

## **'Funding Futures in the NDIS Context – It's a Jigsaw!' Workshop March 8<sup>th</sup> 2018**

### **Transcript of the Q&A following the 'Selling what I'm good at' Panel**

Featuring: Fiona May – CEO ADACAS; Tracy Wright CEO NSW CID & facilitated by Disability Services Consulting (noted as Interviewer 1 & 2)

#### **Interviewer 1: Does anyone have any questions?**

**Person 1:** I think you all are doing excellent work and you might think this question is irrelevant in a way, but I think it is relevant. I represent people with mental illness and when you're talking about intellectual disability....I haven't thought about it all that deeply though.... I haven't known it is that and in many cases it is a significant part of a health problem and it's not as if the person started with not having intellectual disability and they are getting more and more drugs and it starts to affect their thinking capacity. For instance my own daughter - it has been 2 decade since she has been diagnosed with Schizophrenia plus many other disorders and she spent many time with very heavy medication and only when we started to use more psychosocial therapies for her other kind of therapies, not just drugs so she started to get to a point when she said 'I can do something' because before that she really felt like she was a zombie like she was in a fog, not seeing things properly, she couldn't read any longer, she used to play piano really well but it started to get worse and worse because of her memory problems. She was no longer able to read the notes so a lot of her life really became very simple. But with television she could watch things like the Simpsons because she could follow... but anything more complicated she couldn't. When she was a child she was intellectually assessed as a very superior intellect. So then things started to get better and her medications came to good use and she learned how to deal with her situation better. So then instead of saying 'I'm an imbecile' like she couldn't even slice a bean when I asked her to slice a bean she just could not do it. She just couldn't see how to do it, or think how to do it. She started to get better and now she is back to university she has been there for 2 years of that. One subject at a time. Doing very well getting distinctions and high distinctions that helps her feel much better. Also she has written a book which is on mental illness.

#### **Interviewer 1: Is there a question you have there?**

**Person 1:** The question is... there is an intellectual disability there - it comes with most of them these days we see without all these extra services we have paid for they {the person} are really intellectually backwards... they can't function because the drugs are causing all these problems.

**Tracy :** Hence why we are looking into these things, if you look at positive behaviour support and if you look at the things around psychotropic medication and the Quality & Safeguard Commission will kind of oversee and is to hopefully not have that and giving people skills in order to support decision making and making those decisions early. So and I guess any policy of the day when you look back and reflect and see that's how people manage it and see it as an opportunity to learn from stories

like your saying and to...how do we do it better and how do we not have people on medications that may or may not be relevant and for any other reasons so yes I take your point and I am happy to talk to you about this at lunch.

**Person 1:** Yes I would like that because that was the point of me telling you about this because people who have cognitive illness they are not considered intellectually disabled. But a lot of them are and they are not getting the support they need. Thanks.

**Person 2:** My question was going to be linking on from that, you have talked about mainstream services... do you see then merit for advocacy information organisations (given clearly there is only a set amount of money in the ILC...) there are all these people out there in...in organisations going direct to organisations and to be aligning themselves with you know, for want of a better word 'advocating' to those service interfaces they are working with to get them to play ball and partner with them and taking something on in terms of an advocacy ask or a way to fund a project?

**Tracy:** Well I think, I know, that at CID we partnered with a whole bunch of different people for ILC applications. So we partnered with other advocacy orgs around some of applications; we partnered with main stream in terms of particular pieces of work. I think there is value in that. There are pros and cons to mergers and acquiring funds as a consortium. But it does make people work together and as you were saying the funding landscape is very much in that space. And the governments sees that as good value for money if there's those consortiums of organisations. Outside of advocacy one of the things that I feel is happening and is a big risk in the NDIS landscape is where we've we got big organisation hoovering up smaller organisations and I think that the market... that that doesn't give choice or control in terms of the market. There is value in smaller organisations existing so I think there is pros and cons in looking at that back of house stuff that organisations that are front facing still keep their brand names and things like that. If there are different ways that that can be done but unfortunately government see that as 'yes they are all together now.'

**Fiona:** So it's a really interesting questions about who is responsible for funding advocacy. So if you are advocating for advocacy housing should housing be funding the advocacy? That continues to be a challenge in the policy space around advocacy and why should it be funded from the disability space just because that person has a disability. Is it about the issue or is it because of the person? ADACAS actually gets some funding from the ACT health specifically to provide advocacy for people with mental health issues with regard particularly to tribunal orders for psychiatric treatment. Because the mental health system recognised that this is something that their cohort ought to have access to and in order to have access they are funding it.

