



On 18 March 2024 Whaikaha – Ministry of Disabled People announced sweeping changes to how funding can be used by disabled people and family carers. This document shares comments by several hundred of our community in response to the changes.

We also share our perceptions about the changes, and the work we are doing to encourage a return to true flexibility. People need choices to live good lives. The changes are too sweeping and happened too quickly.

We note that since the changes were announced Whaikaha has issued new guidelines with support for more flexibility ... but for family carers the rigid inflexible policy remains.

Our perceptions

Carers NZ has been watching for some time as Whaikaha grappled with budget pressures and growing demand for services and funding support. This is happening across government including Health.

We have wondered about the sustainability of flexible funding for at least five years, since before Whaikaha was established. We have long raised concerns about the need for additional money for Carer Support, for example.

The previous rigid rules across health and disability meant that many family carers could not access respite that worked for them; government budgets relied on them only using some of their Carer Support days. This meant that despite having allocations of respite, carers couldn't fully 'spend' them – they couldn't get adequate wellbeing breaks to sustain them in their important role.

We have long advocated for Carer Support – the only respite funding most family carers get – to be allocated as a personal budget. Family carers know best what gives them rest and a break, be that a massage or an entertainment subscription or a movie or hours of support delivered by someone else while having a break from caring. Or a school holiday programme, or formal facility-based support, or a device, or paying another family member to step in while they have a break. Or trusted services.

We have argued that Whaikaha (previously MoH – Disability Support Services) should introduce a personal budget model for Carer Support that would give family carers their allocations to spend flexibly achieve meaningful respite.

We have come close to this several times over the years but funding sustainability has been a concern, as the system has relied on family carers only partially using Carer Support allocations.

Personal budgets are a 'full allocation' approach: if given their budgets, people will fully spend them. That's good – it means they are accessing respite and supports. It means carers can have respite from what can be a demanding role. It means they can keep going.

We told the last government it needed to allocate more funding to Carer Support to sustain this full allocation approach. It is unclear whether this happened, but we were pleased to hear that more family carers were finding ways to use their Carer Support, made possible due to increased flexibility and choice that evolved through COVID-19.

From 1 July 2023, family carers in the Health NZ / Te Whatu Ora system have also had increased flexibility in how they can use Carer Support. The rules are not as flexible as Whaikaha's have been, but the carer movement has advocated for increased flexibility and choice in the Te Whatu Ora world for more than 15 years; we were so glad when this was introduced for Carer Support last year.

If you receive Carer Support via Health NZ | Te Whatu Ora | your former DHB area, the Whaikaha changes do not affect you. You currently have more options using Carer Support than those who get their allocations via Whaikaha. This new inequity isn't fair in our small country, but we hope balance will be restored and are advocating for this with Whaikaha and the Government.

Feedback to government

Over a long period we have given input into flexibility policy, raising sustainability and funding concerns. It has been an openly debated issue in the disability sector that Whaikaha was experiencing financial strain. More people are entering the disability support system – this means more funding will be needed. Demand for new resources in our ageing society should surprise no one.

We have given feedback to Whaikaha, based on input from family carers in our network, that flexibility should continue, and if there were concerns about how funding was being used – to buy items and services and trips other New Zealanders could not afford, for example – this should be openly raised with the disability community.

While more rules work against the principles of Enabling Good Lives, this is matched by the realities of more people needing disability funding year by year. Whaikaha has used the example of those waiting for basic equipment such as wheelchairs due to insufficient budget – weighed against growing allocations for other disability supports, and government pressures to fund more, do more, spend more.

This pressure will always be with us as our population grows, and as more New Zealanders need support to live well in the community if they have health and/or disability support needs.

We aren't sure how we arrived at a point where the budget implications of growing demand and more flexibility were not anticipated by successive governments.

All we know is that on 18 March 2024, years of work towards a more inclusive and flexible disability system took a retrograde step with the funding changes announced by Whaikaha.

What happens now?

Carers NZ and many others are advocating for Whaikaha's funding and policy 'pause' to go back to the future.

We were all taken aback by the scale of Whaikaha's announcement on 18 March.

And we were taken aback by government comments about spending of public money on hairdressers, manicures, pedicures, massages, Lotto tickets, alcohol and cigarettes.

Firstly, the very small respite budgets most family carers get should be able to be spent on anything that gives them rest – an ordinary life experience. Not Lotto, alcohol and cigarettes, but pretty much anything else, even if there are caps on big ticket items or day to day life purchases we should all fund ourselves.

A 24/7 carer's mahi aroha based on \$25/hour has an economic value of more than \$214,000 a year.

Their usually small allocations of Carer Support (less than \$5000, often well below that amount) is modest recognition for their priceless role for loved ones.

We note that our 2022 *State of Caring* survey showed that more than two thirds of family carers experience depression and anxiety; more than 40% are injured in their role; almost 70% say they are socially isolated and lonely. Most live in economic hardship, putting caring before earning through paid employment. Many are experiencing financial distress. Many can't save for their own retirement.

If a family carer in their important role chooses to have a haircut or massage using their respite funding, we believe New Zealand shouldn't judge their choice – we should be glad it makes a difference to their ability to carry on in their essential caring role.

We are urging Whaikaha and the Government to restore choice and flexibility where this makes a difference, and to make its rules clearer.

It is not clear yet what is still allowed, and how people can make decisions without falling foul of the "rules".

We are urging Whaikaha and the Government to 'unpause' wherever possible.

Already exceptions are emerging due to advocacy, but no one should need an advocate to get answers about their situation. The rules need to be fair, transparent, accountable, clear, apply to everyone, and be able to be impartially reviewed. This needs to happen urgently.

So stay tuned

Like you, we still have more questions than answers. Some flexibility will hopefully return, but not we believe to the extent allowed before. These conversations with Whaikaha and the Government will continue months and years into the future.

In the meantime, if there are indeed alternative sources of funding for services people have been paying for with disability allocations, Whaikaha must produce linkages to these services (therapies, counselling, transport etc) so our community can connect some new dots quickly.

We know that already family carers have had to reduce hours of paid work or leave paid employment due to the rigidly imposed changes of 18 March. This is a loss for them, their families, and the country.

Our word cloud on the cover shows how our community is feeling. We feel for you, and will continue to advocate for you. Things have changed, but they can change again, for the better. This is our hope.

iChoose and Carer Support

We are urging Whaikaha and the Government to give Carer Support allocations as a personal budget as soon as possible. This will go some way towards healing the hurt and broken faith many family carers are experiencing.

It is a small amount of money in return for the huge and mostly unpaid contribution of family caregiving.

Carers' collective unpaid work has an annual economic value of at least \$17.6 billion. We think you're worth this small public investment of, typically, \$5000 or less a year – you should be able to spend it to rest, conserve your wellbeing, and live an ordinary life in ways that sustain you and work for you.

We all need rest and opportunities to sustain our wellbeing.

We all know what works best for ourselves to achieve this.

We all know that if we don't have opportunities for rest we don't function as well - we can't care as well.

You have such an important role.

You do so much.

You matter in your own right.

You should not be funded or treated or spoken about as though you are an afterthought.

We're sorry this has happened at a time when many of you are exhausted after the disruptions of COVID-19 and last year's extreme weather events.

In recent years you've had less opportunity for respite than ever.

But hang in there. We will do our best to advocate for your role, your rights, your wellbeing.

And thank you for caring.

What would NZ do without you?

Following are comments from disabled people and family carers following the funding changes announced by Whaikaha on 18 March 2024. Thanks to those who shared their thoughts and feelings at this historic time of unfair change for the disability community. We will provide this document to Whaikaha, to the Minister for Disability Issues, and to our networks. The comments provide food for thought as we enter an uncertain time for our community.

“This change is completely devastating to us as a family as this has just rendered our funding basically useless. No consultation with this decision and absolutely no warning before making these changes. I'm disgusted. This is a heavy blow to the disabled community of New Zealand.”

“Flexibility is important because there is no relief carer available. We can't trust just anyone to take care of our child for \$80 per day. We need flexibility because all needs are different. This is also to support to the welfare of the carers, not just for our children. We also need to take care of ourselves, so we can take care of them better.”

“This is just beyond devastating. I feel utterly devastated- I don't know how we will survive as a family without these supports.”

“This is devastating for our family. With 1 with ADHD, 1 with ADHD/ASD and an adult with ID - being able to purchase items for them that could be used e.g. sensory items, respite for me (weekend paid for out of town) and things for a support carer to do with them now are no longer allowed. The support carer is unable to have all 3 at once. Why change something that was working so well?”

“This is a really tough decision for my situation, solo mum, all family live overseas and our only relief carer quit in July last year. Not being able to use the funding for purchasing respite items is a huge hit to being able to get any down time. I know there are so many families in similar situations to myself.”

“Well it means I can no longer get overnight respite as my 2 funded kids will not stay away from home but were ok staying home with a carer while I went and stayed in a motel for a much needed break. I'm on the Supported Living benefit and can't afford to pay accommodation costs myself. Now this is longer able to be claimed it means I can no longer get the respite I need.”

“The changes render Carer Support completely unusable for me. I have two dependent autistic children - one adult, and one teenager - and the changes mean I now receive no support. The pool of funding will sit there untouched, just like it did before the flexibility rules were brought in during the pandemic. When I could use it for items, I was able to buy my children things that allowed me to take a break - that was surely within the intentions of supporting carers. Now I can't do that, and giving my kids to some stranger doesn't fulfill their needs or mine. I am distressed about the change, and my kids will be too once I've got the strength to break the news to them - my adult son in particular will be very upset as Carer Support had allowed him access to items that made his life easier and more enjoyable while giving me a break. This is going to be devastating for so many families that I know were relying on the flexible support. Please fight this - please get them to reconsider, please at least get them to consult! This is absolutely not in the best interests of carers or our dependents. Last week I had a reassessment with a service coordinator from my NASC. A support package and plan was put in place to enable me as full time and sole carer of 3 high needs children to be able to not only gain respite from carer duties but to gain a basic human need - sleep. During the conversation it was mentioned that I could buy sensory items to keep one of them entertained, but mostly it was set up to serve a dual purpose of allowing me to either pay for alternative accommodation while an older sibling cared for the children in their own home ie their safe space, or for an older sibling to take children out to do activities which also enabled them to access the community and independent living while allowing me to sleep in my own home. All three options discussed and planned for in the support package are now unfeasible less than a week later. I do not want massages and manicures or TVs or devices. I want

rest and the ability to access actual respite in order to avoid the burnout from being a full time and sole carer. Something that has now been made unlikely and seems to be to contradict the idea of enabling a good life.”

“Hugely upsetting. We use our funding for respite purposes rather than carers as she needs a strong routine. Being not able to pay for individual swimming lessons means she won't be able to learn to swim. We won't be able pay for her flights to her grandparents so we can have a break. We won't be able to pay for the devices she needs that make her and own lives easier.”

“As an autistic solo mother of three primary schoolchildren all with autism and ADHD... these changes will be severely disabling. I have no natural supports around me, so paying for travel for my Mum (the only person my autistic children will allow in the house) to come and help out was a godsend. My eldest also has such severe anxiety and agoraphobia that I cannot coax him to stay overnight anywhere which means I have to go elsewhere which I cannot afford to do. Because of how difficult my eldest disabled person is, I had to resign from my job to care for him which means I do not get a break from caring. All my children have to be supervised constantly and cannot be left alone. The funding flexibility allowed me to purchase items that gave me respite in my house while they were still supervised. I am now terrified that without RESPITE which is what the funding is for... I will no longer be able to care for my three children.”

“My autistic children won't cope with a carer. We get respite by having an occasional night away while family members look after our children. We need to be able to use our IF to pay for accommodation and travel so we can get respite breaks.”

“Support workers are often not accessible to many families due to the support needs of the child or inability to find the right staff. Being able to purchase items for respite is essential to sustainable caregiving.”

“This means I won't be able to take a proper break as it excludes respite accommodation etc now. My hrs are reduced for work because of looking after my child. It was good when changes were made to be more flexible around carer support hrs. So frustrating this is being reduced again.”

“Basically, everything I used the funding for to provide respite for myself & care for my child with a disability has been cut. I don't even know if my current receipts & invoices will be covered.”

“This will strongly affect my family, the lack of consultation and lead-in time is upsetting. Going back to how things were will mean our family will struggle to use our allocation due to our situation and having no carers available to offer respite. This will have a flow on effect to the wellbeing of my whānau- if there was proper consultation and implementation this would not feel so abrupt and there would be better understanding of the future landscape/direction.”

“Our 8.5yr old homeschooled autistic son will not go to other carers. He is stressed when not with us. This leads to a fight and flight response which is dangerous and scary for carers. We also live rural where finding someone suitable and willing is very difficult. Yet the new rules, although acknowledging how useful alternative purchases can be for providing in-house respite for the carer states: ‘purchases of items as a form of delivering respite (including, but not limited to, consumer electronics, sporting or recreation goods that may reduce the need to take a break).’ Such blatant disregard for the reality of many (most?) carers’ situations. This is going to contribute to far greater mental health and hospital costs for the NZ health system. I run an online support group for parents of ND kids who are homeschooling and their reactions today range from furious to devastated. We have a number of solo mums who have had husbands and partners leave them with up to 3 ND kids & these mothers are desperate for any kind of respite, and have no financial cushion to fall back on. Their devastation at the abrupt removal of this one small lifeline is palpable. Shame

on you Whaikaha. Where was the consultation, where were you in terms of standing up for the better lives of disabled people in Aotearoa.”

