

Unpaid Carer Submission.

It is damning I think of our society mores that the there is an enquiry of unpaid carers. Our society does very little and indeed keeps those in the disability groups at poverty levels as recognised by their complete lack of ability to buy their own homes or rent in what would be considered the safer, better socio-economic neighbourhoods, to afford cars if they have the means to drive, to live without fear of meeting basic level comforts for their generalised living means and this extends to the carer.

Unpaid carers, even paid carers, are stuck as I am sure the Social security minister is well aware, of mirroring the poverty levels of their disabled adult children. We do not have any financial means.

The Ndia via government decision making about it's very structure of paid employment for a disability worker /therapist, has put dollar values on simple activities that the carer, especially of those with complex disabled children that the school system is/was unable to manage, naturally did and do for their child. It is distressing in the extreme to think that the public servants did not and still do not see the inherent discrimination in this structure.

A carer of children and also adult children, of which I am one, spends the best part of the day, caring, from overseeing the daily structure of how the disabled child, managing the simple routines of showering, grooming, medical needs, appointments whilst at the same time striving to give the adult child focus for being in that day. I take my 2 children outside to interact within the community, whilst trying to manage the stress they feel whilst being in social settings. I try to keep abreast of ideas to improve their simple lives. We cook and clean with no thanks especially for those in the autistic spectrum, who simply cannot express thanks, who cannot show gratitude, who provide the carer with no conversation to alleviate the rigid same day loop that the carer lives by the very nature of the autistic' child requirements. I noticed with grim amusement the media reporting throughout the covid lockdowns regarding people's inability to cope with the social isolation, welcome, I thought to the notion of what it feels like to be a carer! To not move freely within your day, to not be able to go to work without thought as to how your children can cope without you being in the house.

The carer does not switch off at night like the paid support worker, the task is relentless in it's 24/7, 7 days a week, year in year out burden.

We the carer are overburdened, overworked with very little freedom (it must always be planned), more so since the Ndia introduction, to again oversee the worker and child cooperate, monitor progress, etc.

Psychologically we feel very undervalued. We bear the stress of not having a job to alleviate our financial concerns, the stress of not being free to meet with friends. Indeed our friends base shrinks as people with normal children, cannot understand, nor wish to understand our limitations. This is all formally recognised in literature but once again, the govt is asking us to explain what it feels like to be a carer. We bear the horrible burden of looking to place our adult children into group homes, which the government structure of the Ndia has made very difficult. We bear the emotional scars and stresses of providing documentation over and over again. My child's OT report is just under 2 years old and although there has been no change in his functional capabilities, we must again go through the invasive progress, ie having someone who is a stranger to us inside our home, of having his functionality readdressed to meet new Ndia guidelines. Doi you really think that at 29yo my child has suddenly learned how not to be highly autistic? You have over regulated what would be a simple process if the government would grow up and take responsibility as it used to do for the care of these adult children hence alleviating my stresses as a mother putting my adult child into care, which has a mountain of psychological strain to it, coupled with worries over care and the futility of being a parent of a child that cannot support and care for itself as an adult.

I have never had a holiday from my 2 children. We have just started respite and the lack of understanding of how the autistic person copes is shocking, needless to say, our child has been returned home to us much earlier than was arranged and we cannot and do not have confidence in the people that you have allowed to run such programs, new as they are to the Ndia. What are you thinking? Do you think my job as the carer and as a parent has not been wholly and horribly shaken by the lack of expertise shown to us through this program. You could at least mandate that respite and group homes be placed under extremely competent management, not subject to the whim of government's absolutely childish disrespectful notions of 'oh they'll manage'. As a carer who faces this, unpaid except for the nominal amount as given by the Carer Allowance (approx. \$70 per week), this has exacerbated an enormous amount

of stress, simply because no-one wishes to be the adult in the room for care homes. You instead place the onus back on the carer to hold their children for longer periods of my lifespan. As someone who cares for a husband with a chronic heart ailment, who does office work to provide us with an average wage, I can tell you that this mismanagement of our 2 adult children has us very concerned for our children's future.

Carer's do not get time off, we do not get night's off, we do not get weekend's off. We shop for our adult children's clothing, we get their medications, we haul home their furniture, their groceries, we have simply more burdens than others. We are unrecognised and we feel this. I simply no longer wish to hear from a prime minister of Australia how wonderful I am, put your money where your mouth is!!!! I picked my children up from school, yet received not one part of the teacher's wage for the job they could not do. I have advocated for their health needs, yet receive no income as a health professional such as it is (one of my children has ASD and is highly Marfanoid). I have co-ordinated their supports yet receive no income for that job. The NDIS created such stress for me, I cannot articulate how dreadful this program has been, compared to the simplicity of community and the straightforward allied health plans. I have distance educated my 2 through High school, I have arranged transport to get them to their medical and allied health appointments. I have stood in for them as psychologist and therapists use me to get fuller pictures of my children's lives as they cannot provide this themselves, and yet my bank account actually is in such dire straits, that I cannot afford to leave our house and now bear the strain of having drug dealers living beside us. If I had earned a tenth of the wages due me as a paid carer, over the almost 3 decades, I would have options, options to buy a car, relocate, afford to upgrade our heating system, our carpets, afford better food for myself. I would feel valued because our system of government as it stands does not appreciate me the carer, you mask your relief at not having to shell out dollars to compensate the carer and so I have such disgust for our system and how we have been treated., the parents of ASD kids in particular.

The Carer Gateway? Whose brilliant initiative was this? Carers do not need digital mates, they need people. Competent people, who know how to deal with a 6ft3, screaming adult who opens the door whilst being driven to appointments. Where is my help with this? I have no idea why you put so much faith in psychologists, they should deal with the mentally competent,

from our viewpoint they are totally inadequate in providing any relief or useful therapy for the ASD 2/3.

Children with disabilities grow up not to be cute kids you can use on TV media spots but troubled adults who need particular care, husbands with heart conditions leave us wide open to a very shaky future and again I do not believe that the allied health professionals nor the govt, nor the Ndia, nor the police even (yes we have reported the dealers, thank you) provide us with support or help to overcome our circumstances. It is the commonly held belief that ME/I should have the money to get away from our violent neighbours, Me/I to continue supporting our adult children as we sink further down the socioeconomic scale. Thanks for that! I would no put any of you in charge of looking after a dog, as rude as that is. You lack responsibility.

Last thing, the families of carers, the children that do grow up, move away as they cannot bear their siblings' anger, tantrums, social blocks, etc within their childhood house, that in itself is another emotional deeply distressing hurt that carers bear, could you give these people something? Free tuition at Tafe or tertiary levels, they to are highly disadvantaged from their parents income decline and also the psychological scarring of being part of a disabled, highly complex family.

On a conciliatory note as a single income disabled family, we moved further and further away from our suburban roots to afford housing. A lot of my anger may stem from the sheer inadequacy of services out here in the central west of Nsw. The poor policing numbers, the anger of the rural poor. If I had my time over I would never had set foot here and now we are unable to afford to get out. We cannot even afford a flat in a larger regional town, that too is poor govt management in our eyes. Could you have the decency to restrict immigration until our adult working kids can afford housing? When do you start to acknowledge our pain, as disabled families, as carers?

Thank you for reading this.