CliniKiDS
Research into Practice

TELETHON KIDS INSTITUTE

Department of the Senate
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Members of the Senate Select Committee on Autism,

Re: Inquiry into the services, support and life outcomes for autistic people in Australia and the associated need for a National Autism Strategy

CliniKids is very pleased to be providing a submission to the Senate Select Committee on Autism.

CliniKids is a national centre of autism clinical research excellence, based at the Telethon Kids Institute in Perth, Western Australia. Directed by Professor Andrew Whitehouse, CliniKids is a nationally unique model that integrates cutting-edge research into every-day clinical services. CliniKids supports the complex needs of children (and families) with early social communication delay and/or autism spectrum disorder (autism) through early intervention and diagnostic services backed by leading and innovative research. The aims of CliniKids are:

1. To identify new methods for improving the quality of autism diagnosis and interventions available to Australian families, including creating personalised therapies that are specific to each child's needs;
2. To rapidly translate research evidence into Australian clinical practice for the benefit the autism community.

With more than 50 researchers and clinicians working side-by-side, CliniKids achieves this aims through large-scale research projects, an extensive network of national and international scientific collaborations, research and clinical partnerships with Government and non-Government organisations, and by offering training of new and existing clinical interventions for clinicians across Australia and the world.

CliniKids was launched by the Federal Health Minister, the Hon. Greg Hunt MP, in October 2019, and has since become the largest autism research centre in Australia, playing a leading role in scientific research and clinical advances for children on the autism spectrum.

The 'research into clinical practice' model that CliniKids has pioneered, combined with our involvement in key policy decision previously made in the area of autism, provides our organisation with a unique perspective of the challenges and gaps in the health and disability sectors, as they relate to autism.

CliniKids strongly supports the principle of a National Autism Strategy that describes a coordinated approach to support each individual on the autism spectrum reach their full potential. We have selected items from the Terms of Reference on which CliniKids is qualified, and has expertise, to comment. These centre around the early clinical pathway for autism, from 0 to 12 years of age. Our responses to these items cite a number of publications that we would recommend the Committee review as part of its consideration of these matters.

A summary of our recommendation is as follows:

1. The nationwide implementation of the clinical procedure described in National Guideline for Assessment and Diagnosis of Autism, including matching of Medicare Benefits Scheme (MBS) items to the Guideline recommendations;
2. The development of a National Autism Register to monitor autism prevalence, modelled on the Western Australian Autism Register.
3. The independent development of a National Quality Framework of Best Practice in Early Intervention for Autism,
4. Commonwealth Government investment into research projects that:
    a. Compare the effectiveness of current evidence based interventions;
    b. Seek to identify which intervention is most effective for which individual with autism;
    c. Determine the long-term effectiveness of current evidence based interventions; and
    d. Expand our understanding of the efficacy of interventions for infants showing early sign of autism.
5. The Committee consult the 2019 report from the Autism Cooperative Research Centre on national autism research priorities in order to determine further research priorities for Australia.
6. The Committee examine the ‘research into practice’ model pioneered by CliniKids (Telethon Kids Institute) for potential replication across Australia.

CliniKids and Prof Andrew Whitehouse would welcome the opportunity to provide further input to the development of the National Autism Strategy.

a. current approaches and barriers to consistent, timely and best practice autism diagnosis.

In response to this and other items, we refer to the publication of the landmark National Guideline for Assessment and Diagnosis of Autism (the ‘Autism Diagnostic Guideline’; Whitehouse at al., 2018), which was released in October 2018 and can be downloaded here:
https://www.autismcrc.com.au/knowledge-centre/resource/national-guideline

The Autism Diagnostic Guideline was developed to provide a standardised and consistent clinical process for the assessment and diagnosis of autism in Australia. Because there is currently no established biological marker for autism, ‘gold standard’ diagnosis is presently a ‘best estimate’ clinical judgement based on the behavioural presentation of the individual. However, the variability in early autism symptoms and the considerable behavioural overlap with other developmental disorders means that autism diagnosis is not a straightforward task. While diagnostic manuals such as the Diagnostic and Statistical Manual for mental disorders (DSM-5) provide clear behavioural criteria for diagnoses, the appraisal of individual behaviours is an inherently subjective task that relies heavily on clinician experience and skill.