“We live rurally and can't access respite carers. So now we are penalised twice - once for having a disabled family member and once for living rurally. So unfair.”

“I am not happy. My depressed and already highly anxious ASD boy will not want a stranger looking after him. He has trust issues - I used carer support for respite items to give me a break but also to educate and entertain him.”

“It's such a setback to our family and me as main carer. Having difficulty finding a permanent carer and taking away the ability to use the funding for disability purchases means I can hardly have respite. IF is supposed to be for individual needs not on a number/ rule set by the govt for everyone.”

“Our allocated carer support hours will be of very limited use going forward. We find it difficult to find carers with the skill and relationship necessary to care for our son, especially at the 'pay rate' of \$80 for 24 hours. We have previously bought items that provided respite while my son was still in my care. We can't do that now. I had booked accommodation for my husband and I to have a break away from my son for the first time in a year - this has been booked for several months, as we have to travel to the South Island where family can care for my son, and now I cannot claim this night away. Unfair! How do we recharge and continue to provide care for our family and ourselves with little or no respite, despite having carer support budget allocated to us?”

“I have been able to use funding over the past couple of years and it has saved me and helped me be a better mum for my son. By being able to have a break, knowing that I could have funding for a hotel, I was able to look forward to something and take the time to recharge and then better care for my son when I return. With the changes, this will no longer be an option. A lot of the changes I am finding a bit confusing and will try to figure out as I can. But I do think that in a time where mental health is just not cared about, we are going to see an increase in struggles of mothers who are so burned out and it will only get worse.”

“It means as a family we can't go on holiday as we have to have a night caregiver. If we go away we legally have to pay for her accommodation so how does this work? She has a tracheostomy so can't be left alone at all. We always pay for our accommodation but how do we pay for caregiver flights and accommodation to come with us now? It completely isolates our child from being able to stay outside of her home. We don't care about purchases cause most of our funding goes on paying caregivers but travel and accommodation means she will never be able to be 'normal' and go on holiday cause we can't take a caregiver.”

“It is difficult not to see this as a rather cynical form of cost saving. There needs to be some pushback and tightening of the spending criteria but not this total, blanket, no purchases whatsoever approach. Sad day for those living with disability in NZ.”

“Living in a small town with no support for either myself or my autistic son is a challenge. Having funding allowed us to pay for someone to take him on an outing or offer respite options for myself I wouldn't normally get. These changes are ridiculous and absolutely contradict the meaning of enabling good lives. What a joke.”

“These changes are terrible. Absolutely devastating to see these. My son will no longer be able to participate in activities that he currently can, our access to support from respite items will be severely limited. My ability to get necessary respite time away through use of carer support to pay for accommodation is gone. Our mental health will suffer greatly. If our budget is not changing why the need for the changes? This system has improved people's lives and wellbeing so much since COVID, there was no need to change. All that is going to

happen is the people who need the support and outlets that these funding options supply are going to suffer and miss out.”

“I am confused how we can suddenly no longer be able to use our individualised funding budget as designed and agreed to at the start of this current funding allocation for my son. Our goals were drawn up and decided upon mainly off things by the looks now it cannot be used for? It is not particularly clear to be honest. It is just myself and my son in our house. I have no family support and it's been 9 years since I've had any break from him til he got IF last year. I am fine to not use any of jt for my respite but it is not clear to me if I can still purchase things for him to help him cope at school etc or to help his social engagement like lessons etc that currently have changed our lives so much. I cannot afford these on my own and I cannot work. He has a 54 percent attendance rate at school and is about to be unrolled possibly. This was going to help him by having his IF but now looks like unless he has someone come to the house to care for him I basically can't use it and he will not allow that. This is all round confusing. All round distressing and not clear. The lack of consultation on this in one of the most vulnerable communities is absolutely abhorrent. My mental health and own autistic burnout was close to breaking. This leaves me feeling absolutely hopeless and like everything we have now been able to do to help ease the load is being ripped away even though there is a lot of money left in our budget. It's devastating.”

“As a single parent being able to take a break is essential. Because my son has multiple disabilities and doesn't like to be separated from me the use of respite items is extremely important. Given these changes have come into effect the very first fortnight of having funding I now feel like all hope of achieving a break is gone. Limiting being able to purchase much needed support services that we have already waited for four years and not received severely impacts any further development of skills and the prospect of me returning to work as a skilled professional.”

“I am horrified by the changes. The exclusion of any travel-related costs effectively means we cannot get a whanau carer, and we therefore cannot get respite. The changes make a mockery of any support for carers who live any distance from their whanau and/or support network. Removing the ability to purchase items for respite is similarly problematic and upsetting.”

“These changes will significantly reduce my children's quality of life and my ability as their main caregiver to access respite. Most worryingly of all, my children will suffer as the health system is completely overburdened and under resourced, all services like play therapy, which helps my son with emotional regulation and depression and can't be accessed through the health service, will now be removed, putting his life at risk. The lack of consultation as transparency is underhanded and offensive.”

“Being able to use our carer support funding to purchase items for my daughter was a godsend. Her disability means she will not go to or with anyone other than myself or husband so it was impossible to get respite but when we were able to buy a computer for her to use independently it gave me respite and helped her with her goals. These changes mean that funding is now no longer individual but everyone is the same. It goes against everything that was battled for and everything they are meant to believe it is outrageous.”

“No breaks for the carer - can't go out for lunch or away for a weekend for respite. Can we still get after school activities like swimming lessons, rock climbing etc covered? What about admin devices?”

“After reading these changes, I will have to go back to my host and work out completely new service plans. Respite for me looks like sending my young adults to Australia, they have a sister there and grandparents... My young adults don't trust strangers as they are not consistent. Having the ability to purchase items for my young adults has made it easier for them to find communities online, the purchasing of their pcs has also meant that there has been laughing been heard all thru the house, from playing online games together and with a few friends that each have made overseas. Being able to have contact with my young adults while

they are at their activities thru their cell phones, has saved many meltdowns. Taking the option of allowing purchases means my young adults will sit at home and become extremely depressed. One of my young adults came to me last week asking if we could use funding to purchase a board game that she wanted to take to one of her activities to play with a friend. This now won't be able to happen."

"It means we will not be able to use our respite funding and carer support whatsoever. It is absolutely devastating. We have 3 ASD children and now have no access to respite as we cannot get a carer to stay with them, they cannot cope with it. They will not have access to sensory items that provide us all with respite and they will no longer be able to be supported to be in the community as well. We are devastated as IF was actually making a real difference to our lives."

"This changes things majorly for our funding, due to my son's disability we are not yet comfortable leaving our son with someone else yet and respite activities for our son and items are how we use majority of our funding."

"This is a very disappointing decision that takes away our ability to choose purchases that would enable the full-time carer to take a wellbeing break without engaging a worker. This will mean increased costs for my family as we choose to use our carer support for purchasing items in addition to paying for a carer. We will probably go without buying many of the items we previously would have claimed for, but need a break more than ever. It does not align with the Enabling Good Lives ethos. Would be good to have clarity if paying for programs such as Riding for the Disabled and music therapy would be covered still."

"For us the loss of flexibility to purchase items that give us respite is a big loss, we mainly claim things like sensory swings, fidgets, weighted blankets and other sensory directed things but if we are no longer able to purchase these which are essential to the regulation of my daughter's disability how is she going to be able to live a good life? I can understand MASSIVE ticket items such as spa pools, full gaming se ups, and overseas trips, and can understand the need to minimise these purchases, but there are also people who live rurally who might not have ready access to people to care for their child or tangata whaikaha. There is also a LOT of grey area within these changes - who gets to decide what is necessary for the disabled person or carer? The only people who should decide are them."

"We lose so much, including services we relied on to make my son friends, services to help me with respite after a nervous breakdown. I need help, and I'm never going to get it again."

"It's gone from life enhancing to life depreciating. How can these decision makers sleep at night? Disabled people did not ask to be disabled, nor did their carers wish to spend their lives doing what they have to do. It'll never happen to you until it does. This will hugely impact how we support our autistic daughter. We have no family in NZ and carers are unreliable in our area. We instead rely on a complex balance of purchases, lessons and other items that keep her regulated and enable her to bridge the gaps in the mental health and education systems in New Zealand. As a result of this, not only will we be having to add new carers into her already overwhelming life, it will also increase financial, emotional and physical strain not only on her but on our whole whanau as we struggle to meet her needs in a fragmented system."

"Absolutely shocking that they have removed purchasing respite items. My husband is disabled and half the time I care for him. My 2 kids are disabled and I care for them too, I myself have a chronic illness that makes taking care of myself almost impossible, being able to buy respite items has been a lifesaver, it's the difference between just being able to cope and breaking down. I am struggling as it is, with minimal support people able to watch my children, most of the times it's been while I am injured, but my support person isn't able to help often, if at all now, so all my support has now been pulled out from under me, and I don't know what I am going to do. There is no support for me."

“It means I can no longer use Carer Support. I'm a solo mum of 4 kids, 3 with very high needs. I used CS to give me respite by buying my children devices and a weekend trip away for myself to have a break and breathe for once. That trip once every 6 months saved me from a mental breakdown. I have twin sons with a rare hereditary condition which has made them fully dependent on fulltime cares. I also have a severely autistic son who has a brain tumor plus my daughter. I need these breaks to continue to be the best parent and carer I can be without it. I could be in alot of trouble with my mental state.”

“For my family it comes across as if you don't hire a carer your funding is literally useless. What was already hard to navigate is even harder now. Makes it so much more stressful and not worth having it with the extra stress it's causing.”

“We are very sad at the change. This means respite funding will no longer be useful to us as the carer model doesn't work for our family. We primarily used purchases for respite and small outings for us parents like a dinner out or movie to clear our heads a little and the occasional massage to aid mental health and wellbeing. With all these options are now being removed, we won't have a way to utilise the funding as such. We are hugely disappointed that a ministry that was created to advocate and represent the disabled community and their family has wiped off progress that took years to build. Whaikaha were recruiting not long ago for a transformation board to roll out EGL across all regions and instead EGL principles have been squashed across the board and the 4 purchasing criteria have now become irrelevant since it's been reverted to the old model of paid support carer. Also the sudden change effective immediately and the absence of public consultation meant that those of us who carefully budgeted for our budgets to last over the funding period losing out, and those who didn't budget and used up their entire allocation as soon as they got it or renewed, prior to their change, turned out to be right.”

“I feel it's cutting out any form of respite for parents and caregivers. It means that my child can no longer go away with a carer because their travel is no longer funded. For those of us who spend a lot of time at home because our child struggles outside of it I cannot get any respite by buying Lego or crafts to occupy her for a precious half an hour. Also zero consultation with the disabled community and a clear lack of understanding of how to support a disabled person. Worn out, stressed out carers and unsupported children is what the fallout will be. Parents fought so hard for this support and in 24 hrs it's ripped away.”

“Very angry, just when we have a good system in place for our family it gets turned upside down and we are expected to just be OK with it. The way we have used our funding in the past 8 years has never been questioned and always followed the guidelines. As a full time carer who was just getting back into the workforce this has thrown our plans off and made it harder yet again.”

“Firstly there are still a lot of things that are unclear. There is a nice list of what we cannot do, but no clear information of how we can get access to the support we need if not through this mechanism (eg Occupational Therapists). What is the deal about travel, can we still pay for local mileage for staff? Like to go to activities with the person they are supporting? It means that the amount of respite I can actually get reduces significantly. It means that my child has access to a significantly reduced amount of engagement in the community, as we can no longer access many of the supports that we needed.”

“This completely breaches Te Tiriti, undermines the purpose of Enabling Good Lives, has been made so abruptly and without any consultation with whanau or disabled people. Changes to this means our funding is virtually useless.”

“I am the ONLY carer for my son who is extremely high needs (unable to care for himself in any way shape or form), this means I no longer have access to things that give me respite that is needed BECAUSE OF HIM. I wouldn't need things like a deep tissue massage if I didn't have to support a 25kg person. But then access to equipment and resources?! Our public system is a DISGRACE for what is available, my son NEEDS private

physiotherapy and SLT in order to have any chance of a "typical" life, and now we can't access that under funding because we technically get it through EIS (despite it being a limited amount and not hands on). Ridiculous... This is widening the gap between inclusion for disabled people and back to the ancient types of just hide them away and out of sight, out of mind."

"After reading the changes I am shocked and disappointed the Government don't care about the disabled. This will affect a lot people with children who can't be left with unknown people. Respite items are much more cost effective as you can get multiple uses from them instead of paying someone every now and then."

"I support my 53yo husband who has young onset dementia. I work 30hrs a week now, and while I took a substantial pay cut work is a form of respite, during which time I can provide koha to a friend who supervises him while I'm at work. My husband recently broke both shoulders, which has created more stress on my body. A regular massage was my respite and selfcare from what is a very depressing and sad situation. Now even that is taken away from me."

"Useless. Meaningless. Powerless. Removed in my choices and decisions. Disengaged. Challenged. Overwhelmed. Stressed. Limited options to almost NO options for respite. MY daughter deserves a better system and better choices to navigate life. I deserve a better system and choices to navigate the challenges in life."

"Stupid; now my daughter and wife miss out on things. We struggle right when we were in a good spot it was normal."

"We are feeling a loss of hope today. When flexibility increased we were finally able to use funding to support our whanau in ways that increased our wellbeing as disabled people and carers. Depression was lifted, and hope was restored. We are deeply disappointed to see a lack of flexibility return and an inherent mistrust of people return. We hope that a fairer middle ground can be found."

