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Using translational neuroscience and technology for personalised medicine and impact in child neurodevelopment

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One of the things that Dr Gordon talked about and I've heard repeatedly is the future of science really is about data. It's really about the quality of the data that we can collect. I studied as a clinical psychologist and neuroscience was largely in the dungeons of psychology departments with amazing outcomes, amazing studies but largely confined away from the clinics.

The future of research, the future of neuroscience is in the clinic with the patients, with their concerns, with their needs and using precision medicine to guide the assessments and treatments that we provide for them. I'm going to use Child Development as a way to understand this. You see, there's a massive need in our community. The NDIS is a $30 billion industry to the Australian government. 36% of those children in the NDIS have a diagnosis of autism but the research behind neurodevelopment and autism is very poor. I could give you one book on a shelf to cover the amount of evidence we have for how we assess and how we provide support to kids with autism. And that has to change. And we know, through the work at Sydney University and across our many community partners, that kids are on waiting lists for way too long just to get a basic assessment. You see on average children wait 3½ years from the time caregivers notice a delay to the point of getting their assessment. 88% of caregivers know there is a concern by the time children start school but can't get a neurodevelopment assessment. We need to change the science. We need to change the practices behind how we do assessments and provide supports to families. It's a national emergency. The problem is the current assessments that we have are incredibly complicated, requiring specialised care and lots and lots of training by really wonderful and excellent therapists, allied health medical staff. Most assessments take at least a full day to get a really good understanding of child neurodevelopment.

But there are fundamental building blocks of what we're looking for to try and detect and understand child development and we can do a much, much better job of trying to detect delays using 21st century approaches. You see, it shouldn't be all about a diagnosis. Much of the research we've done recently has shown the fundamental things that if you like diverge in brain development are not unique to a diagnosis. We found that, for example, executive function delays are common across all neurodevelopmental conditions. There are very few unique markers that predict a specific type of neurodevelopmental condition and this brain divergence that occurs or this delay in executive function skills and attention skills

1 This is an edited transcript of the address [Ed.]

seems to emerge by the age of 2 to 3 and get larger by ages for 4 and 5 across diagnosis.

So the question is: how can we develop markers that better assess neurodevelopmental delay without getting caught up necessarily in a specific diagnosis? And we know parents report huge needs for services so we know that the vast majority of parents experience huge waiting lists to get care. They report financial barriers to access specialists to provide that care and they don't know where to go. Despite this, about 50% of families across all of our community health clinics want digital tools and digital support and training programs to support their child and training for them to know what to do. So we've established the largest neurodevelopment research network in Australia, collecting data from firstly hospital-based clinics but also community-based clinics of the most vulnerable families entering services, seeking assessments for their children.

What we're seeking to do is to develop evidence-based data-gathering procedures, methods to track and to support families using digital tools. This means that we're giving access to research for the most vulnerable members of our society. Clinicians can use this search to access reports and data calculations almost immediately to speed up the time they have to provide feedback to families, and we can provide clinical trials to families, personalised care methods almost immediately, so families that typically are excluded from clinical trials are now getting access to clinical trials through our research network.

In just one year of functioning we've had over 2,000 children enter the database for research of vulnerable families, 50% from cultural and linguistically diverse families. These are families that typically never get into research databases, never get into research that guides evidence-based research for the federal government and state governments. And we've become very proactive in highlighting needs. So for example, we know that we've been very active in showing the huge delays to diagnosis but also that families prefer digital tools when completing their assessments. So we know that 88% of families much preferred digital tools to pencil-and-paper tests, that when families use digital tools, their completion rate jumps from 36% up to 90%. So that means clinics are getting more effective data more immediately; clinicians are getting the data faster to provide feedback to families; and families prefer the immediacy of the data collection methods. So now what we're doing is looking at how we can use the digital world with neuroscience to create real impact. Can we integrate the data collection methods into everyday practices, daily living, what the kids do on a daily basis? I believe we're only at the start of this journey. In years to come neuroscience will come to the fore and guide the way for science to drive real change.

There's an opportunity for neuroscience that it's never had in the past: using data in the real world to guide practice through the tracking of systems and circuits. To give you one example, we've been tracking reading in young children and how young children interact with the daily pastime of reading books with their caregivers. We've been using eye-tracking methodologies to understand how that practice might impact on learning and development and might also predict child neurodevelopmental delays. These paradigms have been incredibly powerful to show early divergence in

attention to reading and to the caregiver's face. This predicts neurodevelopmental diagnosis independent of a specific diagnosis like autism.

So we're now able to use these very common, daily tasks that caregivers have with their children to start to detect delays in children, and possibly in the future to intervene. We've been working really closely with our engineering colleagues to video record every assessment that's conducted in the clinic and to try to develop biomarkers just through observation, rather than clinicians having to spend an hour and a half with families and trying to develop some algorithmic score of what they observe. We're using algorithms developed by AI to generate these skills independently. And what we've been able to show is that, by using things like joint attention and eye gaze and facial movement, we can differentiate between a neurodevelopmental diagnosis with 90% accuracy immediately at the point of an interaction. And this means that families will get answers in the future about delays for their children and their interactions faster than ever before. And now we're using these data to guide how we refer families and children into different therapies.

So we heard about the potential of gut therapeutics and we've been involved in an international study looking at the potential of gut therapeutics to reduce irritability in children with neurodevelopmental delays. We've currently done a lot of work around oxytocin (and the potential of the love hormone) and I contend that there's much more to love than the brain. We've been looking at how our children learn in their social environment, if you like — engage in social learning over time using these data collection algorithms so that if children don't respond to the immediacy of therapy, we can use biological or targeted therapies to increase their response. We can make sure that children get what they need out of therapy using biosignals.

This is a snapshot of what we're doing and I guess it flips into a lot of what Joshua Gordon talked about in relation to psychosis but we have the opportunity in Australia through our wonderful public health system to do something more immediate that accesses the most vulnerable families in our society and really to lead the way in progressing change in child neurodevelopment. Thank you very much.