

The Hon Josh Frydenberg MP
Treasurer of Australia

31 January 2020

Dear Treasurer,

We write on behalf of the Kids to Adults (K2A) Alliance - a national research alliance of clinicians, researchers, parents and young people. Our mission is to enable children with chronic illness to live their best lives now and into the future.

We are pleased to attach the K2A FY 20-21 pre-budget submission.

We know that children with chronic disease or disability, and their families, face many problems every day including poor physical health and school achievement, disrupted social networks, significant distress and financial toxicity. There is a substantial gap in life attainment, mental and physical health when children with chronic illness and disability enter adulthood. The aim of K2A is to change this. We will do this through five focussed streams of collaborative research - Consumer involvement; Measuring impact; Integrated care models; Building resilience and School participation.

Currently, there are more than 50 clinicians and researchers from Australia's leading child health services and research organisations actively participating in K2A and this number is growing every day. The goals of K2A are to build on the current work of child health research organisations nationally through collaborative research focused on ensuring that children affected by chronic illness can successfully navigate the journey to adulthood, supported by their families and communities. Parents and young people affected by chronic illness are actively involved in all K2A activities to ensure the relevance and impact of the research.

In the attached pre-budget submission, we call on the Federal Government to invest \$22M in K2A's comprehensive national program of collaborative research, co-created by Australia's leading child health researchers, clinicians, parents and young people. The aim of this research is to find and implement solutions to the significant problems facing well over 1 million Australian children affected by chronic illness and disability.

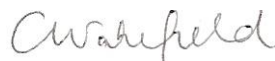
The estimated cost to our community of clinical care for children with chronic illness and lost productivity is \$100B per year. We anticipate that through K2A research and implementation, this can be reduced by at least one third.

Please do not hesitate to contact us if you have any questions on the submission on 0425-220267 (Professor Marshall) or 0417-863688 (K2A Program Manager Professor Moira Clay).

Best regards



Professor Glenn Marshall AM
Co-Director K2A Alliance



Professor Claire Wakefield
Co-Director K2A Alliance



Professor Raghu Lingam
Co-Director K2A Alliance

(on behalf of the Members of the K2A Alliance)

Kids to Adults Alliance

FY 20-21 Pre-Budget Submission

Transforming the lives of Australian children with chronic illness or disability

Chronic childhood illness and disability is a national burden

The health of our children is more important now than at any other time in our nation's history - it is their future productivity, emotional resilience and good health that will support Australia's ageing population both socially and economically. A key health challenge of our time is to address the changing health needs of our young people.

For Australian children, a 50-60% decline in childhood death rates over the last 25 years[3] is mirrored by an increase in the number of children living with one or more chronic illness, lasting well into adulthood.[6] Conservative estimates point to more than 1 million Australian children currently suffering a chronic illness.[7 8] The impact of childhood chronic illness is similar across the western world. In Europe, 79% of all disability adjusted life years lost (DALYS) in young people aged 1-14 years is due to chronic illness; nearly 80% of child deaths, 28% of hospitalisations, and 77% of frequent emergency department attendances are due to chronic illness.[9]

The impact on children, young people and families

Our work, the first in Australia, has shown that children with chronic illness make up 35% of paediatric hospital admissions, 50% of bed-days and 43% of hospital costs, using data from across NSW.[2]

Children with chronic illness live with problems that affect every aspect of their lives, from lower school achievement and disrupted social networks, to severe psychological distress and poor physical health. One in four children with a chronic illness develops a mental health condition, [10-12] most commonly emotional and behavioural problems.[12] Mental health comorbidities not only affect family functioning [13] and parent mental health [14-16] but also exacerbate physical illness through low adherence to treatment.[17-18]. Mental health conditions can also be viewed as a chronic illness in their own right.

The cost of business as usual

We have shown that children under 5 years of age who have frequent hospital admissions have a 2.5-fold increased risk of developmental and learning vulnerability at school entry.[1] Another of our studies showed that 20% of all school students had extended and repeated absences from their school due to their chronic illness: with 75% missing more than one term and 63% missing more than one year of schooling.[4] The impact of chronic illness on schooling and future job prospects extends into adult life, since 40% of students who do not complete year 12 in Australia have a chronic illness.[5]

Chronic illness and disability in childhood means pain and suffering for children and families today and lost opportunity for Australia tomorrow. In 2013, the national estimated cost of hospital admissions for chronic illness in childhood totalled almost \$1 billion, an average of \$5,291 per admission. This does not include the impact of physical ill-health and disability on individual, family and societal costs which are yet to be comprehensively evaluated. Across the life course, 9 in every 10 deaths in Australia is due to a chronic illness.[19] A total of \$67 billion of the health budget is spent on chronic illness. This is however not the whole story. By 2030, chronic illness will cost Australia a further \$20.5 billion in lost productivity, \$7.3 billion in welfare benefits and \$4.7 billion in lost taxes.[19-21] It is estimated that 30% of chronic illness morbidity is preventable with early intervention, especially in childhood.[19]

Why now?

