

From: [REDACTED]
Sent: Thursday, 21 January 2016 4:19 PM
To: FCDC
Subject: Input into services for Autism Spectrum Disorder

Importance: High

Hi there,

My name is Rosemary Doherty and I am the parent of a child Chris (aged 28) who was diagnosed at 24 with autism (High functioning autism –Asperger’s).

- Chris, from around his 15th birthday, started experiencing severe/debilitating headaches –he would wake up with a headache and sleep for many hours every day. He became very isolated from friends and spent many days absent from school. The school he went to received funding for him because of his high absenteeism in Years 10, 11 and 12 (his absenteeism was around 40%). Chris did 2 Year 11 subjects in Year 10, and at the height of his worsening condition he was able to do less subjects in Year 11 (Year 11 English was completed in Year 10).
- Chris received an enter score of 67 in Year 12 and was able to get a second round offer to do Archaeology at La Trobe in 2006, (this was his first choice for further study) however he couldn’t manage the travel from home (Werribee) To Latrobe in Bundoora and (so we know now) he suffered anxiety going into study sessions: he missed many classes, didn’t hand in assignments. We thought that he should have been able to manage it, we thought others his age were doing the university stuff so should he, we backed off supporting him expecting him to grow up and be independent; he was 18 and should be able to do this stuff on his own..... So we thought.
- Chris did not stay at LaTrobe.
- He also tried a creative writing course the following year –he “failed” at this too (same situation as La Trobe)
- Prior to his diagnosis he did some part time work –Big W and at a BP Petrol Station. He has also worked in After School Care. But once he started to study for his bachelors he stopped working as he as receiving Austudy.
- Chris was taken to a paediatrician for help (around 15 years of age), and subsequently referred to the Adolescent Health Unit of the Royal Children’s Hospital (where he went for about 3+ years –until he was too old to be there). When he left there we were left to our own devices –and just our family doctor (who really wasn’t too helpful or interested). I took him to: neurologists, naturopaths, psychologist, life coaches, a dietician, ENT specialist, chiropractor, dentist Many many specialists to work out what was going on with him/why he was having headaches and the amount of time he was spending inside and in bed. From leaving the RCH we weren’t given direction nor a diagnosis.
- So, nearly 5 years ago I was encourage by some friends (also teachers) to take him to see a psychologist at The ASD Clinic in Kew. It was there that it was suggested that we have testing done, which we did. The results showed him to be have/be functioning autism –where the lowest results from the testing were in the pragmatic areas. From there we began regular psychologist appointments. Around the same time we changed family doctors –I wanted to find a doctor that cared, one that would help problem solve and work out what was going on with Chris. The new doctor sent him to a different neurologist, he was diagnosed with migraines and given medication that helped the headaches. At the same time he went to a Sleeping Disorder specialist who diagnosed him with a rare chronic sleep disorder –and Chris began some quite severe treatment/medication. We also decided to see a psychiatrist. Fortunately, all these doctors wrote to each other and communicated to work out a plan for him. So about 3 years ago he started on medication for anxiety as well as melatonin and the use of a blue light to regulate his sleeping.
- So after the diagnosis around 2011 Chris began a uni course at Deakin in Geelong and with the guidance of his psychologist we set very strict instructions for his study (ie I, his mother, was to act like a personal

assistance and coordinate his study time, oversee his assignments, timelines, communication with the uni and his lecturers –this was to happen if Chris was to continue his studies and he had to commit to this,) and with support from the Disability Liaison Officer there. For Chris to complete the course he had to allow me to support him and be his “personal assistant”.

- He completed his study in 4 years, part time off campus –with me basically organising him, nagging him, studying with him, communicating with lecturers (for many many reasons). He received Austudy during this time.

NB- we were able to get his HECs deleted from La Trobe and his first year at Deakin b/c of his diagnosis and supporting letters from specialists.

So since early last year he has been sent by Centrelink to a Disability Employment Service APM. We had a meeting at Centrelink where it was decided to acknowledge his autism as a disability (as evidence in his assessments completed by the ASD Clinic) and have him go to APM as we had the belief that they would be able to best support him to find appropriate employment.

So, as of today:

- He has his 4th worker assisting him in less than 12 months
- He has not any assistance actually applying for a job
- He has had minimal assistance creating a resume and covering letter (we have done that for him and worked through creating a resume and cover letter) –in fact we were told what APM originally did for him would not even get him an interview anywhere
- Not one job interview
- They cannot assist him with further skill development as they say he is already highly skilled (because he has a Bachelor of Arts degree) -for example, we have tried to get them to assist with payment for him to do a job recruitment course that would work on interview skills, where to look on the internet to find work etc et, they have refused to pay for this to happen (given his autism this would be highly beneficial to him to have trained to learn the language/words, eye contact, skills etc)
- He goes there every 2 weeks to meet for a 20 to 30 min meeting and is usually there for 10 mins –they do not help him.

I am now of the belief that this service has disadvantaged him more.

At the moment I do not know where to go to get help for him to get a job. He is intelligent, knowledgeable, he has potential and great skills, he is a wonderful person who has a lot to offer & he is extremely capable I cannot find anyone to help him, or anyone who cares to help him. I find it very uncomfortable for me to ring up and ask about jobs for him, as I am his mother (and he is 28!). He needs someone to mentor him, to work alongside him and demonstrate how to do these things. The longer it takes for him to find a job, makes me greatly concerned about his future. At the moment it feels like he doesn't have one.

I have had meeting with our local parliamentarian. I don't think that they can help at all – I really didn't get any idea of how we can progress so that Chris can work with an agency/someone who can assist him to get work. For me, I have taken so many days carers leave from my work to help him –I attend all appointments he has with doctors/specialists. I have taken days off work for meetings at the university, to attend Centrelink meetings and some APM meetings.

Service for adults, particularly those diagnosed with autism at an older age do not exist.

Anyway, that's where I am at in all this and I am totally frustrated, deeply concerned and just don't know where to turn to.

Kind regards,

Rosemary Doherty