

NEURODIVERSITY &gt; AUTISM &gt; WORKING WITH LIFELINKS

# Working with LifeLinks

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Watch the series: [listeningtofamilies.co.nz/autism/working-with-lifelinks](https://listeningtofamilies.co.nz/autism/working-with-lifelinks)

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## 1. Autism - Working with Lifelinks - Engaging with LifeLinks

Hi, I'm Helen Wagstaff, an Autism Coordinator with Christchurch Hospital. We're doing these videos to help families and to answer some questions. We've asked a couple of agencies to be involved and they've all been really supportive of what we're doing. Today we've got Lifelinks, or our needs assessment agency, that work with families following a diagnosis here to talk to us, so thank you very much for coming along. I'll let them introduce themselves and then Kim is going to ask questions on behalf of parents, so thank you. So I'm Penny Maddock, I've worked with Lifelinks for, it seems like a hundred years, but yeah for over 20 years, and I've had various roles and I'm currently working in a role that allows me to go out and meet families and get information.

their stories down on paper. Awesome, cool. Hi, I'm Stacey Wallace. I am an outcome facilitator on the autism team and I have worked at Lifelinks since about November last year. Awesome, cool, thank you so much for coming. You know that my child has a diagnosis of autism. How do Lifelinks fit into that process? How can you support? Cool, well I guess probably one of the first things we should be saying is that Lifelinks is an organisation that has a NASC contract with the ministry or whaikaha. So NASC meaning needs assessment service coordination. Now we're trying to get away from that role, we believe it's quite a deficit model needs assessment.

You need us, we're going to do an assessment, which isn't actually what we do. So what we do is we come and we meet with the families and we talk about the individual that has the disability, how it impacts them. How it impacts on the people who support them and try and put that on paper so it paints a good picture. So that's the first involvement that you'll have with Lifelinks and then after that we look at that and we think, I think that we can support this family by making referrals here, providing them information on this. So that would be the second part of Lifelinks involvement. So we paint a picture and we see what we can do to support you.

And is Lifelinks, throughout, all of New Zealand? Lifelinks is Canterbury West Coast based. So there are other needs assessment service coordination services around the country. I'm not sure how many are actually nationwide and I won't give a number because I'll probably get it wrong. But they all cover a certain geographical area. So for Lifelinks we cover South Canterbury up to Kaikōura and over to the West Coast.

## 2. Autism - Working with Lifelinks - Getting a needs assessment

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How do I get a needs assessment and can I self-refer myself for that? Am I taking that? Yes, you can self-refer. And like we were just talking about, you don't try and get away from the words needs assessment. So it is more just once you have been referred to Lifelinks, somebody will meet with you or talk with you and talk through painting that picture about your life and your goals and all that sort of thing. So referrals can come from anywhere. So Helen has referred a lot of people to us, which is fantastic. We get referrals from paediatricians, from GPs, from psychologists, from friends, from the individuals themselves.

So any form of referral is fine with us. Thanks. What are the wait times like from your first conversation to actually getting some support? Well, we are contracted to be making contact. From point of referral, we should be making contact within the week. From that point of contact, we should be seeing you to get your story within two to four weeks. And from there, you should be contacted pretty quickly to talk about what we might be able to support you with or to discuss those possible support options. Unfortunately, you know, all good plans can go awry. Right. And COVID had a huge impact on all services.

You know, things came to a halt. Once the COVID lockdown periods came to an end, then people were starting to see their specialists again and having that normal contact. And referrals, we were inundated. So unfortunately, at that time, the wait times were much longer than we wanted them to be. But we are slowly getting on track. And I think we're pretty close to being on track to seeing people within the expected timeframes. Yeah. Wait lists, unfortunately, are everywhere, aren't they? Yeah. Probably like them.

## 3. Autism - Working with Lifelinks - Individualised funding

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What does individualised funding mean? Yours! So individualised funding is a personal budget that's made up of different supports for different people in line with those support needs and your goals. So there are things like an individualised funding respite budget, personal cares and household management that is essentially made up of hours of support that is used flexibly for support and respite across the course of the year how you choose and how you need. Cool. And it's quite individual, isn't it? It is, yeah. Because I've had some families sort of say, oh, but my friends get such and such.

How can I get that? So how would you suggest that I tell families that they can't get what they need? What their friends are getting. Look, it says it in the name, individualised funding. It is completely down to the individual, their support needs, their goals and how essentially it's between that person and their host provider how the funds are accessed. And what happens if the family's needs change or circumstances change? Can they get what they are allocated? Yeah. Amended? Changed? Increased? Absolutely. Absolutely. I mean, people's needs change all the time. Nobody's life is static. You know, things impact on people.

