An Assessment of Fundamental Rights of People Living with ALS/MND Worldwide: Quality of Life

Jessica Mabe \(^1\), Catherine Cummings \(^1\)

\(^1\) International Alliance of ALS/MND Associations

BACKGROUND

A guiding document for the International Alliance of ALS/MND Associations is the Fundamental Rights of People Living with ALS/MND (PALS) that states the aspirational rights of the global community. Originally conceived in the late 1990s as the “Baseline of Services for People Living with ALS/MND”, these rights represent the ideal for individuals living with ALS/MND and caregivers worldwide. They are updated each year by the Alliance’s PALS and Caregivers of People Living with ALS/MND (CALS) Advisory Council.

Although the Alliance and its representatives understand that some of these conditions might not be immediately attainable, this document represents the set of rights all Alliance member organizations should adopt and promote as conditions, systems, and resources allow.

In April 2021, the Alliance created a survey to ascertain the level of agreement that these rights were being respected for CALS. In May 2023, the second survey of its kind was launched to benchmark against the data captured in its first version.

METHODS

The survey was done by Bramm Research, an independent third party, and it was launched both through our member organizations and on social media in May 2023. We received responses from 54 countries. The survey was available in 16 different languages.

SURVEY RESPONSE

*Participation in cultural activities such as art, music, games, sports, and social activities directly impact quality of life for PALS.

*Limitations impacting ability to participate in cultural activities impact over half (53%) of the respondents.

*1 in 5 PALS continues to enjoy cultural activities, which contributes to best quality of life.

DISCUSSION

These results represent right #7, the right to the best quality life possible.

RESULTS

For more information on this project and others please contact us at alliance@als-mnd.org or visit us at als-mnd.org.