In 2014, a review of autism diagnostic practices in Australia was jointly commissioned by the Cooperative Research Centre for Living with Autism (Autism CRC) and the Commonwealth Department of Social Services (Taylor et al., 2016). A key finding from this report was the considerable variability between states in diagnostic practices, including the quality and quantity of assessments administered, the professionals involved and the required experience of these professionals. The report concluded that this variability was highly likely to have contributed to uneven service provision across the states/territories and confusion among clients undergoing diagnostic assessment. The main recommendation of the report was that adopting a national standard for autism diagnosis across Australia would improve diagnostic practices and consistency across the country, and ensure that future diagnostic assessments are in keeping with best practice guidelines.

In June 2016, the National Disability Insurance Agency (NDIA) commissioned the Autism CRC to develop Australia’s first national guideline for autism diagnosis in Australia. Professor Andrew Whitehouse was requested to chair this process, in collaboration with an expert team comprising Dr Kiah Evans, Professor Valsamma Eapen, Professor Margot Prior and Clinical Associate Professor John Wray.

The Autism Diagnostic Guideline was developed through a rigorous research process over a period of 24 month. The development included consultation with over 1000 consumers (autistic adults, family members, clinicians and policymakers, and was guided by a Steering Committee that included representatives from each of the professional, consumer and advocate peak bodies around Australia. The Autism Diagnostic Guideline outlines a clear, evidence-based process for diagnosing autism in a manner that is accurate, timely, acceptable to families, and can be integrated into state and Commonwealth health, education and disability systems. The Autism Diagnostic Guideline has been endorsed by the National Health and Medical Research Council (NHMRC) as representing optimal clinical care in Australia, and in September 2018, was formally launched by the Commonwealth Minister for Health (Minister Hunt) and the former Minister for Social Services (Minister Fletcher). Since this time, the Autism Diagnostic Guideline has been downloaded more than 14,000 times from more than 50 countries.

A critical next step is the full-scale implementation of the Autism Diagnostic Guideline within clinical practice and State and Commonwealth systems. The Department of Social Services has funded a small project to develop resources to support clinical professionals upskill on the Autism Diagnostic

Guideline recommendations. This is a welcome step, and will enhance clinician knowledge of best practice diagnostic procedures. However, we believe there is unlikely to be wide-spread use of the 'best practice' procedure described in the Autism Diagnostic Guideline until there are funding mechanisms to support its use. Currently, there are only few items on the Medicare Benefit Scheme relevant to autism diagnosis, and these have limited funding to support a rigorous diagnostic procedure. This limited funding can promote sub-optimal clinical practices, which has an impact on the quality of care that families receive, and can leave families in excess of $1000 out of pocket (Taylor et al., 2016). For families to receive the best start to their autism journey, it is critical that there is adequate funding to cover the optimal assessment and diagnostic process, as it is described in the Autism Diagnostic Guideline.

<u>Recommendation:</u> We recommend that there are changes to the Medicare Benefits Scheme (MBS) to match MBS items to the assessment and diagnostic procedure described in the Autism Diagnostic Guideline, which will ensure every family in Australia commences their autism journey with optimal health care.

b. the prevalence of autism in Australia;

There is currently no national register that monitors the prevalence of autism diagnoses in Australia. The only State-based registry is the Western Australian Autism Register (the Register), which is administered by our organisation (CliniKids, Telethon Kids Institute): https://telethonkids.org.au/autismregister/. Founded in 1998 as a 'paper-and pen' registry, the Register has since transitioned to an online platform. The Register works through the cooperation of diagnosticians across Western Australia, who are given access to a specially-designed web portal. Once logged in, diagnosticians enter the clinical data (e.g., diagnosis, IQ, symptom profile, functional ability) of any new diagnostic cases. These data are then stored in encrypted form, with confidentiality and data-security procedures that are approved by an ethics committee. These data form an important repository that have the potential to answer key questions for researchers and policymakers around the world regarding autism prevalence.

