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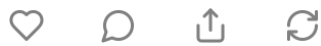


## Whaikaha responds to community questions

### The response from the Ministry to questions from the community.

AWHI NGĀ MĀTUA

JUN 17



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On 25 March, we contacted Whaikaha on your behalf to ask them your questions. We sent them a further four requests for a response. On 7 June they responded. Here are their unedited answers.

Whaikaha has grouped together questions. In bold is the question from an Awhi Ngā Mātua community member.

Awhi Ngā Mātua emailed Louise Upston on 15 May to organise a meeting to provide her with the 350+ stories from the community on the impact of the cuts to flexible funding. She has not responded.

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**Is Te Whatu Ora funded Carer Support affected? If it is, when can we expect an official announcement and updates to the Te Whatu Ora Carer Support website page and Purchasing Guidelines document? Do glucose monitors qualify as a carer support expense? If not, why not?**

Whaikaha: Diabetes management products, including insulin pumps, are considered a health-related cost and not a disability related cost so these could be funded via Carer Support via Te Whatu Ora (Health New Zealand). The change in Purchasing Rules only applies to Whaikaha-funded supports and

services and not other agencies. If you are unsure about who funds your Carer Support, you can ask your NASC.

**My son is 13 and incontinent, under Personal cares, we get four nappies per day funded but for a 13-year-old we easily go through six-to-eight a day can we still claim.**

We are aware that some people we support have used flexible funding where the level of continence products available through Health NZ does not fully meet their needs. No-one will lose access to essential services through the revisions to the Purchase Rules. If you have accessed continence products through Health NZ, and require further products to maintain personal cares, the additional products can be considered “Items that support the disabled person to carry out tasks more independently” and can be purchased through flexible funding.

**Can we claim for ready-made meals that we just heat up for [our child]? Previously, I have been able to claim 50% of the total cost under household management, can I still do that?**

A ready-made meal is any meal prepared ahead of time, which can be eaten at a time of the person’s choosing. Ready-made meals can contribute to the person having greater choice of what they eat, and when they eat it. Take out or food deliveries have some of the features of ready-made meals, and this may be appropriate, occasionally. In practice, it is unlikely that regular use of takeout or food deliveries will be more cost-effective than paying for support to prepare meals.

**Can I claim a lawnmowing service under household management? It is \$45 every fortnight - my son cannot be left by himself at any time so any maintenance to the property is neglected, hence the approval for getting a serviceman in to do the lawns.**

Disability Allowance can be paid to cover the costs of gardening, lawn-mowing, and outside window cleaning for the person's own home or private residence. The allowance can only be paid if the person is unable to do these

tasks themselves because of their disability. This cost cannot be included in Disability Allowance solely based on the client's age.

Disability Allowance cannot be paid for:

- house repairs or house painting as these are part of normal living costs and are not due to the person's disability. (Clients may be able to receive Essential Home Repairs advance)
- indoor household maintenance (for example carpet cleaning) as funding for home help is available through Te Whatu Ora – Health New Zealand. (Refer the client to the local Hospital and Health Services home support services)
- gardening, lawn-mowing or window cleaning costs that are included in a standard service fee charged for all residents of a retirement village or complex. However there are exceptions, for more information see: [Retirement Villages](#).

While Disability Allowance should not generally be paid for gardening, lawn-mowing or window cleaning carried out by family members, you should use your discretion to consider the individual circumstances of each case. The cost can be included if it seems appropriate - such as when the family member does not live with the client and incurs a cost to travel to the clients home to provide the service.

When a client has high gardening costs (for example due to the extra work involved in maintaining a large property, or high maintenance gardens) the client should look at other options for meeting or alleviating the cost.

**Will my allocated budget decrease in the next funding year if I cannot claim under the new rules?**

Budgets are allocated on the basis of disability related need. If there has been no change in need from year to year, it is expected that the agreed budget should continue to be allocated. If there is a change in need or circumstances, this would require a discussion with your Needs Assessment Service Coordination (NASC).

