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IMPROVING ACCESS TO EARLY CHILDHOOD HEALTH AND DEVELOPMENT CHECKS

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Background:

Neurodevelopmental disorders (NDDs), such as Autism Spectrum Disorder (ASD), affect 10% of the population or 2.4 million Australians[1]. About 35% of participants in the National Disability Insurance Scheme (NDIS) meet criteria for ASD, a scheme projected to cost 30 billion per year.

Early childhood development checks conducted by NSW Health have a crucial role in promoting the health and well-being of children in NSW. By identifying potential health or developmental concerns early on, these checks can help to ensure that children receive the support and interventions they need to thrive. Unfortunately, the often don't do this. Families are often placed on a path of watch and wait until more formal assessments can be conducted.

To illustrate, our Sydney Child Neurodevelopment Registry in public developmental assessment services showed that children[2] 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%) do not receive an assessment by school age, even though 88% of caregivers are concerned about their child's development by that age.

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 diagnosis, but they can overlook some of the problems and issues that directly impact the daily lives of caregivers and families[3]. 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 from the assessment.[3,4]

TERMS OF REFERENCE:

1. **Changes needed to address gaps in outcomes for vulnerable children, including those in rural and remote communities, Aboriginal communities, and culturally and linguistically diverse communities.**

The solutions to these problems are complex and cannot be met by a 'one size fits all' model. There is an urgent need to provide flexible clinical decision-making tools for families and services. We argue technology has a major role to play in providing feasible solutions to uplift capacity to increase responsiveness of systems and to address family needs.

These solutions need to be embedded within assessment services and co-developed with stakeholders.

To give one example the Child Neurodevelopment and Mental Health Clinical Academic Group in partnership with Sydney Health Partners is a partnership that extends across child development assessment services across The University of Sydney, Sydney Children's Hospital Network, Central Sydney Local Health District, Northern Sydney Local Health District, Western Sydney Local Health District, and Nepean Blue Mountains Local Health District.

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

This work has already shown that 88% of families in public health services prefer digital tools over pencil and paper tools[2].

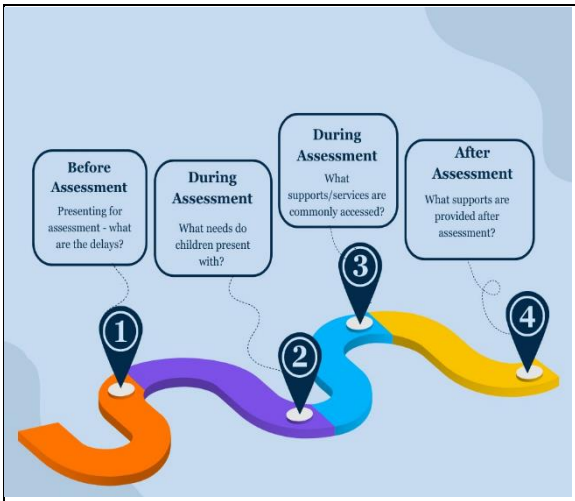
Families are able to use digital tools to access relevant information more easily, which seems to be particularly important for vulnerable families, such as Culturally and Linguistically Diverse families.

Clinicians report that having access to automated digital tools saves enormous amounts of administration time and frees up time to engage in more specialist tasks.

To illustrate, the digital systems we established in community and tertiary services include:

1) **The Sydney Child Neurodevelopment Registry:**

    - The largest child neurodevelopment research registry in the country which is embedded in clinical practices across New South Wales. This registry tracks population characteristics, wait times and family needs from the point of contact to neurodevelopmental assessment services. It then is used to track outcomes throughout the assessment process to the point of referral to other community services (See Figure 1).



1.Embedded assessment and referral tools to swiftly assess and respond to family needs at the time of initial contact.

2.Automated collation and reporting tools that deliver information about strengths and need to a family.

2.Digitised personalised referral pathways into clinical care that address complexity of needs and multiple family and service referral pathways.

4. Access to digital supports that can be used to provide interventions that improve outcomes for the child and family.

Figure 1. Digital tools embedded in clinical assessment pathways.

Evidence for utility:

- Evidence of high acceptability of the registry to families and services above standard clinical care. We showed 88% of families prefer the embedded digital registry above standard pencil and paper clinical tools. This is a largely vulnerable cohort with financial, cultural and linguistic diversity.

- Allows for collating formation and tracking of family and service needs. It also offers opportunities to give families digital supports, and to guide pathways into referrals and interventions based on their specific profiles. This information can be provided immediately, not months after assessment.

- Provides a source of advocacy for accurate information about
    - Wait times and service barriers for different populations[5].
    - Tracking of information about what families need at any given point[6].
    - Service improvements to improve outcomes and reduce cost.

This success of this registry shows potential for further expansion of digital tools into clinical services providing early childhood health and developmental checks, to be embedded one step earlier in primary care and early surveillance services. Such assessment could then be linked to later assessment and referrals supports noted above.

Examples of how digital tools could improve clinical pathways for developmental screening and assessment.

Detect: We have trialled video-based algorithms to detect neurodevelopmental delay. Our pilot studies suggest that we can detect autism spectrum disorder with 95% accuracy using videos of child play and unique algorithms that detect the quality of child reciprocity. This new technology could remove a substantial barrier to detection by not relying so heavily on expert clinical assessment of play. It would also enable assessments to be conducted with video (e.g., smartphone) footage that can be collected in the home.

Collate: 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.

As part of the clinical assessment, automated collation tools allow for accurate scoring and delivery of outcomes and reports for different audiences (e.g., schools, families, health professionals). The generated reports can save hours of clinical time and ensure that clinicians can spend more time personalising reports to each individual family or audience.

Support: Our research has shown that 8% of families currently report access to digital supports[4], 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.

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