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January 29, 2024

Attention: Donna Bethge
Administration for Community Living
330 C Street, SW
Washington, DC, 20201

Subject: Public Comment on Data Collection and Reporting for Fall Prevention Programs

Dear Donna Bethge,

The Amputee Coalition expresses gratitude for the opportunity to share feedback with Administration for Community Living regarding data collection and reporting for Fall Prevention Programs.

Established in 1986, the Amputee Coalition is dedicated to advocating for and supporting individuals who experience limb loss and limb difference. Our mission extends to providing comprehensive support both pre- and post- amputation, ensuring assistance during the recovery process. We estimate that there are more than 5.6 million people in the United States living with limb loss or limb difference (LLLD). Our advocacy work serving the members of the LLLD community aligns naturally with advocating for the broader disability community.

We are writing to provide feedback and suggest improvements for the data collection and reporting mechanisms in the Fall Prevention Programs. As a stakeholder invested in the well-being of individuals with physical disabilities, we believe these suggestions can enhance the inclusivity, accuracy, and effectiveness of the program.

- **Participant Information Form Suggestion 1:** Add a checkbox for a Participant who identifies as having a physical disability.
 - **Justification:** Reports resulting from these programs should include data on participants with physical disabilities. Like the collection of races, age, etc., reporting the percentage of participants with and without disabilities is crucial for a full understanding of a program's impact.
- **Participant Information Form Suggestion 2:** In alignment with Suggestion 1, add "Upper/Lower Limb Loss/Limb Difference," "Low vision," and "Neuropathy" to the list of chronic conditions.

- **Justification/Explanation:** The proposed data collection on chronic conditions should not exclude physical disabilities like lower limb loss or limb difference, given their implications for mobility and increased fall risk. Consider adding lower limb neuropathy or paralysis to be more inclusive of participants with various lower limb impairments.
- **Participant Information Form Suggestion 3:** Insert a question about the use of a mobility aid (select all that apply): cane, walker, wheelchair, crutches, prosthesis, orthosis, others.
 - **Justification/Explanation:** Understanding the use of mobility aids is essential for assessing participants' mobility levels and may guide appropriate interventions. A "select all that apply" option is necessary to capture the varied use of mobility aids, providing context for improvement and identifying participants who benefit the most.
- **Participant Information Form Suggestion 4a:** Insert another question about the use of a mobility aid in the section of fall occurrence.
 - **Justification/Explanation:** Include a question asking whether the participant's mobility aid was in use during reported falls, acknowledging the situational dependence on mobility aid use. This may help identify causes of falls not addressed by the Fall Prevention Program.
- **Participant Information Form Suggestion 4b:** Edit the definition of injury to include damage to a mobility device (as it is seen as an extension of the user).
- **Participant Information Form Suggestion 5:** Revise the outcomes of the fall to (1) I did not seek medical attention, (2) received medical attention from (urgent care, emergency room, or doctor), (3) required hospital admission. Also include self-treatment at home (i.e., Tylenol, bandages, ice, etc.)
 - **Justification/Explanation:** Consolidate options for seeking medical attention to eliminate potential bias for healthcare accessibility and focus on the severity of the injury. **Separating** hospital admission provides a clear indication of injury severity.
- **Participant Information Form Suggestion 6a:** Omit Question 12 if Question 14 is replaced with a validated outcome measure (i.e., The Tinetti Falls Efficacy Scale).
- **Participant Information Form Suggestion 6b:** Replace Question 14 with the Tinetti Falls Efficacy Scale.

- **Justification/Explanation:** Use a validated outcome measure like the Tinetti Falls Efficacy Scale to assess fear of falling and identify specific areas for needed interventions. This change would shift the focus from measuring optimism to addressing participants' underlying fear, potentially leading to more targeted interventions and improved quality of life.
- **Participant Information Form Suggestion 7:** Question 13 needs to provide an example such as “avoiding a friend’s home that has steps to enter”, “avoiding areas with uneven ground,” etc.
- **Participant Information Form Suggestion 8:** Question 15 should describe moderate vs. vigorous activity in laymen’s terms providing an example such as walking speed, physical exercise in a group environment, etc.
- **Post Session Survey Suggestion 1:** Duplicate suggestions 3-8 in the Participant Information Form to the Post Session Survey, as these are identical questions in both documents.

The Amputee Coalition appreciates your time and consideration of these suggestions. We believe that implementing these changes will enhance the Fall Prevention Program's ability to cater to a diverse participant base and improve overall outcomes. Thank you for your commitment to promoting the well-being of individuals with disabilities, including those with limb loss and limb difference.

Sincerely,

Cass Isidro, MBA
President & Chief Executive Officer
Amputee Coalition