

Jenny Rollo OAM
135 Princes Street
Putney, NSW, 2112

jennyrollo@bigpond.com

0407 030 269

9th June 2016

Submission to National Disability Advocacy Program

Thank you for the opportunity to make this submission.

I am writing on behalf of my son who has a profound intellectual disability. He can neither read nor write and is unable to communicate verbally. He is one of the most vulnerable people in our community: a person who cannot advocate for himself on any level.

All his life his needs have been met because of the deep understanding and vast experience of his family, particularly myself as his primary carer. Yet my experiences as his advocate have varied tremendously depending upon who I am dealing with. Most people accept that I can represent him and this has been subtly improving over the years but there are still major frustrations that stymie us every day.

One of my greatest frustrations over many years, and where there has been NO improvement, has been systemic advocacy groups. They have consistently promoted their own ideologies above individual needs. Those ideologies have always been geared towards those who have been mildly intellectually disabled (and can often speak up for themselves to some degree) and those who have no intellectual disability but who have varying degrees of physical disability. I have found on many occasions that my opinions about my son's needs have been dismissed because they were inconsistent with the advocacy groups' ideology, and I felt belittled by their attitude towards me as "just a mother".

But who else knows my son and what he needs? Certainly not someone who thinks they have the right to dictate what services he should receive despite never having met him.

This cohort of vulnerable people with severe/profound intellectual disability is desperately underrepresented in advocacy services. Their families are their only voice but they are belittled and ignored. Without their families they are at the mercy of a system that does not understand them.

Sincerely
Jenny Rollo OAM