September 6, 2018

The Honorable Lee Zeldin (NY-1)
U.S. House of Representatives
Washington, D.C. 20515

The Honorable John Larson (CT-1)
U.S. House of Representatives
Washington, D.C. 20515

RE: Please Pass H.R. 3730 To Protect People With Disabilities' Access To Critical Components Used With Complex Rehab Wheelchairs

Dear Representatives Zeldin and Larson,

This letter is being provided on behalf of the Clinician Task Force (CTF). The CTF is a nationwide network of 50 physical and occupational therapists, whose work involves providing wheelchair seating and mobility services to individuals with disabilities. We are the only professional clinical group dedicated to Complex Rehabilitation Technology (CRT) and Seating and Wheeled Mobility service provision. Our mission is to advocate for professionally sound, clinically based public policies that ensure individuals with functional mobility impairments have appropriate access to seating, positioning and mobility products and services.

As a group of clinicians with experience and expertise in evaluating and treating people with disabilities, when recommending technology solutions, we work to identify the most appropriate system that will address the medical and functional needs of our clients. For people with disabilities, each system is unique and individually configured to each person which is necessary given the needs of this population.

The recommended system is based on a complete evaluation of each person, their routine activities, environment, roles and responsibilities and with the goal of maintaining or improving their health, function, independence and access to their community.

Current Medicare funding for equipment used by this population, known as Complex Rehabilitation Technology, has been reduced. As a result of the latest payment reduction to critical components (accessories) used with CRT manual wheelchairs and cumulative payment, coding and coverage policy changes, access to CRT has declined and people with disabilities are being significantly negatively impacted.

Due to the multiple policy changes over the past few years, it can be difficult for clinicians to identify the reason for the access decline. However, with the recent reduction in payment for CRT manual wheelchair components (accessories) related to competitive bidding pricing, there are particular technologies that are becoming increasingly difficult to obtain unless clients or their families can buy them. In many cases the population that uses CRT are beneficiaries with both

Medicare and Medicaid coverage (dual-eligible). Private pay is not an option for the dual eligible population, so in instances of inadequate reimbursement they are forced to go without.

The CTF routinely discusses access issues, concerns related to our professional responsibility in situations where the technology that can be provided is not the same as recommended due to Medicare funding deficiencies. We would like to share a few of the situations we have encountered to illustrate the real-life impact of reductions in access,

These are merely examples, not a comprehensive report, of the ongoing struggles we experience in trying to obtain the appropriate CRT wheelchairs for our clients with disabilities. This client group depends on this technology for all daily activities. Without the right equipment they do not meet their goals and their healthcare costs increase.

Access Example A

Jill Monger PT, MS, ATP Physical Therapist
Medical University of South Carolina
Charleston, SC

Patient age: 51 years old

Diagnosis: Spinal cord injury, T12/L1 complete paraplegia with onset in 1998. Rod stabilization thoracic spine later removed with spinal instability. History of right rotator cuff tear repaired 1998, left tear never repaired, right failing again this year. Post cervical corpectomy with anterior stabilization surgery C5-7 2005 and post cervical revision C3-T2 then another in 2012 with rod place C3-T4 (basically his neck has rods throughout without an ability to move it). Bilateral carpel tunnel syndrome. Neurogenic bowel and bladder.

Summary: My patient is a manual wheelchair user who has experienced significant decline in arm function/status due to full time wheelchair propulsion since 1989. He has depended on a Titanium manual wheelchair as lightweight as possible to continue to propel rather than move to a power wheelchair. There are several components of the wheelchair that are critical for this patient to continue to use a manual chair without significant further damage to his arms and to allow him to continue to function.

1. Mike has depended on a Titanium manual wheelchair due to severe complications from being a full-time wheelchair user for 29 years. He needs to upgrade to Titanium.

2. The standard rear tires that come with the chair are similar to standard bike tires and do not provide high pressure resistance to shock balancing between enough shock absorption to help minimize trauma to his unstable spine and fixed cervical spine/neck and enough stability for the wheelchair to roll without significant resistance. Therefore, he requires an upgrade to high pressure pneumatic tires.

3. The standard 1" wide casters that come with the chair are much too narrow. He requires wider soft roll casters to allow the chair to roll over thresholds and uneven surfaces without causing vibration and shock which leads to spasticity, severe neck, back and shoulder pain.

4. The standard wheel locks that come on the chair are positioned in front of the wheel at all times. This patient must push "all the way through" the position of these locks. He often injured his thumbs/hands before switching to the upgraded locks that move away from the front of the tire when unlocked.