"Our adult disabled daughters are only comfortable with Mum or Dad looking after them so carer hours being used to pay a carer are useless. I have a monthly massage as respite and am disappointed this is now excluded. We also used the money to purchase items such as Lego which provides respite - it is unclear whether this is included or excluded now."

"We have always found it difficult to find someone to help care for our son so flexibility with our funding was so important. Now I can see thousands of dollars not being used because that flexibility has gone. The government doesn't care about me, my family but most importantly my son."

"The changes will result in me, a single mother with multiple disabled children and little support, not receiving respite as I do not have people to care for my children. Using the CS money to instead buy activities, pay for toys/crafting the equipment, and devices has been the only time i could sit for a moment."

"These changes will cut support and have far-reaching detrimental impacts on my whānau and disabled person. Once again, as has happened throughout her entire 33 years of life living with a complex disability how she lives her life is being controlled by others. You are removing her choice, these changes are NOT person centred, removing respite for full time carers, who cares for the carers? Everything my disabled person wants to use her IF for has been removed. These changes are ableist at the least, gaslighting at the most, do not follow the principles of allowing her to live her best life. It is also discriminatory due to inequity and accessibility. My disabled person is trying to experience supported independence that abled people take for granted, that has now stopped. This will affect her mental health dramatically. Whaikaha - Ministry of Disabled People need to revisit these changes in partnership with the disabled community and whānau so they uphold the UNCRPD and Enabling Good Lives Principles."

“This will have a hugely negative impact on our family. It is exceptionally hard to find carers and a lot of families are only able to use respite to purchase items that give parents some sort of respite such as Sky movies, play equipment or devices. This now won't be possible. If you are lucky enough to find a carer then parents now won't be able to go out for a respite meal or go away for the night whilst their child or children are being looked after in the family home. This was a lifeline for most carers especially those like me who have no other family in the country. Most families that have children with disabilities rely on one income as their child or children's in my case, disability prevents them from being able to work so could not afford meals out or nights away without this funding. As a parents of two children with disabilities you are put under a huge level of additional stress and desperately need a break to keep going. This thoughtless inexplicable move by a government agency is beyond belief and will cause real distress and hardship to so many disabled people and their families. Shame on you Whaikaha. You are a disgrace and certainly aren't improving the lives of people with disabilities.”

“I won't be able to use my respite funding to take a break from caring for my adult son. This paid for my accommodation. It also paid for things to keep him occupied thus giving me a break.”

“This is absolutely CRAP, we have 7 children ALL with complex medical needs including myself. 2 children get disability 'IF' funding. for me to get a DECENT break/ Respite I need to leave the house. I cannot afford to do that with caring for all my kids and the cost of living. So now I only get a half-arsed break at home but still dealing with everyone else's medical needs! I'm far from the worse off but it SUCKS. I can see there will be a CRISIS.”

“It means we can make life more manageable for us all, feeling supported to be the kind of parents our child needs and deserves. It removes stress about having to say no to things that bring so much joy amongst so much struggle.”

“I am so shocked at this abrupt decision! Clearly they don't care about the caregivers & the impact this will have. As my autistic son's full-time carer I get no respite because it's just me, I'm doing it all solo & he doesn't like other people looking after him. I haven't had a night to myself in nearly 10 years, I've never had time away from my son. Everything & all the decisions are mine alone 24/7, 365. Putting these limitations on when it's already strict enough is just terrible. Who cares about the carers?!? I'm really saddened by this, it is extremely unfair.”

“Very disheartening, I have a daughter with autism and we live in a small town, due to our position it's very hard to find a carer and no afterschool care centres provide services for her. We are a solo income family due to the above and will no longer be able to provide the sensory and respite items for her now that the ability to use her IF has been taken away from us. They are targeting the people our government and country need to protect, our most vulnerable.”

“Excuse my French, but WTF are we meant to do for respite care now?? What are we supposed to do with our funding?? There are NO RESPITE FACILITIES suitable for our 11yo daughter. There are NO CARERS available for respite care. Even if there were, leaving our 11yo intellectually disabled and self-muting daughter with a stranger is a recipe for trauma and abuse. What a horrific thing to force families to do. This does not support our family wellbeing or EGL principles or even the very basics of choice and control! What is going on at Whaikaha that such a poorly thought through decision was made? Do they not know the impacts on families? Do they not care about us and our kids?”

“My initial reaction is that limiting the respite funding stream to costs incurred when a full-time carer takes a break and explicitly excludes purchases that reduce the need for carers to take said breaks this is removing some of the most cost-effective and EGLcompatible options for some whanau. As just one personal example, purchases made by my autistic partner for activities help her to self-regulate, both providing her with better

quality of life and reducing my need to deal with emotional crises. Insisting that the only form of respite be "taking breaks" from care perpetuates harmful stereotypes of disabled people as burdens and runs contrary to EGL principles including self-determination, person centred, ordinary life outcomes and relationship building."

"It means my mental health will take a negative turn again because I can't pay for a respite break away. It means I'm not the best mum I can be because I'm exhausted. Clearly whoever made the changes has never looked after a child with a disability before. While I love my son with the fire of a thousand suns, I do need some time away occasionally to refresh and reset."

"My two sons have disabilities. I am exhausted caring for them with little support. Using respite funding to get out occasionally was such a help for me in looking after myself as a mum and care, especially when on the verge of a mental breakdown. I'm so disappointed that this blanket rule has been put in place. My children are not great at going out for respite so me being able to go out is my only form of respite away from using funding to purchase things to keep them entertained so I can have a coffee in peace. I have not been able to find a good and consistent carer and I do not want to add to my workload by becoming an employer either. I'm so disappointed by the lack of consultation and the terrible delivery of this information."

"I feel so many different things about the announcement today. As a mum who is AuADHD and has funding for myself - with 4 children one of which is diagnosed autistic and receives funding and 2 more in the process of receiving diagnosis (number 4 I believe may be autistic also but I am simply too burnt out to advocate further for him currently). I feel ambushed and misunderstood - a feeling I have often felt over my lifetime. I feel as though the funding allocated to my son is no longer the lifeline it was. He is so exhausted after being at school 5 days a week he does not have the ability to go on outings with a carer, nor the trust to be near someone he is not familiar with. On a single income we do not have the funds to go on any respite trips in our nearby area to recover, nor any person who can come and stay in our home to allow us that luxury. I don't really know what to say further but that is just the tip of the iceberg in our home."

"I had so many ideas this year to help support our son. One major one was private swimming lessons, because he cannot handle groups and was just about in tears at school - swimming this week. He just froze and wouldn't move. Water safety is essential as water is a major part of his (our) lives. He LOVES it, it is calming. I feel this funding helped bridge the gap between "normal" life lessons, and private/specialised lessons (eg the Riding for Disabled and private swimming lessons.) I do not work, I cannot work as my son is not in school full-time so how am I supposed to pay for these specialist activities? He has gained some confidence since riding Mac at the RDA, and in fact it's the only time during the week that I see any kind of "calm" about him. I wanted to seek some kind of speech therapy or some respite activity that would help develop his speech more, as it is a massive barrier, the wait list in the public system is long. Now I cannot do that for him. This whole thing makes me feel like a terrible parent - I cannot work because he needs me, we cannot afford these things naturally as the economy sucks, and we are a one income household. What am I supposed to do? I want my kid to thrive. Without respite funding, we as a whole family are going to struggle."

"These changes mean that our funding is basically worthless, we cannot use it as there are very few people our child will be okay if left with. The previous allowance of being able to purchase respite in the home items was great for us!"

"I am absolutely floored and disgusted by the changes sprung upon us today. This is a devastating blow for disabled people and for those who care for them who already struggle with the pressures of day to day life. My son is autistic and has ADHD and high behavioural needs as a result. I am a solo mother with little support and ever decreasing financial means. I cannot use my funding to pay a carer as I cannot find

someone willing to work for such a small amount, who is able to deal with my son's meltdowns and aggressive behaviour, and there is no other parent in the home to give me a break. The purchases I have been able to make with my IF funding have been pivotal in enabling my son to have a safe, calm space within the home to retreat to, and deescalate in. I had plans for the rest of my funding that was going to finally enable me to see a way forward to a better future for myself and to have that pulled out from underneath me effectively immediately - with zero community consultation is insulting at best and downright devastating at worst. Daily I see reports or comments from parents and caregivers of disabled children who have hit rock bottom from the relentless extra needs of their much-loved children. Parents talking about suicide. Parents talking about handing over their children to Oranga Tamariki because they just can't see a way through life as it is. These people need flexible support, not top-down inflexible rules put in place which do not at all address the varying different needs and requirements of our loved ones. You were given the chance to be a truly transformative agent for positive change in the life of so many - and instead you have pulled the rug out from under our most vulnerable members of society."

"This is meant to be "carer" support. now there is no "care" for the "carers". What are we meant to do when we don't have anyone to watch our kids?"

"These changes will severely limit the types of things we can use funding for. We rely heavily on the flexibility of the respite components as parents to have respite as our children are 18 hour a day on average sometimes more. Staying physically and mentally healthy is not easy as parents. Also both children require specialist items that children generally do not. These items will no longer be available. These are not nice to have items and respite. These are essential. The health and wellbeing of our children and family overall will be negatively impacted by this change."

"I have literally only just got back to work after a mental health breakdown and learning to take time out for myself 'staycation' from the kids, massages and support in purchases outdoor equipment to support my daughter's sensory needs and give me some time out. This change in rules could literally put me off work sick again. Without the allocated funding being able to be used in the way I need it to, to support me in getting a break which I otherwise won't get. So this doesn't support me or my mental health and therefore not my daughter either."

"As a family where all other members of our "support bubble" work full-time hours, I am the primary caregiver for my little disabled person. The changes certainly limit the way I can provide for her. Due to the way her disability presents we are sometimes housebound and her ability to socialise with others is limited. So to not be able to access funds towards specific sensory toys or similar that help her regulate is frustrating. Not everyone has other "carers" they can lean on. Many of us are caring for disabled people who rely on us and have limited trust for others."

"From what I can tell it means that transport will no longer be able to be paid. This means I have no way to get my son to his daily program. I was already struggling with the poor funding once leaving school and now I'm stressed about how I can get him to his daily program. In the past we have been able to use the funding for buying items for respite, however once he left school his funding wasn't even enough to pay for his daily program, respite and transport."

"I've just seen this and been completely blindsided. We have only just got carer support in the last year. We have no one else to look after my boy with autism and adhd and I am burnt out. Being able to get him swim lessons and music lessons has been such a relief to know he is doing something he loves and I get a small bit of relief which makes all the difference. I've been able to go away for a night to my parents' house while my husband looks after him which never would have happened without the support. Support like disability is different for everyone there is no prescriptive way to blanket everyone. The fact it came as such a surprise is

also just cruel. We were waiting to purchase an iPad as his screen is cracked and he uses it to regulate (again giving me respite) but now we are going to have to leave it as is as we can't afford to replace it. We have fought so hard to get any type of support and I finally had a sense of relief and this has all just disappeared in a blink of an eye. The weight of the world is back on my shoulders and this time I'm not sure how long I can hold it for."

"In a small town where there are no carers available to provide respite this will mean I will struggle as a single mum. No more respite purchases which saved us big time. This is unfair."

"This will be hugely detrimental to my son and family. We have next to no family support and receive no respite in terms of caring for my son which is damaging to myself and my partner and essentially my son as well as at times we cannot be our upmost best to him. Limiting the respite we can receive, in the ways we deem fit and that work for our family will have a massive negative effect. We are so angry; this is a massive setback! We receive this funding and we should be able to dictate what works for us as each family and disabled person is different. No public consultation no nothing, it's a mockery of the work we do day in day out."

"We're on IF after my husband had a stroke. The changes will completely change our lives. I don't know how I will ever get a break. He has severe aphasia making communication with a constantly changing carer workforce impossible - that's if we can even get a carer from the agency. We were using the funding for community garden activities, weekends for him with family out of town and gym memberships. After talking with our host it doesn't appear we'll be able to do any of this. We're on benefits, we can barely afford food, rent and power - there's no way our limited budget can fund respite activities. He's been crying, I'm feeling distraught and I doubt we'll use our full funding allocation. I assume this is the intention. He gets severe anxiety and won't go to a facility. What am I supposed to do for respite- wander the streets? I don't know what will happen to us. The stroke has already negatively affected both our mental health."

"I feel the rules have come down too hard on item purchases. I agree with restrictions on travel and massages etc. But items for the disabled person can often lead to more respite time wise than paying a person. We have used our funding for a tablet that provides respite daily. I think some of these things need to be taken into consideration and a list of approved, practical items could be added. Things like iPads, Lego. Seem to be universal respite items for autistic kids. As a single income family, because I have to care for my son full-time. He cannot attend school safely. There often aren't funds available to purchase such items without this funding. The whole point of Enabling Good Lives has been to increase the happiness in disabled people and their full-time carers. The swiftness of the decision has also taken me by surprise. I hope that with some feedback you'll also be able to make changes to the guidelines swiftly to include some items."

"Such shock at your decision to targeted disabled people - there will be blood on your hands over this decision and I hope you are all held accountable. You have basically rendered our 'individualised funding' inaccessible, which I guess was your plan all along."

