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The real impact of funding changes to respite care

From those who will be hurt most

AWHI NGĀ MĀTUA

MAR 19



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Parents of disabled and neurodivergent tamariki in Aotearoa have made their voices clear. In less than 24 hours, Awahi Ngā Mātua - a community for parents of disabled, neurodivergent and medically fragile tamariki - collected more than 300 responses from parents about the sudden changes to respite support for families across the motu.

“Devastated”, “heartbroken”, “distracted” are just some of the words that parents described themselves as feeling. Here we share words directly from families - they are edited only for clarity and to provide privacy for tamariki and their whānau. **They are just a tiny portion of the feedback we have received.**

We hope the Government will see the distress this decision has caused and reverse the changes to respite purchasing. It is not too late to do the right thing.

We invite you and any journalists reading to share these words widely. They are the words of your family, friends, loved ones, neighbours, colleagues, and fellow New Zealanders. We hope they have an impact on you as they have on us.

- Emily and Elizabeth, Awahi Ngā Mātua

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How will I get a break now? What about my well-being? Does Whaikaha not care about my disabled child? We already find it hard going and now I can't even

spend a measly \$80 on a massage to reduce tension and alleviate stress? Our family does so much and now I can't even give them a koha to say thank you? I don't think I can keep going on with it all anymore, this is too overwhelming.

We struggle to get carers and have minimal family support. Our son is autistic and has a terminal genetic disease. We use the funding to access activities or devices that help our son to be settled and calm. It is the only way we get a small breather. Now we will not get even that. I am after 20 years of caring at burnout - the mental and physical impacts are huge. If I hit the wall where will my son go? There's barely suitable disability respite available in the community and he needs hospital level care. Will the government fund this full-time? They need to think through the impacts on disabled people and their carers.

These changes will likely break our family apart. Respite was the only thing keeping us together. Financially we cannot provide anything that our disabled child needs without use of the funding which is now rendered useless.

It really limits what we will be able to afford in regards to purchases that give us (and our young person) respite and also an ability for him to increase his independence from us as he gets older. The flexibility gave great options. We do have one carer but that makes us so lucky compared to other families. Our carer comes to our house so that means to have a break we have to leave. All the costs add up. Our son ultimately loses out as it lessens his ability to regulate and develop. His siblings pay a price too, as it is not fair having to miss out on a lot of experiences their friends have as it is not workable if no carer available.

We will lose access to medical equipment which means we have to wake several times a night to check on our child to make sure she does not go into a coma and die. Back to sleepless nights for us.

We struggle to find carers for our daughter so rely on items to help her at home while we get a break. We also use it to bridge the gaps between long Ministry of Health wait times, lost referrals, and systemic issues with the education system that leave her falling further behind her peers.

We have very limited access to carers and our children struggle to be cared for outside of the home. So by not being able to claim for accommodation for ourselves we will likely never get a night away for respite.

We won't have any support to do things as a family or to allow our wee girl the life her friends have. We must have an open overnight caregiver due to airway issues and a tracheostomy. Our child is non-mobile, non-verbal and tube feed. A highly complex wee rockstar. If we go away we claim our caregiver's accommodation and food costs so we can still have overnight care for our wee one. Now she will not be able to have any nights out of the house, no support to live a good life and I don't believe not being able to leave your house to interact with friends or go to family events is a life at all. What if one of my grandparents or parents pass away and they are out of town? How do we take a caregiver to support us now. Does one child have to remain at home purely because someone has decided to govern how and when we can use our caregivers as it now renders travelling unsafe?

As we have little family able to look after our young son, \$80 is insufficient to cover care for a day. We've used the funds to provide him with items so that he can occupy himself safely during the day so his mum can have some respite. The lack of publicly funded speech therapy has forced us to look elsewhere for autism specialist speech support which we have accessed via an iPad app. Having this for three months has resulted in huge improvements in his speech.

