



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

Jessica Mabe^{1, 2}, Angelique Van der Lit³, Catherine Cummings¹

¹International Alliance of ALS MND Associations ²ACELA ³ALS Patients Connected

BACKGROUND

A guiding document for the Alliance is the Fundamental Rights of People Living with ALS/MND 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 are updated each year by the Alliance’s PALS and CALS Advisory Council. In February of 2021, it was identified that the previously melded CALS and PALS rights needed to be in separate documents as the pandemic had exacerbated the Caregiver burden to the point where it was important to consider these rights separately. Therefore in 2021 the **Fundamental Rights of Caregivers of People Living with ALS/MND** was launched.

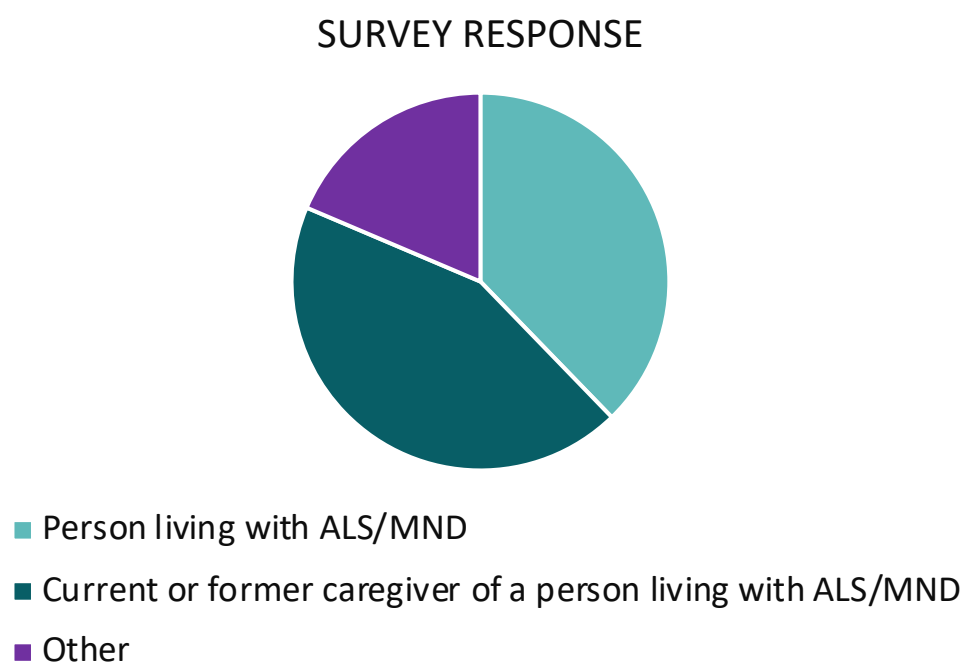
Although the International Alliance and its representatives understand that some of these conditions might not be immediately attainable, this document represents the set of rights all Alliance member organisations should adopt and promote as conditions, systems and resources allow.

In April 2021, the Alliance decided to do a benchmark survey to ascertain the level of agreement that these rights were being respected for CALS.

HYPOTHESIS

The pandemic has caused an increase burden on Caregivers and there has been anecdotal evidence that Caregiver rights are not supported in many jurisdictions. Respect of the Fundamental Rights of Caregivers (CALS) is universally low and there are inconsistent supports, which impacts not only CALS but also the PALS they are looking after.

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 August and it was in the field for 40 days. We received responses from 32 countries. The survey was translated into 10 different languages.

RESULTS

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) 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 (for example: homecare, first aid, handling of equipment and medicines, etc.), and
 - timely appointments and treatments for the person living with ALS/MND
- 2) 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
- 3) 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
- 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.