"I am a single mother with ADHD, depression, anxiety and PTSD. I have two sons who are both ADHD as well as other diagnoses. This change means my respite care becomes unusable. My children are unable to be left with anyone due to their high needs and dependency on me. It is unsafe for a carer to be in my home with my children due to their unpredictable nature. Being away from me causes them both extreme anguish, panic attacks, violent behaviour including self-harming among other things. I use my funding to buy items I wouldn't otherwise be able to afford to give myself some respite care in my home. I'm preparing myself for becoming even more burnt out, depressed and isolated. This is a massive step back for my family. My anxiety is already starting to flare up after this news."

“Our whānau are devastated. The flexibility that the old legislation provided was incredible and supported us to care for our tamariki in neuro-affirming ways. This is a huge step backwards and appears extremely ablest. So deeply disappointed.”

“This is completely absurd! The fact that this change came out of nowhere with absolutely no lead up to let the community know just goes to show they know it’s wrong! It’s horrible for those who don’t have family or friends that can offer respite. Those who look at items or attractions as a form of respite. Not to mention self-care services for parents who need self-love and self-care?! Looking after disabled children is more than a full-time job! It’s tiring and exhausting! This is wrong and 99% of parents who need this support will not agree with this change!”

“No quality respite possible for the unpaid 24/7 carer. My daughter does not have a day program to attend so she attends a range of activities instead. She will now be prevented from doing this too. She has excessive social needs and will be confined to home more often. She will lose independence and will miss out on community participation. The stress in our house will increase 100%.”

“We now have zero use for our funding. The funding that Carers NZ worked so hard to get us, funding that gives us much needed respite and support, funding that helps our kids. With NO warning. Absolutely disgusting.”

“I live in a small rural town with my two younger children, one of which was born with Down Syndrome. I have had two mental breakdowns from the stress of being a solo parent and having to do everything. I have been told numerous times that my carer support would be pulled if I didn’t use it, this was even over COVID when no was allowed to respite care. Then the rules relaxed as to what brought respite care for the family and this allowed me to have respite in our own way. You can’t base every special needs family needs as being the same and providing narrow guidelines.”

“It’s sad that disability is a pain for each government that comes into office. EGL principles just got another facelift but it isn’t really about enabling it’s about being dictated to with no flexibility. It doesn’t take into account the fact that family/whanau also provide care which there is no other place for our people to go or enough carers to go around let alone limited training with basic wage. Very uncaring how this has been rolled out on people who are already under pressure.”

“As someone who struggles to find carer support for my ASD child on the isolated West Coast, we have valued the flexibility of carer support payments to buy items for in house support. Items for play respite, physical therapy respite (like Riding for Disabled fee), and personal respite in the forms of movie prepaid cards that were handy to pass into family members to take my child out for a movie who was reluctant to take cash; the movie cards were something they would take as it was provided for the Government not my personal pay packet.”

“My son now 12, had his first sleepover last year. It was successful because he had a tent and a tablet and his switch (when the tablet ran out) the games on his Switch and his headphones. So he could have his own safe space and something to occupy his mind so he could manage his anxiety. As a parent on the solo parent benefit, I would never have been able to purchase these things. So I would have never been able to get my son comfortable having a sleepover with my sister. Finally getting a whole day to myself after 5 long years!!!! Lego! I homeschool as well clearly. I am with my son 24/7. I am still hunting for a swim instructor to take him one on one. And Waterpolo doesn’t start until the 2nd term. Ya know what gives me a break. Lego....he will behave all day during his schoolwork and he will be happy and safe and settled in his room building a new Lego kit for 2 days with a \$200 kit. Then another 2 days min, playing with it. Tell me who I can pay to get 4 days of respite. I pull out a Lego kit, when I’m about to lose the plot. When everything is just too hard. When I really just need solitude and a break in the nonstop dialogue and verbal thought process. 96 hrs of good

behaviour and 5 hours in consecutive days of pure respite. Because when I leave Tane with anyone I am never truly turned off. I'm always worrying for him at least until I know he's asleep. I'm worrying for my niece who he might play with too roughly by accident. I'm worrying that my sister might take offence to something he says. But I'm not worrying about anything when he's safe upstairs playing Lego. How are purchases which provide respite not the best most equally available thing to help full time carers!??? I'm holding back tears thinking about having to go back. Back to how hard it was before. Now it's going to be harder as well because I promised him a PS5 when he mastered freestyle and backstroke and he's been working hard all term. He needs an upgrade because his current is 4 years old and sounds like an aeroplane taking off. I have to wear headphones with noise control when he's playing it. When he is having trouble my sister would use Minecraft or Roblox \$10 vouchers I had purchased or movie cards to help him along. Not a bribe but so he can push through and be rewarded. And be confident in himself and show himself what he is capable of not just when Mum is around. No more of that because I just don't have an extra \$1 to live off every week on the benefit. I barely manage to buy food and clothes and pay for Disney etc. And now I won't have money for petrol either so no more making it to my sister to have a weekend to myself. I just can't believe it honestly. How is this Enabling Good Lives for my or myself?"

"This is horrible! I am a solo mother, I have heart issues too and have a history of depression where I needed to take medication. I just got funding and was relieved that there was hope. Getting sensory toys, a night away. I have been lucky to get 3 hours' sleep because I have to clean house. This will definitely push me over the edge. How cruel and heartless!"

"It's basically made it inaccessible. We are rural which makes carer support options very limited. But also my child would refuse to go with another carer so me as primary caregiver could have respite."

"Sounds stupid if you don't have people to care for your children to even use carer support. I was told I could buy sensory items with carer support. Guess I can't now. Instead of getting a sensory blackout box my daughter will continue locking herself in her wardrobe which is a safety issue."

"Unfortunately these changes impact us greatly. We have no supports in place for anyone to care for our children. The flexibility gave us options to sensory and other items to provide us respite and a break which we can no longer access due to changes."

"I had my carer support days reduced from 25 to 10 as I wasn't using them then I changed to IF Respite as there was more flexibility with using the funds, now we are back to square 1 with a high needs son with multiple disabilities and a struggle to find someone capable of giving me a break."

"It means that Individualised Funding is no longer 'individualised' it means that 'flexibility' has gone out the window and they no longer can say they 'enable good lives'. It means opportunities have been ripped away from my daughter to support her in achieving her goals. As she grows older, different purchases need to be made to support her and now those things cannot be made."

"This is devastating for our family. Supports we used have been taken away."

"We will no longer be able to purchase items for respite, my son does not do well with people we only have a select few that can take him. So we use items for respite the hours upon hours we get for respite from purchases far exceeds the 3h a week we are approved for e.g. Lego. Endless hours he will play with them quietly in his room no one will travel to us as we are rural for a couple hours a week when we can't even pay for mileage as well! We are left with little or no support with these changes."

"I find these proposed changes almost unbelievable. I find it laughable that a Ministry that claims to offer more support and more changes is implementing incredibly strict criteria on how one is provided respite. They are removing choice and dictating how they believe support should be offered. The fact that carers are

not entitled to 'self care' activities is beyond comprehension. Carers are somehow supposed to fund people to care for their child at a rate of \$10/hour. Once again ignoring the fact that not only is that below minimum wage, but that so many children struggle with change and with people outside of their family. How is this a priority? Do they think our community has no voice and therefore will go quietly into the night? Do they have any idea of the stress and trauma their actions will have on people that they claim to represent? I now no longer know how I will be supported? The lack of clarity makes me question what if any support now meets guidelines. The people who agreed to this should be embarrassed and ashamed. They have no place representing disabled people."

"It will likely break our family apart. In the current economic climate, financially we cannot provide anything that our disabled child needs without use of the funding which is now rendered almost useless."

"We have been so grateful for our funding support. We receive CS and IF for 2 of our children. Mostly we use it within the new guidelines already as we have been fortunate enough to have a trusted family member available for carer support. We will no longer be able to purchase items with our CS money but we often only did this with the anniversary looming. We mostly use our IF for disability-related supports that help move our kids towards their goals such as horseriding therapy, drama classes and individual swimming lessons. These have been game-changers for us so I'm hopeful that we will be able to continue to use it for these. I don't mind not being able to claim for a massage or accommodation as this has not been a priority for us. We feel very blessed to receive this funding, it helps our whanau immensely."

"As someone who parents a young person with neurodiversity & an intellectual disability, I do so without any support network. School has been hard for my son, with stand downs mostly due to inadequate education resources, & lack of support funding within the education sector rather than behavioural issues. Respite support through purchasing of items that benefit our family unit is essential to the health & wellbeing of our whanau. It really places a strain on my other children not utilising the funding to our specific needs. Especially for the likes of my high school student daughter needing space to focus & study, as well as a break for Mum who is doing the lion's share of hard mahi on her own! Respite purchases are often a lifeline & Godsend for parents who are trying to keep their head above water. These sweeping changes feel a sinking ship in slow motion. Simply unbelievable & devastating."

"Our NASC allocation means that we are able to provide our son with ongoing sensory resources that are important to his everyday life. We simply are unable to afford these without the funding. He is excluded from every social opportunity - sport, hobby, clubs due to his autism and ADHD. In order for him to experience everyday things that are taken for granted we can see and Occupational Therapist and have individualised one on one sport or experience. He will continue to be ostracised from his community and peers if we are unable to have these options available to use through funding. This not only enables our family to do more than mere surviving, but chances of thriving. For someone to make these changes to funding (which in itself is not given to carers freely, and is extremely hard to get) it shows they have not been privileged to have someone close affected by a disability. Absolute ignorance and isolation from the wider diverse world. Get out and spend a day on the street, in a school. Get real. The people that you are affecting will add to the mental health crisis because they do not have the chance to have positive or supported moments with their Tamariki. It's an everyday battle on the war front. We are barely coping. Do not take this away from those that need it the most. It is years and years of Dr appointments, diagnosis and professional intervention before we get a look in for funding, not a quick appointment down at the local office. Years. It is not taken or given lightly."

"Less access. Being on a benefit due to disability limits access to community activities and paid activities. Under these guidelines she would have to pay for her carer to go with her and transport costs. Wouldn't have to do this if she didn't have a disability. So no outings. Stay home more sitting on the bed stimming because

she won't engage with support workers in the home. One of her parents will need to be in the home at all times, limited opportunities to go out as a family with support worker if we have to add the cost of the support worker's participation. No family holidays if we can't take support worker. What's the point when we would have to do things separately to care for person? This will lead to a lack of connection in wider family and community. Limited respite as not all carers can accommodate an extra person in their home so a disabled person would have to pay accommodation for carer and themselves and the carer's meals from their benefit. So much more but too overwhelmed."

"By limiting funding to only be used to employ a carer you are taking away my access to any kind of respite. For me to have a break I need to leave my home, if I am not able to use my funding for accommodation, travel etc I cannot have a break. I also can't give my son safe access to a safe place to get some fresh air, he won't be able to go on outings with a carer, he will miss out on sensory/disability items that will dramatically improve his quality of life."

"We will have funding, but we will be unable to use it. If the budget remains unchanged, why can't we access the funds? This means my mental health will deteriorate because we are unable to get a break or buy things/activities that my son can do for himself while we have a break. It will limit what we can do as a family as the support to help him that we could get has been taken away."

"It's going to make our lives a lot more difficult. We don't have a support system close by, and it's very hard to get anyone who can watch our son, as he is too young for most respite facilities, but requires serious medical equipment. I can no longer use carer support to have a break because the only person who is comfortable watching him lives 3 hours away from us and now we can't use it for transport costs. We also can't use it for things like massages, which are basically the only time I ever leave the house by myself, and definitely need after carrying 15kg of weight all day every day. Due to these changes, it is unlikely I will ever have a break from caring."

"This takes away the flexibility that families have to make it work for them, both in the best interests of the child but also the carer. Many people struggle to find suitable carers and so have found other ways that work for them. This removes that flexibility."

"We have no extended family in NZ & no one to care for my child with a disability, I homeschool both of my children & the changes made today mean I won't be allowed to claim for items/purchases which provide respite."

"I was diagnosed autistic less than a year ago at age 50. By that time, my life had become almost entirely hopeless. As an undiagnosed autistic person, my attempts to survive in an allistic world (whether or not I knew at the time that that's what I was doing) had thrown me into autistic burnout and virtual paralysis that has been lasting for years. I suffer from excruciating depression, anxiety disorder, probably complex PTSD. I barely have a social support system. I live pretty much in poverty. I can almost never leave the house anymore. My beloved partner has had to be my carer, and without this help I would surely already be dead. Individualised Funding (IF), and especially its respite stream, which I was approved for only last September, was the first thing in years that made me think that maybe I was not just a useless piece of trash in the eyes of society. It was the first time I felt a little bit of hope in as long as I can even remember. Today, I am not sure that I want to eat, drink, take my meds...ever again... A piece of a Sinead O'Connor song about England under Thatcher reads "If you were off the world, they would love you". This line just keeps running through my head over and over and over..."

"My son loses all autonomy and rather than being 18 and an adult will now have to be a child and I will get no breaks unless he is at school. But I'm one of the lucky ones, my son is 18 not homeschooled and 7."

“It means our funding is unable to be used. Expecting us to be paid a good wage, pay for payroll, employ staff for a few hours a fortnight, for youths with autism who hate change and take a very long time to develop relationships means the funding will be wasted or not used. It will not enable our boys to have a good life or create any equity with their peers. We are disadvantaged as a family enormously because of our children’s disabilities and being able to use funding flexibility has created some amazing outcomes for our boys, these maybe everyday outcomes to some but for our boys they are huge. At 10 my son has finally been able to learn how to ride a bike.”

