


This is a submission in response to iPart's Interim Report into Out-of-Home care costs and pricing, distributed October 2024.


(Please feel free to publish any non-identifying comments, but to keep my name anonymous. Thank you).

My partner and I are long-term carers to three siblings, they have been with us for 3.5 years.

The findings of the report are incredibly similar to our situation. We had budgeted for me to take 6-12 months off work when the children came to us. However, we took care of more children than we expected, as we were keen to keep our siblings together. The needs of the children transpired to be much greater than initially anticipated. Both these factors have meant I've been unable to return to full time work to ensure we are giving the children what they need. Therefore, we have a loss of income, as well as no payments to my superannuation in the last few years. We also had the additional cost of moving to a larger house so we could accommodate all three children. This meant moving an hour's drive from our area as we were unable to afford a house locally due to the current housing situation.

Speaking to other carers, I found that all of us are digging deep into our own savings as the care allowance fails to meet the needs of our children and does not account for the inability of many carers to work because of their caring responsibilities. Everyone had suffered an unplanned loss of income, career and superannuation, and, in some cases, a huge amount of debt.

SUGGESTION

Carers should receive adequate financial support, which accounts for the inability of many of us to work. As volunteers, this should NOT be means tested and should be based on the child's emotional and physical needs, NOT a diagnosis.

SIBLING GROUPS

In addition to the findings of the report, we believe the sibling payment for sibling groups of four or more children, requires investigation. Some sibling groups can support each other, and it is vital that our children are able to stay together. However, this isn't always the case. Our children continued to repeat the abuse they received on one another. We have been unable to find the help our children need as a group, and so I wrote to Noel MacNamara, Deputy Director at the Centre for Excellence in Therapeutic Care, and Executive Manager – Research and Policy. I have pasted part of an email he sent to me:

On the other hand, sibling relationships can be hostile and characterised by intense conflict, insults, verbal and physical aggression, bullying, coercion, and even abuse (Morrill et al., 2018). Empirical findings have indicated that sibling relationships marked by conflict and hostility are also associated with depression, anxiety, low self-esteem and low social ability (Coyle et al., 2017). They were also associated with externalising problems, such as behavioural disorders, lifelong aggression, antisocial behaviour (Dantchev & Wolke, 2019), and lower academic performance (Buist & Vermande, 2014).

This speaks to the fact that the relationship between siblings should be assessed as well as the individual impact of abuse and violence for each of them. The assessment should lead to intervention where indicated.

However, what usually happens in these matters is that the trauma is allowed to play itself out in the relationships between the children.... This commonly results in siblings being separated within the OOHC system. A further trauma in their lives and possibly lifelong. [References in footnote]

The above describes the exact situation our children are in. They live in fight or flight. My partner and I are rarely able to let our guard down, and are often on alert. Fights and arguments happen continuously, and we are always mindful of the children's safety.

Sibling groups like ours are invisible within the system that is meant to protect our children. This is emulated by Sue Buratti, Senior Manager of Therapeutic Services in NSW at the Australian Childhood Foundation in her article *Sibling Relationships in Therapeutic Planning*¹. Each of our children is considered as an individual, which they should be, however there is absolutely no consideration for the dynamics of their group, and this is always lacking in therapeutic planning as well as financial support and plans. When together, our children continuously traumatise each other and it is this reason why I am unable to work full time.

Additionally, there is a 4+ Siblings Options Placement available from DCJ, of \$25,099.22. This is an *Additional payment to support the ongoing infrastructure costs to establish sibling group alternative Placements. Annual payment for the collective sibling group, the period and timing of payment be determined by DCJ.* (<https://dcj.nsw.gov.au/documents/service-providers/out-of-home-care-and-permanency-support-program/contracts-funding-and-packages/psp-and-residential-care-rates.pdf>)

To affirm further that our children are invisible within the system, we recognised very early on that our children needed help as a sibling group, however our agency told us they didn't. Therefore, my partner and I personally paid for OT and Play Therapy for all three children on a weekly basis.

¹ <https://professionals.childhood.org.au/prosody/2020/09/sibling-relationships-in-therapeutic-planning/>

SUGGESTION

That the Siblings Options Placement payment be lowered to those of us with 3 siblings, with investigation as to whether this is also required with two siblings. This would help cover additional therapies required in these circumstances.

There should be recognition of the additional challenges faced when caring for sibling groups, with adequate financial compensation for those of us caring for them and unable to work, full or part-time.

NDIS

NDIS is important to consider in this review, because it is taking the financial strain away from agencies and DCJ, however it is adding additional and unnecessary stress to carers. NDIS required us to work with a Behavioural Support Practitioner. Even though one of our children had seen a paediatrician, and there was no diagnosis, the BSP reported that our child had Oppositional Defiance Disorder. Because we disagreed with this diagnosis, backed by our paediatrician, the BSP recommended to our agency and NDIS that our child be removed as we were a 'barrier to him receiving adequate care'. It transpired that listing a diagnosis made his paperwork easier, however he also did not take kindly to carers disagreeing with him – this attitude is common within the sector. This happened in January of this year, and as parents, we have still not recovered. This was not the first time we had been threatened with removal based on personal agendas and an ignorance of trauma. We feel our family is vulnerable to the whims of people who work in the sector, and are seeking adoption as quickly as possible to ensure the safety and security of our children.

NDIS is not a permanent solution if children have no disability diagnosis – children under 7 can access it without a diagnosis, however older children, with PTSD like our eldest, are not recognised.

Unfortunately, NDIS also judges children separately, so providing therapy for two children and not the other does not help the situation. If one child is not receiving help, then any therapy the other children receive is futile as the dynamics continue day to day. We continue to pay for regular therapy for one of our children, however our agency has helped with an NMT assessment (\$6,000).

