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Karna submission to the Carers Inquiry 2008

We have two children on the autism disorder spectrum. This has affected our family life in many ways and yes we are still together as a married couple now for about 22 years. So in truth I have two different stories to tell. And yes if you are wondering why we have two children on the autism spectrum, it is probably a strong genetic component but as yet the autism genes have not been identified.

Genetic counselling such as we had after Lucette did not help much on the genetic possibility of more autistic kids in the future so we took a punt. My son is very mild compared with my oldest daughter and with him I have a lot more hope

### **The Lucette Caring Story**

Our eldest daughter has mental retardation and low functioning autism. I think she presents as a classic Kanner autism. She was assessed at 18 months as being autistic and things were pretty hard from there on us as a family with the resultant problems that come from caring for a person with severe autism and no functional speech. One of our problems with her was the effect she had on me being able to work as very little child care was then available for kids on the spectrum, We got half a day as integration time at the local child care centre with an aide. The only reason I was able to continue to work part time was my mother cared for her for us. If mum had not provided the care I would not have been able to work. Child Care was less accepting of kids with mental disabilities then but I suspect it is little better for families with kids on the severe end of the scale. We did have a discrimination action against the local after school care committee in the mid 1990s due to their unwillingness to take on the after school care of our daughter but this was a no win situation so we moved her to a after school centre run by a community group more accepting of children such as her.

We were prepared to accept her disability when she was 5 and was glad to access the local government provided respite of about 1 weekend a month. As family we found this better than the local in home provider Fabric as it was then as the carers tended to be hopeless. However more respite would have made our lives easier with her and enabled us to provide a better time for our normal daughter

Therapy here in the ACT was much better in Lucette's time than it is now for our milder son Malcolm. She was provided with speech therapy and occupational therapy and a good play group at CHADS, the early intervention centre. As we were both working we could also provide her with private speech therapy but nothing has ever got her to speak.

Lucette then went into the local special school system at Cranleigh and then Black Mountain School. Lucette is illiterate but this is due to her degree of disability and will never be resolved. Currently they concentrate on "life skills" with Lucette but she is a full on one on one. Lucette became literally too much for me to cope with as I was basically doing all the coping with her care whilst my husband "helped". Things like the constant hassle of having some sort of after school care when she became a teenager, coping with her in the holidays with little community support or activity and coping with the silliness that the school came up with such as her constant impetigo due to poor personal hygiene so they were not happy to have her many days etc. This silliness still continues when she is now in a group home.

This impinged on my work and to be honest my mental state as caring for Lucette wore me down. You don't realise you are burning out until you start either being very depressed or in my case aggressive towards Lucette. Caring for Lucette is like looking after a constant toddler as it is full on 24/7 and this worsened with her adolescence and her cycle.

I got desperate and several time thought of just walking out as I was not coping. My husband compared with many men does help but helping is not pulling your full weight. Care of severely disabl d children tends to fall by default to women. However I became very cranky and active in advocating for her to go into a group home. This I did by appearing on the local Stateline and going to the Canberra Times as a bad news story and going a round of local MLAs. We had also applied three times for Lucette to access a support funding package and had been knocked back twice. We finally got one when I wrote a strident application saying that the State could have her as we needed locks on all the doors and the fridge and a high fence all around our garden as she escaped, even after we had replaced our original wooden fence and had a pool fence and gate at the side. Lucette has no idea of personal safety or leaving things alone such as food in the fridge.

One finally understood I was distraught and desperate and this was by virtue of him once being a special ed teacher he knew the problems and he organised that Lucette would get a place in a group home. To begin with this was one week with us and one week at the group home but this did make it in some ways harder as we had the temporary reprieve of her care and then the following week we had her living at home again. To help her settle into a group home permanently and so we could with our two younger children has a semblance of normal family life, Lucette went into the Twelvetrees group home when she was 15. This placement was not ideal for her as several of the other residents tended to scream and Lucette is sound sensitive. However her later group home placement was a better match with a girl similar to herself who is quiet.

