

Submission  
No 15

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY  
THE DEPARTMENT OF AGEING, DISABILITY AND  
HOME CARE**

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## SUBMISSION TO THE INQUIRY INTO THE SERVICES DELIVERED BY ADHC

### DECEPTION AND DUPLICITY

The Agency of Ageing, Disability and Home Care has a very difficult brief. While funded to meet only a tiny fraction of the demand for its services, it must present to its consumers and to society as a whole as a fully comprehensive and universal support system. This fiction must be maintained so that consumers, who are those families with a disabled member or persons with a disability themselves, retain faith in a support system supplied by a humane and benevolent society. It is necessary to promulgate this belief so that members of our society see that matters are in hand, systems are in place and that disadvantaged people are having a share in the nation's wealth. It is particularly necessary that consumers of ADHC services are convinced that systems are in place and that it will take only a degree of patience before services are available to them. A loss of faith would result in despair, leading to mass relinquishments of the disabled family member at best, murder and suicide at worst.

While ADHC can meet only a tiny fraction of the demand, such as around 4% of immediate and urgent requests in the case of supported accommodation, it must expend scarce disability resources on perpetrating the myth: that it is a caring and supportive network waiting for the right moment to step in and fulfil the needs of the person with disability or the family of the person. All ADHC's documents, its website, its numerous meetings and all its personnel contribute to the illusion. The most important part of the charade are the case workers. The case worker's role is to ensure that each family believes that in due course, the desired service will be provided - it's just a question of waiting. Even when the statistics show that this cannot happen, it is the duty of the case worker to make the family believe that it has a higher priority than others, that its needs are somehow greater than others and that its patience will be rewarded with the prize that few others can achieve.

Some years ago, an ADHC Regional Director almost revealed the truth of the situation when he said "The role of the case manager is one of gatekeeper and triage". That is, the case manager will decide who is admitted through the gate as the highest priority and make the rest believe that if they wait for long enough, their turn will come. ADHC is not fully candid with its employees on this matter and may be accused of deception and duplicity with its staff as well as its consumers. A former case worker told me that she had worked in the job for six months before she became aware of what her true role was. And what was that? To avert relinquishments at all costs - to keep them all hoping and believing.

ADHC is therefore a provider of last resort. It is only the people with a disability whose parents have died, whose support arrangements have totally broken down and who are homeless and destitute that are considered to be of sufficient priority to gain a supported accommodation placement. We cannot allow disabled people to be begging in the streets, after all. ADHC has inherited a legacy of sector neglect that has lasted for decades. It now finds itself responsible each year for around ninety children turning eighteen who are leaving DOCS. It is still supposed to be devolving "institutions", rehousing young people in nursing homes and getting prisoners with an intellectual disability out of jail. This is in addition to facing the growing tsunami of middle-aged sons and daughters of ageing carers who are falling off the perch.

ADHC cannot possibly do all this on its current budget. Even the Stronger Together funding has scarcely hit the sides. As Brendan O'Reilly pointed out, this issue is too big for any state government and there must be federal intervention in some form or another. We have a system that is broke and broken, but the deception continues. As the parent of a man with a severe intellectual disability who is now in his mid-thirties, I can tell you that in recent years I have had many visits from ADHC staff with assurances that plans are well advanced for my son's transition into supported accommodation. The failure of any of these plans to yield results has many reasons: the person making the assurances had no authority to do so, has now left the agency, has lost inside contacts with a power-shift in upper echelons of the agency, the proposed place had to be given to someone whose mother died, or became very ill.....

The truth is that this side of the grave, there is no hope of supported accommodation for any family in this state, unless it is strong enough to relinquish care of its disabled member. I am part of a group of parents in the Ryde area who formed RASAIID (Ryde Area Supported Accommodation for Intellectually Disabled). For seven years we have been trying to achieve our dream of a cluster development in our local area for our sons and daughters. Despite intense media coverage and the support of several politicians, we always come back to this one obstacle: the few places must go to the most needy, and we, being still alive, cannot be considered a high enough priority.

