Summary

Thank you for the opportunity to make a submission to the Standing Committee on Social Policy and Legal Affairs on the provisions and operations of the *Carer Recognition Act 2010* (Cth) ('the Act').

I am an unpaid carer who has recently stepped back from part time paid work to care for my child, who has a significant disability. For more details, see the About Me section (Appendix 1 - Confidential).

In summary:

1. While the object of the Act is welcome, is it not effective in raising recognition and awareness of unpaid carers. Little known Acts with limited scope cannot possibly effectively achieve this. This is a broader societal issue that requires a more considered multifaceted response;
2. There have been limited developments in the policy landscape at a Commonwealth level since the passage of the Act. There have been some developments aimed at assisting people with disability (PWD) that may *indirectly* assist their carers, but little that *directly* assists carers. This requires attention. I have included a few thoughts in the table below.
3. There have already been many inquiries, reports etc that delve into the role and value of unpaid care. These cover important cohorts including working carers, isolated carers and ageing carers – and the highly gendered nature of caring. It's not clear why we need to ask one of our most time poor cohorts whether their role and value has changed ? No, it's still extremely challenging - and we're still undervalued. I've set out some comments on the "value" of unpaid care and workforce participation below.

1. Effectiveness of the Act and Statement

The Act remains "a good start", but without more, cannot effectively raise recognition and awareness of the unpaid caring role. 13 years along, we need to do more.

There are a range of reasons for this:

- Many carers do not identify as such and are not aware of the Act.
- Many carers do not wish to disclose that they are carers. Many are stoics who fear that carer status may be misinterpreted as a sign of weakness, draw judgement and adversely affecting career progression.
- The object of the Act is admirable but toothless ie, *The object of this Act is to increase <u>recognition</u> and <u>awareness</u> of carers and to <u>acknowledge the valuable contribution</u> they make to society.* Acts can't acknowledge contributions, people do – it's demonstrated through behaviour.
- While the sentiment of the Act is welcome, the Act itself is very limited in its scope, and therefore, effectiveness. It is limited to *all practicable measures*, to the APS and there are no effective means of measuring the extent to which the Statements have been achieved, nor consequences for failure to do so (apart from possible mild reputational or social stigma). Any APS lawyer or HR manager could find their way over or under the Act as need be.
- Similarly, the Statement (Schedule 1) is well intentioned, but it's effectively an aspirational statement. It's a statement of the obvious, a codification of decent behaviour buried at the back of a little known Act. Of course carers *should* have the same rights and opportunities as others, *should* be acknowledged, *should* be treated with respect. The fact that we even feel the need to spell this out in legislation is, in itself, quite alarming.

Surely, our society has lost its way if we even need to "recognise carers" in legislation and include statement as to how we "should" treat carers. This cannot be addressed through the existence of limited legislation alone. Our society is obsessed with quantifying and monetising caring, the most basic of human traits, to respect, care and love others who are vulnerable. These things should be part of our DNA, part of what makes us human.

In my home jurisdiction, we don't have legislation, but rather a concise Strategy with a few practical ideas – it's not clear the extent to which these have been implemented, but it's a start.

2. Developments in the policy landscape

The Committee asked about developments in the policy landscape since 2010. In short, I am not aware of significant developments *directed at* carers over the last 13 years. That is not to say there haven't been policy and other developments *affecting* carers.

The caring role is integrally tied to that of our loved ones. So often, it is the carers who are the pivot that connects our PWD with each system. I am my child's advocate – while he is capable and smart, he would simply be overwhelmed physically and mentally having to navigate what I do, the emails, the calls, the discussions, the preparation that allows him to be his best self. For this reason, any developments that help PWD is most welcome. These can reduce the time and the stress borne by carers.

However, we need to think about carers in their own right, not as an adjunct or often, the last person in each disparate system. You'll hear many carers say "oxygen first". We cannot expect that our PWD will be well cared for if we do not look after the person who is responsible for their care and wellbeing, their interaction with the various systems and advocating for them. And we cannot expect carers to return to work unless they have the confidence that their loved one will receive the quality care that they deserve.

Developments for PWD

There's no doubt that the NDIS is the most significant "recent" policy development affecting PWD.

