**Podcast ILO November 2020**

Hi listeners and welcome to Reasonable and Necessary, Australia's premier podcast series on everything you ever wanted to know about the National Disability Insurance Scheme. I'm your host, Dr George Taleporos, and on today's episode, we're talking about Individual Living Options and how people with disabilities can have more control over where we live and who we live with. To help us understand what's possible for Individual Living Options, we're joined by Summer Foundation's UpSkill lead, Linda Hughes, and Terry Mader, CEO of My Supports. Hi Linda and Terry, thanks for joining us.

**LH:** Not a problem, thanks for -

**TM:** Our pleasure.

**GT:** So just when we thought that the NDIS could not have any more acronyms, we have a new one, ILO, Individualised Living Options. That's what we're here to talk about, guys. So Linda, can I start with you, what kind of options are we really talking about here?

**LH:** Well, I think I like to say the I is for Individual, because quite often we sort of fall into the independent, the SIL sort of acronym, so I always start with thinking about the I is for Individual, when we're talking about ILO, the acronym. And I think that it's really - that's key, it's actually when we start with the person themselves and we plan the support and their lifestyle around that person as opposed to perhaps the more traditional approach, which is more a managerial approach to managing the support needs of a few people.

**GT:** Okay. So really interested in what the individual wants, it's not about the system, it's not about the supports, it's about the person. That's exciting, that's what I like to hear. And you're very passionate, Linda, about ILO. Can you tell us why?

**LH:** Just I do, I just love it as an alternative. George, you know I'm the parent of a young man or he's 28 now, so he's still a young man to me, and he's living in his own individual - in a way that's individual for him and I think that I've always had in mind since he was really young that I wanted to have - that my son Jacob would be living in a situation that was suited to him and that was focused around him. I didn't ever think, "Gee, Jake would have to go a group home or an institution" or anything like that.

I always had this plan in mind and not just me, but our family and Jake's networks have always had this idea that an individual situation with perhaps him sharing or something that suits him. But in the early days, we didn't know what it would look like. We just knew we wanted something different than to what's offered traditionally to people with disability. So I think that's where we - that's why I'm passionate about it, because ILO offers that avenue, that pathway to something that's far, far more I think attractive and holistic and interesting than what our disability services have served up traditionally.

**GT:** Okay, I might get back to Jake and his arrangements shortly but I might turn to Terry now. Terry, you're from My Supports, your organisation has been supporting people with ILO arrangements for a while now, haven't you?

**TM:** Yes, we have.

**GT:** Tell us, what do you do, how do you help people and what kind of arrangements have you been supporting people to put in place?

**TM:** Yeah, look, what I - just to reemphasise Linda's words around the flexibility and the individualisation, individual element of the ILO design and the arrangements. People who have the lived experience kind of get it a lot easier than perhaps let me say traditional providers, like, for example, I myself, I am in a wheelchair. I had an accident when I was 15 and I don't want to tell you how old I am now, but I'll let you do the maths, but that was in ’82. In ’82, 1982, people thought different.

My mum was told that Terry would have to stay at home with you but if you have trouble coping, there's a centre in Perth, the city I live, called the Quad Centre, and you could go and live there. And there lived about 35, 40 other people with spinal injuries and essentially it was like an extension. And that's been the options, just like Linda was kind of sketching out, and ILOs give a lot more options for people who need a level of support but want to live on their terms, want to live how they want to live, how the rest of people in society live, where everybody has the different options to share or live alone or live with people they trust.

**GT:** Yeah. So, what I really like about what you're saying is that it's really about breaking down the group home model. It's - yeah, you [inaudible] everyone who needs 24/7 support to live in an institutional environment. ILO is really about saying, "No, let's look at other ways of living", ways that are in line with your interests, how you want to live.

**TM:** That's right. And look, in terms of the process, that's where the actual conversation starts, George. It's about understanding how that person or how the client, in our case, when putting my My Supports hat on at the moment, we start that conversation with the client. The coordinator is also very important, the rest of the family, about how that individual would like to live. And often we remind people, "Look, you have other children, who may perhaps do not have a disability, what's been the process for them?"

And often the - lots of things come in to play, like suburbs you like, what you're doing externally, if you're following a study or a work program or if you're working, the level of support you may need, whether your economics, like lots of people when they first move out of home, do some type of sharing arrangement to help pay the bills. So we go through that process, which looks almost identical to anybody who wants to move out of home when they first move away, using that as an example. And after some discussions, we hope to come to something that looks like how that person would like to live and then we work out how the funding fits in with that, so we put the other way around.

**GT:** I like it. I like it because it's really around, like we talked about before, that we start with the goals or how that person wants to live.