And so, yes, their needs are going to be changing. And if they find that their needs are changing, then make contact with their key person at Lifelinks and ask for a review. Just give them an explanation or a description of this. This is happening for me right now. The support needs are not meeting my needs. Can somebody come and talk with me? And let's see what else can be done. In regards to individualised funding, what sort of things can be funded? Yours. Look, that is completely a conversation to be had with the host provider. If it provides you respite and support from your disability, then definitely that is a conversation to have with the host provider that you choose.

I think the main thing is to remember that it is to support the person around you. To support the person around their disability, around their diagnosis. So, if it was something to do with needing a break, then how does that happen for that family, for that individual? How do they actually benefit from a break? How does that break occur? Then have that conversation with your host provider and just say, this is how I need a break. This is what works for us. Can this be funded? Now, in terms of individualised funding, some families have said that they get, household management, some help with the household.

Other families don't. What is it? Do they have a requirement to be able to get that household management funding? I mean, it is dependent with children, the age and stage, and in relation to their age and stage, what naturally they would be doing with contributing to household management tasks. So, obviously for adults, it's slightly different. But yeah, it is dependent on the support need. It is also a requirement that there is a community services card. That's what I was going to ask because I wasn't sure. And it is difficult when families are talking to each other and one gets it and one doesn't.

But when you say, well, actually, is there a community services card? No, there's not. Well, that unfortunately or fortunately is one of the criteria. I mean, we'd love to be able to support all families around maintaining the home, but it's not always possible. Are there different fund holders? There are. There are a few options that you can choose from that are available in Canterbury. Your coordinator can talk through those host providers with you and send you links. You can have a read through and decide which one you'd like to go with. And they are contracted through Whai Kaha to hold the IF budgets.

Thank you.

## 4. Autism - Working with Lifelinks - Information for LifeLinks

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What information do I need to have prepared before I meet with Psychophysicists? You need to have your knowledge. Your knowledge of the person who has the disability. That's the information you need. And you're the expert. Yeah, exactly. You are the expert in your child's life, or if the child's able to speak for themselves, let them tell us their story. That's the information you need. We will, of course, require confirmation of diagnosis, and usually that's come through the likes of paediatrics, or Helen will be able to provide that for us. But in order to receive supports from the disability sector, we need to have confirmation of diagnosis.

But yeah, your knowledge, what you know about your child, what supports they require, that's the information you need. So, with the increase in autism, autism diagnosis, and I've been doing this job for a number of years now, and I've seen a huge increase. Is that affecting the way Lifelinks operate? Is that the things that Lifelinks are doing to help support families around the increase? Definitely is. Yeah, definitely. So, Lifelinks have put together an autism team. Autistic? Yeah. And that is with the aim of meeting that need. And getting to people faster. And in that team, we are directly contacting the families and discussing those support needs and goals via phone calls, text messages, emails, Zoom calls.

Whatever that person or that family is comfortable with. And then able to discuss those potential support options with the family immediately. So, that means the wait time is a lot lower for those families. So, I think what we've recognised is that families who are supporting children with autism have travelled a journey already. You know, they have waited for the diagnosis. They've waited to see the paediatrician. They've waited to see occupational therapists, physiotherapists, speech language therapists, exactly. So, what we want to do is to make that journey not so complex when it comes to their involvement with Lifelinks.

Let's make it quicker and easier for them. For families. So, is there a way that me, as the autism coordinator or paediatricians can help support that? Does it help that you get our clinic letters or our diagnostic letters or our support plans? Oh, absolutely. It saves families having to repeat their stories over and over again. So, yes. What we will do with that information is have a good look at it. And it supports the person who's making contact. You know, to say, I can see that this is happening in your life. You know, what is it that you think we can do to support you? That's fantastic because you're so right.

Families tell their story over and over and over. And, yeah, the knowing that professionals are actually reading some of those bits of paper and not having to ask me that same question again is very good.

## 5. Autism - Working with Lifelinks - Carer support

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How does carer support fit into all of this? So I think it's remembering carer support can be allocated to support the full-time caregiver of somebody who has a disability or who has autism. So it's to allow that person to re-energise, to have the breaks, because we understand the importance of having a parent, a full-time carer, to support somebody with autism. If you don't keep them strong, then it's going to impact on the child. So the whole idea of carer support is to enable a full-time caregiver to get regular breaks so that they can continue to be the full-time caregiver to provide the support that the individual needs.

What about for some families who don't live with their mum and dad but go and stay with mum or go and stay with dad? Do those families get any... support? So you're talking about people who might be in 50-50 shared care? Yeah, mostly. That's the one that I get the most questions around. So if you look at it, those parents are actually getting natural breaks because they're having half a week without the child, half a week with the child. So they're getting those regular breaks. Carer support enables regular breaks. So it's kind of, you know, these people are getting it already. So we would likely not be putting in carer support in that situation.

