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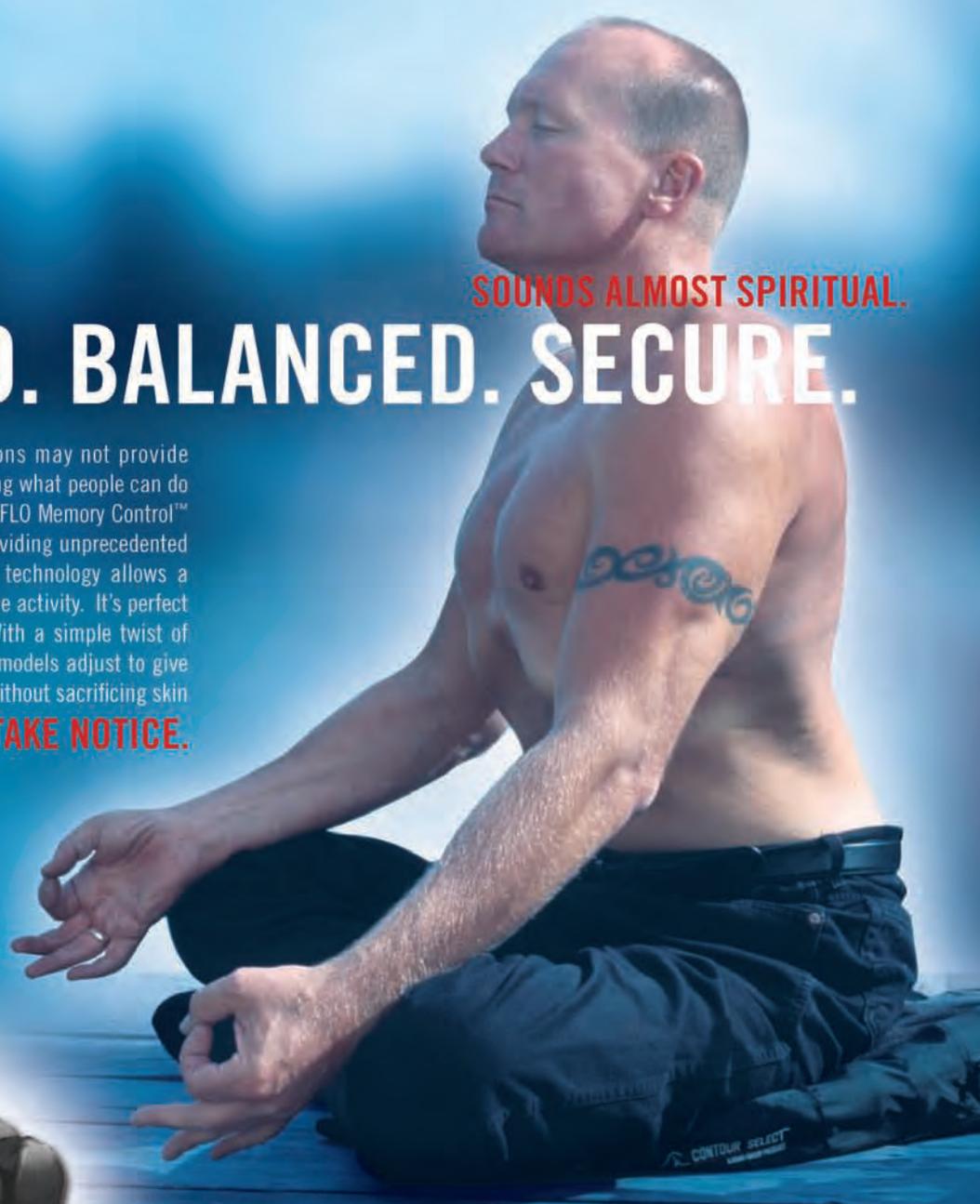


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THE VANISHING WHEELCHAIR

BY JOSIE BYZEK



The durable medical equipment industry is under attack by the federal government and has been for some time now. Over the past five years alone, Medicare reimbursements for all types of DME have been slashed by a whopping 37 percent — leading some manufacturers to fear a “Walmartization of wheelchairs.” And yet the feds keep cutting deeper. Before it’s over, it’s possible that 90 percent of all DME providers will be out of business.

