New South Wales

Special Commission of Inquiry into Healthcare Funding

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Juvenile Arthritis Foundation Australia

A submission to:

The NSW Special Commission of Inquiry into Healthcare Funding

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Submission from the Juvenile Arthritis Foundation Australia.

The Juvenile Arthritis Foundation Australia (JAFA) is pleased to have this opportunity to make a submission to the Special Commission of Inquiry into Healthcare Funding. This submission is made on behalf of children and young people with juvenile idiopathic arthritis /childhood rheumatic diseases (JIA/CRDs) and their families in NSW. It is informed by consultation with parents, arthritis consumer organisations, health care providers and policy makers, published standards of care, and comparisons with specialist paediatric workforce and services in equivalent economies, as well as comparisons with NSW paediatric services for other similarly serious chronic childhood diseases.

The key points of this submission are:

1. The NSW healthcare system structure and funding are inadequate to provide effective, accessible and equitable care to children and young adults living with chronic diseases such as JIA/CRDs.
2. Chronic diseases in children are common and affect 1.2 million Australian children. It is particularly inequitable that NSW has a health system which does not cater for the needs of this significant section of our future generation.
3. The current NSW healthcare system lacks the flexibility to address and rectify inequity when common childhood chronic diseases such as JIA/CRDs are disproportionately underserved.

Inequity is a major problem in the delivery and funding of healthcare in NSW which compromises quality of care and achieving desired outcomes. This inequity relates to:

- care of people with chronic diseases v acute care.
- low recognition and priority given to chronic diseases in children and young adults.
- allocation of funding across childhood chronic diseases.

Achieving equitable care of children and young adults with chronic diseases rests with NSW Health.

This submission begins with background information on JIA/CRDs and highlights the inequitable under-resourcing of paediatric rheumatology services in NSW. This is not done to focus on how we got to the current situation, but rather as background on what is required to rectify the situation in the context of rethinking the NSW healthcare system.

About JAFA (www.jafa.org.au)

The Juvenile Arthritis Foundation Australia (JAFA) is a registered national charity founded in 2019 in response to the urgent need for a national voice dedicated exclusively to advocating for and addressing the needs of children, adolescents and young people with juvenile idiopathic arthritis and related childhood rheumatic diseases (JIA/CRDs) and their families and carers.

Its core focus is on political advocacy to raise awareness of JIA/CRDs among high level policy makers in order to effect systemic and sustainable change to improve the lives of children and young people with these painful and potentially debilitating disease. Implicit in this is connecting the juvenile arthritis community and raising awareness among health professionals and the community.

About Juvenile Idiopathic Arthritis and Childhood Rheumatic Diseases (JIA/CRDs)

- there are an estimated 3,000 children in NSW with JIA/CRDs with JIA accounting for over 80% of patients.
- JIA/CRDs are a serious and complex group of painful, chronic auto-immune diseases diagnosed between 0-16yrs of age.
- JIA/CRDs are not rare conditions - they affect around 1-2 in 1000 Australian children and have a similar frequency to childhood diabetes and childhood epilepsy and are six times more common than cystic fibrosis.

- a recent Australian Institute of Health and Welfare report estimated there are as many children and young adults upto age 25 in Australia with JIA as people with type 1 diabetes in the same age group.
- if not diagnosed early and treated effectively, they can cause permanent joint damage and loss of vision up to and including blindness and, in some cases, also affects the skin and internal organs.
- around 80% of children with arthritis experience pain daily and many children are socially isolated due to missing school and an inability to participate in school activities, sport and play. As a result of this and frequent medical interventions, many children develop mental health problems.
- they suffer a high burden of permanent disability, lost educational opportunity, limited participation in social and physical activities, mental ill health and a very poor quality of life.
- in 50%, arthritis continues into adulthood, accounting for thousands of young adults at risk of severe disability.
- 30% of children with JIA also have uveitis - an inflammatory eye disease that causes visual impairment and eventual blindness if not detected early and treated effectively.
- there is currently no cure or means of preventing JIA/CRDs and treatment aims to drive the auto-immune process into remission in order to preserve joints and vision while maintaining normal childhood growth and development. Treatments are often aggressive and highly complex, involving powerful immune-suppressing medications which can have serious side effects.
- there is overwhelming evidence that early diagnosis and treatment vastly improves outcomes and reduces, or even prevents the risk of disability.
- children need rapid access to highly specialised multi-disciplinary paediatric rheumatology teams for acute episodes of their disease as well as regular ongoing monitoring. A typical team is made up of paediatric rheumatologists, specialist nurses, physiotherapists, occupational therapists, psychologists, social workers, and ophthalmologists trained to detect and treat uveitis.

