Overcoming challenges in caring for a child with multiple disabilities

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I would like to take the opportunity to thank my new friends Michael Gordon and John Franze from the National Rural Health Alliance for inviting me to share my story with you today; and in particular offer my thanks as a service recipient for their contributions to ensuring that rural Australians have a voice in the rollout of the National Disability Insurance Scheme.

The sole and only reason I am here today is because of my daughter Jaime and I’d like to introduce her to you. Jaime is 12 years old and in August will be a teenager; scary thought!! She is a beautiful girl and when she laughs you can’t help but laugh with her. She’s cheeky and funny and very often naughty. She knows what she wants and can be incredibly stubborn (naturally she gets that from her Dad).

But life isn’t all hearts and butterflies for Jaime. She has a collection of diagnosis, the most significant of which are: Ataxic Cerebral Palsy, Epilepsy and Intellectual Disability. Jaime has no speech or language and almost certainly never will. We’re not really sure how much she understands of what we say to her. She can walk, but not for long distances so she needs a wheelchair and she is not continent. Jaime continues to struggle with seizures that aren’t completely controlled by the two anticonvulsants she takes twice a day. She stopped eating and drinking when she was about 3 and has been fed by gastrostomy ever since.

To all intents and purposes Jaime was ‘normal’ at birth; there were no immediate indicators that anything was wrong. When she was about 6 months old we started to notice that she didn’t seem to be hearing properly. Either she didn’t respond to sound at all, or if she did, she couldn’t locate where the sound was coming from. At that time we were regularly visiting our Child & Youth Health Nurse and she referred us to the GP who referred us to the Women’s & Children’s Hospital. The very first test Jaime ever had was a Brain Stem Evoked Response to determine whether she was in fact ‘hearing’.

My husband and I live 3 hours from the Women’s & Children’s and he wasn’t able to attend the appointment with me. I’m blessed with a big family though, so one of my sisters came with me. I remember that day as being quite traumatic. They had to sedate Jaime and then hook her up with electrodes which measured her brain activity whilst firing sounds into her ears. The good news was that the test results concluded that Jaime’s ears were functioning because her brain responded to sound, but they couldn’t tell us what sense she could make of the noises she heard.

By the time Jaime was 10 months old it was clear that she wasn’t meeting developmental milestones. Through a series of referrals we found ourselves at the local Community Health service.

Our first appointment was a “multi-d” assessment, attended by a Speech Pathologist, an Occupational Therapist, a Physiotherapist and an Early Childhood Intervention Coordinator. They confirmed that Jaime was “Developmentally Delayed”. Our very first label and it was overwhelming. It’s interesting to me to look back and remember how distressing it was. In the scheme of what was to come, that label was pretty insignificant, but nevertheless, it was very difficult to hear.

The therapists decided that Jaime needed intervention and we proceeded into a period of whirlwind appointments. We had weekly sessions of Physiotherapy, Occupational Therapy and Speech Pathology, sometimes joint and sometimes singular and over the next year or so attended a weekly Early Intervention Group and a Hydrotherapy group.

All of this therapy provided a particular challenge for me; at the time I was living in Loxton North, the children were in childcare in Loxton, therapy was in Berri and I was working in Barmera. The three towns are in a bit of a curved line with Berri in the middle. This meant that in the morning I would travel 6kms back into Loxton to drop the kids at childcare, and then travel 35kms to Barmera for work.
On days where Jaime had therapy or group sessions I would drive back to Loxton to pick her up from childcare then return half the distance to Berri for her session. After the session I’d do the trip in reverse. By the end of the day I had travelled 194kms and I did this once or twice a week for 6 months until I got a job in Berri, which meant less travelling.

When Jaime was 12 months old I noticed that when she was eating, her eyelids would sometimes flutter or her eyes roll back into her head very briefly. Back to the Paediatrician again who thought that it was probably ‘behavioural’, but just in case he referred us to the Women’s & Children’s for an EEG. At our follow-up appointment with the Paediatrician for results, he said that she had ‘a bit’ of Epilepsy. Over the next two years and despite trialling multiple anti-convulsants, Jaime was having up to 2,000 seizures a day on a bad day.

It’s very hard now for me to remember an exact chronological order of events; I find that there are key moments which stand out for me and that I remember vividly, like the introduction of the label ‘Ataxic Cerebral Palsy’. I wasn’t able to see the Paediatrician in Loxton where I normally did because he had no vacancies, so I had to travel to Waikerie; a journey of 76kms each way. We spent some time talking and he observed Jaime and then dropped the bombshell. Up until that day I had spent a lot of time wishing that we just had a diagnosis for Jaime, but on the way home, amidst my tears I remember thinking that you should be careful what you wish for.

In the first 3 years of Jaime’s life she was subjected to more assessments and tests and treatments than I care to remember and had had somewhere in the order of 23 general anaesthetics. All of these tests were undertaken three hours from our home. She also had numerous hospital admissions at the Women’s & Children’s hospital, which meant leaving our son at home with his Dad whilst I stayed in Adelaide with Jaime. Hospital was a traumatic place for Jaime to be. She wasn’t able to tolerate the hospital wards for a range of reasons, so for most of the time we were there I would push her up and down every corridor in the hospital, over and over again until she would sleep. If my husband managed to make the trip we would take turns pushing her.

