I welcome the opportunity to make comment on how to improve disability care and support in Australia.

For most families, an understanding of the complexities of the sector only occur when you become one of the people directly affected by a family member with a disability. It is a little understood area and many have assumptions about how it operates and what is available.

A little over seven years ago, my second son was diagnosed with Angelman Syndrome, a rare neurogenetic disorder that has resulted in severe intellectual disability that will require lifelong care and support and he will never live independently. At the time, many family and friends told me that there was lots of support and we could access great programs and assistance but no-one could ever help me when I asked them how I could access these supports or who to call. Even with the internet and the availability of vast amounts of information, trying to sift through all the different service providers and who they support and how is time consuming and wears you down. It took me whole days on the phone every week for many, many months to set up even some modicum of support. This is time that you don’t have to spare when you are also caring for your disabled child (let alone other family members)and dealing with the trauma of diagnosis.

How to move forward:

Categorise the level of disabilities. Severe intellectual with medium physical disabilities require different support to those who are mildly intellectually disabled and severely physically disabled. Autism is distinct from many other genetic syndromes. Who makes the decisions and has the power will be dramatically different in each circumstance.

Recognise the long term nature of our circumstance: Caring for a severely disabled child is a marathon not a sprint and support needs to consider this. It is overwhelming to think that we will always be caring for our son and the physical, emotional and financial burden this will be. We are both trying to continue working as we know our superannuation will have to support three people not two. Yet there are no additional tax breaks or incentives for us. In fact the system almost encourages us to drop out and go onto welfare support such as the carer’s payment as the less we earn the more support we will get in the short term. Legitimate expenses such as the gap payment for wheelchairs should be tax deductible or eligible for the medical expenses rebate where you also qualify for the carers allowance (the systems to cross check already exist to ensure the system is not exploited). We have private health insurance and would think the government would want to encourage families in our circumstance to keep this up and cost shift where possible from the public to the private health sector. Make it a little bit easier by allowing tax deductibility of our health fund fees. These are steps that encourage us to keep up the juggle of working and caring with practical support to help our dollars stretch a little bit further. The carers allowance scheme will allow cross checking of those that are eligible.

Allow greater flexibility for people to solve their primary concerns: Our current priority is afterschool care for our son as there is no outside hours care provided at his school. As the parent of a disabled child we qualify for in home care. That means that if we have an approved carer work in our home we can claim the childcare rebate (50% of out of pocket expenses) and the childcare benefit if where eligible (a reduction off the hourly rate). At the moment, approved carers are primarily the family day care scheme and wait lists are years long to find someone (if at all) or if we can find our own carer they must register with the agency and pay their own costs to register often around $400 (insurance costs). If you are only looking for a low number of hours there is little incentive for someone to register and the family start from scratch if that carer moves on. Make it possible for families to broker hours off existing service providers (who already have the insurance programs). The service providers are reimbursed by the family, the carer is covered by the service provider and is paid through their system (reducing likelihood of cash in hand, under the table schemes) and the family can claim half the expenses back through the child care rebate. These service providers are already monitored for service standards through HACC schemes and audits. Families can keep working to pay for the costs of their child and contribute to the economy therefore reducing the likelihood of them dropping out of the workforce and onto welfare programs.

(Again – the systems are already there and only need a minor modification to make a big difference – along with making sure families know it is available!)

Avoid having to continually prove the disability: It is acknowledged that some circumstances may change and improve as a result of therapy or medical breakthrough. However for most severe genetic syndromes, this will not be the case and if it is it will make the news so people will definitely know! Across state systems and federal systems and for different funding applications, forms have to be filled out as to what the syndrome is and why this or that piece of equipment/therapy/house modification is necessary. Angelman Syndrome (along with many others) is very consistent and having to rewrite the same argument and chase after therapists/doctors/specialists to support and approve the applications is time-wasting and draining. The carers allowance has been streamlined for angelmans and this has been a great help but can’t this logic be applied elsewhere?

Income becomes irrelevant: It doesn’t matter what you earn (unless you are in the millionaire club) as it doesn’t make it any easier. You still have to toilet your child, clean up the poo and wee, feed them and be up all night (angelmans has a severe sleep disorder component) dress them and carry them and lift them. You still worry, cry, fight with your family and have the same stress and anxiety so you cannot use this as a criteria to determine support. Don’t wait for families to break down and be at total meltdown.

Early intervention and support for carers: The mental health agenda recognises early intervention and prevention. Carers are just patronised as “unsung heros” and platitudes of! “I don’t know how you do it”. When I answer – “well I do it with the help of prescription medication” people don’t know where to look are run away! I do it because I have to and I have no other choice. At the time of diagnosis I would have received more support if I had post-natal depression! State and Federal governments need to work together to have appropriate support for families at initial diagnosis. For rare conditions there are no support networks apart from other families who volunteer support to newer families but this is haphazard and although I perform this role now, I have to fit this into my already stretched schedule and am not a qualified counsellor. I have personally witnessed multiple marriage breakdowns and suicide attempts of parents with children with angelmans. This sort of breakdown is not relevant to income, education, location or background. A tangible way to make difference is to ensure public servants who deal with carer applications or queries are trained in this area and can understand the trauma that families are dealing with. We are not at our most polite and rational when sorting through the paperwork and are usually sleep deprived and at breaking point. This can be difficult for those at the customer service end to help people through the maze.

Make sure policy is enforceable: At both the state and federal level there are multiple plans and strategies and commitments to carers and supporting people with disabilities. These often become useless documents as unless they are embedded across all departments and all policies are considered through this “lens” then the strategies have no teeth. If new infrastructure policies are being considered, environmental impact statements must be considered. This same approach should be taken so that new initiatives (or reviews of existing ones) across all portfolios (at state and federal level) are required to be considered from the disability/carer perspective. This will at least demonstrate a commitment to the disability sector and perhaps even improve policy outcomes.

Make it just a little bit easier: Many disabilities have difficulty stabilising body temperature and require air-conditioning to assist sleeping, comfort and prevent seizures. Incontinence results in washing machines going regularly. Increase electricity and water costs could be offset for carers/severely disabled by reductions to those who qualify. Carbon emission issues will become greater over the next decade and price will be used to deter certain behaviour but often this isn’t a feasible option for carers/severely disabled. We want to do our share but some acknowledgement that we are in difficult circumstances by a small reduction or offset in costs will demonstrate an understanding of our circumstance and a commitment to improving our lot.

Time off for good behaviour: This may seem tongue in cheek and perhaps it started that way as an idea but I believe it can be a valid initiative. A scheme that will guarantee a one week respite for parents/siblings/carers who have been looking after a severely disabled family member for 10 years would at least recognise the effort and strain involved. Knowing there will at least be some break helps. (5 years would be even better!) It’s a practical and meaningful idea.