NSW Paediatric Rheumatology Services

- JIA/CRDs are the 'Cinderella' of the common chronic childhood diseases with services around 40 years behind similarly prevalent diseases such as childhood diabetes. This is the result of significant and prolonged underfunding.
- Australian paediatric rheumatology services fall well below international standards with almost 50% of Australian children with JIA/CRDs without access to recommended standards of care.
- within Australia, the number of paediatric rheumatologists falls well below specialist numbers for other similarly prevalent and serious chronic childhood diseases.
- ***NSW has by far the lowest number of paediatric rheumatologists per population in Australia.***
- there is only 1.1FTE paediatric rheumatologist and 1.0FTE paediatric rheumatology nurse in the NSW public sector to care for the estimated 3,000 children and young people with JIA/CRDs, no psychologist and no social worker. This compares unfavourably with less populous states eg 3.94FTE paediatric rheumatologists in Victoria and 1.8FTE each in Qld, WA and SA.
- NSW does not provide state-funded outreach services for JIA/CRDs forcing many rural and regional families to undertake costly travel to Sydney for their child's treatment.
- the lack of a critical mass of paediatric rheumatologists in NSW means that NSW is not approved to undertake advanced traineeships in paediatric rheumatology.
- the recent *Parliamentary Inquiry into Childhood Rheumatic Diseases* confirmed the serious under-resourcing of paediatric rheumatology services (March 31, 2022). https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/rheumaticdiseases/Interim_Report

Beneficiaries of an improved NSW healthcare system for JIA/CRDs

- improved health, mental and socio-economic outcomes for children and young adults and their families and carers.
- the community, employers and the broader economy which are affected through:

- Parental absenteeism (lost productivity incurred in caring for and taking children to appointments), and parental presenteeism (stress/distraction while at work)
- Reduced household income/savings eg when a parent must reduce / cease employment to meet the child's care needs
- The direct costs of illness and disability the NSW paediatric rheumatology workforce which is under unsustainable pressure to meet service demands that are unachievable with current levels of staffing.
- the NSW health system which will benefit from increased capacity and public confidence.

Detailed comments addressing the Terms of the Inquiry
The following addresses the issues around current models of care and funding for chronic diseases and particularly paediatric rheumatology services, and potential solutions, under the specific headings and terms of the Inquiry.

A. The funding of health services provided in NSW and how the funding can most effectively support the safe delivery of high quality, timely, equitable and accessible patient-centred care and health services to people in NSW, now and into the future.

The current funding and provision of health services for children and young adults with chronic conditions is inadequate and inequitable and consequently lacks quality and compromises safety.

The current funding model fails to recognise and take into account the present and future impact of chronic childhood diseases on physical and mental health, and social and economic consequences on future generations.

B. The existing governance and accountability structure in NSW Health.
i] The current health funding system is not designed to address endemic systemic shortcomings. At the service level, decisions about funding priorities are left to the Sydney Childrens Hospital Network (SCHN). The result of this devolved responsibility is obvious with paediatric rheumatology services being 40 years behind similarly prevalent childhood conditions.

Furthermore, a model centred around SCHN decision-making to prioritise services is incapable of fixing the situation, as illustrated by the unsuccessful concerted efforts of the paediatric rheumatologists over many years and JAFA's efforts in recent years. ***SCHN has demonstrated that it is either not willing or not capable of rectifying the current inadequate situation.***

The only way to remedy the current inequitable system in paediatric rheumatology is to replace the SCHN devolved priority-setting decision making with a centrally controlled state-wide co-ordinated model with a dedicated budget.

A NSW state-wide plan for a hub and spoke model for paediatric rheumatology services was developed in 2013 but was never implemented. A future health funding paradigm for NSW Health must include the capacity to implement State-wide recommended and agreed models of care. The experience of paediatric rheumatology emphasises the need for a high-level commitment from Government and NSW Health to implement an adequately funded state-wide model. Considerable benefits would have resulted had the 2013 model been implemented.

