TELETHON KIDS INSTITUTE

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18 November 2022

Sophie Simpson
Committee Clerk
Select Committee into Child Development Services
Legislative Council
By email: sccds@parliament.wa.gov.au

Dear Sophie

I am pleased to provide the attached submission to the Select Committee into Child Development Services from the Telethon Kids Institute.

The Institute welcomes the Select Committee's inquiry and would be pleased to provide any additional support or assistance if considered helpful to do so.

Should you require any clarification or further information to assist the Committee, please contact Fiona Roche, Head of Government Relations, at the Institute on Fiona.Roche@telethonkids/org.au or 0405 420 052.

Yours sincerely

Professor Jonathan Carapetis AM
Executive Director

Discover. Prevent. Cure.

SUBMISSION TO THE LEGISLATIVE COUNCIL SELECT COMMITTEE

INQUIRY INTO CHILD DEVELOPMENT SERVICES

TELETHON KIDS INSTITUTE

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About Telethon Kids Institute

The Institute was founded 32 years ago by Professor Fiona Stanley. Under the leadership of the current Executive Director, Professor Jonathan Carapetis, the Institute is WA's largest medical research institute with a dedicated and diverse team of more than 1200 staff and students.

With its head office in Perth Western Australia, and offices in Joondalup, Cockburn, the State's North-West and in South Australia, the Institute prides itself on the translation of research into impact to improve the lives and wellbeing of children and young people in WA, Australia and around the world.

We have a strong commitment to early childhood development and education, illustrated by the following:

- Co-located at Perth Children's Hospital with the Child and Adolescent Health Service (CAHS), the Institute's researchers collaborate with clinicians to translate the latest science into clinical practice to improve outcomes for children and their families and to develop new evidence-based treatments. The Institute also has a strong commitment in engaging consumers in all aspects of its research so that lived experience guides the research process.
- We led the roll-out across Australia of the AEDC - the Australian Early Development Census. Recognised as the world's first ongoing proven and reliable measure of early childhood development, the AEDC collects data in the five domains of: Physical health and wellbeing; Social Competence; Emotional Maturity; Language and Cognitive Development; and Communications Skills and General Knowledge. AEDC data underpins most major early years initiatives in Australia and continues to steer policy direction in education and health, future research and the decisions of local governments, schools and community groups. In 2020, we were proud to work in partnership with Aboriginal and Torres Strait Islander leaders and their communities to adapt the AEDC to measure targets under the Closing the Gap.
- The Institute was instrumental in establishing the Early Years Initiative (EYI). With over $25m in funding from Minderoo, matched by the State Government, the Department of Communities is leading the coordination of EYI (Co-Lab) across Government to ensure we have a system that enables healthy, happy and thriving children who enter the schooling system with the highest potential.
- The Institute led work in the 2000s on the *Western Australian Aboriginal Child Health Survey (WAACHS),* the largest and most comprehensive survey ever undertaken into the health, wellbeing and development of WA Aboriginal and Torres Strait Islander children.
- We developed the "Bright Tomorrows" App to assist parents of children aged 0-5 years for parents to support their child's development. With over 1000 "tips" for activities that parents can do with their child to help them learn and develop in five core categories, the App helps parents to identify what to expect in their child's development and, when they think there might be an issue, provides information on trusted services for parents to access.

- Together with UWA, the Institute leads the WA Node of the Australian Research Council Centre of Excellence for Children and Families of the Life Course (the Life Course Centre) investigating the critical factors underlying persistent disadvantage in children to provide life-changing solutions for policy and service delivery.
- With the Autism CRC, the Institute led the development of national guidelines around the assessment and diagnosis of autism, and more recently, how to provide best practice support to autistic children. These landmark guidelines are now used across Australia and the world.
- CliniKids is the Institute's first clinical service for children, integrating research with a clinical service for children with developmental delay and/or an autism diagnosis, and their families. Putting research into practice, CliniKids is a registered NDIS provider and offers early support services including speech pathology, occupational therapy and clinical psychology for children under the age of 9 years. It also runs workshops for parents and caregivers and professional training in specific therapies for clinicians and autism professionals.
- The Institute has been part of a global collaboration working with early childhood education and care (ECEC) services to develop, implement and evaluate the evidence-based Play Active Physical Activity Policy to provide guidance on the amount of physical activity and sedentary time (including screen time) for children, and - in a first for the industry - evidence-based face-to-face and online training to support educators to provide children with the recommended daily physical activity while at ECEC.

Points Addressing the Terms of Reference

The following information is provided in the context of the Institute's role as WA's leading paediatric research institution.