If I can't have a respite break my mental health goes downhill and I burnout. Looking after an autistic child is a 24 hour a day thing, it's parenting on steroids. It also means if mum is away or unwell I have no one else to support us. My son

won't do strangers in our home. It also means I can't go anywhere. Do I pay someone to stay and sit in the car?

Being able to purchase items has been a massive help to us....I struggle to get a break. He prefers to be at home and using items that I have purchased for him using Carer Support has helped me get some sort of time to myself. Taking that away is just going to make things so much harder.

This will have a massive negative impact on my mental health and my ability to care for my daughter.

We will not be able to use our funding under the new guidelines. Our lives changed for the positive in many ways under the guidelines that existed prior to today. None of those things will be possible now.

This will impact us massively, we have only had this for two years and it has changed our lives as we have no family close. We cannot find a caregiver, even if we did we couldn't afford to pay to get a break. Every day is exhausting with a child with a disability, having this funding to buy items or to get a break away or to keep my son busy while I have time to breathe has been a huge support to us, not just for my son but also for me as a full time caregiver for him. Every day you fight for their rights and as an advocate for him it is very upsetting to see this change.

This will limit us hugely as we have used our carer support to pay for travel for my son to go to his Nana's for respite. We have been doing this since he was five and it has been a very valuable time for him. We have also purchased items for him which have provided respite but these things would no longer be covered. There has been a total lack of consultation around this and the Government has definitely not considered the needs of disabled people or their whānau. Respite and care are different for each child and their whānau.

It removes nearly all the respite we as a family were receiving. It makes our funding allocation basically unusable. I am exhausted from navigating the basic needs of my high needs children on a daily basis. We have difficulty allowing new people in our home or around us and have limited "safe people" to support us. I am already in autistic burn out and have been for a long time (over a year) and the respite purchases we have been using funding for has contributing to that beginning to lift.

Stress and anxiety will increase which we had made huge progress with, with the choice to purchase items through carer support. There's potential for a decline in behaviours that was being well managed by having choices. It saddens and angers me that a group of people have made this decision with no engagement from carers and families and clearly no understanding! Goals will now be hard to achieve. I could write a novel - just ugh - feeling disappointment - feeling defeated - feeling hugely insulted.

It will mean I will not be able to get respite if we have to pay for our accommodation. Being on a benefit means I don't have the money and I may lose my child's support worker if we are no longer able to claim for their travel costs.

My children use respite items for sensory regulation, activities to keep them in school safe, and safe playing at home so I can rest and be the best mother to my children. We will be deeply affected by these changes.

It's already a rough ride with autism and anxiety, we got funding last year and it has helped so much, it's provided a respite for us both..I am very worried and stressed about these new changes.

We will have funding, but no way of using it unless they provide specific guidelines on what can be used. This will also mean that my mental health will deteriorate as I will be unable to get a break.

It will be horrendous! Will our carers even keep coming if they don't get a fuel allowance? Our son doesn't take to people easily! He is 21 years old and can't be left alone. The flexibility of the funding allowed us to purchase items that allow our son to be more independent, which gives me as his main carer, a much needed break.

I am very concerned that my mental health will plummet.

I have very little, if any family support. I have a child who refuses to leave the safety of his home and this makes it impossible to get the respite that we both need. Being able to purchase items makes life easier on both our mental health.

Respite will be harder to receive as it is not easy to find someone willing to have my child to provide myself with respite. It is a lot easier to purchase items which will help my son and provide myself with respite.

The changes will severely impact our whānau now that I cannot purchase items that provide me with relief. As an independent Māmā things are already stressful enough trying to balance all the extra appointments and my sons' individual extra needs. This changes should have been implemented gradually so we had time to purchase what we needed for respite. As someone who doesn't have much whānau support these changes will mean that my sons' funding allocations are pretty much meaningless now. What's the point in having funding if we can't choose how we use it? It's probably the way our govt like it, to make already struggling whānau struggle even more. Probably end up costing the government in other ways because we need more support not less.