But again, every situation is different. So taking it a step further, we understood from our conversation with Explore that lifelinks need to do that referral. So if they're not going to get carer support, do they need to still be with lifelinks? Lifelinks provides or allocates more than carer support. Okay, cool. So their involvement with Explore is usually around behavioural issues. So yes, they would need to be involved with lifelinks in order to get that referral through to Explore. But Explore, and you would have talked to them, provide a whole lot more services than just the behaviour support for children.

So they do a lot of supports for parents as well. But we heard from them saying that you're the ones that make that referral. So I just wanted to clarify that. What can I do if I run out of carer support days? Before my allocation runs over, can I get more? So clearly, if you've run out, there's possibly a change in need. So if there is a change in support needs, then have that discussion with your coordinator at lifelinks. Yes, we have allocated more. And there have been occasions when we have said, no, we can't allocate because the disability support needs haven't changed. So yeah, carer support is an allocation that you can use flexibly over time, and it's usually allocated for a 12-month period.

So we would think that you would be able to pace out your usage of carer support so it lasts for 12 months. Yes. What happens if in the telling of the story, or what your needs are, what support that you need, you haven't actually been completely truthful, you haven't said everything, but you've swept your concerns, I don't know, off the top of your head. Yes. And it turns under the carpet, it then all falls apart, doesn't it? When you then get your allocation, and it's not as much as actually what you really require. Can that be changed from that point of view, just with a conversation with your coordinator?

Yeah, look, the conversations are important, and the conversations can happen at any stage during that coordination period. So yes, if they haven't been fully open. We can understand that. You know, it's not always easy to tell your story to a complete stranger who's sitting in front of you at day one. However, as you become more relaxed and trusting in the person that you're working with at Lifelinks, then you might be inclined to be more open. And once that becomes known to us, then we would review the situation. So it comes under a review. Yeah, and a review can happen at any time. It doesn't have to happen at 12 o'clock.

It doesn't have to happen in a 12-month period, you know. Things change. It does. Is the carer support payment taxed? If I want to ask my mum to provide care for my child, but she's worried about her benefit being affected? No, it's not taxed. It is a form of reimbursement, so it should not affect anybody's benefits. And if it does? Or if there is concern, who should I ask? Who should the parents ask? It could always come back to the coordinator, who will then make direct contact with the carer support payment office and get clarity. But yeah, our understanding is it is not taxed. We can have a discussion with Work and Income if you feel that it is affecting any payments that you're receiving.

What is the difference between carer support respite and individualised funding respite? So carer support is a form of reimbursement, either a half day or a whole day, whereas individualised funding respite, if you choose to use that for a support worker, to pay a support worker, it is a taxable form of income. Right. I understand you can use carer support days flexibly now to purchase items that help your child. Can you explain a bit more about that? Yeah, well, let's take a trampoline for example. So the way the parent is getting a break is that the child is occupied safely on a trampoline. So some families have purchased a trampoline using their carer support, remembering that that is how they get their break.

So because that money has been used there, they no longer have the ability to take more breaks throughout the year. It's a choice that families make. Flexibility is absolutely brilliant, but they need to remember also that carer support is there for a 12-month period, and unless the disability support needs change of ability, it will not be increased.

## 6. Autism - Working with Lifelinks - Enabling good lives

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What does enabling good lives mean? Enabling good lives means many things to many people. So it's exactly that. It's enabling a good life. And everybody's good life is different. So what you require to enable you to lead your good life could be very different to what your neighbour needs to enable them to have their good life. So it is working together to do exactly that. Let's support you. Let's help enable you to live the life that you want to live.

## 7. Autism - Working with Lifelinks - Respite

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How do I find someone to provide respite? I mean, there's quite a lot of different options for finding somebody to support you and provide that respite. It depends how that support is being delivered to you. There is family whānau support, which is through a contracted provider. There's individualised funding, which means that you can choose the person that you want to provide that support. If you don't know somebody, there are options through the host provider. They can potentially put you in touch and help you find somebody that can deliver that support. There are also websites online that have support workers advertising their support and what they can provide you with, which your outcome facilitator can always give you the links to those websites and support you to find those links and make those connections.

And it's not always easy. You know, to find that alternative person to be that respite provider or that person to, you know, it's developing trust. And yeah, so it's easy if people have got big family, big circle of friends. You know, it makes it easier to ask, you know, can you help me to support my child? Not everyone does. No. And I think one of the things that I often suggest to families is students and they can, or teacher aides. Because, previously as a teacher aide, I only got paid when I was at school. Yeah. So there's lots of different

options. Another thing that parents often worry about is the fact that someone's going to knock on their door and grab my child and take them away.