**Person 2:** Was that something you pursued or something they came to you with?

**Fiona:** Actually ADACAS already had it and I am not too sure how it came about but I am reminded years ago I actually used to work with lifeline and lifeline in Canberra had a gambling counselling service and we actually received about a million dollars over three years from the gambling industry to provide a gambling, an additional problem gambling training to their staff and a whole bunch of other things, so there is a parallel example if you like of the industry that is part of the problem also having some responsibility for what the response of what the problem ought to be. It was a tricky thing to set up because people were going 'how could you possibly be getting into bed with the gambling industry!?' And we had to make very sure that we *weren't* getting in bed with the gambling industry and in fact the independence of Lifeline and their service and their ability to speak up about the issue of problem gambling in the systemic sense was not compromised. So there are example of other things that I don't know that it's going to be easy in the advocacy space because there are SO

many different issues on which we advocate, to get each of those systems to fund advocacy adequately would be a very difficult and disjointed exercise.

**Interviewer 1: Any other questions? Yes....**

**Person 3: I just wondered how you fund the support of decision making. Is that part of your advocacy funding or....**

**Fiona:** No its project work. So we've been doing support of decision making for 6 years project by project. So it is still uncertain in an ongoing way but I have to say we've had 6 years' worth of projects. We kept getting more projects so I would love to sustain it with more funding certainty and that is obviously my aim but we just are not quite there yet unfortunately.

**Interviewer 1:** Yes don't ever underestimate the value of one off projects because you can build...

**Tracy:** Especially if you've evaluated because then you can show outcomes, collecting the data and stuff.

**Interviewer 1: Anymore?**

**Person 4: Just touching on that, when you started, how sophisticated was your method of data collection?**

**Fiona:** How many advocacy organisations in the room use the EVO system? Just me and you x? There you go.

**Person x:** That's right, just you and me Fiona.

**Fiona:** So ADACAS still has the same data collection system it had before. EVO is a data system that was actually created by advocacy organisations within the mid noughties a bunch of advocacy organisation came together and said we all have the same problem lets solve it together, and EVO was born for its sins and um I don't think any data system is perfect. Whatever data system you have your going to love or hate parts of it. EVO was developed though with the purpose of advocacy in mind and we still had the opportunity to say we want you to tweak this, add this. It continues to evolve to meet our needs what are we looking for in the future a system that will manage to meet our needs, that isn't so cumbersome for our staff to use.

**Tracy:** I think that is a key point because you can have all the best systems in the world yet you have to put the numbers in and be able to use it.

**Person 4:** That's reasonably easy to use...

**Fiona:** Well what do you think x?

**Person x:** Well it is... I think it's not too difficult as long as you keep up with it but it's also beneficial if you're on the DECS system because it assist you to transfer facts into the DECS system. EVO by the way is also the patron saint of advocates so get on board!

**Interviewer 1: Any more questions? Yes....**

**Person 5:** Yes a couple of things. Are both of your organisations.... does all your staff work from the same place or do you have staff working elsewhere as well?

**Fiona:** So ADACAS only has one office in the ACT although our staff spend more of their time out of the office than in it because they do most of their client work out and about wherever our clients are but we still have just one office.

**Tracy:** Yes same, for we do NSW but we do have a HUB in Sydney.

**Person 5:** Well I guess the reason for asking that is that < the organisation that I used to work for > has now merged with < another organisation > as we were essentially doing the same thing in NSW and so now we have pulled our resources and now both organisations are able to do more and particularly for our members in NSW and ACT. But many of us are working remotely all across 2 different offices and we have staff in Tasmania, Victoria, NSW and QLD and the majority of us have a disability so you got me thinking about how to manage the stress because we aren't just working it we are living it, and we are all in remote locations, so do you have any suggestions?

**Fiona:** So we provide both internal supervision and clinical supervision for all our staff. So ADACAS actually pays for all of our staff to spend an hour a month with a clinical supervisor who is external to the organisation. That is one of the key things we do to ensure staff support that kind of mechanism could be implemented for an organisation that has a dispersed model like yours. I think how you build a team across a dispersed model is much harder than having them all in one location. I am not going to tell you how to suck eggs because I haven't done it. But I absolutely appreciate the challenge.

**Interviewer 1:** We are very dispersed in DSC, so some of the ways we build collegiality is online through a platform called 'Slack' and we find that, that is very good too. We have all different channels based on different topics but there is a social channel and internal channel so some interesting stuff happens.