**TM:** That's right.

**GT:** And then you find out, well, what is it that we need to put around that person to make that goal a reality. I like that. Let's go back to Linda then. Sorry, Terry, were you going to say something?

**TM:** Well, I was just going to say that, look, the final thing I'll mention on how My Supports work is we do emphasise the working with coordinators. Coordinators have a longer, deeper knowledge of the client, who've maybe known the client for years and the families and understand just the complexities that might be there. Because often housing and where you want to live has been a background discussion in a lot of things going on. And so we try and plug into those insights and that knowledge, that's probably a little bit of the emphasis of our model.

**GT:** That's really interesting because what I'm hearing you say there is that whoever is involved in supporting that person to do this important work, that they need to be very, well, grounded and experienced in that person and what that person well how they want to live, it's not something that a new person could necessarily pick up terribly easily. Is that right?

**TM:** Exactly.

**GT:** Well, on that note, Linda, you know your son, Jake, very well.

**LH:** Yep.

**GT:** And I sense that you are heavily involved in setting out what was not technically ILO because you'd been doing it before ILO was even a thing, but it's an ILO type arrangement, is that right?

**LH:** Yeah, yeah. So one of the - I suppose some of the things that we were thinking about, sort of as my son sort of started in his 20s, it became really obvious that he really liked it when I went away and I'd come back and he's a bit like "Oh, you again." And so we could really get this sense that Jake was really enjoying his time away from me, he was enjoying going out in the evenings, there was just lots of things where we could see that he was a young man, a grown up, and really right for that sort of next stage of adult life, which was sort of leaving home.

In our situation, our family home is really well modified for Jacob and his support needs, so it just made more sense for me to leave home, so I did, and - but there was a lot of planning. I think that we spent about a year really working out what would work for Jacob. Jake's got difficulty with communication, so there's a lot of it, that as Terry said, it's really about knowing Jake really well and he's social, so we knew that he would really enjoy sharing with other people. One of the things he likes to do in the evening is chill out in front of the telly, so we sort of knew that when Jake shares, he needs to be sharing with someone who likes watching The Bachelor and those sort of shows, you know, reality TV -

**GT:** All class, isn't it?

**LH:** Yeah, so it's sort of really kind of thinking about what would sort of - yeah, how would we find the housemate that would be really suited. And also the other thing that we really spent a lot of time on was safeguards to make sure that Jake wasn't left in a vulnerable situation and that there was sort of plenty of - lots and lots of things going on that sort of meant that Jake would be safe, I suppose, in that situation. And that includes around managing his complex health and a range of various things. So I had to feel comfortable and with the plan as well. So it took a while to really unpack what would work and it's a bit of a work in progress, even as I speak now.

**GT:** Okay. So effectively what we have with Jake is an arrangement which is about sharing his home with someone in exchange for someone being around -

**LH:** Yep.

**GT:** - to effectively mean that he doesn't need a support worker there 24/7, is that right?

**LH:** Jake needs someone around 24/7, he doesn't need active support 24/7. So, you know, when he's chilling out, watching TV, as most people when they chill out, watching TV, he's just sitting on the sofa. So it's not - if there was a fire, Jacob needs someone to take them with him, you know, take him out of the house. He doesn't have great independent mobility. There's some things like around his - once again, his complex health, that if something arose, then he would need someone there to provide some assistance or call for help or - but quite often it's just that sort of someone else there just to provide support as needed and it's not onerous or it's not personal care support, it's just really being there.

**GT:** Absolutely. It sounds like it makes a lot of sense to do it that way. Terry, can I ask you, I'd like to just dig a bit deeper into the different kinds of arrangements. And the one that Linda talked about is a bit of a house sharing arrangement, but I was looking at your website and there's like, I don't know, 9 different types of options that you put forward. I'm sure there's even more than that. But can you talk us through some of the main types of arrangements that you've supported people to set up?

**TM:** Yep, certainly. Well, look, obviously it starts with the individual but what you often find is people like to share and there's lots of different ways to share. What's popular, some of the popular arrangements are around hosts, that's where someone with a disability goes and lives with somebody who has perhaps a larger house and wants to share their life, share their home, and that's provided by the host. So that's a host arrangement.

What's also increasingly popular is people with - who are perhaps participants in the NDIS, meeting each other via different work programs or social programs or even people who know each other from a group home, and saying, "Look, let's go out and share together and because we get along, we share a lot of interests" and so the arrangement starts with how those individuals want to share together. And that can be 2, 3 or 4 even. It can be quite large. The frat houses, as I call them, once you get up to 4 young blokes who working on an ILO where 4 young blokes discussing living together, I call that the frat house. There's people who perhaps need some more directed supports - so you might've read about co-residents.