“Bar the holiday program we won't be able to use our funding. Besides the programmes which have been a life changer for us we have little family support nearby (and they have busy lives so we don't want to put pressure on them for help) and the respite items/devices have meant we have long term respite. It's meant the meltdowns have cut back a bit and it's meant our other children have also managed to avoid the constant attacks. My own mental health has improved as it's meant I get a break, my marriage has improved as we have had the tools to help manage meltdowns prior to them happening in advance as it's putting less pressure on us and the ability for someone to be able to have a break. We literally just had our funding increased and part of it was discussed how it could be spent what we were looking at using it on which was agreed that we would get regular respite. All this is now gone. To get the holiday program we do need to pay an annual cost which I was informed would be available and no longer an option. We're heartbroken and already stressed about the prospect of the changes.”

“It means we likely won't be able to access our allocation of CS days and they will now sit unused. We have limited options of carers having only a small family and often the aftermath of having someone else watch our son isn't worth the respite it provided or we would spend the entire 'break' worrying that he is safe or happy. Being able to use our CS funds to replace his iPad when needed, ongoing restocks of fidget toys and other items that made our life easier in occupying him actually proved to be such a stress relief in our daily life, really sad that we now revert back to pre-COVID when we had to try and fund this stuff in our tight household budget.”

“It is very important to us to have some flexibility in how respite funding can be used. We don't have any relatives here and find it difficult to try to find someone trustworthy to look after our special needs sons in order for us to have respite.”

“This is horrendous. We now get absolutely no assistance. None. We had gone years without using a cent, simply because we had no feasible way to use it. Now, we are back to this again! My poor sons and family. This is going to cause so many issues. This is a “gym membership” mentality. We know it’s there, but we are not going to use it... but we could. But we can’t. It’s useless now. Absolutely useless.”

“My disabled person doesn't cope with outside carers so by not allowing us to use the funding to take the disabled person and a carer away, we cannot get a break. I used to have massage to relieve pain and discomfort from lifting and also a bit of time out. The use of items such as iPads are helpful when you need to take a shower, cook dinner or talk to the specialist, not to mention apps that can help with communication. Yes there are other agencies that can assist with this but wait-lists are 2 years for some of them which means that you lose precious time to assist your loved one. There are hardly any carers available to do respite work so families use the money to get breaks anyway they can. These changes have removed equity for the disabled community that we fought so hard to get. It's removed the ability to care for your family member the best way you can whilst maintaining the carers health both mentally and physically.”

“Our daughter will lose access to physio, speech language therapy, dance classes, trips out in the community, transport support with Driving Miss Daisy and Big John mobility. I will lose access to meaningful respite as we won't be able to afford to stay outside of our home and she can't go elsewhere. This could

effectively mean that I can no longer work outside of the home. I am currently a teacher and the workload at school coupled with the extra work I will have to do to support my daughter will mean that I likely won't be able to work outside the home."

"As a single parent household with 2 children with disabilities and high needs being able to buy respite items was the only way I could get a break. This will greatly affect me mentally and my children as stress levels will be extremely high."

"I am deeply upset about the recent funding changes, as they have rendered support services practically inaccessible and unusable for me as a single parent of a high support needs autistic 5 year old. These changes have left me feeling overwhelmed and abandoned, struggling to navigate the challenges of parenting my child without the necessary support and resources. It's incredibly disheartening to see how these decisions have directly impacted our ability to access the assistance and services we desperately rely on to thrive. As a parent, I feel helpless and frustrated, unsure of how to provide the level of care and support my child needs without the proper resources in place. The system has failed us, and it's devastating to see the toll it's taking on our well-being and quality of life."

"I am furious. Obviously they have never had to care for a special needs person. Some of us don't have people to call on for respite so providing items to occupy our son helps us have a break. This cold uncaring government just taking another stab at our most vulnerable. I am beyond angry and what I would really like to say to them would not be printable."

"I have two non-verbal ASD boys and I rely hugely on their carer support to provide them in-house respite which I now cannot offer. I also can't use carers as there is no-one qualified enough to bloody help us!!!"

"The changes announced by Whaikaha will impact our family severely. My eldest child has a mixture of ASD and ADHD and in his case experiences severe, explosive and violent meltdowns through day to day life and for a prolonged period of time after being cared for by anyone other than his parents. This means that he is home with us 24 hours a day, 7 days a week. Which for a parent of a high needs child, is ALOT! We use the funding to purchase/replace sensory equipment, low stimulation entertainment, swimming lessons, climbing equipment etc. These purchases provide my child and myself with a well needed break in a comforting home environment. Without this funding, our family will go back to being a battleground on a bed of eggshells. We will not survive as a family unit without being able to supply our high needs child with the resources he needs to thrive."

"These changes are absolutely devastating. I am a solo mum to two children with disabilities. I receive a very generous allocation which reflects the heavy load I carry. I use my carer support funding for the following: - my own psychotherapy appointments. These cost \$120 per session. I couldn't meet this cost without my carer support funding. I will have to stop attending these fortnightly sessions now, and this is one of the most important pieces to my ability to cope under the heavy load I carry alone. - Family therapy sessions: these sessions have helped us to connect through play and art therapy, that will no longer be possible - A monthly massage - the physical strain of carrying and caring for my children takes a toll. This provided me with respite and "me time" and I greatly valued it. That's now gone. - Purchasing items such as a trampoline to meet my son's sensory needs (he wore out the last one we got 5 years ago with CS funding) - Sensory items such as weighted blankets, sensory sheets, a swing for in his doorway, foam play couches to create dark safe spaces - these provide huge relief and respite for me as the sole carer - this funding no longer being available for these items means I cannot purchase them any longer and my son's miss out. They use these items every single day. - Having the ability and the funding to take a night off - I had a hotel stay and I recharged my batteries. It was absolutely amazing. I couldn't do that without the funding. It is not within my financial reach. It feels so unfair that I had a taste of pure respite and it's been taken away. My whānau survives on my

income alone. The carer support funding added so much to our lives, especially in regards to my mental health and capacity to parent at a higher level. I have been in tears all afternoon since hearing the news and I can't imagine what I'll do now. The fact there was no consultation is terrible. I am so angry. It shouldn't be like this."

"This is so saddening. After being able to best support my disabled son and us as carers/family, changes to the criteria of funding will mean we can't provide the support that will be best for my son, especially as we won't be able to get a break from him."

"Carer support pretty much is useless now because we don't have anyone that we can trust to look after our kids. This is taking away the whole idea of respite support for carers. What's the use of financial support for carers when there's so many restrictions on how we can use it. It's unfair for the disability community. We've been deprived of our own rights to use these funds to gain respite."

"If we are unable to find a qualified person who is capable of looking after our son's very high needs, we can't claim our Carer Support eligibility/allocation anymore. In the past we could use our allocation to buy items that would provide respite for us (eg an iPad with appropriate apps). This is no longer an option. People who are qualified to work with our very high needs son are hard to come by. Our lives have just been made that much harder and we have been unfairly penalised, if we cannot find appropriate care for him so we are able to use the funding. Funding we are entitled to (to support me as the main carer) will sit unused and go into the Government's pockets, while my mental and physical health deteriorates due to lack of flexibility in the use of the funding that is allocated to support me to get a break from the intensity that is 'parenting a child with very high needs 24/7'. We feel unsupported, unseen and blindsided by this sudden, unexpected change to a system that is meant to support those living with a loved one who has a disability. Would the Government rather we all put our kids into residential care? It'd cost a bucketload more to do that, than to support me a meagre amount, to use in a flexible way to give myself a break so I can continue to care for our son at home, rather than putting him into residential care."

"Being able to use funding to purchase items such as a wobble chair, PlayStation and TV have been a lifesaver in providing stimulation and respite for our 18 year old with ASD and ADHD, who otherwise struggles with all social interactions. It has improved our lives drastically and given us a genuine improvement in the quality of our lives and our boy."

"Not all disabilities are visible and not all disabilities mean that the disabled person need disability aids. Some need regular household items to enable them to do normal day to day activities or learn how to interact with society. The benefits they receive is so low these other items can be claimed through IF or Carer support to help them. Many of us despite having funding can't entice support workers due to where we live or the few hours we can only offer due to the low IF allowance or low number of carer support days. We also have no family support here in NZ . The new rules haven't come as a surprise but we're shocked at the lack of notice and media coverage. Typical for people with disabilities."

"I found this out on the way back from a respite trip so technically I am up for all of today's expenses. And people who made purchases today will also be up for them. I also have an employee who transports my daughter in her own car therefore I reimburse mileage. Under these rules travel is not allowed therefore I now have an employment issue. Never mind the severe restriction it makes on the ability for a disabled person to lead a good life."

"Not having family in New Zealand the purchase of items was a way of respite for me, as it is not easy to get people me and my son trust to leave him with. Flexibility to use the funding allocated helps the disabled person and the carer."

“I am absolutely so angry about today's changes. As a single parent of a 23 yr old autistic son life is hard enough especially with having a disability myself and now we're hit with this major change with no consultation or information prior to the announcement. I feel the Government has completely let the disability community down by doing this. It's like we aren't as important as the rich and famous in this country. I certainly hope that they seriously look at doing better for our community because we will fight this if it's not changed. It seems just so unfair for many families who are in the same situation as me and now it's left me worrying about our future and I'm sure there are many other families out there who feel the same. With the changes outlined today this will certainly make things so much harder for us with not having the flexibility to buy items etc for respite that allow rest and such things that recharge my batteries and fill my cup so I can continue to care for my son. During lockdown it was great to be able to purchase things with not being able to find a suitable support worker and not being able to leave the house due to the high risk to our health and this needs to continue as it took the pressure off during a hard time. I feel like our plan for the future has gone completely out the window as the little savings I have will now have to be used instead to pay for those extra things that bring joy and a bit of relief to our situation. I'm already having challenges with my mental health now due to not being able to take a decent break and not having the support of family I can call on to help and we get absolutely no support from my son's father. I hope and pray that the Government can put something together that meets the ongoing needs of having a family member with a disability and that has the same or similar flexibility as the it was before. It seems so unfair that we have to take on the extra costs of caring for our children etc on our shoulders and not being able to actually get a break by purchasing items etc. There needs to some flexibility in funding in the future moving forwards or it will cause more undue harm and place even more pressure on parents who are already not coping well like myself. Why should we have to struggle so much. I understand the government has to make cuts but to do it to parents of disabled family member who are already overburdened just sucks.”

“I don't think I will be able to use my carer support funding anymore as my son is too complicated to have an outsider care for him, and my husband and I are just so burnt out. I was trying to do things with the funding to reduce my stress levels to increase my ability to cope with caring. I'm just even more worried now that I will burn out and we will both end up in institutions. I am also so shocked and heartbroken that we had no idea this was even a possibility - it just really ruins my faith in the health services. It's just all about politics and no one actually cares about our vulnerable people. It does reinforce that feeling of being alone, and being beneath everyone else, and of course it will disproportionately affect women.”

“We won't be able to use our carer support as that is what we used for respite. Our individualised funding paid our carer and we used our carer support for respite purchases as \$80 for 24 hours is not sufficient to use to pay carers especially with high needs children. This is really heart breaking for us as a whanau especially the way it has been done secretly.”

“I have two children who get carer support - I get the maximum allowable for my 4yo who was just assessed last week. I am absolutely distraught that I will no longer be able to buy items that give me respite. I only have my husband (a shift worker) and my mother (retired) who can look after them because they cannot/will not go with anyone else. The last break I had from the children was when I was isolated with COVID in January. The time before that was an overnight stay in hospital in 2022 for gallbladder surgery. I work school hours/term time and I have an hour a night to myself when HOPEFULLY someone doesn't wake up and need me but I need to do chores during that time. I am struggling with my own physical health currently and the constant stress I am under is not helping. I can't keep going on like this, but what else can I do? I was going to buy some duplo for my 4yo as soon as her hours were confirmed because that will give me an extra 20 minutes a day where I am not being climbed like a tree, licked, hit, poked, or screamed at (her older brother won't share his) and honestly the thought of not being able to afford to do this now has me in tears. The funding we get for carer support is token at best - \$80 for 24 hours of care is laughable - but to now have

autonomy taken away is criminal. How is it providing for the needs of the disability community when the community, their whānau, and stakeholders were not informed or consulted? This feels like instead of cutting costs, they're trying to make it so we won't make claims and they'll save money that way. It's appalling."

"I am a solo mum with disabilities myself as well as my son. We live in a rural town and cannot find any support workers. The only respite I get is staying away from my son once a month. Without this my funding will just sit there and not be used."

"The new changes mean the funding is useless to me as a carer. There are extremely limited respite options to me so for example being able to purchase a tablet for my child means I can go to the toilet without worrying that they're unsafe or my house is being trashed or resorting to locking my child in their babyproofed safe room or locking them in the toilet with me. Heaven help me if I get food poisoning or gastro as an extreme example."

"We have respite funding that we cannot currently use for actual respite as the facility that we need can't accommodate our son at present. We've been using our funding to purchase items for our son that will entertain him for short periods of time to give us a break. We won't be able to do this now. Our son is 15 and weighs 50kg, he is 100% dependent on us for all of his cares. If we have to use our respite funding for actual respite, perhaps the Government can provide some respite facilities that are actually accessible for all levels of abilities and disabilities."

"I provide specialised education in a therapeutic setting with a main focus on safety and managing community engagement for our disabled community. I provide Safeguarding Adults from Abuse too. I have been formally trained and provide training for new support teams, no other organisation can claim the same. I am now out of business. My son is an autistic adult who will now lose so many things that gave him his purpose and a sense of some future. He took himself to bed when he heard and he has not got back up again, no lunch, no dinner and I now have to try to support myself and him with nothing. My years of hard work & study for my son and our disabled community, removed, flexibility gone, control and choices gone. No consultation, just blindsided insult that removes the EGL principles in the blink of an eye."