My child was diagnosed prior to the commencement of the NDIS, so we are familiar with the pre NDIS fragmentation – it was hard to find programs that could assist, then squeeze ourselves into their criteria, hope that they had capacity – then put up with erratic and suboptimal service. The NDIS has addressed some of these issues. My child is a participant and with a lot of time and effort, we've been able to obtain most of the services that he needs. We have been able to get him a wheelchair that would otherwise have cost more than many new cars. There are issues with resourcing, continuity, costs, price gouging, delays, the endless paperwork and some astoundingly poor administration etc – but overall, we are very grateful to have the NDIS. I am pleased to see that the current NDIS Review has recognised some of these issues. Addressing these would in some part, relieve the current time and stress borne by carers.

However, the NDIS is about *participants*. It is not about *carers*. As carers, we spend hours and hours managing multiple service providers, scheduling, invoicing, recruiting, preparing for plan reviews, managing a mountain of paperwork, politely trying to manage NDIS mishaps. It's a lot of work on top of managing complex interactions with the educational system, the health system, other government agencies, let alone attending to personal care for the child, being a parent to their siblings, maintaining other family relationships, work etc.

There have been other developments focussed on PWD, that *tangentially* help their carers:

- Greater support for accessible housing
- Greater visibility of inclusive sports for PWD
- Accessible communities eg, Changing Places bathrooms for PWD
- More flexible educational pathways for PWD
- Being able to get 2 repeats of some medications, reducing trips to the pharmacy

Developments for Carers

There are limited policy developments aimed at assisting carers - with the exception of the Carer Gateway. This provides some useful links and information. It may provide some people with a useful start. After a rough spot, I tried the carer coaching – nice enough, but I was essentially told to try and make more time for myself and do small things I enjoyed doing. Easier said than done. It's almost another thing to add to the list. For many, there is limited suitable paid care available and there's more stress in arranging everything to go out than staying at home.

There were some Fee Free TAFE places, with priority eligibility for unpaid carers and identifying care as a priority skills area. This is a welcome initiative. Carers develop skills that are very valuable in the workplace. But for many carers like me, returning to the workplace (ideally one that uses the skills that I've already worked hard to gain) will require a significant rebalance where my child's needs are met through formal care eg, SIL, and a flexible employer. Moreover, I have to overcome subtle but persistent discrimination based on gender, age and carer status.

Other

There have been some other developments that *indirectly* benefit carers:

1. Post covid (and in a tight skills market), more workplaces are offering flexible work arrangements, 48/52 etc.
2. Post covid, more educational institutions have developed, by necessity, flexible learning alternatives.
3. There continues to be discussion about gender equity, pay equality, board representation etc. Most carers are female, so it is essential that their voices are heard and help shape workplace policies and culture.

3. The role of unpaid carers

To better identify the role of unpaid carers, you need to hear their stories, feel their frustration, their fatigue, their fear and invisibility. Most will not have the time to sit down and write their story. Many feel over-surveyed, but not listened to. We're tired and cynical. Some will put in a carer statement as part of their NDIS paperwork. Listen to associations. Listen in the waiting rooms of specialist medical clinics. Listen to the parents of kids with special needs at schools. Ask them "what does an average day look like", "what keeps you awake at 3am?" and "what can I do to help".

Carers often live in the shadows. They can be seen in hushed meetings with schools, doctors and allied health providers. They can be heard on phone calls trying to navigate their way through the intractable medical, educational and government systems. Those who can work won't generally discuss their caring role at work. It may be perceived as a weakness. It can make others feel uncomfortable and for many, domestic matters are intensely personal and carers appreciate a division in their daily headspace.

The real caring work is done at home, day in day out, 24/7/365. We don't clock off. Our work is largely hidden, unrecognised, not discussed. It's cumulative work, made up of many small things, large things, unpredictable explosive things, all with a rich emotional overlay – over many years, leading to bone weary fatigue. Sometimes we hear, "oh, you're such an inspiration". We don't need that. We just want our work to be recognised, respected and supported. It's the selfless glue that helps hold our families and communities together.