**Interviewer 2:** So I use SLACK for DSC work and also Summer Foundation has it also and it works beautifully for DSC we are all in different locations and that is the primary communication tool so it's very vibrant and we throw out some questions and we are very interactive when something happens, every day, every minute just about. But for Summer Foundation people aren't interested, it hasn't taken off because we have an office and there is only a few people offsite so there is not that driver behind wanting to communicate so you have to consider and be thoughtful on your audience and the environments.

**Interviewer 1: So just before we thank you all for all your knowledge and wisdom, thank you so much for being that generous. Are you around at lunch time Fiona?**

**Fiona:** I am around, I am at Yvette's disposal.

**Interviewer 1:** So if you would like to talk more about what support coordination might look like from a base line of advocacy maybe you could have a chat with Fiona, because we are conscious of time. **But I did want to ask Tracy - you were saying that you have just started thinking about support coordination?**

**Tracy:** There has been some work done before I got into CID in relation to support coordination 'should we or shouldn't we', we are just investigating what that might mean and so I am really keen to talk to Fiona, because one of the tensions has been if you step into that what does it mean in terms of advocacy work. We have it clear in our business services work that every contract, particularly with government, we say 'yes we are happy to do this piece of work but there is a clause in there that doesn't stop us from doing or challenging around our advocacy', systemic advocacy work. So we are just in that thinking about.

**Interviewer 1: So you said that you aren't registered yet as a provider?**

**Tracy:** No we just went through TPV this week. The national standards should be up soon...

**Interviewer 1: Any of you feeling like you are in the space that NSW CID are in?**

**Person 6:** A bit... but I think more far along, but we have a similar model to what CID have in that we are independent above all other things and that independence brings people knocking on the door, like every week we have new clients. We haven't done any advertising, we haven't told anyone!

**Tracy:** That was one of the principles of support coordination, that it wasn't supposed to be done by providers and it was supposed to be independent but what has happened is we have seen in NSW it hasn't been a very good process and people have not had that choice to even go knocking on the door particularly if they are already in the system.

**Person 6:** There just is not very many... you know there really aren't! You know in our area we are (providing support coordination) and two individuals who are functioning independently!

**Fiona:** So I think on a broad level, support coordination has changed over the four year of the NDIS. The way that they were describing it when we were making the decision and what they were saying the Support Coordinators were there to do looked an awful lot like advocacy... indeed they were *using* the word advocacy in description of support coordination at the time, so our decision to go into it was informed by the information we had at that time and the fit was really really good. *Now* when you look at support coordination descriptions that the NDIS put out it's shifted a little bit. Also if you look at what they are saying their intent with support coordination is which is 'you might get it in the first year but you probably won't need it after that' (because after all the support coordinator would of built your capacity, and after all building capacity is binary, you either have it or you don't!) And also 80% of people won't *need* support coordination because the LACS have *nothing* else to do besides provide support connection for people because they're not already doing the planners jobs. So we are in a different landscape to that which we are. I think that if ADACAS was making the decision now it might not have seemed as obvious as it seemed to us three years ago.

**Person 7:** Just to comment on that, we provide support coordination, I am a support provider. Some of it sits very separate to all other operations to the organisation. We have very strong barriers if you like, and the guidelines say it's not advocacy. However there is a certain element of advocacy because you can't do it unless you do because it also says in the guidelines 'solving points of crisis' and you can't do that unless you do.

**Fiona:** So understanding why the NDIS do that is really important. The NDIS changed the language because they were sick of support coordinators coming to the agency advocating on behalf of the client for inadequacies in the plan... they started to say 'support coordinators aren't allowed to advocate' cause they didn't want support coordinators speaking up on behalf of clients to *them*. So the motivation of the NDIS is.... in some ways it's not really right if you think about what the client really needs from support coordination.

**Person 7:** We actually now refer those people who are going through those situations to those advocacy organisations that specifically do NDIS appeals because we feel that we need to maintain our independence and that is one of the parts of the strong barriers that we face. Likewise internally in the organisation we have other parts that go knocking on our door because we sit separately, even on a different floor, we are on one floor, the other part of the organisation is on floor 8 and we say 'no you have to be treated the same way as everyone else'.