Figure 1. The Fundamental Rights of People Living with ALS/MND

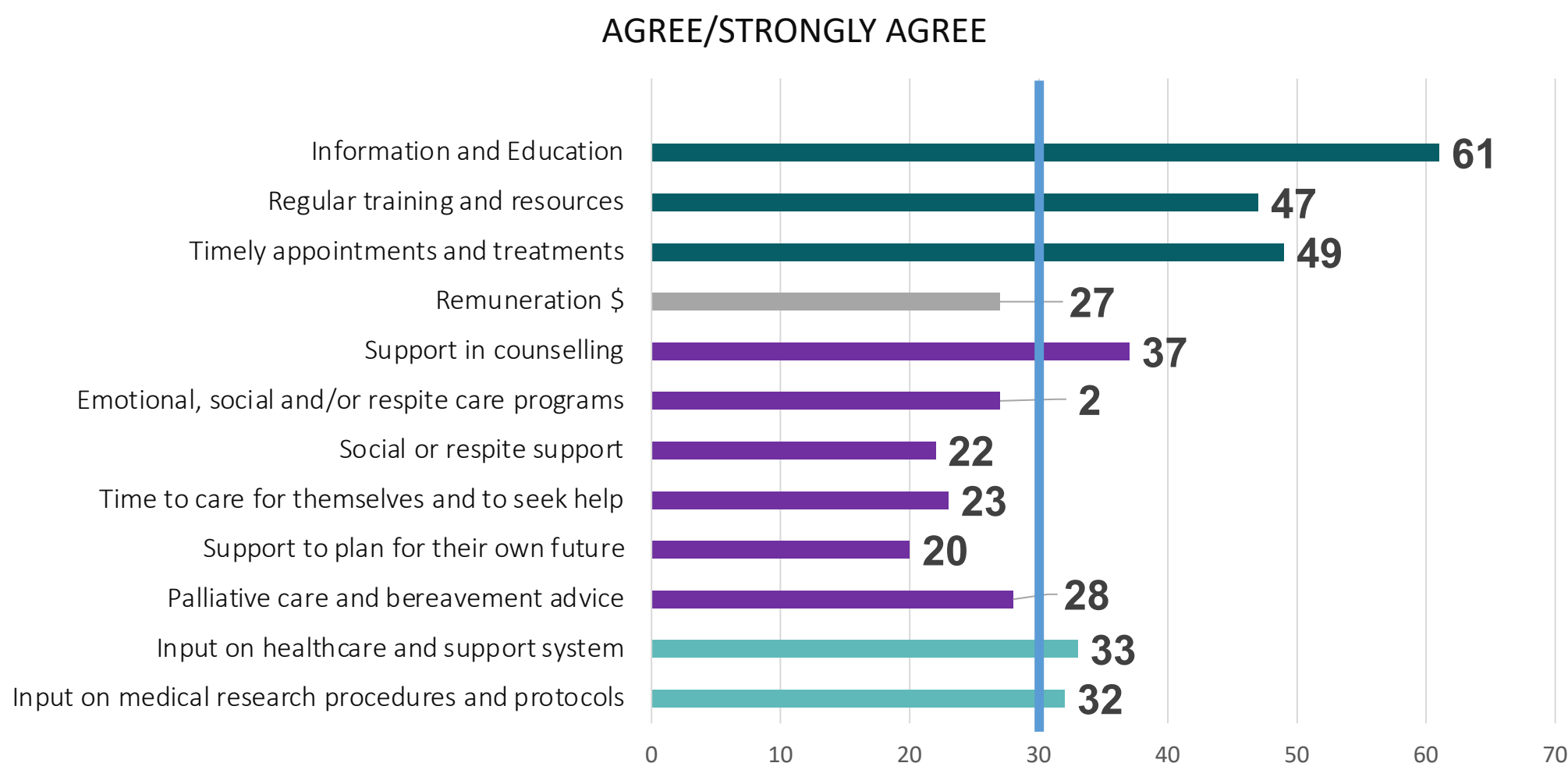


Figure 2. The assessment of CALS rights indicates that they are not well respected globally with the median at 30%.

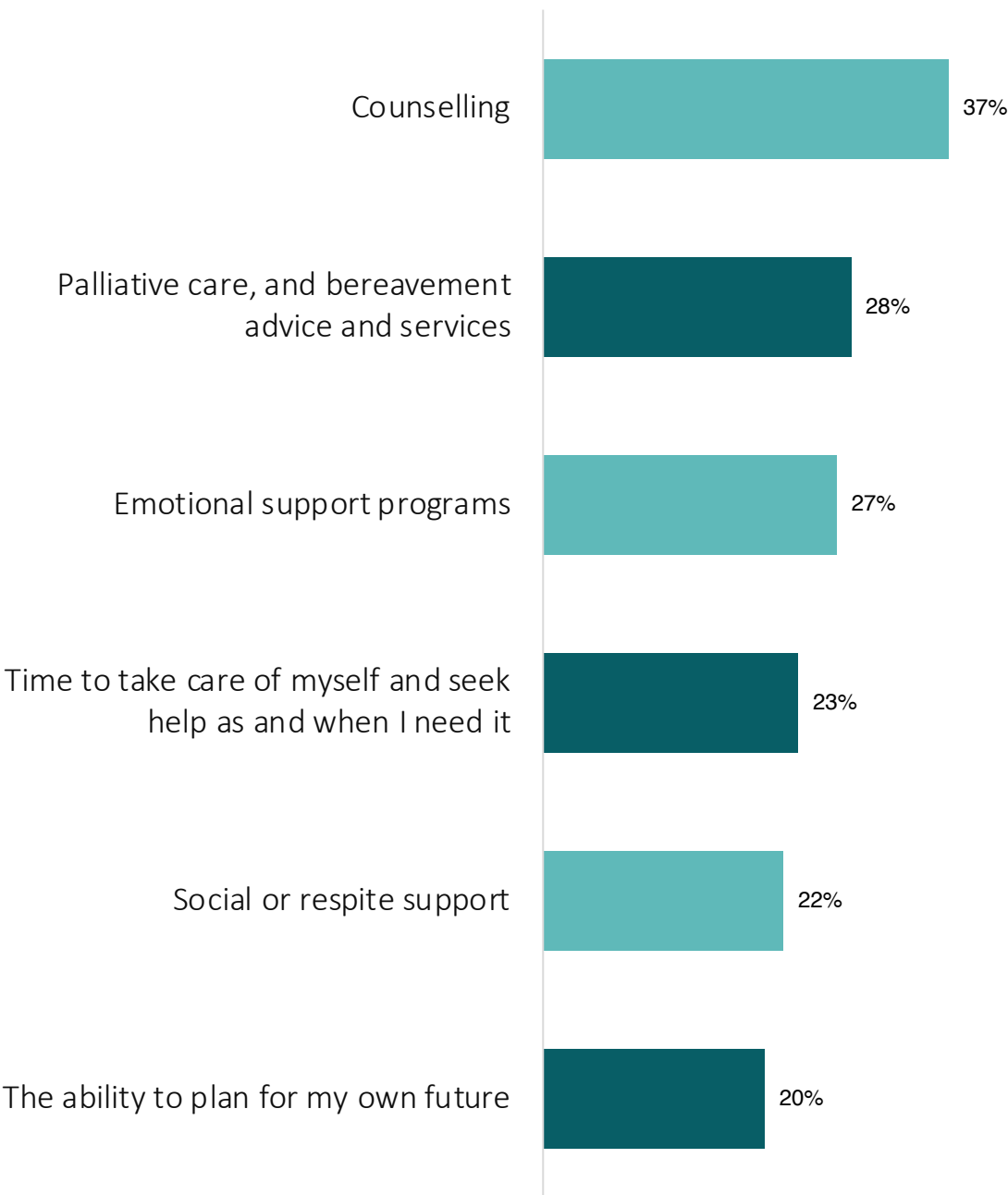


Figure 3. Although 61% receive adequate education and access to resources, and 37% received counselling, less than 30 % reported that they had support for respite, time for themselves, and palliative care support. This may be a discrepancy between what we want and what is reasonably attainable based on time constraints and lack of supplemental support.