The reality is that it is too difficult for many to engage in. Despite small improvements in discussing mental health, as a society, we are still painfully uncomfortable in talking about disease, disability and death. Social media continues to narrow the perfect norm. We cannot "recognise" the role that carers play, nor the essential work they provide, unless we engage and hear their stories. While some of these stories are love stories (thanks, Trent Dalton) many hide a far more uncomfortable truth, of fatigue, loneliness, despair, entrapment, loss, poverty. As a society, we have become better at calling out discrimination on the basis of race, gender, sexual orientation and disability, better at calling out bullying and harassment – but we are still treating carers, who work unseen and unpaid, as second class citizens. Recent discussion about the cost of the NDIS has led to some thinking that carers too are "building verandahs on their beachhouses". Nothing could be further from the truth.

Legislation alone cannot change the fact that most people don't see carers and they do not hear their stories. They cannot value what they do not understand, what they have not experienced. The average person sees a glimpse of stressed parent struggling with a child stimming in the supermarket or struggling to unload their adult child in a wheelchair in a carpark. They turn away. Sometimes it's worse. A friend recently found an unused condom left on her car windscreen on the mobility parking pass – possibly a youth who tends to new right thinking and eugenics. It's so offensive and ignorant. For the last few years, I've kept a list of carer "razzies" – it's my way of dealing with some of the appalling behaviours that I see. It's a long and hotly contested list.

A recent example

I recently went to the bank (one of the big 4) to change an account. The bank wanted to update my profile at the same time – "are you still working in the same sector?" "No, I'm a carer". "Ah, so you're not in paid work ?" "No". "OK, we'll put "unemployed"". "Actually, I'm not unemployed – I am very fully engaged, overly so – I work at home with a very broad job description, unlimited hours and am not paid for it. I'm a carer". "Oh, OK. Well, let's see, uhmm - we don't have any other category that fits, so we'll just have to put "'unemployed'".

So, is the Act effective in achieving its stated object. No, of course not. How can an Act that few know about, is limited in scope and is little more than a statement of the obvious be "effective". Legislation is just one part of a much larger and more complex social issue that needs to be addressed through a multipronged strategy.

Who Are Carers ?

Each carer's role will vary – carers will explain it differently, depending on their day and their audience.

A carer's work is physically, emotionally and financially draining. It is isolating and requires sacrifice, endless patience and fortitude and ultimately, so much loss. It requires love and respect. While I would not wish our experience on anyone, I would hope that anyone that was faced with the same prognosis could approach it with humanity, dignity and respect. It could have happened to anyone.

We are Chief Operating Officers

I sometimes try to explain my role to corporate friends as a being the COO of a small company or perhaps an EA. I manage my "clients" health, financial, educational/vocational and social and recreational domains. I manage his diary; transportation requirements; procurement, maintenance and operation of equipment; recruitment, scheduling and management of support staff; accounts receivable and payable; amateur allied and mental health requirements; government and other stakeholder relations; catering; project planning and management – and personal care etc. And so much more. It's quite the job description. The hours are unlimited, no leave, no pay, no super, no training. Don't bother applying – this job can choose you, anytime, anywhere. I'd love to see this advertised as a job in newspapers, as part of a national awareness campaign.

We are Volunteers

We are proud of our volunteers in Australia. We celebrate those who help on the front line, our firies, our nurses, those who coordinate help for those affected by natural disasters. We see those people. We nominate them for awards and give them a platform. So why don't we recognise our carers ? They work on the front line every single day, through average days and disasters. They don't get any training, fundraising BBQs or hi viz vests – but they fight for their loved ones every day. Yet we don't see carers – their work is hidden. And because they do it every day, it's normalised, it's not considered "over and above". I beg to differ. It takes enormous strength, commitment and care. The shifts are relentless, there's no back up. These are the quiet heroes. And they are usually too busy and too dispersed to come together and effectively advocate for themselves.

We want a voice

Our nation is on the brink of giving another marginalised and dispersed group a voice. This is about ensuring that indigenous people, many of whom are carers too, are heard with a view to sharing their rich experience and improving the effectiveness and fairness of policy that may affect them. In some ways, there are parallels. I'm not advocating constitutional change here, but carers too have rich experience that is not heard and as a result, they are not seen, respected or valued. And their voice is too often overlooked in shaping policy.

