An Assessment of Fundamental Rights of Caregivers of People Living with ALS/MND Worldwide

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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. In 2021, the previously melded PALS and CALS rights became separate documents, and the Fundamental Rights of CALS was launched.

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.

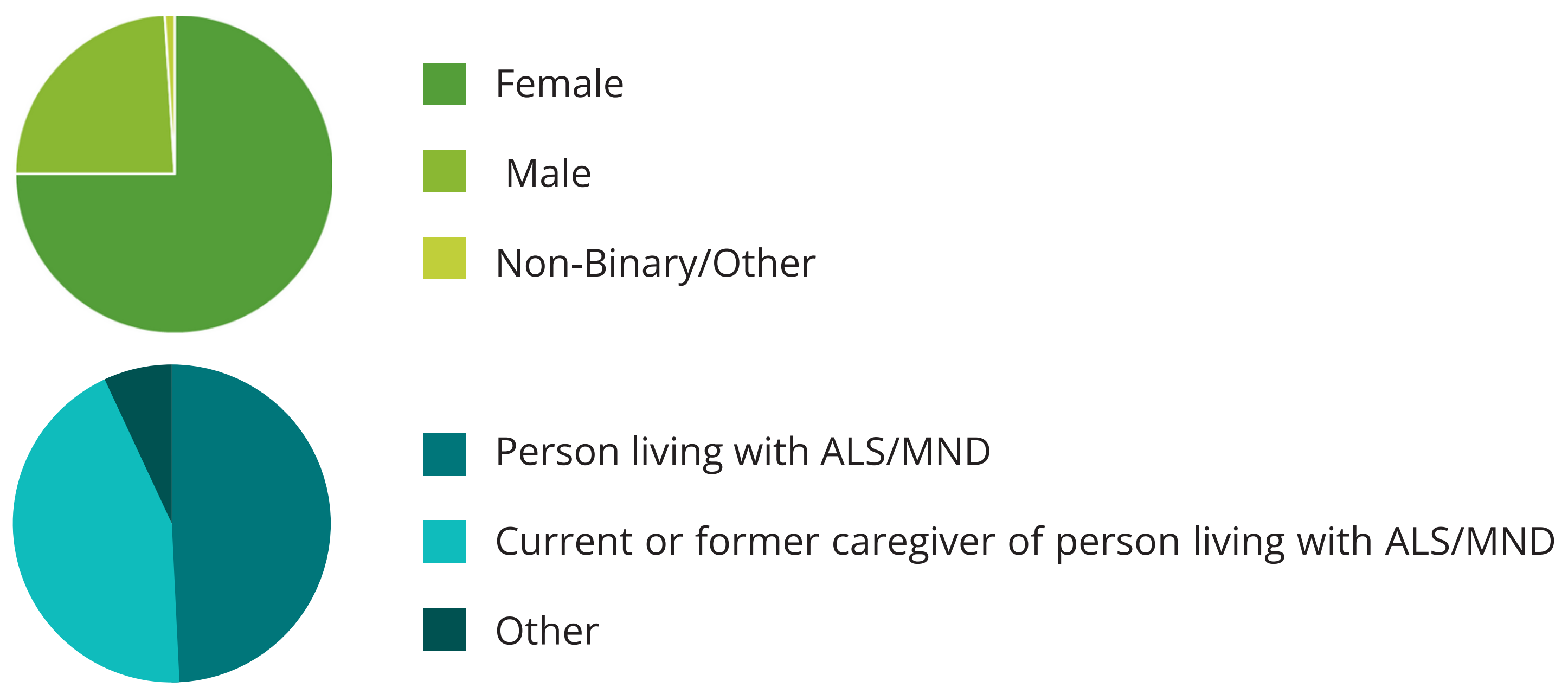
HYPOTHESIS

Respect of the Fundamental Rights of Caregivers (CALS) is universally low and inconsistent, lacking support in all areas including access to remuneration, emotional support programs, palliative care, bereavement advice and services, and social support and respite.