The Federal government was hopeless in helping us financially cover the cost of Lucette's group home placement as Centrelink and the local politicians were adamant that the Disability Pension only kicked in at 16 and there was no flexibility at the age when it could be accessed. This should be resolved in the light of individual circumstances as Lucette and many others like her will only ever have the income of the Disability Pension and some support from us her parents.

I understand from many other parents with now late teenager children that the ACT government tell them that it is not opening any more group homes. If Lucette had not finally got a Support package (ISP) and her group home placement I think I would have abandoned her as I was so fed up and worn down. Things are better for us as family as we no longer have the onerous task of daily care for her. I think it should be made very clear that most families need some form of adequate supported care if they have moderate to severe mentally disabled adult children as you cannot expect older parents to keep on providing endless care for such children. I tend to think it is beyond bearing that many parents in their late middle to old age still has to provide care for such adult children and yes most of the care is still provided by mothers.

Our next concern for Lucette as we are her guardians is to provide her with some daily activity once she leaves school. She will not be capable of any work even in a sheltered workshop due to her mental retardation and autism. I am yet again beginning the tedious process of applying of increased funding for her to access a local activity program called Sharing places in the ACT. So now at Lucette's stage of life as she is 19 she needs continuity of supported accommodation and some scheduled daily activities. She is still at Black Mountain School as currently they can keep them to the age of 20 as most will never attend CIT or university or even get any sort of work.

Despite the negativity you may read in the outline of the problems we have had with Lucette, never doubt we both love her and have concern for her well being. I often think our tale is sort of triumph over great odds but as her guardians her care is never ending in some ways.

To conclude the Lucette saga, the federal government should note that as her carer I could have done better with more respite, teenage child care as she will never care for herself like a normal teenager so I could work with more mental relief and in general more community support when I had her full care. We are now considered lucky to have her in a group home but I consider this option should be readily available to all families who need to avail themselves of it when their disabled children become older and too hard for them.

### **The Malcolm caring story**

My son, Malcolm is the youngest of our three children. He is mildly autistic compared with Lucette but has an intellectual deficit. Currently he is attending an autism unit at Holt Primary school with 5 other boys who are on the autism spectrum from Asperger Syndrome with behavioural problems to more autistic like Malcolm.

Malcolm's needs are many and he has an impact on our overall family that a child without problems does not cause

Currently his main needs are for therapy. His major deficit is speech. He does talk but not like a normal child of his age. We have received minimal help if you can call it that from Therapy Act. Their theory is that you teach the parent to do your work and by doing this you spread the minimal supply of therapy around. We have had two terms of such "help" at the school to help the teacher and at home. What he needs is constant and ongoing individual speech therapy at least weekly. This is very hard to get in Canberra as the private sector has few practising speech therapists and many have closed their books to new clients. Malcolm is going to see [redacted] once my husband is better but she really now only does once a fortnight. Again you have to pay for this service and at about \$60 a session it adds up. Malcolm could also do with occupational therapy and a major benefit would be a sensory integration diet to help him overcome his poor fine motor and his odd senses like sound and touch sensitivities. This we have not yet got from Therapy Act as the 5 week session they offered was on a day I work

Currently what we are receiving for our son is coming from our own pocket. We have [redacted] a well known educational consultant in autism come into our home once a week and give Malcolm one on one on the Wednesday that I take off. She has also come to the school for the individual learning plan session that either my husband or I go to, to organise Malcolm's educational goals for the term. By having Gay come we feel less on our own and believe that the school takes more notice of what we want for our son. All of this costs us \$90 per session so therapy for an autistic child does not come cheap. Malcolm needs other therapies which we have to pay for such as a sound integration course which we will pay for in the hope it improves his hearing and reduces his sound sensitivities making it easier for him to cope with what the world throws at him

We also have our son on the gluten free casein free diet in the hopes he will improve as has happened for other autistic children. Several of the other boys in the unit have also been on the diet. This again cost money as I take Malcolm to [redacted] the only biomedical doctor in Canberra who is very expensive for his consultations and I buy the supplements that are suppose to help such

children such as the more refined fish oil supplements and a range of vitamins etc. The diet means more expenses like organic meat which is an expensive item in our grocery budget and me having to make gluten free bread, an added chore for me. The gluten free products are mainly available at Coles and are not cheap, adding expenses to our weekly grocery budget.

