

The Chair  
Standing Committee on Health Community and Social Services  
Legislative Assembly for the ACT  
London Circuit  
Canberra ACT 2600

Dear Committee Chair,

I am writing to make a submission to the Enquiry into Respite Services in the ACT. I am the mother of a 19 year old who has low functioning Autism, Epilepsy and has high support needs. Several years ago there was a "major shake-up" in the service provision for home based respite care services in the ACT. Prior to this we had had the same coordinator for 5 years and this coordinator knew us and our son and knew exactly what our needs were. Since this "shake-up" we have had approximately 10 coordinators (most of whom we have never met) so one wonders how high quality respite services can be provided. Luckily for us we have had the same respite carer for 18 months so respite is fairly stable at the moment but we have difficulties if our regular carer can't work for some reason. Recently our usual allocation of 6 hours each Saturday (which we have had for at least 8 years) was decreased to 4 hours PER FORTNIGHT on a Saturday due to budgetary constraints. Sunday respite was also affected. It doesn't make sense to severely limit access to respite on week ends for families with a school aged child with a disability as this is when respite is needed the most.

So in summary Continuity of Care is vital at the times most needed by the family.

#### Regarding Centre Based respite services

We have been using these services regularly for years-starting at Kese House then Teen House and now our son is being transitioned to adult respite at Eloura House. We have found that respite is only offered according to a set template of care (either Fri to Mon or Mon to Fri) on a take it or leave it basis which doesn't always meet our needs. Our son is now so big that I find I can't look after him by myself, so required services whenever my husband is away. Allowing families to have flexible respite when they need it would be much better. I am worried about the lack of communication between us and the respite houses- even written notes seem to be ignored and the communication book (vital for a client who doesn't speak) is often not returned or when it is returned it is often not written in.

Currently there are 2 adult respite houses in the ACT which are to service everyone who turns 18years. My concern is that as more and more clients reach this age the respite offered will get further and further apart to accommodate everybody. Of the 2 houses-one seems to have a lot of clients who use wheel chairs. It seems unbelievable to me that this house shares a vehicle with another facility so does not have wheel chair transportation every second week end! Our son is mobile but would not be

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|  | A.C.T. LEGISLATIVE<br>ASSEMBLY<br>COMMITTEE OFFICE |
| SUBMISSION<br>NUMBER                                                                | 15                                                 |
| DATE AUTH'D<br>FOR<br>PUBLICATION                                                   |                                                    |



happy being house bound due to lack of transport. Activity and outings are essential for our son.

As our son will require full time residential care in the future, respite services are vital to us in the interim. If we can have quality respite when we need it our need for full time care can be put off for a few years. This will save Government money as respite is cheaper than full time care. We are in the position where we have to use respite services because we wouldn't survive as a family without them.

In Summary Respite needs to be client based and the clients individual requirements need to be considered. It needs to be flexible and a safe quality service should be provided. Future planning needs to look at the expanding need for adult respite services in the ACT.

I hope this has been helpful. I am happy to be contacted to discuss this further.

Yours sincerely