

RSC 17/7/08

Caroline and Edwin

Submission No. 895
(Inq into better support for carers)

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600
AUSTRALIA

Dear Parliamentary Secretary,

I am writing to inform you of our views with regard to your Terms of Reference and to convey some of our horror story experiences as carers.

What we believe our contribution and role as carers in society is

We are the parents of a 7 year old child with autism and severe intellectual disability. We were told prior to his birth that his chromosome screen, chorionic villus sampling, and other pre-natal screens all indicated a healthy male foetus. Unfortunately, for us all, he was born a child with a disability in a society that is rife with atrocities committed toward people with disability everyday. Especially against those who are also unable to ever, ever, advocate on their own behalf.

As carers and young carers, my husband, our non-disabled children and I save the Australian tax payer hundreds of thousands of dollars over a lifetime by taking on the day to day role that State paid carers would otherwise have. We also finance disability specific services, medical appliances, communication equipment, continence and transport needs that we can afford to give him. Not a week goes by when we have not made sacrifices in terms of our own health, job and promotion opportunities, financial security, social, spiritual and emotional well-being, recreational activity, marital relationship and education. **That is our contribution to society.**

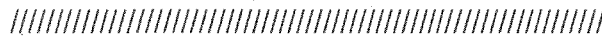
We could of course simply dump our son at the local police station and have a vacation, look after our health, sleep through the night etc and pretend he doesn't exist. **However, we see our role as the providers of a safe, happy and caring environment for our son because we love him and because he cannot advocate to secure these basic human rights for himself.** We would like to think however, that our role could be shared between people who, if they don't necessarily love our son like we do, will at least be kind to him, include him in all aspects of Australian community, and protect him from abuse, neglect and discrimination. We would like to share this role because we would then have time, money and energy to look after our own health better, contribute to the taxation system, recharge our batteries, pursue recreational and work related opportunities, volunteer our time etc. Sad to say, we are horrified to find that such people and service providers are virtually non-existent.

How we would like our caring role to be recognised by society.

We definitely don't want a medal or a party or even a formal thank you. What we want is acknowledgement and understanding of the daily difficulties of being a carer and of being a person with a disability in a largely discriminatory non-disabled society.

We would like our role as carers in society to be acknowledged in the following way.

We would like to see each and every Australian that is physically and emotionally able to, allocated a disabled buddy from their neighbourhood that they would take out in the community once a month for as long as they lived in that community. Sometimes it could be for a trip to the beach, an appointment to the hair dressers, a shopping trip, a visit to the library, a snack in the park etc. This would provide an opportunity for the disabled person to be demystified, for the non-disabled person to develop a positive long-term relationship with a disabled member of their community, for the non-disabled person to learn to appreciate what it is like to be a carer and what challenges a person with a disability faces in order to achieve even the basic of human rights. It would also provide regular respite for usual carers and help to provide opportunities for the development of "Circle of Friends". That is, a non-disabled or disabled person who values and chooses to play an active role in the disabled person's life. Like any all friends, their roles will be defined by their relationship dynamic, interests, time commitments etc. It might mean being their advocate, regularly having lunch with them or checking that their paid carers and others are treating them well.



OUR (HORROR) STORY

Barriers to social participation

We noticed something was "wrong" with our son when he was 9 months old. At first we felt he might be deaf and we sort a referral to a private paediatrician who referred our son to hearing specialists. When we learnt that our son's hearing was normal but our son still remained odd or did not reach usual developmental milestones, we took him back to our GP. We believe we have a very good GP but we could not get her to address our concerns and so for almost a year and a half we were continually asked by her and by our local community well-baby clinic nurse to wait and see.

During this time I joined a mothers' group only to give up one day in frustration and exhaustion because my son's weird behaviour prevented me from enjoying the company of the other mums and their children.

In fact while my son's peers were playing with toys in the sandpit at the park, I was chasing my son back and forth, to and from the car park where he found the dirt there and his reflection in the cars; paintwork more fascinating. At this time I think I also began to feel hurt and detached from my son as he never allowed me to comfort him like my other children had done.