The punch line of this slashing and burning? All durable medical equipment, from granny walkers to top-end power chairs that tilt and stand, comes to only 1.7 percent of Medicare’s entire budget.

It’s obviously not all about saving money. Rather, some think it’s a gross misunderstanding on the feds’ part about what it takes to get people the equipment they need to live independently in their communities.

Ian Ruder, a C5 quad, is not a disability rights advocate as it's usually defined. "I went to a couple of meetings at the local Center for Independent Living's advocacy group," says Ruder, injured 12 years ago in a roll-over accident. "It didn't resonate with me." Ruder, 29, lives in Portland and is a freelance reporter with articles in such pubs as *The Oregonian*. He's mellow, laid-back, not a sign-holding, chanting kind of guy.

And yet, when NEW MOBILITY and the National Registry of Rehabilitation Technology Suppliers put out the call for wheelchair users willing to travel to Washington, D.C., to talk about their equipment needs, Ruder jumped at the chance. NRRTS paid the way for 30 wheelchair users to attend its annual Continuing Education and Legislative Advocacy conference in April. Part of the conference is the opportunity to speak with legislators about the importance of complex rehab (see sidebar, next page).

"Access to quality equipment resonates with me more than other disability issues," says Ruder. "It seemed like a no-brainer. When I first started out, the companies were able to fund customizations, like a custom hand control or foot rest that would work better for me personally, and that's gone



Ian Ruder got a chance to meet with Sen. Merkley (D-Oregon) at the Continuing Education and Legislative Advocacy conference in April. "I was cynical before about Congress," Ruder says, "but just seeing how receptive most of the aides and legislators are was heartening."

now. No one does it. And that's huge. The right customization can be the difference between having a pressure sore or not having one."

Also, Ruder has watched suppliers and vendors that he used to depend on fold or sell their businesses to other companies. "They had to, since reimbursements keep getting cut. The ones that still exist are stretched thin. They can't provide the service and support that people with wheelchairs like me really need. Buying a chair is not a one-time purchase — I need help a lot. If I don't have a company I can rely on, it means staying in bed."

Having dealt with a pres-

sure sore that was a result of ill-adjusted equipment, Ruder knows what he's talking about. About two years after his accident, when he was 19, Ruder left home to attend college in Berkeley, Calif. Unfortunately, he was in such a hurry that he didn't have his new power chair configured by a professional. "Someone there at Berkeley messed with it and the way they adjusted it put a lot of pressure on one part. That is probably what popped my ROHO cushion, and then I got a pressure sore." Eventually he had to get a skin flap.

The problem was, back home in Portland he spent most of his time in a manual chair, and

just never got around to having his power chair configured. He didn't realize how important it was for a chair to fit right. "I didn't think to have someone look at how my power chair was set up, and I'd never spent more than two or three hours in it at a time back home. It was a learning experience, that's one way to put it," he says.

But what does Ruder's experience way back then have to do with Medicare cutting reimbursements today?

Well, Ruder ended up in the hospital because he didn't have a certified technician work on his chair for him. And with today's ever-shrinking reimbursements, there is less money to hire certified techs. This puts providers in a bad position. Either they hire fewer techs or they lean on manufacturers to provide cheaper chairs, or — as is often the case — both. So Ruder can still get a power chair, and still have a certified tech to configure it for him, but the wait might be longer, and the chair might have fewer customizable features.

The Walmartization of Power Wheelchairs

"When reimbursements shrink you get a more margin-driven industry, which creates a cheaper product, which in turn affects quality and features,"



Thirty wheelchair users gathered on Capitol Hill in April to educate Congress about the need for complex rehab technology. On the cover: Andrew Davis, a consumer advocate at the National Registry of Rehabilitation Technology Suppliers, the organization behind the lobby day.

