LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON ECONOMY AND GENDER AND ECONOMIC EQUALITY
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Submission Cover sheet

Inquiry into Unpaid Work

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Legislative Assembly for the Australian Capital Territory
Standing Committee on Economy and Gender and Economic Equality
Inquiry into Unpaid Work

Submission by [redacted] on 17 May 2024.

Dear members of the Legislative Assembly,

I would like to thank members of the Standing Committee on Economy and Gender and Economic Quality for the opportunity to provide a submission outlining my experiences as a carer to people in my family, and a foster carer, all of which fits within the scope of unpaid work for this inquiry. I have responded to each of the six points noted within the Terms of Reference (ToR) for this inquiry. I will give the background on how my particular situation relates to a number of the types of unpaid work outlined in point one, how my situation is captured under the ACT Government's well-being framework, the dynamic between my unpaid carer responsibilities and my employment, opportunities to support and recognise unpaid work in the ACT, and challenges that I have faced as a woman who lives with disability and is an unpaid worker in the ACT. Under other related matters, I outline why I don't feel carers are suitably recognised under the banner of "unpaid work" as listed in point one of the ToR.

BACKGROUND AND UNPAID WORK ROLES

My name is [redacted], and for the last eight years I have been an unpaid carer in several capacities in my family. My husband and I became first-time foster carers to a 10-month-old infant very shortly after our biological son was born. Unfortunately, the timing coincided with my husband's epileptic seizures significantly and suddenly increasing. The combination of those factors required me to become both a carer to my husband, as well as our children, and that had a very negative impact on my capacity to earn an income both in the immediate sense, as well as reducing my future financial security and career progression.

When we married in 2014, my husband's epilepsy had a very limited impact on our lives. Following the birth of our son though, his seizures began to increase over the following 12 months and at their worst, he was having clusters of three of seizures in a night, one following the other over a period of five or six hours. Suddenly, I was responsible for caring for my two young children and my husband, while also trying to maintain an almost full-time job (four days per week). I didn't know where to turn as I'd had no experience directly caring for anybody but after calling Carers ACT, I was kindly provided some practical support, such as assistance with grocery shopping and basic housecleaning. At no point did anybody suggest any form of economic support, such as carers allowance or NDIS, and as this was my first time in a caring role, I did not know to look.

In mid-2019, following investigation and treatment by one of Australia's leading epilepsy specialists, my husband started what is now an almost five-year period with no seizures. He continues to remain well, and my unpaid role as his carer came to a happy end.

However, the following month, we faced the first significant impact in our lives from our foster daughter's then emerging disabilities. We were aware she had suffered severe substance exposure in utero, but it wasn't until I started my degree in social work that I realised even with diagnoses of autism level III, ADHD, dyslexia and dyscalculia, and a trauma disorder, her picture was not nearly complete. When I opened my textbook onto the page that described and outlined fetal alcohol spectrum disorder (FASD), my heart dropped because the photo of the little girl in the textbook section could have been a police photo fit for my daughter at that age. The features were so similar in their disparity from peers, and I booked in with her treating child psychiatrist immediately. She was referred to the Care and Intervention for Children and Adolescents Affected by Drugs and Alcohol (CICAADA) clinic at Westmead Children's Hospital in Sydney and due to existing diagnoses, she was placed on a fast-track assessment process to diagnose FASD. Under this process, her existing diagnoses were used in combination with a computer analysis of images that were taken under specific direction from the CICAADA clinic. Due to the physical characteristics that can be caused by alcohol exposure in utero, the diagnosis was definitive and over the last year, we have spent an inordinate amount of time learning and training ourselves to understand how her permanent brain injury affects her functionality in the world and how we can best support. All of this must be done within our own time, and although some costs are covered by the NDIS, the hundreds of hours of work I put into both establishing and maintaining a sufficient and effective NDIS support plan is the reason we get any financial support. I self-manage our daughter's plan to ensure she has access to appropriate and effective therapeutic services for her disability, but in effect, that means I'm not only unpaid, but working for free for the NDIA to process the invoices and payments relating to a plan worth over $100,000 per year. If I was undertaking these duties in any employment role, I would be receiving a salary as an accounts payable officer, but a condition of self-managing supports means I must also provide this service free of charge to the NDIA.

