Submission No 29

IMPROVING ACCESS TO EARLY CHILDHOOD HEALTH AND DEVELOPMENT CHECKS

Organisation: Murrumbidgee Local Health District

Date Received: 29 February 2024

About MLHD Genetic Services

The genetic counselling service for Murrumbidgee LHD (MLHD) based at Wagga Wagga Health Service Hub currently has a 1.0 FTE genetic counsellor, at grade level 4 on the NSW Health Professionals Award. It is a sole practitioner position which covers all facets of genetic counselling including general genetics (paediatrics, neurology, oncology, cardiology, metabolic disorders, complex adult-onset disorders, newborn screening, infertility/ART/IVF, preconception and genomics) as well as familial cancer services. There is provision through historical funding established by NSW Department of Health in 2010 for a 0.6 FTE Clinical Geneticist based at the Liverpool Hospital, to provide outreach clinical genetic service for Greater Southern Area Health Service (GSAHS). Additional funding through the Rural Doctors Network (RDN) enables this clinical geneticist to attend for 10 (one day) outreach clinics in Wagga Wagga per year. This equates to approximately 68 clinical appointments per year. These appointments are critical for specialist examination in children with complex developmental, learning and health problems.

Since 1992, when the service in Wagga Wagga first started, there has been no enhancement of staff, yet there has not only been an increase in population, but also significant advances in genetic and genomic knowledge and understanding which has contributed considerably to the diagnostic yield of genetic disorders, as well as therapies and interventions to minimize the development of symptoms. This has resulted in a significant increase in workload for the genetic counsellor who is the primary staff member responsible for coordinating genetic and genomic services.

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As a consequence of the lack of resources not only in the MLHD but in all regional and rural LHD's in NSW the ability to identify children early who are not meeting developmental milestones which may be due to an underlying genetic disorder are delayed. Many families are waiting over 2 years to be seen in a clinical genetics service, further delaying specialist diagnostic testing, treatment and counselling on potential implications for future pregnancies. There is a risk that without a formal diagnosis and intervention there could be a recurrence of the condition in other family members in some cases.

I believe the limited access to clinical genetics services in regional NSW are part of the block to specialty assessment services for children who are not meeting developmental milestones. Furthermore, there is a growing number of conditions where new therapies, including gene therapy, have the potential to significantly improve outcomes if started early enough. A significant financial investment in additional genetic counsellors in regional and rural NSW and clinical geneticist FTE would be required as soon as possible to increase the equity of access for families to clinical genetic services. The increase in genetic counsellors could also provide necessary support to paediatricians and other paediatric specialist in the integration of mainstream genetic testing in regional and rural NSW.

I would be happy to answer any detailed questions in relation to the above submission.

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