

Easing the burdens on people with disabilities, and the people who care

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There are 410,000 families in Australia for which the introduction of the national disability insurance scheme legislation in Federal Parliament this week will represent a monumental day in their often difficult lives.

The mother who cannot take her eyes off her autistic child for a moment lest he run out to the street. The husband who has had to give up his career for a wife cut down by stroke. The young man catastrophically injured riding his bike to work who now cannot go to the bathroom unassisted.

These disabilities are the result of life's lottery, and for far too long families have been left to somehow manage the life of a disabled loved one along with their own.

They stopped being wives and mothers and husbands and fathers, and became carers. It was not a career choice.

The stated aim of the NDIS, according to the Productivity Commission's recommendations, is to allow for all people who have or acquire a "permanent or significant" disability before the age of 65 to be able to access "reasonable and necessary" support.

It is an idea whose time has come, and this legislation should be supported across the house. It is not a time for political point-scoring, nor "badass" speeches. It is a moment in which a much-maligned parliament can finish the year by doing some permanent good.

Initially the NDIS will serve five trial zones from mid-2013: the ACT, South Australia, the Hunter, Geelong and Tasmania. After three years - by which time \$16 billion annually will need to be found in the federal budget - it will be implemented nationally.

The legislation has been viewed by state ministers, who have warned that the disability community may be disappointed. They say the legislation is "rigid" and "overly bureaucratic".

The NSW Disability Minister, Andrew Constance, said the bill "will potentially risk some of the fundamental outcomes of having a national scheme in place, such as people's ability to have choice and control when it comes to development of their own plan."

Yet the NDIS aims to allow funding and assistance on a case-by-case basis, rather than the rationing system currently in place through Social Security and other measures such as Better Start for Children with a Disability and Helping Children with Autism, which both allow \$12,000 for early intervention regardless of the severity of the disability.

The legislation cannot duplicate the rationing system or it is pointless. It must help those who need it most, and it must help them properly. It is likely that subordinate legislation will be the subject of a Senate inquiry in order for the details to be fine-tuned, but the federal government and the disability community are confident the trial will begin next July.

Accusations by the state ministers that the Minister for Families, Housing, Community Services and Indigenous Affairs, Jenny Macklin, and parliamentary secretary for disability, Jan McLucas, have failed to consult the disability community sufficiently are unfair. Much community consultation has occurred, and carers could easily make a submission through the NDIS website.

Certainly the autism community's push for early intervention to be included has been heard, with Macklin and McLucas promising: "You [the disability community] told us that early intervention needed to be explicitly included in the definition of eligibility. Of course, support for early intervention is one of the key ideas behind an NDIS, but the feedback we received made us realise how important it is that this be stated upfront. So it will be."

The autism community is one of the louder disability groups - backed by spiralling diagnosis rates and parents desperate to help their children. The number of Australians under 30 afflicted by the disorder was 64,000 in 2009, an increase of 34,200 over 2003. While research into the cause has revealed little, research into treatment has been excellent and shows early intensive (and therefore expensive) intervention can help many children function in a normal environment - and move out of the NDIS system as they get older.

The economic argument to fund best-practice intervention fully is unquestionable. If disabled children have better access to intensive therapy their chances of becoming taxpayers rather than a tax burden are heightened. If carers' loads are lightened they may become more able to work.

These are the people for whom the legislation needs to progress smoothly through Parliament. But not until it is right.

LISA Comment: The original intention of the NDIS was, (a) to reduce or eliminate the service waiting list and, (b) to ensure all services were user-entitlement-based. Not as most are now, and have been for decades, charity hand-out based. Whereas, the current NDIS proposals ignore the residents of current group homes.

Those currently living in supported accommodation group homes, as many have been for years, and have been for years the victims of charity based, hand-out, block funding, where service providers, especially the DHS/DS Victoria, treat the residents and their families like dirt – :Like they are so lucky to get anything, they should never, ever, complain. And, if they dare to complain or adversely comment, they can expect reprisals.

Whereas, at little or no extra cost to the state government, the said block funding could, at the mere stroke of a pen, be re-defined as ISP funding.

Together with residential tenancy rights, the residents of current supported accommodation group homes, DHS/DS especially, would have similar ISP choice to that being envisaged with the NDIS, but now.

The residents of current supported accommodation group homes would have, (a) the means to individually seek an alternative supported accommodation group home or similar and, (b) the right, as a group, to seek an alternative service provider, and negotiate a service contract to their needs and liking.

Naturally, the said state funding could be transferred to the federal government, and all current group homes would be directly under the NDIS process at little or no additional cost – most likely less.

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