

very important contribution to the debate by pointing out that the marketization focus delivers a very narrow version of Choice and Control and only by viewing those concepts within a Human Rights framework can we hope to make genuine Choice and Control possible for people with disability.

*Simon Viereck, Executive Officer, Mental Health Community Coalition ACT  
www.mhccact.org.au*

## Choice and Control – a caring perspective



One of the major changes in the national reform agenda on age and disability community care services is the choice and control model that aims to provide increased and more meaningful engagement in economic, social and political life for older people and people with disability, carers and families. The Choice and Control: Strengthening Human Rights, Power and Inclusion for People with Disability paper provides a comprehensive overview and discussion about the genesis of ‘choice and control’ and delivery of disability services through a market environment versus a human rights environment. It recommends a combination of

both to better effect choice and control outcomes.

The ‘choice and control’ risks and limitations associated with delivery of the National Disability Insurance Scheme (NDIS) in a market environment are evident. Many organisations and individuals have proposed solutions to rectify the challenges people with disability, service providers, and carers and families encounter through their respective engagement with the NDIS, but there is a time factor associated with their implementation and benefits are still to be determined. Community sector concerns about the capacity of the soon-to-be rolled out Information, Linkages and Capacity Building (ILC) Framework to meet its improved choice and control objectives are also evident. A key question is: Will its allocated funding be sufficient to meet the framework’s objectives to improve choice and control for NDIS participants, people with disability who are outside the NDIS and carers and families in the framework’s, primarily, project based environment?

The paper also identifies that choice and control for people with disability has its foundations in a human rights framework, in the UN Convention on the Rights of Persons with Disability and the National Disability Strategy. Carers ACT’s premise is that to truly realise choice and control for people with disability (or those who are aged) is the need for them to be informed and enabled to use this power supported by legislated rights and recognition.

In the context of the paper, it’s important to identify that for many people with disability their lives are intrinsi-

cally linked to the rights and recognition of unpaid family or friend carers who underpin disability care in the community. It’s also important to acknowledge that many people with disability live independently in the community with formal support, and the aims of the NDIS are to increase their rights and capacity to do so.

While most carers identify that their caring is rewarding, many also experience similar reduced opportunities for employment and education, and social and financial disadvantage as people with disability. We know that many carers also have a disability, and some carers are supporting multiple people with disability and this can increase these disadvantages.

The paper considers choice and control across outcomes included in the National Disability Strategy, and carers and families are identified in some – NDS Outcome 3: Economic Security, and NDS Outcome 4: Personal and Community Support. But, too often, carers and caring families are not recognised as a recipient of these outcomes.

The Carer Recognition Act 2010 (Clth) aims to increase national recognition and awareness of the role carers play in providing daily care and support to people with disability, a chronic condition, a mental illness or disorder or who are frail aged. The legislation’s Statement for Australia’s Carers has ten key principles that establish how carers should be treated and considered by agencies and service providers. The first and second principles state that all carers and children and young people who are carers (respectively) should have the same

rights, choices and opportunities as other Australians and children and young people to reach their full potential.

Barriers to the rights of people with disability to fully achieve their objectives under ‘choice and control’ are apparent, but less apparent are the barriers that take away the rights and recognition of carers and caring families to achieve their own objectives under a ‘choice and control’ model. Further consideration and action are required to truly provide rights and recognition for carers and caring families in our communities.

Just as we have required care to survive and thrive, so we need to provide conditions that allow others – including those who do the [unpaid] work of caring – to receive the care they need to survive and thrive. (Eva Feder Kittay, *Love’s Labor*, 1997, p.107. Extracted from *Does your carer take sugar?* See reference below.)

### Further reading:

Commonwealth Government (2010) Carer Recognition Act 2010 (Clth). Accessible: <https://tinyurl.com/ms4a6vq>

Carers NSW (2013) *Does your carer take sugar? Carers and human rights: the parallel struggles of disabled people and carers for equal treatment.* Author Professor Luke Clement, first published in the *Washington and Lee Journal of Civil Rights and Social Justice (JCRSJ)* [2013] Volume 19.2 and reproduced with permission. Accessible: <https://tinyurl.com/knb9fpo>

*Colleen Sheen, Senior Policy Advisor Carers ACT*