

26 May 2020

The Hon Stewart Robert  
Minister for Minister for the National Disability Insurance Scheme and  
Minister for Government Services  
Parliament House  
Canberra ACT 2601

Dear Minister

**Re: Restrictive eligibility criteria for NDIS ILC grant round**

In September 2019 many community organisations working with people with progressive neurological diseases were eligible to apply under the family organisation category as more than half our board members met the criterion of being carers or family members of a person with disability.

This March the eligibility requirements have been updated to read BOTH board AND staff must comprise at least half carers or family members of a person with disability.

Many of our organisations are no longer eligible as our staff frequently don't meet the requirement.

Many carers and family members of people with progressive neurological disease may fit into one or more of these categories:

- Too busy caring for their person with disability to be able to work effectively in a demanding job
- Too traumatised by the whole disease process to want to work on a daily basis with others facing the same situation
- Too worried about the implications of association with a potentially stigmatised disease to be prepared to be counted as a family member in a government funding submission

Many progressive neurological diseases are rare, so there would in any case be very few "eligible" people available to work in the field.

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Furthermore, our staff recruitment processes are based on merit, and (intimate personal / family) knowledge of a particular disease is normally only preferred not essential, and as noted above, there are so few people with some neurological diseases that we would be creating too small a pool of candidates to draw from if we required this.

If people with disability apply for a job with us, we would of course encourage them. However, if we made being a person with disability or family carer of a person with disability an essential selection criterion, we would again be artificially limiting the candidate pool, and potentially facing discrimination charges.

Thus, it seems you are "cutting off the nose to spite the face" in this situation.

Is it possible please to re-consider this restriction which is disadvantaging people with disability caused by progressive neurological disease?

Yours sincerely



Brian Rumbold  
President  
Huntington's NSW ACT



Jodette Kotz  
Chief Executive Officer  
Parkinson's Australia



Bronwyn Byrne  
Manager  
Leukodystrophy Australia



Gillian Thomas  
President  
Polio Australia

CC: Hon Bill Shorten MP  
Shadow Minister for the National Disability Insurance Scheme  
Shadow Minister for Government Services