

SO **EVERYBODY** CAN MOVE

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Who We Are



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What is the Amputee Coalition?

- Today, over 4 million Americans have experienced amputations or were born with limb difference. Another 28 million people in our country are at risk for amputation.
- Started in 1986, the Amputee Coalition is the nation's leading organization on limb loss, dedicated to enhancing the quality of life for people who experience limb loss or limb difference and their families, improving patient care and preventing limb loss.
- In 1997, the Amputee Coalition developed the National Limb Loss Resource Center (NLLRC) after receiving a cooperative agreement with the Centers for Disease Control and Prevention (CDC).
- The NLLRC supports programs and publications designed to help people return to an active lifestyle and function as a productive member of society.
- The Amputee Coalition currently receives a competitive grant through the Administrative for Community Living (ACL) which continues to fund the successful activities of the organization.

What is "So Every BODY Can Move"?

- Movement is medicine and physical activity is a right, not a privilege.
- But today, thousands of individuals living with limb loss or limb difference are unable to afford and access orthotic and prosthetic care that helps them be physically active due to inadequate insurance coverage.
- So Every BODY Can Move (SEBCM) is mobilizing grassroots advocates to champion state-based legislative advocates to champion state-based legislative change, ultimately inspiring a national movement.

So Every BODY Can Move Mission

- So Every BODY Can Move is a grassroots policy and advocacy initiative with the mission to create equitable and life-changing access to orthotic and prosthetic care necessary for physical activity for individuals with disabilities.
- Through the collaborative effort of our national partners, we are achieving this through powerful storytelling and mobilizing grassroots advocates to champion local, state-by-state legislative change, ultimately inspiring.

What is the Public Health Problem / Disability Rights Issue?

- State, federal, and private health plans routinely deny access to orthotic and prosthetic (O&P) care for physical activity as “not medically necessary.”
- Without health plan coverage, children, adults, and families are forced to incur prohibitive out of pocket costs (ranging from \$5,000 - \$50,000), risk harm or injury using an improper device, or live sedentary lifestyles with costly health complications, including obesity.
- Individuals with disabilities need specialized prostheses and orthoses to be able to equitably participate in physical activity and exercise, just like their non-disabled American peers.
- While policies such as Insurance Fairness have mitigated some of the costs and barriers individuals face in receiving proper prosthetics and orthotics that allow them to perform activities of daily living (such as bathing, eating, dressing, etc.), exercise and recreational needs have been left largely unaddressed.

Physical Activity is Medically Necessary For Every BODY

- Physical activity is one of the most important factors in maintaining overall health throughout one's lifetime.
- Whether it's vigorous exercise or simple day-to-day movement, being physically active increases strength and balance, improves mental health, supports better-quality sleep, and reduces the risk of disease and cancer for every body, including people with disabilities (PWD).
- For these reasons, the U.S. Department of Health and Human Services' Physical Activity Guidelines for Americans recommends children with disabilities get 60 or more minutes each day of moderate or vigorous intensity aerobic physical activity; for adults with disabilities, the recommendation is 150 minutes weekly.
- However, without access to appropriately designed prosthetic and orthotic devices, trying to meet this goal is not only impossible, it is dangerous and harmful when utilizing the wrong device.

Physical Activity is Medically Necessary For Every BODY, continued

- Secondary O&P devices are required for individuals with either upper or lower limb loss and limb difference to participate in physical activities such as running, biking, swimming, rock climbing, skiing, snowboarding, and more.
- Without appropriate O&P care, knee or hip problems can result in health care costs ranging from \$80,000 to \$150,000 over a lifetime.
- Putting more strain on a daily prosthetic or orthotic device may also result in damage to the device, resulting in more expense for insurance providers.

Physical Inactivity, Obesity, Chronic Loneliness & Isolation: PWD Disproportionately At Risk

- Physical inactivity, obesity, chronic loneliness, and isolation are the fastest-growing public health problems in the U.S. today, and PWD are disproportionately at risk.
- In fact, adults and children with mobility limitations are at greatest risk for obesity.
- Without equitable access to O&P care for physical activity, individuals are left to risk harm and injury using their standard prosthesis(es) or orthosis(es), or subjected to a more sedentary and less socially connected lifestyle. Both greatly impact whole body health (i.e. social, emotional, and physical health) with the dangerous potential to worsen health conditions that are far more expensive than the cost of a prosthesis or orthosis.

Physical Inactivity, Obesity, Chronic Loneliness & Isolation: PWD Disproportionately At Risk, continued

- In a new advisory from the U.S. Surgeon General, chronic loneliness is a public health crisis; lacking social connection is as harmful as smoking up to 15 cigarettes a day and loneliness increases risk of cognitive decline, cardiovascular disease, and death.
- According to the advisory, studies find the highest prevalence for loneliness and isolation are among people with disabilities. At the same time, it is well understood and research supports the inextricable link between well-being and mobility.
- Returning individuals to mobility through appropriate prosthetic and orthotic care that enables physical activity and exercise prevents isolation and loneliness, improves quality of life, and builds invaluable social connections.

