



Largest Survey of People with Limb Loss and Limb Difference Demonstrates Actionable Ways to Improve Care

The Amputee Coalition is proud to share the results of the largest survey to date of people with limb loss and limb difference (PwLL/LD). This is the first survey of its kind to address the community's physical and mental health priorities and challenges often faced when accessing care. These findings will assist the Amputee Coalition with raising awareness and informing priorities to improve the quality of care that PwLL/LD receive.

The Amputee Coalition thanks the more than **1,700 individuals who participated in the survey** for the time they devoted over the holiday season and their invaluable contributions to building a broader understanding of the community's lived experience.

Key Takeaways from The Survey

- Survey respondents identified a **need for pain management**; similarly, improved sleep was identified as a major mental health priority.
- The ages of PwLL/LD influenced their physical and mental health priorities, access challenges, and the services they needed. This finding **demonstrates the need for age-appropriate solutions** (e.g., different methods for developing individual strength and balance) for improving physical and mental healthcare for PwLL/LD.
- **Physical and mental health often affect one another** – For example, a person's strength and balance (the top identified physical health priority) greatly influences their ability to exercise (the top identified mental health priority).
- Respondents noted the **need for increased resources** to help the community in understanding the Americans with Disabilities Act (ADA) and navigating health insurance.

Methods

The Amputee Coalition administered this survey online through SurveyMonkey from December 2020 through January 2021; the survey was distributed to individuals identified from the Coalition's membership as well as via email and social media.

The findings were analyzed using the analytic plan included in the survey study protocol and addendum, to help identify the strongest relationships between respondents and their physical and mental healthcare priorities with the goal of prioritizing action plans to address the needs of PwLL/LD.^{1,2}

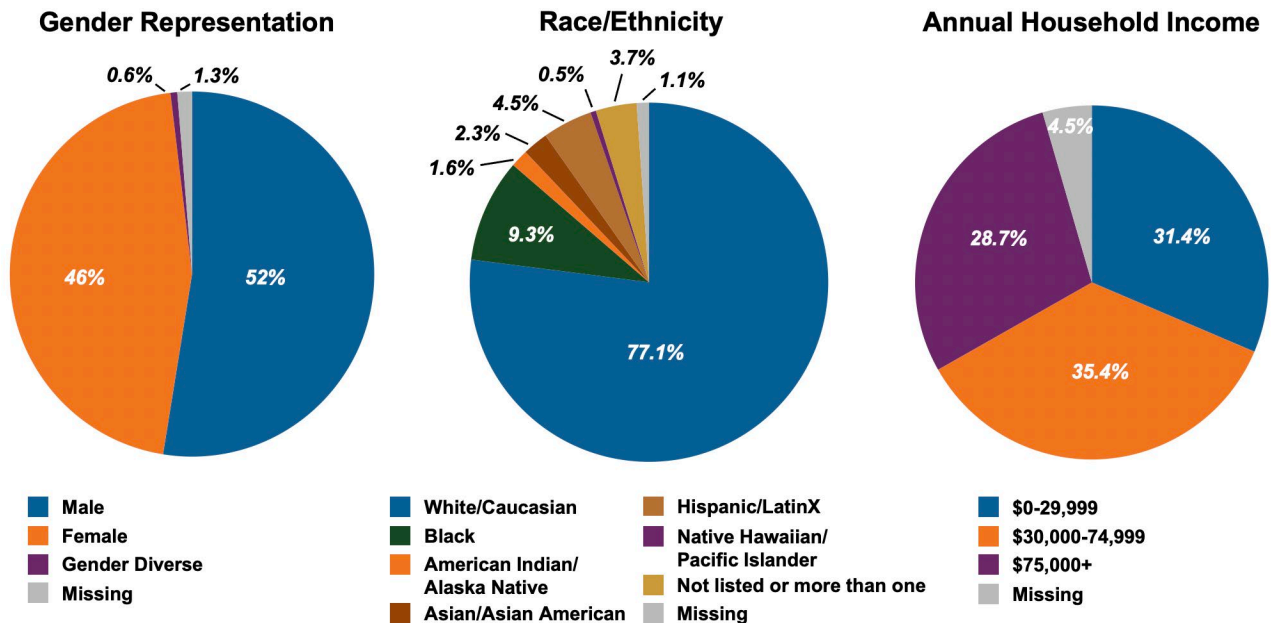
¹ Data was cleaned and coded and a frequency analysis was conducted on each variable to describe participation and response. A bivariate analysis was conducted between each outcome variable and each covariate using a Chi Squared test of association, using a $p > 0.05$ level of significance. A linear regression was conducted to understand associations and a multivariate regression model of all covariates was applied to reveal interrelationships between patient characteristics and survey responses.