The drive to Adelaide for appointments was a source of distress; Jaime hated travelling. She would be OK for about the first half hour of the trip and then she’d start screaming. We would stop and get her out to stretch and move, but the minute we started driving again she’d start screaming. In the end we kept ear plugs in the glove box of the car. Instead of taking 3 hours, the journey took 3 and a half.

When Jaime was about 3 the Paediatrician decided that desperate measures were called for to control her seizures and recommended that she be put on a Ketogenic diet. In very simplistic terms it is a high fat, low protein, low carbohydrate diet that mimics the effects of starvation. The diet forces the body to use fat for energy rather than carbohydrate and can have a significant effect on seizures. Starting on the diet required that Jaime be admitted to the Women’s and Children’s for a week, and undergo daily blood tests to check the level of Ketones in her blood. Thankfully my husband was able to do that with me. Once we returned home Jaime needed daily blood tests, involving a 30km round trip. After a few months when she’d stabilised on the diet we were able to reduce to weekly blood tests.

We experienced significant difficulties maintaining childcare arrangements for Jaime throughout this period; the centre we used didn’t have the resources to cope with a child who had Jaime’s level of care and behavioural needs. The centre Manager suggested to me once that we were probably going to have to pay higher fees than other parents to counteract the extra care that Jaime required. My husband and I both made the decision to work part time so that we would reduce our reliance on the childcare system; a situation which lasted for 6 months until things fell apart.

I vividly remember the day things fell apart; it was Mothers Day and I was talking to one of my sisters on the phone. Jaime was screaming and my husband was working down in the shed and I was in tears. Unbeknownst to me my sister made some phone calls to other family members and the next thing I knew, my Mum and my brother drove to the Riverland and took Jaime with them back to Adelaide for a week. My family (bless them) shared the care of Jaime over that next week.
I’d like to take a moment to read you part of a letter that I wrote to the Minister for Disability at that time because it gives a pretty good idea of how things stood for us. I should warn you that in the letter I am brutally honest and you may find that parts of it are quite difficult to hear. The beginning of the letter gives an overview of our situation and then goes on to explain...

Jaime screams ... a lot. And bites herself ... quite badly. At the moment her little arms and legs are black and blue and there are grazes on her upper arms where she has managed to bite through a jumper and a T-shirt and broken the skin, causing herself to bleed. She wears wrist bands to try to protect her forearms, but she just bites her upper arms and her legs ... or a carer. There are times when she’s happy and she will laugh and play peek-a-boo games with us and she likes going for a walk in her stroller. But to us it feels, particularly at the moment, that the bad times far outweigh the good. Andrew and I feel like we lurch from one crisis to another with often very short quiet patches in between. We have had four weekends of respite in the last year and a half, none before that. When we do have respite we can’t afford to let ourselves enjoy it too much because then we might never want Jaime to come back.

About four weeks ago Jaime stopped eating and drinking. The time since then has been pretty harrowing for us. She had a naso-gastric tube put in about 2 ½ weeks ago, which has had to be replaced twice because she pulled it out. Needless to say that having it put in is traumatic for all involved, most especially Jaime. She is booked to have a gastrostomy on May 25th at WCH which will put a permanent tube into her stomach by which we can feed her. Of course there are potential complications involved with that and we’re not even sure that Jaime will tolerate the feeding process. It generally takes two of us to feed her through the naso-gastric tube so that we can keep her calm enough for the feed to go through. About a week after Jaime stopped eating we literally feared for her life, she was so unwell. Since the tube has gone in her ‘behaviours’ have worsened dramatically and she has regressed significantly. She is unhappy most of the time, needs to be held constantly (for hours during the day) and is now not sleeping well either. Before she went to hospital she was waking up hourly through the night.

The problem that we face is that the system we belong to doesn’t have a place for us. We are given the impression over and over again that this is our child, our responsibility; we just need to learn to live with it. The services that we deal with ‘would really like to help, but there just isn’t any funding, or she doesn’t meet the age criteria, or there are no services for this kind of thing, or are stretched to the limit by the demands of other clients’. So we find ourselves in a place, after 3 ½ years where we can no longer ‘live with it’. In the past when things have gone wrong and we’ve faced a crisis we just ‘step it up a notch’. What’s the alternative? There is no choice. But now there are no more ‘notches’. We have reached a place where we pray for our child to die so that the pain can end, for her and for us.

Can you even imagine wanting so desperately for your child to die? And how that makes you feel? I have found myself handling her with more force than necessary, I get so angry. And what I’d really like to do is just hit her so hard, but of course I’m a rational person and I know that that won’t help things, it will only make them worse. It’s not her fault, but sometimes that doesn’t matter.

Andrew and I have asked ourselves where it will all end. Surely there’s a better answer out there somewhere for us and our family?