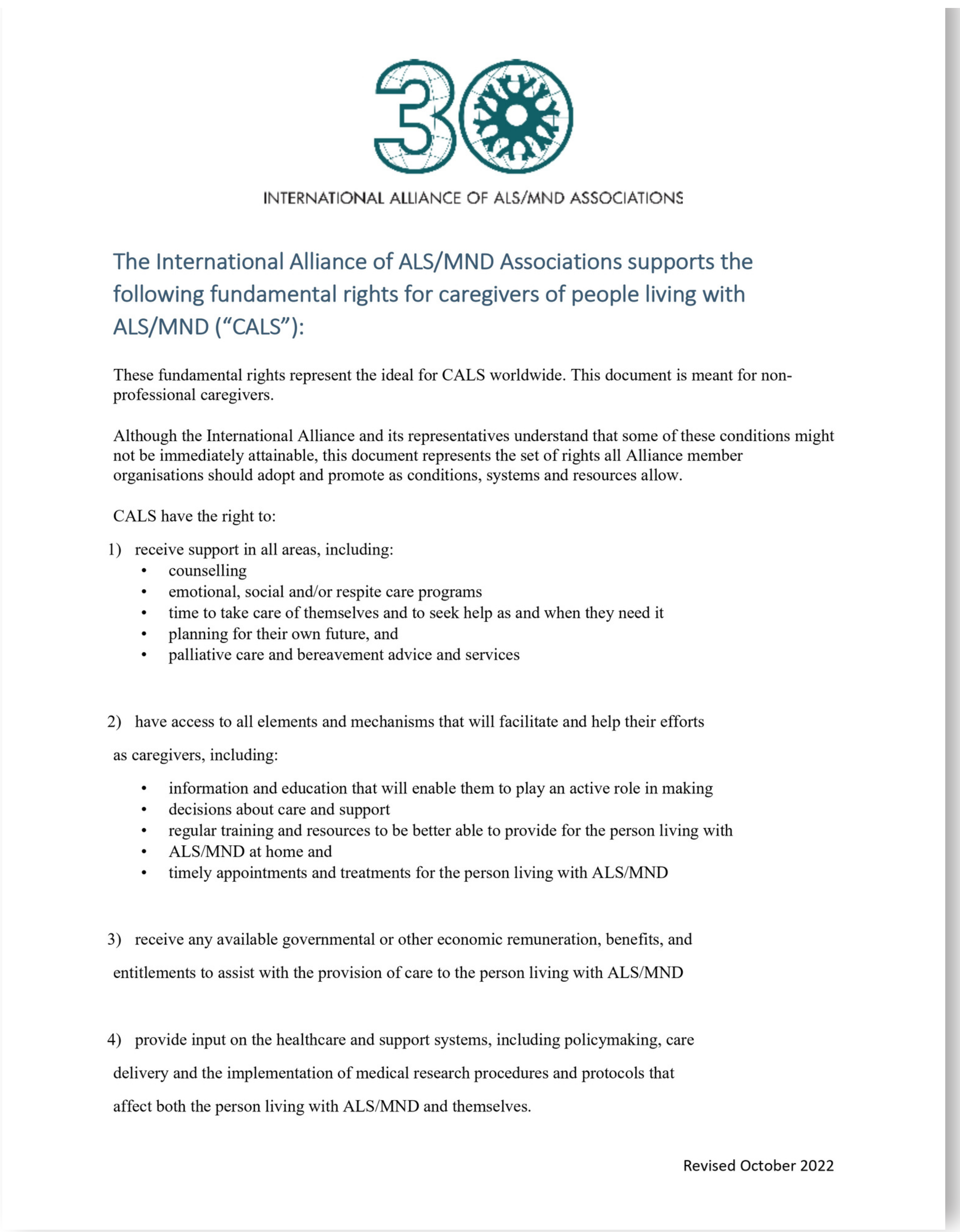
METHODS

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 close to 2000 responses from 54 countries; 53% of the respondents are CALS. The survey was available in 16 different languages. 75% of CALS respondents are female.[JS1] [JM2]
This could also be represented in a pie chart. Female 75%, male 24%, non-binary/other 1%.

SURVEY RESPONSE



RESULTS



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

The International Alliance of ALS/MND Associations supports the following fundamental rights for caregivers of people living with ALS/MND ("CALS"):

These fundamental rights represent the ideal for CALS worldwide. This document is meant for non-professional caregivers.

Although the International 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 organisations should adopt and promote as conditions, systems and resources allow.