"My daughter is medically complex and medically fragile - Due to the lack of capacity with MOH and ridiculous backlogs for supports our IF covers my daughter's OT, Physio, hydrotherapy, Riding for the Disabled, etc plus sensory and respite items that help her through painful recovery periods - all of that not only gone - I have signed contracts which I now have to give notice on across the board as I am a full-time caregiver to my child. Not only that - we signed contracts for service in good faith based on the criteria we were given. How can this be legal? According to new rules I also can't repay caregiver travel costs - how is that legal? Due to my child's complexity, it is virtually impossible to find an experienced and qualified caregiver as it is - so we use our funding to pay for social events we would not otherwise be able to do or justify. This is actually dangerous for my daughter's health - mentally and physically. Also - I can't work full-time due to my child's needs, how on earth am I going to be able to cover these costs (I can't) or get any respite if I can't even pay for accommodation elsewhere from my house. It's heartbreaking and scary and overwhelming and such an awful way to find out. It's also demeaning and dehumanising that they've said if these services can be funded by charity grants we can't claim - so we have to resort to begging for charity and even if everyone says no, apparently we still can't claim? It's just soul destroying."

"I am a professional working with disabled whānau and I am appalled by these changes. Whānau are already struggling to access and utilise appropriate support, so to put further restrictions on the use of IF is discriminatory and is in total contradiction to EGL. In addition to this I am highly concerned about the proposed changes to EMS funding and a move back to prioritisation. Using a prioritisation framework was utilised 14 years ago and the only thing we found was it delayed access to communication systems which is a

huge safety concern which is not necessary when systems ultimately get funded as people are still eligible for funding.”

“Just reverse this change. Leave this alone. Don't take from vulnerable children with disabilities the flexibility of being able to be included, and have sensory needs fulfilled. The "govt" should be ashamed and disgusted in themselves but they won't, they don't care, they take from those who genuinely need IF to fund the tax cuts for the rich.”

“These changes are a backward step in the progress of caring for the carers. This funding has allowed me to be able to look after myself and helped give me a rest and a breather from the constant care I need to provide. My child is able to have items that provide her safe spaces to go and safe things at home to regulate her sensory issues and social issues which I will no longer be able to provide. Very disappointed in this decision.”

“In the past we have used our carer support to purchase items for our 8 year old autistic son. This includes an iPad, noise cancelling headphones and Lego. These items have provided our family with many, many hours of respite. Our son isn't a fan of being looked after by others, so we likely wouldn't be able to utilise our full carer support entitlement in the future with these changes.”

“I want to stay anonymous due to me working in the sector. As time has gone on I have seen more and more items going through that are not related to the person's disability but rather put in under respite and contributing to the whanau's benefit rather than the person's. Things like everyday items, purchases, and luxuries being paid for with taxpayers' money that many are unable to afford themselves. Holidays, top of the line devices, massages, haircuts and colour, meals out, staying in 5 star accommodation. This was to give the person freedom to decide how they could spend their funding; what does respite look for them. Also considering EGL and quality of life. Now we get to have real conversations about disability, barriers they are facing, using it on needed supports. Rather than it ultimately being replacement income. My only concern is there is not adequate support through MOE and MOH and people in need of specialist supports are getting lost in the system. This was where IF was able to pay for these supports privately. Much needed therapy is now harder to access for those in need. Ultimately it was time the purchasing guidelines were made clearer. I think it needs to be revised how IF can be used to solely pay for main carers supports leaving them exhausted and no money for respite options. I think this should be done as a benefit and IF solely used for respite facility options, independent contractors/employees, and agency support workers. With the ability to support sensory and disability needs taking into account other funding options.”

“Not being able to claim for costs associated with taking a break away from my child or paying for a family member to travel to us to look after our daughter means I will not be able to take a respite break going forward. I am a fulltime 24/7 carer for my child and need breaks!”

“It was already hard enough having to justify and explain every single purchase but we spent the little time and energy we had to fill those forms out as it meant that our child would get the supports they needed. To simplify disability supports down to simply using a substitute carer is narrow minded and treats disabled individuals and their families as replaceable. Caring and needs are never the same for disabled individuals. To assume that finding people who can do the countless tasks involved with caring as well as trusting and building relationships with carers is as easy as winning the lottery. I would love to have one of these decision makers spend one day trying to care for my disabled child on minimum carer wage and then justify their decisions. These changes have made burnt out, exhausted families who are barely surviving as it is to be completely depleted.”

“Today's changes have left me feeling despondent. We had just moved to IF and our Enliven person had filled me with such hope and suggested ways to make our autistic daughter's life so much better. The things

that would make a real difference to her aren't being attached to a care worker who may or may not turn up. She's at the wrong age for that. I feel exhausted and scared at what the next wee while holds. I worry for the children and other vulnerable folks who will have very tired, very stressed caregivers making decisions and/or behaviours that may not otherwise have occurred. There will be repercussions. Also, what does this continued reference to "equity" mean? I've just been through a three hour needs assessment that was gut wrenching to have to list my daughter's requirements and challenges. Strangely enough I thought the huge report that generated and then the review by the health team was to consider the basics like equity. I am so disappointed, worried and, well, disgusted. I've gone from hopeful for making her future (and thereby my whole family's future) better to now wondering how I can juggle it all without the support I had envisaged. I may have a budget on paper but how do I use it now? Some minimally paid worker who barely knows my kid and has to quickly upskill on her high complexities? As if. I'm screwed."

"We are a young family with a 3 year old with autism. We have had to pay privately to get anywhere with diagnosis because the public health system is overloaded. We are privately funding speech therapy as the MOE support wait list is crazy. We recently had our needs assessment and we are so desperate for support and now the support that's available has been wiped out overnight. We have no family support. Taking support away from the most vulnerable New Zealanders is absolutely atrocious. This has a very real impact on our family and anyone involved in this unilateral decision should feel ashamed of themselves. The lack of flexibility of how to use allocated funding is shocking."

"Criteria 2 under purchasing guidelines says ...is it a disability support .. specific to your disability and if you didn't have your disability you wouldn't need the item .. with this are you still able to purchase specific disability related items eg PPE .. or devices that provide support or sight impaired .. I understand everyday expenses may now not be covered (as flexibility has meant lots of people have taken advantage) but specific disability related items or linking it to your individual service plan should be able to be... Also health & safety. Lots of us are considered employers under IF .. eg paying our own support staff from our IF .. we then have an employment responsibility to have H&S covered eg hoist for lifting or gloves for nappy changes etc .. our funding should still be able to be used to meet H&S employment responsibilities. Whaikaha need to fix their web information and if MoH carer support isn't affected then it thus creates 2 rules ..unequal, unfair. Which was something Carers NZ fought to change over COVID as moh/dhb funded carer support initially wasn't flexible... going round in circles if you ask me."

"Due to the challenges finding appropriate carer support for our severely disabled son we used our IF respite to help us with accommodation and fuel (of reasonable value for money) to have a couple of nights away. We have no family support and have a limited income. We essentially have no time to be a couple. This will have serious consequences for our son. We also use funding to pay for petrol and admittance to a sensory room experience given the nearest is quite far away."

"An example of how flexible funding has been meaningful to my daughter. She wanted to attend a hui of an organisation she is involved with that was in another city. Unable to drive, only train at 6am, buses not wheelchair friendly, she paid petrol money to get a ride there, and stayed overnight in a hotel. With these funding changes she will not be able to do anything like this anymore."

"I have an autistic son. The flexibility we had using IF funding seriously saved my life. I was so burnt out I was on the brink on suicide. Oh what a simple break using IF Respite could do! These changes mean I can no longer take a moment to reset. I'm a single mother with no family support, I will struggle which means my son will struggle. Flexible spending also meant I could purchase NEEDED sensory items for my son. They have proved absolutely valuable to him. These sensory items make his life better that is evident in his behaviour, goal progress and over all wellbeing. The rule changes take so much away, I cannot afford respite accommodation on my own, I cannot afford to purchase sensory items, I cannot explore options to aid his

goals as freely. We will have allocated funding we can no longer use because I AM the only carer he allows to care for him. And I know I'm not the only parent whose autistic family member is anxious about strangers especially doing their personal cares! How are we expected to relax when we know our disabled person isn't comfortable or happy with a stranger caring for them. How is that making THEIR life better or OURS (their carer). What a blow to our disabled community!"

"My daughter's future looks bleak - how depressing. Where's the community consultation? The weak communication has caused an absolute uproar. Sort it out Whaikaha!"

"I cannot find a respite provider so using my respite dollars to take a break for myself is the only way I can utilise the funding. My family members take over so I can take care of my mental and physical health through massage because I lift a heavy person. Now I will not be able to take care of my physical wellbeing in that way. This will only lead to more pressure on the healthcare system because I will have health issues. Also mental health, I use respite funding for small retreat classes that help heal mental fatigue and anxiety and depression that comes with being a 24/7 caregiver. Now I will not have access therefore NZ's mental health crisis will include more individuals who cannot access these beneficial classes. Not only will I suffer but my loved one that I care for and my family that needs me to be at my best physically and mentally."

"This makes me physically ill. Every child deserves the best, they deserve so much more than we can give them. They require so much more assistance and help, and as parents we have no problems giving it. This is detrimental to our health, the long hours, the "no breaks". Why punish those who are doing their absolute best for the ones who struggle!"

"My 12 year old autistic child doesn't need or want a carer. The respite that helps us the most is items that help her entertain herself, eg equipment for gaming, items for her special interests, headphones to help her focus. These have been hugely beneficial to us, especially as her autistic profile includes dyspraxia which means she accidentally breaks equipment at times and we need to replace it. The funding has also been useful to give me a break, eg to go to a retreat for parents of disabled kids. The change to only being able to use it for carer costs will render the funding useless for us and put our family under extra financial and emotional strain. We're very upset."

"A poem by Eleanor, Aged 13. Autistic, ADHDer, with ARFID. *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 too, 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."

"One thing I'd like the government to know is that these changes are going to cost them money, at least in my family's case. The Carer Support funding isn't nearly enough to actually employ a carer. So the only kind of respite care that's affordable would be in a group situation like a school holiday programme. My child's medical condition means he is hospitalised for a night or two every time he gets a cold, so we avoid groups of children where illness easily spreads. If that's the only kind of childcare option available to me, it would drastically increase our number of hospital days. My child currently only gets sick a couple of times a year because we use our respite funding for safe activities and items that give me a break. But in the past, before we were able to avoid group activities, he was sick 12-13 times a year. Why not just let us use our funding in a way that works for us?"

“I am a Flexible Support Coordinator with a Host Agency for Flexible Funding and help our tangata use their allocations in accordance with the Purchasing Rules and Guidelines. I am disappointed that there was no warning or communication for anyone involved in the disability sector. “Ministry of Disabled People” and you haven’t shown evidence of communication with the community. These new rules come across ambiguous and contradictory within themselves. How am I as a support person within a Host Agency supposed to help my Tangata and the whanau I work with, if I do not understand these new guidelines myself? I am angry on their behalf, I am angry for those who have just got the needed supports and finally seem to be making positive progress towards their goals and personal good lives, these changes negate all of that and put them back behind square one. I have had non-verbal tangata learning Sign Language and the whanau learning it alongside them – years of stress and making progress of even saying “Hello” is now at a standstill. I have had tangata that have developmental delays in progress to now be able to write their letters and their name, huge progress that you are now removing the resources needed from the purchasing guidelines. I am working with young parents that are scared for the changes this means for their Tamariki and how they are going to now continue to survive without the much-needed support that now falls outside of the guidelines. I have whanau in this system. I have worked with Oranga Tamariki Complex Youth in Residential – whereas per the policy documents, that there is funding as they are in care rather than with their families for \$149.97 per 24/hr period (Aa per the Funding Policy and Guidance For Shared Care (October 2023)) Where is this support in funding for our tangata that are still with whanau and not living in the system? Do you know what those timelines look like if they can get supports funded elsewhere? Do you know the pain of making it to the end of that process to then be denied ESSENTIAL supports? Do you know what it is like waking up in the morning and not knowing if you will ever be independent again? You don’t. You get to go home and cook dinner for yourself, you get to have a shower alone. You get to have disposable income for “luxury items”. Luxury items shouldn’t be considered supportive equipment to manage a task independently. Please provide further clarity here so that we can support our communities most vulnerable. The Ministry of Disabled People need to DO better and provide appropriate notice because this shock is causing extreme stress.”

“This has actually taken away our right to choose the best path for our children and families. I don’t want my child with a stranger and my child doesn’t want to be with a stranger, but I was getting respite when he played on/with the trampoline, sandpit, tablet, Lego or watched Netflix. Things I can’t afford normally. Now I really worry for my mental health, and this will in turn affect him.”

“I’m horrified and furious at the changes. Individualised funding is supposed to let us choose how we spend our respite funding. The changes mean far less choice and also gives my son less independence. Please put it back immediately to how it was.”

“This will mean carer burnout for me as the full-time carer to my autistic toddler. I have given up my career to care for him - he is on so many waiting lists that I’ve been told are years long, we have no extra help and my husband works long hours so how so I get respite? My autistic child won’t go to other carers so without flexibility or items or even accommodation how do I get a break? So many carers will burn out and I believe the suicide rate will increase as there is no support from the government.”