All comments and suggestions are intended to build on the existing relationship between the Institute and CAHS/CDS. Many positive relationships and collaborations exist on mutually beneficial projects to enhance child health and wellbeing outcomes related to community health priorities. We recognise that CAHS/CDS actively engage in reviewing processes and systems, and that delivery of child development services to the community is complex and challenging.

(a) The role of child development services on a child's overall development, health and wellbeing

- Research shows that child development services (CDS) are critical to child development.
- There is overwhelming evidence that the years from 0-5 are vital in a child's development and hence it is fundamentally important that a comprehensive and equitable CDS be available and accessible to all children and families as part of our public health system.
- Early years research has provided evidence of the importance of prevention and early intervention as the relationship between the experiences of early childhood and have a direct and lasting impact upon a child's future life trajectory.
- We also know that, to be effective, early support and intervention services need to be community based and set within the context of the child and family, be focused on prevention and be multidisciplinary in its approach.
- The difficulty lies in matching services to needs, with needs growing faster than services can cope.

- This is particularly the case for Aboriginal children living in regional and remote locations, who are often the most vulnerable and in need, but are not provided with the same access to CDS as those living in the metropolitan area.
- As a research institution, we believe there should be greater opportunities for the Institute to work with CDS to translate research into practice by increasing awareness and understanding of why children need access to services, eg. neonatal issues, FASD, autism assessment, mental health impacts, etc.
- With this in mind, the Institute recommends a greater and ongoing partnership between Telethon Kids and CDS to look to how research can add value to how services are undertaken, to improve models of care and to evaluate service delivery to maximise and measure impact and outcomes.
- Clinikids, outlined above, is a good example of a model that can operate as a helpful adjunct to the public system – providing a research ally to develop and trial new interventions, as well as being able to train CDS staff on best practice assessment/diagnosis and intervention methods.
- By way of specific examples,
    - Clinikids has developed two key practice guidelines for autism - the assessment and diagnostic guideline and the autism intervention guideline – which have been endorsed by the Federal Government as representing best practice.
    - “Inklings”, developed by the Institute’s Professor Andrew Whitehouse, is a new early intervention program for babies showing early behavioural signs of autism. Initially trialled in close partnership with the CDS/CAHS, positive findings from the pilot program have led to plans to roll out Inklings across WA with funding from the NDIS, in partnership with CAHS and the Institute.
- The importance of children getting access to services and the inability of CDS to cope with increasing demand needs urgent attention. It can not only be about increased funding or resourcing. CDS staff are committed and highly skilled and while more staff would always be welcome, it is equally as important to explore different models of delivery and better systems and processes.
- No matter what the level of funding is to CDS, resources will always be finite and hence there is a need to identify how best to re-route children to other avenues when CDS is unable to meet demand. Increased collaboration and connection between CDS and private sector and NFP organisations (eg. Ngala, Clinikids) is needed to address this.

(b) The delivery of child development services in both metropolitan and regional Western Australia, including paediatric and allied health services

- The challenges of delivering an equitable CDS across our vast State are not to be underestimated. The tyranny of distance is an enormous impediment to providing children in rural or remote areas, particularly Aboriginal communities, with the support they need to maximise their development.
- CAHS has a Statewide service delivery model but a child living in a rural or remote community has a much more complex pathway to services than one living in urban areas. Early intervention opportunities are available, but it is challenging for families to have access or be aware of relevant programs.

- Early intervention is traditionally intensive and hands on. To better support the delivery of services in WA's vast geographical region, additional investment is needed to explore alternative models and technology solutions. For example, wider use of telehealth services, greater reliance on trusted sources of information such as the Brighter Tomorrows App, and the use of technology and robotics to develop diagnostic and treatment aids such as wearable devices.
- The value of Child Health Nurses, and the associated "Purple Book", is an important component of the WA CDS system, with a visit to the local child health nurse the main (and often only) way for parents to seek information about whether their child is growing and developing as they should. It is also one of the ways in early risk factors can be identified and followed up on.
- The Institute considers additional investment in Child Health Nurses to be critical to support the parents of babies and children to understand child development and assist in the very early identification of development issues. Through regular contact with families, they provide trusted, non-judgemental support in areas such as infant feeding, child development, injury prevention and child safety and protection, and importantly help connect parents and families by encouraging ongoing social support networks. Continued and additional Government support for these services is needed.
- The Institute is strongly of the view that State needs to introduce a "Statewide electronic health record" for all children as information on health and wellbeing is siloed and often difficult to access.
- Aboriginal children are among the most disadvantaged and vulnerable in the State and yet in many cases wait the longest to receive child development services. The following research underway by the Institute is just some ways in which we can better understand how to better assess, support and deliver services to Aboriginal children and families that could be translated into clinical practice by the CDS:
    - Journey Together – funded by BHP, and co-designed with the Aboriginal communities, Professor Alex Brown, Head of Indigenous Genomics at ANU and TKI, and Glenn Pearson, Director of First Nations Leadership and Advocacy, are leading work involving early assessment of Aboriginal children.
    - Ear Health - the Djaalinj Waakinj program, based at Cockburn, is examining the prevalence of OM and hearing loss in Aboriginal children living in the metropolitan area, showing that hearing loss is prevalent in city as well as rural areas. The team are developing telehealth approaches to improve access to ear and hearing healthcare and developing treatment and management guidelines for clinicians.
    - SToP Trial – Aboriginal people living in remote communities are at increased risk of skin infections including impetigo, scabies, and crusted scabies and their sequelae, which in turn have a high burden and contribute to health disparities experienced by Aboriginal people. The SToP trial is strengthening and building on current skin health practices to improve the awareness, detection, and treatment of skin infections (sores and scabies) in the Kimberley.