The Register has formed the basis of many important research advances (e.g., Alvares et al., in press; Whitehouse et al., 2017), and provided key data to the first autism prevalence estimate in Australia, published in 2008 (Williams et al., 2008). Since this time, studies of the prevalence of autism in Australia have relied on datasets that were collected for broader research or administrative purposes, such as the datasets relating to the Longitudinal Study of Australian Children (May et al., 2017) and the Helping Children with Autism funding package (Bent et al., 2015). While these datasets are impressive in their own right, the methodological and design challenges involved in autism prevalence studies means that these datasets are suboptimal for this purpose. For this reason, we do not currently have a good understanding of the true prevalence of autism in Australia.

An understanding of the prevalence of autism, and any trends in this over time, is critical for planning both broad and targeted policies and services that are effective and responsive to community needs. A national autism register is the ideal infrastructure to fill this need.

<u>Recommendation:</u> We recommend that the Commonwealth Government establish a national autism register, based on the model provided by the Western Australian Autism Register, with the aim of monitoring prevalence of autism across Australia.

c. misdiagnosis and under representation of females in autism data, and gender bias in autism assessment and support services;

Autism is diagnosed more commonly in males than females (Bourke et al., 2016; Randall et al., 2016), with an often reported male-to-female ratio of 4:1 (Lai et al., 2015; Randall et al., 2016). However, there is accumulating evidence that this male preponderance may not reflect the true gender ratio of autism, but represent a bias towards males in the diagnostic process. Several studies have found that boys are more likely to be identified with autism than girls, even when symptoms are equally severe (Russell et al., 2011). There is also evidence that females are better able to ‘camouflage’ their symptoms by using compensatory strategies to mitigate communication and social difficulties (Dworzynski et al.,2012; Tierney et al., 2016), particularly when IQ is in the average or high range. Furthermore, the diagnostic criteria for autism and the instruments used to assess these behaviours reflect a presentation that is more common in males than females (Lai et al., 2019), and may not have adequate sensitivity and specificity to identify autism characteristics in females without intellectual disability (Rynkiewicz et al., 2016). Symptom differences between genders has been raised as one factor that may contribute to a later age of diagnosis among females on the autism spectrum (Begeer et al., 2013; Van Wijngaarden-Cremers et al., 2014).

Given the importance of early diagnosis and intervention in promoting positive longer term outcomes in children on the autism spectrum, an understanding of how autism may manifest differently between genders is critical. It is essential that the assessment of females incorporates an evaluation of whether the core symptoms of autism are masked by learned behaviours (Rynkiewicz et al., 2016; Tierney et al., 2016). This is particularly important for females who have an IQ in the average or high range.

The Autism Diagnostic Guideline, which was discussed in response to item (a), includes a full and detailed description of the behavioural differences observed between males and females in autism, and how it is critical to take these into account during diagnostic assessments. The nationwide implementation of the Autism Diagnostic Guideline is the most powerful tool we currently have available to ensuring that every individual on the autism spectrum has access to the highest quality clinical care, irrespective of gender.

Recommendation: We recommend that the Autism Diagnostic Guideline is fully implemented across Australia, which will ensure that gender and misdiagnosis, under-representation or poor clinical management of females throughout the diagnostic process is minimized or ameliorated.

d. international best practice with regards to diagnosis, support services and education, effectiveness, cost and required intensity;

We focus our response to this item on three areas in which there is evidence that Australian clinical practice does not meet international best practice:

i. The consistent use of a best-practice diagnostic assessment protocol across Australia;
ii. The use of evidence-based early interventions;
iii. The provision of supports based on functional difficulties.

The consistent use of a best-practice diagnostic assessment protocol across Australia

Current practice: As described in response to item (a), current diagnostic practices vary considerably between states. A key research report produced by the Autism CRC (Taylor et al., 2016) identified considerable variability between states in diagnostic practices in the quality and quantity of assessments administered during a diagnostic process, the professionals involved, and the required experience of these professionals. The report concluded that this variability was highly likely to have contributed to uneven service provision across the states/territories and confusion among clients undergoing diagnostic assessment. In response to this report, the Autism Diagnostic Guideline for the assessment and diagnosis of autism was developed.