It will impact our family massively. We don't have family who can take care of our children and they can't be cared for by strangers (a problem for most autism families). Using carer support for respite items was our lifeline. The respite items are essential for family's like ours. Out of touch, suit-wearing ableists have made this decision, without any idea what the knock on effect will be. One of those said effects is going to be severe mental health issues with carers heading into burnout. It's going to end up costing more for the government in the long run.

This will profoundly impact us. Due to my child's disability and explicit needs, outsourcing respite care to an external person is not suitable or safe.

I have used Carer Support funding for respite items that would educate and entertain my son as he cannot be with a carer.

My child is autistic and relies on outings with his carer to activities as part of his routine. Activities are no longer funded as well as his socialisation classes and support for his his special interests. That's all cut now and he will immensely feel the change in routine and will cause massive violent outbursts. Our goals are no longer available so how do we complete them?

I'm sitting here crying about this right now, my son has been in a meltdown all afternoon. Respite purchases are the only things that keep him calm and provide relief from sensory overload....he also needs to go to the hydrotherapy pool....I need to be able to use his funding for the hydrotherapy pool, for travel to this and for respite time away, we have managed one respite stay with him and it was so therapeutic for him and our family. I'm devastated at how I see this will affect our family and particularly my son. No one told us this was going to happen, we have found out on social media and don't even understand it.

It will make getting any respite almost impossible. It was already very hard and confusing now we are so limited I don't have the mental energy to even work out what's allowed. I can not pay someone to watch my disabled children.

My children will be suffering from this, we already have burnt out parents, how is this acceptable? No one was informed prior to this, my children won't settle with just anyone, my youngest is non-verbal, mickee fed, autistic, cerebral palsy, deaf, under critical care. This is unbelievable, I never spent the money on myself anyway, my children don't go out.

We have no whānau near us We use carer support for items to occupy our son to give us a break. It's tough. We do use it occasionally to bring my mother-in-law to us to provide some respite but that is not often. She is elderly.

I cannot leave my daughter unless I am able to leave what I am doing and be there in two minutes due to her complex and frequent seizures. We have a wonderful therapist that comes to the home, but we have to cancel a lot as my daughter is either at appointments, in hospital or completely drained from seizures. I had just put a claim in to pay for my partner to travel to two hospital admissions that are ten hours away from our home to help me, and I can't see this getting approved anymore. I have no idea how I'm going to travel by plane twice a month with a 25kg disabled child who has just had surgery, with seizures that are triggered by travelling, on my own.

I had just put in a claim for a smart watch so I can be reached 24/7, time seizures, and call ambulances quickly. I needed to use some of our funding to go towards an overnight monitor that will alarm me if she stops breathing during the night. I don't sleep. I don't have the money to feed and pay for a carer to travel to us. I cannot work anymore. I am feeling for everyone who cannot leave their disabled loved one to get a break.

It will significantly reduce our capacity as carers to be present with our children, therefore impacting on their own sense of wellbeing.

I have been going through the public system for autism diagnoses for both of my children. I have been buoyed by the fact that at the end of my two year wait for both, I will be able to access support in the form of respite care. My youngest son, who has more challenges than my oldest, received his diagnosis last week, and now I am confused and upset at the changes, and I feel like the main support that I need to provide him with a supported parental unit has been taken away.

I am also confused as to what HAS been taken away in full, as the wording and speed of these announcements has left my head spinning.

I wish this was a clearly understood change with time for consultation. Overall I find the system hard to become familiar with.

It will impact us in a big way as it means I will not catch a respite break away, which is valuable to me as I have a very high needs daughter.

It will impact the mental health of both the carer and disabled person. I was planning on a proper respite holiday this year for me to get a break that is much needed. Now I can no longer do this and now I'm worried how can I get some rest. Being on a benefit means I can't pay for items for my child to support him and myself with respite. I depend on the funding and now that's been taken away. Many families will struggle more. We already fight for so much now we have to fight even harder but without rest.