So that's where a person with a disability has their own home and somebody comes and lives with them and provides that level of support. There's family arrangements where people do want to live with families but there's an additional level of support needed around that to make sure that's sustainable and safe. Under the current NDIS, there's also living alone arrangements, where people do want to live alone but perhaps need some support of a friendly neighbour or some really well structured drop-in supports to keep everything on track. They're some of the arrangements that we've seen and we've been arranging.

**GT:** I'm curious about this frat house arrangement, mainly because I've seen all the movies. No, not really. Mainly because I'm picking there might be some listeners, saying, "What 4 people with disabilities living together, that's a group home. Isn't this about alternatives?" What would you say to them who are thinking of that now? How is the frat house any different to a group home?

**TM:** Well, look, that's only - there's one arrangement. Most of those sharing arrangements are just with 2 people, who meet each other through some social and want to share together. So that's kind of the standard sharing arrangement. I guess, George, we're just working on the arrangements where there's 4 young men who know each other and they want to get together. And you know what, they're young men and it reminded me of a lot of what I saw when I was younger and people - you know when you move out of home, sometimes you do share in those type of arrangements. A little bit chaotic, a little bit looser. You might just have to afford the rent, you get 3 or 4 of you together. I think 4 is an extreme but I haven't seen - that's only this 1 arrangement. I don't want to give the impression it's kind of standard. But look, I -

**GT:** I just - can I add something, Terry?

**TM:** Go ahead.

**GT:** What I'm hearing you saying though and I don't want to put words in your mouth but the difference here is that these men were in charge, they made that choice and effectively they're the boss. So, it's not about a provider, it's not about them going to a provider and moving into the provider's house, this is them coming together, setting up the share house and then working it out on their terms, is that right?

**TM:** You got it. You got it, George. You've obviously been to a few group homes in your time and -

**GT:** Yeah.

**TM:** - even the best group homes can have a bit of a feeling that you're living in someone else's workplace because, you know, the stresses and strains of running that home, the staff coming in and out, it's a provider responsible for that house, who owns that house. The research reports show that often people don't necessarily feel it's their home and I think what you're saying there is what people look for in those sharing arrangements about ILOs. They're not looking for someone saying, "Lights off at 10 o'clock." They're not looking for saying that you can't have other people sleeping on the couch. They're looking for somebody to say, "Look, I know we don't normally go to McDonald's on the Wednesday but we really want to." You're looking for that freedom and you're looking for that individual element.

**GT:** Yes, absolutely. I think that is the key, the freedom and the individuality of the option. Linda and Terry, I was interested in both of your views on this, there are probably support coordinators who are listening to this who are getting quite excited and want to work out sort of what their role is in helping people to set up these types of arrangements. Can you talk us through the role of the support coordinator and how they can help this?

**LH:** Yeah, is that for me, Terry - for me, George?

**GT:** I'm interested in hearing from both of you.

**LH:** Oh okay, do you want to go first, Terry, or shall I?

**TM:** You go first, Linda.

**LH:** Yeah, okay. So I think as a support coordinator, I think you really have to kind of really readjust your thinking on support. So the first thing you have to do is sort of throw out any sort of models that come up with SIL that we all sort of become quite familiar with over the years. So I think the first thing to do is sort of almost free your mind of the traditional ways of supporting people. So -

**TM:** Good advice. I was saying, "Good advice".

**LH:** Yeah, yeah, yeah. So free your mind of that and actually I would be really encouraging support coordinators to get really well informed about Individual Living Options. I think one of the tricky things in discussing with people I've worked with as support coordinators is that we don't have a lot of good examples of this on the ground. So I'm always really trying to sort of show people where there might be some resources, where you can actually see a bit of a snapshot of someone living in their own place. There is a few resources around. Adam Moves Out is a terrific resource to sort of thinking about the process of setting up an ILO sort of arrangement.

But just really having that sort of opportunity to see what it can look like, because we've just become so sort of familiar with the group home structure and so it can be hard to sort of think about how it could be somewhat different. And I think the other thing about it is actually just thinking about most people who don't have a disability have their housing and support arrangements set up. And I say that we all - you know, people need support from each other, we're all interdependent, and actually thinking about how everybody else lives and actually trying to sort of really use that kind of framework and understanding to apply it to the people you're supporting, if you're a support coordinator.

**GT:** That's great advice. Terry?

**TM:** Yeah. So look, how we work is coordinators, we encourage coordinators to contact us. There's usually a little bit of - there's some phone conversations about the arrangement. So there's a bit of, I guess, an arrangement discussion. Once we feel that between the coordinator and our ILO team there's a little bit of a - that we've given some direction, what we ask the coordinator is on our website, we have what we call our starting questions form. And so that's a list of questions which stimulate the coordinator, but also allows us to get that level of deeper knowledge around the situation. Based on that, we do a draft proposal, how it could look. And that's really just a discussion to get things on paper, to have a bit more of a discussion. Usually there's a bit of back and forward around that.