Best practice: The Autism Diagnostic Guideline was developed to the highest international standards. The development process involved two research elements. First, we generated a synthesis of the limited existing evidence regarding autism diagnostic practices. The existing knowledge base was first examined through a scoping review, which mapped the breadth and depth of the available evidence on the autism diagnostic process across the world. Three systematic reviews were then conducted focusing on how different elements of a clinical assessment may impact on key consideration for the Guideline: (1) Accuracy to diagnostic outcome; (2) Acceptability to families; and (3) Impact on waiting lists. This new knowledge provided the foundation for the Guideline. The second element was a series of empirical research projects that established a 'best practice' clinical protocol for Australia. Four different studies were completed, each involving a nationwide data collection effort, including: (1) Face-to-face workshops in each Australian capital city (n = 265); (2) A Delphi survey of diagnosticians (118 diagnosticians); (3) Targeted surveys and semi-structured interviews with adults/adolescents with autism or their family members (98 individuals); and (4) An open feedback process on the draft version of the Autism Diagnostic Guideline (161 organisations). This process generated more than 1000 pages of research evidence, which was then used to make the 70 recommendation for the diagnostic process.

The final Autism Diagnostic Guideline was reviewed by 7 international experts, and was unanimously approved by the National Health and Medical Research Council (NHMRC) as representing optimal clinical care in Australia. As it currently stands, the Autism Diagnostic Guideline represents best diagnostic practice not just for the Australian community, but for anywhere in the world. Nationwide implementation of the Autism Diagnostic Guideline across Australia will ensure that every Australian has the access to highest standards of clinical care at the very earliest point of their autism journal.

Recommendation: We recommend that the Autism Diagnostic Guideline is fully implemented across Australia, which will ensure every Australian has access to best practice diagnostic processes.

The use of evidence-based early interventions

Current practice: Early intervention is a term used to describe therapeutic intervention designed to improve developmental outcomes that is first applied during the early years of life (typically defined as being prior to 6 years of age). There is now a solid body of research that has investigated the efficacy of a range of interventions seeking to improve developmental outcomes in children with autism (Magiati et al., 2012). Key learnings from this research are:

i. Early interventions that are based on behavioural and/or developmental principles can be effective in improving developmental outcomes.
ii. There is no 'one size fits all' approach to autism intervention; that is, there is no one therapy model or intensity that improves outcomes for all children. Some children may receive the greatest benefit from highly intensive intervention delivered by a therapist, while other children may benefit from less intensive intervention that are provided by caregivers within the context of the home.
iii. Evidence-based behavioural and/or developmental interventions that are tailored to the learning style of the child, align with the goals of the child and the family, and are delivered by properly trained therapists, are more likely to generate the most positive outcomes.
iv. The interventions used for a given child will likely change over time as that child develops. For example, early intensive intervention may be most appropriate when a child is 2 years of age to support the acquisition of verbal communication skills. However, it may be most appropriate at 6 years of age that intervention focuses on reducing comorbid anxiety, or supporting the development of social skills.
v. There are several key research gaps:

- There are currently no published studies that compare the relative effectiveness of different evidence-based interventions of equivalent quality and intensity, and so we do not currently have a good understanding of the superiority of any treatment in improving developmental outcomes.
- There is currently no evidence-based method for selecting the most appropriate intervention for a given child. The lack of an evidence-based approach means that intervention selection is often on a 'trial and error' basis, which leads to inefficiency, resource wastage, and less-than-optimal clinical provision for families.
- There is little evidence for the long-term effectiveness (i.e., into adolescent or adulthood) of early interventions. This knowledge is critical to contribute to the economic argument for the provision of early intervention services.
- While autism interventions traditionally commence at the point of diagnosis (typically older than two years of age), there is reason to believe that commencing intervention prior to this period may be particularly effective in reducing long-term disability. The infancy period (<18 months of age) is a particularly sensitive time for brain development, providing an optimal period for a child to benefit from therapeutic intervention. We recently tested a developmental intervention for infants (aged 12 months of age) showing early behavioural signs of autism. We found that, while the intervention did not reduce autistic symptoms, the children receiving the intervention had better parent-reported communication and social skills compared to a control group when assessed 6 months later (Whitehouse et al., 2019). This is a very promising area of research that may lead to significant improvements to the way that we provide early intervention for young children.

