

## Submission No. 771

(Inq into better support for carers)

AOC 15/7/08

**From:** Alexandra  
**Sent:** Friday, 27 June 2008 4:47 PM  
**To:** Committee, FCHY (REPS)  
**Subject:** I am a carer for a 4.5yo autistic boy and 21 month old girl

Hi - just an idea of what it's been like for the Family.

David was diagnosed with high functioning autism at 3yo (Q Health, Mackay) but we had an idea something wasn't right at 2yo (speech delays, not huggy). We have had a very stressful time since his birth (screamy baby, wouldn't breastfeed, reflux/spewing lots) - it was a big strain on our relationship. I went back to fulltime work and David went into fulltime daycare between 1-2 yo (which I now regret, but we didn't know he was autistic). There was a lot of screaming at drop off time and that really upset us both, but to be honest I enjoyed working as it was "quiet time".

We pulled David out of daycare at 3yo when we moved from Cairns to Mackay and had his sister Beccy (who is not autistic). Have been here 2 yrs at home together. I haven't been working so have felt a bit isolated/ socially invisible but thanks to local Autism Support Group could learn about autism from other mums and realise that what David is doing is normal for someone with his condition. I take David & Beccy to playgrounds a lot so he can build up his social skills (Bunnings & MacDonaldis are best). Had a lot of conflict to start off with as he shoved and shouted at other kids, but he's learnt to stop that. My main issues have been an inability to get him into local daycare (for 1-2 days/week) or kindy as they are full and not interested in applying for autism support worker when a child is on waiting list so there was no hope of respite this year. Next year he's due for prep (he's 5 in Oct 08) and I'm putting him in at Moranbah where we're moving in a couple of months. I'm hoping to get part time work as a mining engineer at the mine (where my hubby works) for 2 days a week (that's if BMA would be interested in someone with my "baggage") and put Beccy in day care for those 2 days if possible. I know there's limited availability at day care centres especially if you aren't on the waiting list for a while and I think it might cost more than I earn. I am just trying to find a way to keep up my skills and work network so I'm not out of circulation for so long that I'm almost unemployable (and fat).

David has dietary issues - limited to fish fingers, sausage rolls, hot chips, crisps, dry white bread and spag bol (cooked a certain way), occasional chicken drumsticks. So it's affected my diet as I tend not to cook proper meals when I know no-one will eat it. I've put on 20kg since having the kids (I'm now 72kg). That's affected my self esteem a lot and knowing I might be going back to work will motivate me to lose the weight. My issue is how do I get the exercise as I have no respite to get away for a fast walk or to a gym (my hubby works away and his breaks are his "time out"). David falls over his own feet and Beccy hates the pram so no fast fat-burning walks for this mum!

We're not a severe case, just a borderline case. David does get occasional speech and occupational therapy, but they don't seem too concerned at Qld Health. Autism Qld visited us at home recently and they said he's bright and high functioning. Qld Health say David's behind in development by 1-2 yrs (needs to improve social skills, speech, holding pen/drawing/writing compared to other kids his age).

I'm a bit of a strict mum and I don't put up with any bad behaviour (using time outs in room and a bit of bribery), so by being consistent and fair I think I can overcome the behavioural issues that come with autism (as long as I remain compassionate and alert to the reasons for the meltdowns and times of anxiety). Hopefully as he grows up and learns to cope (and not meltdown when things aren't to his liking) he'll blend in with the rest of the world and be happy!

One more thing - it takes a long time for dad to come to terms with it. A bit of rejection/ anger happening still. Grandparents have come around nicely after being given a fair bit of reading about autism which helped me get an idea of what David's going through (still putting the puzzle together). During the early days (around 2yo) I perceived my family to be thinking I was a "bad mum" as I didn't have control over David (bad behaviour, tantrums/screaming etc). It was a bit hard, embarrassing in public etc. We try not to do anything too overwhelming for him now. Very limited activities outside of home to keep things calm.

Contact me anytime for more info.

Cheers

30/06/2008

Alex