A NARRATIVE BASED UPON INDEPENDENTLY HELD FOCUS GROUP DISCUSSIONS HIGHLIGHTING CURRENT DURABLE MEDICAL EQUIPMENT ISSUES AND RECOMMENDATIONS FOR ENHANCED ACCESS

We can build power into policy but the community of people with disability must desire to create the change. Lakeshore Foundation’s Policy and Public Affairs Department has undertaken a project to amplify the messages of our community of people with disability as it relates to the personal and vulnerable experiences of those who use and rely on Durable Medical Equipment (DME) to sustain a physically active, functionally independent, healthy and vibrant life.

We invited a diverse group of participants who are consumers with disabilities to partake in this discussion. Men and women aged 18 to 56 participated in 4 small discussion groups. Each group met individually over the course of 4 separate days. An additional group was held for parents of children with disability. Each group met for approximately one hour and fifteen minutes and was asked to answer general questions about their DME experience(s). Information gathered is to assist in generating a dialogue between those who use DME and those who inadvertently create the barriers to its use. A level of sensitivity of the subject is often required to facilitate real change within local and national policy therefore, some of our participants also volunteered to share their experience(s) on a public video platform; providing both a face for the faceless and voice for the voiceless. The link is attached here.

https://www.youtube.com/watch?v=b2KHVquijjEY&feature=youtu.be

People with disability live in complex times of health care reform facing multiple barriers to even the most basic insurance coverage options. Whether it is decreased or limited access acquiring insurance, changes in the competitive bidding program or changes in insurance codes, a navigational insurance compass seems to be required. Participants within our discussion groups have coverage under Medicare, Medicaid, private insurance, workers compensation and Veteran Affairs benefits. Some of our participants who are seeking employment, in school or already employed have also used the state occupational and vocational rehabilitation programs as a secondary source to fund their DME needs.

We have contained the scope of interviews towards key issues surrounding our participant’s consumer experiences with Durable Medical Equipment that support physical activity and functional independence.
WHERE IS THE DISCONNECT

A majority of our participants often used the word “disconnect” to describe their DME experiences. They wanted to know where was the disconnect when they all felt as if they were doing exactly what needed to be done in order to efficiently receive their Durable Medical Equipment. The equipment discussed ranged from catheters, shower benches, wheelchairs (manual and power), wheelchair cushions, prosthetics, prosthetic sleeves and liners, tubes for feeding, walkers and orthotics.

When asked: “how long did it take from the initial conversation with your physician to actually getting your equipment, most responses repeatedly included the word “disconnect”. For example, one participant said:

“I called my doctor, got the appointment...had the appointment, he signed the prescription, and his assistant sent the prescription to the cushion company. I went to get measured for the cushion and 6 months later, yes 6 months later I had a cushion that was 2” x 2” too big? How is that possible? There must be a “disconnect” somewhere?”

This participant had been sitting on a flat cushion for 6 months waiting for her new cushion. During that time she expressed the fear of a) getting a skin break down and b) time retaliation if she called the DME offices, believing that if she called to remind them about her cushion, more delays would be created. To date, the participant does not have the correctly sized gel cushion, after repeated calls to their offices. She has given up on receiving her cushion from this company and will have to re-do the entire process.

All our participants are aware of the many layers involved with procuring DME. Some even joked about writing a book from the consumer’s perspective.

“No one should ever have to go through this type of process and be made to feel as if they don’t exist” said one of our participants.

Creating ease of access to resources and those with insider knowledge of the DME system was also discussed repeatedly.

Parts of the layers in the process include assistive technology professionals, “ATP’s” as they are known in the industry. They are extensively trained individuals who spend quite a bit of time navigating a consumer’s needs. There are also direct support specialists who understand insurance coding and documentation; a funding coordinator that has a knowledge of Medicare and various insurance guidelines, there are physical and occupational therapists who usually have what’s called “seating clinics” for those who are in need of wheelchairs or scooters. The lengthy process continues with price quotes, home assessments, input from specialists on reimbursements who make sure all documents support the coding requirements so the funding is not denied, then, in an ideal world, the ATP has a discussion with the consumer detailing their potential co-pays, what the approval process entails and the probable delivery time. The equipment is ordered and delivered to the customer perfectly and in the time guaranteed.

The “disconnect” can happen during any part of the above intense, time consuming, complex process.
Cultural Competence: Lack of Knowledge about Persons with Disability and Activity levels

Cultural competence involves understanding and appropriately responding to the unique combinations of cultural variables that includes people with disability. There is much to be learned from the interactions between medical professionals and people with all levels of ability and disability.