My next experience of the social isolation of disability was at Playgroup. It happened that as my son grew, he became more difficult. Not having had boys before, I put this down to his being a boy and to temperament. For example, he would scream blue murder if I put his hands in play dough or finger paint in the attempt to shape his play with them and he and I would run between the 6 or so power points in the hall. He would turn them on and I would turn them off as he ran to the next one to turn it on. Eventually, whenever the other kids sang

nursery rhymes, my son would bash his head so violently on the door to escape that the sound drowned out the singing. **We were asked to leave and he was again isolated from normal peers and role models and I was isolated from a potential support network.**

A third and perhaps more severe example of social isolation of my child and I occurred as a result of not having our concerns about our son being listened to. This led to a crisis point which eventually forced the Local Community Health Centre to listen to us and that in turn resulted in getting a diagnosis.

Specifically, around about 2 years old, my son rapidly lost all of the language he had started to develop and he began to beat me up so seriously that a day didn't go past when I didn't have a split lip, a bite out of my hand or arm or an egg on my head from where he had head butted me when dressing or feeding him. I tried to get an appointment with a private specialist paediatrician but after having waited almost two months, I called to see if any cancellations were available and was told that if my son's behaviour was as bad as I described, I should take him to emergency and that she didn't really have an interest in children under school age. Needless to say I cancelled my appointment because she showed such disinterest in my child or our concerns. At emergency we were told that our GP or baby clinic nurse should give us a referral to the Child Development Unit. I went back to our GP and got this referral and was told that it could be months before we saw anyone at the CDU but I registered him in the wait list anyway. I then went back again to the baby health clinic nurse to secure the opinion of a developmental paediatrician (DP) at our local community health centre. Months went by without an appointment being confirmed so I sent my husband to the baby health clinic and told him not to come home without an appointment with a DP. The clinic nurse told him we would have an appointment within the week to address our concerns but the week went by without a call from her. Eventually we were told that we would not be able to see an DP for 6 months or more. We tried to soldier on but when I got to the point of having to lock myself away in my bedroom in order to protect myself from my child's abuse, I had my husband call the local Community Health Centre to tell them that as he spoke, I was packing my son's bags and about to come down with my son to give him to them and to have them fend off his attacks and have their clothes and couch covered in blood for a change instead of mine. This is when we were offered an appointment with a DP the following week. **Having to lock myself in our bedroom certainly isolated me socially from my community but also from my other children and my husband. Also, my son became a prisoner of his behaviour as we could not take him out unless we were willing to watch him hurt himself or for us to be attacked too.**

(After a 20 minute exam, the PD announced that my son had a life long disability called autism and global developmental delay. He also gave me a letter for a mobility parking permit and told me to come back in a month. One month later, when I saw him again, he was surprised when I burst in to tears during the appointment. He asked me how long I had been crying about my son's diagnosis and I told him ever since I went home from the first appointment and looked up autism in a book and realised that it really was a life long disability. In denial, I later sort a second opinion from the CDU and they made the identical diagnosis without knowing the first doctor's diagnosis. The DP at the CDU commented that she could have diagnosed our son had seen him at 6 months of age. I felt so much valuable early intervention time had been wasted.

The only good thing about our son's diagnosis was that once we did get it, I knew that my son had not been pushing me away at playgroup because he disliked me or because I was a failure as a mother but because he had a disability. This also explained the head banging when children sang. Later, I asked another play group if we could join and I warned them

about my son's potentially disruptive behaviour. The members discussed this and welcomed us with open arms. Finally, I did not feel segregated from my play group community but supported by it. Inclusion in playgroup worked well until my son started to lose his ability to speak and he started to hurt him self many times a day.)

Finding and Funding Good Quality Early Intervention (or how we lost our retirement nest egg)

During our appointment at the CDU we were told that our son would benefit from at least 15 hours of Applied Behavioural Analysis early intervention therapy a week but not to worry if we couldn't afford to do this as other cheaper therapies were available, comprising an hour a week. We left feeling tremendous guilt at not being able to fund the therapy that we were told had empirical evidence behind it but cost between \$45,000 and \$75,000 per year. We searched for months to find cheaper scientifically sound treatments but found none.

Soon we found ourselves going through a series of wholly inadequate weekly one hour sessions of early intervention. Including: Rosehill Early Intervention, APEX, Lifestart and the then the Autism Association's Building Blocks program. Although every therapist was very nice, we judged the service to be inadequate and/or ineffective because every year our son was re-assessed by the CDU, he was shown to have regressed significantly. Eventually, DADHC gave him the label "profoundly disabled".

