REHAB CASE STUDY

Listening Leads to Better Outcomes

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This issue is about education, knowledge transfer and mentorship. My approach for this case study will be on hard lessons learned.

I began to work in wheelchairs and seating about 10 years into my career as an occupational therapist. One of the hardest lessons for an OT focused on solving and managing problems was to stop looking for the perfect seating and learn to listen more. OT/PT/ATPs are used to offering suggestions, tools, equipment, adaptive techniques and advice, with experience to back up our views. The challenge is that our experience isn't necessarily the lived experience of a particular client. I learned the hard way that talking clients into a certain chair style, change or upgrade can lead to unhappy clients and poor results. It is very disappointing to hear from a client that they are still using "their old chair" four years later, instead of the newer one.

A lot of this dichotomy comes from the therapist or Complex Rehab Technology Supplier being the perceived expert in the wheelchair evaluation process. This expert status can come from clients and families feeling out of their depth or from the expert themselves. Add possible ableism to the mix, where the client with the disability is seen as less capable or less able to make important decisions. Most of us have come into this industry to help clients with disabilities get what they need and make their lives better. The problem comes when the "expert" assumes the client with a disability needs assistance to make good decisions or live a better life.

Keeping the client in charge is so important. Once the client is educated about the options and the pros and cons of each choice, it ultimately is up to them. When the client makes decisions the seating specialist would not have made, careful attention to autonomy and the client's reasoning is vital. What follows are three case examples, which will highlight the challenges the seating specialist may face with shared decision making:

- It can be difficult to predict the future for clients with progressive disorders, and the first chair is usually a big deal. The team usually introduces power wheelchairs with education about the benefits of the CRT product for longer-term use. The team may urge the client toward a Group 3 power wheelchair to have long-term flexibility for any changes. Inevitably, the client and family fight with the thought of "such a big chair" when they really wanted a scooter or a folding PWC. Accommodating future needs can be a challenge both to present and to accept. Perhaps encourage a self-purchase or loaner scooter or folding PWC for now as clients come to grip with the changes to come.

- A client with cerebral palsy came to the seating clinic because someone thought he required chair changes for better positioning. His legs are windswept to the left, pelvis rotated with the right side forward; he continually slides forward and leans strongly to the left. The team discussed changes with the client, including hip and thigh supports, lateral thoracic pads and other items to improve posture and stability. The client is pleasant but is unwilling to add thigh guides or any other supports as he notes they "get in the way" during lateral transfers to bed. This client lives alone at home and he cannot consistently put on and take off any supports by himself. He understands the potential concerns with not having supports, but is firm in his refusal. After 55 years of living with his spasticity/contractures, the client is aware of his strengths and limitations as well as the impact of his choices. No one had asked the client if he wanted more support on his chair before sending him to our seating clinic to be fixed.

- A client who has used a K5 manual wheelchair for 20+ years wanted a new chair ordered "exactly the same as the old chair." Many clients want to duplicate their current chair as much as possible, even though the chair may be five to 20 years old. The team sees many improvements they could make for this client, such as a solid back instead of fabric, a better cushion with rigidizer, longer seat depth, adjustment to the center of gravity, a raised footplate, and more. The client is leery of making any changes, but the team's enthusiasm for the impact of the changes gets them to agree. The client "hates" it after the first day of use, mostly because the changes are substantial and the transition is too difficult to absorb functionally.

Working with clients with progressive diseases for the past 22 years, my job is to assist clients to potentially act before they perceive they need a device; to be proactive and avoid "house

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on fire" moments. The line between planning ahead and pushing clients to take action sometimes blurs and may come across as overbearing and directive or as not really listening carefully enough to clients and their needs and concerns. Ableism often has a kind heart and the desire to help at its roots. As the old adage says, "the road to hell is paved with good intentions." The actions taken by the team in an attempt to help make life better for the client must also strive to be client-led and directed. Really listening and fostering shared decision-making is pivotal to an excellent long-term CRT result and a happy client.

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Amber Ward has been an occupational therapist for more than 32 years, most recently in an outpatient clinic serving clients with progressive neuromuscular diseases and in a wheelchair seating clinic. In addition to working in the clinic full time, she is an adjunct professor in the master's Occupational Therapy Program at Cabarrus College of Health Sciences in Concord, North Carolina. Ward has held her Assistive Technology Professional and Seating and Mobility Specialist certifications for many years and is a past board member and current member of the Clinician Task Force. She is the author of numerous articles and book chapters, as well as a speaker and presenter locally, regionally, nationally and internationally.