



Special Commission of Inquiry into Healthcare Funding

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Prof Adam Guastella

Level 2, 100 Mallett St

Michael Crouch Chair in Child

CAMPERDOWN NSW 2050 AUSTRALIA

And Youth Mental Health

Telephone: [REDACTED]

Facsimile: [REDACTED]

Email: [REDACTED]

Purpose: To establish a digital hub and decision-making tools for neurodevelopment for use in developmental assessment services.

Neurodevelopmental disorders (NDDs), such as Autism Spectrum Disorder (ASD), affect 10% of the population or 2.4 million Australians¹⁻³. About 35% of participants in the National Disability Insurance Scheme (NDIS) meet criteria for ASD, a scheme projected to cost 30 billion per year⁴. Individuals with NDDs have much higher rates of mental health concerns^{5,6}, hospitalisation and mortality, and poor social, academic and occupational outcomes across their lifespan^{7,8}. Children and adults with NDDs are also significantly overrepresented in acute care services⁹. Their presentations to emergency and inpatient hospital settings far exceed those of the general population. In fact, in adolescence, these hospital stays represent one of the most frequent reasons for admission in the public system for adolescents⁹.

Despite this enormous demand, economic burden, and need, healthcare for people with NDDs is characterised by expensive, sub-optimal and complicated processes that create multiple barriers to accessing support.

To illustrate, from our Sydney Child Neurodevelopment Registry in public developmental assessment services, we reported that children (N=916)¹⁰ were waiting, on average, 3.5 years for a multi-disciplinary assessment, from the point at which caregivers first identified concerns. In fact, most vulnerable children (54%) did not receive an assessment by school age, even though 88% of caregivers had raised concerns about their child's development by that age.

For clinicians, the writing of reports and administrative collation of data takes up a significant amount of developmental assessment service time. Independent evaluations of the clinical teams have shown that these tasks take up an estimated 20% of clinician time.

We have also found additional concerns that leave many caregivers without the supports that they need for their child. Provided assessments can be focused heavily on diagnostic needs, due to how funding for supports can be activated, but they can overlook some of the problems and issues that directly impact the daily lives of caregivers and families. For example, we found that caregivers often present to services wanting information about academic supports, mental health, and supports to address non-diagnostic features of child and family concerns¹¹. This means that while families can be on wait lists for very long times to receive the assessment, they may not get the information they need when receiving feedback. Moreover, the information provided can be overly technical and difficult for families to understand, often requiring a year 11 education level to understand the content provided.^{11,12}

More recently, we have shown that even after a high-quality assessment, families struggle to get access to specific supports, particularly supports that are funded by state health systems. For example, more than 50% of children with neurodevelopmental conditions report significant mental health concerns¹³. The rate of mental health concerns increases to 70% when children have more than one diagnosis. Yet, while a large majority of children with neurodevelopmental conditions can access speech and occupational therapies through the NDIS, many families reporting wanting to, but being unable to, access psychologists. In fact psychologists remain one of the most sought after therapists for children with neurodevelopmental conditions¹², but funding to access such services is largely driven through overburdened state based supports (community mental health) or private referrals, leaving many families without financial reserves unable to access such services.

Solutions: A statewide digital hub for neurodevelopment assessment and support

The solutions to these problems are complex and cannot be met by a ‘one size fits all’ model. Some local health districts have very limited resources to conduct neurodevelopmental assessments and to provide support. Some services largely provide secondary supports to community paediatricians and general practitioners. The focus for these services may be best placed in provide supports and digital tools that help paediatricians and medical practitioners to provide effective supports and educated referrals to specialist assessment only when needed. Others services provide a more comprehensive assessment for more complex cases that require a high degree of specialisation and technical skill. These services need much more support in managing administrative demands of assessment, but also provide families with seamless pathways into future supports.

The tools needed to support different models of care may differ, but I believe technology has a major role to play in providing feasible solutions to solve some of the administrative burden for clinicians, and address issues around access and barriers to provide evidence-based solutions for families.