Problems encountered: Medicare reimbursement for the casters and tires and wheel locks is inadequate and Medicare recently decided that titanium is included in the base price of the wheelchair. In each case, since the CRT item and the standard item are in the same HCPCS code, not only is the reimbursement too low to accept Medicare payment, but Medicare policy does not allow a patient to upgrade when both items are within the same HCPCS code. My patient's only choice is to purchase the entire chair and components with personal funds. He states this is a financial burden. He will pay for several of the component upgrades privately as he simply cannot function without them.

Consequences: The patient will receive a new wheelchair, but the Titanium feature will not be provided and the many critical components he has depended on for years will need to be purchased privately and remounted to the new wheelchair. Paying out of pocket is not something all of my patients can do, and if they also have Medicaid as a secondary insurer paying out of pocket is not an option. So, access is limited to only those who can pay for it themselves.

Access Example B

Jill Monger PT, MS, ATP Physical Therapist
Medical University of South Carolina
Charleston, SC

Patient age: 42 years old

Diagnosis: Spina Bifida, paraplegia, neurogenic bowel and bladder, history of pressure wounds with surgical repair, carpal tunnel syndrome, shoulder pain.

Summary: This patient is a manual wheelchair user who has been using an ultra-lightweight manual wheelchair with specific critical components all of her adult life. Jessica drives a personal vehicle that requires her to lift her chair and all components in and out of her vehicle many times a day. She started to develop several overuse symptoms (carpal tunnel syndrome and shoulder pain) that have been kept to a minimum by last wheel chair being upgraded to Titanium and addition of the ergonomic hand rims. That chair is over 7 years old and needs too many repairs to be usable, so she is using an old chair which is heavier with standard hand rims, as a result her symptoms have increased, and she now has back and neck pain.

She requires the following wheelchair upgrades, options and critical components:

1. Jessica depends on a Titanium manual wheelchair to be able to lift it in and out of her vehicle with as little strain on her upper body as possible. She has already begun to develop some overuse symptoms that have been kept to a minimum until this chair failed and she is using an old aluminum wheelchair.

2. The standard forks (are stiff) and caster wheels (are too thin) that come "with the wheelchair" do not work for this patient. She requires the wider caster tires and shock absorption forks to minimize vibration as she rolls over thresholds and uneven surfaces to minimize further development of back and neck pain and to keep her feet from falling off of the foot plates.

3. Natural Fit Ergonomic Hand Rims are required (and have been used previously with good result) to prevent full development of carpal tunnel syndrome and further shoulder injury. Before she began to use these upgraded hand rims she was having severe pain from CTS and surgery was planned. Since using them she has prevented the need for surgery and tolerates the minimal pain and tingling.

Problems encountered: Medicare now considers ALL materials to be included in the base price of the wheelchair (Titanium and Carbon Fiber which are more costly materials) Medicare reimbursement for the tires and forks are based on standard products and is inadequate for the provision of CRT products. Since the CRT and standard products are in the same HCPCS code, Medicare also does not "allow" a patient to pay the "difference" on upgrades. We discussed this with the patient and she will have to order this equipment and install them privately. She indicated the total is too high of a financial burden for her and she can only afford the caster upgrade.

Consequences: The patient will receive a new wheelchair, but it will be a heavier version similar to the one she is currently (temporary chair) using and which is not working for her. In addition, the critical component she has depended on for years, natural fit hand rims, will not be provided and she will be forced to transfer her hand rims that are currently on her >7-year-old wheelchair to her new wheelchair. The >7-year-old hand rims are used and in poor condition (lots of deep scratches in the surface of the rims causing nicks and cuts to her hands).

Access Example C

Penny J. Powers PT, MS, ATP
Level IV, Adult Seating & Mobility Clinic
Vanderbilt University Medical Center
Nashville, TN

Diagnosis: Cerebellar degeneration with profound ataxia and Parkinsonism, repeated falls with injuries – spinal fracture, obesity (230# - height 5'5"), nail fungus with loss of nail.

Summary: My patient is non-ambulatory without physical assistance and demonstrates the ability to independent propel an ultralight weight manual wheelchair on smooth level surfaces to complete/participate in MRADLS with the following critical components:

1. Casters – needs soft roll casters because the standard ones bury down in her carpet. Current Medicare reimbursement does not allow access to soft roll casters. If she wants the soft roll casters she will have to pay out of pocket.