A key challenge within the Australian clinical community, is the widespread use of interventions for which efficacy is unsupported (Paynter et al., 2017). The use of interventions unsupported by scientific evidence would not be supported in clinical practice for other conditions, and it is not a standard we should accept for autism.

<u>Best practice:</u> The variable use of evidence-based interventions in the Australian clinical community highlights the existence of a 'research to clinical practice' gap, whereby research knowledge that improves clinical care is not taken up by the clinical community. That this research-translation gap is not unique to Australia (Dingfelder & Mandell, 2011) makes this critical issue no less important to the clinical care of children with autism. A 2017 study found that a key element to improving this situation is promoting the knowledge of, and training in, the use of evidence based interventions (Paynter et al., 2017). To this end, the development of an independent, authoritative and accessible framework that collates and disseminates knowledge of evidence based early interventions would be highly valuable to the clinical and autism communities.

While our scientific understanding of the efficacy of early interventions has grown over the past two decades, there are still large gaps in our research knowledge. A particularly critical research goal is to obtain an understanding of which intervention is most effective for which individual, and at which period of their life? Currently, these clinical decisions are often made on a 'trial and error' basis, which creates the potential for patient harm, and wastage of limited financial resources.

<u>Recommendation:</u> We recommend that the Commonwealth Government invest in the independent development of a National Quality Framework of Best Practice in Early Intervention for Autism, which is updated each year with the most recent evidence. CliniKids and Professor Andrew Whitehouse would welcome the opportunity to provide input to this process.

<u>Recommendation:</u> *We recommend that the Commonwealth Government release specific research funding for projects that: (1) compare the effectiveness of current evidence based interventions; (2) seek to identify which intervention is most effective for which individual; (3) determine the long-term effectiveness of current evidence based interventions; and (4) expand our understanding of the efficacy of interventions for infants showing early sign of autism.*

The provision of supports based on the presence of functional impairment not the presence of a diagnosis

<u>Current practice:</u> Autism is a syndrome that covers a wide range of domains of functioning and support needs (Alvares et al., in press). Some individuals who meet diagnostic criteria for autism will have minimal support needs, while other individuals will have significant and urgent needs for support and treatment services but will not meet diagnostic criteria for autism at the time of assessment. In the context of neurodevelopmental disorders such as autism, it is critical that an individual's needs, not the presence or absence of a diagnostic label, are used to determine eligibility and prioritisation of access to intervention and support services.

This view is entirely consistent with the National Disability Insurance Scheme Act 2013 (NDIS) Act, which states that entry to the scheme is (among other criteria) based on the "substantially reduced functional capacity" of the individual (Section 24 of the Act). Despite this, there is evidence, or at least the community perception, that a diagnosis is required for children with autism to receive entry into the NDIS. One example is outlined in this news report: https://www.abc.net.au/news/2020-02-13/childrens-access-to-disability-funding-depends-on-their-suburbs/11917466 . List A and List B of the Operational Guidelines also list autism – that is, an individual with an autism diagnosis – as a condition that is likely to meet the disability requirements in Section 24 of the NDIS Act. While the inclusion of autism on this list was no doubt well intentioned (i.e., to help guide determination of entry into the scheme), it appears to have entrenched the community perception that a diagnosis is required to become a participant of the NDIS. Given that there is often a substantial waiting period to access autism diagnostic services (Taylor et al., 2016), a reliance on diagnosis to determine eligibility may lead to delayed early intervention, which is an approach that does not meet international best standards.

