. That's what made us cry, he was so excited [...]. And we came home, and we were crying, and we said, 'They're gonna help us get another chair so he can sit in his chair and not on the couch.' So, we were excited for Michael to have some of his life back.*

Through collaboration between Michael, his family, the CRT supplier and the clinician, he received a power wheelchair with a custom seating system and mini joystick that met his needs. He regained independence and returned to the activities that brought him joy as a father and husband. More than 20 years later, Michael continues to work closely with a CRT team to adapt his equipment as his condition changes, maintaining as much independence as possible.

When asked what qualities he values most in CRT service providers, Michael answered with a single phrase: "Patience, awareness, consideration, sensitivity and intuition." When I asked him to elaborate, he added:

"I would say that they should be open-minded and receptive to the client's information. There are some people that just assume that they know what you're going through, and what you need and just give you that."

Without realizing it, Michael had described the essential elements of person-centered care. His story illustrates how profoundly different a person's health care experiences can be when person-centered care is or is not provided.

## The Case for Person-Centered Care

For people like Michael, a wheelchair is far more than a convenience; it is an essential medical device. He uses it for several hours each day, and it must be configured precisely for his unique body, needs and goals.

To improve outcomes for wheelchair users like Michael,

**"Michael family pic"**
Michael with his wife, Desiree, and their son, Michael, in a recent family photo.

experts in the seating and wheeled mobility field recommend a person-centered care approach as the industry gold standard for service provision (Arledge et al., 2011; Cohen et al., 2013; Federici et al., 2015; Plummer et al., 2013; World Health Organization, 2023). A person-centered approach is much more than asking individuals about their goals. It is a holistic care philosophy that includes:

- **Collaboration:** Teamwork built on transparency, listening and effective communication.
- **Autonomy:** Respecting each client's individuality and self-determination.
- **Holistic assessment:** Understanding physical, emotional, social and environmental factors.
- **Therapeutic alliance:** Building trust and partnership between providers and clients.
- **Shared decision-making:** Ensuring clients make informed choices about their care.

In short, person-centered care is fundamental to quality care and best practices in CRT provision. Research consistently supports its value in reducing technology abandonment, improving satisfaction and user-device match, and minimizing medical complications (Arledge et al., 2011; Federici et al., 2015; Holloway & Dawes, 2016; Johnston et al., 2014; Kittel et al., 2002; 2000; Scherer, 2002; Verza et al., 2006).

Person-centered care is also associated with long-term cost savings, reduced provider burnout and better continuity of care (Epstein et al., 2010; Mead & Bower, 2002; Stewart et al., 2000). While it may require more time initially, it saves time and resources over the full episode of care by preventing poor outcomes and

dissatisfaction (Federici et al., 2015; Verza et al., 2006).

Unfortunately, as Michael's story demonstrates, person-centered care is not consistently implemented across the field (Federici et al., 2015; Johnston et al., 2014). Research shows that "a provider-centered/controlled approach continues to occur" (Johnston et al., 2014, p. 422). Clients are too often denied opportunities for informed decision-making, such as trialing devices before purchase (Riemer-Reiss & Wacker, 2000). Systemic pressures —including profit motives, bureaucratic processes and time constraints — can lead providers to limit choices, rush processes or adopt ineffective service delivery models (Breaux, 2024).

While the barriers to person-centered care are multifaceted, an important first step is increasing awareness and understanding of what this approach truly means and why it matters. It benefits clients, caregivers, providers and health care organizations alike. Most importantly, as Michael's story reminds us, person-centered care is not merely a "nice" thing to do — it is essential to a person's health, function and quality of life.

When we listen, collaborate and design with the person at the center, we don't just improve outcomes, we change people's lives.

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Becky Breaux, PhD, OTR/L, ATP, is an assistant research professor, occupational therapist and Assistive Technology Professional with over 30 years of clinical experience in seating and wheeled mobility and assistive technology provision. As a clinician, she works with individuals of all ages, and those individuals have a wide range of disabilities who require Complex Rehab Technologies. Her research focuses on the intersection of disability and technology, exploring factors that shape best practices in the provision of CRT. She also investigates the impact of underutilized interventions, such as dynamic seating, on user experiences and outcomes. Through her work, she advances user-centered research to highlight social and systemic barriers in assistive technology provision and to promote improved health, participation and quality of life for people of all abilities.