**Can I claim annual passes for things like Motat, zoos etc?**

**Are horse riding lessons, not riding for the disabled lessons still allowed?**

**Can I pay for a carer to take him out to activities and outings, can I pay for the carer's movie ticket, pool entry, zoo tickets?**

Activities that accommodate or include disabled people can simultaneously provide a break for the main carer. Where this is the case, the organisation providing the activity is effectively the relief carer, and IF Respite and Carer Support can contribute to those activities as a cost of providing support. Claims need to continue to meet the purchasing rules – including Rule 3 – cost effective. They do not need to be disability specific supports, and in many cases, mainstream options will be more cost effective.

Expenses that are a necessary part of supporting the disabled person can be funded through flexible funding. This includes the cost of entries to events or activities, travel on public transport, or other similar costs that a carer might incur in the course of being available to and supporting the disabled person. Claims need to continue to meet the purchasing rules – including Rule 3 – cost effective. When attending with a support worker / carer, it is expected that the disabled person pay their own costs of participating in the activity (for example their entrance tickets etc.).

**Can I still sign my child up for classes, clubs and activities that will give me respite while he's at the activity? Like Riding for the Disabled, drama classes, swimming?**

**Are gym memberships for the child and full-time career allowed? They provide many different respite and health benefits.**

**Can you do a cruise in NZ waters for a child to go with grandparents for a five-day cruise for the main carer to get respite in the home?**

**I have severe back, neck and shoulder pains constantly, and need to see a physio and chiropractor fortnightly. These are from getting my daughter's wheelchair in and out from the car, getting her in and out of the bath and holding her full weight while she has seizures (20 + a day) can I use funding to pay for these sessions?**

In the context of IF Respite/Carer Support:

Carer Support and IF Respite generally are allocated because disabled people and whānau require breaks more often, or of more intensity, than other whānau might. If an activity provides relief care, we consider that the cost of the activity includes the cost of providing support and expenses necessary to provide that support.

Activities that accommodate or include disabled people can simultaneously provide a break for the main carer. Where this is the case, the organisation providing the activity is effectively the relief carer, and flexible funding can contribute to those activities as a cost of providing support.

It continues to be the case, for example, that an organisation providing a programme can be the relief carer claiming the Carer Support subsidy.

In the context of IF Household Management and Personal Care:

The scope of these services is specific to providing supports that assist the disabled person to complete tasks and participate in activities.

Our general position is that the scope of IF HM and PC allows the disabled person to pay a support worker, and their expenses (for example entrance tickets, transport costs) when undertaking an activity, but that the disabled person and their family must pay their own costs of participating in the activity (for example their entrance tickets etc.)

**Are outdoor equipment like trampolines, pools, bikes, tents etc allowed?**

**Are arts/crafts/lego allowed for the child or carer for respite/coordination/stimulation/sensory play?**

**How long will the EMS prioritisation be in place?**

**How can delays to communication assistive technology not be a cut in essential, frontline service?**

**I want to know how the priority list will work for EMS. Eg how do you compare a physically disabled person who needs modification to their wheelchair for mobility, to an autistic person who uses AAC to communicate? And what difference will age make? I fear that wheelchair using adults will always be prioritised over nonspeaking children - as communication devices are seen as an 'added extra**

**Our son is Autistic and has an iPad (which currently is broken and urgently needs replacing) and YouTube premium. We need both of these to keep him calm, if we take him to appointments of which there are many it is essential, it also helps sooth him in the home. We don't know how we will manage without them. The iPad makes taking him out possible. Will these still be covered? This is a disability aid not a respite item.**

**Can I buy sensory items related to disability eg fidgets, sensory swings, weighted blankets, noise cancelling headphones?**

**Can I buy Lego for my autistic child eg to keep him busy while I go to an appointment or for while he is in hospital?**

**Can I buy electronic items to help my child communicate?**

**Could I buy a printer and laminator to make visual communication tools and learning stories for my autistic child?**

Tablet devices, noise cancelling headphones, sensory items (such as fidget spinners) and weighted blankets, are all able to be funded from Carer Support, Individualised Funding Respite (IF Respite), EIF and EGL Personal Budgets, where this creates a break for family carers. These items – and only these items – can be purchased through Carer Support and IF Respite.