To begin to solve these problems, we have formed a research and clinical collective at the University of Sydney (The Neurodevelopment and Mental Health Clinical Academic Group in partnership with Sydney Health Partners).

The established partnership extends across child development assessment services across:

Sydney Children’s Hospital Network

Central Sydney Local Health District

Northern Sydney Local Health District

Western Sydney Local Health District

Nepean Blue Mountains Local Health District.

Moreover, we have received interest in expanding this collective to South Eastern Sydney, Illawarra Shoalhaven and Hunter New England Local Health Districts.

The principal goal of this collective is to use evidence-based practices to drive new technologies to deliver assessments and supports for children, families and clinicians that can drastically improve access and efficiencies for assessments and supports. With the right

investment in these digital tools, we will have a platform that can be used state-wide, in rural, remote, regional and urban areas, to support clinicians and children and families on their journey in neurodevelopmental assessment.

Much of the foundational work we have conducted has specifically been conducted in partnership with the Child Development Unit at the Sydney Children Hospital Network. This work has already shown that 88% of families prefer digital tools over pencil and paper tools¹⁰. Moreover, when families complete information using digital tools, completion rates increase from 36% (pencil and paper) to 90% (electronic). When families provide information using digital tools, they also report being able to access relevant information more easily, being able to seek assistance from other people more easily (which seems to be particularly important for Culturally and Linguistically Diverse Families) and are better able to keep track of the information. When information is saved online, it is less likely to be lost and can be better used to track change over time.

For clinicians, digital tools save time although there can be a significant initial change management burden in process. Clinicians report that having access to automated calculating tools saves enormous amounts of administration time and frees up time to engage in more specialist tasks. In creating this digital platform, we have established:

- 1) The largest child neurodevelopment research registry in the country, building capability, capacity and collaboration across Local Health Districts and the University of Sydney.
- 2) A harmonised research dataset that can describe the needs of children and families attending developmental assessment units, optimised for partnership across services.
- 3) Innovative automated digital tools to improve responsiveness of assessment and streamline efficiencies for clinicians and families.
- 4) Community advisory groups to consult, including children, youth and caregivers.
- 5) A hub for researchers and clinicians to engage in translational research that will improve health services and outcomes for families.

Digital tools have potential to:

- Develop an Australian based and NSW based neurodevelopment data registry for identifying, tracking and responding to needs dynamically over time and within clinical services.
- Provide analytic tools for data collation and automated report writing. The aim is to reduce administrative burden as much as possible so expert clinicians can spend more time conducting assessments and writing personalised reports from the data that has been automatically collected. Clinicians already report these tools save them hours in administrative time so that they can write better quality and more personalised reports.
- Clinical decision-making tools to guide identification of needs and support responses to needs. The decision-making tools help clinicians and families know where to go and what to recommend as needs are identified.
- A digital support hub for interventions, education and infrastructure to provide families with digital tools for support. Our research has shown that 8% of families currently report access to digital supports¹², yet more than 50% report a strong desire to access digital

supports that can more immediately be accessed to equip them with the skills to help themselves and their family. This could include educational tools for intervention and management, and it could also include mental health and other transdiagnostic supports that families currently struggle to access.

Finally, having access to evidence based information provides critical data to make policy decisions and advocacy for change. Our group has led numerous conversation articles and representation to government based on the snapshots and reports from the data.

Please see:

<https://theconversation.com/wondering-about-adhd-autism-and-your-childs-development-what-to-know-about-getting-a-neurodevelopmental-assessment-197528>

<https://theconversation.com/around-half-of-kids-getting-neurodevelopmental-assessment-show-signs-of-mental-distress-we-can-support-them-better-205225>

<https://theconversation.com/gps-could-improve-access-to-adhd-treatment-but-we-still-need-specialists-to-diagnose-and-start-medication-210803>

Investment is need to uplift what we have developed thus far and in partnership with clinical services in hospital and local health districts. The investment will quickly pay for itself in improving healthcare pathways for children, families and clinicians and directing future policy changes.

Professor Adam Guastella

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