There remains no way we can plan for the futures of our sons and daughters, no way we can see them gradually transitioned into a new residential setting, no way we can avert the tragedy and trauma that will befall them when they will lose, in one fell swoop, the primary carer, the only home ever known and the local community. And this will be for a person who, because of his or her disability, has adaptive capacities that are less developed than in the general population. I rail at the injustice of it, in a rich and prosperous nation enjoying a mining boom, with waste afoot at every turn and money for everything, it would seem, except our most needy citizens.

Meanwhile, ADHC continues to send me my case worker, who continues to assure me that my son is a very high priority. I am continually offered bandaids in an attempt to convince me that there is, in fact, a network supporting me until the nebulous relative needs approach places me at the top of the pile. I am offered some ageing carer respite or a three-hour per week recreation program. Maybe I would like to read some of the "Good News Stories" published last year by ADHC, all with the subtext "It could be you!" Or perhaps I should take heart at one of those announcements by the Minister, always with the words "more,

better, improved and expanded".

ADHC would serve our needs better if it were to admit it could fill only a fraction of the requests and come clean with a register of unmet need. Making one hundred new supported accommodation places would be preferable to employing one hundred new case managers to boost our faith in services that do not exist. For people like myself who have been playing the game for decades, no case manager will ever convince me that the ageing parent carers of people with a severe dependent disability have not been betrayed and exploited by our governments.

## NON-GOVERNMENT ORGANIZATIONS

A large slice of the ADHC budget goes to fund NGOs. While there are many responsive and responsible NGOs, there are also many who are not. The only criteria for receiving ADHC funding, it would seem, is the ability to write a convincing and long tender, couched in all the correct inclusive and person-centred jargon. Once the funding leaves the ADHC coffers, there seems to be very little accountability for the way in which it is spent. I am aware that the NGOs complete acquittals, which prove that the funding has been spent. However, whether it has been spent in direct care for the person for whom it was intended is quite another matter. There would appear to be no mechanism to ensure that the funding goes where it was meant.

We have in our local area a particularly crass NGO. It seems to have more staff behind computers than in the field. This block-funded organization sees fit to put people with a cognitive age of six or seven into the "community" with an hour or even less of direct care per person per day. This is passed off as "social inclusion", "community integration", "dignity of risk" and "individual choice". It may also be called "abuse by neglect". If a child of this chronological age was left alone with an hour per day of care, we would be phoning DOCS. If the NGO does it, it is apparently permissible.

This same NGO fails its clients by not providing transport. From their pensions, after having paid all their expenses, clients then have to pay taxis to day and work placements and to medical appointments. There is no money left at the end of the week for any personal or recreational pursuits.

When these issues have been raised with ADHC, the response from the Agency is that it does not field complaints about NGOs. In other words, once the funding leaves ADHC, the NGOs are free to use it as they see fit. Many use it frugally and deliver as many hours of face-to-face support for their clients as they possibly can. Others build great bureaucracies, with layer upon administrative layer, company cars, junkets to conferences and many other perks. Yet ADHC remains oblivious to all of this and seems to have no facility to separate the good from the bad.

My son received a funding package for recreation which was to last for twelve months. I was referred to the provider by ADHC. After some months it became clear that the NGO was not delivering the promised service and doing none of the things that the glossy brochure claimed it would. Its care worker was turning up only half the time. I approached ADHC

and asked if my son could have the remaining funds transferred to a more responsible provider. The answer came back to me that this was not possible.

This is an example of the frittering away of scarce disability dollars. This sort of wasteful, "keep them believing" package, if not allocated to ten or fifteen people with a disability, would give a most desperate family a supported accommodation placement and change the lives of all the people in that family. I would gladly hand back this sort of bandaied funding if it could mean that one deserving family would received supported accommodation.