A Movement Rooted In Disability Rights

- The Americans with Disabilities Act of 1990 intended to establish a right for people with disabilities to participate equally in all facets of society.
- Yet, more than thirty years after this civil rights achievement promised to legally end much disability-based discrimination, people with disabilities — including children — continue to face insurmountable barriers to equal participation in exercise and athletics.
- Disparities in healthcare coverage perpetuate this discriminatory treatment of athletes with disabilities.

A Movement Rooted In Disability Rights, continued

- For example, to an athlete without a disability, orthotic and prosthetic services are comparable to surgeries and procedures that enable athletic performance. Many athletes, particularly basketball, soccer, football players, and downhill skiers, often suffer from anterior cruciate ligament (ACL) damage, one of the most common sports-related injuries.
- While repairing the ligament is considered an elective procedure, health plans usually cover it because the treatments are necessary to restore the body to its full potential. Between 100,000 and 300,000 ACL-related procedures take place in the U.S. each year, and public and private healthcare spending exceeds \$500 million per year on ACL reparations.
- Yet, comparable assistive technologies and habilitation services for athletes with disabilities — including orthotic and prosthetic care — that also enable the body to perform athletically are not covered.
- Insurers should not be able to deny a prosthetic or orthotic device benefit for an individual with limb loss or limb difference that would otherwise be covered for a person without a disability seeking medical or surgical intervention to restore or maintain the ability to perform the same physical activity.
- So Every BODY Can Move is working to ensure this.

So Every BODY Can Move Goal & Partners

- Our goal is to enact this legislation in 28 states by the 2028 Paralympics & Olympics in Los Angeles, California, a campaign we're calling "28x28," so we can then pursue federal reform.
- National Partners
 - American Orthotics and Prosthetics Association,
 - National Association for the Advancement of Orthotics and Prosthetics (NAAOP),
 - American Academy of Orthotists and Prosthetists (AAOP, "The Academy"), and
 - Amputee Coalition



How Does So Every BODY Can Move Legislation Fix It?

- As a national mobility movement, So Every BODY Can Move is working to create equitable access to prostheses and orthoses utilized for physical activity as medically necessary healthcare by championing local, state-by-state legislative change.
- Legislative change, unlike one-time charitable support, can impact millions of people for generations to come with a solution rooted in dignity and equal rights.
- The public health problem and disability rights issue described in detail above is complex and requires systems-level change; only this can be solved through systemic policy intervention.
- As such, So Every BODY Can Move has provided model legislation that can be adopted by states to fix this widespread inequality.

So Every BODY Can Move Legislative Goals

- Creates orthotics and prosthetics parity, ensuring state commercial insurance plans provide coverage for orthotic and prosthetic care at a level that is equivalent to the federal Medicare program.
 - So-called “Insurance Fairness” legislation of this type has already experienced widespread support across the country with 21 states enacting similar legislation into law over the past 20 years including: Arkansas, California, Colorado, Connecticut, Delaware, Illinois, Indiana, Iowa, Louisiana, Maine, Maryland, Massachusetts, Missouri, New Hampshire, New Jersey, Oregon, Rhode Island, Texas, Utah, Vermont, Virginia.
- Creates coverage of orthotic and prosthetic devices for physical activity purposes for all ages by state commercial insurance plans. In states that already have “Insurance Fairness” legislation, So Every BODY Can Move’s model legislation builds on existing mandate language to recognize the prosthetic and orthotic needs of the limb loss and limb difference population to engage in physical activity.

So Every BODY Can Move State Initiatives

Legislation Passed

- Arkansas (HB 1252)
- Colorado (HB 1136)
- New Mexico (HB 131)
- Maine (LD 1003)
- Illinois (SB 2195)

Legislation Introduced

- Indiana (HB 1433)
- Massachusetts (HD 4491)
- Minnesota (HB 3339/SF 3351)
- New Hampshire (SB 177)
- New Jersey (HB 3919)

Common Challenges to Passing SEBCM Legislation

- Building awareness of the problem among legislators and other organizations
 - Many people assume that SEBCM legislation is already how things work and are surprised to learn that receiving a prosthetic designed for physical activity is something people must fight for.
- Overcoming discriminatory perceptions of people who have disabilities as incapable of intense physical activity
- Fiscal impact on private health care providers

Steps to Start your Own State SEBCM Campaign

From So Every BODY Can Move Advocacy & Lobbying Toolkit

Step 1: Build Your Team

Step 2: Prepare Your Assets

Step 3: Start Legislative Process

Step 4: A: Manage Legislative Process

Step 4: B: Expand Your Coalition & Collaborate

Step 5: Celebrate Your Legislative Victory

Step 6: Begin Legislation

Questions?

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