

Submission No. 766
(Inq into better support for carers)

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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

PO Box 2068

Boronia Park

NSW 2111

Phone: 02 9817 1197

Email: allen_lyn@hotmail.com

INQUIRY INTO BETTER CARE FOR OUR CARERS

RASAIID stands for Ryde Area Supported Accommodation for Intellectually Disabled. RASAIID is twenty families who banded together more than five years ago with the goal of achieving supported accommodation for their disabled family member. The parents of RASAIID are mostly in their fifties, sixties and seventies, while our oldest member is eighty-five. Our disabled sons and daughters range in age from mid-twenties to mid-fifties and their disabilities are across the spectrum. We have supported each other in our caring role for decades and our adult children have grown up together, attending school, day programmes, work placements and social groups together. We have between us over seven hundred years of experience in caring for a person with an intellectual disability.

Our vision is to develop a model of supported accommodation which we believe will best suit the needs and wishes of our particular group of people. The model is a small-scale cluster residential setting which will be built in the Ryde area. We have witnessed over many years the pleasure and the support our sons and daughters derive from each others' company and we believe that this residential model will allow them easy access to their friends while ensuring that each has privacy when desired. Networking extensively across the country confirms that this is the model preferred by the majority of parents. The advantages of our model are:

The person with a disability stays within his/her own locality so the transition from the parents' home is much easier because the surrounds are familiar.

The person with a disability stays with a group of disabled peers with whom he/she has grown up, again making the transition much easier and allowing for the maintenance of a wide social network.

The person with a disability remains close to work or day programmes, thereby reducing the necessity for long and expensive travel across the city as now often happens. Each one of our sons and daughters attends a day placement in this area.

The transition happens in a planned and orderly way instead of the crisis-driven, trauma-causing way that occurs now. There can be nothing more inhumane than a person with a severe cognitive impairment losing at the same time the primary carer and the only home ever known.

The transition is aided by parents who are still well and active enough to smooth

over the inevitable bumps and to ease the way by having the person with a disability home for weekends, holidays and special occasions.

There will be twenty-four hour a day staff support .

The support arrangements will be enhanced by assistance from parents all of whom will live close by.

The local community will be encouraged to contribute to the development by parents who are well-known in that community.

The recurrent costs of such a model will be lower than a group home because staff ratios, particularly overnight, will be lower.

The families of RASAIID are all in the final years of care-giving and it is anticipated that not one family will be still supporting its disabled member five years hence. This is due to a number of factors including age, ill health both physical and mental, exhaustion and fatigue and the increasing support needs of our people. It is also due to the strongly-held conviction that there can be no true inclusion, equality and independence for our disabled people while they reside with their parents. Some of the people with disability are themselves aware of this and have been asking for some time to be permitted to leave home. The members of RASAIID are offering a practical and cost-effective alternative to the group home model. We firmly believe that our model will work well because we are already a community of like-minded people and our sons and daughters are already a socially cohesive group.

Our dream is as yet just that - a dream. This is why we are making a submission to your inquiry. The best support that can be given to a carer is to provide an exit strategy from the role of carer. Lifelong carers like us need to know that there is a succession plan in place and that their caring days are finite. They need to be able to look forward to a well-earned retirement as other Australians do. In fact, it seems inequitable to us that those people who have worked the hardest and longest at parenting are the same ones who may never experience a retirement. The contribution of thousands of lifelong carers such as the families of RASAIID can be acknowledged in only one satisfactory way: by allowing us the peace of mind of seeing our beloved family members settled securely outside the family home. This must happen in the immediate future so that we may have some retirement before we die. The well-described poor mental health and poor psychological wellbeing of carers can be attributed quite simply to having nothing to look forward to in life, combined with the stress and uncertainty about the future care of a dependent family member.

