# Fixing and Replacing Power Mobility Devices - Making it Work 01.17.23 - Version 1.1 June Kailes, Disability Policy Consultant

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Terms used in this brief:

- Manufacturer company that makes the device.
- Suppliers a company that operates in local communities. Some may be a single business, and some may be regional companies covering multiple states. There are two national providers/suppliers: National Seating and Mobility and Numotion, with over 100 plus locations and operating in most states.

## Introduction

This brief describes the many policies needing fixing and recommends an advocacy path forward regarding repairing and replacing power mobility devices. A robust exploration of the history and a complete list of the issues needing fixing extends beyond the scope of this brief.

# **Original Intent**

Whether an emergency, a catastrophic disaster, or a disruption caused by a breakdown, damage, or need to replace a power mobility device on a sunny day, the challenges, consequences, and sometimes nightmares are similar for many power mobility device users.

## Sources:

- A broken wheelchair can bring life to a standstill and create multiple problems:
   WBUR | By Gabrielle Emanuel, January 5, 2023
- Despite a first-ever 'right-to-repair' law, there's no easy fix for wheelchair users,
   Health News Florida | By Markian Hawryluk, June 2, 2022

- My Quest to Find the Right Wheelchair | By Seth McBride, March 1, 2021
- Forced to Pay Wheelchair Rental? | By Michael Collins, December 1, 2016
- Why Is Durable Medical Equipment Such a Problem? Patients Rising | By Kate Pecora, September 25, 2020

The current system puts people with disabilities at elevated risk. To protect users, policies and procedures must focus on preventing and mitigating the cascading adverse effects of loss of mobility devices. Like a house of cards, the loss of devices can quickly disrupt or collapse the usual precarious balance of resilience, health, safety, employment, and independence. Moreover, the loss of devices can be a callosal, life-altering, life-shortening and life-threatening event which can lead to institutionalization and sometimes death.

For example, when an air carrier damages or destroys an individual's powered mobility device, and the airline pays for repair or replacement, usable loaners are not always quickly available. Repair and replacement is a time-consuming process that can take many months.

## Reference:

- <u>Disabled Activist Engracia Figueroa's Cause of Death Revealed</u> | By US Day News, Fall 2022
- <u>Disability Advocate Engracia Figueroa Died After An Airline Damaged Her</u>
   <u>Wheelchair</u> | By Forbes, January 8, 2021

The original intent of this brief was to:

- Address many power mobility device users' emergency-related complaints by creating an accountability and solutions roadmap to improve the ability of people who use powered mobility devices to quickly repair or replace their devices after disruptions, emergencies, or disasters.
- Describe the challenges, including getting immediate help, immediate transportation, usable and safe loaners, long waits for approvals, and long waits for replacement parts or a new device.
- Make recommendations regarding what it would take for suppliers of critical life: saving, supporting, and sustaining equipment and supplies (upon delivery, service, and repair) to instruct users on activating emergency procedures for their equipment.

# **Shifted Focus Based on Findings**

Interviews with subject matter experts (See: Subject Matter Expert Interviews) and user reports reveal a broken structure riddled with enormous and complex systemic and policy failures that are not working for many on non-disaster, sunny days. The findings necessitated the focus of this brief pivot to summarize what is not working with the system in general and suggest recommendations for a call-to-action. The issues are pervasive and convoluted, with a tangled and complicated history. Rules initially intended to combat abuse contribute to a

broken system brimming with deeply flawed, ableist, and discriminatory public policy that brutally hurt end users.

## References from WBUR Search:

- <u>Letter to John Cronin and Ryan Fattman: Re: Expanding Wheelchair Warranty</u>
   <u>Protections</u> | February 11, 2022
- Wheelchairs repairs can take a month, or longer, leaving people stranded | By Gabrielle Emanuel, March 9, 2022
- <u>Facing breakdowns and slow repairs</u>, <u>Mass. Wheelchair users call for stronger state law</u> | By Gabrielle Emanuel, March 10, 2022
- Wheelchairs break often and take a long time to fix, leaving millions stranded |
   By Gabrielle Emanuel, March 19, 2022
- Consider This: Lengthy wheelchair repairs are leaving people stranded | By Darryl C. Murphy and Gabrielle Emanuel, March 14, 2022

# **Issues Needing Immediate Attention**

Below is a sampling of problems related to state, territory, and federal legislation, policies and practices that need modernizing and upgrading. These problems include device repair, loaners, replacement, and authorizations:

- Significant reduction in the number of suppliers and fewer choices for equipment repair.
- Device users report great difficulty finding repair services, and when found, they sometimes report experiencing months of waiting for approvals, parts, repairs, replacement, and loaners.
- Replacement parts are often unavailable or require long waits. Keeping parts in stock is challenging for suppliers due to supply chain and outlay of costs issues.
- Out-of-Warranty repairs are not covered, and suppliers are not obligated to provide these repairs.
- For device users who have the capacity and resources, including the funds, to obtain the parts, do-it-yourself home repairs can be difficult to impossible because of the lack of availability of technical assistance from technicians via phone or a virtual/video connection.
- There is nothing that obligates the supplier to do repairs. No rule states, "if you sell and supply it, you have to repair it." For example, under Medicare suppliers are only required to repair items during a capped rental period.
- Suppliers need reimbursement for service at competitive rates. In many cases, current reimbursement rates for repairs do not even cover the cost of buying the parts.

