



Susanne

23<sup>rd</sup> JUNE, 2008

Dear Ms Ellis and Committee

It is a pleasure to be able to make a submission to your inquiry that is hopefully and positively address Better Care for our Carers which includes ME

My role as carer began on 31<sup>st</sup> March 1992 as a new mother of healthy twin girls. Alas in 1994 that role altered to a role of mother and carer to twin autistic girls.

My familie's lives since that time have been a psychological and emotional rollercoaster to say the least. My husband, David and I have attempted to give Kara and Jenna the best chances in life and as normal as possible but that has not always been possible or has it come easy. Our health physically and psychologically has taken a beating nearly every day. I have had to give up work full time as a Emergency Div. One Nurse so as to give the girls the best possible chance at some routine but it is getting harder. My independence and individuality has melted away. We have suffered financially as well, as the income into the household has been halved so at times it has been difficult to "stretch the dollar" at times. We are also socially isolated from the community in a big way as to take the girls out takes risk assessment to the maximum so as to minimise disruption to their routine and keep their "public reputation" intact. We are not able to participate in the local netball matches, freely go to the movies, stand in the line at the shops. As you can see the "normal" family asctivities just don't happen in this household.

I could rave on for pages or volumes to tell you about our lives as carers but you would not have time to read it. It is damn hard and as we get older and the girls get older harder for them also. Our focus of concerns are also shifting now that they have nearly finished their schooling at the Hamilton SDS and in 2 years will embark on the next stage of their lives where ever that may be!

We as carers do not want public recognition for task we have been set we just desperately want what is best for our children and if they are sorted out and happy then we can be a bit happier. There needs to be more facilities and infrastructure available to access for all concerned. Our present concerns are the lack of respite services and long term assisted housing in the area where we live, Wannon Electorate, particularly in Hamilton.

I am aware that the Victorian Government states that per capita that we have adequate respite places here but when was that census performed.

Five child places operating on weekends and school holidays only

Three adult places on weekends and that increases to 7 during the week as they use the child facilities.

Eleven long term beds

This number of places beds is not enough for the present or the future. My desire is that by the time Kara and Jenna are 21 years, at the most, that they will be settled into assisted housing and living independently from us exhausted parents. We love them dearly but they need to be independent of us and we need to get a bit of our own independence back. I personally know that in this immediate community of at least 6 families that are intending to seek permanent housing for their child in the upcoming years and this does not include others that I am no networking with.

The number of respite beds also needs to be addressed especially for adults and during the week for all. If there was an increase of service and its availability our longevity as carers could be extended maybe. I understand it comes down to the almighty dollar but I am quite aware of the money that has been saved closing institutions in the 80s and 90s that would have provided care. I do not want institutions to be rebirthed but more modern day facilities needs to be made available.

Frankly I cannot put into words my frustrations, fears and concern with what the future holds for my girls and other disabled people. It upsets me and stresses me to tears and withdrawal at least once a week. Our lives are not easy and I know that you don't have a magic wand to wave and fix but to be able to be heard helps a little and maybe if some changes can come about from your inquiry that may help also.

I think I may have taken up enough of your time now but just want to re-iterate that my main concerns as a carer at this stage are the future pathways for my children

THEIR HOUSING OPTIONS

RESPITE OPTIONS

PARENTAL PHYSICAL AND PSYCHOLOGICAL BEING

We are parents and concerned carers of these 2 special autistic girls and if any further info or "real life picture painting" required do not hesitate to contact me. Hopefully you will gain a clearer idea of what it is like in our lives and how the Australian Government can make it a little easier no matter which party is in.



SUSANNE .....