CALS have the right to:

1) receive support in all areas, including:
   - counselling
   - emotional, social and/or respite care programs
   - time to take care of themselves and to seek help as and when they need it
   - planning for their own future, and
   - palliative care and bereavement advice and services

2) have access to all elements and mechanisms that will facilitate and help their efforts as caregivers, including:
   - information and education that will enable them to play an active role in making
   - decisions about care and support
   - regular training and resources to be better able to provide for the person living with
   - ALS/MND at home and
   - timely appointments and treatments for the person living with ALS/MND

3) receive any available governmental or other economic remuneration, benefits, and entitlements to assist with the provision of care to the person living with ALS/MND

4) provide input on the healthcare and support systems, including policymaking, care delivery and the implementation of medical research procedures and protocols that affect both the person living with ALS/MND and themselves.

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Figure 1. The Fundamental Rights of CALS

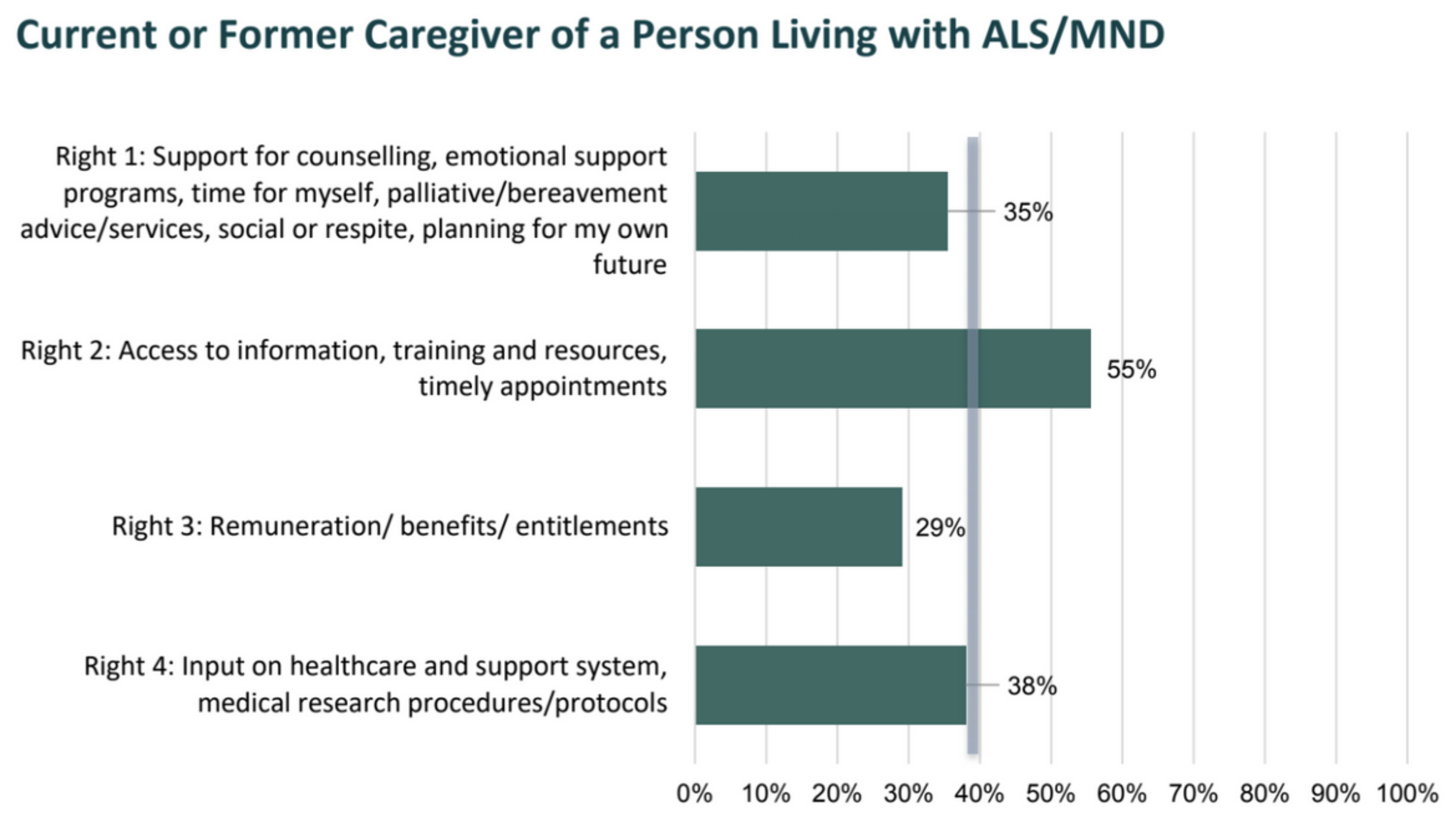

Figure 2. The summary assessment of CALS rights indicates that they are not well respected globally with the average at 39.5%.