'Complex Rehab': What Is It? Why Should We Care?

"Complex rehab" is an industry term unfamiliar to many readers, so we asked Simon Margolis, executive director of the National Registry of Rehabilitation Technology Suppliers, to explain complex rehab as defined by folks in the business of making and distributing assistive devices to people with disabilities. Here's what he said:

Q. What is complex rehab technology?

A. Complex rehab technology includes medically necessary, modified or adapted manual and power wheelchair systems. It also includes adaptive seating equipment such as Jay cushions and Ride custom seating systems, alternative positioning equipment such as standers, as well as other mobility devices like gait trainers. These kinds of equipment all require evaluation, fitting and adjustment.

Complex rehab technology products are designed to meet the specific medical and functional needs of people with disabilities, including people with spinal cord injury, multiple sclerosis, spina bifida, cerebral palsy, muscular dystrophy and many other conditions.

Q. How is the technology prescribed?

A. The rehab team assesses individuals on a case-by-case basis to determine what complex rehab equipment is best. This team, which usually includes a physician, a physical or occupational therapist and a complex rehab technology supplier, considers the person's immediate as well as anticipated medical and functional needs. These needs may include, but are not limited to, activities of daily living such as cooking, bathing and driving a car. Consideration is also given to functional mobility, positioning, pressure relief and communication. The team then prescribes complex rehabilitation technology products that foster as much independence as possible in all environments the person is expected to encounter.

Q. So is complex rehab a product or a service?

A. Complex rehab technology requires

complex rehab specialists, so products and services are interrelated.

The clinical component includes the physical and functional evaluation, development of a treatment plan and goal setting.

The technology component includes the evaluation of the home environment, assessment of transportation needs, equipment demonstration, selection and fitting of equipment, adjustment and service of equipment, and training.

Q. Who is working on access to complex rehab?

A. Consumer advocates, clinicians and industry professionals are working together to improve and protect access to complex rehab products and services for all individuals with complex needs, disabilities and medical conditions.

Q. How can we improve access to complex rehab?

A. We need to secure a "separate benefit category for complex rehabilitation technology" under Medicare.

Q. Why is this necessary?

A. Advocates are lobbying for the separate benefit because it would improve product choice for all people, of all ages, whether covered by public or private insurance.

Right now, complex rehabilitation technology is lumped together with standard durable medical equipment, such as crutches, walkers, commodes and other products and supplies. Though standard DME suppliers provide much-needed products for people with disabilities, this equipment requires little or no specialized training to dispense.

Complex rehabilitation technology, however, requires a number of specially trained professionals to evaluate each person individually and recommend the best equipment to meet his or her needs. These specialists spend many hours on each system they provide.

Incidentally, this need for expertise provides a safeguard against fraud, and complex rehabilitation technology sup-

pliers are not considered by the government to be companies that defraud or abuse the system.

Nonetheless, the government and private insurance companies are providing less money every year for people who need complex rehab equipment. Decreased funding has already reduced many consumers' access to appropriate products and services. If these funding cuts continue, more people will have to do without the proper technology to meet their physical and functional needs and to support a good quality of life.

A separate benefit category for complex rehabilitation technology would allow the government and private insurance companies to treat complex rehabilitation technology differently than DME. The idea is to have different rules to make sure suppliers are qualified; to ensure that evaluations are done properly; to provide appropriate funding to support the time and effort needed for individual evaluations; and to assure that all Americans with significant disabilities get the equipment that they need. The cost of this program to the government and to taxpayers is much less than 1 percent of the total Medicare budget — a very small amount.

Q. What can readers do to help?

A. Contact the office of your members of Congress and tell them that as a voting citizen you want them to support a separate benefit category for complex rehab technology under Medicare. Tell them that the potential cost of this new benefit category is nothing compared to the benefit to the people who need this equipment to maintain their independence, health and well-being.