Medical advances across paediatrics mean that children with previously incurable diseases and disabilities are now surviving into adulthood. The health system is overloaded managing long term, chronic conditions. Though these children are now surviving into adulthood, there is a substantial gap in life attainment when children with chronic illness enter adulthood, compared to children without chronic illness. The success of prolonging the life of a child with chronic illness has created a new challenge for our nation: to help children with chronic illness and their families live their best lives, attain their personal and vocational potential, and go on to make their contribution to the economic, social and cultural fabric of a future Australia.

Many of the risk factors for long term adult chronic illness have their origin in childhood. For example, adult cardiovascular disease and stroke relate to childhood inactivity and obesity. With technical and knowledge-based advances in digital technology, big data and genomics, we can now better predict and manage these “whole-of-child-life” problems. We have a unique opportunity to alter the life trajectory of these young Australians so that their improved life circumstance becomes a vital part of our nation’s future productivity and growth.

The Kids to Adults (K2A) Alliance

The K2A Alliance is a national network of more than 50 clinicians and researchers from Australia’s leading child health services and research organisations, working together with parents and young people. Our shared mission is to enable children with chronic illness to live their best lives now and into the future. The goals of K2A are to build on the current work of child health research organisations nationally by leading new, collaborative research focused on ensuring that children affected by chronic illness successfully navigate the journey to adulthood, supported by their family and community. We will build an enduring national research and implementation program that drives awareness and generates solutions to the many real-world problems facing children with chronic illness and their families. We aim to foster culture change to adapt medical management of the chronic illness to minimise its impact on a child’s life. We see these health problems as international imperatives and have begun collaborative discussions with colleagues in the UK. At the heart of the K2A program is ongoing meaningful involvement of children, young people, families and clinicians in all activities to ensure relevance and maximise the impact of our research.

The K2A Alliance is a hub and spokes model. K2A is led by Co-Directors Professors Glenn Marshall, Raghu Lingam and Claire Wakefield, based at the central hub (Sydney Partnership for Health, Education, Research and Enterprise - SPHERE). The K2A Executive oversees the activities of the Alliance. This group meets bi-monthly and is comprised of research leaders across the Alliance and across Australia.

What needs to be done?

Little or no national data exists on whole-of-child-life problems faced by children with chronic illness. While the lost productivity for these children now reaching adulthood is a major future issue facing the nation, there are no data measuring its impact or official reviews of potential solutions. There is no recognition by state or federal Departments of Education or Health that the missed schooling incurred by a child with chronic illness is indeed a problem, Nor is there an acceptance of their joint responsibilities to compensate for this deficit. Services for children with chronic illness vary enormously by state and regional jurisdiction. Regional, rural and disadvantaged children with chronic illness do not have equal access and in many cases are regularly forced to travel long distances to acute care hospitals in major cities. Parents of these children are often burdened with the dual role of spending several hours each day delivering medication, and, providing an education to their child. They are often so grateful for the role of science and medical care in saving their child’s life that they do not feel empowered to question whether changes can be made to reduce the impact of the care model on their lives. K2A aims to give these people a voice. We hypothesise that research and its implementation can improve the lives of these children and their families, thereby improving the overall productivity of our nation.

Our recently completed Kaleidoscope project [30] was the first attempt to determine what issues young people with chronic illness and their families thought were important to them. This audit merely “scratched the surface” and a great deal needs to be done before we get to the point of full consumer integration in research: a true “no research about us, without us” approach.

The outcomes of the Kaleidoscope project have given us five research streams around which we can begin to understand the magnitude of the problems and start to develop solutions:

- Stream 1 Consumer consultation and involvement in childhood chronic illness research;
- Stream 2 Measuring the impact of childhood chronic illness across Australia;
- Stream 3 Changing the clinical care system for children with chronic illness and their families (integrated care models);
- Stream 4 Building resilient, well-informed and connected families; and,
- Stream 5 Reducing the impact of missed learning and school participation.

We anticipate new domains of research such as the impact of genomics and the NDIS, will begin over the next 12 months as more researchers join our network.

What does success look like?

The K2A Alliance will conduct national research into the scope of, and solutions to, the system-wide problems we have described. Thus, providing government and legislators with the tools and information to help children with chronic illness live their best lives. We sit firmly in the translational research space – developing, implementing and evaluating systems and services that will affect the everyday lives of children with chronic illness and their families. Each of our research streams will share knowledge, central resources and expertise. Together the research streams will create national cutting-edge translational research to change the lives of children with chronic illness and their families across Australia. Success will see a whole-of-government approach across departments, acting on advice from parents, young people and researchers to bring about a measurable improvement in school and vocational outcomes, mental health problems, equity of access for rural and regional families, educated and empowered families and primary care clinicians, financial toxicity for families, health system costs, and productivity of young adults with chronic childhood illness.

The estimated cost to our community of clinical care for children with chronic illness and lost productivity is \$100B per year. We anticipate that through K2A research and implementation, the financial and social burden on our community can be reduced by at least one third.

The K2A Alliance calls on the Federal Government to invest \$22M in K2A's comprehensive national program of collaborative research, co-created by Australia's leading child health researchers, clinicians, parents and young people. The aim of this research is to find and implement solutions to the significant problems facing well over 1 million Australian children affected by chronic disease and disability.

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