

RARE CARE CENTRE A NEW HOLISTIC AND CROSS-SECTOR MODEL OF CARE

JANUARY 2023

An interview with Dr Gareth Baynam, the Medical Director of the Rare Care Centre and a clinical geneticist with a long-standing commitment to improved health care for indigenous communities and equitable access to health.



The 'hallmark' characteristics of rare diseases are their rarity, complexity, and diversity, which all too often affect all aspects of life for both the individual and their family. Persons Living with a Rare Disease (PLWRD) often encounter barriers to accessing essential services, education and employment, as well as participating in society. However, **there are new and innovative approaches that promise to truly integrate services across different sectors to address the needs of individuals and their families.**

The Rare Care Centre was launched on Rare Disease Day 2022 to lead the way to improve the lives of children and families living with rare conditions through a new cross-sector model of care.

The new **Clinical Centre of Expertise for Rare and Undiagnosed Diseases (Rare Care Centre)**, at the Child and Adolescent Health Service in Western Australia, addresses the next steps following a diagnosis, or whilst awaiting diagnosis.

INTERVIEW

Where was the idea for the Rare Care Centre born?

For the past 20 years, we have concentrated on diagnosis, including over the last six years through the Undiagnosed Diseases Program-WA. Following a diagnosis, we saw a dearth of coordinated and integrated services that were equitably accessible, culturally safe, responsive and touched on all the aspects of what it means to live a full and beautiful life. So really, the Rare Care Centre was born from the idea of helping children and families (diagnosed and undiagnosed with a rare disease) to live the best lives possible.

The only way to achieve this goal was to take a **cross-sector approach that employs people from all the different sectors**, within and beyond the health system and from all parts of the social and community sectors.

How was the Rare Centre Centre developed?

We are extremely grateful and indebted to all the different services and people that have been involved in the co-design process, and who have been so generous in sharing their experiences, opinions and goodwill. **It was an extraordinary co-design process**, including over 400 stakeholder meetings with people from all sectors – education, employment, community, disability, primary care, Aboriginal health, mental health and welfare sector. We engaged people from all parts of the community – young people, indigenous communities and remote regions in the Youth Reference Group, Community Reference Group and Non-Government Organizations. Their collective input has been critical in designing the whole program and unearthing some critical insights into the needs and fears of these communities, that needed to be addressed through a cross-sector approach.

An important element of our co-design was the Aboriginal Health Leaders and the Aboriginal Health Council, which oversees the 23 Aboriginal Controlled Health Organizations across Western Australia State. The Rare Care Centre design and implementation were based on Aboriginal Health Principles, and this will be of benefit to everyone. This approach also allowed us to build training on rare diseases into Aboriginal Health Care Worker training in a sustainable way. We are currently designing and implementing modules on rare diseases for Aboriginal Health Care Worker training that can be provided locally and nationally.

Furthermore, **this enables our Centre to enhance its focus on remote region care**, enabling access to people living more than a thousand miles away from a main city. Western Australia is massive and is three times the size of Texas! It is the world's single largest public health jurisdiction, so it is critical for us to have a focus on remote and regional health, which also makes the overall service better for everybody because you end up having to design things that are accessible and sustainable for all. I think that's been a real plus and an area of innovation!

Can you explain more about the new 'cross-sector model of care'?

We believe that if we employ people from different sectors in one team, then we will have a better chance of making sustainable and systemic change, connecting existing services, reducing duplication, and avoiding adding layers of services to an already complicated journey.

The Model of Care has been developed by integrating people from all sectors at the different levels of the governance of the Centre – from an operational level, executive level and a global strategic level. This approach enables us to resolve issues experienced by individual families. We have a mechanism to raise the issues at the highest levels across and within the different sectors, to address barriers and create systemic change.

Culturally safe and responsive care is a cross-cutting theme, including for indigenous and other culturally and linguistically diverse children and families. Alongside its clinical service, the Rare Care Centre also has streams of work to build multi-stakeholder capacity, support health systems, and enhance equity and scale, including Education and Workforce Capacity Building; Digital Technologies and Devices; Peer-to-Peer Mentoring and Systems Advocacy; Global Partnerships and Connection to Global Expertise; and Research and Evaluation. The Centre is traversed and fuelled by innovation.

How is the Centre funded?

Everything in rare diseases is about partnerships, relationships and trust. We have been fortunate to have a high level of enthusiasm and support across the sectors and benefited from philanthropic funds, which have catalysed a new state-wide service. It has been remarkable that multiple philanthropists have come together in partnership and now partner with the Public Health Service to support the Rare Care Centre. Driving the way forward together sets us up for sustainable and high-value impact. It gives our community a lot of hope that this model can be replicated elsewhere - nationally, regionally internationally.

The Rare Care Centre is a learning community system. The Centre's co-design is strength-based; it ensures that the community voice is listened to, empowered and responded to. It builds on the success of other rare disease initiatives through compassion, innovation, and action to serve better the needs of children and families living with rare diseases.



More info on the **[Clinical Centre of Expertise for Rare and Undiagnosed Diseases \(Rare Care Centre\)](#)**.



Stay tuned for more interviews and articles in the series



Please find this article and others on the **[Rare Diseases International Website](#)**



Follow RDI on social networks

