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Committee Secretary
House of Representatives Standing Committee on Social Policy and Legal Affairs
PO Box 6021
Parliament House
Canberra ACT 2600

20/07/2023

Dear Secretary,

I am writing to you as a confidential submission for the inquiry into the Recognition of Carers in Australia. I request this to be confidential as I want to maintain our privacy. I am a single parent of two children, a [redacted] daughter and [redacted] [redacted] son. I have full time care of both children. My son has [redacted]

The 10 Key Principles of the Act currently are:

1. All Carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.

Due to the nature of my caring role I don’t have the opportunity to engage in paid work which I otherwise would do. This greatly impacts my families socioeconomic status as well as limits what choices we have. I don’t have the same opportunities to socialise and make and maintain friends as my son has severe behavioural issues and it can be very challenging to take him to events. I rarely have a paid carer to look after him so that I can attend events either. This limits how I can participate in society. For example I don’t attend social family nights at school as I cant take him due to his behaviour but it means my daughter also misses out on attending such events and strengthening social bonds.

2. Children and young people who are Carers should have the same rights as all children and young people and should be supported to reach their full potential.

I do everything I can to try and limit the impact the situation has on my [redacted] daughter but ultimately she is impacted by being a young carer. She limits how many extra curricular events she attends as she knows it will be hard to facilitate her attendance and that money is tight as well. She is dropped at school early and stays there late due to his therapy schedule. She is limited in having friends over as my sons behaviour is very unpredictable. She has seen her brother try and kill himself as he didn’t understand what he was doing. She has also witnessed him being violent many times. I have created a young carers group for her to try and provide links for her to others as she found it very beneficial when she was in the young carers group [redacted] which was unfortunately defunded several years ago. She doesn’t always feel supported in her role, for example she was greatly distressed when my son tried to [redacted] and I tried to get counselling for her through the carers gateway telephone counselling service but we were advised they don’t provide counselling for people under the age of 18. I then reached out to the kids helpline and they at least were willing to help her.

3. The valuable social and economic contribution that Carers make to society should be recognised and supported.

I feel very unrecognised that the support I give my son saves the government at the detriment to our lifestyle and our future. I have very minimal superannuation as I am existing on the carers pension and I worry about how I will afford necessary large expenses in the future. I have to lobby and push for what he receives via NDIS and have had to go to the tribunal to ensure he is supported. I take him to all his medical and therapy appointments, this saves the NDIS travel fees by me taking him.

4. Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.

My health has suffered since I have become a fulltime carer. I have recently had surgery which I put off for 3 years as it is so hard for me to get help and look after my son. I have other health conditions which require surgery that I am putting off as it is too hard to organise with my carer responsibilities. I also struggle to exercise due to lack of time and exhaustion. My son sleeps attached to me and wakes multiple time during each night for feeding and changing. I frequently am up every 1.5-2.5 hours which leaves me exhausted. I try and have a nap in the day a couple of times a week if time permits. I get sick easily due to the strain on my body. I still had to look after my son and attend to him throughout the night when I came home from hospital even though I could barely walk. I undertake all the necessary errands while he is at school between his appointments as taking him to the shops etc is usually a disaster. I struggle to have a social life and attending functions is a rarity. If I do socialise with people it is usually when he is at school.

5. Carers should be acknowledged as individuals with their own needs within and beyond the caring role.

I have been told when I asked for a paid carer to mind my son so I could attend a parent information evening for my daughter starting [redacted] that it was respite. This was an evening covering [redacted] requirements and was not a social event. I have also been told that his therapy is my respite even though I am in the room with the therapist helping. I am rarely seen as an individual outside of my caring role.

6. The relationship between Carers and the persons for whom they care should be recognised and respected.

This is usually respected possibly due to his age and being my son and I am always with him.

7. Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of Carers.

This is usually respected as I self manage his NDIS plan for him and tell his therapists they are on [redacted]

8. Carers should be treated with dignity and respect.

Yes we should be and dignity may increase if payments to us increased and superannuation was paid at a minimum of a base rate. We are usually desperate when we contact a carer support agency and they are frequently under resourced and you have to have what you need examined and decided if its appropriate and there isn't much dignity in the process.

9. Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.

I don't see how this would work in my situation as I don't have anyone to care for my son and I basically work a night shift for him each night and I am absolutely exhausted but still get up each day and take him to therapy. I did investigate doing a part time course but the course requirements could not fit around my caring commitments.

10. Support for Carers should be timely, responsive, appropriate and accessible

Yes it should be and it can be so hard to find carers groups and a lot of them were defunded when the national carers gateway initiative happened a few years ago. I actually felt a lot more supported before the change as I was accessing groups consistently and easily and they provided respite to attend if it was required. A lot of the events that are run by carers groups now are one off events that you don't necessarily know anyone attending and may never see them again either. I had my name down for a carers break and I was emailed at 3pm of the Friday (of a long weekend) that I was attending a carers break on the following Wednesday during the day and it was booked and paid for. Noone had ever checked a date with me at all, I emailed back immediately that I was unable to attend as my son had a hospital procedure booked for the Wednesday and never heard anything back from them. I had my name down for a carers break since October 2022 and was contacted for one June 2023. Also, with the carer breaks that are available there is no respite provided, I would have loved to go on a camp that was advertised for carers but who would have looked after my son?

I attend MyTime which is a consistent group and that has been very beneficial except it has recently been changed from 8 session each term to 6 and seems to be under threat of cancellation frequently.

My daughter went on a camp with [redacted] and still talks about it years later and desperately wants these camps to return for young carers as it gives them a break and just lets them be kids for a while and meet others in the same situation.

When I have travelled interstate with my son and have needed help with him and rung carer organisations, I have been told they can't help as we are from a different state and to ring the SA support services who then say they can't help as we are not currently in SA. This leaves us unsupported when we travel unless I can engage help via NDIS funding.

Conclusion

Being a fulltime carer has damaged us financially, I am unable to pursue my interests and my health is suffering. I get very little support to help with my son and had to fight the NDIS in the tribunal to get 3 hours a week support finally after 14 months of fighting. When I ask support organisations for respite it is only for bare necessities not usually social activities. Have you considered providing carers with their support budget and leaving it up to us on how to spend it? This could save a lot of overheads on support organisation and could potentially cut red tape.

Kind Regards

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