

RASAID



THE RASAID JOURNEY

We are nineteen families from the Ryde area in Sydney's North West. We all have sons and daughters with an intellectual disability. These adult children of ours are in their twenties, thirties, forties and fifties while we are mostly of retirement age. Our oldest member is now eighty-seven and still caring for her middle-aged son. Four of our members are single mothers and four come from non-English speaking backgrounds. Our children have disabilities across the spectrum, from severe to mild. We came together for our first meeting in October 2004, united in our determination to achieve supported accommodation for our sons and daughters.

In that first year, we clarified our vision and our goals, decided on our name and drew up our constitution. RASAID stands for Ryde Area Supported Accommodation for Intellectually Disabled. Not only did we desire supported accommodation for our family members, but we determined that it must be in the Ryde area so that they remain in their known community. In consultation with each individual family, we gradually arrived at the idea of a cluster residential setting or intentional community. It was this model that we came to see would best suit the needs of our particular group of people. Having watched them grow up together and engage with each other, we realized that the accommodation model that would be most appropriate would be one in which they could have both their own privacy when desired and the opportunity to interact with each other when desired. It was with the vision of the *Ryde Hamlet* in mind that we went forward.

Our main supporter and mentor at this stage was our local state member and deputy premier, John Watkins. He shared our vision and our determination to make RASAID a reality. In 2006, he helped us to get an interview with the policy advisor in the office of the then disability Minister, Della Bosca. Extra funding had been acquired for disability under *Stronger Together* and our ideas were well received. Later that year, one of our members addressed the Labor Party Conference and spoke of the desperate need for supported accommodation in our country. In that same year, one of our foundation members died. We watched with dismay as her son, grieving and bewildered, was shunted from one respite house to another. Finally, more than a year after her death, he was found accommodation, but not in our area. This incident strengthened our resolve to achieve our dream and see that this scenario is never repeated amongst our membership.

2007 brought both a state and federal election and we used this time to raise our profile. Several of our members stood on the ticket for the Carers Alliance, which was formed to give carers like ourselves a voice and to highlight the unmet need in our sector. We took part in protests outside the offices of our local federal member, John Howard, and in pre-election forums around disability issues. At this point, we were receiving supportive feedback from politicians on both sides of parliament, both state and federal.

During 2008 we became serious about our project. We took part in Maxine McKew's 2020 Bennelong Summit and met with Bill Shorten, the federal Parliamentary Secretary for Disability. John Watkins took us to see the then disability Minister, Kristina Keneally who received our ideas with enthusiasm. She claimed that she was eager to see a wider choice of residential models and to break the stranglehold that is held by the activists who object to cluster developments. She referred us to an NGO whom she felt would be best placed to work with us.

A series of meetings with ourselves and the NGO commenced and discussions between their CEO and the director general of our disability department led us to believe that both capital funding and recurrent funding would be available to us if we could secure some land locally. Meanwhile, we presented our accommodation model on the carers virtual 2020 discussion website and received positive response from all over the country. We put in submissions to DADHC on their draft policies for supported accommodation and respite and met with them to discuss our thoughts.

John Watkins resigned later in 2008 and Kristina Keneally moved on, but the new Minister, Paul Lynch met with us and the Labor candidate for Ryde, Nicole Campbell, on 15th October, 2008, to assure us of his support. He was enthusiastic about our project, endorsing our cluster model and saying he planned to make it a reality. When we asked for this in writing, he signed his name in the air, indicating that this was all we needed, his word his pledge. His policy advisor, Cecilia Anthony, reiterated that when the Minister wants it to happen, it will happen. Believing we had an iron-clad guarantee, we left the meeting on a positive note.

2009 brought renewed vigour and determination as we believed realisation of our plan to be in sight. Our NGO started to do individual PATH assessments on each of our sons and daughters, to determine what hopes and dreams and support needs each has. Our solicitor drew up a family governance deed which clarified the roles of ourselves and the NGO in managing our project. A block of public land was identified as perfect for our development and initial plans were drawn up for the site. Our local council and Rotary club came forward to offer us their support. John Watkins met with Minister Lynch to discuss our needs, particularly the land.

The director general of our department retired, saying that disability service provision in this country is a "disgrace". In June, 2009, we had a meeting with the Health Department and DADHC. The representatives from the Health Department were to make us an offer of the identified block of land upon guarantee by DADHC of support for our project. Instead, DADHC quoted their vacancy management policy. They support the project but they will determine who fills the places. There is no guarantee that all, or in fact any, of our sons and daughters will be accommodated within it.

Having hit this bureaucratic brick wall, we hastily returned to the Minister. Who, we wish to know, runs the department? Why were we given assurances by so many for so long if departmental policies and procedures are insurmountable? What does a parent do in this country to plan for the future of disabled offspring? Our questions remain unanswered as the Minister refuses to answer our letters, much less meet with us.

2009 has come and gone. One of our members became seriously ill and there was no immediate emergency respite for her daughter. Another of our families' marriages broke up after thirty years. One of our families could wait no longer for RASAIID. Pushed to the edge and with much anguish and regret, they relinquished their son to the department. After blocking a respite bed for six months, he is now placed in a group home, but it is not local or with anyone he knows. Another of our families won the jackpot: this family was offered a supported accommodation placement by the department. With a supply rate of only seven per cent of demand, to be offered a place is rare, but to be offered a place that is local and appropriate is almost unheard of. We rejoice for this family.

Meanwhile, we continue to fight for our cause. Our sons and daughters have a right to move out of home like their non-disabled peers. We have a right to retire after having cared for so long. We must not die while still caring because it means we have made no provision for our person's future. He or she will lose at the same moment the primary carer, the only home ever known and the familiar community. We cannot let this happen. What we are asking is something that families in other developed countries accept as their due. Our country falls far behind on this issue. Governments must accept that they have a responsibility to look after their disabled citizens when they reach a certain age.

In September, 2009, we took a decision to go public. We have decided that it is time to tell our story. It is a sad story of promises made and broken. We have been taken on a long ride but we are not finished. In November, we held a public rally in Ryde. This was covered on the front page and editorial of our local

Cumberland newspaper. At the rally, the shadow disability Minister promised that his government will fund our project if elected in 2011. We commenced work on this website. We wish our community to be aware of our issues and assist us in our fight. In February 2010, our group was featured in a Four Corners program entitled "Breaking Point", which is where many of our families are.

We cannot rest until our family members are settled in secure permanent supported accommodation. We wish to make a pioneering cluster model that may be emulated across the country. We would like to see a similar development in every suburb and large country town, because we believe this is the model that many parents wish for. We are dedicated to the completion of our project and we will do whatever it takes to bring it to fruition. If we have to hold a gun to the head of our governments, that is what we will do.

Estelle Shields