Supplementary
Submission
No 13a

INQUIRY INTO SERVICES PROVIDED OR FUNDED BY THE DEPARTMENT OF AGEING, DISABILITY AND HOME CARE

Name:	Ms Bernadette Moloney
Date received:	30/09/2010

We first started dealing with ADHC about 15 years ago, when Charley was 2 or 3 years old. He wasn't sleeping much more than 1 or 2 hours per day and we needed a break.

We were referred to an ADHC centre based respite house and received about 2 nights respite per six week period. I think we used it 2 or 3 times. I never saw the same person twice. Charley was a toddler with an intellectual age of less than 9 months. I hated dropping him off with complete strangers every single time. It goes against all maternal instincts – but I was desperate. Finally my older son, who must have been 6 or 7 years old at the time said to me one day as we were driving away "Don't leave Char there Mum, go back and get him". I don't think I did go back, but we have never used an ADHC managed service since then.

We found out about St Anthony's respite service at Croydon. Same deal, 2 nights per six weeks, but altogether different quality of care. We will never forget Joy and Marion. Joy was there every time we dropped Charley off and every time we picked him up. We had real communication about how Charley had been during the weekend, not just a log book. We used that service for years until Charley went to Kingsdene Special School.

Though we felt comfortable and confident that Charley was being looked after well, it still took us a while to learn how to use our respite weekends. We used to try to fit 6 weeks of normal family fun and relaxation into 2 days. With such high expectations and pressure, inevitably each weekend ended with a hollow, defeated feeling and usually a fight somewhere along the way. We soon figured out that it was silly to expect so much from just a couple of days. Respite weekends can't really be anything more than just a bit of breathing space and then back into the old routine at the end of it. What can you change or achieve in one weekend per six weeks?

When Charley was about 8 years old, we started using Sunnyfield respite services. This is a non-government-organisation funded by ADHC. This service had the same problems as the Department respite service, i.e. Rotating rostered shifts with an endless stream of staff. At least we got to save up our 2 nights per six weeks to make 4 nights per school holidays – this was useful and allowed us to do some normal school holiday stuff with our other children and their friends. But ultimately I felt I was betraying Charley. I never knew who was caring for him; never saw the same face twice. Once, I picked Charley up and his pants were wet because he was wearing no nappy. Whoever was caring for Charley during the last shift did not even know he was incontinent. What else didn't they know? They clearly did not know Charley at all.

Then, when Charley was 10 years old, came Kingsdene Special School – with real person centred care. Charley attended the school during the day and then boarded at the residence four nights per week, Monday to Thursday night. At the residence there is one "family Mum" for each 3 or 4 children. Obviously she/he is not on duty around the clock, but she is the key carer for these children and she knows them inside out. And we know her.

With strong communication between school and residence, Charley's skills improved markedly and he loves being with his mates (instead of stuck with Mum). It provided really useful respite for the family and allowed us to plan and achieve goals that normal families take for granted. (Mum went back to Uni and rejoined the workforce.) Weekends and school holidays Charley joins the family again, where he belongs. Kingsdene is closing at the end of this year due to lack of funding. There is no other facility like this in Australia.

When Daniela Dawes killed her autistic son and attempted to take her own life (in 2003?) there was a heavy silence amongst the Mums I know through Charley. We all knew that it could easily have been any one of us. We've all come close. It was like we had all been playing the same game of Russian roulette and poor Dianna got caught. She was the unlucky one who got pushed just a bit further at the wrong time in the wrong place. She didn't have Kingsdene. She had been screaming out to ADHC for more help. The judge who heard her case did not convict her but said that he hoped we learned from this case that we needed to provide better support for our disabled.

Well, with Charley turning 18 next year, we will have to re-enter the ADHC system 10 or so years after turning our backs on it. I have been dreading this. I have watched the many launches of new programs, seen the shiny new brochures about services with new names – but the services are the same. THERE HAS BEEN NO CHANGE. NO PROGRESS.

With Kingsdene closing, all the ADHC case-workers of Kingsdene students have done a workshop on "Person Centred Planning ". Kingsdene has been **doing** Person Centred Caring for years. ADHC is just **talking** about it. They're good at talking the talk – but that's as far as it goes. "After the 'person centred planning', will the resulting needs be met?" asked one Kingsdene parent at one of the many meetings. The response was awkward silence and vacant looks. We know what that means.

I'm no good at remembering numbers, but I think last year there were 64 supported accommodation placements in NSW, and 1700 on the waiting list. (I'm sure you have more accurate numbers.) I could tell you some heartbreaking stories of families that have done "The DOCS Dump" – left their adult child at respite because they just can't cope anymore and there is no hope of a supported accommodation placement. We will be wanting a supported accommodation placement for Charley eventually, but I haven't yet bothered to put his name down on the list – I know it is never referred to. "The DOCS Dump" is becoming so common that ADHC are building up policy and procedure around it. They provide counselling for the traumatised parents. Is this the new official route to a supported accommodation placement?

I have heard, and believe, that ADHC have all their money holed up in the Crisis Response Fund. When will ADHC show some initiative, create some new and innovative services in response to growing, unmet need? I'm sick of meetings, talk-fests, 'person centred planning' workshops, talking the talk and shiny brochures. I want some action. When will we see some pro-active, forward planning to avert crisis, rather than the crisis driven, bandaid service and blame shifting response that we are currently getting from ADHC?

To the Judge who sat on the Daniela Dawes case, I haven't seen any change in support offered to our disabled over the last 10 years, only increasing, unmet need. I feel scared and hopeless about the future for Charley and myself, at the mercy of ADHC.

Bernadette Moloney and Charley Armstrong

30-9-10