Both Rosehill and Building Blocks kept telling us how well he was doing. I found their comments laughable and believed that their reports main purpose was to secure more funding for their positions rather than to help my son reach his potential. Life start however acknowledged that he was not even staying still but regressing. Consequently, we were one of the few families to be offered an extra hour a week of therapy to try to help our son make some progress. In hind sight, the lack of progress, coupled with the continuing self-mutilation, made my husband and I very depressed. Our other children were also distressed by our son's apparent misery. We took up Lifestart's offer and continued with them for yet another term but he had so many changes in staff and he was so hard to get into and out of the car that the appointments did not seem worth the beating I was getting and the trauma he put himself through in taking him there. Once again we became more isolated caring for him.

Near this time we accidentally discovered from a work colleague of my husband's that we could take out our superannuation to pay for therapy so long as a PD approved the treatment and was under the guidance of a DP. Hence for a year, we had one to one therapy, 6 hours a day, 5 days a week for our son. This was great for us as when we were not involved in his therapy, we were able to have some respite from caring for him and we were able to hire the people we wanted to work with him so we were confident of their ability and that they were meeting our son's particular needs rather than a "one early intervention program fits all" eclectic approach offered by ASPECT the other services we had used in the past. ABA therapy was the only therapy that made a difference to our son's quality of life and our family's wellbeing and it was the only therapy with empirical evidence supporting it's efficacy.

Needless to say after finally having our son making gains instead of regressing, we were devastated to have to stop therapy because we had run our super dry. Again we grieved. **We now also have very little money to support us when we retire.**

The Assault on our Physical and Mental health

After ABA therapy stopped, we tried to keep up the program with the help of our other children but **we found we couldn't run a household, keep our one and a half jobs going, give our other kids time to be children, look after our marriage, replenish ourselves from the job of being a carer and provide therapy 30 hours a week too.** Hence our son regressed again.

At this point we were also unable to get long-day care at either of the centres our other children had been at. In fact one of them told us that "they didn't do autism" and not to bother applying. I was taken around all the pre-schools and long day care centres in our area by our useless DADHC caseworker, (who often gave me jobs to do and told me her problems), and even some outside our area but we were either told that there would never be a place for our son as they only had enough places for a few kids with disability and so were filled until those children left to go to school or, that there was no funding for an extra support career until the next round of funding. Our name never seemed to come up for funding and eventually I got tired of calling them only to be told we were still on the wait list. One day in tears I rang a friend of mine who happens to be a police woman and she found my son a place in occasional care a few days a week. He stayed there until, due to a careless mistake on the part of a staff member, his arm was broken in an avoidable accident and he had a pin inserted into it.

After this I went back to looking after him at home again and giving up on having a life at all. **Needless to say this put a great deal of stress on our marriage and on our other children because we all became more tired and because as our son became totally non-verbal, he began to self-mutilate.** He would: bite his hands until they bled and he had a flap of skin hanging off, punch his head so hard with his fits that his skull became permanently deformed and punch himself in the face until his nose, chin and cheek bled and wept. Our son also went through 5 windows and a glass door. I met a woman in a K-mart store that told me I could get the Children's hospital to make him a pair of custom made gloves. This took ages and now they have become inadequate. (Better appliances can be made but so far this year we have already waited 6 months for the hospital to get us an appointment to do this.) Again, help came not from DADHC or a service provider but we accidentally stumbled onto it.

Eventually, through another chance meeting, we found a place at pre-school many suburbs away and we enrolled him 3 days a week. **We were eventually called buy the preschool so many times to come and take him to the children's hospital because they couldn't stop his bleeding when he repeatedly punched himself in the face that we ended up withdrawing him as we were only getting a few hours of respite anyway.**

Again I tried to survive with our son at home while he was so unhappy. I sort behaviour intervention from ASPECT but we waited 3 months before they told us that we were ineligible by one suburb. **During this time, I became quite stoic about my injuries but when he started to hurt his sisters, to scare them and us by the amount of injury he was causing to himself, I lost all hope and begged DADHC to call DOCS to come and take him away.**

