Background to our caring role

My daughter Lucette is severely autistic, mentally disabled and non verbal. She is now in a group home operated by the ACT government. However she lived in our family home until she was 16. She will turn 21 in August and left school last year. In Canberra she went to Black Mountain School. When she left school she like all mentally disabled young adults graduated into nothingness

Looking after Lucette is a full time job as she is mentally equivalent to a toddler and requires constant supervision. I now do not understand how I did the caring for her for so long and you do not understand the stress you and your family are under until you have some perspective away from the situation. As an example of how onerous the role is to care for her, it took me 5 solid years to toilet train her and even now I do not know how I did it. She did toilet train unlike others who never even achieve that milestone. However. she is unable to do a lot for herself and as a result made life difficult for us as a family as she grew older. This in turn made it hard for us to have a semblance of a normal family life. This really only happened when she was in respite.

We got her into a group home after much political lobbying on our part to the ACT government. This we could do as we are articulate, middle class and “know” how the system works and how to advocate. I doubt if anyone but other parents who care for a severely disabled child know the constancy of looking after such a person. Lucette has many good qualities but on reflection I think what drags a family down or rather the main carer usually the mother is the constancy of care such a person requires. Such constancy of care impinges on the martial relationship which in many cases comes asunder. Too often one partner clears out and leaves the other to struggle on alone, The usual excuse for the absconder and in most cases, it is the male, is that he cannot cope. In our case what was tough only made us stronger and we have always struggled through often not in the best frame of mind but we seemed to struggle along together. Having a severely disabled sibling also impinges on normal brothers and sisters and I think our caring situation did affect our other daughter.

I was lucky to have the help of my caring mother. If she has not helped me with my daughter, I would not have been able to work part time as very little childcare was provided then as now for disabled children, Childcare became a much bigger issue when she became a teenager as childcare cuts out for normal children at 12. It is only recently that the ACT government has funded afterschool and holiday care for severely mentally disabled adolescents and once again this sort of service is threatened by stupidity on the part of both the ACT and the Commonwealth governments.

We unlike so many other families no longer have the day to day care of Lucette. As mentioned before this was a case of knowing how to work the system to get her into a group home and how to get her an individual support package (ISP). To get an ISP for her took about 3 applications and constant advocacy on my part. Since this happened for Lucette the group home situation or other supported accommodation for mentally disabled people has become worse and the ACT government like the Commonwealth blithely assumes that families usually aging parents and in many cases the mother will gladly do it until they drop dead. Literally dropping the entire care burden onto families is unconscionable and callous especially when the disabled adolescent leaves school. Then to assume that such families will undertake to provide the entire raft of social services for this person by governments in the euphemism of family caring is simply economic based and a denial of natural justice. I will return to this issue later.

I have also said that my daughter graduated into nothingness. Since she has left school after much campaigning she now attends a local day program for tow afternoons w a week. We as a family are paying half the current costs for this program which will be over $5000 a year. This is currently manageable for us as we are both working but once my husband retires, I fully intend that the entire burden will be assumed by the local authority as on one income it will not be possible. Lucette really needs at least 3 full days at this day program to give her structure and consistency which she needs to thrive as she has no real life of the mind. She does not read or watch TV so is unable to entertain herself constructively and without routine tends to lose skills, go backwards and have behavioural challenges. You should remember that her day program “Sharing places” is another service created by parents for their school leavers and not provided by the local government where on the burden should rest.

You should notice I am still able to work unlike many other carers usually women who are assumed to be willingly and able to give up work and look after their disabled teenager and then adult because no care is available. We will face this issue ourselves later on as we have another child on the autism spectrum. However like the old adage, I do not intend to give up work or go into the night silently.

Generic issues that affect mentally disabled adolescents and school leavers

The Commonwealth government does very little for disabled adults other than provides the disability support pension and funds a number of disability services

However after much consideration on our own experiences with our daughter we can extrapolate on what the major issues that affect mentally disabled teenagers and young adults are.