A hub and spoke model of care is not controversial and would include:
- treatment through multi-disciplinary care and whole-of-family engagement
- an integrated system of primary, secondary and tertiary care, including virtual care
- specialised tertiary services

- integrated clinical outreach services provided by secondary services with support and capacity building from tertiary paediatric rheumatology services.
- appropriate evaluation and reporting against specific paediatric rheumatology service relevant KPIs.

ii] Consumer lived experience is critical in the design and specific details of care models to ensure they meet the needs of the consumer. Although health service planning and professional staff are familiar with the theory, they often lack important relevant information of what best meets consumer needs. JAFA has a key objective of encouraging health departments to include meaningful consumer engagement and listen to the voice of the lived experience when planning services.

iii] Currently responsibility for paediatric rheumatology services is appropriately located within the Health System Strategy and Patient Experience section of the NSW Ministry. However, overall control would be better co-ordinated by a high-level, dedicated state-wide group with meaningful consumer representation, supported by adequate funding

v] As detailed above, the paediatric rheumatology workforce is dangerously inadequate to deliver a safe and equitable service. A further consequence of this, is there is an insufficient critical mass of paediatric rheumatologists in NSW to enable NSW to undertake advanced traineeships in paediatric rheumatology, which only serves to perpetuate the lack of an appropriate workforce into the future.

This not only applies to paediatric rheumatologists but also to paediatric rheumatology nurses and specialised allied health professions eg physiotherapists and occupational therapists etc.

C. The way NSW Health Funds health services delivered to public hospitals and community settings, and the extent to which this allocation of resources supports or obstructs access to preventative and community health initiatives and overall optimal health outcomes for all people across NSW.

Devolved priority setting responsibility is the major obstacle to childhood chronic diseases, such as JIA/CRDs. Engagement with community settings is virtually non-existent. However, there are opportunities to improve access to community services for JIA/CRDs – for example access to affordable community-based physiotherapy, occupational therapy and hydrotherapy.

An integral part of a state-wide paediatric rheumatology service is an outreach service based on locally available staff in outer-metropolitan and regional hospitals. This is a major problem as illustrated in the following case studies:

‘The local hospital won’t do her infusions so we do the 6 hour drive to Sydney every month. We have family to stay with but it’s still costly and very stressful for the whole family and we have to take 2 days off work every time’ (mother of 8yr old Alicia).

‘We used to fly to Sydney for his treatment but he’s on strong immune-suppressants and gets every infection going so since COVID we do it by car. The driving is really tough on him especially when his joints are so sore’ (mother of 6yr old Toby).

Outreach service can address this need provided there is sufficient staffing and funding. Wagga Wagga provides an example of a successful outreach service which was implemented through local community support.

D. Strategies available to NSW Health to address escalating costs, limit wastage, minimise overservicing and identify gaps and areas of improvement in financial management and proposed recommendations to enhance accountability and efficiency.

Improved communication and data linkage between health services are required. This would be facilitated by a single patient electronic medical record (eMR) linking inpatient, outpatient, pathology and radiology which was accessible (with appropriate consent) to primary care and community services.

E. Opportunities to improve NSW Health procurement process and practice, to enhance support for operational, decision-making, service planning and delivery of quality and timely health care, including consideration of supply chain disruptions

Not applicable to JIA/CRDS

F. The current capacity and capability of the NSW Health workforce to meet the current needs of patients and staff, and is sustainability to meet future demands and deliver efficient, equitable and effective health services.

The paediatric rheumatology workforce is too small to provide a high quality, equitable and safe service. This can only be addressed by the Ministry of Health through an appropriately funded state-wide service.

The NSW paediatric rheumatology workforce is working harder than any other state but cannot meet demand because there are simply not enough of them. This is illustrated in the table below.

Australian Paediatric Rheumatology Group Survey – May 2023
Paediatric Rheumatology Public Outpatient Workload – NSW Compared with Rest of Australia

Paediatric Rheumatology Public Outpatient Workload			
	Clinics per month per 1.0 FTE Paediatric Rheumatologist	**New Patients per clinic**	**Review patients per clinic**
NSW	18.4	4.3	9.7
The rest of Australia	15.2	1.6	4.6
Workload in NSW represented as a percentage of national workload	121%	269%	211%

Various strategies could be introduced to encourage upskilling of the non-specialist workforce to acquire basic knowledge about JIA/CRDs supported by appropriate referral pathways. This particularly applies in rural, regional and remote services.

G. **Current education and training programs for specialist clinicians and their sustainability to meet future needs.**
Previous comments under B(v) are relevant here.

Training programs for nurse practitioner and allied health workers should include basic knowledge in a range of chronic childhood diseases, especially for those based in rural and regional areas.

H. **New models of care and technical and clinical innovations to improve health outcomes for the people of NSW, including but not limited to technical and clinical innovation, changes to scope of practice, workforce innovation, and funding innovation**.

What is available in paediatric rheumatology is so basic and deficient that innovation is not relevant until capacity is increased to meet minimum basic requirements.

I. **Any other matters reasonably incidental to a matter referred to in paragraphs A to H, or which the Commissioner believes is reasonably relevant to the inquiry.**

No additional comment.