2. Ergonomic hand rims are grouped in the same code as standard hand rims. She has impaired coordination and needs the widest grip access to propel the wheelchair. She has a fungal growth and her finger nails are separating from the nail bed (complication from a medication) and once she missed the standard aluminum rim and she nearly ripped the nail from the bed. This is considered "harm". She does not have the money to buy the ergonomic hand rims.

Problems encountered: Medicare groups standard and CRT products in the same code. Current Medicare reimbursement does not allow access to the components my patient needs. In addition, Medicare does not "allow" a patient to pay the "difference" on upgrades that are in the same HCPCS code or if the standard item is considered to be included in the base price. We discussed this with the patient and she will have to consider private pay. She has a degenerative neurologic disease and has many, many expenses.

Consequences: The patient will receive a new manual wheelchair but will need to pay out of her own pocket if she is to receive the critical components and they will need to be mounted to the new wheelchair after the wheelchair is delivered.

Access Example D

Susan Christie, PT, ATP
Advanced Clinician, Outpatient Wheelchair Clinic
Bryn Mawr Rehab Hospital
Malvern, PA

Patient age: 66 years old

Diagnosis: Adult-onset form of muscular dystrophy, getting her first power wheelchair after many years using a scooter. Presents with tetraplegia, unable to lift arms and legs against gravity or to shift her weight when sitting. Recently fell and fractured her femur, leading to a decline in overall function

Summary: Recommended equipment is a Group 3 power wheelchair with multiple power seat functions and seating system. In addition, my client is unable to wear shoes because of foot deformities and padded foot box was recommended to protect her feet from pressure injury.

Problems encountered: Medicare used the reduced reimbursement for heel loops, toe loops and leg straps to determine payment for foot box technology and the reimbursement is inadequate to allow access to the footbox that she needs. My patient cannot afford to pay for this out of pocket.

Consequences: High risk of foot injury.

Access Example E

Susan Christie, PT, ATP
Advanced Clinician, Outpatient Wheelchair Clinic
Bryn Mawr Rehab Hospital
Malvern, PA

Patient age: 52 years old

Diagnosis: Encephalitis as an infant leading to hemiplegia and intellectual disability, unable to ambulate.

Summary: This patient was recently transitioned to Medicare when her father retired. She requires supportive seating because of very poor trunk control as a result of her hemiplegia and had a successful trial of equipment at her evaluation appointment in Wheelchair Clinic.

Problems encountered: The DME company stated that they could not provide the recommended equipment because their cost exceeded the reimbursement. With much persuasion and multiple calls from the therapist, the consumer eventually did get the correct equipment, but the supplier was clear this was a one-time situation and that they would not provide product when reimbursement was inadequate going forward.

Consequences: Inadequately funded product will no longer be available.

Access Example F

Twala Maresh PT, DPT, NCS, ATP
Senior Clinical Instructor
University of Central Arkansas
Conway, AR

Patient age: 26 years old

Diagnosis: Spinal Cord Injury with C5 Tetraplegia (sensory but no motor function)

Summary: Patient travels by airplane monthly for work and needs a portable option for independent mobility and transit around unfamiliar cities. A rigid ultra-lightweight custom manual wheelchair was recommended with a Spinergy Power Assist package. The patient is unable to functionally self-propel a manual wheelchair but can operate a joystick controller, which enables a portable mobility option for travel, transit and independence in all environments which a traditional power wheelchair will not allow. Due to impaired trunk control the patient requires firm back support to maintain a neutral upright position for function, pressure distribution and breathing.

Problems encountered: I have had difficulty getting coverage for power assist options added to rigid manual wheelchairs for clients with SCI. However even if Medicare covered the item the

reimbursement is too low to allow access. While the inability to access the power assist option is a Medicare coverage issue, the inability to obtain the solid back support is related to the reduced reimbursement. Furthermore, if the solid back was being provided on a power wheelchair the reimbursement would be adequate. However, since the back will be used on a CRT manual wheelchair the reimbursement is inadequate.

Consequences: The cost of the manual wheelchair and the power assist system was shifted to the patient and the family had to cobble together funding over time to acquire the necessary equipment.

Access Example G

Erica Walling MPT, ATP/SMS
Physical Therapist
Brooks Rehab
Jacksonville, FL

Patient age: 48 years old

Diagnosis: Cerebral Palsy with Spastic Quadriplegia, Scoliosis, Stage 3 Pressure Injury Heel of Left Foot

Summary: The patient has a 3-year-old Ultralightweight Folding Manual Wheelchair that he self-propels with his right arm and leg. He lives at home alone without assistance. Following a recent hospitalization for a UTI he developed a Stage 3 Pressure Injury on his left heel. His open wound is sterile, and dressed, requiring support to prevent further injury and promote healing. At the time of the evaluation it was noted that the 3-year-old manual wheelchair had other repairs that were needed.

