An Assessment of Fundamental Rights of People Living with ALS/MND Worldwide: Multidisciplinary Care

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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), which 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 PALS and CALS. In May 2023, the second survey of its kind was launched to benchmark against the data captured in its first version.

The terms Global North and Global South refer to lists created by the United Nations. Global North countries are mature economies, wealthy, and politically stable. The Global South countries’ economies are still developing and have faster population growth than the Global North.

HYPOTHESIS

*Access to the highest quality of care remains globally unbalanced between the Global North and the Global South.
*Access to a multi-disciplinary clinic is impacted by economic factors as well as geographical factors (rural – urban divide).
*The relationship between ALS/MND specialists and high-quality care is directly related.

RESULTS

Multidisciplinary care, as it relates to fundamental right #1, the right to the highest quality care available within their healthcare system.

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. It was in the field for 60 days. We received responses from 54 countries. The survey was available in 16 different languages.

DISCUSSION

The services offered at multidisciplinary clinics are part of the quality of care that a PALS is able to receive. There are some noteworthy points:

*Access to multidisciplinary clinics remains significantly higher in the Global North and in English speaking countries due to economic and geographical factors. Additionally, these results are the same as in 2021.
*Urban versus rural location did not have a significant impact on data results, despite the hypothesis that urban respondents would have greater access.
*Access to health care specialists is highly-connected to strongly disagreeing or strongly agreeing with whether or not PALS feel they’re receiving high-quality care.
*Access to various healthcare specialists plays a significant role in how PALS perceive the quality of the care they are receiving. The main specialists mentioned as providing care are neurologists (76%), physiotherapists (57%), and respiratory therapists (45%).
*Having access to social workers and psychologists is a driver of the perception of highest quality care available.

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