² While this survey received responses from a large number of individuals, the study sample is a convenience sample that has not been controlled for amputation cause, duration, and level or laterality. These factors have an impact on the generalizability of specific findings; however, the size and make-up of the response group is an accurate representation of categorical facilitators and barriers to care experienced by PwLL/LD.

Respondent Demographics

More than 1,700 individuals who responded to the survey have a diverse set of backgrounds and experiences. Their contributions to the survey revealed that addressing the community's needs is not a one-size-fits-all approach.

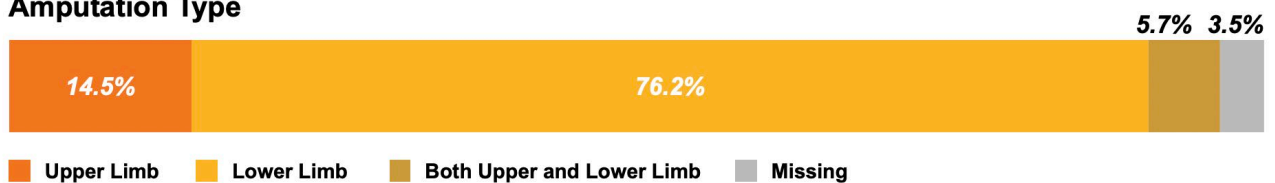
Demographics



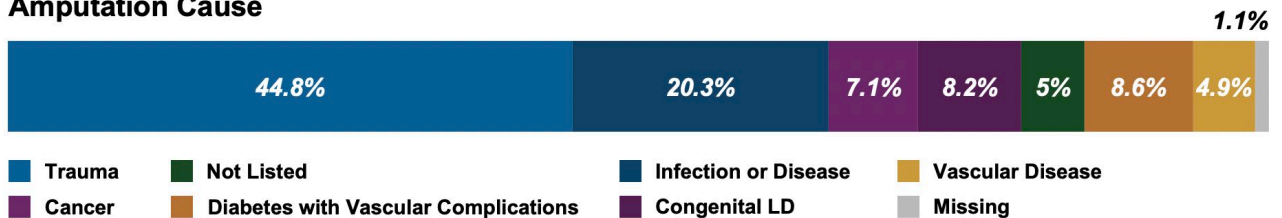
Across gender, race and ethnicity, and income, respondents' ages ranged from 18 to over 65 years old, with an average age of 51.3 years.

Experience with LL/LD

Amputation Type



Amputation Cause



Respondents experienced a wide range of years living with limb loss or limb difference, from less than 1 year to as many as 77. The average period of time a respondent noted they lived with limb loss or limb difference was 10.9 years.

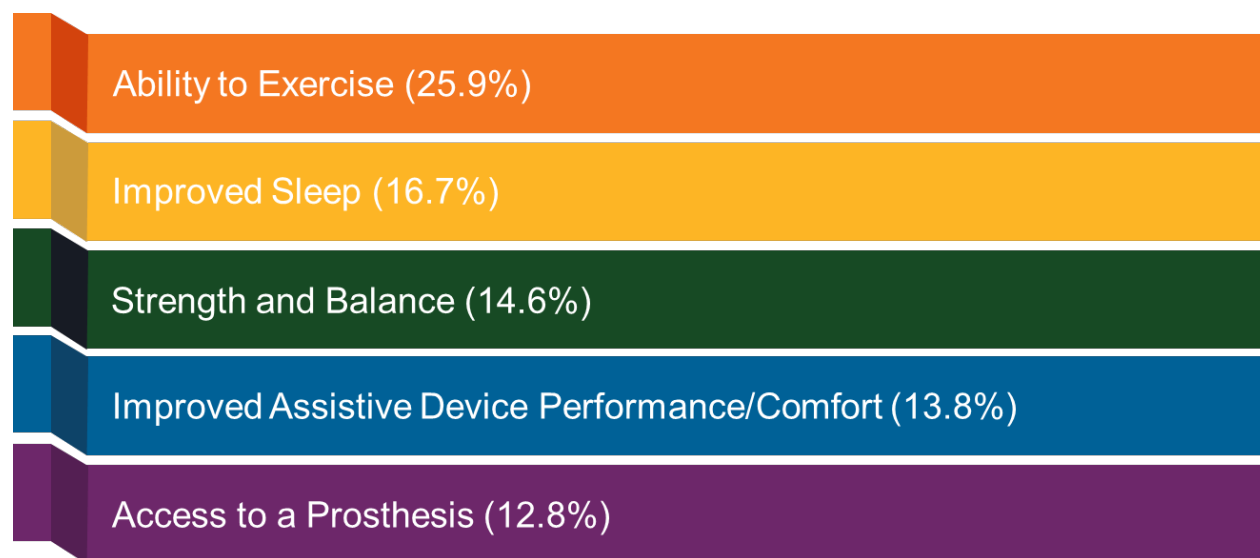
Importantly, while survey results provided significant evidence for Coalition action, **it is likely that the full diversity of the LL/LD community is under-represented**. The Amputee Coalition understands that these characteristics are not closely aligned with our knowledge of the causes of limb loss and limb difference and is committed to reaching PwLL/LD wherever they are located by addressing outreach barriers.