“We don’t have support and our son will not stay with just anyone - we need to fly his grandmother up from Wellington - these changes just took that option of us having respite away, good one! I am not sure who Ministry for Disabled People spoke to but it was no one in our community! Impossible for us to have respite now.”

“With a 5 year old autistic child, it is impossible to leave them at a holiday programme, book them into regular group lessons, or leave them with “just anyone”. This funding allowed me the additional money to book them into private lessons so that they can learn to swim like other children, participate in learning about sports that may interest them but to pay for additional support from someone until they are confident.

It allows me respite from having to constantly be the carer/supervisor where other children may play by themselves during school holidays with by allowing me to purchase art supplies for a special interest, an i-pad to quench the insatiable appetite for knowledge, sensory items that aid in regulating emotions due to wild outbursts that can harm them and or/younger siblings. In changing IF and CS to "just paying for carers", we are told "here is funding for respite, it's yours to be flexible with," but it's juuuuuust out of reach because you can't use it the way we expect you to. It's like giving someone false hope of respite. We are families that have had to fight the medical systems to get recognition for our children, fight on behalf of our children to have regular lives, give up careers ourselves, give up socialisation ourselves. This respite provided a tiny sense of relief and normality, a glimmer of hope for us in a world that continually knocks our children or disabled persons whom we care for down. Please reconsider your decisions and allow some flexibility back into purchasing. It does make a huge difference to us."

"It needs to be flexible so this that have no one who can mind there child or adult with disabilities can still get respite in a way that works eg supplies that allow they person to do something they love at home which allows carer to have respite in knowing the person is occupied and safe while they have time to themselves but still in house."

"As a single parent, the ability to take some time out for myself, whether that be a night away nearby, a massage, someone else coming to care for my daughter: it should be up to me to decide what works best for me. I am also disabled myself, and now the support I have to help be a better parent and person, has been removed. I hope you take into consideration the number of people this change affects, and it's not a positive change either."

"I fought for 9 years to get support for my son that worked for him and for our family situation, 9 years fighting against unhelpful Ministry of Health supports to now have the support that was working ripped away. Right as my son has just been diagnosed with more disabilities with two very serious heart conditions likely to require a stay in starship for surgery. I'm a solo mum and the old traditional respite does not work for us, my son has many complex needs due to multiple disabilities there is no where he can go for respite except his grandparents who are 8 hours away but I am on a benefit so can't afford for him to go there now. I used to use some of the respite towards the cost of travel for my son to go and stay for a week or so at his paternal grandparents 8 hours away a couple of times a year and now we can't do that. This is a massive leap backwards, MOH are a joke don't provide the therapies or treatments needed. 😞 . There just are no words. What Whaikaha have done is unforgivable. I'm a solo freaking mum I'd love to see any of the decision makers or pen pushers spend a month caring for my son alone with no access to any respite. Go on bet they wouldn't last a week in my shoes or any of the other disabled people and their families' shoes."

"This effectively means we will be unable to use a large amount of the funding we have been allocated and it will be clawed back as it does not roll over. I'm sure the government made this change knowing full well that many will now have funding leftover that can be taken back. There is no doubt in my mind that funding will next be slashed because it is not being fully utilised. National are stealing from the most vulnerable."

"We have just started receiving funding for our 11 year old daughter which was going to change her life getting her out and about in the community as she is terrified to leave us, she has an interest in cyber forensics and music. I can't afford to buy her instrument as I am on ACC from a injury. Her funding could have helped pay for this and give me respite while she practices on her own as well as music lessons which would help with her fine motor skills and anxieties of leaving me to do music lessons. Funding could help with her interest and at the same time given me respite. What am I supposed to do with a child that doesn't want to leave me as she has a fear of something happening to me when she is not around she will not go with people she doesn't know so I cannot travel now for her to stay at her sister's house that is 500km away while I stay at a friend's to get a break?"

“I am devastated. For the last 6 months I haven't been able to find a stable carer for my son so we have used his funding in other ways to keep him busy and give me a break or disability supports Here are some examples. Travel to get to Auckland so I can have family look after him. A trampoline to help with his excess energy. Tablets to help reduce his anxiety in public places or hospitals. A quiet washing machine and dryer - previous to this my washing machine and dryer were too loud and I was unable to wash or dry items while he was home and because he likes smearing food etc my items would become mouldy and I would have to throw them out and replace them. He also isn't allowed in daycare longer than 10 hours a week because of behavioural issues. Swimming Lessons, horse riding lessons and gymnastics which were disability supports for him. It helped socially but also with safety around water because my son would jump in (so I could have a break too). Funding for travel costs to all of his extra activities that helped support him. A large enough stroller to support him and help him feel safe in the community and provide him with a safe place whilst in hospital. Now there's no flexibility I'm going to struggle to get any type of breaks which is going to be incredibly hard on me mentally.”

“It's confusing, my son has IF Respite funding and goes between two houses as his father and myself have shared care. It states we can pay someone to give the full-time carer a break but no more purchases that provide respite, yet when going through our original needs assessment they said to us because there is no full-time carer because of the 50/50 arrangement, purchases would be the best way for respite. Does this now mean we have funding but are unable to use it without breaking the new rules since we now cannot buy items that provide respite (which often gave my son a way to socialise or work on self-regulation) nor can we pay someone to look after him to provide respite because neither parent has him in their care full-time? It was working, it was allowing me to cook dinner, to tend to his younger sister, have a shower and use the toilet without worrying about meltdowns that would often become violent towards myself or his sister. Without sticking him in front of a screen 24/7 now, things will be largely disrupted, and for how long we are unsure. It might not be a cut in the funding allowance but instead it has cut off the ability to use his entire allowance. In what world is that fair?”

“I haven't applied for support yet (2/3 kids probably qualify, but we have slipped through the cracks in the system and, 7 years in, are just starting to understand what support we can ask for). Even though I'm not financially affected by this, I am affected. The support our friends and colleagues, and our kids' friends' families, has received, has enabled a "normal" life. I want to be able to take my kids on bike rides, to go out for a walk with my husband, to take my family tramping, to not have to pick two between: career, friends, high needs children, and fitness. I saw hope that this support would be a path forward. Now feels like a slip back to the 80s, when if you had a disabled child/sibling, you just wouldn't have a normal life. It was God's will. Not everyone can have board game night as a family on the 3rd Sunday of the month. It feels like carers and siblings of disabled children are being punished for being part of the same family. It takes me back to my childhood, when my parents would look at families with a disabled child and say "thank God that's not us". It feels like the exhaustion, burnout, my husband's depression, they are all things we "just have to deal with". It's honestly triggering a lot of "you don't deserve to be okay" messaging I spent years working to unlearn.”

“I personally do not have the availability of any persons to look after my child when I feel I need a break, so having the ability to apply for funding for respite items has been amazing and well worth it. I have had two recent purchases for items that benefit him through his intense interests in cars, my purchase gives me the respite and peace of mind that he is in his own space, keeping himself busy by use of an interest activity (purchased), no hassle of having to organise a carer etc. taking away this type of respite funding really limits or restricts my ability for respite.”

“These changes are horrendous and will mean my disabled daughter who is already excluded from most activities will suffer even more. Not only this but having reduced options as a caregiver for respite will affect

my mental health even worse than it already is! What is the point of funding if it can't be used for the benefit of the disabled person or their caregivers? A huge step backwards for NZ."

"My daughter who is autistic, and myself, who is disabled with multiple medical conditions and currently on Supported Living payment with my partner, and claiming as much as we can from WINZ, are now currently barely making ends meet. We have been so grateful that our Individualised Funding and Carer Support funding have been flexible enough that we can purchase items to provide us with some respite from the constant questions and day to day issues our daughter faces. Electronic equipment especially so she can look up answers to her questions, and have videos to help her wind down after school and on weekends, especially when something unusual is happening. Removing our access to flexible purchasing has broken both my heart, and my daughter's. We cannot afford, on SLP with all the other funding options we can claim, to feed ourselves after paying rent, necessary bills and insurance, utilities and the absolute basics in groceries to suit our daughter's limited diet and preferred items (she will refuse to eat if we get any of these things wrong or buy the wrong looking packaged item). Suffice to say that we have all the supports that the basic funding rules now state. We cannot afford to purchase the items our daughter needs to assist with her educational methods of easiest learning, and to help her grow skill sets, independence, and alternate ways of learning which help her retain the information. We can no longer afford to purchase holiday travel for our one family member in a different town 600 kms away, to give us a respite break during holidays. The cost of living crisis and high prices for pretty much everything, have already left us struggling. The further cuts to beneficiary assistance, and the stress of being unsure about whether our income will be suddenly cut further, have only added to our stress and anxiety. And the unnotified, and non-discussed changes (as we were never notified of potential meetings to discuss and voice our concerns, and outcomes prior to this change being notified effective 18 March and notified 18 March). The changes are completely unfair, will cause extraordinary stress for those of us who have no support network locally except to provide our child with items to keep her busy for a few hours here and there. It is a breach of our daughter's human rights to an education she can understand, and for us the inability to provide sufficient educational activities, items to support learning differences, and to provide opportunities for our daughter to stretch her limitations and for us to have breaks from 24 hour UNPAID caring. It is also a human rights breach for me as a disabled person to be given an unpaid and unrewarded care and recovery/respite by removing the ability for carers to draw on funding to keep their mental and physical situation in a good enough place for the child I care for to benefit. These changes are unfair, limiting opportunities and the best life for our child. Enabling Good Lives is impossible under the new rules and restrictions put in place without consultation."

"This means a lot of stress and anxiety for our whole whanau that had started to be resolved by being given IF with flexibility. Our child missed out on having a parent that is coping and able to engage and instead is likely to have one that is exhausted and mentally checked out. Not being able to purchase items to keep my son busy takes away the opportunity for me to have those small micro pauses that get me thru till bedtime and it also takes away his opportunities of calm imaginative play as he is at peace and hyper focused when using things like lego for up to an hour. Not being able to get away and pay for accommodation etc means no respite. Being stuck in a situation when you end up getting burnt out and questioning you being their parent. We were in a dark place before IF a year ago and it had made the difference to our family of being able to stay together and keep our child with us and for us all to get some respite to cope. It affects our kids deeply if we are not able to take care of ourselves."

"These changes will really affect my daughter. She uses devices and app for self emotional regulation, sensory toys help with sensory regulation, these new rules rule those things out, she also has physical disabilities so am very concerned about physical aids such as wheelchair and bed etc, I'm terrified about losing her social activities we have purchased with funding such as Riding for the Disabled, the zoo and Antarctic Centre as she absolutely loves animals, and I worry about the other therapy and specialist help we

have used funding for to support my daughter's daily struggles with her autism and GDD. This is a real kick in the guts, and I'm so angry these things are being taken away from her for no reason. She hasn't done anything wrong, why is she being punished? It's just made everything a lot harder and she will struggle with this, as will our immediate family and carer. This is so wrong."

"For our family it has effectively removed any funding. My daughter has issues with someone other than me caring for her and at \$10 per hour there is no-one I can find to care for her. We have previously used funding to provide her with some supports for her interests which in turn give her focus and enable me to take a step back. That's what respite means in my household. And now it is gone."

"The changes basically mean that the carer support funding is useless in our family. My daughter has ASD and anxiety, meaning she almost never lets me do things away from home even with my husband watching her. We live away from family so don't have them to help for respite. She won't let anyone else watch her, therefore we have been using the carer support money for other things that give us respite such as a basketball hoop and xbox. These are things that she is able to do without us, so even though we are still at home with her, we aren't having to do the activity with her and can have a quick 'break'. If the funding changes terms, we will no longer be able to use it for anything that suits our child and family's needs."

"The support to buy things for my sons when needed. This is a big slap in the face for our children as others too. So unfair."

"I am horrified that those with a disability are being targeted in this way with no consultation. Why is transport not being funded? Does this mean support people will not be able to take people shopping.? This is cost cutting at its most cruel. Why target the vulnerable?"

"I use our funding to buy equipment, toys, subscriptions to educational games. I do not have anyone to care for my children to give me respite and I am not comfortable hiring a stranger. I am a solo mother and without this funding and being able to spend it on things that help my children/family, I don't think we would survive. If these changes go ahead we will not be able to use our funding simply because the new guidelines do not meet the individual needs of my children. And as a flow on affect, my children will be further disadvantaged because I will not be able to afford the equipment. I am raising 2 special needs children on my own, I am here 24/7. I am tired, I am stressed, I am barely holding it together, but this funding helps me teach my kids to be a little independent and gives me a small amount of time each day to breathe and regroup."

"Cruel elitist policy that excludes disabled people from participating in society. Disgusting and in breach of human rights."

"My daughter is autistic with severe anxiety and ADHD. She is only 12 doesn't like change or new people so we are unable to use support workers we have no family support 6m ago we were given flexible funding and were able to provide her with sensory items that gave her a way to regulate which gave our family a huge amount of much needed respite now with the changes we will not be able to provide her with the items she needs as she grows and her needs change. We only had flexible funding for a small amount of time but it made a huge difference in our family's lives."