- Lack of payment of suppliers for loaners for as long as needed to complete repairs or replacement. Suppliers are only paid for 30 days when the typical process takes longer. Thirty days is based on how long expected repairs are projected to take and not the process of getting approvals. Medicare doesn't require prior authorization but Medicaid and other payers do.
- Suppliers need to be paid for the labor time it takes to transfer existing sophisticated input devices and /or seating systems from a power wheelchair being repaired or replaced to a loaner chair or a new chair.
- The adequate payment for all costs needs to apply to payers across all lines of health insurance plans business, including employer-sponsored coverage, individual and group insurance market, and public programs (CHIP, Medicare and Medicaid including Managed Medicaid and Medicare Advantage, ect.).

#### Reference

- New Medicare Beneficiary Wheelchair Repair Survey | By United Spinal Association, May 1, 2014
- Compiled by Rita Stanley, Merriman Innovation Consulting, Principal/Consultant, available here
  - Emergency Replacement and Repair Policy Issues
  - A Timeline of Medicare Policy and the Centers for Medicare and Medicaid Services (CMS) Interpretation of "appropriate for use in the home"; Impacts Medicare Beneficiaries with Disabilities

# **Disaster Repair and Replacement Issues**

Emergency waivers do exist:

Medicare policy on replacement of durable medical equipment (DME) is a standard policy that is available for beneficiaries that have DME that has been lost, destroyed, or damaged. However, during many disasters, additional flexibilities may be made available through a waiver process.

When the President declares a disaster or emergency under the Stafford Act or National Emergencies Act and the U.S. Department of Health and Human Services (HHS) Secretary declares a Public Health Emergency under Section 319 of the Public Health Service Act, the Secretary is authorized to take certain actions in addition to their regular authorities. Source Student (Manual Guide (PDF) page 18).

Durable Medical Equipment ("DME") Suppliers. DME MACs Medicare Administrative Contractors ("MACs") may waive replacement requirements, including the face-to-face requirement, a new physician's order, and new medical necessity documentation, for DME Prosthetics, Orthotics, and Supplies ("DMEPOS") that are lost, destroyed, irreparably damaged, or otherwise rendered unusable as a result of the emergency. The supplier's claim must include a narrative description that explains the reason for the replacement. The supplier must maintain documentation indicating that the DMEPOS was lost, destroyed, irreparably damaged or otherwise rendered unusable, or unavailable as a result of the emergency.

Appeals Process for Fee for Service, Medicare Advantage ("MA"), and Part D Plans. The blanket waivers include an extension to file an appeal and waive the timeliness requirements for requests for additional information to adjudicate appeals. The appeal may be processed even with incomplete Appointment of Representation forms through communications with the beneficiary. CMS will also process requests for appeal that do not meet the required elements based on the information available. CMS will use all flexibilities in the appeals process if good cause requirements are met.

Source: New and Pre-Existing Federal Waivers and Flexibilities Available to Health Care Providers During a National Emergency | By Epstein Becker Green, March 20, 2020

Disaster repair and replacement issues must be addressed to protect device users before, during, and after disasters, but many of the issues may not be fixable until the systemic problems detailed above are solved. Therefore, these recommendations should be implemented when the above systemic problems are fixed.

# Suppliers:

- Upon delivery of a new device, repair, or service, must instruct and provide users on how to activate emergency procedures for their equipment. These instructions include alternative ways to safely power the equipment with clear verbal, text, (including pictures) directions in usable and understandable formats and preferred languages.
- Must provide written content and require the user to sign confirming the receipt information below on the sample (See Device Information Sheet).

## Manufacturers:

- Need to guide payers and consumers regarding what to buy if the users choose to, beyond a battery station or a generator, that would work as an emergency aftermarket converter product that could safely temporarily power a device from a vehicle battery.
- Need to provide content in instruction manuals and on their websites on activating emergency equipment procedures. These instructions include alternative ways to safely power the equipment with clear (including pictures) directions in usable and understandable formats and preferred languages.
- Need to conduct annual reviews to assess and update the accuracy and effectiveness
  of emergency instructions (clear, practical, plain, understandable, and culturally
  appropriate.) These reviews need to include user feedback consisting of content
  testing via interviews, focus groups, and surveys to assess clarity, i.e., understandable
  and actionable.

#### CMS:

Should implement emergency standards for DME pavers, manufacturers, and suppliers.