The patient needs:

1. Single padded footbox mounted on the left swing-away footrest hanger. A standard basic footplate would not be able to provide adequate pressure distribution and promote healing. The patient is sensate and would not tolerate a hard surface.

2. Swing-away hardware for lateral trunk support- The patient has a moderate scoliosis with pelvic obliquity that can be partially reduced with support. The swingaway lateral trunk support hardware broke on the right side due to wear from trunk spasticity requiring replacement. The lateral supports are critical to support his trunk in a midline posture to free his arms to self-propel the wheelchair. Without lateral trunk supports he is unable to sit unsupported or functionally propel his wheelchair for independent mobility.

3. Wheelchair tray with heavy duty removeable hardware – the patient uses a tray y to carry items for cooking, for basic daily living needs, and to move items room to room as he does not have a caregiver or paid assistant. The basic tray attachment is broken. A replacement Wheelchair tray with heavy-duty hardware is needed to support the weight of items needed for daily use.

4. Padded pelvic belt- The basic safety belt issued with the wheelchair was worn and eventually ripped due to trunk spasticity. Also, the patient was experiencing pressure and redness on the anterior surface of his pelvis. A padded pelvic positioning belt can be tightened to support his pelvis in a neutral position and endure the forces exerted from his spasticity.

Problems encountered: The patient's existing 3-year-old manual wheelchair needed to be modified and repaired due to a change in medical condition and wear from normal heavy from spasticity. The Medicare payment amounts for new and replacement critical components was inadequate when needed in conjunction with a manual wheelchair to allow access.

Consequences: Due to current Medicare reimbursement the supplier was not able to provide these components and therefore the patient's family had to purchase the items out of pocket.

Some of our clinician members also shared additional comments on their experiences with the availability of CRT wheelchairs and related critical components. These included:

- "The reimbursement trend has been decreasing slowly overtime but this last cut is impossible. Clients that need these items, truly need them, and the other components of the wheelchair become useless without this critical component/item."

- "I have had difficulty obtaining a power assist device for a rigid manual wheelchair for a client with paraplegia even when she could no longer effectively push a manual wheelchair due to a chronic shoulder injury."

- "While technology is improving, and many wheelchair critical components are more effective and have become commercially-available, Medicare reimbursement is declining and shifting the burden of payment onto the beneficiaries for items they previously could get by paying the co-pay."

- "Continued changes will result in the failure of the complex rehab industry. These components are vital to the wheelchair. You try sitting in a chair without leg rests, with your feet dangling for 12+ hours and tell me what happens. Or, if you have scoliosis and don't have lateral supports or a positioning belt, you can't control your body, fall over and out of the wheelchair and injure yourself."

- "Wheelchair cushions seem to be subject to the five-year rule, meaning Medicare won't pay to replace them for five years. The problem is that they are often damaged and ineffective in a much shorter time and consumers are sitting on a damaged cushion which does not effectively protect their skin. This is dangerous and may lead to their skin breaking down, which causes the consumer to lose productive time and possibly be confined to bed and costs the health care system a large amount of money to treat. Medicare expects the consumer to buy replacement cushions that have become ineffective before the five-year mark."

We recognize that some of the comments shared are not directly caused by reduced payments for CRT, but we left these comments in because it can be difficult for clinicians to tease out the ultimate cause for the access denial. The impact on our clients is the same when they cannot obtain the technology they need regardless of the reason. It is very clear to those of us who routinely evaluate clients with profound disabilities in our wheeled mobility and seating clinics across the country, access to CRT products, especially critical components used with CRT manual wheelchair bases, is on a steady decline.

Increasingly the cost of these critical items is shifted to the beneficiary and their families when they have the financial capacity to pay for them. Unfortunately, a large portion of the population that uses CRT cannot afford to pay for technology out of pocket. In addition, a high percentage are dual-eligible for Medicare and Medicaid and therefore, by statute self-pay is not an option, so they go without the necessary critical components.

We have previously written to Congress in support of the passage of H.R. 3730 and restate that support through this letter. Passage is urgently needed to eliminate the current situation of reduced payment rates for critical components used with CRT manual wheelchairs being based on competitive bidding pricing information. It would also eliminate the current policy disparity which pays higher amounts for the same component if it is used on a CRT power wheelchair.

If you'd like to speak directly with any of the CTF members, we are happy to provide contact info or make arrangements. Should you have any questions please do not hesitate to contact me.

Sincerely,

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