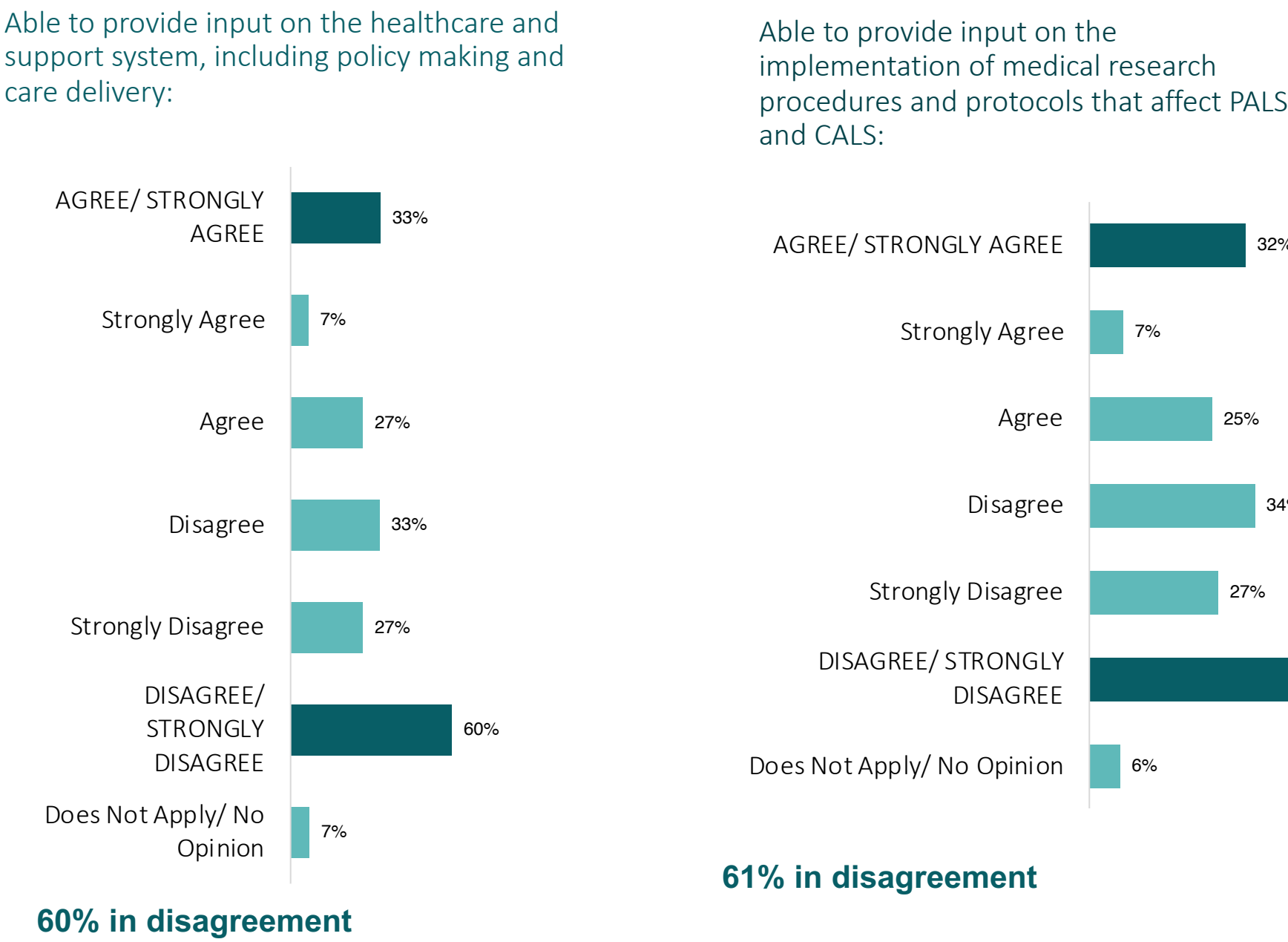


Figure 5. Caregivers and PALS are consistent in their disagreement that they have the right to input or to advocate in their healthcare systems. The data in all of these categories indicates the feeling of a lack of voice.