The RASAIID parents have spent decades searching for appropriate services for our sons and daughters. These have been things like early intervention, therapies of various sorts, play groups, pre-schools and schools, recreation, day and work programmes and respite - always respite. Our preference is that rarest of all commodities - centre-based respite. We have badgered government departments for the services our children must have, attended forums, visited politicians, written letters, filled in forms (we can do this with one hand tied behind our backs) and at times marched in rallies and waved placards. Many of the things we fought for have become a reality and many of us have felt well-supported in our caring roles. But there is one area in which our governments are failing us and this is the area of supported accommodation.

Across the developed world, governments are assuming responsibility for the provision of support services for their disabled citizens, particularly the accommodation of those citizens. Australia lags far behind many comparable countries. We believe it is a national disgrace that a country with a budget surplus the size of ours can permit aged and often ailing parents in their seventies, eighties and even nineties, to continue to care for its disabled citizens. We believe that the practice of leaving adult disabled people at home with their parents contravenes the rights of the disabled and violates all principles of choice, inclusion, opportunity and independence. Currently, less than one in twenty disabled persons has an accommodation placement in Australia and parent carers are dying waiting.

RASAIID submits that there is only one way to **Better Care for our Carers** when those carers get to the stage in life that we are. There comes a time when it is no longer possible to prop up a situation, to find **practical ways to improve or extend support ..for carers**. This is the time to be relieved of the caring role and allowed to retire. RASAIID further submits that we have had enough parliamentary inquiries and the latest Senate inquiry has well documented the overwhelming unmet need and recommended that far greater resources be allocated to the disability sector. This has not happened, and **while recently announced additional Federal funding for new supported accommodation facilities represents a step in the right direction**, it is one step when we needed a mile. It is not difficult to **assess what more can be done to support the as yet unmet needs of carers** when they get to our ages. The **key priorities for action** are those which will allow us **to access the same range of opportunities and choices as the wider community**, but not within our **caring roles**. Rather, they will see us relinquish those caring roles in a timely and ordered fashion, to **transition ...out of caring and effectively plan for the future**. They will see us enjoy a well-deserved retirement while we oversee the safe and gradual transition of our sons and daughters into their new homes in the Ryde area. It is our hope that RASAIID's cluster model will prove to be a great success and will be emulated across the country, a template to be used in every suburb and large country town. It has the potential to be a new way forward for people with an intellectual disability and it needs only a few far-sighted statesmen or women to make our dream a reality.

We wish to end our submission with the words of Gwynnyth Llewellyn, one of Australia's foremost researchers in the field of disability.

Many older parent-carers, after years of thought, have developed innovative strategies that deserve the undivided attention of politicians, government bureaucrats and service providers alike. We ignore these at our peril faced with a steadily increasing and growing number of older, older parent-carers and older, older adults with intellectual disability. (p47)

Many older parent-carers previously involved with whole of life non-government services are now required to negotiate complex and challenging service system primarily designed to suit the needs of younger carers. With the loss of institutionalisation and parent initiated organizations, older parent carers are likely to be increasingly isolated from the support provided by other parents and a "caring" organization. (p36)

Among the recommendations in this paper is a call to :

Provide accommodation options including village style accommodation, which is (anecdotally) much desired by older parent-carers.(p38)

Invisible Carers: Facing an Uncertain Future - Possible Solutions from Service Providers Perspective. Gwynnyth Llewellyn, Lindsay Gething, Hal Kendig & Rosemary Cant. Faculty of Health Sciences and Faculty of Nursing, University of Sydney, May 2003.
www3.fhs.usyd.edu.au/fssp/pdfs/invisible/pdf

We would add that it is not only older parent-carers who wish to see village and cluster style accommodation but parents of every age. In response to the loss of community-based, caring organizations to support disabled people and their families, you will see in the future calls for a new wave of twenty-first century parent initiated services such as we are proposing. If you truly wish to care better for our carers and those they care for, you will heed those calls and respond with haste.

Thank you for the opportunity to be heard.

The Parents of RASAIID