Act Now

Find your U.S. representative at www.house.gov and your senator at www.senate.gov. Or, for either, call 202/224-3121. For talking points on complex rehab, contact the National Registry of Rehabilitation Technology Suppliers, www.nrrts.org; 800/976-7787.

says Mike McNamara, eastern regional sales manager for Frank Mobility, a manufacturer of products like power-assist for wheelchairs. “The more features you have, the more benefits for the consumer, but they’re not automatically reimbursed. So you reduce the features, and that has an effect on the quality and the materials. That also affects access to choices. There are fewer choices in a product category because there are only a few of them that meet the margin in which they can be sold.” Again, this is because the largest single purchaser of medical equipment is the federal government, and this drives the entire market, so quality is reduced for everyone, not just people on Social Security.

“For example, Medicare is required to provide the least costly alternative, and the coding only pays for a certain product with certain features,” explains

McNamara. “So batteries that last longer because they use better technology might not be paid for because the code just pays for a certain battery, not necessarily the longest-lasting. Another example is titanium. It’s getting paid for less and less because it’s a higher-cost material.”

And what about his company’s products — are they affected by this? “If we were U.S.-based we’d build a power assist add-on system as cheaply as possible to fit into the code. Fortunately our product is made in Germany, so we have lightweight, long-lasting batteries, all these benefits. But it doesn’t do us any good in the U.S. market because none of these benefits are paid for.”

McNamara says that even though right now his product is manufactured in Europe, the growing trend is to have DME made with cheaper labor in Mexico and Asia. It may not be

Competitive Bidding Explained

The CMS competitive bidding program is designed to work like this: DME is divided up into categories, and vendors are allowed to bid on a certain number of those. Manual wheelchairs are in one category, oxygen in another. Complex rehab — the name for types of equipment like high-end power wheelchairs for people with disabilities such as quadriplegia — has its own category. That doesn’t sound bad, but what it means is that instead of having five to 10 Medicare providers to choose from, a person may only have one per region. Plus, where previously it was possible to get all necessary DME from one place, now consumers may have to go to different providers for each necessity. Like, the guy who sells oxygen may not be the guy who sells power wheelchairs or even shower benches anymore. And anyway, what if you don’t want to do business with the same guy the government likes?

too long before we see ‘Made in China’ emblazoned on wheelchairs. “We’re promoting a Walmart mentality of our medical equipment,” he says.

But why is the federal government going after DME as hard as it is — what is the motive? It can’t be to save money, since at 1.7 percent DME is such a pitifully small part of the total Medicare budget.

“We feel that both the Centers for Medicare and Medicaid Services and the Office of Inspector General do not understand the service component offered to Medicare consumers,” says Alexandra Bennewith, senior manager of government affairs with the American Association for Homecare. “That’s where they’re coming from, they don’t see the value in it. So we’re always educating about the importance of qualified clinicians, home assessments, adjustments, making sure measurements are accurate. Right now there is only a limited amount of money the provider can charge for these things, and so a lot of the service provided is above and beyond what’s paid for.”

The overarching goal is to get Congress and CMS to understand how important complex rehab is to the people who use it, and also how crucial it is to have

qualified technicians configuring this technology. This goal is broken up into smaller objectives. One was to carve complex rehab out of the existing competitive bidding program, and that was successful. Next is to push for passage of HR 3790, a bill calling for an end to the competitive bidding program. So far that bill has over 245 cosponsors in the House, and advocates are looking for someone to sponsor it in the Senate. Also, language is being tossed around for a separate benefit category under Medicare for complex rehab technology, which would require certification of technicians, and also allow for their services to be reimbursed.

Hitting the Hill

On the second day of the CELA event, participants were bused to Capitol Hill, where meetings had been arranged with their U.S. reps and senators. Some were lucky enough to meet with the actual congressperson, while others met with legislative aides. This was a professional event, and participants were carefully prepared by attending workshops on how to tell their stories and make their points, and there was even a basic dress code. Those going to the Hill were asked to dress “business casual,” and those who had done this

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It's Not Just a Medicare Issue

Kathy Peters says she had to travel from California to Washington, D.C., just to get a wheelchair to replace her 10-year-old model that's literally falling apart. Peters, who has MS, was one of 30 wheelchair users who attended the National Registry of Rehabilitation Technology Suppliers' Continuing Education and Legislative Advocacy conference in Washington, D.C., in April. "I actually was approved by my insurance company to get a brand new wheelchair two years ago when my daughter was born, and it has everything I needed except for backpack clips. But then the medical company said they weren't expecting me to be approved and since I was, they now wanted \$18,000 for my co-pay. Mind you, I already should have had my total co-pay covered, since I had met my deductible already — having the baby helped me reach it."

