

The Unheard Symphony: Orchestrating a Healthcare System for All

Imagine you're the director of Spotify, making decisions that shape the universe of musical experience. You yearn to create an app and algorithms that will bring joy to everyone, but there's so much to do and new features take time. What do you focus on? How do you prioritise? What do you put front and centre? How do you design your experience?

Would you throw your algorithmic might behind promoting the top 40 hits? A world where every user's discovery feed serenades them with only the most-listened-to artists, the chart-toppers, the viral sensations? Well... that would cover a lot of people... Highly played songs do get played a lot... So why does such a scenario of big-hits-focus seem untenable, almost backwards to my ears?

Because many people are not most people.

Spotify eclipsed the radio by being able to effectively cater to an immense, diverse set of interests under a single system. Can the same be said of our healthcare?

I thought about this visiting the Pītau-Allenvale school, coming across children with Angelman syndrome, a condition I'd never heard of in over 4 years of medical school, and then met three children in the same day. I thought about this while researching my dad's Myeloproliferative Neoplasm diagnosis, a group of conditions that occurs at 3.4 per 100,000 New Zealanders. I thought about this when I read the RDNZ report that there are likely to be around 300,000 people of Aotearoa affected by more than 7000 rare disorders.

I thought about how many things happen every day. That even the phrase 'one in a million' describes events that happen all the time, describes five people in Aotearoa. Unexpected things are expected once you add enough people.

In statistics they teach us about the long tail – where the aggregate of rare things can be as big as the big ones. In aggregate, rare diseases are just as common as diabetes, but it's hard to see the aggregate.

As a future professional in the health system I hope to be part of this creation of dynamic responses to the diversity of human conditions.

Understanding the importance of adaptable systems, especially for conditions that are often overlooked or misdiagnosed, emphasises the need for a healthcare system that values understanding, navigability and transparency in equal measure. It is a powerful reminder of the responsibility healthcare professionals have to all their patients, not just those with common or well-understood conditions.

This knowledge compels me to advocate for and implement a more inclusive approach in my professional practice, ensuring that every patient feels seen, heard, and valued, regardless of the rarity of their condition. It has instilled in me a commitment to continuous learning. Now who's on the music?