

## Submission No. 1024

(Inq into better support for carers)

Doc 28/7/08

### TO THE HOUSE OF REPRESENTATIVES STANDING COMMITTEE RE. BETTER CARE FOR CARERS

To save precious time see below my letter to the ALP Candidate for Kooyong ( Vic.) in the last election – followed by some further notes cobbled together on the run!

Dear Dr. Harvey

I will be voting for you on Saturday. For the first time both major parties have some policies on autism - however only in children. Children with autism grow into adults with autism. I have a son with autism and a mild intellectual disability aged 39 who is "isolated out in the community" in a unit that is part of my mothers estate. I also have siblings doing it hard in the Goulburn Valley who would benefit from the sale of that unit ( to which they are entitled). My son pays very much below market value for the unit as he is on the Disability Support Pension. I subsidise him as the costs involved in day services and recreation "out in the community" are often beyond the capacity of people on the DSP. I also subsidise my daughter with schizophrenia. After 10 years experimentation we have found a drug on which she is stabilized - and as a result she, occupying a flat auspiced by the Richmond Fellowship, was given the opportunity to move into a OoH flat. She has moved and all is going well.

The ALP has agreed to support the \$1.8 billion offered by Howard for disability accommodation, support, and respite. It is to be over 5 years - so it is chicken-feed compared with the need. It is far short of any parity with aged care. We need bench- mark funding for the disabled as well as well as the aged. You cannot do anything for the disabled or mentally ill until you have stable accommodation. An analysis of the figures shows that at the rate of funding proposed by Howard means that a disabled person now aged 25 will have to wait another 15 years before a supported accommodation place becomes available. I call it the policy of "kill the mother"!

I am 62, am separated and working 4 days a week. I am exhausted and my health is breaking down ( I developed Meniere's disease in my 30's - probably from the stress of caring for my autistic son). I have now developed a heart condition. I have been serving on committees for autism for 20 years. Since the advent of disinstitutionaliszation the advocacy groups have rightly promoted the rights of the disabled - we parents ( especially mothers) have been left out of the equation. Economic rationalism dictates that the government keep costs down and develop surpluses at our expense; hence the shortage of everything - especially accommodation.

I hope the new Deputy Prime Minister has read Marilyn Waring's book "Counting for nothing ; what men value and what women are worth"(ISBN 0868615714 latest printing) because since deinstitutionalization we carers have been exploited as care in the home is still grossly undervalued - as is indicated by Howards determination to get women as cheap labour ( especially single-mothers) - a consequence of the lack of planning and labour shortages as a result of the myopia of his government.

When it gets into government I am expecting the ALP to stop developing surpluses and start investing in the well-being of those for whom the ALP was supposed to take into consideration - the workers! That includes carers - professional and non-professional ! A niece who worked in the disability area has decided to move sideways into something else. She was very good at her job. She has also decided not to have children - in case she has inherited some of the genes I have inherited!

I have been very disturbed by the move to "middle-class welfare" by the ALP before the pressing needs of the most vulnerable people in the community are taken care of. The private sector will

not provide accommodation for the disabled and the homeless - there is not enough money in it!  
The Commonwealth State Disability Agreement is a disgrace - a priority for the new government.

I hope the ALP has not completely lost its soul in the competition to buy votes. We should look to the Scandinavian countries not the US for economic modelling.  
We need real leadership that promotes other things besides consumerism - I live in hope!

Exhaustedly yours in anticipation

Post Election :

I am happy to report that, coincidentally, since the election, my son now receives 22 hours a week of autism specific support in the unit he occupies. It is provided as "outreach" by any autism specific service who also run his day program. This outreach program was axed about 10 years ago and has now been resurrected as support packages to individual clients can now finance the "new" outreach.

It is very important that adults with autism have workers trained in this complex disability – however I am "lucky" !! that my son has a mild intellectual disability otherwise he wouldn't be eligible for support. **Autism should be recognized nationally as a disability in its own right** – higher functioning people with Aspergers are just as much in need of assistance ( compared with us "neurotypicals " as they call us) as my son with an intellectual disability – it just manifests itself in a different way.