It was only then that we got some regular respite but we still did not get any help with his behaviour for over a year. DOCS provided us with in-home care so I could get a break but 3

carers walked out on us due to our son's violent and self-injurious behaviour. They bought us a helmet and a \$700 pram that took kids up to 63kg. **Needless to say just looking after me was not enough.**

Eventually, a counsellor I had set up for my other children to see happen to tell me about DADHC's Statewide Behaviour Intervention team and they came and asked us what help we would like. **After a total of 19 months of waiting, we finally got behaviour intervention from DADHC but not before our marriage and the well-being of our other children and ourselves had suffered greatly.** Unfortunately, during the waiting period our son was referred to psychiatric medicine at the children's hospital and turned away twice before we got to see them. **Also, the delay in help caused my son to learn and to have us reinforce a great deal of self-injurious behaviour.**

Barriers to Economic participation: Segregation and Discrimination

Until recently, we have cared for our son 24 hours a day, seven days a week for seven years. We did receive a respite package from Sunnyfield last year but almost every respite hour was taken up with medical appointments and meetings with prospective schools because we could not find a mainstream school that would take him or a support unit that did not offer the same opportunities for a safe school environment as mainstream classrooms. Hence, we have battles for almost 2 years with the Education department to find him a school that gave him at least close to the same amount of protection from abuse and neglect as his sisters and other non-disabled peers. **During this time, not only have I been prevented from returning to work for fear that my non-verbal, intellectually disabled and self-injurious son will be vulnerable to abuse and neglect in lock down unit away form public scrutiny but I have been made ill by the amount of work involved in the lobby process.** In the United States where teacher sexual abuse is reported to the general by the Federal Education body, 15.2 percent of all childhood sexual abuse is perpetrated by members of the teaching profession. Moreover just since November last year, three teachers have been convicted of assaulting children, with another one has committing suicide after having been accused of being involved in a pedophile ring and another one attempting suicide for the same reason. Because my son self-injures, I have no way of telling whether when he comes home with an injury if he has injured himself or a teacher or aid has hurt him because he cannot advocate on his own behalf and because he is in a lock down unity away from public scrutiny.

Now that our son is at a more inclusive, relatively safer school than his old, highly segregated school, we are doubling our efforts to redress the dangerous environment the NSW Education Department allows.

At most schools, children in mainstream classes benefit from the presence of volunteers such as parents, retirees and other community members within the classroom and in other areas of the school. The volunteers not only contribute directly to the children's education but also provide transparency which contributes to a sound multi-pronged regime for the prevention of abuse and neglect. Sadly, many children in support units within mainstream schools never see volunteers within their classrooms. This robust protection from abuse and neglect is denied to children who are perhaps non-verbal, physically or intellectually unable to advocate on their own behalf, protect themselves or report any incidences of abuse or neglect to people whom they trust.

Environments where vulnerable children are isolated from public scrutiny, and where many are toileted and bathed alone with an adult provide a haven for unscrupulous people to seek

employment and once employed, perpetrate abuse and neglect. National and international research, Sullivan, P and Knutson, J (2000), shows that isolation significantly increases the risk of abuse and neglect and that the risk increases proportionally with the degree of disability. Therefore, denying children with disability access to volunteers disadvantages them compared to their mainstream peers.

Children with developmental disability, (such as autism for example), often self-harm. If suitably trained and screened volunteers from the community are never allowed into classrooms, parents and other community members interested in the safety and well being of these children have no way of knowing whether injuries have been inflicted by a teacher or aide.

No empirical evidence suggests that children with disability benefit from social isolation, in fact, the benefits of social inclusion, regardless of ability are well founded in the literature. Briggs, F (1995). The practice of isolation appears to be arbitrary in Support Units as some Support Units in mainstream schools and in many Schools for Specific Purposes do have parent and other community volunteers within their classrooms.

Why in an era of "social inclusion", do we allow some children in Support Units access to the public scrutiny and other benefits provided by volunteers in the classroom whilst other students, largely non-disabled students are denied such benefits?