ACT GOVERNMENT'S WELL-BEING FRAMEWORK

Before writing this submission, I had not been aware of the ACT government's well-being framework. After reading into it, I realised I had accessed supports under the framework. During COVID lockdowns in 2021, Carers ACT notified registered carers of the small value grants ($500) available to those who provided unpaid care services called "Respite Effect and Recovery Grants". The process was extremely efficient, and the funding was flexible and simple to use. I applied to the simple process online, and within the advised number of business days the funds were deposited into my account. The flexibility of this program is fantastic; I work in international research grants myself and have a good working knowledge of how most grant programs are administered. The ease of the application process, and the allocation of funds on a per application basis, meant the funding was distributed quickly and it provided us with some additional much-needed funds that were flexible for us to use how we saw fit without onerous reporting processes.

DYNAMIC BETWEEN PAID AND UNPAID WORK

The flexibility and support given to me by my employer has allowed me to maintain my employment and pursue career progression. The organisations willingness to allow me to work from home at a time when this was unusual (pre-pandemic), and work at times that suited my caring situation, was critical for me to manage all of the things I was trying to take care of at the time. Had I been with an employer who had not agreed to the adjustments I needed to meet the care needs of the members in my family who required it, there is no way I would have been able to continue my employment. I was unable to work regular 9-to-5 hours, Monday to Friday as the needs of my family simply wouldn't permit this. Unfortunately, even with the ongoing and flexible support my employer provided, my ability to progress in my career was still significantly impacted by my role as a carer because I was unable to be flexible at all with what times I could work, commit to any role that required specific work times or undertake any type of travel for work.

OPPORTUNITIES TO SUPPORT AND RECOGNISE UNPAID WORK IN THE ACT

I would greatly encourage more of the practical support programs run for carers such as the Respite Effect and Recovery Grants as they fill an immediate gap for unpaid carers, as well as provide opportunity to gather data on what unpaid carers find most difficult to manage within the Canberra community. There is no doubt the cost of caring for family members to the community is significant in lost employment, mental health costs, and other factors that are unmeasurable. Although it may not have an immediate measurable response, the knock-on effect of providing additional financial support to families struggling to meet high living costs will be positive. In addition to this, running such programs will also provide a unique view of challenges and barriers encountered by carers. This data could support more effective and targeted programs and funding initiatives that would assist unpaid workers in the ACT to continue to be able to undertake the undervalued, and frequently irreplaceable services they provide to those in their care, and by extension, to our Canberra community.

CHALLENGES FACED BY UNPAID WORKERS IN THE ACT

The most impactful and challenging barrier to earning a wage that I faced as an unpaid worker in the ACT was our inability to access out-of-school hours care. By the last term of mainstream preschool, our daughters out-of-school hours care provider withdrew services. They advised they were not able to manage her challenging behavioural presentations, and following several meetings, it was clear this decision would not be reconsidered. We requested permission to provide the paid, professional support worker to assist our daughter in engaging in the after-school care program but were advised that no external supports would be permitted as they were not employees of the company that ran in the program. The practical result was we were excluded from accessing out-of-school hours care. This was the second out-of-school hours care provider who had withdrawn services for our foster daughter, following a different company doing so in the year prior when she had attended the early entry Koori program at Wanniassa preschool.

We were approved to access a government funded initiative that was designed to provide out-of-school hours care to children in regional areas and those unable to access mainstream programs due to high needs. Although the initiative is delivered by Communities@Work, a large organisation that provides many types of care services (and the company that had just withdrawn their services from us), the employment structure of this program is entirely different to that of any standard childcare program which again, meant it was quite inaccessible. Childcare workers under the scheme were required to set themselves up as contractors, complete with their own ABN, managing their own tax, superannuation, insurances, and any other required obligations of running one’s own business. Quite unsurprisingly, there is very little uptake of this program by childcare workers who wish to work under those arrangements and due to this there is an excessively long waitlist that never seems to move. This meant that after nearly a year of being on the waitlist, no childcare worker had been identified for us. We then, at the advice of the program coordinator, tried to set up our own childcare worker and even paid for them to undertake the required first aid course they needed for this position.