Should institute new training criteria and quality controls for content targeted at disaster responders, emergency staff, and state and CMS regional offices. This training example of Administration for Strategic Preparedness and Response (ASPR) / CMS lacks roots in the reality of the disaster environment.

"Replacing Durable Medical Equipment & Prescription Drugs after a Disaster: Addressing the Needs of Medicare Beneficiaries." From: <a href="mailto:cms.gov link">cms.gov link</a>

09.14.22 Training for disaster responders, emergency staff, and state or territory and regional offices

- Video Replacing Durable Medical Equipment & Prescription Drugs after a Disaster: Addressing the Needs of Medicare Beneficiaries
- o Student Manual Guide (PDF)

<u>03.12.22 Training</u> for the State of Colorado National State Level Access & Functional Needs Meeting

This training proposes, in theory, what should work. This almost final version release is problematic because of the following:

- Lack of understanding and acknowledging the severity of the problems and reality of the lived experience.
- Failure to recognize that people are at significant risk (described in this brief) without the speed of response for repair, or replacement in the disaster environment, in hours, not days or months.
- Failure to account for the incredible communication and time challenges in the disaster environment.
- Failure to account for people on fixed and low incomes who rely on Medicare, Medicaid, or CHIP and cannot afford out-of-pocket expenditures and wait for reimbursement. Many face huge barriers in getting emergency devices repaired when an upfront payment is required.
- Planning for, instead of with, responders and disability-led organizations which are
   "for, of, by, and with" people with disabilities, including people with diverse seeing,
   hearing, breathing, speaking, walking, moving, understanding, learning, mental health
   conditions, and chemical sensitivities needs.

## **Action Plan Recommendations**

A stellar and seasoned array of advocates with decades of experience continue to chip away at the many aspects of these issues. Unfortunately, the incremental progress, sometimes imperceptible, is excruciatingly slow.

The <u>ITEM Coalition</u> (Independence Through Enhancement of Medicare and Medicaid Coalition ) is a key advocacy organization in this advocacy challenge. ITEM is devoted to raising awareness and building support for policies that will enhance access to assistive devices, technologies, and related services for people with disabilities and chronic conditions. The coalition <u>membership</u> is consumer-led and includes various disability organizations, aging organizations, other consumer groups, voluntary health associations, and non-profit provider associations.

Its related major advocacy policy priorities include:

"Develop Advocacy and Communications Strategy on Revision of "In the Home" Requirements."

Improve Access to Timely Repairs of DMEPOS (durable medical equipment, prosthetics, orthotics, and supplies)

Reform Healthcare Common Procedure Coding System (HCPCS) Coding System

- a. Continue Working to Improve the Coding, Coverage, and Payment Process for DMEPOS
- b. Work to Ensure Benefit Category and Payment Determination Processes are Fair, Transparent, and Accountable

### Recommendations:

Sponsor a summit convening all interested parties, including manufacturers, suppliers, trade associations, and disability advocates to:

- Accelerate progress by joining forces and doing better together through collaboration, coordination, communication, and cooperation.
- Work on the multiple tipping points to contribute to the mosaic of needed and incremental state, territory, and federal legislative and regulatory solutions focused on public and private insurance coverage, repairs (including routine maintenance), authorizations, usable and safe loaners, replacements, and payments.
- Negotiate any competing interests and differences.
- Pool financial resources and funders to support the convening and subsequently to add dedicated policy staff.
- Agree on paths forward and division of leadership responsibilities.

All agree that what is needed is streamlining the ability to get, repair, or replace powered mobility devices by modernizing the process and the regulations and eliminating the ableist and discriminatory practices. The work must focus on the problems' roots, not the symptoms.

# **Subject Matter Expert Interviews**

- Julia Beems, Emergency Preparedness Program Coordinator, Assistive Technology Program of Colorado Outreach Coordinator, Center for Inclusive Design and Engineering, Department of Bioengineering, College of Engineering, Design and Computing
- Alexandra Bennewith, MPA, Vice President, Government Relations United Spinal Association

- Mary Lou Breslin, Senior Analyst, Disability Rights Education and Defense Fund (DREDF)
- Donald E. Clayback Executive Director, National Coalition for Assistive and Rehab Technology (NCART)
- Stephen Lieberman, Director of Advocacy and Policy, United Spinal Association
- John Mattes, Invacare Corp
- Jean L. Minkel Senior Vice President, Independence Care Systems, New York
- Greg Parker, U.S. Rehab
- Rita Stanley, Merriman Innovation Consulting, Principal/Consultant

<b>Device Information Sheet</b>	Last Update	/ /20
Equipment Type		
Manufacturer's Name		
Manufacturer's Website		
Model Name (many include a number)		
Serial Number		
Payer/Purchaser		
Purchase Date		
Supplier - Company Name		
Company Phone Number		
Repair Contact Person		
Repair Contact Phone Number		
Repair Contact Email Address		
Repair Business Hours		
Battery Size		
Replacement Date		
Alternate Charging Methods		
Backup devices & location		
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Pictures paste or insert		