Community Needs and Challenges

The survey responses provided the Coalition with a greater understanding of physical and mental health priorities of the PwLL/LD community as well as crucial access challenges. Over the course of the next few years, these survey answers will shape the Coalition’s policy and advocacy initiatives by continuing to raise awareness about the community’s needs and advocating for policies to improve healthcare access and quality. Social support needs highlight institutional challenges that are unique to individuals with disabilities and demonstrate a role for the Amputee Coalition in **improving health equity for the PwLL/LD community**.

Physical and Mental Health Priorities

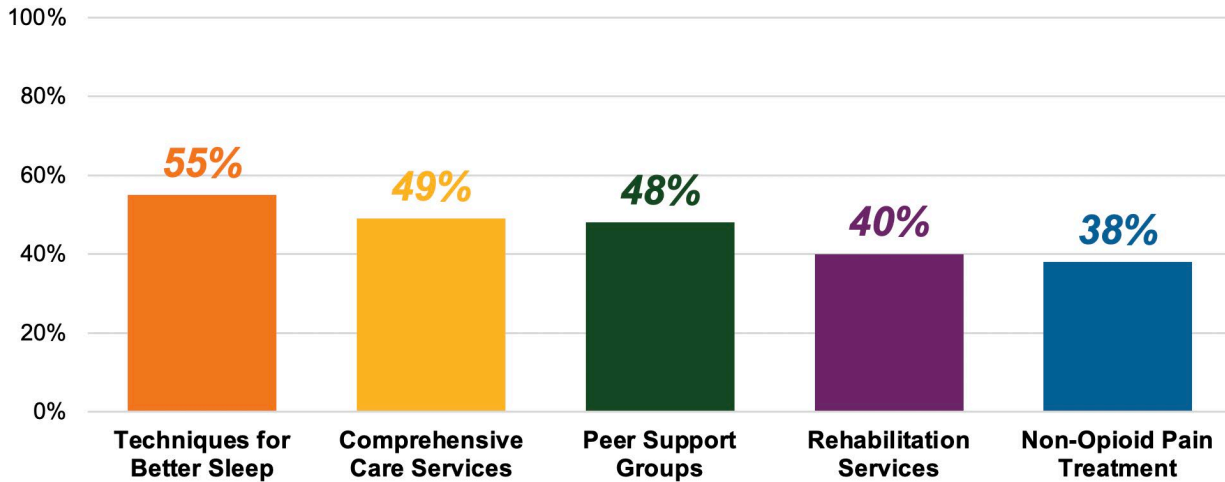
Survey participants were asked to rank what physical and mental health priorities would improve their health. Participants highlighted their top priorities:



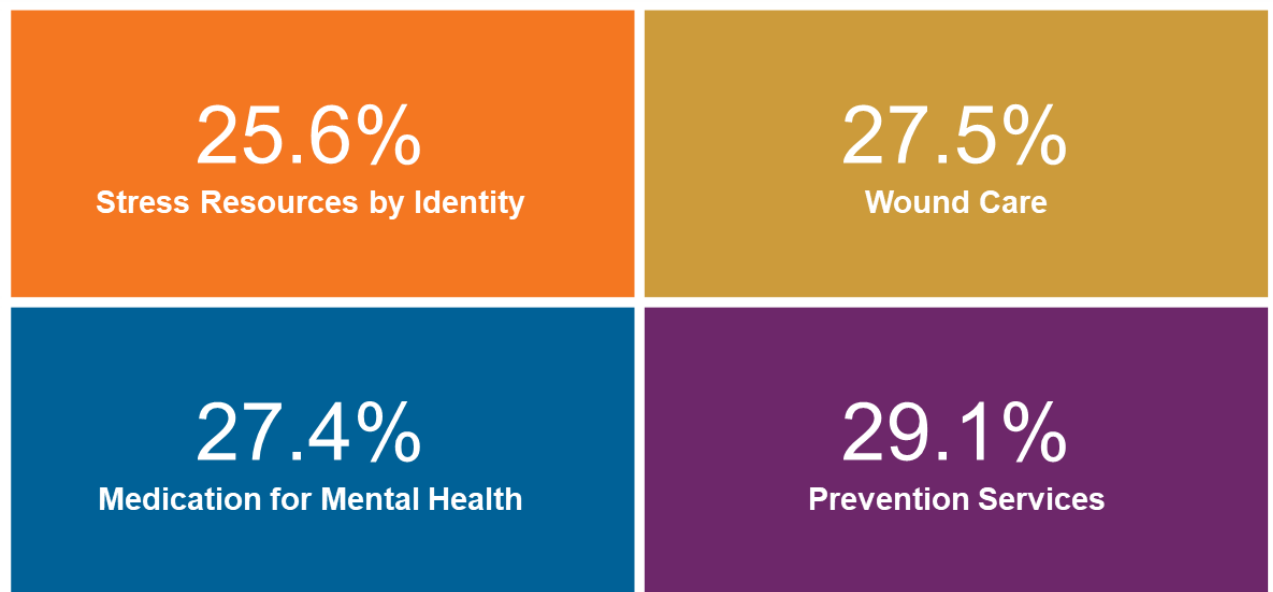
A respondent’s age had the most influence over their choice of physical health priorities, followed by income, amputation cause, and amputation type. A respondent’s age and income had the most influence over their choice of mental health priorities.

Access to Physical and Mental Health Services

PwLL/LD were asked where they most experienced access challenges or knowledge gaps about certain physical and mental health services.³ Survey results showed that most participants were unable to access or did not know about the following services:



Participants were most familiar and experienced the fewest access challenges to:



Respondents of color more often reported access challenges to receiving comprehensive care, rehabilitation services, non-opioid pain treatment, and mental health services than White respondents. Additionally, younger respondents and individuals with lower income reported barriers to access to physical and mental health services.

³ Many individuals responded "N/A", which could indicate these individuals have access to the service, are already utilizing the service, know about the service but don't want it, or decided not to answer.

Ranked Community and Social Supports

PwLL/LD were asked to rank the importance of social supports, community resources, and amputation prevention strategies. Top priorities included:

Social Supports	Help Understanding the Americans with Disabilities Act (17%)	Assistance with Insurance (14%)	Improved Quality of Care (13%)
Community Resources	Community Connections (16.8%)	Practical Home Adaptations (16.4%)	Self-Advocacy Training (15.8%)
Amputation Prevention Strategies	Earlier Identification through Routine Assessments (16.3%)	Injury Prevention (6%)	Medical Interventions to Prevent Amputation (5.7%)

A respondent's age and race/ethnicity correlated with their ranking of both social supports and community resources. Further, the cause of a respondent's amputation correlated with their ranking of prevention strategies.

Conclusion/Next Steps

Results from this survey provided the Amputee Coalition with tremendous insights to inform the Coalition's future activities.

- **Support:** Ensuring PwLL/LD have robust social and community support services to navigate daily life with limb loss or limb difference
- **Education:** Teaching individuals about LL/LD to improve access to care and quality of life
- **Prevention:** Providing resources to the broader community to understand how to prevent LL/LD, including through early diagnosis and medical interventions
- **Advocacy:** Increasing engagement with community leaders, particularly in underserved communities, to provide effective support and promote health equity

To ensure the Coalition is adequately representing the full PwLL/LD community, future studies will seek to address outreach challenges and ensure all PwLL/LD are represented. The Coalition recognizes that many of these barriers to care occur at greater rates in communities at higher risk for developing limb loss. The Coalition believes that assessing the true impact of social determinants of health on the unique challenges that PwLL/LD face will present the greatest opportunities for improvements.