I am a solo mum with zero family around and no one to watch my child. These rules make having funding pointless. I will no longer get a break ever and be stressed out even more. My mental health will suffer because I won't get a break, the kids will play up due to extra stress....I already felt alone, now I have zero help at all. Not only do I as a parent miss out, so does my child, no longer having

assess for care for him, activities for him. Now we ALL miss out. And I'm scared at how stressed our house will be.

Almost all of the ways we, as parents of disabled children, get respite will no longer be accessible. How can they dictate one way only of getting respite. What about those of us for who support workers are not available and/or not practical?

We have tried to use support workers but not only is it incredibly hard to find someone willing to work legitimately for a low number of hours per week, it is even harder, in fact it has proved impossible, to find someone who can handle our autistic children that have high support needs.

There is then the added layers of our autistic children becoming very anxious around people they aren't familiar with and resisting spending time with the support worker, then becoming distressed at the thought of the parents leaving or being forced to go out with the support worker. This escalates behaviours and in turn actually creates a child with even higher support needs.

This new 'rule' forces children to spend time with paid carers, in effect institutionalising them, when they would surely choose a variety of supports for their caregivers that enhance all of our lives.

The previous guidelines that allowed us flexibility were life changing for our family, for the better. For the first time in our lives as parents we were able to take a meaningful, restorative breaks and provide our kids access to opportunities, supports, activities and therapies that we could not otherwise afford. Do Whaikaha have any idea of the emotional and financial distress this change has caused?

It seems that absolutely no consideration has been given to the individual needs within the disabled community, or the harm losing our vital supports will cause. Please, please, please do not proceed with this change.

My son is nonverbal and hates being with new unknown people. I consider him to be extremely vulnerable I was relying on the CS and IF to give me respite from home while knowing he is still in a safe and secure place. Now items are not an option I will not be able to use the funding in the way that best suits him and will feel as though I am failing him due to these changes. It will impact my family in

the worst way possible, having a carer for my ASD child is impossible, so being able to buy supports for my son to have respite at home or use the funds for travel so family could come help for myself to have my own respite away from him was a huge huge help and taking that away is going to be like going backwards by many years and I can say it is going to be very tough times ahead.

I am unable to work much because of my own health needs and my children's. We each get IF and respite and it's a life line. My 13 year old wrote this poem in response and is happy for to be public.

By Eleanor,

Strings.

My limbs cut,

My future not mine to control,

Like a puppet on a string.

The scene around me changing constantly.

The Taniwha controlling me, tugging and snapping my strings one by one,

They do not know me,

They do not know my movements, my thoughts, my needs.

And yet they decide what is best,

And yet I am not in control of my own future.

I am falling, falling, falling,

And the net that would have once caught me, has now been cut.

And I worry, not just for me but for my family, friends, community, city, country.

And I know that others struggle to,

I know that for many it will be life altering, myself included.

My dream ripped away by people I do not know or trust,

And it hurts,

And, and, and...

So I fall, and hope...

hope for understanding,

hope for better leadership,

hope for kindness,

Hope for those strings of fate to weave a tapestry of peace and acceptance.

Hope for change.

These changes will impact our family greatly on our mental health. The Carer Support allows me to be able to take much needed breaks away from the demands on supporting my children; the financial strain on our family is more than enough on its own. If I don't try and fill my own cup first it impacts hugely on my family. This has brought such anxiety to me as a Mother and also as my sons' carer. I am truly shocked by this decision as it is definitely not supporting the EGL principle.

It has caused huge stress for us as a single parent low income family, in a region where it's really hard to find carers and we don't have in-house family to pay.

Without being able to pay for carers to travel somewhere and buy tickets or stay somewhere I will mentally break down. I'm already close to burn out.

