Select Committee on Autism inquiry into the services, support and life outcomes for autistic people in Australia and the associated need for a National Autism Strategy

28 July 2020 Hearing

QUESTIONS ON NOTICE

QUESTION 1 -

CHAIR: Among all of the reports we get from parents, I'm yet to find a parent who has told me they've had wonderful follow-up care from the public diagnostic process. I know of a number of parents who have had the diagnosis and basically been told, 'Yes, it's autism,' in the most unfeeling of ways. They have been given a very vague report and sent on their merry way with a tissue. Perhaps take that on notice, and maybe you can have a look for me at what the process is and if there is any follow-up. In particular, we need to acknowledge—and there have been multiple studies done—that many autism parents suffer levels of stress equivalent to soldiers in combat, yet in New South Wales people are going to paediatricians in the public health system because they don't have local supports. Where are you referring them back to if they don't have a local support? Perhaps you can take that on notice for me, and I'll have a look at your submission and see if anything has touched on it. I will, potentially, send some questions on notice to you as well.

ANSWER

NSW Health guidelines on pathways to care for children and adolescents with intellectual disability and challenging behaviours, and/or mental health problems, outlines a role for the general practitioner (GP) and the general paediatrician to provide information and advice about additional services and supports that are available. NSW Health paediatricians determine on a case by case basis how best to provide any additional information for families.

Importantly, parents of young children, including those receiving a diagnosis of autism, can receive advice and support from a range of sources including their child and family health nurse, community health centre, Aboriginal health centre or the Building Strong Foundations service, as relevant to their unique circumstances. They may also receive support from a National Disability Insurance Scheme (NDIS) funded Early Childhood Early Intervention Service.

A key priority for the NSW Health system is the design and delivery of high quality, effective and safe health care services for children, young people and families, from conception until 24 years of age. In 2019, NSW Health commissioned a review of health services for children, young people and families. All seventy seven recommendations from this review (The Henry Review) have been accepted. Developmental assessment and services were identified in the report. Implementation planning has commenced to address recommendation 52 *“undertake a project to determine the most efficient and effective way both to perform developmental assessment and to focus on increasing the capacity of families to adjust to and optimise management of their child’s disability*”.

QUESTION 2 –

Chair: Either you, Dr Wright, or you, Dr O'Meara, might be in a position to either answer this or find out for me. Hunter New England health service had a policy in place about six or seven years ago—I can assure you this occurred—that children with a disability were no longer to be seen by community health speech pathologists et cetera. Children who had speech issues but no diagnosed disability were able to access community health, but children who were diagnosed with a disability became, all of a sudden, the problem of ADHC and then the NDIS. This was even though in a lot of rural and regional areas, which the Hunter New England health system, remarkably, covers, there was no access to other public speechies, particularly if children were funded through ADHC—let alone private speechies when they do get an NDIS plan. Do any of the health services in New South Wales still have that policy, and, if so, how is it being reviewed?

Dr Wright: I'm not aware of any such policy. I would have to take that on notice.

CHAIR: I can absolutely tell you it was the case, because my son was kicked out of speech therapy on that policy.

Dr Wright: I appreciate that, Senator, but we are talking seven years ago. We're asking about today—

CHAIR: We are talking about seven years ago, but we're seeing the states vacate the space all over the show when it comes to what responsibility they have. As soon as a kid seems to have a disability it's all the NDIS's problem. Anyway, if you can take that on notice to make sure that it doesn't exist in any health system across this state, that would be much appreciated.

ANSWER

NSW is committed to meeting NSW Health’s responsibilities as agreed by the Council of Australian Government’s (COAG). More information is available at: https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf.

NSW Health Local Health Districts and Speciality Networks provide universal access to health services. Where appropriate, NSW Health will support patient and consumer access to funded services which are the responsibility of, and provided by, other programs or schemes. If there are no alternative services funded through other programs and schemes, NSW Health can provide services based on priority and need.

Hunter New England Local Health District service criteria is based on the Commonwealth agreement regarding health services versus disability services. In line with COAG guidelines, NSW Health provides short term, goal focused and time limited treatment instead of the longer-term multidisciplinary support which is generally required by children with disabilities such as Autism.

Currently, children who live in regional and rural communities in the Hunter New England Local Health District can be provided an assessment and interim access to services such as Speech Pathology when there is no NDIS funded service options available in their community.

QUESTION 3 -

Senator GRIFF: I'd like to go back to Senator Hughes's comments in relation to waiting times and actually get some numbers from you, which we will be asking from other states as well. I know you might have to take some of this on notice. Given Australian and international guidelines recommend children wait no longer than three months for a developmental assessment, what are the actual current time frames for an autism diagnosis in the public system in New South Wales?

Dr Wright: I certainly don't have that number to hand. I'd defer to Dr O'Meara but I suspect he doesn't have it to hand either.

Senator GRIFF: You can take that on notice.

Senator Griff: I'd also like to ask: how many families in New South Wales are currently waiting for an autism diagnosis? Is this the same for all postcodes in New South Wales; for example, is it easier to obtain a diagnosis in the eastern suburbs compared to Western Sydney—again, in the public system? What is the wait time for a diagnosis in regional and rural areas in New South Wales? And are you using telehealth services at all in the diagnosis of ASD for people in regional and rural areas?

Dr Wright: I can answer the last question. We do use telehealth services. There's a service which is run out of the Sydney Children's Hospitals Network at Westmead, called CAPTOS—that's an acronym, but I can't remember the words it describes. It's a telehealth service provided across the state, particularly focusing on rural and regional areas. It supports both clinical assessment and case conferencing for those areas where there's limited access to specialist child psychiatrists.

Dr O'Meara: I can add to that. There's also a virtual service, the Paediatric Developmental Program, run through Royal Far West and supported by New South Wales Health.

Senator GRIFF: If you could let us know the number of people accessing that, that would be beneficial as well. The Tasmanian government's submission—which you may or may not have seen—states:

> *establishment of the NDIS has compounded workforce issues, with many allied health professionals leaving the public service to set up private practices …*

which is impacting diagnosis and availability of services. Has this also been the case in New South Wales?

Dr Wright: I'm not aware of that as a concern. That may be restricted to other jurisdictions. I'm not aware of it in New South Wales.

ANSWER

The NSW Ministry of Health does not have centralised data on waiting times for children presenting to NSW Health facilities for developmental assessment, including for diagnosis of autism spectrum disorders (ASD).

The NSW Ministry of Health also does not have centralised data on the number of people accessing telehealth services for the diagnosis of ASD.

Data may be available from the individual paediatric child development clinics and other services such as developmental mental health clinics.

To gather and report this data for the purposes of answering this question taken on notice would require a longer term project to map services across NSW and to analyse their individual waitlist data. Data quality would also need to be tested to ascertain whether it represents an accurate report on the current waiting times for a diagnosis of ASD and telehealth services in the public system and the variations between metropolitan, regional and rural areas of NSW.