

4th July, 2008.

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
PO Box 6021
Parliament House
Canberra ACT 2600

AOC 17/7/08

Submission No. 873
(Inq into better support for carers)

Dear Secretary

Our informal support group of carers wishes to make a submission to the House of Representatives Standing Committee on Family, Housing and Youth's Inquiry into Better Support for Carers.

Our group brings together a number of mothers from a diverse socio-economic background, aged between 33-60, who are united in their role as carers of their children aged 11-23, who have an intellectual disability and whose needs are many and varied and in some cases made more complex by physical and medical issues such as epilepsy, poor muscle tone, depression and diabetes. We value the opportunity we have to meet regularly over coffee to network and share with each other our knowledge and experiences as carers.

Our Caring Role

- **We attend to the personal care needs of our children.**
This care is needed long past the usual age when "mainstream" children start to care for themselves and it is ongoing. Personal care duties include the supervision of and/or physically doing the showering and shampooing the hair of a 21 year old; cutting up a piece of chicken for an 18 year old; cleaning the teeth of a 14 year old; ensuring pads are changed during menstruation; brushing hair and making sure appropriate, clean clothing is being worn.
- **We are our children's teachers.**
One of our main objectives as the carers of children with intellectual disabilities is to teach and train our children to be as independent as possible within the limits of their capabilities. This takes an enormous amount of time, energy and patience (so much more than when doing the same thing for "mainstream" siblings). We teach our children to read and to talk; to shop; to cook and to clean; to wash their clothes; to observe their environment; to catch public transport and to use community services. For our children, learning these skills takes a life-time and even then most will still need significant care and supervision for the rest of their lives. We recognise that the more our children are able to achieve for themselves, the greater the benefit to their self-esteem and confidence and to the community as whole, especially when we are no longer able to fulfil the caring role.
- **We must help our children "fit-in".**

Teaching our children how to modify their behaviour can be a thankless and exhausting trial. Constant reminders, well into adulthood are required for basic manners, holding a conversation, keeping safe, refraining from inappropriate behaviours and remarks. Teaching them to make appropriate decisions and choices is challenging and demanding.

- **We are the source of our children's entertainment and recreation.**
Our children do not have the skills to form and maintain friendships and organise their own recreational pursuits. We are responsible for either organising and managing their recreational activities and ensuring they can attend or accompanying them to these activities. This is a significant and ongoing role as our children reach their teenage years and then adulthood, unlike their siblings who become independent. Without support to participate in recreational activities, our children have little initiative, beyond the TV/Computer, to sustain entertaining themselves in their free time. We need to keep them stimulated, healthy and productively occupied.
- **We are the "Go-Betweens" – the Negotiators.**
The extra demands of managing a family where there is a child with an intellectual disability was recognised by the group as an important role. It is important to allow time for everyone else in the family and be watchful that their needs are not impinged upon by the needs of the person with the disability.
We must learn to negotiate with a vast range of professionals – teachers, medical personnel, Centrelink, service providers, employers and employment networks – all of which is demanding of our time and energy. We need to develop skills to enable these negotiations to be as beneficial as possible for the person in our care and be acknowledged as having our own expertise and knowledge about that person.
- **We are Advocates.**
Our children are often unable to verbalize their needs clearly or express their concerns. We work to advocate for services from local councils and service providers, to enable our children to participate in inclusive or "special" recreation and to obtain work experience – often a humiliating experience for us. We are members of disability organizations e.g. VALID, ACD, WRDN and attend many meetings and read mountains of literature all the better to serve the needs of our children.
- **We must be available.**
We need to be at home when our children are getting ready to go to school, training, day centres or work, and to ensure they leave on time. We need to be home when they return for their security and supervision. If they cannot travel independently we need to accompany them to and fro. We need to be available to drive them to medical and therapy appointments.
- **We are our children's sounding boards.**
As our children (young, teenage, adult) have an intellectual disability, they often exhibit uncooperative and repetitive behaviours and patterns of speech and can be "in your face". We have to be there to listen, to calm, to help with their understanding. This is a constant and demands extraordinary patience. Often we feel trapped, but no matter how draining and frustrating, we love our children and are willing to look out for them 24/7.

Barriers to Employment

Our group agrees that the juggling act of work and caring is extremely difficult. Consequently some of us have decided not to work, while others work only part-time. This has meant a significant drop in income and not following the career paths we might have.

There are a number of issues that impact on making work a feasible option:

- The availability of before and after school care at Special Schools.
- The availability of reliable, competent support workers at a reasonable price.
- The fact that our local council's HACC program does not allow people to use respite time as a means to work.
- The need to re-train
- The need for work with flexible work hours.
- The need to work in a low stress environment, considering the "second job" at home.
- The extent of extended family support available.
- Having an empathetic and flexible employer (in order to be able to arrive late; leave at a moment's notice, to be able to make medical appointments to suit the child and the service).
- The medical and therapy needs of our children, who require frequent appointments with specialists, one on one exercise sessions and in some cases, 24 hour supervision for their own safety.
- The nature of our partners' jobs.
- The need for time to engage in networking and de-stressing at social support groups and other advocacy groups.
- The need for *time* to teach our children independent living skills as well as managing the multitude of tasks our caring role encompasses.