(c) The role of specialist medical colleges, universities, and other training bodies in establishing sufficient workforce pathways

- While medical colleges, universities and training bodies will always have a critical role, research institutions can also make a greater contribution to workforce development.

- Translating research to clinical practice needs to be a key focus. With CAHS and the Institute co-located at PCH, more resources should be directed to funding Institute researchers to work with clinicians to put research outcomes into practice.
- For example, in areas such as diabetes, cerebral palsy living evidence guidelines are being developed that should be informing how best to that change the way we deliver services. Further, more support and funding is needed to translate work the Institute is leading on infant mental health and LGBTQA+ suicide prevention into clinical practice.
- Working with clinicians on how to Implement research outcomes is key way to ensure CDS is delivered in way that maximises service delivery and outcomes. A training partnership between CAHS and the Clinikids at the Institute is one example that would see the translation of evidence-based interventions into clinical practice.
- Research institutions can also play a role as part of the workforce pathway to clinical practice. The Institute and CAHS have put in place PhD opportunities for researchers who are embedded in clinical services. This is an important model for ensuring research and clinical practice are seen as a complementary and routine feature of how CDS are delivered.

(d) Opportunities to increase engagement in the primary care sector including improved collaboration across both government and non-government child development services including Aboriginal Community Controlled Organisations

- One of the findings of Professor Stephen Zubrick's ground breaking research following 4000 children from birth to year 9 is that risks to a child development rarely occur in isolation. Rather they typically appear in one or more of the four domains of family, school, childcare and in interactions with peers (virtually or in person). This provides compelling evidence for the importance of collaboration between and across all those in the primary care sector.
- There continues to be a lack of coordination in service delivery by Government departments that contributes to children and families "falling through the cracks", with parents having to navigate how to access services in different agencies that makes little sense to those external to Government.
- Further, the myriad of funding programs and support services designed and delivered by different agencies that seem to have no connection to each other contribute to the chaotic and unconnected services in child development.
- We know that parents need better pathways to navigate how to access services when searching for advice and support. This is another way in which improved collaboration can occur – so that regardless of which "front door" a parent goes through, there should be consistent and quality advice and information on how to access services.
- It is also important that services not only be accessible for those able to proactively reach out to see them, but that the services are talking to each other in a way that maximises the likelihood that the appropriate provider will find their way to that child and family.
- The Institute has played and will continue to play a role as a "trusted source" of expertise on child development. The development of the "Brighter Tomorrows" App is a good example of where the Institute can work with the sector as a whole to ensure parents have access to what indicators they should be looking out for in their child's development and where they can go to access high quality services if they have any concerns.

(e) Other government child development service models and programs operating outside of Western Australia and the applicability of those programs to the State

- The Institute recommends that benchmarking be undertaken across States to better understand the key factors that contribute to effective and efficient models of delivery, building on existing work with Children's Healthcare Australia.
- The introduction of "inequity maps" using spatial analytics data to map and track demand and inform modes of care and delivery of services, as seen in the Eastern States, should be considered for WA. The Institute has considerable geospatial mapping expertise, currently used in malaria research and Covid modelling, that could be adapted for this use.
- The Institute is aware of the Federal Government's commitment to develop an "Early Years Strategy" (EYS), drawing on evidence associated with children's early development and wellbeing and examining programs and funding delivered by the Government. A key objective is to identify ways to reduce silos across departments and better integrate and coordinate functions and activities across Government. While we understand the focus of the EYS will be on Commonwealth agencies, it will be important for any changes to WA's CDS and early childhood framework to align to, and potentially build on, the Federal Government strategy.
- The Institute believes much can be learnt from the 'Improving Access to Psychological Treatment' (IAPT) program in the UK. While this program is focused on mental health disorders, such as anxiety and depression, the challenges experienced are strikingly similar to child development services, and the successes could also be similar. The reform undertaken to this sector, and its relevant to CDC, is contained in Annexe 1.