Peters has tried everything to budge the medical supplier. She's a professor at Cuesta College in San Luis Obispo, Calif., and even asked the school's human resources department to try to help, "but they had no luck," she says. "So then I tried to find a new company to sell me the wheelchair, but I couldn't find anyone locally. There aren't a lot of retailers here where I am, in the middle of California. Fortunately, at the conference I found some people who would come down here."

Which was very lucky.

But what does any of this have to do with Medicare's slashing reimbursements and trying to implement competitive bidding programs? After all, Peters works and has good insurance. "All the private insurance companies use Medicare as their primary negotiator," says Peters. "If Medicare does something, the others follow suit most of the time and do very similar things. So with the company I went to for my new chair, they were basically saying, 'We're not going to get enough reimbursement for the chair,' just like Medicare wouldn't." And so the company refused to fill the order, even though the chair was approved by Peters' insurance company.

And the impact of something like competitive bidding would have on the company that wouldn't serve Peters? "What if that company got the contract? Or what if the company that got the contract was 200 miles away? Are they going to be there to fix my wheelchair when it breaks down? And when they do these big bids, they want the same wheelchair set up for everybody because it's easier."

Of course, the single mother of two young children says she's having trouble even now getting her chair serviced. "When my dad comes to town, he does things here and there. He even put in a new power cord for me, and a whole new [control] system. I'm lucky that he can do electrical stuff."

But getting a quality power wheelchair and keeping it maintained shouldn't depend on luck.

type of thing before generally wore black slacks, blazers, and then a colorful blouse or tie underneath.

But some lobbyists didn't get the memo, so in addition to the 30 professionally-attired wheelchair users who attended the CELA event, the halls of Capitol Hill hosted wheelers in colorful tie-dyed ADAPT T-shirts. It turns out that Kathleen Kleinmann, executive director of the Washington, Pa.-based Tri-County Patriots for Independent Living, was encouraged by ADAPT to have advocates from her CIL, in town for a demonstration, come on over and give CELA a helping hand. Most of these advocates were still wearing their "ADAPT uniform," and the contrast was a nice symbol of how much the issue of quality DME affects wheelers from all corners of the disability community, from ADAPT to professional organizations like NRRTS.

Kleinmann didn't ask her people to come out for the industry, though. She did it to protect consumer choice, which is a cornerstone of the Independent Living movement. "I want to determine the competition, I don't want the government to determine the competition," says Kleinmann. "I want service providers to compete for my service dollars, to give me such high-quality service that the relationship is based on trust and respect. If the government is buying in bulk at competitive prices, then it has stolen the role of customer from me."

After all, if CMS keeps slashing reimbursements and succeeds in getting all equipment under competitive bidding, then that means all the vendors and providers will only answer to CMS. All of the community's hard work at establishing consumer-driven wheelchair clinics and workshops will be undone if price continues to be the driving force in wheelchair selection.

Also, this is a hard-core ADAPT-worthy freedom issue. "The secret to keeping people

in the community at this point in time is well known to depend on attendant care, and assistive technology is an answer to avoid nursing homes," says Kleinmann, whose CIL has helped hundreds of people leave nursing homes and institutions. And what she says makes sense. Currently, personal assistance services are doled out by the hour, and it would take twice as long to do all kinds of activities of daily living without proper equipment. For example, if a person's wheelchair doesn't align well with her toilet, she may need help transferring five or six hours a day. But with the right equipment, she may be able to do it herself.