Practical Assistance

As carers of children and young adults with intellectual disabilities we need help with:

- **Respite** – most of the time we just "get on with it", but we all experience moments of despondency and frustration and need respite. Families too need this respite time to collect themselves and it helps family members stay together and support each other. We need to engage in social activities with our partners and other children, while knowing our child with the intellectual disability is being well cared for and enjoying themselves too.
- **Recreation** – one practical way of helping here is by extending the Companion Card concept (as in Victoria) to a nation wide program. This would help financially with family holidays and help us with our role as entertainer and recreation provider. The Companion Card enables us to take our children out without extra financial burden and for our children to be more stimulated as a result. This is a win-win situation as we take our children to venues we otherwise wouldn't because of the duplicate cost.
- **Outreach** – as our children get older, we need more "outreach" support to further develop their independent living skills. We know there is a limit to what we as parent/carers can do and our children will often be more responsive to non-family who have different approaches and ideas. This would help by freeing up our time to engage in other aspects of the social and economic life in the community.

- **Medical Costs** – the medical and therapy costs of caring for a child with an intellectual disability, who also has ongoing medical issues, are substantial for some carers. For example, swimming programs or sport programs to increase body awareness and improve muscle tone need one on one teaching and so are more costly. Other costs involve specialists such as paediatricians, neurologists, occupational therapists, physiotherapists and speech therapists. Compounded with the restrictions to being able to work regular hours or work at all because of the caring role, these extra costs have a huge financial impact for many carers. There are probably a number of ways of providing equitable financial assistance, but perhaps a medical supplement to carers where needed would help alleviate financial stress.
- **Centrelink** – the application processes relating to a person with an intellectual disability could be made more straightforward and it should be recognised that the carer's role involves more than 'mere' personal care. Centrelink could be more upfront regarding financial support available.
The Social Security Act regarding psychological tests which measure intellectual capacity should be updated and made consistent with modern day practice. This would perhaps reduce the time of doctors, clients and their carers in completing forms for support and job capacity assessments.
The tax rules relating to how much the carer's pension is reduced on the basis of income earned should be reviewed. Once a person earns above the tax free threshold (including the low income rebate) they are penalised twice – tax and a pension reduction per dollar. This is a disincentive to work, considering the extra costs of working (child care, transport, clothing) as well as the costs (time, stress and money) of caring well.

Other Strategies

We think the Government could further help Carers by:

- establishing **employment agencies** that can better serve and support the particular work needs of carers. Perhaps the current DEN's role could be broadened to do this as long as there was no conflict of interest.
- better supporting **disability support workers** with training, pay incentives and career paths and recognising their worth in the community. This would help us because at present there is a shortage of support workers. Our children are happier when there is a reliable pro-active person consistently in their lives. And so we are happier and can do our job better too.
- working with State Governments to open up the **Departments of Human Services** to cut back on bureaucracy and make their role and the services they provide in disability more transparent. This would help us to understand how DHS can help, what pathways exist, what financial and other support is available and how and when to access this.
- recognising that people with intellectual disabilities need a broad range of **recreational opportunities**. We are aware that much is being done in this area, but there are

waiting lists and the cost of recreation can be prohibitive. Recreation options need to be maintained for adults who still require support. Sitting at home watching TV is not what we, the carers, or our children want and neither do they want to be always out with their parents. They enjoy the company of their peers, all-be-it in a supervised environment. Though respite (see next item) is crucial, and needs to have a recreational focus, funding to service providers and local councils for recreational pursuits should also be a priority. Local Councils and service providers should be able to be more flexible and less bureaucratic with regard to how "respite" money is spent. In our experience, successful "mainstream-like" group activities such as discos, youth clubs, dining out/social groups are much needed. This would help us as our children would be happier, healthier and stimulated which must improve their home life. And of course, funding for recreational purposes has the add on benefit of providing respite!

- recognising that though we all need time to "recharge our batteries" and engage in social and recreational pursuits for our personal well-being, the **respite** needs of carers vary widely according to individual and local circumstances. A diverse range of reliable, appropriate, locally based respite options needs to be available. This may be daytime only or overnight, and range from short to long term. Our children are happier when respite is part of their routine in a familiar environment and with familiar faces. It would be of mutual benefit if government could work in partnership with and support local communities and groups to establish respite facilities and programs to suit their needs.
- "centralising" or putting under one umbrella the vast range of resources and assistance available to carers. A "**one stop shop**" where initially a resource 'officer' who knows the ropes comes to the carer when a disability has been determined. This would help us, as often carers are not sure where to go for help or what is available. This resource person could explain the differing roles of DHS, Centrelink, Local Council, service providers, advocacy/support organizations etc and help sift through what is appropriate, guiding carers to relevant services over time as their needs and the needs of the person they are caring for change.
- facilitating longer term, home-based support for the children of older carers so they can go away for extended times if needed. As we get closer to **retirement**, we dream of being able to go away for extended holidays. We recognise that this will be difficult and more expensive for us as we have to consider the life of and care of our adult child with an intellectual disability. Inevitably we will take our adult child with us on many occasions, but having to do this can build resentment and despondency, especially as we see our peers doing what we would like to do. How many retirees do you see on holidays with older adult children? Also, as our adult children get established in their own lives (be it volunteer work, supported or other employment or a day or training program), it is problematic to disturb their structured lifestyles for any lengthy period of time.
- addressing the issue of the **future accommodation, support and occupation/employment** needs of our children especially for when we are no longer able to provide and care for them. Although these needs are not within the terms of reference of this review, the future care of our children is probably our main worry and

dealing with these issues will help us, improving our health and well-being by lessening our anxieties and giving us peace of mind.

Thank you for taking our views into consideration as part of the Committee's Inquiry. We look forward to reviewing any recommendations you make to improve life for Carers in Australia.

Yours sincerely,

Ruth
Contact person for this group submission

Contact Telephone Number:

Members of the group were: Marie Patricia Helen Angela
Maria Joanne Janine and Ruth