Tablet devices and noise cancelling headphones can be purchased no more than once in an allocation period (usually 12 months).

Purchases of tablet devices and noise cancelling headphones must continue to meet the requirements of all four purchase rules. Tablet devices and headphones can be purchased where:

They are related to the specific disability-related challenges that the disabled person encounters.

They are reasonable and cost-effective. It is not cost-effective, for example, to purchase another tablet device or set of headphones if the disabled person has one that works and was purchased from a previous year's allocation; and

Attempts have been made to access relevant other agency funding, including, for example, Ministry of Education funding for some devices.

While a wide range of things might serve this purpose, the range of things Whaikaha is providing access to, through flexible funding, is limited to small, portable items, and does not extend to larger and more expensive options such as spa pools, trampolines, play gyms etc.

**We used our son's funding to upgrade his own and his paid carers privately paid for flight ticket for a family holiday because he needs to be sedated and lie flat due to seizures and stress. Under the new rules do we just send him to some sort of secure facility and go on family holidays without him? I thought this was about supporting the disabled person?**

**Our son has 6 monthly appointments in Hamilton with his developmental paediatrician and a specialised speech therapist. Our son is autistic, with Down Syndrome and multiple other conditions. Only recently we have been allowed to access his funding to help cover the cost of mileage to these appointments, some nearly 300km from home, a night's accommodation and the fee to see the specialist speech therapist twice a year. We have had to cancel his upcoming appointment as it now seems we will no longer be able to take him to these appointments which are so extremely important. What are we supposed to do?**

Domestic travel refers to the costs of travelling between cities or regions to, for example, go on a break. These costs can no longer be paid from flexible funding.

Travel to and from school is funded by the [Ministry of Education Specialised School Transport Assistance \(SESTA\) external URL](#).

Local transport is part-funded by other agencies through the [Total Mobility Scheme external URL](#). NZTA and Regional Councils subsidise the costs of local transport for eligible people, which we understand includes most disabled people.

Our expectation is that these subsidies are accessed before considering the use of disability support funding to pay for local travel undertaken independently of a support worker.

‘Expenses that are a necessary part of providing support’ may include the costs a support worker incurs when taking the disabled person to go to the supermarket or engage in other activities outside the home. These costs can continue to be met from flexible funding.

If you have accessed the Total Mobility Scheme the disabled person can also use flexible funding for additional disability-related costs for local transport that don’t require the use of support workers, where this is more cost-effective. Examples including driving services, ride share services etc.

In Between Travel refers to the time and travel costs that support workers incur when they are travelling from one client to another, as part of working for the same employer. In Between Travel is not generally paid to support workers where disabled people and families are managing their funding, as they employ people to work with them, rather than with multiple families.

If someone providing support must travel more than 15km to work, and the person’s specific requirements mean that there are few or no alternative workers who are more available, ‘exceptional travel’ may be funded in line with the general In Between Travel guidance. You can find out more in [section 4 of the](#)



implementation guidance for providers and funders on Health NZ's website external URL.

Generally, In Between Travel is unlikely to be relevant to managing your flexible funding yourself.

If you are a Flexible Disability Support Provider managing personal budgets, and either ordinary or exceptional In Between Travel has been included in the personal budget, you can continue to claim for those costs.

**I have funding for physical therapy which is for my son - it is a purpose in his budget, and I will still get the money each fortnightly but now you are saying I can't use it? How does this make any sense and you are taking away his right to further his development. This is NOT provided anywhere else. Therapy is all about maximising independence in the real world. Every disabled person deserves the best chance in life.**

**We spend our IF on Physiotherapy for my daughter. She has cerebral palsy and was discharged from MOH when she started school despite being unable to walk properly. She doesn't receive any funded physio only what we pay for through IF. Can I still use her IF for this? It gives me a lot of respite as I do all her other therapy myself as her mum plus it is great being able to choose a physio that has a good rapport with my daughter and meets her needs at a time that suit our family like when I'm close to therapy burn out.**

**Do they mean that the disabled person who is using their funding to pay for private therapists should immediately stop attending their appointments?**

**What is the process for them to find out whether therapies are managed/priorities through the public system?**

Where a disabled person has been engaged in a course of therapy before the 18th of March, that therapy can continue to be funded from flexible funding, including where other agencies might otherwise have funding responsibilities for that therapy.