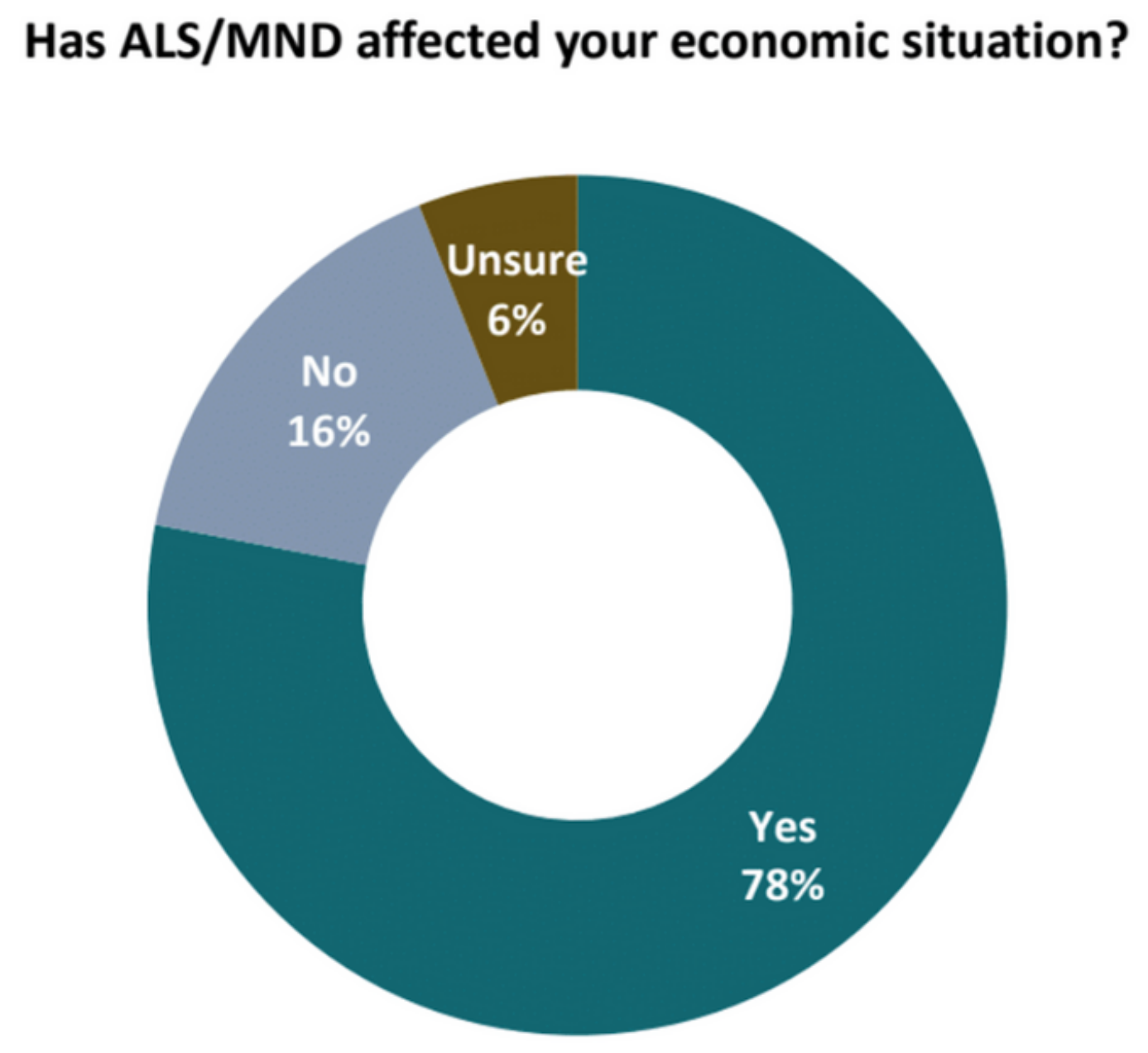

Figure 4. Almost 4 out of 5 caregivers reported having their economic situation changed by ALS/MND (78%). Caregivers ithe Global South (87%) are more affected than those in the Global North (72%)