Our daughter has a lot of ongoing health issues after being born extremely prem and is still in and out of hospital at nearly five years old. The use of our daughters funding was amazing for buying things for respite which in turn helped me help her. Now we are no longer going to be able to purchase these things for her making our funding pretty useless.

It will make our allocation unusable. Having more than one autistic child in the house, we can't leave them with other people and have no family to help. We can't work full time. The respite provided by devices especially is essential. The funding for resources to help calm and make their lives more comfortable has been essential. This leaves us in an awful situation and will affect the mental health of the whole family.

Due to behavioural difficulties I find it hard to find anyone who will care for my child so I can have respite. Using carer support days to claim for items and travel for myself means that I am able to think outside the box of respite for myself and get creative in ways that work for both my child and I. People who could have her for me are further away so for me to have a decent break that requires us to travel which incurs costs.

I believe these funds would be better managed as an overall budget than allocated days, so long as the person claiming can demonstrate how the purchase can go towards enabling respite for the main carer - instead of limiting families to using alternate carers only. These changes seem like a huge step backwards in an already broken system.

We don't have a network of support carers. There is a lack of support activities in West Auckland. The items we have claimed for had longer term benefit for my disabled son. Which in turn gives me respite from care.

I am hugely disappointed in this sudden change and feel really sad for our disabled and whanau who can't get any carers for their tamariki as I myself can't as my child won't go to anyone and is more settled being in his own space with his respite items to keep him happy.

I have no family or friend support so I am unable to get normal respite, my son is also very high needs and not good with communication and struggles being around people he doesn't know. Not being able to get him sensory items or things to offer him and myself respite will be putting us back to square one and I won't be able to give him the happy environment he deserves and needs. I also won't be able to get him the things that will be able to help support him and become better in the outside world and help to regulate himself.

Taking away our choices limits the support our children get, the respite items were not only beneficial to them but to the entire household. And removing other options for a carer to get respite is going to cause burnout. I could go on but I'll be here for a long time.

Since learning about funding for myself last year and starting it about nine months ago my life had drastic changes for the better. I am devastated today to learn that there seems to be near to no respite options for my son as he cannot be looked after by a carer outside of our family. His respite is through items and activities that offer him participation in online communities. All the things I as a solo mum can't offer him.

Both my son and I get massive respite by being able to visit our whānau. This allows us to reset and have time resting away from our normal everyday environment. Something only dreams were made of before I knew of the funding. For myself I am terrified that there are many things I may not be able to get

funded anymore that enable me to have a good life, the same as a non disabled person.

I am solo mother who lives rurally. I have no one to pay for support and even if I did, I should not be expected to hire some complete stranger to look after my child who is non verbal, autistic and has global developmental delay. He could not be left with a stranger. I have never used my funding to treat myself. I have only ever used it to contribute to the costs of items which support my son's disability and in turn provided me with some down time (or respite). Our wonderful neurodiverse children in this country already get next to no support. I have to pay for his private therapy each week because the system is failing him (that's right I also can't use carer support even though its supporting his disabilities). I also have to take a day off work to do this as its over two hours each way to the therapist. What a disgrace, where is the mana?? Whakamā!

My son has just started using Driving Miss Daisy to his day service three days a week, I used to take him. This has been a game changer for us, giving him independence and me respite. If I employed a care giver to take him it would cost more.

No longer being able to get items for my son that give me hours of respite care over and over, items that give him more independence and opportunities to learn new calming strategies will significantly impact my family situation. My son has been able to get so much from the activities in the community with support workers, items and other sensory things this funding has allowed me to get, I am a solo single mother this honestly is so devastating to hear with no notice I can no longer have him thriving as he has been.

It will impact my already struggling mental well-being as I can't have a break from my high needs son. He will not go to a carer.