When asked the question: “Does your physician have knowledge of your lifestyle? Do they know that you are active in sports?” Our participant Chris responded with:

“Not at all. Even though I have told her numerous times that I play wheelchair basketball, it seems like she doesn’t listen or doesn’t care. She seems to only see me as a patient and my options for changing doctors are limited. I asked her recently if she could give me a prescription for my catheters. She responded with: ‘…no that is what you have a urologist for.’ I feel if she understood how active I was in my life, she would treat me differently and not be such a barrier to my physical activities.”

John, also a participant, agreed and wanted to know:

“…why do we even need a prescription for catheters? It would make my life so much easier if I could just go buy them where I want and when I want.”

One of the parents interviewed, who has a child with a physical disability, offered a solution to make physicians and medical personnel more knowledgeable about her son’s disability was to write a summary of who he is beyond his disability. She includes all the physical activities he participates in as well as pertinent medical information. She explains that the benefits of her efforts provide an ease of access for the doctors and they are all more inclined to acknowledge her son as a “whole” person. The physicians happily write the necessary DME documentation because she has created what she refers to as a “cheat sheet” for her physicians to reference.

“We can help to expedite the process; we just need to provide the information for them sometimes. I know they should know, but sometimes they just don’t. We can help them know more about what people with disabilities are able to do. It’s frustrating, but they just don’t know.”

One of our participants, who is an amputee, spoke admirably about her physician’s level of communication. He has an active communication with her prosthetist. Both physicians know she is an avid mountain biker and any delay in acquiring the DME she needs would create a barrier to her participation. They have a deep understanding of how physical activity manifests itself positively in the lives of all their patients both with disabilities and without.

John spoke of his frustrations having to continue to explain how important his equipment is to his physician.

“He doesn’t realize I have two boys and I need to keep up with them outdoors on surfaces that aren’t
conducive to the tires on the wheelchair I use daily. I would like for him to understand that I am a father who actively participates in my sons’ lives on and off the field of play. It’s easier when I have access to a free wheel or larger tires to assist on the more tedious surfaces. I can just be a part of the process with my sons instead of them always having to wait for me. I want all medical personnel to know this about people with disabilities. We live active lives. I just want to be a good dad for my kids!”

Assisting physicians and medical administrators in understanding that people with disabilities must often go to extreme measures to acquire the benefits and resources they need in order to be physically active and participatory in a healthy lifestyle was emphasized in our discussions. Their willingness to learn will remain a key factor in expediting the DME process so that persons with disability can also have access to increased physical activity.

Customer Service Efforts

Mentioned by all participants in each separate group, was a lack of customer service during the various stages of DME procurement. Participants spoke of unreturned phone calls and emails about orders placed, unexplained cause(s) of equipment not being delivered or replaced as promised and consistent lateness for phone and in-person meetings. Participants simply wanted basic confirmations of their orders and knowledge of where in the process of receiving their equipment they were. When asked on a scale of 1 to 10 to rate their experience; 1 being awful and 10 being amazing, the average rating was 3.

Education, Awareness and School Curriculums

Many of our participants noted that they were continuously surprised at the lack of basic knowledge physicians and medical personnel had about people with disability. Comments ranged from:

“How did this doctor ever make it through medical school? Didn’t they teach you about the Americans with Disabilities Act? How is it that your office bathroom isn’t wheelchair accessible? You are a doctor!”

There was a strong consensus among the participants about their physicians not understanding the importance of learning about disability issues. One of the participants described a medical appointment interaction between her and her doctor:

“I asked her if she knew that one in five people had a disability and that people with disabilities represented twenty percent of the population. She responded with this: ‘….there was little to no emphasis on disability in medical school and we really did nothing clinical around people with disabilities. There was a chapter on the ADA but nobody really paid too much attention to that.’ “

As a result, many physicians are unprepared to work with the population of persons with disability in a proactive and positive way. They are taught about the Americans with Disability Act within a structured curriculum that promotes fear of non-compliance versus creating inclusion and access for people, who happen to have a disability. Participants suggested, whether medical school
curriculums or any medical service industry curriculum, should include the knowledge that disability can be the result of illness, injury or merely the process of aging; referencing all people could dissipate some of the fear-based reactions towards the population of people with disability. Participants also encouraged the industry to gain a consciousness of disability; learn about the history, culture and politics of people with disability.

