General issues around the implementation and performance of the NDIS Submission 20

I am an alternate family carer for a young man with significant disabilities including profound intellectual disability, complex physical and medical issues. He came to live with my family as a young adolescent after his mum was no longer able to care for him and a care home set up to care for him in Canberra was unable to deal with his needs. Since he moved in with us we have basically given up our lives to provide the 24hr care he requires. For this we have been given a small fostering allowance, carer reimbursement by our State disability Department, much much less than it would have cost the government to continue housing him in a group home. The nature of group home already failed to provide for his needs and saw him deteriorte in his overall health and break an arm involving surgery, his behaviours also increased causing him to display significant challenging behaviours which would endanger himself and others. It is essential that he be able to remain living safely with us.

For the first 2 years of the NDIS the NDIA honoured the State government alternate family care allowances for people who, like him, had aged out of out of home care placements or had entered the foster care system on voluntary basis.

However, last year, without warning to carers or anyone, they suddenly stopped paying the allowances. People like myself, who have to be available virtually 24 hours a day to tend to the endless needs of absolutely THE most most vulnerable people in our country are now expected to do so in exchange for living in total poverty on Centrelink Carer's payments only.

We have been reminded numerous times that a foster care reimbursement is not an income stream, obviously not, who else would work 24/7 for less than \$100 a day? What this tax free payment allows us to do is be at home and be on call through out the day for the calls from school or day centres, or be able to be awake all night when he is having seizures and not worry about calling into work the following day. It's not a wage, no one would work for that amount!

One NDIS phone operator actually suggested that we could foster a younger person if I need to retain the fostering allowance or someone that is on a child protection order as the state is still responsible for foster care payments if under 18 and on a court order! Like the kids are disposable, we'll throw one out on the street and get a younger one, just like that!

The NDIS no longer pays alternate family care allowances for people over 18 or kids placed voluntarily as in the case of our 17yr old foster son. Have I mentioned I am totally bound up in my work with this young man whose needs I've been tending for the last 3.5yrs with very little support apart from that small allowance which I am now to do without?

The only choice many foster carers will have is to send the people they care for off to the government so they can be 'cared for' in very expensive to the tax-payer, very unsuitable for everyone group homes.

We're now in the process of getting a review of our foster son's NDIS plan as it was woefully inadequate. We've had to fight just to get funding for him to go to a day centre next year as

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he turns 18 in October. Surely Funding us to continue caring for him through a tax free payment of less than \$36,000 a year compared to a minimum of \$152,000 that it would take to have him in a supported accommodation/group home sharing with 7 others (if you can find a place!) makes far more sense???

NDIS is meant to be supporting individuals with disabilities and yet this extremely vulnerable group is being either totally ignored or further disadvantaged simply because of 'debates' between different depts over who's responsibility it is to continue funding their placements with foster carers. We've had both NDIS workers and DHHS state that they have no idea who is now going to pick up the tab, so, for now, we sit and hope that in the next few weeks someone comes up with an answer...... We've already gone for 8 weeks with no carer reimbursement while NDIS and DHHS fought amongst themselves back in April, now we're waiting to see what happens once he hits 18 in October.

Someone must know what is to become of these young adults who are living out of home, who do not want to go into group homes, or are not suited to a group home situation and who at present have foster carers wanting and capable of continuing to care for them at a fraction of the cost a group home would cost.

We need answers.