



LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

**STANDING COMMITTEE ON HEALTH, AGEING
AND COMMUNITY SERVICES**

(Reference: [Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT](#))

Members:

MR C STEEL (Chair)
MRS E KIKKERT (Deputy Chair)
MRS V DUNNE
MS C LE COUTEUR
MR M PETERSSON

TRANSCRIPT OF EVIDENCE

CANBERRA

WEDNESDAY, 30 MAY 2018

Secretary to the committee:
Ms K Harkins (Ph: 620 70524)

By authority of the Legislative Assembly for the Australian Capital Territory

Submissions, answers to questions on notice and other documents, including requests for clarification of the transcript of evidence, relevant to this inquiry that have been authorised for publication by the committee may be obtained from the Legislative Assembly website.

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Privilege statement

The Assembly has authorised the recording, broadcasting and re-broadcasting of these proceedings.

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Amended 20 May 2013

The committee met at 2.01 pm.

ELKINS, MS ANN, Director, Service Design and Development, EACH
D'ARCY, MS MARGARET, Manager, Strategy and Operations, EACH

THE CHAIR: I formally declare open this public hearing of the Standing Committee on Health, Ageing and Community Services inquiry into the implementation, performance and governance of the national disability insurance scheme in the ACT. This afternoon the committee will hear from representatives of EACH. On behalf of the committee, I would like to thank you for attending today.

I remind witnesses of the protections and obligations afforded by parliamentary privilege and draw your attention to the pink statement before you on the table. Could you confirm for the record that you understand the privilege implications of the statement. I remind witnesses that the proceedings are being recorded by Hansard for transcription purposes and are being webstreamed live. Before we proceed to questions, would you like to make an opening statement?

Ms Elkins: Yes, we would like to make an opening statement. We will share the opening statement, if that is okay. I acknowledge the privilege statement.

I recognise this is National Reconciliation Week. We acknowledge and pay our respects to the traditional owners and custodians of the land, the Ngunnawal people, and their elders, past, present and emerging.

To provide you with some background, EACH is a non-profit health and social support organisation with an extensive 41-year history operating in five states: Victoria, Tasmania, Queensland, New South Wales and the ACT. EACH provides a range of health, disability, community and social services. We are committed to servicing all communities to help address the physical, mental and psychosocial needs of disadvantaged and marginalised people at both community and individual levels.

In our suite of services, the early childhood services include kindergarten, long day care, maternal and child health, early childhood intervention services, paediatric speech therapy, occupational therapy, psychology, specialist GP clinics, a family relationship centre, diverse family counselling and fully integrated support services.

EACH is highly experienced in assessing complex needs, developing service plans and coordinating diverse regional service responses across multiple agencies and stakeholders. EACH defines its purpose as creating supportive environments where everyone can build on their strengths and enjoy better social and economic opportunities.

EACH has been a service provider in the ACT since 2013, when we were successful in a tender for the provision of aged-care services in a home maintenance contract. The services in the ACT expanded in 2015 when EACH commenced delivery of early childhood intervention services as one of six providers invited and supported to establish in the ACT because of the lack of maturity in early childhood intervention services in the ACT.

EACH was delighted when we were advised that we were successful, following a formal tender process, in being appointed the early childhood early intervention partner in the community for the ACT with the NDIS for ACT and Ipswich in 2017.

The implementation of the NDIS is a transformational change for people who live with a disability. The impacts are felt by all those who have been involved in the lives of people with a disability. As with any transformation, it is important to reflect, learn and improve. Because of that, we really welcome the opportunity to appear at this inquiry, and also to hear the voices of those who have appeared before us and who have contributed with their submissions.

To give strength to our expertise in early childhood as to why we are the partner in the ACT, the early childhood services provided under each umbrella include kindergarten, long day care, maternal and child health, early childhood intervention services, paediatric speech therapy and occupational therapy, and the range of services I mentioned earlier. Most of these services are located in Victoria, but each leverages the expertise gained from operating these services to inform our practice as an early childhood partner in the community. EACH is highly experienced in assessing complex needs and developing plans across regions.