In summary, the Institute would direct the Committee to consider the following actions as a matter of priority:

1. That there be a greater focus on prevention and early intervention, with targeted increased resources/funding needed for CDS and Child Health Nurses.
2. That targeted and focused efforts be directed to address the tyranny of distance experienced by children and families living in WA's rural and remote areas, particularly Aboriginal families, who struggle to receive support. The Minister for Medical Research's recent $5m "Challenge" is a model worth considering: https://www.mediastatements.wa.gov.au/Pages/McGowan/2022/10/5-million-dollar-global-challenge-to-boost-health-outcomes-in-the-Pilbara.aspx
3. That an increased partnership between CAHS/WACHS and the Institute be supported to facilitate an even stronger working relationship that would see clinicians and researchers working together on ways to:
    - translate research outcomes into clinical practice;
    - develop clinical guidelines on new models of service, assessment, diagnoses and treatment; and
    - introduce workforce pathways from research to clinical practice through programs such as internships, scholarships and mentoring.

4. That further attention be given on how to improve enhanced coordination and funding for the delivery of services to children and families by Federal and State Government agencies;
5. That the Federal Government's commitment to develop an "Early Years Strategy" inform improvements to the CDS and WA's broader early childhood development framework, including across Government integration and coordination,
6. That a Statewide electronic health record be introduced for all children;
7. That benchmarking against other jurisdictions be further developed to better understand key performance indicators in CDS delivery and outcomes;
8. That the concept of an "Inequity Map" as used in the eastern states be explored; and
9. That the UK's IAPT program be considered for introduction in WA.

Thank you for the opportunity to present this submission to the Select Committee.

For further information or clarification, please contact the Institute's Head of Government Relations on Fiona.Roche@telethonkids.org.au or on 0405 420 052.

18 November 2022

ANNEXE 1 – REFORMS TO THE NATIONAL HEALTH SERVICES (NHS) IN THE UK

Like many health systems in Australia, the National Health Service (NHS) in the UK had significant challenges addressing the demand for mental health services.

After several Government reviews, the UK Department of health concluded that traditional training pathways (eg. clinical psychology, family therapy, child psychotherapy) were failing to meet the demands being placed on the NHS, and that a 'low intensity' workforce was required to provide services to people with mild to moderate depression and anxiety. The view was that a new 'low-intensity' workforce might help to reduce wait times and free specialist clinicians (e.g., clinical psychologists, psychiatrists) to work with more complex cases.

There are several key elements of the IAPT program. The first was the two levels of therapists, described above, that is one for children with complex cases and one for children with mild to moderate severity.

The key innovation here was the training of a 'low intensity' workforce of professionals traditionally not included in the mental health system (eg. community workers), who completed training on a select number of evidence-based therapies known to be effective for mild/moderate data collection. The second was high quality training on evidence-based therapies.

The IAPT is considered a major population health success. In the 10 years (2008-2017), it has trained a further 7,000 therapists, and over 580,000 people were seen in IAPT clinic. Critically, the data collection indicated very positive results on patients. Over 50% of people recovered after their initial block of therapy, and 66% of people showed reliable improvements. Economic analyses have indicated substantial reductions in healthcare utilisations and costs.

The experience of implementing the IAPT model is highly instructive to the current challenges faced by WA child development services. The WA child development services is also seeking to address health issues where early intervention is critical (i.e., developmental delays), but is experiencing significant work force shortages and substantial wait times for children and families. Traditional training pathways (i.e., speech pathology, occupational therapy, physiotherapy, psychology) are also not meeting the demands placed on the system.

The Institute believes that the WA Government has the key ingredients to explore implementing a similar system in WA. First, WA could seek to develop a 'low intensity' work force, who could be used to provide support to children with milder developmental delays. Potential professionals who could make up this cohort include early childhood educators, therapy assistants and other associated professionals. Second, a highly efficacious evidence-based therapy for children with developmental delay, Inklings (as outlined above) has been tested in two randomised controlled trials, and found to be efficacious in reducing developmental problems and increasing skills in infants (aged 6-18 months) showing developmental delay.

The Institute would welcome the opportunity to roll out this therapy across WA as a way to achieve broad access to child development services while simultaneously reducing work force capacity shortages.