



# Navigating the System



**A life that includes disability is a life that includes interaction with multiple systems.**

Colloquially referred to as 'the system', in reality what we experience are many siloed systems that in theory have been created to assist and support us, created to make life easier, and to 'help' us. What is quickly evident to even the newest of us, is that theory and reality can be two very different matters.

We are indeed fortunate to live in Aotearoa NZ. Having spent time with people and their families in Papua New Guinea, India and Indonesia over recent years, there is a deep thankfulness in my heart for the cross governmental, multi layered social, health, education, disability, and income support we have access to here at home. We are indebted to our forebears who laid the foundation for what we know today and if not for their vision, hearts of social justice and practical application, we too could be living in a very different space.

Notwithstanding my gratitude, I find navigating all of this 'helpfulness' an immense challenge both

personally and professionally. **My experiences often leave me feeling:**

- › Disempowered and confused
- › Like a frustration to the system as well as frustrated and at times angry myself
- › Time poor from the endless follow-ups, chase-ups, initiations, deliberations, and attendance at appointments that suit the schedules of the servers and take little account of the needs of the served
- › Sick and tired of having to go back to the start with yet the next person 'assigned to our case'
- › Living with an internal tension that on the one hand knows we need assistance but on the other (regularly) not wanting anything more to do with the dysfunction and ongoing difficulty of being 'another number' in the system.

Of course, these are not all my feelings or thoughts, many of which I still struggle to give voice to. What I know is that in our life, and in the lives of many other whānau, a very difficult reality exists. This reality is born from wanting and needing help but having to experience it through systems that often place more bricks onto our already heavy load, instead of removing them. This reality often forces us to be worn down and submissive or to become 'that parent'. Of course, we are more likely to fluctuate between the two, neither of which enable us to be equal partners who are treated with the respect that is spoken about on every agency's website.

Some folks respond by going all in to change the system, but for me, after almost thirty years of being a paid functionary within many systems and the last four years experiencing the system as a parent, I'm not at all interested in trying to change it, surviving it is all I've got right now.

**So, I'm looking for wisdom, insight and success strategies to help us and that we can then share with whānau across our nation. This is the primary purpose of this inaugural edition of Korero. We would love to hear from you! Some thoughts from my kete:**

## Stop Looking For Logic

So many whānau I speak with are operating on the assumption that the system and the intersection of its many components have a logical base. They offer logical and sensible rebuttals to some of the craziness they encounter such as, "if we did it this way it would be so much cheaper", and they are often absolutely right. Their error is in believing that the system(s) operate on the principles of logic, which they simply do not. Systems operate on all manner of principles (and personalities) such as:

- › The needs of funders, government, and budgetary cycles
- › Political agendas, cover-ups, and 'butt covering'
- › Conflicting and incoherent internal policies
- › Incompetence, career advancement strategies
- › Stubbornness
- › A deep desire to do good without the necessary skill to know how to do that
- › Out of date funding methodologies and ideologies and;
- › We could add many more.

Instead of looking for logic I often talk with whānau about the system being more like a 'game'. Not a funny, haha game, but when we think of it as a game that we can learn to play with strategies, techniques, methods (inside knowledge so to speak) we have a new framework within which to operate. For me at least, this approach, as opposed to a wrestling for non-existent logic, has been much more fruitful. Of course, not fool proof, but at times less painful.

## Learn the Game From the Inside

Every server / functionary / worker / professional in our modern system(s) can be characterised as a cog in the machine (I understand some folks may take this comment personally and as an indication of disrespect, however it is not intended as such.) Systems theory tells us that when all of the cogs are working optimally, the overall machine works as it was designed and its product 'helpfulness to service recipients' is maximised. However, it doesn't take too much insight to see how impossible that is when our cogs are of the human variety.

In just one small example of this, whānau encounter everyday opposing and at times completely conflicting advice from different people from within the same entity. One worker says one thing, the next says another and yet another could have still another perspective. I often think of this experience as trying to put together a jigsaw, one piece at a time, while never being sure all the pieces are from the same puzzle.

The good news is there are a few exceptionally helpful humans who do have both a deep insight into the specific system and who also possess a gift for explaining things in a way that is helpful as opposed to creating even more confusion. These are the folks you are looking for. They are rare, but they do exist. When you find one, share them with your friends.

## Call a Friend

I am eternally grateful to a small group of people connected to our whānau who totally get it. The majority (but not all) are other whānau. These folks have saved me on more than one occasion. I can call them, download to them, tell them about the most recent 'crazy-making' experience we have just encountered, get it all out and then usually be lifted by an equally or at times even more ridiculous experience they have recently had to endure. Once I've downloaded, I'm better placed to re-enter the battle (because a battle is exactly what it is for us at times) refreshed, revived and relatively sane.

This strategy doesn't mean I don't get caught out from time to time as was recently the situation when my wife, daughter and I unsuspectingly walked into a 'meeting' with 11 professionals, but it certainly builds my fitness for these moments.

## We'd Love To Hear Your Strategies

How do you make your way? What have you found to be of benefit?  
If you are willing to share your suggestions so we can share even further,  
email us on [tony@alliesaotearoa.co.nz](mailto:tony@alliesaotearoa.co.nz)



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Tony McLean lives with his wife Ange and three children in the beautiful Bay of Plenty of Aotearoa NZ. Their eldest experiences life with chronic and debilitating health impairments. Tony has worked in both paid and voluntary roles within the disability sectors of Australia and New Zealand since 1993 and is the founder of Allies Aotearoa. He is also involved with cbm NZ – an international NGO that serves disabled people in some of the world's poorest communities.

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Allies Aotearoa is a small independent service that seeks to be helpful. We receive no funding from any source and as such speak as independent allies. This publication is offered as something to ponder and korero about with your whānau, friends, connections and colleagues. While this paper is primarily written for whānau, we are hopeful these thoughts may also be of value to people in paid service roles as another lens through which to consider practice paradigms and service frameworks.

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