Respite services in the ACT

A families experience

I am the parent of three children, one of whom has High Functioning Autism. We face ongoing and varied challenges that can be exacerbated by respite rather than overcome by it.

Briefly, and in no particular order, my comments are:

There is insufficient respite available – TANDEM has recently cut families down to 4 hours per fortnight for weekend respite. This halved our respite in one swoop. Families need weekend respite and as a priority funding to enable weekend hours to be reinstated is a must.

Availability and turn over of care workers is a perpetual problem. The role appeals to students and we have had a succession of adequate carers who last only until their last day at Uni. Sometimes there has been a smooth handover, other times we have had gaps in service before a new person is found.

Tandem short hours respite is not sufficient. We do not qualify for residential respite and although we were accepted some years ago as clients of the Barnardos foster care program we had respite for just 3 weekends over 3 months before the worker withdrew from the program for personal reasons. More than 2 years has gone by and we have not been able to get this service resumed. Is it true that no new families have joined that program in 2 years or is it true that we have fallen off the list despite my periodic phone calls looking for support?

> Please understand that respite is not just about going to the shops alone. It is about waking up in the morning knowing you don't have to have a battle, coerce, cajole, beg, bribe or encourage your child to go through the usual routines of a morning and a day. It is about peaceful mealtimes, participating in community activities, perhaps a restaurant, spontaneity, relaxing evenings without having to wake and toilet a sleeping child. It's about not having to allow for transitions to go wrong all day long. We can't get these things from short burst of respite lasting a few hours, we need full days and overnights to recover our energy and will for the ongoing stresses of raising a child with autism.

We have had some wonderful support from Carers ACT emergency respite programs but of course they are spasmodic and cannot be called on all the time.

In home respite means that there are additional costs associated with the respite. For us to go out to get a break we have to go to a movie or restaurant or other activity when we would rather be putting resources into other priorities.

Like many other parents I have not worked full time since my children were born. In a few years they will be in high school and we will loose access to after school care. I have no idea how I will continue to work then as my son cannot bring himself home from school and be here without an adult.

We experience a range of social exclusions and barriers as a result of his disability and our inability to access appropriate respite.

> I am battling to make it possible for him to join his sisters in cubs. It has become clear that without support he cannot sustain engagement in these kinds of activities so not only do I have to find the funds for their fees but am now also faced with the cost of a tandem worker accompanying him to cubs evenings and weekend activities. That is if we can fiind a worker, who is available etc etc etc.
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> I am forced to take employment that does not recognize my skills and talents and underpays me for what I can bring to the role, simply because I can only work part-time. My inclusion in the workforce is limited and any career aspirations and prospects I once had go unfulfilled.
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> We do not go to community festivals, events, etc very often because of the difficulty of taking a carer with us to make participation possible for my son. His sisters therefore miss out on a range of experiences that other kids take for granted.

In reviewing respite services please take into account:

> The desperate need for increased availability – more funded service, better recruitment of workers – requiring a change to employment conditions.
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> The qualification and rules criteria for respite services need to be overhauled. They throw up barriers and deter families from accessing support they desperately need
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> removing some of the arbitrary rules like not providing respite for siblings, or children of someone with a disability. It should be about giving overworked carers a complete break not a partial one.
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> Provide alternatives to in-home respite for all families, perhaps day stay or overnight places that children with so called less acute disabilities can attend so that the parents can have time at home.
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> School holiday activities for children on the spectrum would ease the pressure of holidays on families

Thank you for the opportunity to provide input – lets hope this time it makes a difference!