

Legislative Council

Wednesday, 12 May 2010, Page 120

AUTISM SPECTRUM DISORDER

The Hon. A. BRESSINGTON (17:27): I move:

That this council calls on the Minister for Disability as a matter of urgency to —

- 1 . Increase funding to Autism SA and any other similarly funded non-government organisation to enable them to provide services and support for people diagnosed with Pervasive Developmental Disorder —Not Otherwise Specified commensurate to those available to people with Autism and Asperger ' s Syndrome; and
2. Implement measures to—
 - (a) address any disparity in services and support provided by Disability SA between people diagnosed with Pervasive Developmental Disorder —Not Otherwise Specified and Autism and Asperger ' s Syndrome;
 - (b) ensure a single definition of Autism Spectrum Disorder that encapsulates Pervasive Developmental Disorder —Not Otherwise Specified is used universally throughout government departments and agencies;
 - (c) improve access to and expedite diagnostic services for Autism Spectrum Disorder; and
 - (d) increase awareness of this condition so as to aid early identification, community acceptance and decrease the associated stigma.

I put this motion before the council to highlight the current disparity in services and support available to people living with disorders classified under the umbrella of autism spectrum disorder. This motion specifically refers to Pervasive Development Disorder—Not Otherwise Specified (PDD-NOS). For those unfamiliar with PDD-NOS, I will start by providing a brief outline of the condition. To do so I will rely upon the definition used by the federal government and other states, for here in South Australia PDD-NOS is largely unrecognised and misunderstood, with no consistent definition in use. PDD-NOS comes under the heading of autism spectrum disorder. Nationally, this heading covers autism, Asperger's and PDD-NOS.

This condition differs from autism in that sufferers display only a limited number of autistic traits, be they impairment in either verbal or non-verbal communication skills, displaying restricted repetitive patterns of interests and behaviour, or difficulty coping with change. According to the Diagnostic and Statistical Manual of Mental Disorders IV, it is typified by late-age onset.

However, it is still captured in the literature and in other jurisdictions under the umbrella term autism spectrum disorder and is referred to by many experts as atypical autism. As with autism, there is presently no cure for PDD-NOS so it is imperative that early diagnosis occurs to enable interventions to be accessible. Early intervention is critical to children who are on the autism spectrum scale to encourage them to live as independently as possible in their adult years.

Of course, early diagnosis and intervention also allows families to participate in developing constructive family systems to support the child, as well as allowing them some comfort

knowing that, when the parents are no longer able to oversee their children, they will have gained sufficient life skills development to be able to care for themselves, often with minimal supervision and monitoring.

As mentioned, the South Australian definition of autism spectrum disorder differs from that in use nationally, in that it does not include PDD-NOS, with only autism and Asperger's being captured. While this may seem a quibble over words, it is this distinction that sets South Australia apart as a national delinquent of service delivery for those living with PDD-NOS. Despite displaying many of the symptoms of autism and requiring the same interventions and support, South Australians with PDD-NOS are unable to access any of the state-funded services automatically available to those diagnosed with autism.

While the recognition of PDD-NOS and funding for services differs from state to state (and I am sure the government will respond to this motion by pointing to similar failings by other backward states), it would seem from research that South Australia is unique in not identifying PDD-NOS as belonging to the autism spectrum disorder and funding services accordingly. Monsignor David Cappo, the Commissioner for Social Inclusion, evidently came to the same conclusion, stating in a letter to a constituent, 'SA is the only state that does not fund, in some form, PDD-NOS for disability services.' In fact the only services, other than the tokenistic access to the disability library and the info line, that a South Australian diagnosed with PDD-NOS is automatically eligible for are those which are directly funded by the federal government; namely, the Autism Advisor Program and the Early Intervention Funding Package, provided as part of the Helping Children with Autism Package.

