

It is a daily struggle and a constant challenge living with Autism. My daughter Chloe who is 16 (was born in March 1999) has autism. She is the youngest of three children: she has a 23 year old sister and a 22 year old brother, both of whom are neurotypical kids. Unfortunately for her, myself and the family, she did not qualify for the Helping Children With Autism Package HCWAP ( which became available in 1996) as she had already turned 7 in 2006, too old, as it is for children 0-6. She did receive the Medicare sessions with an OT & speech therapist until 13 yo, which helped but for Chloe and her complex needs she will require on going OT, Speech and psychiatry sessions, which are very expensive. These sessions need to be on going ( to cap it at a particular number, seems unrealistic as all children are different. That's great offering the HCWAP but children with Autism do not suddenly get better...It is a life long condition. We have found that older children/ teenagers living with Autism are forgotten as the funding is not available and they are suddenly supposed to be 'normal' which is certainly not the case. In fact Chloe has regressed as she approached puberty and her anxiety and behaviour have become extremely challenging as she is frustrated, angry and lacks the communication and ability to regulate her emotions. As Chloe has become older the sensory processing disorder which is associated with Autism has compounded and it is really distressing and impairing for Chloe, myself and the family as we are confined to home because it is too difficult to take Chloe out, even to go shopping, to the movies and even out to dinner are all so difficult that we don't go and it's easier to stay home. When she was younger she was able to tolerate short visits to the supermarket and other short outings. We now feel like prisoners in our home.

Once Chloe turned 12 she was unable to attend the local Holiday programme that was offered at the Primary School, so now I dread every holiday knowing that Chloe will be missing school terribly and stuck at home with not much to do. When she was younger, Chloe really enjoyed attending the local school holiday programs and she was supported with a helper and although she was older than the other able children, developmentally she is like a 7 yo and loved to play at the centre with all the other children. This Christmas holiday she attended a two day holiday program at South Kingsville community Centre for special needs children (they offered 3 days but the 3<sup>rd</sup> day was at the wonderland fun park and Chloe would definitely not cope at a place like that). Chloe loves centre based activities as she knows what she will be doing, that's why she loves school so much. She is also very social and loves being around people and likes routines and rituals.

RESPIRE is a major concern as we desperately need a regular break on weekends and in school holidays!! Last year Chloe was able to attend her first 2 day camp at Blackwood with People outdoors and she loved it and so did we. There most definitely is a lack of regular respite for children/teenagers with autism. All Chloe does is attend South Kingsville Community Centre One Saturday a month & that's if they stay at the centre. However, some sessions they take the children out and for us spells disaster and ends up with them calling us to pick up Chloe as she has had a meltdown. So it maybe 2 months before there is respite! Some of the respite sessions have been at the Yarraville Special development school and that is fantastic, as it safe and has wonderful equipment designed for students with special needs. It would be wonderful if there was a social/ communication group every Saturday at the school! She does not play sport and even if she did, she would not be able to play in a team with able people her age, because of her developmental stage & cognitive ability...totally unrealistic to expect that of her. However, I do think that maybe she could do milo cricket or Netter or teeny tennis , but she is ineligible because of her age. It is age based not ability.

Through our Council we receive 2 hours a week respite which we use in 2 X 1 hour blocks and that covers the time Chloe comes home from school until I return home from work. It has been a real struggle for both my husband and myself to work. The special school, Chloe attend finishes at

2.50pm (It baffles me why it finishes so early) I am a teacher and we finish at 3.30pm! We chose to send Chloe to Port Phillip Special School so as we live in Williamstown, we are not in the bus route so have to get Chloe to and from School each day. There is no before or after care available at the school nor is there any holiday program available at the school which makes it incredibly difficult for both of us to work.

I do find it disturbing that one council can offer so much for children with Autism and other councils offer very little eg Moonee Ponds were offering a holiday program for children with Autism these holidays, but you needed to reside in the area and be under 12 years old. It is also offering a respite pilot program for residents with disabilities which hopefully will be successful and rolled out for others living in different areas. When I was visiting Nursing homes for my father, they would say these are the temporary rooms for elderly people whose carers need a break. I thought wouldn't it be great if there was something like this for people with disabilities so that their carers could have a break or even book a week holiday knowing that their loved one was being cared for in a quality home which was safe and caring!

Finally, I am seriously concerned about the fact that she will finish at Port Phillip special school when she is 18 years old (although cognitively functioning at half her age, so expecting her to transition to young adulthood at 18 is absurd) and have a limited option of attending a day centre with people aged from 18-65 years. Surely, the age difference is concerning for any parent, regardless of disability. In America students with Autism are at their special setting until they are 21 which makes much more sense, considering many of these children had a very slow start to their life and reached their milestones much later and cognitive function years below their age. Transitioning from school is a crucial time in any young adults life and is particularly challenging for young people on the autism spectrum. Young people and their families have been significantly under resourced during this important life stage. It would certainly make more sense to have them supported in their education until the age of 21 rather than transition at 18 when they are trying to cope with puberty and hormones. An idea would be to develop a setting for 18-25/30 year olds with autism, that can continue to cater for their specific needs in literacy, numeracy personal development, daily living skills and industry specific and work related areas.

There is a huge gap in Autism between knowledge and reality. I know in the past, there has been money put into research however, the research doesn't seem to help my child catch the train by themselves or keep them safe. I want to see real changes for my child and in order to work out which areas need the greatest investment the government needs to listen to people living with Autism about what they want from research. I believe there needs to be better educational opportunity, more support, help and respite for the people living with Autism here and now!

I am happy to discuss this letter further and look forward to the outcome.

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