Also, we have decided to end our relationship with NDIS. This means we will be asking our agency for funding, as well as funding therapies ourselves. This is because in our personal experience, the treatment and attitude we have received from NDIS has been utter disdain. As well as NDIS not being fit for purpose, requiring reports from so-called experts with no psychological experience and little engagement with families, we have decided that the stress is too much and will not continue with NDIS when our children's funds are up for renewal.

DIAGNOSIS AND TREATMENT

Due to me being unable to work full time, we have searched for financial help but are continuously unable to apply as our children don't have a diagnosis. They all have CPTSD, but this is not enough for a Carers Payment.

Without adequate treatment, PTSD can affect the brain and nervous system and increase health-risk behaviours (e.g., smoking, eating disorders, substance use, and high-risk activities). Research shows that child trauma survivors can be more likely to have long-term health problems (e.g., diabetes and heart disease) or to die at an earlier age. Traumatic stress can also lead to increased use of health and mental health services and increased involvement with the child welfare and juvenile justice systems. Adult survivors of traumatic events may also have difficulty in establishing fulfilling relationships and maintaining employment (The National Child Traumatic Stress Network (USA) <https://www.nctsn.org/what-is-child-trauma/about-child-trauma>)

Unfortunately, as the system refuses to accept CPTSD as a diagnosis in need of urgent and serious attention, we are putting children at risk, more strain on carers, and more cost to the system.

Treatment

Children have difficulty accessing therapy with adequately trauma-informed therapists. For example, we met with one therapist that believed our son's behavioural challenges were due to us being unable to attach, and that if he were able to attach to us, he would not have PTSD. That therapist also recommended to our agency that one of our children be removed because I was stressed (due to the lack of support from the system). She gave no consideration to the impact on the future social and emotional wellbeing on the child that was taken away, as is confirmed on the DCJ website.²

In addition, children are waiting anything up to a year to see a psychologist, psychiatrist, or OT. In my experience, you can see someone sooner, e.g. within 3-6 months, but these people have little to no experience with trauma.

SUGGESTION

We need to recognise that recovering from PTSD is a lifelong journey, and the earlier we start that recovery, the better.

We need a central system that ensures children access trauma-informed care in an appropriate time manner. This is because:

² <https://dcj.nsw.gov.au/documents/about-us/facsiar/facsiar-publications-and-resources/32-2023-placement-stability-summary.pdf#:~:text=Changes%20in%20caregivers%20and%20multiple%20placement%20moves,a%20child's%20placement%20and%20includes%20findings%20from>

- Children with trauma should not be waiting to see paediatricians and therapists for 6-12 months. This delay in care adds to the strain they and their carers experience, putting families more at risk of breaking down.
- As children commence through the system, more of their trauma reveals itself, so they should be assessed immediately coming into care, and then every 6 months after that, in order to catch any issues before they become embedded and more difficult to deal with.

Another suggestion, Coral Tree is a residential facility for families in NSW that provides psychological and psychiatric therapies for children. It took us a year to have our first visit, we have had one more since. The work we did was so successful that we won't be returning. It has been life-changing for our children and our family. The team of psychologists work with care givers to develop strategies that help the children with their challenges. They then work with the family to test out these strategies, and adjust them as required. It astounds me that we do not have a service such as this which caters only to foster, kinship and adoptive families, when it could potentially save millions of dollars in costs in the long-term. Plus, we could so easily make a difference to so many children.

ADOPTION

We know that adoption can give children a sense of belonging, security and identity³. Belonging is shown to bring happiness, health, contentment, mental health and longer lives.

However, adoption is not a cure for trauma, so carers are holding back on adoption because of the cost implications. Children are missing out on this vital sense of belonging, this ability to trust and feel safe by permanency.

In addition, responses to trauma can take years to surface, with issues such as substance abuse, self-harm, suicide ideation occurring after adoption or guardianship. There is no support for families dealing with this, with many families breaking down as a result.

SUGGESTION

It is vital for the well-being of children for their families to be given ongoing financial support which is not means tested, following adoption. This is to cover the inability to work (if this is the case), as well as funding for adequate ongoing therapies.

I also suggest an investigation into how many families are struggling after adoption or guardianship.

³ <https://www.nsw.gov.au/family-and-relationships/having-children/adopting-a-child/understanding-adoption>

INDEPENDENT CARERS GROUP

We cannot expect to implement successful change if we do not take into account the experiences and opinions of *everyone* in the sector. Currently, carers tell me they are concerned that organisations responsible for representing carers have strongly vested interests, which influences who is chosen to speak and the perspectives that are represented to government and decision-makers.

In my experience, as a member of My Forever Family's Metro CRG, any concerns raised are not responded to in following meetings, and myself and others have lost trust in the process. Carers feel unheard and frustrated, and that the only way to ensure their concerns are being addressed is if they are represented by fellow carers, and that these carers have a seat at the decision-making table.

SUGGESTION

Carers have repeatedly told me they want a representative and independent carer voice. Moving forward, this is the only option that will ensure carers are involved in the system and decision making.

DIVISION

We need to work to reduce the divide between carers and agencies, DCJ and peak bodies such as My Forever Family. The impact of this divide is that carers are in fear of retribution so won't speak up. This divide has led to carers losing faith in the system, leaving the system, and advising others not to become carers. It has also forced families to push children back into the system, due to the strain they live with, and further damaging the children we are meant to be protecting. We are failing so many children, almost every carer I've spoken knows of children who have fallen through so called cracks in the system. These are not cracks, they are ravines and making it through this system unscathed, as a child or a carer, is more rare than those who do not.