You know, it's not about that, is it? No. It's about who you feel comfortable. Exactly. That's the first thing that you're going to be looking at. And who your child is comfortable. Yeah. Absolutely. So yeah, friends and family generally are the first port of call. Because you know them. But, you know, people don't always have those networks. So being able to tap into other resources is an option there as well. Do you find sometimes that some families, they know each other and they'll look after my child and then I'll look after their child. And that's a good way of doing it? It certainly happens.

Absolutely aware that it happens. And people's energy levels are different at different times. Yeah. You know, people will often say, well, gosh, she gets care and support. She shouldn't be looking after somebody else's child. But, like I said, your energy levels are different at different times. And when you prepare yourself to be looking after one or two or three children with special needs, then psychologically you're there. But then you will need a break. Not just from there. Totally. But looking after your own child. It's having that break and recharging those energies and coming back. Yeah, filling up your cup.

Sort of a little bit refreshed instead of something for yourself. Yeah. I think burnout is a very real thing. Very real. Yeah. Absolutely. And we hear it all the time. And so, you know, and it is, it's sad to hear because, you know, a parent wants to be a parent and a good parent all the time. But we know that the impact of a child with autism that it has on the parent and their siblings and, you know, it's huge. So to be able to have the opportunity for those regular breaks is what keeps people going. Yeah. Oh my gosh. I am still thinking about it. Love you. Bye-bye. Good night. Woo. Good night.

Good night. Bye-bye. Good night everybody. So get your books out and play football if you are at home with your kids, if you are cannot. Yeah.

## 8. Autism - Working with Lifelinks - Purchases

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What if I have declined for a purchase? Do I talk to Lifelinks or do I talk to the fundholder? That's a fundholder question. They can certainly help you or talk you through that process that that's not a Lifelinks decision. I guess some families find that one fundholder will say yes to an item, the other fundholder will say no. Is there any way to even that up? Is there something that the families can do to... So, Whai Kaha have purchasing guidelines and so all the fundholders should be following those purchasing guidelines. So, I guess if the families are having issues with a particular fundholder, they can have that discussion with Whai Kaha. Okay, that's cool. It's good to know that there's somewhere else that they can go. Because I do have some families who will say... Oh, but it's just too hard. And then they don't bother using the funding that's available for them for that support that they need. So, are they able to have that discussion with their coordinator, Lifelinks coordinator? Oh, absolutely. I mean, our role is not only to refer to agencies, but it's also to provide any information that we're aware of where those supports might be able to come from.

## 9. Autism - Working with Lifelinks - Who will help me

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What if I can't understand any of this? Who will help me? Helen! It is hard and tricky, isn't it? I mean, it might be that you need somebody to walk beside you, and we'll look at the wider networks. We'd talk to Helen, Helen, do you know if anybody has been through this and had trouble? Have you worked with anybody who supports people? We tap into the DIAS, the Disability Information Support Service, and, you know, they are often able to point us in the direction, oh, I know this person, or I know this person. So, look, talk to your coordinator at Lifelink, and they will do their utmost to make it, present the information in a way that is able to be followed and understood.

And I guess you're right. I do have families who come and ask me that question. And particularly for families who have English as a second language, if I'm able to, I will put them in touch with someone else with the same language who understand the process, or that I've already walked that walk with, so that then I don't have to do it again, but I am able to get families together. And often that forms another bond or another thing for them that they can then work out. Excellent. And I think we're all learning. We're all learning as we go because there are services that, you know, crop up. There are people who have experienced this and then they want to offer this to somebody else.

There's a Facebook network as well, you know. You belong to that, don't you? So, you know, there is just, you just have to say, I'm not understanding, somebody will come forward. There are no silly questions. No, no silly questions. If you don't understand anything, just call, email, teach your coordinator and ask. So I'm more than happy to talk it through with you.

## 10. Autism – Working with Lifelinks – Key messages

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So thank you so much, Lifelinks, for coming along today. You're welcome. And it's been great having you with us, talking about what you guys do. Just wondering whether you could let families know, what is there a key message that you would like them to take away about Lifelinks? I think that people need to know that we see the individual. Each person is in front of us, and that's the person we see. That's the person that we want to be working for and working with. And we see also that there's a support network around the individual as well. No person is able to live alone. Support networks are very important. So I think let's work together to see the individual, to identify that individual's support needs, and work together to help those support needs get met. Awesome. Thank you. Look. As facilitators or coordinators, we're here to help. We're more than happy to answer any questions. No question is too silly. If you need help or support, or you have anything that you need to discuss, just give us a call. We're more than happy to... We're here to support you, essentially. We'll do whatever we can to do that. Fantastic. And whatever we can might be something that's completely different to what we're doing today. Yeah. So we're open to change. Awesome. Fantastic. That's great. Thank you very much for coming along. It was great to talk to you. Thank you.