"Just like having a microwave in your kitchen reduces your cooking time by hours, so can technology reduce your need for attendant care," says Kleinmann.

Kleinmann's had her own struggles getting necessary equipment paid for, though in her case the fight was with a private insurance company. "It took me three or four years to find a chair that would stand me up, and I need that because of a multitude of secondary conditions" — osteoporosis, digestive concerns and cardio-vascular concerns. "When I started using the stander I immediately felt the impact on my heart rate and breathing. It took me quite a while to stand for a whole five minutes, my system was so weak." Again, as Medicare goes, so goes everyone else. Medicare resists paying for standers, and so even the executive director of an agency that holds quite a few state contracts has to fight for the right piece of equipment.

And, really, what can you expect from a system that's as backwards as ours, wonders McNamara. "The whole system is a little strange. We have these codes, and so we don't really build products toward the need. They're being built toward a code that CMS comes up with, and we fit our products in these categories. It's not necessarily benefiting the end user." **NI**

Advocacy Made Easy

Ian Ruder, a C5 quad from Portland, Ore., was one of 30 wheelchair users selected to attend the National Registry of Rehabilitation Technology Suppliers' Continuing Education and Legislative Advocacy conference. This annual conference usually has a day of workshops on legislative issues, followed by a second day on Capitol Hill educating lawmakers about issues affecting the industry. Although wheelchair users certainly are regular attendees, this year was the first time CELA reached out to wheelchair users like Ruder for help explaining the importance of quality equipment to members of Congress.

"The trip was an eye-opener for me," says Ruder, 29. "I was cynical before about Congress. But just seeing how receptive most of the aides and legislators are was heartening. I want to be more involved in the future, to help explain what I think are simple issues that obviously are not that simple to other people."

At first it was a little bit intimidating, as the Capitol Complex is among the most stately and iconic pieces of architecture in the U.S. "The beautiful old Senate building, very marbly with its majestic wooden doors was something to see," says Ruder. "My first meeting was with Sen. Merkley, and there were probably 15 to 20 other people with us, including doctors from Oregon University, and everyone there had something different they wanted to talk to him about."

Ruder and the other CELA advocates were at a regularly scheduled coffee hour that Sen. Merkley hosts for his constituents. At first the CELA advocates just mingled, but finally the senator took notice. "He comes up to me. Now, I've seen him on TV, and I voted for him. But he looked at me, very direct eye contact, and my mind went completely blank. Hello, Senator!" Ruder says that once he adjusted to meeting Merkley one-on-one, he was able to talk about the issues that brought him to Washington, D.C. "There was this feeling of power I had that I really didn't expect. It was a cool experience."

After this meeting, the other congressional appointments went very smoothly. "All together, just the amount of comprehensive, intensive listening we received from the legislators and their aides, it made me think, 'they're doing this for me, the people here on behalf of complex rehab.' Also, I can imagine all of the interests they are doing this for every day. It made me feel optimistic about how our government works. It was very affirming, and gave me confidence that things are better than I thought."

Before he even left the building, Ruder had already received five or six immediate follow-up e-mails and a phone call from legislative aides. The whole experience was so good that now Ruder won't think twice about picking up the phone and calling politicians to share his concerns or ideas.

"I went with some expectations and hopes, and it was one of those rare trips where everything was surpassed," says Ruder.

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A Call to Action

BY JEFF LEONARD

As you've seen throughout this publication, Medicare and private insurance companies are making it tougher for you to get the equipment you need. Just recently Medicare reduced the amount it pays providers for your equipment by 9.5 percent. Private insurance companies such as Blue Cross, Aetna and United Healthcare follow the lead of Medicare and have also reduced their reimbursement.

This cut in funding has a big impact on manufacturers. The more reimbursements are reduced, the more likely they are to cut their own costs just to survive. The result? Lower quality chairs with fewer customizable features.

If we don't act quickly, you may be left with improper equipment and perhaps no product choice at all. Well, maybe you'll be able to choose silver or black. But forget about seat elevation, standers, tilt, suspension, recline. Remember the days of the 50-pound E&J chair? That's where we're heading.

