

Submission S081

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Family and Community Development Committee

# Victorian Parliament Family and Community Development Committee: Inquiry into services for people with autism spectrum disorder

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cohealth welcomes the opportunity to contribute to the inquiry into services for people with autism spectrum disorder ("ASD"). Our response to the inquiry will focus on the following two terms of reference:

b) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services; and

d) evidence of the social and economic cost of failing to provide adequate services

## **cohealth**

cohealth is a not-for-profit community health service operating across the north and western regions of Melbourne. cohealth provides an integrated platform of health care and social support services. This integrated platform includes medical, dental, allied health, counselling, mental health, health promotion and prevention, youth services, community support services and other programs to promote community health and wellbeing. These services are delivered from 44 sites across 14 local government areas in the north and west of Melbourne.

cohealth prioritises people who experience disadvantaged social circumstances and who are consequently marginalised from many mainstream health and other services. This includes people who are homeless or at risk of homelessness, people who live with serious mental illness, vulnerable families, Aboriginal and Torres Strait Islanders, refugees and asylum seekers, people who use alcohol and other drugs, recently released prisoners and LGBTI communities. Many of the people who access our services experience barriers that prevent them from accessing mainstream health services.

cohealth provides a range of paediatric allied health services for preschool aged children and their families in the early stages of identifying developmental delays or differences. Some of these children require referrals to specialist ASD assessment and intervention services.

## **Summary of Recommendations**

- 1. An item called "query ASD" should be available so that families can qualify for a range of support services in the *interim period* (see definition of interim period below) between the preliminary screen and the paediatric assessment for ASD.**
- 2. Provide support packages of \$3,000-\$5,000 for families during the interim period to purchase:**
  - a. Occupational Therapy**
  - b. Speech Therapy Services**
  - c. The *More than Words* program<sup>1</sup> (for children 5 years and under).**
- 3. Continue to fund a family services coordinator to conduct home visits to support families to access services in this interim period following the commencement of the NDIS.**

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<sup>1</sup> See <http://www.hanen.org/Programs/For-Parents/More-Than-Words.aspx>

4. **Create and fund a network of multidisciplinary autism spectrum disorder assessment clinics in community health settings. Clinics would include paediatricians, speech pathologists and psychologists.**

#### **Issues with the Current System**

- The current system of diagnosing young people with ASD is varied. In the community health setting this involves an initial consultation between the family and the child and a speech pathologist or other allied health professional. If required a referral for a paediatric assessment is made.
- A diagnosis of autism may need to occur over a period of time, and a number of sessions, using a range of diagnostic options
- Families waiting for a paediatric assessment are not eligible for health and social supports during this interim period
- Adequate support is required for children during the interim period to respond to the range of needs that many of these children and their families present with.
- Clear pathways for families awaiting a diagnosis of ASD need to be established and resourced
- In relation to the NDIS, there is a need for the State Government and the NDIA to communicate to promote the inclusion of pathways to an ASD diagnosis as items available through individual packages in the NDIS

Vulnerable and disadvantaged families of children who are screened for ASD face an interim period before a public paediatric assessment is performed on the child. This interim period can be up to 12 – 18 months long for families who are reliant on the public health system. This wait places pressure on families and is a lost opportunity to implement early intervention strategies to support a child’s development.

There are two types of Interim periods:

1. Families referred to Early Childhood Intervention Services (ECIS) and waiting for intake following preliminary screen (approximately 4 – 12 months)
2. Families not referred to ECIS and waiting for paediatric team assessment following preliminary screen due to uncertainty with diagnosis (approximately 12 - 18 months)

Providing a funding package of \$3,000 - \$5,000 would enable families to access specialist services to support their child’s development. This package would fund occupational therapy, speech services and the *More than Words* program.

#### **Recommendation 1**

**An item called “query ASD” should be available so that families can qualify for a range of support services in the *interim period* (see definition of interim period below) between the preliminary screen and the paediatric assessment for ASD.**

#### **Recommendation 2**

- **Provision of support packages of \$3,000 - \$5,000 for families during the interim period to purchase:**
  - **Occupational Therapy**
  - **Speech Therapy Services**

- **More than Words program<sup>2</sup> (for children 5 years and under)**

It is essential that families have the support required, firstly to gain access to the funding, and then to exercise choice about the services and supports available throughout the decision making process, and in the final decision. Depending on the challenges facing families there might be a range of views as to the best available options. This is where the support of a family services coordinator is needed to assist families to make the best decision possible about services and supports. There is also a particular need to support culturally and linguistically diverse families who require interpreters to navigate their way through the service options available.

### **Recommendation 3**

- **Continue to fund a family services coordinator to conduct home visits to support families to access services in this interim period following the commencement of the NDIS.**

Diagnosing a child with ASD requires specialised care. This process is only available through engagement with multiple medical specialists. An additional model would see specialist multidisciplinary autism health clinics in accessible and inclusive settings such as community health services. Community health services have years of experience in running similar clinics, using a person-centred, locally-based approach that brings together a team of appropriate professionals and includes specialists on outreach from acute hospital services.

Current examples at cohealth include:

- Multidisciplinary diabetes clinics including diabetes nurse educators, dietitians and podiatrists, plus others as required, and run in collaboration with Western Health endocrinology specialists
- Hepatitis clinics which include GPs and nurses plus outreach by infectious disease specialists from Royal Melbourne Hospital.

Receiving care within a community health setting provides many benefits for the service user. These include welcoming, non-judgmental attitudes, easier access, reduced wait times, improved continuity of care and ease of linking in to further health and wellbeing services as required.

cohealth also has experience in providing clinics for particular groups of people who have been identified as being at high risk of poor health outcomes; and/or who experience significant barriers in accessing mainstream health services. Current examples include targeted services for: people who are homeless or at risk of homelessness; refugees and asylum seekers; and Aboriginal and Torres Strait Islander people. These services provide an accessible space for people to seek health care, safe in the knowledge that their needs and circumstances will be respected and understood.

Clinics for specific groups and/or purposes do not necessarily need a large amount of new infrastructure, but can be set up as a designated time period (e.g. one day or even one session per week) within established clinical services.

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<sup>2</sup> See <http://www.hanen.org/Programs/For-Parents/More-Than-Words.aspx>

Clinic models would draw on the skills of a range of appropriate health professionals (GPs, nurses, allied health, mental health professionals etc.) who are trained in ASD. They would utilise both outreach models and care pathways to link with medical specialists (paediatricians etc.) and hospitals as required.

By creating a network of multidisciplinary ASD health clinics in community health settings the clinics would provide accessible places where a diagnosis of ASD can be performed, following a referral from a speech pathologist in the generalist community health setting. Working in partnership with appropriate specialist services would build local capability through mentoring of clinic staff and increasing the capacity of the health system to work knowledgeably and sensitively when dealing with ASD.

#### **Recommendation 4**

- **Create and fund a network of multidisciplinary autism spectrum disorder assessment clinics in community health settings. Clinics would include paediatricians, speech pathologists and psychologists.**