When at school

Inadequate after school care and holiday care programs for adolescents who need supervisor so parents can continue to work

In Canberra there are two afterschool care services for such adolescents and both have been reduced in services. The Noah’s Ark service on the Southside does not provide holiday care. Basically families are expected to provide the full gamut of care for their teenagers and give up work. To add insult to injury there are also long waiting lists for these inadequate services.

After school

As I have said before our daughter graduated into nothing and this seem to be the fate of too many disabled young adults who leave school. Basically for too many the whole load is dumped onto the parents and in most cases this tends to be the mother. Too many parents accept the bland story from Disability ACT that we do not provide group homes for your children it is up to you. The Post School Options Expo hosted by the local government each year is a very cruel hoax which promises a lot but delivers nothing for most families. What is available to each individual depends on the level of functioning of that person. To make matters worse in Canberra the local government has in its wisdom lowered the school leaving age for the pupils at the local special high school from 18 to 20 without providing adequate services in its place.

Lack of meaningful activities for the lower functioning young adults

- Day programs are expensive and often the cost is foisted onto parents
- Why not let them stay on at school and learn life skills, reading etc for those who are capable of it as it gives them somewhere to go and something to do
- State governments should make provision for this continued education for mentally disabled adults as they tend to learn more slowly and need more time to consolidate than their normal peers.
- Day programs should be funded by the local state government rather than expecting parents to cover the cost and should operate around a full day especially if parents are caring and working

In Canberra, day programs could be provided in the many empty primary schools and carried out by the local Department of Education and Training as part of its brief. This is because young disabled adults based on their cognitive development would benefit from school until 30. Able young adults graduate from school and can then go on to attend university and CIT but nothing similar is provided for young disabled adults, extended schooling would meet some of this need. In the United States some of the universities and community colleges fill this gap for young disabled teenagers with programs pitched at their life skills and literacy needs.

Lack of supported accommodation options

Most after school care is left to the family i.e. the parents to provide full care for disabled adult children

Need to have accommodations options available to parents especially elderly caregivers or those who are fed up with the role

- group homes based on the current ACT model
- community villages such as the ACT Community Living Project for those that need supervised care
- hostels for the more able such as young adults with Aspergers Syndrome as many of them have good intellectual skills but suffer from severe social deficits and mental illness sometimes
- where they can learn life skills and have someone to help them with reality checks such as not being gullible and managing their money.

Parents who want to continue to provide the care

- Need much more respite available to them
- Home modifications if required
- Many should automatically get the carer’s pension especially if one of them has forgone paid employment to mind their disabled adult because basically the government is foisting the care onto them and saving public money.

Work for the more able

- Social enterprises are dropped again on parents to develop and then run to occupy their adult children
- The parent becomes the case manger and employment coach as well as caregiver
- Not enough or adequate post school options funding
- The public service at all levels should provide work opportunities for those with mental disabilities and those with social deficits.
- Job coaching services, and specialized employment services should be funded to help the more able train, find and hold work
    - Sheltered workshops should be encouraged to employ the less able in purposeful social activity and to earn some money. It needs to be remembered that work for the intellectually disabled like normal people provides structure and consistency and for many this is probably more important than money.

Other issues

- Life planning needs to be provided for all disabled young adults especially those who are leaving school.
- Guardianship procedures should be much simpler and less bureaucratic; many of the hearings should be carried out at school before the young adult turns 18.
- Young adults need continuing therapy services to be available to the as many continue to develop skills into adulthood and need help with physical disabilities and speech.

Conclusion

Everyone deserves a good life and this should be the same in the case of the mentally disabled as for the rest of community as Australian citizens. All of this requires partnerships between all levels of government with the Commonwealth government supplying the bulk of funding and monitoring programs. The State governments on the whole have a very poor track record in this respect. The Department of Health and Aging should become Health and Care to administer these programs and policies. The Commonwealth needs to recognize its responsibilities in the respect and create a Minister for disability

To provide the funding for such a long-term support and disability scheme to help disabled adults, the only way forward is to have a levy on all Australians similar to the current Medicare levy.