Hear us. Don't be afraid to ask us what you can do to help. Some people don't want to hear the answer or don't want to pry. Don't assume that all's OK, even if we look like we're managing. We're good at masking. Then please help us in the small ways that you can. Be kind.

Value of unpaid care

The Committee asks about the value of unpaid care.

I refer the Committee to the The value of informal care in 2020 (Deloitte Access Economics, May 2020). The issues canvassed here largely reflect my own experience.

As a primary carer to a person with profound disability, I worked part time for many years, then withdrew from the workforce as his needs intensified. I am "on call" for him 24/7 (less 15 hours or so paid care). I actively provide his care, or manage associated appointments and administration, for over 60 hours per week. If you apply the NDIS hourly rate, my *replacement cost* is a huge number.

The *opportunity cost* is even greater. I could have worked full time, pursued opportunities to work my way up the corporate ladder like my fellow graduates, earned an above average salary, paid a high tax rate and had more disposable income to flush through the economy. Instead, I burned out, stepped back from work to care for my child as his needs intensified, pay support workers a healthy per hour NDIS rate so that I can occasionally get out to do the grocery shopping, attend to my own health needs or manage the mountain of administrivia. I can't contribute the same amount of tax, I can't contribute to my super and I don't have the same disposable income that can help others.

But a purely economic valuation of unpaid care is crude. It completely misses the human element of it. This is my child. Even if his lifespan is limited, he deserves a happy life, a life that includes opportunity, love, respect and the dignity of quality care. He is a smart young person with a lot to contribute – I will not have him framed as an economic burden, nor will I be made to feel guilty for not being in the workforce. I am uniquely placed to take care of one of the most vulnerable people in society. It is a privilege to have this time with him.

The opportunity cost model also overlooks the fact that paid carers are simply not available in the current market and cannot provide the reliable, skilled and emotionally invested care that my son needs. He is medically and psychologically complex and he is a young adult. He does not want complete strangers turning up to give him a shower.

Cohorts

The Committee asks about the needs of specific cohorts. The needs of carers vary enormously and will vary throughout their own caring journey. Please consider the following:

- Working carers
- Isolated carers (those of us who have very limited informal supports due to small or dispersed families). There is no longer “a village” of informal supports.
- Ageing carers (so many parents care for their adult children – as well as their own parents, whilst putting their own health and wellbeing at risk)
- The highly gendered nature of caring. Statistically, most carers are female. Like childcare, nursing and aged care, these roles are essential – yet undervalued. This must be recognised in broader conversations about childcare, workplace equity and flexibility, superannuation etc. Carers cannot hope for any respite unless there are enough skilled paid supports, so workforce planning is also essential.

Flexible Workplaces

Many carers are like me – they’ve worked hard to attain good qualifications and experience. I have post graduate qualifications and have worked in essential services and other areas in high demand. It is usually the mothers that perform most of the care work, juggling the professional and domestic, working part time in the workplace and full time at home. Working provides important financial benefits but also, important mental health benefits. Mixing with other workers reduces the loneliness and isolation experienced by many carers and there is the satisfaction that comes with contributing to society.

I was very fortunate to have had a good employer, that demonstrated empathy and flexibility to carers. My manager trusted that I would approach my work with the same passion and commitment as I did the care of my family. It created a very positive culture, with loyal and highly productive carers, high retention rates and a deep well of experience.

Carers are some of the most focussed and productive workers – they get jobs done without the water cooler conversation. By necessity, they are organised, focussed, practical, tenacious and know how to prioritise. They are good at project management, crisis management and managing difficult people and situations. If I were in a crisis situation, I would want the carers that I know with me. They are fierce, focussed and resilient.

The reality is that some employers are only just getting their heads around parental leave, let alone managing carers. I revealed in one interview that I was a carer. One of the panel made a snide comment about the additional hours expected in the role. Another from the panel later called and apologised. I was employed, but was on the back foot from day one. In a workplace that worships billable time rather than productivity, that seeks to minimise risks rather than understand people, I was a problem. I felt guilty, measured, judged and misunderstood, stressed and tired from intense hours at the office, then caring at home. I didn't stay long.