<u>Best practice:</u> The key challenge in this area is how Australia reframes clinical systems that have historically provided support based on the presence of a diagnostic label, to systems that provide support based on the presence of functional impairment (as described in the NDIS Act). The solution to this problem is nation-wide implementation of the Autism Guideline, which provide the optimal framework through which this can be achieved. The assessment approach outlined in the Autism Diagnostic Guideline recommends that individuals undergo an initial assessment of functioning. If this assessment identifies functional impairment, then the individual is referred immediately for supports through the NDIS. Concurrently, the individual undergoes the diagnostic process for autism. This framework, which is entirely consistent with the NDIS Act, has received endorsement from all of the major professional peak bodies, consumer groups, and service provider organisations. Nationwide implementation of this agreed assessment framework will help move Australia towards a system of disability supports that is in line with best international evidence.

<u>Recommendation:</u> *We recommend that "functional capacity", irrespective of the presence or absence of an autism diagnosis, remains the key element that guides entry into the NDIS. Nationwide implementation of the Autism Diagnostic Guideline will help move Australian systems towards this goal.*

f. the interaction between services provided by the Commonwealth, state and local governments, including:

- **i. health and mental health,**
- **ii. education,**
- **iii. employment,**
- **iv. justice, and**
- **v. housing;**

We have observed numerous differences between Commonwealth, state and local Government systems, which create additional challenges for families seeking support services. An important example of this is in the case of diagnosis. It is not uncommon for a child with autism who moves interstate to require a new diagnostic assessment because the relevant system in the new state does not recognize the diagnosis from the previous state. Discrepancies also exists between systems within states. For example, it is common for families whose young children receive a diagnosis of autism through the Health system, to then be required by the Education system to seek a re-assessment when the child is school-age. These inconsistencies create significant abnd unaceptable emotional and financial strain on families, clinicians and systems.

Recommendation: *We recommend that the Autism Diagnostic Guideline is fully implemented across all Health, Disability and Education systems, in every state of Australia.*

Recommendation: *We recommend that the process of Autism Diagnostic Guideline implementation is coordinated by the Council of Autsralian Governament's Disability Reform Council, which will achieve consistency across Commonwealth, state and local systems to the great benefit of Australian families.*

i. the development of a National Autism Strategy and its interaction with the next phase of the National Disability Strategy;

CliniKids wholeheartedly supports the development of a National Autism Strategy. Given the relatively high prevalence of autism, the lifelong nature of the condition, and the breadth of the Commonwealth and state government ministries that are relevant to the support and care of the autistic population, it is critical that there is a nationally coordinated approach autism in Australia. CliniKids and Prof Andrew Whitehouse would welcome the opportunity to provide input to this process.

Recommendation: *We recommend that development of a National Autism Strategy that guides coordinated action and investment across Commonwealth and State government departments.*

j. the adequacy of funding for research into autism;

While our understanding of autism, and how we can provide optimal clinical care to the autistic population, has increased substantially over the past two decades, there remains numerous knowledge gaps that provide significant barriers to our collective aim to improve long-term outcomes. Scientific research is a key way that we can fill this gap, and make clinical advances. It is clear that there is both an inadequacy of research funding for autism, and suboptimal targeting of the current funding pool.

Given the relatively high prevalence and lifelong nature of autism, the funding allocated to the study of this condition appears disproportionately low. While it is difficult to identify concrete figures in this regard, one recent analysis found that $19,319,780 was allocated by the NHMRC to autism research projects during the period 2013-2017 (den Houting & Pellicano, in press). This represents a very small fraction of the estimated >$3b allocated in NHMRC research funding over this period.

During this period, research in a variety of areas have been funded. However, the largest pool of NHMRC research funds have been allocated to biological investigations. Although this funding has led to many interesting and potentially important scientific advances, there is no clear or tangible evidence that this research has created better outcomes of individuals on the autism spectrum. A focus on this latter goal is important to fill critical research gaps. In 2019, the Autism CRC published a report that outlined key autism research priorities for Australia (https://www.autismcrc.com.au/sites/default/files/2019-10/AARC%202019%20Autism%20Research%20Priorities.pdf). The report was the product of a large consultation of over 1000 individuals within the autism community, a process that was chaired by Prof Andrew Whitehouse and Dr Wenn Lawson. A key message from this report was that research that is focused on improving the life outcomes of individuals on the autism spectrum is more valued by the community than research focused on identifying biological causes for autism.

