

In any discussion of models of accommodation for PWD, it is firstly necessary to acknowledge that for the vast and overwhelming majority of those people in Australia, there is no accommodation of any sort, and without an NDIS, no hope of accommodation this side of their parents' grave. In opening I wish to pay tribute to all those PWD who at this moment are languishing at home with an elderly parent, a parent who is hoping desperately that he or she will outlive the dependent person. Sometimes I think that if we had one residential placement for every one thousand words that had over the years been written or spoken on this subject, we would have no waiting lists and no terrified parents. As I have been saying for many years, we are debating the merits here of butter over margarine, while most of us don't have the bread to put them on.

RASAIID stands for Ryde Area Supported Accommodation for Intellectually Disabled. It was formed almost seven years ago when a group of concerned parents from the local area gathered around Lyn's kitchen table. We were mostly in our fifties so we were just concerned. In your sixties you get worried, but it's in your seventies that you start to be terrified. The terror is not that there will be no place for your dependent person when you die. In fact, the one sure way to secure a place within the disability system is for last remaining parent to die. No, the terror is about the abyss.

I must disgress for a moment and tell you about the abyss because it never seems to get an airing at gatherings like this, although it looms so large in the lives of families like ours. The abyss is where our children go when we die, before we have been able to gradually transition them out of our care and into an alternative residential setting. In one fell swoop, on the death of the last parent, they lose their primary carer, the only home ever known, the familiar neighbourhood, day or work programs, recreation groups and friends. They lose the lot and this for people who often cannot communicate easily, who cannot email, text, drive, phone. They often cannot access their previous life in any way. They might as well be on the moon. It would do us well to imagine how we would cope with such an upheaval and then to magnify our response many times, because we know that PWID have a greatly reduced adaptive capacity and find change of any sort much more difficult.

This is the abyss that so terrifies parents. It is the trauma and grief and bewilderment that they have set their person up for by being unable to plan for the next stage in life, by being unable to effect a gradual transition for their person. My sister-in-law worked for twenty years at a hostel in Redfern run by the Sydney City Mission. The saddest cases she ever nursed, she says, were the ones with intellectual disability who came in after the parent died. They were not very old, she says, and not particularly sick, but they never lasted very long. They just pined away.

I think this is the worst thing I have ever heard. Surely this must be a human rights violation. But we never hear a word about it. All the disability activism is around people who have secure accommodation, but in settings that we are told are too large. Not a word is spoken about a far greater number, possibly ten times greater, who are languishing at home with ageing parents and facing the abyss. Last year, there was a great outpouring of sympathy and concern for a little boy who was left an orphan on Christmas Island. Australians are not told that possibly every day, somewhere in our country, a person who is a citizen of this country and who has a cognitive age the same or lower than that little boy has been left an orphan, with no plan in place for the rest of life, about to fall into the abyss. I do not understand how this can happen in a wealthy country that thinks it can afford a National Broadband Network and all the rest.

So it was October, 2004, and twenty families met to think up a way to avert what looked like an inevitable abyss for our sons and daughters further down the track. We are a cross section of society: five are single mums, five are from different ethnic backgrounds and our kids' disabilities are across the spectrum. We agreed at that first meeting that we would commence a campaign of lobbying and raising awareness of our predicament. We didn't, however, spend time debating a suitable model. There was overwhelming agreement that any accommodation must be in Ryde, right under our noses where we could still be a big part of the lives of our people. And there was consensus that the community that our sons and daughters comprise must be preserved: they who have grown up together and who clearly enjoy each others company must be allowed to continue to do so.

At inception time, the RASAIID families boasted a total of six hundred years of collective caring experience - now it is more than seven hundred. Each family is informed by daily observation of and interaction with its dependent person over many years. So I will tell you about mine. My son is 34 and he has a severe intellectual disability of no known cause. He is highly social and loves to meet people. He has many people in his life. Because we are originally country people, our house is the city hotel for all the country cousins. But the ones Daniel asks for and looks forward to seeing are the PWID like himself. For many years, I have watched him as he pours over the pictorial program sent out by the recreation group, asking how many more sleeps till he goes out with them. I have witnessed his delight in the company of his friends. So too, did an advocate that we engaged for some time from PWD. She conceded upon getting to know my son that his heart's delight was in his engagement with his friends. She pronounced him "the exception to rule" because what she saw defied what she had been taught. However, he is not the exception - he is totally typical, as all our other RASAIID families will testify.