As noted above, many carers are unable to realise their potential in the workplace. It can be more difficult for them to travel, to take meetings out of hours, to work all weekend on project deadlines etc. I had to "drop and run" when emergencies arose – or a paid carer called in sick. While working from home during covid, I'd have to pause online negotiations to attend to my son's "personal care", then resume as if nothing had happened. I'd regularly have to wait on hold for extended periods to get through to government agencies, while working, then find a private place to have a sensitive conversation. My husband is often on work calls when we take our son to interstate medical appointments. Specialists often run very late, so it's hard to say yes, I'll be back to work at this time. All this affects how work is allocated, expectations, perception, performance and opportunities for advancement.

Both carers and employers need to discuss these matters openly, with mutual respect and pragmatism and without prejudice. In this respect, I note that the Carers Australia Women Who Care hub provides some useful information for carers and employers on these issues.

What would help ?

I recognise that the Committee's inquiry is limited to the objects of the Act. The best way of recognising us and acknowledging our contribution is to hear what we need, then make small changes to effect change. We don't need a "great job, carry on", we need people to understand us, then practical help. Here's some thoughts:

Greater NDIS efficiency	There are some easy wins here. The paperwork is relentless. Every year, I ask our allied health providers to put together very detailed reports. These document just how much loss there's been. It's confronting. Our plan expired without anyone contacting us to arrange a review, despite the NDIS clearly stating in writing, we'll contact you prior to expiry. I had to lodge a complaint. The nominee process was farcical – many kids turn 18, it should have been a simpler less stressful process than it was. And the whole process seemed to duplicate the enduring power of attorney that we'd already put in place.
Measures that attract and retain a functioning paid carer workforce	Unpaid carers cannot undertake paid work, or sometimes even breathe, without skilled and reliable paid carers. We need career carers. And we will never have them if the role is not both respected and adequately remunerated. We also need to make this a viable and attractive casual option for students, particularly those studying adjunct subjects, like physio, nursing, medicine, pharmacy etc. Again, it needs to be valued work, with reasonable pay, something that helps them pay their way through uni but also enriches their experience. Caring work is intensely personal, so it is important to have regular workers. Can we look at having skilled paid carers on au pair like terms ? We would love to have a student help with our son's care - we have the space for them and could offer accommodation, living costs and pay in exchange for set hours per week.
A functional health system	Most carers have first-hand experience of the health care system and some hair raising experiences. As a developed country, we should be able to do better. Our neurologist resigned recently. There's no replacement. They can't do certain scans, not because they don't have the equipment, but because the room wasn't designed to accommodate a wheelchair and their staff "aren't trained" to use a hoist. I offered to bring my own, take photos and send them to our MP. So we have to travel 8 hours to access specialists in another capital

	city – this adds time, cost and stress etc for both our child and us, as carers. On one trip to emergency (about 2am after a long wait), I had to ask the doctor to look up my son's condition – he didn't know that it affected the heart. It takes a month to get an appointment with our GP, often just a check in, with review of the many scripts and referrals. It's rare that we are bulk billed. We need to address the skills shortage and Medicare pricing model. It affects carers too.
Healthcare navigators	Our son's condition is complex. At last count, we have 4 specialists in one jurisdiction, 4 "shared care" "specialists" in our own city, a GP, pharmacists (hospital and general), 3 allied health providers, one mental health support – on top of dental and surgical specialists from time to time. My son has recently transitioned from paediatric to adult care, so there was a huge shift. There were new arrangements for supply of his medication that had to be approved by the hospital board. This takes time. My son risks organ failure if he doesn't get this medication. I have to go to the hospital every month to collect it (the paediatric hospital could courier 3 months' supply, which was easier). Managing all of these (on top of educational, NDIS, equipment, personal care, daily "psychosocial" challenges etc) is tiring – let alone being a parent. The NSW Health System offered an excellent "trapeze" service to help identify and navigate the changes (but have only 3 people covering NSW). Please consider whether a permanent "healthcare navigator" service could be offered to some carers to support them optimise their complex interactions with the health system.
Empathy training	Many people think that they know what caring looks like. After all, they may have been a parent, they may have had elderly relatives. Awareness would improve if everyone could stand in the shoes of a carer, at least for a day. The CEO Sleepout is one way of helping CEO's understand the homeless experience. Whilst it would be great to replicate that in some way, every carer's experience is different and every day can be different. And caring is never one day – usually, it is the cumulative physical and mental challenges of many years. Greater understanding might help the broader community understand small things, like parking in disabled parking spots without a pass. I keep seeing diplomatic vehicles in disability spots without passes. Or parents who say, oh, I'll just be a minute. Or teachers who said, oh, I only use it when it's not being used by others – or use disability bathrooms as bike storage areas. That's so selfish. Perhaps instead of fining them, they should be required to "do life" in a wheelchair for a few days and document their experience.
Accessible housing	There has been some progress in accessible housing and design, but not enough. We looked for 2 years, then ended up building to suit our son's future needs. We did it all at our own cost. It is his home, his safe place. As carers, we cannot downsize until he moves out, or on. As we approach retirement, our income will reduce – so it would be helpful to have some housing based concessions (rates, utilities) that recognise that we are still working full time, and then some, as unpaid carers.
Accessible transport	Goodness, there's an issue for PWD and their carers. If airlines understood that wheelchairs are in fact people's legs that cannot be easily fixed or replaced, then they might not get damaged. And why are wheelchair taxis so often late ? Carers have to manage the pointy end of all of this.
Accessible design	More generally, we need to design for accessibility. My son's university is generally well set out but doesn't include a hoist, so if "nature calls", he either has to stay at home and miss a class - or get home, quickly. As a carer, that