"I have always understood there is not an unlimited budget that can be allocated. I am a single parent and the main carer for my neurodivergent son who requires my daily support to manage. It is a role that requires a lot of energy and putting my son first - anticipating needs, managing environments, sensory input and regulation. My ability to work aside from my caring role is hugely affected. For myself for instance I use carer support for my weekly fitness class - the importance of being outdoors, exercising and connecting with others has such a positive impact on my wellbeing and resilience to continue as a carer as well as having something that is for myself and not wholly connected to my son. I will no longer be able to pay for these. I

don't see how the changes to the purchasing criteria is going to save money. It is short sighted to not look at the impact this is going to have on a carer's mental health and within other areas of the family structure. Without the flexibility to use the carer support/funding to enable the carer to re-energise, maintain their wellbeing and looking at the disabled person and family/whanau as a whole it will create less opportunity for the carer to relax, increase their resilience and ongoing ability to care for their disabled person. This is in direct contrast to the EGL principles. I would like to know that my health and wellbeing is just as important as my son's and that I'm an expert in the way my family lives not the politicians. There needs to be considerable consultation with the disability community before making changes."

"We will no longer be able to access any respite as no one we have found will care for my daughter because of her needs and my daughter has huge anxiety and fear of anyone not extremely familiar to her."

"The changes mean that I will have funding allocated, but will not be able to spend it due to the restrictions. Not being able to use the funding in a way that meets the needs of our whanau will give the impression that I don't need it, which is not true at all."

"I am mum to 2 neurodiverse kids, and previously worked as a private paediatric OT. I saw lots of kids whose parents used their respite care hours to subsidise therapy because their kids were really struggling to engage at school or access the community and we're not eligible for MoE or MoH funding. Without using respite care, these kids would have been without help; we know there longer kids are out of school or r restricting their environments, the harder it is to reintegrate them. It's criminal that these kids will again be without options. I really hope families hold the current government to account, legally, for harm done to their kids by removing what is really pitiful funding given their needs."

"So I have funding, respite for myself and EIF for my son. Except now I can't use any of it, as I can't claim for respite items and sensory items which were really our only options. Individual funding should mean exactly that - funds used for the individual's needs. Respite funding should be exactly that. Different caregivers find respite in different ways."

"For the 6 years that my daughter was entitled for carer support, it was only in the last 2 years that we were able to use it. And for only two things which we were grateful for- music therapy and her movement gadgets - trampoline, bike and helmet. The recent changes puts us back to the first 4yrs of her carer support - with allocation but with nothing to use it for. Not all persons with disability can be left with someone else and not all parents can take a "break" knowing that their special one is left with someone else be it a friend or a professional. My daughter is still not able to tell how her day been, or what happened at school, hence, the very reason why we cannot leave her with someone else's care. A very few people we can entrust her with would not care for those dollars and will be happy to give it back to her in another way, gifts etc. My point is, if the government is really pressed with budget issues, there should be more thought on what the policies should be rather than dangle a supposedly budget for a person which they will never be able to access. The reimbursement system puts the money back to the economy, eg helps the music therapy company keep afloat, goods were bought to support our retail industry. I think they have limited the access to carer support fund to much that even the basic needs of the disabled person eg speech and music therapy now has to be paid from our own pockets. So that's me making extra hours at work which would have been my hours spent with my child or me resting."

"Confusing. I have MS, my daughter has ADHD. My stubborn husband actually has a problem with his leg, but he doesn't want to care & share. We moved from Auckland in 2022 as I had my anxiety with antisocial neighbours. Now we are in a small town, still lack of some accesses. We do depend on internet connection. Purchasing restrictions and travel, accommodation, food no more are not funny. We need to visit Auckland for our old friends who have become like our family. Not often. Also more options for international and halal

foods in Auckland. We are an immigrant family. We do love New Zealand. I am disabled but want to contribute more including to raise my daughter here. She's born in Auckland. Purchasing is our helpful need, please. The kid magazines mostly from overseas: she can learn and read more also share and spread the word to the world. We just do at home. She's very very energetic while MS just makes me easily tired and powerless. She's my only generation. My best wishes and hopes for my daughter. We live in Te Kuiti, with only one paediatrician who lives in Hamilton. I also must go to Hamilton for my MS appointments. Deep praying in Ramadan month for better policies. Ameen. A prayer from a disabled family in a very small town."

"I am mum and primary caregiver to my 8 year old daughter who is classed as having very high needs, is ORS funded, nonverbal and lives with both lifelong intellectual and physical disabilities. The IF respite support and carer support days to us were life changing in terms of being able to use the supports in a flexible manner to best identify and use them specifically for Ella and her best outcomes. Using these supports in their prior flexible manner meant we were able to provide her experiences, purchase recourses for her that enriched her learning and life experiences, provide equipment for example (equipment that the MOH had prior declined), partially pay for items for her, all of which was so incredibly important to be able to do for her, to give her the best life and opportunities we could, given her diagnosis. We as parents know her best so to remove the flexibility in such a drastic and swift manner with no regard of personal circumstances is just horrific in the worst way. We fought so hard and for such a long time to navigate our way through this system to receive the support she deserves and now I feel it's been ripped away. Regardless of the fact we are told the supports will not reduce in terms of dollars the point is now there are very few meaningful ways in which we can use these supports to their best result for Ella's quality of life. To say we are devastated is an understatement."

"These changes are extremely depressing as a family with 3 children with autism, 2 of which also have been diagnosed with ADHD. Our earning potential has been slashed due to the requirements from us as parents to safely look after our kids. The flexible funding allowed us a chance to be able to afford things we wouldn't be able to dream of otherwise. Using it to buy autistic son a tablet was lifechanging. Having that tool in the toolbox is very often the difference between him being able to occupy himself in a safe manner, allowing us a break, and him smashing his head into nearest hard object or surface over and over. Being able to use the funding to pay for a trampoline allows our kids to run and jump outside, in a safe environment, rather than trying to meet their sensory needs in a dangerous manner. Before this they would be running into furniture, climbing book shelves and jumping. Many injuries occurred. School holidays are incredibly difficult for us. We feel isolated. Taking 3 autistic kids anywhere with larger school holiday crowds does NOT work well and we are limited in what we can do. Being able to use the funding to purchase entertainment for these times was game changing. These are just some examples, there are countless more. I have chosen to include some specifically around the purchasing of items because this was the main change that they were attempting. There are also activities and groups that our kids have been able to attend that actually give them a shot of making friends and being able to socialise. Before having access to the funding my wife and I were NOT coping. Stress was bad enough that we were both starting to have physical symptoms. There are still many challenges for us but the funding flexibility gives us many tools we would not otherwise have been able to afford."

"It will mean I can't replace the iPad we got our disabled son to occupy him instead of me having to use my own unpaid time to entertain him as he's high needs and hyperactive and can't bear to be alone / the iPad means he does not feel alone. It reduces his anxiety greatly."

"I have a daughter who has a genetic disorder. She was nonverbal, has seizures and doesn't walk. She needs assurance with feeding, changing nappies, drinking, and full-time care due to her condition. She is 7 years old and her weight is 23kg. I am small in stature and I lift her all the time from the floor to the chair, to the car, to the wheelchair, bath, etc. I am mid 40s and my back is sore. I had some back massages and those has helped

me to align my body and have a break. I do believe that the rules need to be better but it also needs someone who can overview the expenses. A deep muscle massage is what you need when the entire day you are lifting half of your own body weight. If I don't have them regularly. I will be going to ACC. Which it is also an expensive system. Can't you imagine to do lifting your entire life? I will be doing it until I am over 70. Unfortunately, my daughter won't be able to walk and be independent."

"As a parent and a registered nurse I see both sides of the story. But what I see most is that you have cut funding to those who need it most and made it inaccessible. Respite doesn't mean leaving the home as that can cause more problems for the child and add to carer stress, but items that provide regulation and time out for a coffee can be just as valuable if not more. If you need to cut funding, change your system to a more centralised platform. Having moved here from Australia there is no doubt that the system here is difficult to navigate and costly for you to run. Like Te Whatu Ora, it is time to stop outsourcing to all these agencies which operate in effectively and different in each region. Look inwards rather than cut the funding to the desperate."

"I am genuinely concerned for our mental health. Due to the way my son's autism presents, we struggle to find people who are suitable to care for him. Additionally he is so overwhelmed with managing school, that he struggles with managing himself around other people for the remainder of the week. If we do manage to get carers, it means he doesn't get the required amount of down time to deal with school (and he uses every spare non-school hour to regulate). We have been excluded from school 3 times already, so we do not want to put added pressure on him. For these reasons it really helped our family to buy items for respite to keep him occupied for blocks of time where we could take moments to ourselves for mental down time. Additionally we bought stuff like sensory sheets to help him sleep better, otherwise he will get up and do dangerous things when we sleep...like lighting out kitchen lino on fire. I'm scared for our mental health, our physical health and his schooling future."

"I need flexibility to purchase items for my son that may give me respite because I'm not able to find a carer to look after him. He's a teen that's larger than me and will get a little violent and run during a meltdown. Understandably its hard to find a person willing to take that on. We have no family or friends who are able to step in either. At least some items like a sensory swing as well as a Lego project gave me some moments of quiet and respite."

"These changes mean so much limitation on support for my daughter. Like many children with ASD my daughter suffers terrible anxiety and having someone else care for her is extremely challenging and can only be done on very limited occasions to keep her regulated. I am deeply hurt for those with more challenging circumstances than our own. I wish those making decisions could come and walk in our shoes before making such changes, with such far-reaching repercussions."

"It is unbelievable that you have introduced new rules without any consultation. So disappointing when it is such a battle to get any funding and now you make changes with no discussion with those that it effects. You obviously have no understanding of what it is like being a carer of someone with additional needs and how hard it is to get funding. I could not work full time and be a carer."

"The IF Respite we have been funded was explained as 'for the main caregiver to receive a break' - I felt us using it to pay for my sons one on one movement therapy was ideal, as it met two purposes: one, it provided physical activity to address the muscular discomfort he receives during his seizures, helped him maintain core strength, agility and cardio in a body that was often sedentary due to the disabilities he is impacted by. But also the hour long session provided a small break for me, I was able to get a micro break, grab a coffee and decompress knowing he was engaged and supervised by a qualified instructor. I had also used the IF Respite funding for a Ring camera in his room, this allowed us reassurances about letting him have space

alone without continuous checking, I could let him close the door but know I would hear him if he had a seizure via the camera. All of the items I purchased were approved and met the goals of his funding and criteria stipulated by his host Florence Nightingale, every single item purchased was presented with a direct link to his goals and how they related. I am disgusted at the MP's reference that we have been squandering funding for ourselves, I demand the raw data to be released, so we may see the intentional misrepresentations circulating in the media - I expect the Minister to resign for making such false statements, particularly that the funding had 'total flexibility and no restrictions'. But also I want it known that for families in these situations a manicure, haircut, pedicure or whatever the MP felt was unacceptable use of RESPITE funding, that if that was what the families felt gave them a break in order to continue their care giving duties then that's actually ok, as it's not up to someone with zero understanding or lived experience to dictate what RESPITE looks like...if I had to look after a severely disabled person 24/7 toileting, feeding, abuse, physical demands and overwhelming workload on a daily basis I think a massage would be a small thing to let me have in order to maintain my support to continue care giving and not have my child or dependent put into state care."

"After waiting nearly 2 years for an assessment with child development we finally had a diagnosis of ASD for our son. 3 months on and we just had an appointment with our NASC we discovered we could get much needed urgent behaviour therapy for him as the current waitlist is 2 years with Explore. The changes look like this may no longer be an option. He is having a challenging time at school, not engaged, getting into fights and doesn't want to go. His teacher who has 5 high needs kids in her class has no full-time teacher aide support. Our son gets zero funding from MOE so we are left without ANY help. We finally felt like things could get better with the therapy as an option. Now it looks like this has been whisked away from under us before we've even started. It will also impact things like specialist swimming lessons and a hanging sensory hammock/chair we were hoping to get to help him regulate at home. I already have another high needs son with ID, autism and epilepsy. I'm hoping we can still access the supports we have for him to. It's also frustrating when you hear the Minister say that there were no restrictions on how funding could be spent. There were. You had to fill in a full-page document stating how the proposed item or equipment was eligible in 4 different categories. I'm so disappointed with the way these changes were communicated and implemented immediately without consultation with the community. It makes us feel as though we really don't matter to this government."

"These changes make it impossible for me to access respite. I live 50km from the closest respite services. Without travel expenses we cannot drive to any activities, nor can we cover the expenses of a carer to come to our rural location. We had previously travelled to visit whānau with a carer who would provide care without charge as long as we covered their travel and accommodation. We will no longer be able to access this support or visit our whānau (they are unable to travel themselves and I cannot travel with my daughter without support). We have used our budget wisely and we have always submitted expenses that fell within the four guidelines and met the goals outlined in my daughter's plan. The exclusions prevent us from accessing supports we had put in place and will have a negative impact on our entire extended whānau."

"The news has rocked our family's life. I could not believe that New Zealand's government could do what they have. As if our lives are not hard enough already. I never asked to have 3 autistic girls and an ADHD son. I never asked to lose my passion job as my kids needed me. I never asked to live off of one income with my husband of 24 years and so on and so on.....So would someone in the coalition like to spend a day at my house and see if they can justify the shock changes? We as parents wake each day to the prospect of the unpredictable behaviour of the people in our home. Everything we do is harder than most other people in the context of a daily life. We yell for understanding. We yell for help. We yell to be seen and heard. Shame on the Government for doing this to the most vulnerable people in the country. Ps I never asked to become a grandparent to 2 of my autistic daughters and so it repeats...."

Carers NZ thanks everyone who took the time to send their comments at a stressful time for disabled people and family carers. The comments are a record of community reaction to the sudden changes announced by Whaikaha and the Government on 18 March 2024. We will continue to advocate for better, fairer, kinder disability policies for our community. And thank you family carers for all you do. New Zealand would be poorer in every way without your mahi aroha.