However, eligibility for these services requires that a child is diagnosed by the age of seven years, which, according to Autism SA, is a very rare occurrence. Hence, if a child is diagnosed at the age of 7½ or eight years of age, they are excluded by the services funded by the federal government altogether. Of course, this is a matter for the Minister for Disability to take to the COAG meeting to have rectified.

In contrast, for those living with autism, a range of state-funded services is available as an entitlement of diagnosis, with either Disability SA or Autism SA providing specialist early intervention therapies as part of their Early Childhood Program or Early Development Program, respectively, in addition to respite, intensive case management, and educational supports offered in conjunction with the Department of Education and Children's Services.

I do not pretend that the services available to those diagnosed with autism are ideal and without deficiency. To do so would be to ignore the woeful plight of the disability sector as a whole. However, for those living with the diagnosis of PDD-NOS and their carers, the difference between the services outlined above and the support of those with PDD-NOS that they receive is enormous, because those with this particular condition get little more than shuffled from pillar to post, between mental health services and disability services, with no real see/touch/feel assistance at all.

Ms Sherallee Andrew, a carer, has battled the system for the last 17 years trying to access the services that her daughter Joanne so desperately needs. From an early age, Joanne was showing autistic symptoms but, due to the failings of our diagnostic system and the difficulty in diagnosis of PDD-NOS, it was not until only recently—at the age of 20—that she was finally diagnosed. From her early learning difficulties and language and speech delay, it was not until Joanne was six years old that she started saying her first few words, and it was obvious to all that she had a problem.

During primary school, Joanne's learning and emotional delays became increasingly noticeable, with Joanne falling so far behind that by grade 7 the school exempted her from

participating in the basic skills test as it was thought that she would be unable to cope. With little specialist intervention, Joanne was still at this stage speaking like a much younger child, and unfortunately Joanne suffered the teasing by other students that so often accompanies participation in mainstream schooling.

Consequently, Joanne became increasingly self-conscious and more introverted. Despite endeavouring to access services for her daughter, and having Joanne diagnosed with multiple learning and language-based disorders, Sherallee was confronted with a system that offered few services that met her daughter's needs, and the little on offer progressively diminished as Joanne aged.

By high school, Joanne had been engaged by the Child and Adolescent Mental Health Service, who treated her as a mental health patient, despite Sherallee seeking a diagnosis through Autism SA that her daughter was in fact autistic, as she rightly suspected her daughter to be. Additionally, Joanne's high school endeavoured to get her into a special needs class but was told that, due to Joanne's diagnosis, she did not fit the funding criteria.

During this time, Joanne became angry and distressed and, while having to watch her daughter's deterioration, Sherallee decided to withdraw Joanne from school and keep her at home. This decision was made because of the distress her daughter suffered through having to engage in mainstream education, which spiked her sensory perceptions and had her daughter living a nightmare every day.

Like so many people who are diagnosed with autism or Asperger's, Joanne has a gift: she has a highly analytical scientific mind. She can grasp facts, figures and statistics like second nature and can rattle them off. If you have one green and one blue eye, she will rattle off the statistics of how many people in the world have that condition and why they have it, and she has all this in her memory.

She also had to develop her own language because our symbols, our alphabet, make no sense to her. She is actually writing in what is believed to be an ancient Rune language. The signs and symbols of that Rune language, which is no longer used, make perfect sense to her, and she has written volumes of books on her revelations, her light bulb moments, if you like. She has also had to develop a language specific to her and her family because of the disorder she has.

These light bulb moments, as her mother calls them, can occur at 1 o'clock in the morning, when she has a flood of information coming into her mind and she has to write it and get it out. She can go for 36 hours straight, just writing what is coming into her mind in her own special language. Once that 36 hours is up, or the information stops flowing, she will drop for two days and just sleep it off.

Joanne, like others with PDD-NOS, is sensitive to smells and unable to tell the difference between a fragrance and an odour so, if you are wearing perfume, to Joanne you just smell. She is highly sensitive to sharp noises, such as bells and buzzers, and also to music. Those three things set her off on the rocking that is quite often linked to autism and Asperger's.