## RESPITE

There is one service that I would not give up and that is centre-based respite. My son was ten years old before I heard the word "respite" and its meaning had to be explained to me. Then I used respite for a few years and the facility was then closed, leaving us with no other. Now, however, ADHC runs an excellent respite facility in my local area, with experienced, caring and long term staff who have come to know their clients and families well. I can tell you that almost everything that has made my life worth living in the past ten to fifteen years has happened because my son has been in respite. There have been other times when blocked beds have precluded his attendance at respite and all plans have had to be put on hold. Not only does respite give me a break, but it gives my son a social experience and prepares him for the inevitable move out of home.

I wish to state that ADHC centre-based respite has made a big difference in my life and I am immensely grateful for it. It is unfortunate that when each three-monthly request is made, there is a requirement that we paint a picture of our dire circumstances so as to be prioritized against other needy families. This aside, ADHC deserves a big tick for unblocking beds and for making more centre-based respite places available. There comes a time in life, however, when a respite service no longer cuts the mustard and when something more permanent is required.

## VACANCY MANAGEMENT

Seven or eight years ago ADHC introduced its vacancy management system. Hailing it as transparent and equitable, ADHC was responding to the overwhelming demand for supported accommodation. Prior to this, when a vacancy occurred, NGO's had been able to select a client who was known to be compatible with existing clients from within the community of families known to it. ADHC's rationale was that since it was funding all the places, it should be able to select the most needy person in the state to fill the vacancy. It claims that a family with a connection to an NGO may gain a priority ahead of a more needy family without a connection to an NGO.

It is my belief that this policy needs to be re-examined. In the past years, I have witnessed a total breakdown of sense of community within families with a disabled member. These are the families who need each other so greatly. They, together with their friends and extended family, used to gather around a local provider, supporting it and raising funds, forming a close-knit community and hoping one day to receive a placement for their person within that

circle. The provider, in turn, came to know the families and the people with disability, often through work, day, respite or recreational programs that it ran. It became familiar with the circumstances of each family and the care needs and personality of their person.

All this vanished with the Vacancy Management System. Over-stressed families have little incentive to support an NGO who will not be able to accommodate their family member in the future. NGO's are forced to take people from far away whom they have never seen before and who may or may not be compatible with existing clients. Almost invariably, the person with a disability is placed in a distant location when a crisis occurs and immediate accommodation must be found. (Only last month, one of our Ryde families had its son placed in Campbelltown). Conversely, when the local NGO has a vacancy, it will almost certainly be filled with someone from out of area. Meanwhile, ADHC is spending a fortune transporting people around the city (and no doubt country) from out of area residences to original day or work programs. Perhaps an audit of exactly how much this is costing the agency would be in order?

Ask any family what is the most pressing issue regarding supported accommodation and they will tell you that it must be local. Our people are most at risk of abuse and they must have their families close at hand to protect their interests, extend their social lives, continue family relationships and just watch over them. However, since the Vacancy Management system has come into effect, this is almost never able to happen. In its attempt to be fair and to funnel all requests for support through one very narrow gate, ADHC has inadvertently created a monster that is breaking up families and destroying lives.

ADHC has admitted that this is so. In response to a question asked in the Budget Estimates last year, ADHC responded:

Given that supported accommodation is a highly interventionist service with significant potential to distance a person with disability from their family and community ties, the Department does not keep waiting lists.

However, it is not the supported accommodation per se but the Vacancy Management Policy which is doing the distancing. Of course, supported accommodation is highly interventionist but it is also highly necessary, given that we are all going to die, and most of us well before our disabled sons and daughters. This is why it is so essential that we can see our family members settled in their local community, preserving their family and community ties. Why is it so impossible to conceive of a system which will acknowledge and respect the long standing ties between local providers and families, while ADHC itself services those people without such ties?

Grass roots groups of families, such as our RASAIID organization, are springing up throughout the country. They are a response to both the lack of supported accommodation and to the Vacancy Management Policy. We all know that if we were ever to be fortunate enough to achieve a residential placement for our son or daughter, it would unfortunately be in a far-flung suburb. We are really re-inventing the wheel, because we are trying to replicate, albeit in a more modern context, the same model as earlier families established for

their disabled offspring. These have become the NGOs of today, but their locality-specific origins have been destroyed through ADHC's policy.

Thank you for considering my opinions.

Estelle Shields