**Fiona:** So that's one way of doing support coordination. ADACAS actually has chosen a different approach because we were very conscious of wanting our support coordination to look and feel a lot like advocacy because that's who we are. Our advocates have a mix of case load. They have some case load which is support coordination and some case load which is individual advocacy and that has been a deliberate decision on behalf of the organisation because we didn't want support coordination to drift and our support coordination to start looking like everyone else's support coordination. For me, for the moment, the only way I could ensure that *didn't* happen, was if it was being done by people who were completely inculcated in being an advocate because if you separate it, the opportunity for drift in culture and drift in practice seems to me a risk I was concerned about managing. That was a choice that we made at the moment but each organisation has to make their own choice on what is happening.

**Person 7:** I think what drives it is where you are sitting in terms of locality, what is in your demographic and how you are operating in your area.

**Fiona:** That's right and I wouldn't at all criticize the decision your organisation has made

**Tracy:** Depends on the landscape

**Person 8:** I believe we have taken the practise model and it's not case management, it's not advocacy, its somewhere in between. It's about capacity building... with the individual it has to cap build with the service providers because there is an inordinate amount of that at the moment cause everyone wants learning and capacity building for the NDIA and vice versa, and the community. So there's that whole kind of model is really based on that work which is exhausting so and it's that long term community work that we are not going to get that project approach you know which is hard but it's interesting because you're right about that differential at work the people who are doing support coordination directly. So we have tried, we have a couple of little buckets on our end but we got that project work so they have that project work *and* support coordination because they were getting exhausted - that was really the big driver for us.

**Person 9:** Support coordination I gather it's the lowest.... support connection I'm just wondering the percentage and the rates...

**Fiona:** No there are 3 funding levels, support connection is funded \$50 an hour; support coordination is \$90 an hour and therapeutic is \$170 so when we had a look at that we decided that support connection what they thought a lot of organisations can do and that support coordination which is the middle level is the one that described most like advocacy so we don't offer the support connection we only offer Support coordination and Therapeutic because I got staff in my organisation that were social workers and what have you so we can do that. We also have work around what is the amount that would cost us to deliver an hour of advocacy we did this before we made the decision for support coordination so we were very clear about what we need in order to deliver and we wouldn't of been able to deliver our service in the quality that we were able to with the staff paid at the level they were paid in \$50 hour a market.

**Person 5:** How did you manage working out how much an hour your advocacy cost?

**Fiona:** We got.... so again it was a little piece of business development funding I don't know how much it was... \$20,000 or something, it was actually Deloitte Access Economics. It was actually a separate project about a year later and we went back to them and asked them to do that piece of work for us.

**Person 9:** How much.... how many hours do you bill....just getting down to the nitty gritty....

**Fiona:** 6.3 hours

**Person 7:** 6.3 - 6.5 hours a day

**Person 9:** We work it out between 57 - 60% billable hours a week, so we're aiming and that's the hard part with coordination is supporting those billable hours, the only other people who do billable hours like that are lawyers. Nobody else does billable hours like this.

**Interviewer 2:** The big consultancy firms do...but yes traditionally lawyers...

**Person 9:** So we have looked at 3 years of losses with taking on coordination of support this year.... this year we will probably break even obviously several thousand dollars out but ... the pressure on coordinators because ... is billable hours. And we had a traditional role of an advisors service and as advisors and they work with them until the planning process and we generally get the core management support after that so we tried to separate those two so....billable hours there's no, it's a business model.

**Interviewer 1:** And that mindset is difficult at times to shift...

**Person 9:** That's why we haven't tried to shift...we've gone straight in!

**Person 8:** Now that 6.5 hours now because I worked all that out I had no business consultants I sat down and did it, it also takes into account annual leave, sick day people are likely to have off during the year as I worked out that formula.

**Person 5:** how are you able to work out how many potential clients you would have?

**Person 8:** So that's difficult but I did work out that we would have to have at least X amount of clients so it was worked out on a case load basis on what came along but also take it down to that intensive support and monitoring but also building in that capacity building potential hours in there as well. Some of the capacity building we have also done in small workshops with let's say 1 support coordinator, people coming to those workshops they love it because they also make connections with other people, it's very much an adult learning culture as well.

**Interviewer 1:** So clearly there are quite a few questions getting down into the nitty gritty of support coordination which is great but we got to be careful that it does not compromise other sections.... so I am just wondering if we could wind this up.

**StT:** If you have any more questions please put it on the board there and I can collate them and send them out to people on the Yahoo page and even send them to our guest speakers to see if they have any responses, because it does sound like it is something that people are interested in. Is that ok? And if there is nothing then we won't send around.

**Interviewer 1:** Let's thank our very generous presenters now.