We can only imagine what this young girl's day was like, having to live in an environment where almost all her symptoms were triggered from minute to minute. Joanne is also highly analytical and sees patterns in almost every aspect of life, but she has been unable to learn how to control those impulses or develop a strategy to cope with them because she has not been able to access any services.

Life became so difficult for Joanne that one night she actually wrote on her bedroom wall, 'I hate humans.' Eventually, when Joanne came of age, her mother signed her out of school. Not

having had any support or help for her daughter during her early years, she has become a recluse and is progressively getting worse.

At the age of 20 Joanne does not know how to access public transport, she has not learnt how to read a timetable, and she is unable to travel alone on buses and trains because of her disorder. These were life skills that she would have developed had she been able to access the services and supports available to those with a recognised autism spectrum disorder.

Some years later Joanne was fully diagnosed with a condition that matched her symptoms, that being PDD-NOS. However, as explained above, this was no relief to her mother Sherallee, who soon learnt that, despite her daughter requiring the same interventions as required by those living with autism and Asperger's, these specialist services were not available to Joanne or were out of financial reach to Sherallee as a pensioner. As an adult with PDD-NOS, Joanne is not able to participate in the adult programs offered by either Autism SA or Disability SA. She does not receive automatic support from Housing SA to assist in the transition to independent living, nor is Sherallee able to access respite to give herself a break from the 24/7 job of being Joanne's carer.

Additionally, this diagnosis did little to address Joanne's exclusion from mainstream society, with PDD-NOS not enjoying the same level of recognition or community acceptance as autism or Asperger's. In Sherallee's own words in a letter to minister Rankine, 'The tag of PDD-NOS is just a barrier to access and inclusion'. The only barrier that has existed to those with PDD-NOS is that in South Australia we have failed to include PDD-NOS as an autism spectrum disorder.

Everyone in the industry that services those with autism and Asperger's knows that PDD-NOS is yet another division of autism. Everyone knows that the early interventions, treatments, services and supports for PDD-NOS are identical to those for autism and Asperger's. Yet, because of what appears to be a bureaucratic glitch, many are excluded from any access to services at all. It was not until Joanne was assessed as meeting the criteria for Disability SA's exceptional needs unit that Sherallee was able to engage any of the specialised services available to those with autism. Unfortunately, even this was only temporary, with Joanne no longer meeting the criteria.

Today Sherallee is working towards her daughter being rediagnosed with autism so that as an adult Joanne will be able to access at least the limited socialisation and housing support services on offer. Additionally, it is Sherallee's fear that if Joanne is not rediagnosed and PDD-NOS continues to be neglected, and if something were to happen to her and she was no longer able to be Joanne's primary carer, her daughter would be left to her own devices—which, because of red tape, are very limited indeed.

While Joanne's story highlights many fundamental failings within the diagnosis and treatment of autistic spectrum disorders, it typifies many of the experiences of those who are diagnosed with PDD-NOS. Another constituent, who is caring for his nine year old grandson, is today reliving Sherallee's experience, with his grandson being denied services by Disability SA and Autism SA due to his PDD-NOS diagnosis. Instead, he is being handballed to mental health service providers who are failing to meet his needs.

Of course, this leaves the door open for practitioners to purposely misdiagnose those with PDD-NOS to ensure that they have access to services and support, which in turn creates another long-term problem in that the occurrence of PDD-NOS will not be reported, and governments will see no need to increase funding or services and support specifically for those with this condition because it will not be seen as an increasing problem. I believe this

was exactly the same situation that we had with Asperger's when the differences between that disorder and autism were becoming apparent.