	makes me very nervous – I can't make other commitments if I'm "on call". Or even just an accessible community – as carers, we spend our time "gutter spotting" and dream of the day we can enter shops with our PWD, rather than having to duck in without them, or avoid them altogether. This is a threshold issue in choosing our dentist, hairdresser, allied health providers etc. We had to part ways with certain providers as my son's condition progressed and he could no longer access them. This is stressful and time consuming for carers.
Carer health "fast pass"	Some carers, ourselves included, care for multiple family members of different generations. The impact on carer health is significant. It is difficult to get time to attend to our own health needs, difficult to get appointments at times compatible with caring needs and very difficult to care in case we are hospitalised. Last year, I was hospitalised for a few days. I wasn't thinking about me, I was just hoping that all was OK at home. Is there any way of giving carers some priority or concessions to assist ? If we fail, so too do our loved ones.
Carer training	Carers are required to do a lot of manual handling work, with limited or no assistance. We transfer my child with a hoist, often 5 times per day. Technically, this is a 2 person job. If we were in a nursing home or hospital, it would be 2 people. At home, we have to manage solo. Our carers association recently offered a suite of mental health care courses. It would be very helpful to offer free online manual handling training courses for carers, possibly through the Carer Gateway, St Johns or the carers associations.
Superannuation	At some point, carers may not be able to work owing to the complexity of their loved ones needs, no matter how flexible the employer. This marks the point at which they can slide off the radar and start to struggle without regular income, particularly with the current interest rates, cost of living and healthcare. Relationship breakdown is common, accessible housing is hard to find – and often it is the women who have worked part time to manage care so have limited superannuation. As care needs increase, they cannot work nor contribute to superannuation. So, while I acknowledge that the scope of this inquiry does not include carer payments, I implore the Committee to consider other super concessions or contributions that may help prevent carers from sliding into poverty, homelessness and ill health.
Income splitting	As noted above, carer is gendered. It is often mothers who work part-time or step back to manage caring. This allows fathers, who often earn more, to continue to work. Both mother and father are working to keep the family afloat, one paid, one unpaid. If we cannot directly address the inadequacy of carer payments, perhaps families with high level care needs could be permitted to income split, thereby reducing the tax payable by the father in recognition of the significant unpaid work performed by the mother (and father, when he gets home). It would be a small but tangible and significant gesture.
Workplace transparency	The current Act is limited to the APS. We need to go further. My understanding is that many large corporates are required to implement and report on certain measures, including executive pay, gender equity (WGEA) and modern slavery. Some will already have HR policies or workplace agreements that recognise carers. We need to look at extending the reach of the current Act to require that a broader range of employers have considered carer engagement policies, together with transparency and reporting to encourage some accountability. They need to "walk the talk". This could help employers in a tight skills market, increase workplace diversity, improve workplace culture – as well as helping carers keep their heads above water.

END.