So, here are the legislative issues that are currently on the floor in Washington, D.C., and the impact they'll have on you:

Competitive bidding — In a nutshell the competitive bidding process reduces your access and choice for quality home medical equipment products and services. The program selectively contracts with a very restricted number of home-care providers based on the lowest bid prices. This means that you might need to travel hundreds of miles to have your wheelchair serviced, and you may lose the equipment choice you currently have.

Complex rehab separate benefit — Complex rehab technology (wheelchairs, sip 'n' puff, pressure mapping cushions, tilt, power, etc.) refers to products that need to be fitted for your unique medical needs. Access to complex rehab technology is severely threatened because of its inclusion in Medicare's outdated classification system for durable medical equipment. Congress must act to estab-

Politicians say they 'want to do the right thing for people with disabilities.' But do they really understand the importance of the right equipment in your daily life? Absolutely not.

lish a new and separate benefit category for complex rehab products and services that recognizes the customized nature of disability-related equipment.

Now, we've all seen politicians using people with disabilities in their campaigns, complete with official statements saying that they "want to do the right thing for people with disabilities." But do they really understand the importance of the right equipment in your daily life? Absolutely not. That's why more wheelchair users need to speak up.

For years, the disability equipment industry has tried to improve reimbursement, but it's been unsuccessful. With all medical equipment reflecting less than 2 percent of Medicare's budget, manufacturers and suppliers don't get the attention they deserve from the government. Your elected officials keep reducing your product choices, reducing funding for the equipment you need and minimizing your place in society. Yet — America loves people with disabilities.

How many times have you seen "feel good" stories in the news about wheelchair users? One problem with these stories is that they never express why quality equipment is so important: independent living and full participation in life. Our community's voice, our denial stories, our desire to be employed, our desire to be part of the solution (not the problem) needs to be delivered to Congress and local politicians.

You may think your voice will not make a difference. But every time we remain silent, decisions are made without us, and we lose the chance to be part of the solution. Your voice matters.

If 80 percent of our success is "just showing up," the rest is learning enough

about the issues to have an informed opinion, and then making that opinion known. Let's show up — not one of us, not 10 of us, but all of us, the entire disability and wheelchair community — and let the government know that the proper equipment will save the government money, improve our society, promote employment, and add to the number of taxpaying Americans. Imagine what tens of thousands of documented stories to legislators on Capitol Hill can do.

Thanks for reading. Now — want to get involved? Here's how you can make a difference in 25 minutes:

- Take 3 minutes to join Users First Alliance (www.usersfirst.org).

- Take 5 minutes to learn more about advocacy by visiting www.spinalcordadvocates.org or www.spinalcord.org.

- Take 5 minutes to find the websites of the politicians who represent you.

- Take 10 minutes to e-mail your U.S. representative and senators, as well as your state legislators. Share with them a personal anecdote about how equipment affects your health and quality of life. Negative stories are generally more effective — how denial of equipment or poor equipment caused a health problem or restricted your participation in life. Tell them you don't support competitive bidding and you do support a separate benefit category for complex rehabilitation technology.

- Take 2 minutes to e-mail the same anecdote to us here at NEW MOBILITY (jeff@newmobility.com). We and Users First will be compiling reports from people with disabilities, and will personally be meeting with members of Congress and industry officials to spread the message and enact change.

BE AN AGENT FOR CHANGE



DARREN JERNIGAN – *Activist*
Director of Government Affairs, Permobil, Inc.



www.USERSFIRST.org

I LIKE TO TAKE CHARGE.

I am a lobbyist, a mediator and an advocate. As the Director of Government Affairs for Permobil, Inc., I want to improve the quality of life for all wheelchair users. That's why I joined the Users FirstSM Alliance. This organization of individuals, corporations and providers strives to ensure

you have the state-of-the-art products that you deserve and that companies continue to develop solutions for your specific mobility needs. Users First seeks to empower all wheelchair users through education and information. Join us today and demand what is rightfully yours!



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