RECOMMENDATIONS FOR ENHANCED ACCESS TO DME

During our discussions it was noted that our participants recommended the following:

• Create a DME Moderated Town hall/Roundtable: an event for people with disability, health care providers, Durable Medical Equipment suppliers, physicians, therapists, legislators and all those interested to have an open discussion to clarify the process of the DME industry. Provider to end-user.

• Create an active monthly peer group to discuss topics of DME and what products are the best and worst based upon actual consumer information.

• Sensitivity training for all those in the DME industry; an actual working knowledge of equipment use. (i.e. use a wheelchair for one week all day)

• Provide speaker series for Universities, Medical School classrooms; Pediatrics conferences; medical conferences etc. to give accurate information on people with disabilities using actual people with disabilities to teach the class and/or present at conferences.

• Lakeshore Foundation to host a 1) monthly “repair a chair” program; 2) Loner/rental program (DME equipment) 3) “Learn about” series; an education series with guest speakers on varying subjects of disability.

Conclusion

Recent changes to overall coverage have made access to Durable Medical Equipment even more challenging than ever. Inconsistent observance and implementation of coverage across the United States continues to create confusion for people with disability who simply desire the same access to live a physically active and functionally independent life.

The old ways of speaking about disability as a curse, catastrophe, disaster or just plain old bad luck is no longer appropriate. We know that often times speaking about disability can feel like a puzzle of niceties, politeness and at times, offense. We must continue to address and clarify verbiage and its intention and create opportunities of awareness to assist lawmakers to know the issues and the ways it affects our everyday lives. Creating information, knowledge and awareness is our best defense.

Having appropriate and uncomplicated access to Durable Medical Equipment will create opportunities for the population of people with disability to move from isolation to community. We can make a difference and get the access to Durable Medical Equipment Americans with disability deserve.
Excerpts for DME Focus Discussion Groups

“DME companies need referral sources to Champion this change. Complaints that come from business owners and patients seemingly make NO difference.” – Director of a DME company

“I'm hoping we can make more people aware of these regulations so we can all come together and change it for the better. I can understand they want to cut costs and save money but at what cost to their patients that they are trying to protect? What's worse is they direct their funds elsewhere, instead of paying for that bath bench or safety bars, which would help prevent falls they prefer to pay for the hospital stay, rehab, hospital beds, wheelchairs etc. It's just a bogus way to do business.” – Employee, DME provider

“I acquired my disability when I was 12. Our house was not wheelchair accessible. Thank God I had a handy grandfather who installed everything for me. I have Transverse Myelitis and back then, no one knew what that was, so they did not prescribe assistance or even explain what I might need. They told me to be careful about bed sores. That's it” – Focus discussion group participant

“Being paralyzed isn’t as bad as your wheelchair not fitting.” – Focus discussion group participant

“It was bad. I lived in the basement and my wife had to help me do everything since I had no access to my upstairs for a long time; I felt isolated. But when I got grab-bars and access to my entire home with good equipment, it literally turned my entire life around; it gave me the ease of life back. I was able to get back to the gym independently. I have become so healthy because of the access to good equipment.” – Focus discussion group participant

“They just don’t listen. I just wish they would listen. Can they just add a chapter in their school books on listening to what a person with a disability is saying? We may know our bodies and what we need better than you!” - Focus discussion group participant’s reaction to physical therapist

“I feel like I’m a lifelong DME experiment” – Focus discussion group participant

“I wish this process would work for me or with me, instead of against me” – Focus discussion group participant

“It’s not so bad for me since I have my VA benefits. Most of the time, I just ask and I get whatever I want. I can’t imagine what others have to deal with” – Focus discussion group participant

“I just want to have good equipment and participate in physical activities just like everyone else.” – Focus discussion group participant
“It's just a nice feeling when you don't have to worry about any of your equipment – you are just free to get on with your life.” – Focus discussion group participant

“When my leg is not working good, my gait is bad and it makes me angry. When it's working correctly it’s like I don’t have a disability. I have independence and freedom to be active when my prosthesis; my leg is correct.” – Focus discussion group participant

“I haven’t had to buy a socket for my leg in 10 years, but I’ve had to buy sleeves and that is always a project. Any little thing I need, I have to have a prescription and a letter of need. The process takes so long.” Focus discussion group participant

“My primary care physician? She doesn’t know anything about me.” – Focus discussion group participant

“I love my physician. He gets it. He listens and asks ‘what do you need’, so he can get the wording correct.” – Focus discussion group participant

“You don’t feel like a customer; you feel like a burden.” – Focus discussion group participant

“Those in my peer group joke around and say: ‘don’t worry they’ll get it right by your 3rd chair’.” – Focus discussion group participant