Of course in all of this it must never be forgotten that there is a 5 year old little boy who has lived with more stress than a child should have to live with in a whole lifetime. He complains of ‘stomach aches’ a lot. We know that he is affected by all of this and we know we need to address those issues, but we don’t have the strength. There are no longer any reserves left in these barrels.

So here we are. Jaime is at WCH at the moment and I don’t know for how long. I jump and my heart pounds every time the phone rings because I’m scared that they will ring and say that I have to come and take her home. And if she comes home I’m scared about what we might do to her. We say over and over, “We can’t live like this any more”, but we’re very frightened that there aren’t any answers out there for us, or that the answers that we will be given won’t even
come close to meeting our need. We want to have the opportunity to live a ‘normal life’ and not be prisoners in our own home.

Please help us.

That’s the end of the excerpt of my letter to the minister.

Reflecting on our story so far, it might seem that what came next is a rather extreme response, but what I’ve shared so far is only a broad brushstroke. My husband explains it well when he refers to our situation as “death by a thousand cuts”; there was no one single thing, but a thousand, one thing contributing to another that led to what came next. We never actually made a choice per se in what came next; there just wasn’t any other option open to us.

We signed a ‘Parental Request to Place’ with Families SA; for those from other states, Families SA is our child protection system. It was very clear that at the end of the 6 week order we still weren’t able to cope with Jaime at home, so it was extended for a further 6 weeks. After that we signed a ‘Voluntary Custody Authority’, which lasted for 3 months and was then extended for a further 3 months. At the end of that period Disability SA had sourced a ‘Carer’ and funding and Families SA administered the funding. Our first care arrangement broke down and a place was found for her with another family; a situation which continues to this day.

Andrew and I continue to be responsible for all of Jaime’s medical care and make all trips to Adelaide for treatment and specialist services. Jaime stays with us overnight every second weekend and is still very much a part of our family. She doesn’t recognise us as ‘Mum’ and ‘Dad’, but she seems to think that we’re nice people and she loves to cuddle.

I’m not sure quite what the single biggest catalyst for change was, but it is fair to say that my letter to the minister contributed to a directive from his office that allowed three agencies to step over previously insurmountable boundaries. More specifically, three women from 2 of those agencies stepped in and saved my family.

I don’t want to dismiss or minimise our early experiences because they shaped the journey we found ourselves on and the destination at which we arrived. I think it is critical to understand though, that even what seem like the direst of circumstances can be navigated to a successful and positive outcome when families and service providers work together, when people step outside of traditionally held roles, when they are prepared to cross funding and service boundaries, when they put families at the centre of decision making.

There are a few things I’ve learned throughout our journey ...

- I pick my battles. I can’t fight and win them all, so now I decide what’s most important. That might mean saying no to specialist consultant services in Adelaide. At one point it meant negotiating with the school to have Jaime moved to a different classroom where she was appreciated and respected.

- Problem solving and negotiating is a necessary skill. When Jaime started school she was able to catch the school bus back to and from our house on the weekends that she was at home with us. A few years ago that situation changed and although I spoke with the school and the Department of Education, there was no way around it from their point of view. To get around the problem I negotiated to use some of our allocated respite hours to have a staff member pick Jaime up from school, bring her home and give her her afternoon feed. It’s not ideal, but it works.

- I am now willing to ask for what I need. Through my work I discovered a Chronic and Complex Care Nurse at the Women’s & Children’s Hospital whose role is to help facilitate appointments, particularly for rural and remote people. We’ve recently had a number of appointments at the hospital and instead of trying to coordinate them myself, I ring Anna and say “this is what I need” and she’ll do all the legwork for me. It isn’t always possible to have appointments fit smoothly
together in one or two days, but at least I don’t have to do all the ringing and negotiating for that myself anymore

Lastly, it was suggested to me that I should share some thoughts about what I want service providers and governments to know.

- A system in which a family can end up in ‘child protection’ purely because of a lack of any other alternative is fundamentally flawed

- It would appear to an outsider as if our situation has stabilised and to a large extent that is true. However, what we have always known is that we’ve built a house of cards, which at any point could come tumbling down. We have constantly received the message that what we have is unusual and unique and nobody else has access to the same. Maybe some day someone will decide that we shouldn’t have it either. It’s not reasonable for families to bear this burden

- Services which are bound by eligibility criteria, either due to funding or financial management or even case load management and which are prescriptive in the nature of the service they will provide invariably create cracks and gaps through which families and children will regularly fall

- Ignorance is not bliss. We don’t know what we don’t know and if we don’t know what we need to know, how can we ensure that our children are supported in the best way possible? Good communication is key.

- Future planning is a critical element that is sadly lacking. A Psychiatrist asked me recently, “what are your goals for the future”? The answer is easy. I have none. We don’t know what will happen in Jaime’s future and therefore can’t afford to plan anything too major for ourselves. When her Carer’s are no longer able to care for her, who will? It is our fervent hope that the NDIS will hold some of the answers to these questions.