Submission S118
Received 22/04/2016
Family and Community Development Committee

Family and Community Development Committee
Parliament House
Spring Street
EAST MELBOURNE VIC
3002

19/04/2016

Inquiry In to Services For People With Autism Spectrum Disorder

This submission is from a non-related family carer who has supported an adult with ASD who is aged in their late thirties for over 5 years. To protect the privacy of the person with ASD their given name is withheld and they will be referred to as Alex, also the specific genetic syndrome Alex has is withheld and will be referred to as one of the Rasopathies.

When Alex is well enough, Alex contributes to the creative arts and serves on a board of charity for a health issue. Alex could be contributing more and potentially even working a small amount with the right support and suitable job, at the moment Alex's only income is a disability support pension.

Alex has many goals and potential to live a meaningful and productive life but there are many barriers to this. Alex has strengths, weakness and difference in abilities but because the weakness's are not being addressed or supported adequately, Alex's strengths are not being utilised or are over shadowed by the stress and constant survival mode of trying to cope with difficulties.

Health Services

Diagnosis

The first request by Alex and myself for an assessment of Alex's cognitive issues as an adult, was to a Local Area Mental Health (LAMH) service while under case management for mental health problems in 2015. We wanted to know what the problems were due to and whether they were getting worse. After a brief general overview of some of the problems (social, memory, comprehension, functional impairments) the psychiatrist acknowledged that because Alex had a Rasopathy1 then it was a good idea to be assessed and was given a time to return for this. Alex returned on their own and was given an assessment for dementia using the NUCOG2. The test showed that there was no rapid decline in cognition but found issues that were of a long term nature. The psychiatrist was fine with this result and did not wish to test further. Alex was given information of a University Psychology clinic that could do further investigation at a more affordable rate.

We were both confused as to why Alex would have been tested for dementia considering Alex's age and as far as I know early dementia is not an issue with Alex's genetic syndrome. Alex then tried to obtain old medical files for any clues as to previous diagnosis, history or problems as a child. I then had to go back to doing my own research.

A few months later Alex had come across Autism after a homecare worker asked if Alex was autistic as the worker has clients with Autism. Around that time after doing some research I was realising Alex's problems looked like Autism traits. We contacted the Dual Disability service (DDS) after finding out the cost of private cognitive testing. Alex specifically asked for testing for Autism, whereas I had wanted a more broader assessment after noting in childhood files comments relating

to IQ. There was resistance from the LAMH and the specialist personality disorder service Alex was with to get assessed.

After persisting and Alex doing a preliminary ASD test, Alex was assessed by the DDS as being on the spectrum and given a diagnosis of ASD level 1 because Alex did not have a clear memory or full knowledge of early development and there was no family member to consult for further information the diagnosis is a provisional one.

The diagnosis came as somewhat of a relief for Alex and an explanation as to the difficulties, difference and behaviours Alex has. This gave Alex insight and revelations and also the opportunity to find others on the spectrum to relate to. Had a diagnosis been earlier this would have been more helpful.

Accessing services and quality of service

The DDS advised Alex that there were not really any services for Adults with Autism, so while the diagnosis was a helpful starting point to understanding Alex's difficulties it was disappointing and upsetting for Alex to realise there was nothing to help Adults with the specific difficulties of Autism.

There are no carer groups specifically for people supporting adults with ASD, they are all parents and caregivers of children.

There are no ASD peer support groups for adults.

There are gaps of no specific services for adults with ASD.

Finding support services is difficult.

Mental health

Alex is presently and has been in the past with a community mental health services, these services so far have not been adequate enough to make improvements in Alex's functioning alone. The service is too limited in the amount of time per week to help. I am not sure that the Collaborative Recovery Model[3] is appropriate or effective for people with complex needs, people with ASD or Intellectual disability. I am confident that this programme on its own is not sufficient, it could possibly be helpful in addition to other supports.

Alex has used the GP better access mental health plan but these sessions are limited and will not be able to cover all of the issues Alex has.

The lack of or limited amount of preventative and supportive services, means that mental health problems do and will end up at crisis point. For Alex this has resulted in self-harm, suicidal ideation and suicide attempts. Crisis managing mental health problems without working on the reasons things get to that point are not helpful or a sustainable ways of preventing and managing mental health problems. Alex has a chronic risk of suicide and so do many others with Autism I believe because their needs are not being met, and a lot of people with ASD do take their life[4]. Accessing crisis services are also more stressful and traumatic, because of unfamiliar environment, can trigger sensory sensitivities, being around people who are also distressed and unpredictable can increase anxiety further. Having to present to emergency hospital services can be more stressful, trigger anxiety, frustration etc. Mental health and medical professionals have been unhelpful in their attitudes with a tendency to blame the patient and be generally unsympathetic.