Opportunistically the service provider asked if one of my son's confreres with Asperger's Syndrome, 13 years younger, who is in the day program they both attend and does not have an ID, could occupy the second bedroom in the unit my son occupies, as he was the victim of abuse in his present unstable accommodation – and there was nothing in the system!!!! What could I say? They now live parallel lives under the same roof.

My son recently wrote a letter ( for me to post) to the Real Estate firm in the small country town where I have family and previously owned with my estranged husband 24 acres and a "shack" that my son and the rest of the family used during school holidays ( staying with grand-parents was too much of a strain all around).

My dream was to erect a cluster of about 10 units plus common areas, ( similar to “Woodbine” in Horsham) on that land - it is inside the town boundary and within walking distance of the main street - for adults with autism from the surrounding community. This location is within easy reach of a large regional town that has many community facilities including “supported employment”. It would have been set in a sensory garden setting, with space to roam, ride bikes in safety, with animals ( my son had a much loved Labrador as a child and has asked for a cat for his birthday) other farm animals as pets, a vegetable garden and chickens.

A Melbourne based professional who visited suggested I would be setting up a dreaded “institution” ( undefined). As I became the only person in the family earning a salary it was too difficult to establish such a project on a week- end basis and as my daughter had her supports in Melbourne and we had not yet discovered the “right” drug to stabilize her schizophrenia, I was forced to abandon the idea. I have since been asked by a “social entrepreneur” if I still had the land – he was interested in seeing how he could help! I can remember the feeling of hope for my son’s future drain out of me as the land was sold – never to return – so far!!

Since that time St.Martins Court in Beaumaris (Melb.) has been established to house young people with brain injuries. These young people had previously only found accommodation in inappropriate aged care facilities.

St Martins started its life as an aged care facility but was considered by the Uniting Church as not economic to upgrade to Federal Government standards. An active group of concerned parents approached Supported Housing Limited – a housing association ( now called Housing Choices Australia ) and Australian Home Care ( as the care provider - who also put some money into the project) to purchase and manage the property for their disabled adult children.

To me this model of housing ( a “community within the community”) is as close as I might get in suburbia to my dream of a peaceful, low stress retreat in the country for people at a certain level, with autism who might be able to establish some degree of long-term relationships that they need, but have great difficulty in establishing in the rat-race of suburbia. Like many people with autism with little social skills, my son still does not have a “particular friend”; creating such “communities” is one obvious way of establishing the living conditions under which it might be possible.

ASD is a wide spectrum and I am not suggesting that one model fits all! It is ironic, however, that all over Melbourne there are “gated communities” for the aged – and nobody questions that! Professor Cummins from Deakin University has suggested that the over emphasis on “independence” and “rights” has done little to create “real” integration into the community ( as against just being “physically there”); my son has never been “institutionalized” but I don’t regard him as “integrated” and various “incidents” have demonstrated how vulnerable people such as he is, to

exploitation. He is aware of his autism and effective isolation and has been known to say "I hate being autistic, I wish I had never been born".

I understand from a professional who has worked at high levels in aged care developments, that there are many aged care facilities now not regarded as up to federal standards – maybe more could be upgraded like St. Martin's, for the likes of my son and his confrere (where they could each have their OWN SPACE). The cost of housing is prohibitive and there is no sign that the new Federal government is going to do anything much to solve the whole problem of the back log of accommodation needed for people with autism and/ or intellectual disabilities (over 1300 in Victoria). We are still going to be subject to the economically rational regimen of "kill the mother" and "crisis mode" when a carer falls apart. I have heard from managers of CRU's how inappropriate placements are a fact of life under the present strategy of "crisis management".

If you happened to be affluent enough, you create your own accommodation for your disabled adult child. A few weeks ago I visited Ardyne House in Murrumbidgee – a parent established and controlled cluster of 6 units with common areas for the intellectually disabled. Unfortunately the number of parents able to do that are very limited! , but at the moment it seems the only way to establish housing.