Targeted grant calls that are focused on the research priorities outlined in the Autism CRC report is one important mechanism through which more impactful autism research can take place in Australia. A second key mechanism is by providing longer grant funding periods. Truly impactful research rarely occurs in one-year bursts, but instead requires large projects that are often shared across multiple research teams and multiple years. The Autism CRC (https://www.autismcrc.com.au/) has demonstrated the importance of this latter approach. The Autism CRC was established under the Commonwealth Government's Cooperative Research Centre scheme, and Professor Andrew Whitehouse is the Research Strategy Director for the organisation. Autism CRC has acted as the 'research glue' within the autism community, bringing together the many disparate research, clinical and Government organisations to cooperate on nationally-important research aims. Across its 8-year research program, the Autism CRC has worked with more than 50 partner organisations to generate a numerous important research output for Australia. The sustainability of national research networks, such as the Autism CRC, which can deliver answers to large and important questions, is critical to further improvements in the clinical care of individuals on the autism spectrum in Australia.

Recommendation: We recommend that the Commonwealth Government identifies existing autism research networks across Australia, such as the Autism CRC, and invest in these networks to deliver large-scale, high quality, and impactful research outcomes.

Recommendation: We recommend that the 2019 Autism CRC report on research priorities provides a starting point for determining autism research priorities in the National Autism Strategy.

n. any other related matters.

Our organisation, CliniKids (clinikids.org.au), is a nationally-unique operation that was founded with the aim of increasing evidence-based autism practice in Australia. CliniKids is auspiced under one of Australia's most successful medical research institutes, Telethon Kids Institute, and combines internationally-leading research expertise (led by Prof Andrew Whitehouse) with high quality clinical care. Families from the community are able to access the evidence-based clinical services on offer at CliniKids, and are also invited to take part in new research projects. CliniKids maintains a focus on development new clinical interventions (for children under 12 years of age), and so a substantial proportion of families are offered entry into clinical trials of these interventions. This 'research into practice' model means that the general community has access to the cutting-edge clinical techniques that have great potential to enhance their child's development even further.

CliniKids also provides a busy training service, which upskills the clinical community on new, evidence-based intervention techniques. This ensures that any new clinical advances are disseminated as widely as possible within the general clinical community. In 2019, CliniKids trained more than 100 clinicians across Australia on diagnostic and intervention methods. The research outputs from CliniKids have provided important advances to our understanding of autism, and have ensured the swift translation of these advances to improve clinical practice. The research outputs of CliniKids can be viewed here: clinikids.telethonkids.org.au/research/publications/ . Through the combination of research and clinical practice, CliniKids could be thought of as a 'Headspace' for children on the autism spectrum. Headspace (headspace.org.au/) has revolutionised mental health care for young people in Australia, creating a nationwide clinical network that reoutinely embeds cutting-edge research into their clinical practice. The 'research into practice' model developed by CliniKids provides the template for a similar revolution in autism clinical management across Australia.

The research and clinic partnership that is brought together by CliniKids provides unprecedented opportunities to expand evidence-based practice in Australia, and in turn, improve long-term outcomes for children on the autism spectrum and their families.

Recommendation: *We recommend that the Senate Select Committee examined the CliniKids 'research into practice' model, and explore replicating this across Australia as a means of improving evidence-based practice.*

We thank you for the opportunity to contribute to this important and historic initiative. Professor Andrew Whitehouse and CliniKids would be very willing to assist the Committee on advancing the development of the National Autism Strategy.

Yours sincerely,

Professor Andrew Whitehouse
Director of CliniKids
Angela Wright Bennett Chair of Autism Research

Gemma Upson
General Manager of CliniKids

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