We have a 30-year history of providing early childhood intervention services and have been operating as a model for best practice based on international and local evidence since 2012. In that time we have changed our model to keep up to date and change practice as evidence-based practices have come to light.

EACH is a member of Early Childhood Australia and participates in the Victorian, Queensland, New South Wales and ACT branches. EACH was represented on the expert panel in the development of best practice guidelines for early intervention.

EACH understands the significance of building child and family capabilities to increase the potential for children and families to have a greater opportunity to live an ordinary life. EACH is committed to ensuring children and their families are actively involved and that we deliver a flexible service to accommodate changes as needs change.

I will now ask Marg to continue with our early childhood model.

Ms D'Arcy: I am just going to talk a bit about the model and how we operate. I acknowledge that I have read and understand the privilege statement. I have responsibility for the two early childhood early intervention programs that we have in the ACT and in Ipswich in Queensland.

I thought it would be useful to talk a bit about best practice, first of all, in early childhood early intervention. Best practice in early childhood intervention is focused on developing a family's capacity to support their child's development. This involves having one person who acts as the key contact person for the family, with the family defined quite broadly as everyone who has responsibility for the care of the child on an ongoing basis, one person who works in partnership with the family to identify their own and their child's needs and who brings in specialist expertise as required to either work with the family directly or support the key worker to implement strategies

with the family in particular areas.

Part of best practice is working with the family in their everyday settings, so in their natural environment as much as possible. This can include the home, educational settings or long day care; it could also include going out to the local park with a family to observe the child's behaviour in the park or to support the parent developing strategies. Or it could be grandparents' homes.

Operating in a best practice model can create challenges where doctors and clinicians have traditionally operated in a therapeutic model. We see that with referrals where a family come to us saying their child needs speech therapy or occupational therapy. What we do is unpack that with the family to identify what is actually happening with the child on a daily basis to enable the worker and the family together to identify how the child's delays or disabilities are affecting their ability to function in their daily life—for example, teasing out what happens when you go out, what happens at meal times, or with toileting—so that we can work with the family to develop goals, which will often cut across a number of disciplines.

Our model is that with our initial engagement, we are the primary point of contact for children in the ACT who are zero to six with development delay or disability. We play a critical role in working with the family and carer to determine the initial supports needed. Often it will be the family who contacts us directly after a suggestion from a doctor, clinician or educator.

We have developed arrangements with the child and family centres and the children's development service so that they can refer particularly vulnerable families directly to us. Often this will be by actually bringing the family to us and introducing them face to face. Otherwise the family will ring our 1300 number, where some basic information such as contact details will be collected. That is then passed to our initial engagement coordinator or intake position. Our aim is to get to the point where we can make that call back to the family within two days.

Families can come into our program either through the early intervention pathway, which does not require a diagnosis, or through the disability pathway, which does require a diagnosis. Basically, for families to come to us before they are six they do not have to have a diagnosis of a disability; there can just be concerns about developmental delays. When we work with children who turn seven before their next plan review, we do need to establish whether they will meet the criteria for other disability or ongoing early childhood supports or whether they have achieved the developmental milestone so they no longer require funded supports from the NDIS, which would be a cause for celebration.

From the time of our first contact with the family, we see our primary goal as developing an effective engagement with them. We know families are contacting us because they are concerned their child has a developmental delay or disability. For some families, they may have just received a diagnosis which has put a name to the fears and concerns they have had over a period of time. These families will often be anxious, experiencing grief and loss as they have to adjust their expectations of their future and their child's future. Others might just be concerned about a developmental delay where they have noticed the child is just not developing in the same way as they

see other children around them develop. Others may have expected the diagnosis pre-birth and will be well prepared for it. Contacting us might be the first time they have talked about it or we might be a point in a long pathway that has included paediatricians, therapists and educators who have alerted the family.

Whichever way families come into contact with us, our job is to reassure them that there is support available, that we can work with them and their child to help them understand what supports they need and how we put those in place. This will include asking about any formal diagnosis or assessments that have been done or reports and observations from people who have worked with the child and family.