In a recent interview with *Stateline*, minister Rankine stated that she was mindful of the problems with this disorder and that she agreed that a national approach was necessary. She also stated that she was waiting for the next COAG meeting to bring this problem to the table. I remind members here that the federal government already provides funding to the states for PDD-NOS, which is included in autism spectrum disorder funding, and that the South Australian government is the only one that fails to recognise this disorder outright, according to Monsignor David Cappo.

The obvious question is: where is the funding that is provided under the federal umbrella actually going, and for what is it being used, if it is not including PDD-NOS sufferers in South Australia? Further, why has this government failed to allocate services and support while in receipt of that funding? This government, apparently, is prepared to receive funding from the federal government for a disorder that it fails to recognise as being in need of services and supports because, and only because, the DSM-IV has not been specific enough for SA. Yes; that is right—we have based our exclusive approach for those with PDD-NOS on an oversight of the DSM-IV.

So, we are unlike other states, and, with the knowledge that in 2013 it is likely that the diagnostic criteria of the DSM-V will have changed and done away with Asperger's and PDD-NOS for a sole diagnosis of autism spectrum disorder, when I say this is a bureaucratic glitch, that is exactly what it is.

As a result, those with PDD-NOS will continue to be excluded until this minister is prepared to make the call for the people of this state outside of a COAG meeting with merely the stroke of a pen to ensure that children with PDD-NOS can access the services and supports they so desperately need. How much funding is it going to take to house those adults who are cruelly diagnosed with this disorder and then denied the early interventions that have proven over time to be so very successful?

With premier Mike Rann's promise to reconnect and re-engage with the people of this state and to aim towards fostering confidence through ongoing consultation and by listening to the concerns and aspirations of South Australians, perhaps the Minister for Disability (Hon. Jennifer Rankine) might want to re-engage and reconnect with this part of the community and put her hand into her bag of empathy and compassion and make a decision in the true welfare of those people in this state who are currently left out in the cold, are not recognised as being in need and whose families are placed under enormous pressure trying to cope with the difficult traits of PDD-NOS, as well as the deterioration over time that they are forced to sit and witness. It is all avoidable.

I note that, in this government's disability policy of 2010, entitled Disability Support Policy: A Social Inclusion Approach, premier Mike Rann uses all the right words, and we would expect nothing less, of course. The policy states:

We believe in the fundamental right of people with a disability to have access to services they need and to have greater control over the decisions that impact on their lives. To help ensure this, we are developing a more socially inclusive approach to supporting people with a disability, as well as their families and carers.

Our Social Inclusion Board, chaired by Monsignor David Cappo, has been asked to develop a blueprint for the long-term reform of disability services in South Australia. It is a responsibility this government takes very seriously.

Yet it would seem that this Labor government has again failed to recognise PDD-NOS, with this policy promising only to recognise 'students with autism and Asperger's disorder to streamline support for these students'. There is no mention at all of PDD-NOS.

Additionally, in its policy the government promised that two of the new special education units for children with a disability would have a specialist focus on autism spectrum disorders becoming 'centres for best practice in autism spectrum disorder learning'. I suspect the answer is evident, but I ask whether these units will include children with PDD-NOS as part of their best practice.

Is it too much for the people of this state to ask that the minister of this government who is paid to meet the needs of some of the state's most vulnerable dare make a decision for the people of this state without first having to consult with other states about a disorder that they already acknowledge?

According to Monsignor Cappo, SA is the only state that excludes those with PDD-NOS from essential services and supports. No doubt by 2013 when the DSM-V is released, all states will move towards a national, united approach, but the families of those with PDD-NOS in South Australia should not have to wait until then to receive what they are entitled to.

It is this disparity between the services available to those living with PDD-NOS as opposed to autism disorder that gives rise to the wording of the motion before the council. I call upon members to support PDD-NOS being rightly recognised as an autism spectrum disorder and for services to be provided accordingly. I also inform the council that Autism SA is in total support of this motion. I commend it to the council.

Debate adjourned on motion of Hon. J.M. Gazzola.