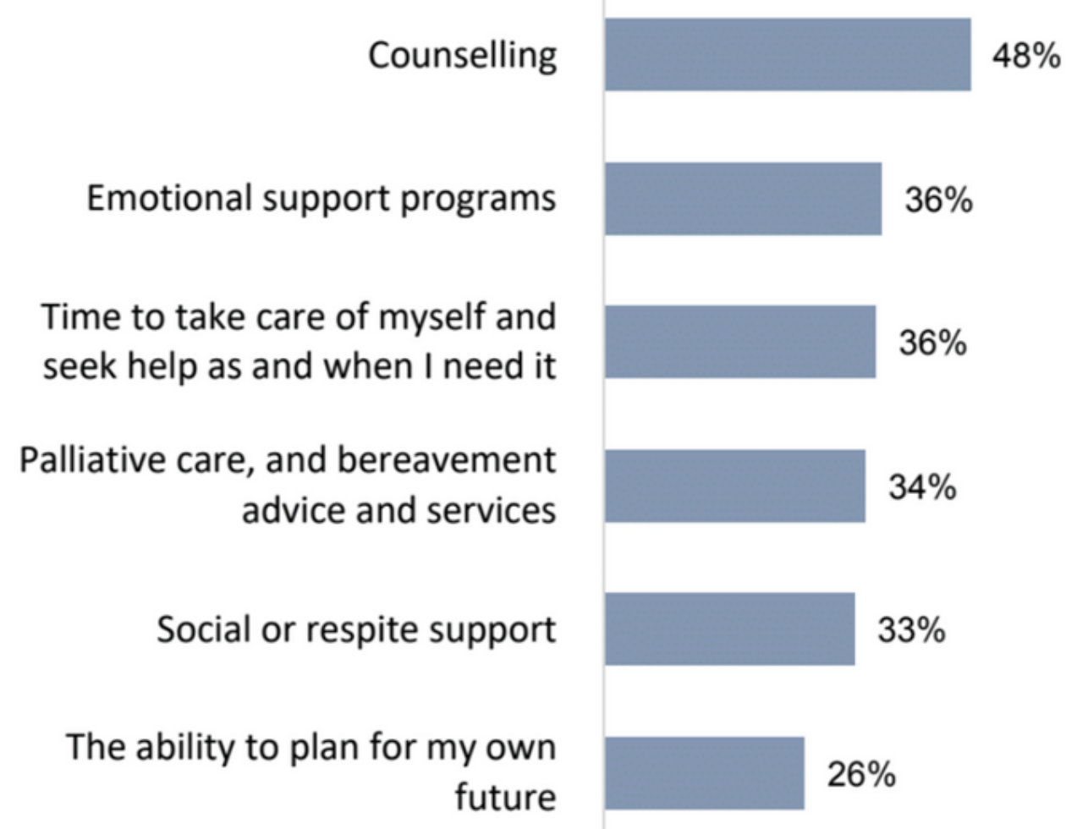

Figure 3. CALS support rates are slightly higher in 2023 compared to 2021 across all categories but remain low in all parts of the world.