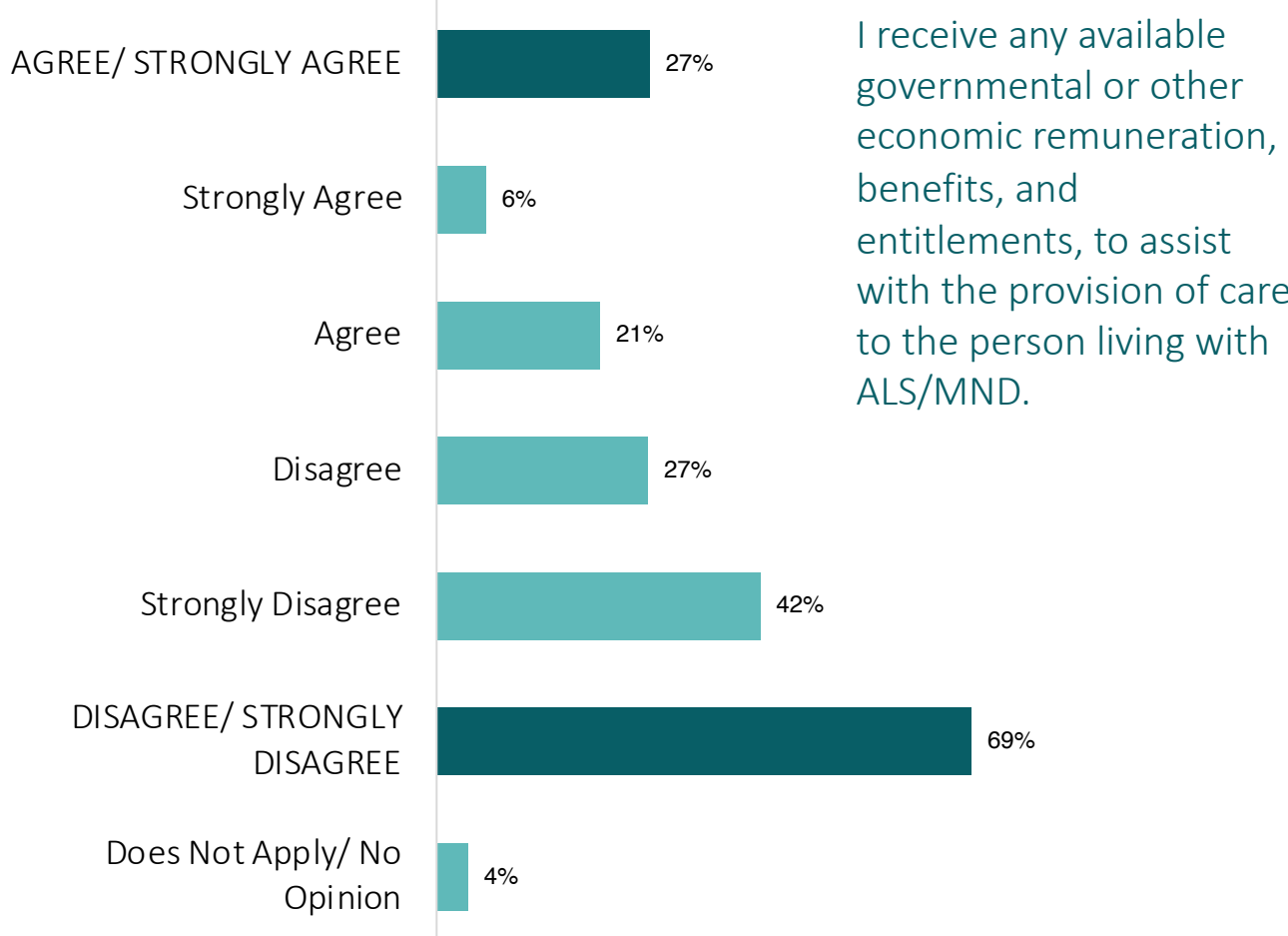


Figure 5. Overall, a large proportion of Caregivers disagreed (69%) than agreed (27%) that they receive economic support.

DISCUSSION

Overall the figures are low with a median of 30% of Fundamental Rights being respected for Caregivers, which is significantly lower to the companion survey for PALS which had a median of 45%. Caregivers feel an overall lack of support in all areas. Some specific findings that merit discussion are: These results clearly illustrate the saying “it is easier said, than done”. With many Caregiver indicating that they had access to education, resources and counselling but also indicating that they had little access to time for themselves, and time for future planning.

Caregivers have little right to remuneration (27%) and even less so than the PALS (40%). We know that a person living with ALS/MND needs a high element of care and that often a Caregiver needs to leave full time employment. If there are no economic supports in place this has a huge impact.

There is an overall feeling of not being listened or having a voice. Caregivers are unable to provide input about their experiences or feedback on procedures and protocols at the individual level and no input into public policy and healthcare at the community level.

ACKNOWLEDGEMENTS

We would like to thank the 1000+ people who responded to the survey, particularly the people living with ALS 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.