We therefore envisaged as our model a cluster of five houses around a central common area. This has now changed somewhat as an older clientele may prefer individual apartments. However, the basic idea has not changed. We see a place where our sons and daughters may have their own private space and easy access to their friends. We see the pooling of individual funding for better outcomes for our people. We see economies of scale that will leave more funds left over for leisure activities. We see the highest level of family governance which will give us control of the day to day running of the project, including the hiring of committed staff. We will write our own vacancy management policy which will ensure that any future client will be from the Ryde area and compatible with our people. We see our sons and daughters having a full life, engaging in community activities individually and with each other. Central to our vision is the fact that our venture is not crisis-driven. We will have time to plan and to oversee the transition of our sons and daughters - to avert the abyss. The core philosophy of our group is that we will look out not only for our own person but for each other's. And that we will surround our project with family, extended family and friends who wish to be a meaningful part of our adult children's lives. This will include the siblings to whom we intend to hand over the baton of responsibility further down the line.

If we take a moment to consider our own lives, it becomes evident that the three main cornerstones for most of us are our families, our careers and our friends. PWID seldom have a family of their own and usually do not have a rich and rewarding career. So it follows that the social life assumes an even greater importance. Once at a meeting I attended, an advocate with a physical disability said "I enjoy the company of my friends, too, but I wouldn't want to live with them". How do our people access their friends if they can't read, write, drive, telephone? They need to be physically present in order to interact. It is, in fact, cruel, to keep highly social human beings apart when their great need is to engage with each other.

The other reason that the RASAIID parents chose this model is that the alternatives that we see every day are so bad. We see negligence posing as independence as people with a cognitive age of only six or seven are left with an hour or less of drop-in support each day. We see people from our area sent to far-flung suburbs where their best support, their families, have difficulty accessing them. We see people from other areas sent to our suburb and we see what goes on in group homes: living with strangers, casual staff, poor food, no vehicle, few or no activities, reliance on television, poor hygiene and worst of all, no mechanism for accountability or complaint. We see these things every day right under our noses and we know we must do better for our sons and daughters.

This is not some innocuous little academic debate. For the past three decades a one-sided campaign based on evidence from other societies has delivered and continues to deliver poorer outcomes for many PWD. Some unscrupulous service procurers hide behind the rhetoric of social inclusion and are encouraged in their negligence because the only yardstick in the measurement of service is the size of the roof. This country has failed to provide a humane model of accommodation for its most needy people and in the RASAIID project we are trying to show the way forward.

LYN: When RASAIID was formed in 2004, a cluster model was not an approved option. Shortly after this, we had an opportunity to make a submission to DADHC's inquiry into "Models of Accommodation". The results of this inquiry showed a majority of parents favored cluster models. However, it was not until Carers Australia sponsored its 2020 website in 2009 that we were able to see how much parents favored this model and by what a large majority. It was the response to a special stream around models of accommodation that families from all over Australia showed overwhelming support for our RASAIID model. Carers are often housebound, isolated and without representation or forum. It was not until this moment that we realized that with RASAIID we were doing something of national significance.

Our children have spoken and their message is quite simple. They have told us that they want to be with their friends. They want to be part of the wider community but they want to keep their own group of friends intact. The hearing impaired community has its own vibrant social network, as do thousands of other special interest groups across the country. Why should our children be any different? They see their siblings, cousins and grandparents choosing to live with friends, in retirement villages or apartment complexes. Sharing meals and plans for the future. Our children also attend established recreation groups and workplaces and they are generally well known to the community. They deserve a choice.

All families are concerned that their family member will be subject to abuse and neglect. We believe that by setting up a vigilant community of interested persons we will best ensure that this cannot happen. Our disabled sons and daughters have also shown us that they have the capacity to look out for each other and to report on each other. We believe that other safeguards, such as being able to choose our own staff and govern the entry of new clients, will ensure quality of life for our people. We hope that by writing air-tight documentation at this point in time, we will put in place measures to secure the futures of our family members. Many hopes are invested in the next generation, our non-disabled sons and daughters, whom we hope will continue our vision past our lifetimes.

RASAIID is still a dream. On 1st June this year, after working for nearly seven years and lobbying five disability ministers, we came closer to our goal. Andrew Constance lived up to his promise to give us recurrent funding for our family members and sufficient funding to build our cluster. However, at this stage we do not have land in the local area to do it. We continue negotiations for this and we are confident that we will be able to jump this one last hurdle in our marathon. It seems sad, however, that so many local large care facilities that used to cater for PWD have been sold to developers or given to other government departments. Now, when we need a relatively small piece of land, there appears to be none available. Let's hope we are not squeezing our people out of our communities.