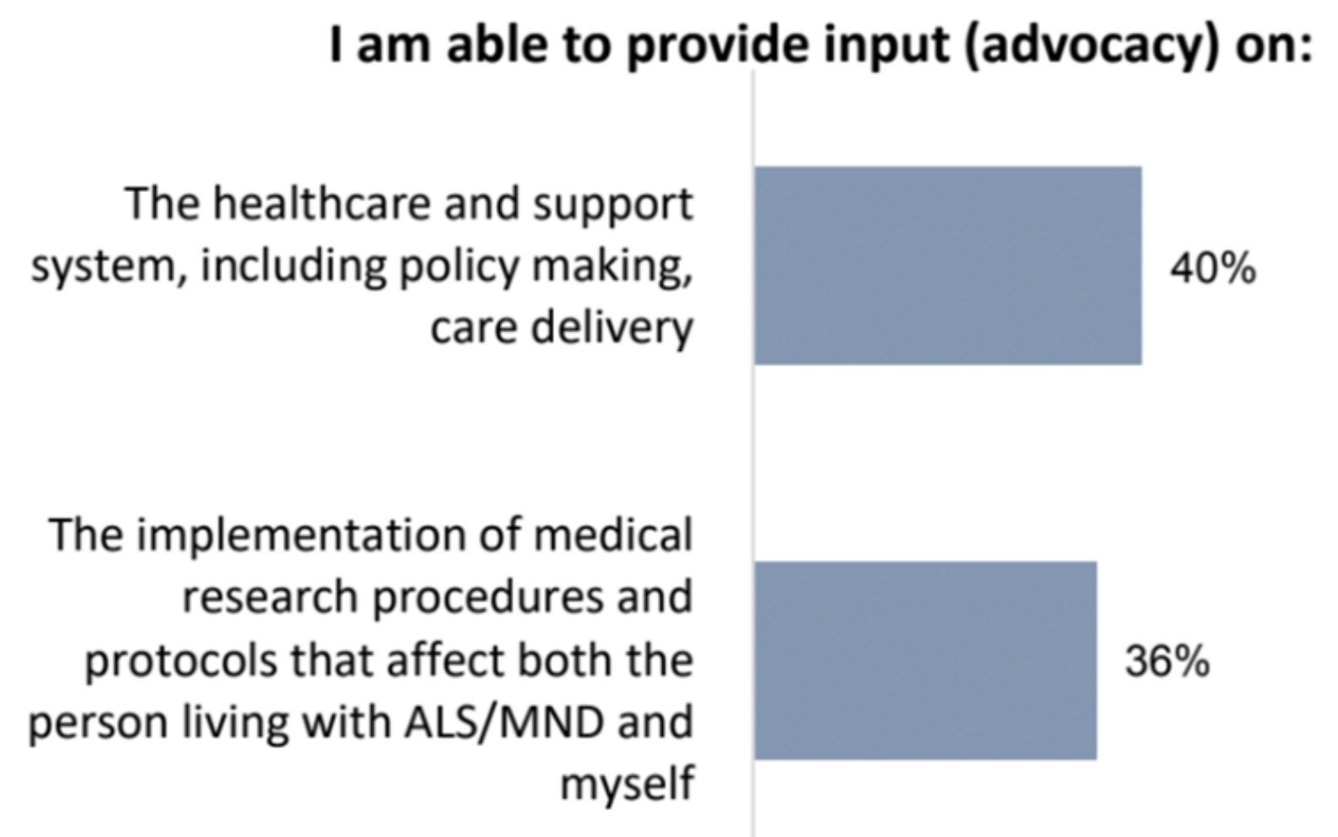

Figure 5. Advocacy remains at minority levels in providing input in both a) support system, policy making, care delivery, and b) medical research procedures and protocols that affect both PALS and CALS.

DISCUSSION

Overall, the figures are low with an average of 39.5% (up from 33.8% in 2021) of Fundamental Rights being respected for caregivers, which is significantly lower than the PALS Survey which had an average of 52%. Caregivers are mostly female (75%) and feel an overall lack of support in all areas. Some specific findings that merit discussion are:

- Only 36% of caregivers report being able to have time to take care of themselves. Only 1 in 3 caregivers agree about receiving social or respite support.
- Rates of support for caregivers in the Global South (34%) were higher than in the Global North (21%).
- The economic impact of ALS/MND is significant: 4 in 5 respondents' economic situation is affected, 1 in 5 caregivers leave employment, 1 in 5 caregivers make adaptations to their job.
- Support to plan for their future is higher in the Global South.
- Overall data indicates that advocacy remains low. Caregivers are unable to provide input about their experiences or feedback.

ACKNOWLEDGEMENTS

We would like to thank the 1900+ people who responded to the survey, particularly the people living with ALS/MND and their Caregivers. We would also like to thank the PALS and CALS Advisory Council of the International Alliance of ALS/MND Associations who provided feedback and guidance on each iteration of this survey as it was developed.

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