23.\_org\_ Carers NSW

This submission is on behalf of an organisation: Carers NSW

Person submitting: Sarah Judd

Question 1:

No comment.

Question 2:

No comment.

Question 3:

No comment.

Question 4:

Carers NSW believes that there should be a nationally consistent approach to defining capacity so that there is continuity between states, especially for situations where the carer and the care recipient live in different states, or either person moves interstate.

We also believe that capacity should be reviewed regularly, as capacity can develop through training and life experience, and may vary over time in the case of a more episodic condition. Carers supporting or substituting decision making should be able to request a review of capacity as well as the person with disability or a government representative.

Question 5:

Commonwealth and NSW anti-discrimination legislation recognises that people associated with people with disability, including carers, may also experience disability related discrimination. The pattern should follow that other rights of people with a disability and of carers should be seen as interconnected, and not mutually exclusive. Carers may also experience legal barriers as a result of caring for a person with disability that further disadvantage the person.

Carers NSW also believes that carers should have the right to choice and control over their level of involvement in formal decision making roles to modify their status if their circumstances change. The NDIS rules on nominees, for example, explicitly state the necessary consideration of carers' willingness and ability to perform the role of nominee.

Both supported and substitute decision making arrangements may operate informally among family and friends and these should also be encouraged and supported if they appear to be in the best interest of the person with disability. Where carers have a formal decision making role, they may need accessible information and training in order to confidently, effectively and ethically perform that role. They also may require ongoing support in this role if they encounter challenges.

Carers taking on formal and informal roles to support or substitute decision making should have access to an easy to read document outlining the definition of capacity and any expectations and requirements involved with their role. The Capacity Toolkit by the NSW Attorney General is one example. Nominees and guardians should also be trained and supported to help the people they represent build their decision making capacity. Supported decision making is preferable to substitute decision making where possible.

Question 6:

The Disability Discrimination Act 1992 acknowledges that the associates of people with disability may also experience discrimination and should therefore be protected by law. The NSW Anti-Discrimination Act 1977, however, like other state legislation, refers specifically to discrimination on the grounds of caring responsibilities, which may be a useful distinction to add to the Commonwealth legislation.

Question 7:

No comment.

Question 8:

No comment.

Question 9:

No comment.

Question 10:

No comment.

Question 11:

No comment.

Question 12:

No comment.

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No comment.

Question 37:

No comment.

Question 38:

No comment.

Question 39:

No comment.

Question 40:

No comment.

Question 41:

No comment.

Other comments?:

Carers Australia has endorsed the content of this submission.

File 1:

File 2: