# AREAS FOR TARGETED PRACTICE AND POLICY CHANGE

## *"Make it as clear as possible for us to understand."*

People and families with DMD want clarity and accuracy in the processes and timelines for getting equipment. They may be balancing multiple types of insurance and assistance programs and need to order equipment in advance to account for long wait times and other delays. Navigating coverage is especially challenging when approval differs across companies and agencies.

**Clinicians** can help by providing information and anticipatory guidance on future equipment needs.

**Policy makers and system agents** can help by advocating for transparency in the expected timelines for equipment and for a simplified, streamlined insurance review process.

## *"We had trouble getting a new manual wheelchair approved after I got my first power wheelchair."*

Insurance companies often take into account past coverage claims when determining coverage of future equipment of the same type. This requires families to sometimes delay getting needed equipment, such as different types of wheelchairs or lifts for different uses and circumstances.

**Clinicians** can help by providing clear, consistent, and coordinated documentation of equipment needs, including anticipated changes over time.

**Policy makers and system agents** can help by advocating for coverage options that better match the day-to-day and year-to-year needs of people with DMD.

## *"All (insurance companies) want to do is fight."*

Justifying equipment needs is a time consuming and frustrating process for many people and families living with DMD. Re-authorization processes are often particularly mismatched with this progressive and lifelong condition. Delays may result in young men having to use equipment such as poorly fitting wheelchairs that can cause them pain.

**Clinicians** can help by assisting people and families navigating insurance claims and appeals.

**Policy makers and system agents** can help by adapting policies to align with the lived realities of DMD trajectories.

## *"We need to roll up our sleeves and get to work."*

A deep understanding of the day-to-day lives of those living with DMD – including the necessity of certain equipment types or features – must inform decisions about equipment coverage. Systems and processes need more input and participation from people with lived experience expertise.

**Clinicians** can help by making sure people and families with DMD are treated as active partners in their care and future planning discussions.

**Policy makers and system agents** can help create opportunities for people and families with DMD to have a seat at the table, such as through advisory boards.

DMD RESOURCES

## ABOUT DMD

- Parent Project Muscular Dystrophy (PPMD) | Fighting to End Duchenne
- Duchenne Muscular Dystrophy (DMD) - Diseases | Muscular Dystrophy Association

## EQUIPMENT AND COVERAGE

- Resource Guide - Access to Medical Equipment and Assistive Devices
- Access & Coverage Advocacy - Parent Project Muscular Dystrophy
- Cure Duchenne - Medical Equipment Guide

## GENERAL COVERAGE

- Patient Advocate Foundation
- When health insurance is not enough - HealthWell Foundation
- GotDME? — Find Free Places to Borrow or Donate Medical Equipment

## OTHER

Your local clinic and support groups may be able to connect you with local resources and advocacy groups that sometimes offer financial assistance.