I live with my husband and he works massive hours. We don't have family support so we rely on funding to give respite so I can avoid burn out and so my child can have sensory items which help with the violence etc. Good carers are so hard to find and sometimes leaving my child with one is just not an option. The fact that I could use his funding for respite items has helped me significantly. Taking this away from us means more anxiety from myself, more over stimulation in the entire household and more violence from my child. The ability to purchase items to help with respite has meant my son has left the house more (he is usually stuck in his dark bedroom).

It will change the ability to take our disabled child out in the community and live a normal life. Transport is a big thing for those with disability they can't go out independently compared to non disabled people and this funding is being cost. It's going against the values of having funding to allow disabled people to live a normal life.

It removes the flexible purchases to give breaks in other ways. As respite care is not always easy to obtain people to do as rates aren't great either. An iPad for my autistic child means you can get an hour to yourself while they learn on epic book reading app.

I no longer can provide my support worker's travel expenses, food expenses and no longer provide respite for myself. It is very disappointing.

The changes made to the disability funding we receive (for myself and my child) will completely derail any progress made in recent years. I have finally gotten to the point of being able to work part time and start part-time. However without that ongoing flexibility and true embodiment of the EGL principles, our needs as autistic people will not be met. Either they forgot about us, or they intentionally drafted the new guidelines to exclude most of the support that is relevant to making our lives better.

This is such sad news for our family and will impact us immensely, as my child is unable to be left with anyone and therefore being able to buy respite items on carer support has made a huge difference to not only myself as a single parent, my physical and mental health, but also to his siblings. Respite comes in many forms and is really only something that each individual family can decide how best to have the most benefit.

It will make my entitlement worthless. I have no family in New Zealand and no one is able to handle my child or is willing to take care of her so I can get respite. Items such as electronics were my only way of getting any respite. This news makes mine and many other carers life's even more depressing and quite honestly worthless. Life really shouldn't be this hard and unsupported, it's no life!

It will be huge, we purchase respite items and my precious person's goals all revolve around social inclusion and outings for the next year, neither can now be achieved. I am a single parent, who lives rurally with no access to carers, so my daughter's funding is now null in void.

There will be little to no support available to us. So what is the point in the funding?

When you have no family that are willing to help with respite and your child won't cope with a facility or isn't eligible for one, the only way to get respite is to remove yourself but now no funding to do that it will land up back to hiding in the wardrobe with our own mental state compromised.

We have to travel far and wide for his specialist services, we need specialist sensory equipment. I as his mother get nervous breakdowns and need respite. But all of this has been taken. I'm am so gutted and so is my family. We won't be

able to go out anymore when his headset breaks, it means I can't get away when I am being wailed on to find my own head. This is just devastating.

I currently receive carer support for two of my children. I have no family support. I work full time, and am unable to return to the office as I need to be home 24/7 for my kids as they are not all attending full time education due to their needs. I have multiple different appointments, or things to oversee during the week alongside working 40+ hours. Until now, I have been able to purchase items to keep them occupied, engaged and calm enough to give me a break whilst still being at home. I for the first time in my entire parenting journey (20 years now) was able to take a holiday last month. I don't have \$2 spare at the end of each week by the time my essential bills are paid to save for any form of holiday, break or respite options. Because of the flexibility of the funding I was able to take this break, and have the kids taken care of without ending up in massive debt. Because of this break I had gone from wanting to place my children into Oranga Tamariki's care and taking my own life, to being able to stomach getting up in the morning, organising the kids, working, juggling appointments and various mental health and behavioural challenges without having a complete breakdown myself.

Share

*These are just a tiny amount of the feedback we received from parents. We will continue to share from our community over the coming days. **Please share this post.***

Please please share this post with your local MP and with the Minister for Disability Issues is Hon Penny Simmonds and Prime Minister Christopher Luxon, and Deputy Prime Ministers Winston Peters and David Seymour.

Emails to cut and paste: P.Simmonds@ministers.govt.nz,
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David.Seymour@parliament.govt.nz

More information: [Changes to respite item funding.](#)

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