R.A.S.A.I.D.

Ryde Area Supported Accommodation for Intellectually Disabled Inc.
ABN 87 321 781 096 DGR endorsed
Donations of $2 and over are tax deductible
www.rasaid.org.au

PO Box 2068
Boronia Park
NSW 2111
Phone: 02 9817 1197
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SUBMISSION TO DISABILITY AND CARE INQUIRY

RASAID was formed seven years ago by a group of nineteen Ryde families who have sons and daughters with an intellectual disability. It was a response to the lack of supported accommodation in our state. We saw our adult children reach their late twenties and thirties with no hope of achieving the independence that moving out of home brings. We saw ourselves caring until we die, with no hope of humanely and gradually transitioning our people into a new residential setting.

The formation of RASAID was prompted by the Disability Agency's Vacancy Management Policy, which has seen local service providers disempowered as they may no longer choose which person from the local community will fill a vacancy. Instead, they now must accommodate whomever ADHC sends through its single point of entry policy. This invariably results in crisis driven placements (and they are all crisis driven) being sent far out of area, while other placements come from far away to local providers.

The RASAID parents determined that this was not good enough for their sons and daughters. The most important consideration for the housing of our charges is that they remain close to us, in the local area. We envisage a small cluster setting, consisting of five or six ordinary houses grouped together. In this way, our adult children can remain with their friends, the people with a disability similar to their own, that they have known all their lives. They can continue with day and work placements and maintain close community ties. We will be nearby to watch over them, each others' children as well as our own.

Our proposed model is more cost-effective than a dispersed group home. We have identified many ways that this can be so. Staffing, particularly overnight, can be reduced and other economies of scale can be made. We have widespread community support for our project, many promises of assistance, sponsorship from Rotary Clubs and fund raising happening on our behalf. We have identified a suitable block of government land in our area and ascertained that it is potentially available for our use.

The RASAID parents have between us six hundred years of caring experience. We know what is best for our particular group of people with a disability. We have been lobbying strongly for seven years, have had significant media coverage, the assistance of several politicians and more than one hundred meetings, including those with four successive state Disability Ministers. Yet we are today as far away from achieving our dream as we ever were. There is no way that we can be considered a high enough priority in the Agency's nebulous needs-based approach. Although our oldest member is eighty-eight, although several of our members have health issues and all our members are desperate for supported accommodation, there is no way in the present climate that our project can get off the ground. Because we are attempting to plan a future for our sons and daughters, we have been accused by the Agency of trying to "queue-jump".

We continue working to make our project a reality, because we have no choice. It is imperative that parents in our age group be permitted to see their sons and daughters gradually transitioned in an ordered and timely fashion. It is imperative that we, who have devoted our lives to our family member, be able to pass on the expertise that we have gained in caring for our person. It is imperative for our peace of mind that we see how our vulnerable adult children will be cared for after we are gone. And it is imperative that our sons and daughters be spared the tragedy and trauma that results from losing the primary carer, only home ever known and local community in one fell swoop, when no transition has been made.

It is inexcusable that in a rich and prosperous country such as ours, there exists no way for these things to happen. This is a grave breach of human rights and human decency. Our sons and daughters and all the others like them have, by virtue of their disability, a reduced adaptive capacity. Change is more difficult for them to accept than for the general population. Yet these are the cohort who, in the Australian context, stand to lose everything they have known upon the death of the parent carer. That there can be no supported accommodation until parents die must be acknowledged as a national disgrace and unworthy of a civilized society.

We know that you have received very many stories to support the need for a National Disability Insurance Scheme. At the heart of your project must be the concept of a fair go, that is, a level playing field for all. Currently, the disabled population, and in particular, the intellectually disabled population and their caring families are excluded from the common good in a way that does not happen in comparable countries. Also driving your deliberations must be the concept of the value of the disabled person, particularly the intellectually disabled person, who currently has the status of a pariah in parts of our society. Recognition must be made that a truly diverse and pluralistic society includes all people and gives them a chance.

It is clear that there needs to be a far greater disability budget. It is also clear that much of the existing budget gets nowhere near the people for whom it is intended. There needs to be one centralized point of collection and dissemination of funds, as in Medicare. Those people or families who wish to individually control their funding must be permitted to do so. Far greater accountability is necessary from non-government organizations and from state disability agencies. The consumer always knows how to get the best deal and when allowed to choose providers, will select those who respond to need. Families are currently unheard and unrepresented. There must be a way for families, who do by far the greatest share of care and support, to have a voice in policy making in the future.

We look to the advent of a National Disability Insurance Scheme with renewed hope for the future. We dare to hope that families such as ours, who have cared for decades and who have long awaited supported accommodation placements, will be the first beneficiaries of the Scheme. We look forward to finally being able to have some say in the future lifestyle of our sons and daughters and some ability to plan for that future.

We even dare to look forward to a few years of retirement for ourselves.

Please make it happen.

Estelle Shields
Mike Crook
Jenny Rollo OAM
Marilyn Jones
Lyn Allen
Megan Poole

for the RASAID families