Another key need of carers of adults with autism - especially for my generation of carers - the first to suffer the effects of deinstitutionalization without any real planning of the long term effects on families - is training in how to manage "Family violence" ( see article "Family violence" in the May issue of A4 -Autism, Aspergers, Advocacy Australia) . I had no training in how to manage the behaviours of my son ( it is usually a son as girls with autism represent ¼ of the population and present differently). I read a lot and did the best I could. I very much appreciate the need for early intervention for children for autism.

I was lucky in that my son benefited from being one of the recipients of 1.5 years (age 4 ½-6) of early intervention ( my GP thought he was just a "slow developer" – it was not till he got to kindergarten that he was diagnosed.) The intervention program was in an old church hall with 2 brilliant teachers and many volunteers. However it would have been better if, simultaneously I had intensive training - "in house support" on how to manage his behaviour. I am fortunate that I have my deceased mother's unit and he does not live with me and now has increased support – but I do not see this as a long-term solution ( he needs more space, more confreres "in community" and the unit belongs to my siblings.) My heart goes out to all those other mothers trying to manage 6'2' adult sons in their homes – and in most cases without training and very little respite! ( They effectively have no rights!)

Because of my deterioration in health my son comes to the parental home on an occasional week end ( it used to be every week-end – then every second week-end). However I still have difficulties controlling his behaviour . I know the strategies at a theoretical level, but I am very tired and it takes a lot to remain at the level of psychological alertness to plan strategies and see things developing. Because I didn't

implement enough when he was younger – it is a bit difficult for him to make changes at the age of 40 ( as he will be in a couple of weeks). However now with access to Medicare rebates for payment of an autism-trained psychologist, I can do some catch-up and deflect his attempts to physically coerce me into doing his bidding - such as grabbing me by the arm in a tight grip, hitting me on the shoulder from the back seat when I am driving ( I don't drive with him in the front seat – mirrors and sun visors are too vulnerable), throwing or breaking things to get attention. Sometimes the reaction is just, shall we say, a “startle reflex” when something happens quickly that he finds disturbing – a loud noise, a VCR not working, something has been lost that he highly values.

The other huge stress on carers of people with autism/disability is not being able to see an end in sight to their responsibilities. Mal Brough might like to picture us (for his own purposes) as having “chosen” to care; the fact is we have drawn the short straw and our society ( and most of the Anglophone societies as against the Scandinavian and some of the other European societies) put low taxes before the general well-being of the population. It is not beyond economists to have population based strategies for aged accommodation; we need similarly population based calculations of accommodation for the mentally ill and the intellectually disabled and/or autistic – so we (usually mothers) can see some time when it will come to an end. We also need to be able to be part of the input on the kind of accommodation/service so our disabled adult children can be eased into changed circumstances with the help of families – rather than dropped into something ( often with inappropriate companions) when a crisis arrives. **Anything else is tinkering around the edges – which all governments seem to do.**

Moreover people on the autism spectrum should be recognized as marching to a different drummer and their **social and physical environment planned with that in mind**. As Wendy Lawson “Life behind glass” commented when TV came online and she saw all the different identities appear on screen “ I clearly wanted to be more popular. I could play the clown or the beggar, act educated or dumb, always using someone's else's identity and not my own. The real “me” was kept to myself as it was not acceptable” (p.51) . **People with autism need structure, predictability and sameness in order to feel comfortable and have some feeling of control over an unpredictable world that they do not understand.** While some behaviours are clearly a cry for help and an attempt at communication – and often inappropriate and need behaviour modification (and there are too few skilled psychologists to do this) – others should be tolerated . They are just, to use the language of the “Aspies” themselves, not “neurotypicals”.

Carers need:

- timely accessible diagnostic services initially
- early intervention
- specialist educational provision - either within mainstream schools or in special schools. I am glad I did not have to “fight the system” for appropriate education as my son went to an excellent special school and

then received specialist services through an autism specific service – on whose committees I served for a considerable time.

- Access to specialist psychologists and psychiatrists and GP's who are autism trained
- Specialist autism day programs and vocational programs
- Specialist employment programs / social firms
- Timely and appropriate housing in a variety of models according to the degree of impairment - and including retirement planning. All in consultation with the family.

**I await the outcome of this enquiry – please don't let it be another useless enquiry “tinkering around the edges”!!!**