The DET must consult with independent Government Organizations and Non Government Organisation's whose primary concern is the welfare of children and particularly, those with disabilities. Many of these organisations believe the current situation inadequately protects children with disability. They argue that policy which strengthens the prevention of abuse and neglect should be applied to all children across all schools. These include the Australian Childhood Association, the National Research Centre for the Prevention of Child Abuse and the National Council on Intellectual Disability. Policy which addresses this inequity must be implemented so that unlike their non-disabled peers, children with disability are not isolated from suitably trained and screened community volunteers within the classroom. Precedence for outside consultation and Department wide policy formulation by the DET, already occurs, for example, with anti-cancer groups regarding sun safe policy. Individual principals and teachers do not determine whether children with disability or children without disability should be taught sun protection strategies and participate in sun safe programs. All children are provided this protection equally across all schools.

I have two masters degrees in medical science and unlike with my older children, *I been prevented from returning to the work force because a school not even as safe the school that my other less vulnerable children attended was not provided by the NSW Education Department.*

Only if he is a valued and visible member of his community will he have a good quality life. After all, isolation from transparency and public scrutiny allows opportunities for abuse and neglect and statistically, paid carers abuse and neglect people with disability more than fathers, uncles, brothers, mothers, friends of the family and extended family. *Similarly, once my son leaves school, I am not going to remain at work if my son is forced to endure unsafe and inflexible accommodation.*

Practical measures we require to better support us

We have seen abuse by paid carers first hand and have heard the horrific experiences of intellectually disabled children in institutional care, (such as Robert Strike). Therefore, to be a just and economically savvy society, we must continue to fight for our disabled children's right to be included in and valued by society. ***This can only be achieved if he is allowed to experience the same lifestyle afforded non-disabled people. Allow the people who have the greatest stake in a disabled person's life to have a say in how and where and with whom they chose to live.***

It is not enough to meet the unmet need in supported accommodation; parents need to know before they die that their child will be at the very least safe and happy and this is not possible with institutional models and where people with disability must conform to a lifestyle most convenient to paid employees to full fill their roles as personal attendants etc.

For example, ***allow people with disability to choose to do the things in their day they want to do by giving families and guardians opportunities, perhaps through volunteers working with our disabled children at school and in other areas of the community, to build "circles of friends". This would also cut government costs for paid carers and make the lives of disabled people safer and more inclusive.*** The development of "circles of friends" might be achieved by providing a National screening and training program for volunteers so that they can to work with children and adults with disability in all walks of life. Also, volunteers should in most cases be supported to meet the individual requirements of their disabled friends and their families.

Give us opportunities to eat out and go to the movies and do normal everyday things with our entire family. ***In other words help us educate the general community and carers about the rights of people with disability to fully participate in the community. Support and recommend legislation and policy that supports this.***

Key priorities for action

- 1) Stop the discrimination of children with disability in NSW Education Department schools by allowing volunteer participation in the classrooms of Support Units and Schools for Specific Purpose as it is allowed in the classrooms of kids without disability.
- 2) Educate the general public, families and guardians of people with disability about the increased risk of abuse and neglect and the UN charters of rights of people with disability so that tolerance and acceptance of peoples' differences becomes a social norm.
- 3) Educate people with disability about their rights to a safe and happy and discrimination free life in the community, not hidden away from it looking in.
- 4) Set up National conscription programs of "neighbourhood buddies" in order to demystify people with disability and to allow them opportunities to become part of their community. This would give the general population opportunities to learn about the role of carers and service they provide to them in society.
- 5) Close all institutions and "institutions-ettes" and allow families of people with disability to choose models of truly flexible supported accommodation that best suits the individual needs of their children and themselves. Eg Homes West and others.
- 6) Allow "appointment day respite" (i.e. time for respite workers to support carers in taking people with disability to doctor's appointments for example or for carers to

attend seminars relating to the care and well-being of their children with disability). In this way "Carer respite" time can be used by carers to re-energise. (for example to relaxation, pursue a hobby, sleep or having a meal with friends etc.)

Increasing our capacity as carers to make choices within our caring role,

We reiterate that there is only one way to effectively plan for and secure a good future for our son and to increase our capacity to make choices within our caring role. That is to allow us to choose to use **non-segregated**, **flexible** and **supported** accommodation in the community.

National (Homes West) and international evidence tells us that community inclusion is not only the best and safest environment (even for people with severe disability) but it is also more cost effective than institutions and "institution-ettes" models such as villages, clusters, massed villas, collocations and group homes.

Lastly, thank you for giving us an opportunity to tell you how we want you to support us and our children with disability to have a better, and fairer life.

Yours sincerely,

Caroline and Edwin