Once we feel there's something there, we put that up into a proposal to the NDIA. We submit that to the NDIA. When we've submitted that, we start working on the ILO partners. So there's often a need for a host or a co-resident or perhaps somebody would like to share with somebody but doesn't necessarily know who they'd like to share with yet. We start working around who that could be because that's the role of the ILO provider as well, to find those partners. And then once we've got that all together, hopefully we get an approval from the NDIA and then we sit down and we work out an implementation plan and putting everything in place. So that's a really quick snapshot, George.

**GT:** So I'm just trying to get my head around the technicalities. I know that there is a line item now in the NDIS Price Guide for the Individual Living Options exploration and design.

**TM:** Yep.

**GT:** Is that effectively a line item that allows a person to purchase support coordination that will then be used to develop an ILO?

**TM:** Yeah, that's right. So what you're referring there, George, obviously is in the current price guide, there's 2 ILO elements. There's the design element and then what they call the service model, which - and the design element is the research, the discussions, the exploration of what ILO may suit, and then the second one is putting it in place. What we do at My Supports is we focus on the second element and what we encourage is coordinators to use that first element. So they have the hours to go on that journey with the client, because they're starting from, as we started talking about, they're the ones who know their client over the longer term, they know the details.

And working with us, coordinators can get up to speed with the technicalities and we worry about - we do the application in to the NDIA, so we know the ins and outs of the ILOs. But the key element is knowing the ins and outs of the person and that's why we encourage coordinators to use those design hours. There can either be 20, 50, can be quite some hours available for the coordinator to take that on. And then what we do, as the ILO provider, we do the ILO model itself, the service model. So we put in place the different supports and the arrangements that the ILO requires.

**GT:** Yeah, that's really, really helpful, the explanation. And just to summarise, I think the take home message there is that the support coordinators, when they're going to a plan review, if the person wants to develop an ILO, that they make sure that they have those 2 items in the person's plan so that when their plan comes through, they can then start working with the person and with an ILO provider, like yours or someone else, to put it into action.

**TM:** Exactly.

**GT:** Fantastic. Sounds like it's pretty much a reality. I understand that currently the NDIA is finalising some guidelines that they're going to have available towards the end of November 2020, which is not far away for us. And so people will be able to learn more when that comes out. Linda and Terry, before we finish up, if somebody's interested in setting up an ILO, what should they do now? What's the first step they can do?

**TM:** You go first, Linda.

**LH:** Okay. Yeah, look, I think the first step is - well, it's pretty much as Terry said, I'd be talking to my support coordinator, I'd be - if I was looking at an ILO, I'd be talking to the support coordinator, I'd be looking at when's your plan review. It'd be really important to have a housing goal around living individually. I think it would be sort of another really important key thing to get the funding in your plan and really sort of having a chat to support coordinators who understand this and - or are really prepared to go on a learning journey with you and particularly if it's a support coordinator who really knows you well already, as Terry was saying, that's the person who already has a big head start in understanding what might work for you and understanding your support needs.

**GT:** That's really good. Terry, any other -

**TM:** Yeah. Look, absolutely agree with that. I would start those discussions with your coordinator. Ask your coordinator to reach out to some ILO providers to present with you some ideas and to assist you with the technical nature of the applications into the NDIA. That's definitely an area that that coordinator would need to plug into. And be prepared for a little bit of a discussion around what suits you. And then have confidence that the NDIA will listen and want to fund your steps to live individually and independently.

**GT:** Absolutely. Because it's a win-win situation, isn't it? The - you as a participant, benefit from an individualised plan and the NDIA wins because, hey, they're going to save money if this is done properly and the outcomes are going to be a lot more positive for everyone. Sorry, Terry, what did you say?

**TM:** No, no, I was just nodding in agreement but I may be made a verbal nod there.

**GT:** Thanks, Terry. It's been really great having both yourself, Terry, and Linda on the show. Thank you for your time and I look forward to having you on the show again in the future.

**TM:** It's been my pleasure.

**LH:** Thanks a lot, George.

**GT:** Bye bye.

**TM:** Bye bye.

**LH:** Bye, thanks, George.

**GT:** That's all we have time for on today's episode of Reasonable and Necessary, brought to you by the Summer Foundation. Check out our website for all previous podcasts and transcripts. We also love hearing from you, so please contact us with your comments and suggestions for future episodes. Until next time, stay well and reasonable.