Examples where other agencies may have funding responsibilities include (but are not limited to):

- speech language therapy.
- psychologist involvement in behaviour support; and
- occupational therapy.

If something is a form of therapy that is prioritised by another government agency, new courses of therapy cannot be entered into (including where the main carer would get a break whilst that therapy occurs).

Some things may have some therapeutic benefits but can also be understood to be a respite activity.

These are not forms of therapy that we consider to be within another agency's funding responsibility. Whether they are treated as an activity that provides respite, or as a form of therapy, they are within scope of flexible funding. This includes:

- equine therapy.
- art therapy.
- music therapy.

The purpose of supporting ongoing commitments is to mitigate any potential risks to continuing in employment, study, and therapy.

Whaikaha is aware that some people may have reorganised their supports and family lives to continue in employment, study, or therapy after the 18 March 2024 revision of the Purchase Rules.

Where that is the case, disabled people may resume any previously, in place, supports that they consider mitigate risks to their continuing in employment, study, or therapy, so long as those supports are:

- the costs of delivering support,
- expenses that are a necessary part of supporting the disabled person, and/or
- the travel-related costs of support workers (accommodation, transport, meal allowances) can continue to be paid where those costs are incurred as part of supporting the disabled person when they engage in domestic travel (including between cities and regions) for work.

All of these claims must continue to be within your existing allocation, and any other conditions upon accessing flexible funding.

### **Retrospective costs**

Some disabled people and families may also have begun to pay for some supports they were previously in receipt of, such as therapy, privately after the 18 March revisions to the Purchase Rules.

Where those costs were part of support delivered previously, costs incurred between 18 March and 24 April 2024 may be claimed for retrospectively. Where you are claiming for these costs under Carer Support, the usual 90 day claiming period applies, although we encourage you to make these claims sooner, and to mark them clearly as “RETROSPECTIVE PAYMENT FOR CONTINUING IN EMPLOYMENT, STUDY, OR THERAPY”.

All of these claims must continue to be within your existing allocation, and any other conditions upon accessing flexible funding.

### **Are you still committed to ensuring an enabling good lives approach to disability support? And if so, how does this change align with Enabling Good Lives principles?**

Whaikaha is committed to working with disabled people, tāngata whaikaha Māori and whānau to develop longer term settings that are aligned to the Enabling Good Lives vision and principles, UNCRPD and Te Tiriti o Waitangi.

### **Why is there no Q and A on this and why is the information not in Plain English\*? [*\*Editors note: This is now known as Plain Language*]**

The Ministry always tries to make our information as accessible as possible. Everyone’s situation is different. If people have questions relating them or their whānau they are best to contact their primary disability support provider (IF Host, NASC, or EGL site /connector).

### **Is the public health system ready for the ramifications of this?**

This is not a question for us you need to ask the Ministry of Health and Te Whatu Ora.

**Why is the PM and Ministers and Whaikaha saying that no disabled person will lose access to funding for essential services or support when this is exactly that?**

This is not a question for us.

**Does Whaikaha understand the ramifications of this on disabled people whose lives revolve around the therapies they do? Eg people who are brain damaged and wheelchair bound and do a range of therapies to maintain what mobility they have, and try to improve it?**

We recognise the changes have been distressing and caused confusion for the community, and for the service providers who support disabled people.

On 30 April 2024, the Minister for Disability Issues announced an independent review of disability support services administered by Whaikaha. Further information can be found here

<https://www.beehive.govt.nz/release/independent-review-disability-support-services> .

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