Unfortunately, after all this effort the childcare worker decided not to continue with our foster daughter following her very first shift. We did not recover any of the money for her training and so were left in a worse position than when we began the process.

The withdrawal of out-of-school care services significantly impacted my capacity to undertake my job role and again, I was only able to maintain employment due to the ongoing flexibility and support provided to me by my employer. They were not required to do this and would have had all grounds to tell me that due to my inability to work within the outlined times, they would need to end my contract. Thankfully for me, this did not occur, and I was again supported to manage this unfortunate situation caused by a significant gap in the care services provided for those with disability in our community. There is a major gap in the ACT for higher support out-of-school hours care services and I am in a privileged position where I can work from home, but it still required me to be working extremely early in the morning (from 5am) or late at night (after 8pm) so that I could complete my work because I was unable to work while caring for my daughter, and unable to access out-of-school hours care. Had I worked in a different role that did not allow this immediate flexibility and adjustment, I would have again lost my employment role at this point.

OTHER RELATED MATTERS

To provide stability and normalise her foster daughter's life, we applied for guardianship orders (called enduring parental responsibility in the ACT) and following an assessment and court date, we were granted guardianship when she was four years old. Only a short 12 months later, our daughter's significant needs started to emerge, and we commenced what became a 4-year long journey to find answers for her and ways to support her development. Following her diagnosis of FASD in 2023, it became much clearer the significant impact her disabilities would have on her life and ours. FASD is a permanent brain injury and carries risks of over 420 different comorbidities that can occur, including a 50% chance of congenital heart defects. FASD impacts all areas of our daughter's world, from her cognitive development and capacity to develop and maintain relationships and social engagements, to the physical complications and difficulties she will have to face throughout her life.

There was no way we could have anticipated this diagnosis, and as is the way with several neurocognitive disabilities, people are frequently not diagnosed until they reach school age or later. As we had already received guardianship, we were unable to now seek appropriate subsidy support for her very high needs and care requirements from ACT Together. We have been significantly impacted by the inability to seek any further financial support for the high costs caused by our foster daughter's significant care needs. We had requested consideration for a more appropriate subsidy rate from ACT Together but were advised it would be highly unlikely we would receive an increase subsidy as an ongoing support. We were told that if we could provide extensive supporting documentation (such as an outline of all pending medical costs for the year to be preapproved, of which there was no possible way to do), we may able to receive reimbursement for some of her additional medical costs that are not covered by NDIS or Medicare.

Due to the level of medical support our foster daughter requires, we had already passed the Medicare safety net as a family (over $2500 out of pocket expenses) by March this year and so seeking reimbursement of the small out-of-pocket expenses for the remainder of the year is redundant. Even if we did pursue this, we would not be covered for the more significant costs, such as the house and property damage our foster daughter inflicts while in violent meltdown. This includes holes in walls, broken windows, broken electronics (TVs, iPads, laptops and phones), broken bed frames and scratched flooring, as well as destroying many personal items of her own and other family members. The ongoing and unrecognised cumulative cost of these repairs and replacements is enormous.

We seek significant engagement with her behavioural therapist and psychologist to support the school and ourselves in managing the challenging behavioural symptoms. We are trained in how to best respond in an effective and supportive way to allow her to de-escalate out of these situations, but she will still experience meltdowns and distress as part of her disability. Without recognition of this, and the damage and financial burden that it brings to our family, it will continue to be an additional and unnecessary pressure.

“Unpaid work” is an extremely broad phrase to cover highly varied roles in our community. To try to measure the financial impact of being a periodic community volunteer with the 24/7 role of caring for a dependent loved one does not seem equitable. The ability to manage paid work while volunteering for the regional firefighters or the SES would carry its own challenges and financial impacts that should be recognised and supported, however, the relentless and exhaustive full-time role of being an unpaid carer to a dependent family member is not comparable. The carers in our community are undervalued, unseen and frequently unrecognised, but if we were all to stop what we were doing and no longer provide valuable and necessary care, it is unlikely our community could continue to function.

More support is needed for all unpaid carers in our community. I welcome this inquiry into such an important area, and thank MLAs James Milligan, Suzanne Orr, and Laura Nuttall for leading this very important piece of work.