Currently as Malcolm is only seven, I have not thought beyond this stage. However I can see into the future that he will create problems for us. There is little after school care for disabled teenagers and even if Malcolm improves a lot more he will still require some form of after school care due to his autism and then you have holiday care. My "career" if you can call it that has been a series of library and metadata jobs at the APS6 level now for 20 years as my two disabled children have placed me in the endless carer role and this will not end in the foreseeable future. We are considering that my husband retire at 60 so I can have a go of securing promotion as an EL1 as I am very tired of carrying the cares can. I can foresee that my son will need help from his dad as many autistic boys are more difficult to manage as teenagers particularly in the early adolescent phase. He tends to pinch and bite even now at school when under stress despite knowing he is not meant to.

As an employee having disabled children puts you in a quandary and this seems to mainly affect women as all these I have met through the Autism Association in the ACT and through my son's school placements are mothers doing the bulk of the caring.

Currently I am at ABS which seems to be genuinely good at practising flexibility for employees when many other government agencies really live in fairy land talking the talk of being aware of work life balance but hypocritical when it comes to practising it. This I encountered recently at the one big government agency when I went for a job again at the APS 6 level which I would be good at and enjoyed and really fits into project work. However at interview despite me not mentioning it in my application or at interview, the chair of the panel raised the issue that the job was all or nothing. The chair of the interview panel was to me very hypocritical when I heard on the grapevine when she was part-time for a long time with her own children. This agency talks a lot about their wanting to be an employer of choice and their mantra of being flexible. Well then they should be prepared to implement it in reality as many other agencies are now able to do such as DEEWR and ABS. This sort of attitude I find both perplexing and annoying when most of the women who would apply for a taxonomic job come out of librarianship and most have at some stage young children or in my case a older child who requires more care. I think Federal government agencies should be more aware of families caring needs and recognise many will require either flexibility or part-time work to accomplish this. It should be noted that in many ways they are saving the government vast amounts of money whilst caring. Such mega agencies such as Tax and Centrelink are more able to carry this than smaller government agencies and should be made to enforce their talk of flexibility to help staff attain worklife balance especially carers who carry very heavy burdens.

Many women I know, have men who have abandoned them and their children claiming that they cannot cope with the condition and blithely leave their wife or partner to carry the can thus making it hard for the mother to work. Others like my husband "help" however Julian is doing much more for our son than he did for our daughter as he realises that I am more likely to leave these days especially when I am stressed and fed up with caring for Malcolm. He will take my son to speech therapy once he is well and has taken him to music therapy for over two

years. I tend not to cope well at times and find some of Malcolm's behaviour and education problems a real worry and this then becomes overwhelming. This seems typical of women caring for disabled children as you worry about them and their future and worry what will become of them in the future and how you are coping.

In conclusion I believe that if the Federal government really does not act to improve the lot of carers with mentally disabled children at every stage, you may find more literally dumped on state care as families get burnt out with the 24/7 care demands. Unless you live with this care burden all day every day, you cannot conceive of the mental and physical strain it places on the carer usually the mother. You do not understand how it can limit her capacity to earn an income, provide emotional support to her other normal children and just look after herself to have a bit of a life. I don't think carers should have to ask for the support they need by asking the broader Australian society as charity towards them. Instead if you do not provide the help across the life stages to support their caring needs, you will find more and more families unwilling to keep such severely disabled children. In the case of autism you don't know that your child will have it yet before birth unlike other syndromes and conditions. Autism is like a lucky dip and it is increasing in numbers of affected children these days. Why should families be stuck and have no choice especially as their children become adults from relinquishing the caring burden. If the federal government provided better therapy and help for such children at the earlier stages, more would become independent. I also don't think that intensive therapy should be limited to the children under five and nothing is directed at my son's age group of 7 and above as my son who needs speech and occupational therapy to make him more independent

So that is our caring story for Lucette and Malcolm to date and I would be very happy to discuss it further with you