Prescribing psychiatric medication and poly pharmacy has not been helpful, it adds to the burden of health problems because of the side effects and the poor effectiveness of these drugs. Drugs do not address the reason people have mental health problems.

Often I am coming across the intersection of ASD and Borderline Personality Disorder.

General Health

Taking care of health problems is a difficulty because Alex has trouble identifying personally what are symptoms in the body, when it is appropriate to seek medical attention and also communicating these problems to medical professionals. More health promotion targeted to people with ASD and those with comorbid disabilities could be helpful. If I did not help Alex in actively seeking medical attention then many preventable health issues can go unattended, and people with ASD generally do have more health problems[4,5].

Another issue I have come across is medical appointments can be anxiety provoking if Alex does not understand the process of investigation or treatment of medical problems. For example because Alex can take language very literally then a procedure may be interpreted differently, which can be scary and lead to avoiding seeking help and treatment. Eg interpreting a 'hip replacement' to mean the whole pelvis is to be removed and a donor pelvis is transplanted in the body.

Impact of NDIS

Alex is excluded from the NDIS based on residency status and holds a non-protected special category visa.

Education

Alex was assessed by special education, psychologists and school guidance councillors. Alex remained in mainstream classes and also attended special classes, due to poor performance in some areas. Behavioural problems were picked up, Autism was not mentioned to Alex. This occurred in other states of Australia so I cannot comment with regards to Victoria.

Housing

Private rental accommodation is expensive and because of this there is a higher risk of not being able to afford expenses and increases the risk of homelessness. In order to live well Alex would need to be supported to do this. At the moment Alex lives with myself but it is becoming increasingly difficult to remain living together and supporting Alex because of the stress and lack of supportive services. Alex is at risk of homelessness because there is no service available that will actively help someone seek, view and move into a private rental.

Alex is excluded from public housing based on residency status.

Group housing situation can be a problem because living with people who you don't know can cause anxiety and be stressful.

Research into ASD and its prevalence

One way of approximating the prevalence of ASD is taking a percentage of the current prevalence in genetic syndromes as ASD occurs at a higher rate in these then the general population[6]. There could be an underestimation of ASD because adults are not being diagnosed until they are adults.

Community participation

Alex is limited in participation because of difficulties in mobility and navigation, at the moment Alex only leaves the house when I am able to help.

I have run out of time in making a more detailed submission but I think these two articles bring up some important issues.

https://spectrumnews.org/features/deep-dive/the-measure-of-a-life/

https://spectrumnews.org/features/deep-dive/living-between-genders/

Works cited:

1. Katherine A. Rauen. The RASopathies. Annu Rev Genomics Hum Genet. 2013; 14: 355–369. [PMC free article]
2. Walterfang M1, Siu R, Velakoulis D. The NUCOG: validity and reliability of a brief cognitive screening tool in neuropsychiatric patients. Aust N Z J Psychiatry. 2006 Nov-Dec;40(11-12):995-1002. [PMC]
3. Collaborative Recovery Model http://socialsciences.uow.edu.au/iimh/collaborativerecoverymodel/index.html
4. Tatja Hirvikoski, Ellenor Mittendorfer-Rutz, Marcus Boman, Henrik Larsson, Paul Lichtenstein, Sven Bölte. Premature mortality in autism spectrum disorder. The British Journal of Psychiatry Nov 2015, DOI: 10.1192/bjp.bp.114.160192
5. Croen LA, Zerbo O, Qian Y, Massolo ML, Rich S, Sidney S, Kripke C. The health status of adults on the autism spectrum. Autism. 2015 Oct;19(7):814-23. doi: 10.1177/1362361315577517. Epub 2015 Apr 24
6. Richards C, Jones C, Groves L, Moss J, Oliver C. Prevalence of autism spectrum disorder phenomenology in genetic disorders: a systematic review and meta-analysis. Lancet Psychiatry. 2015 Oct;2(10):909-16. doi: 10.1016/S2215-0366(15)00376-4. Epub 2015 Sep 1. [PMC]