There are some children who will be immediately identified as meeting the criteria for access to the scheme—an example is hearing, which you discussed yesterday—in which case we will start that process for them to get access to the scheme immediately.

With others, it might not be quite clear that they will meet access—a child with a mild speech delay, for instance—in which case we would generally refer them, if that is all they are presenting with, to one of the drop-in clinics that the children's development service provide or other services in the community such as local libraries. In those cases, we do give the message that if circumstances change or families have other concerns in the future, they can come back to us.

The third group is where we are not sure whether they might need access and we need to do more observation and assessment. We would therefore refer them to what we call our initial supports team.

Whichever group the child fits in, we will ensure that they have a contact point, either in the community, for the second group that we are not going to continue to provide services to, or with an appointment for their first meeting if they are in the first or third groups. Our aim is to have that meeting within two weeks of the initial contact. All information collected through the phone call is handed over to the coordinator who is providing appointments so the family do not have to start from the beginning to tell their story again.

Following the initial contact where it is identified that the child will require funded support, EACH will walk alongside the family through the process of developing the request for access for a first plan, conducting annual plan reviews, supporting families to implement the plan, and monitoring the family's utilisation of the plan.

Just to talk about delays, because I know that has been a bit of an issue that has come up before the inquiry, EACH acknowledges that while we work to provide a timely response, we recognise that the earlier intervention starts for children with developmental delays and disabilities, the better the long-term outcomes are.

It is fair to say, though, that there have been unacceptable delays, and it has not always been possible for us to provide the timely response to families that we aim to. There have been a number of reasons for this. As has been already noted in this inquiry, recruiting people with paediatric expertise in some disciplines has been quite difficult, in the ACT particularly. Speech pathology has been one of the most challenging that we have found, but I am pleased to say that we now have two speech

pathologists amongst the other disciplines on our team.

While we were operational within eight weeks of signing our contract, we were not able to attract a full team with the expertise that we were looking for until November last year. We are continuing to recruit to enable us to meet our aim of an appointment within two weeks of first plan, and plan reviews completed within four weeks of expiry. We are continuing to recruit more staff than we need, if you like, so that we can catch up on those delays. We have introduced a triage process so that we can identify and fast-track families with urgent needs. The feedback that we are now receiving from families is that they appreciate the expertise, flexibility and understanding that we bring to the process.

EACH is working with the ACT government, the NDIA and providers to clarify the pathways for families and to be clear about our areas of responsibility. We know that there is still some confusion about what the children's development service does and what we do and where all of that fits together. I am pleased to say that we have a good working relationship, so we can work together to try and resolve that.

We meet with the NDIA every week to discuss issues for individual families and identify solutions. Where there have been delays, we will escalate the process, whether it is from our end or the NDIA end. When we first started that process of the weekly meetings, we had quite a list to work through. Now I am pleased to say that we have very few issues that we have to address at those weekly meetings; we often actually finish them before time, which is always nice.

Just to conclude, we want to acknowledge that there have been problems with the implementation of the early childhood partner in the community approach in the ACT. But through our continuous improvement process we have identified and implemented a number of system and process changes to achieve improved and more timely outcomes for children and families.

Despite the problems, we see the improvements that have been made in the lives of families and children. We feel confident that as we move forward, hear the feedback from families and continue to work with the ACT government, NDIA providers and the community, and develop strengthened approaches, we will achieve our aim of timely and quality service provision for families. Our connection with the child and family centres particularly is a strong basis for connecting with those families, particularly the vulnerable families who may otherwise have been unable to access supports.

I can give you an example of the way that we work, particularly with some vulnerable families. This was a single mother with three children who we worked with. Her youngest was aged two and had a significant developmental delay. She was a recent immigrant and she was struggling with the care of her children to the point where two of her other children were living with their grandmother because she felt unable to provide them with the care that they needed. She was living in a one-bedroom flat with her two-year-old son and she was absolutely overwhelmed by the circumstances and not knowing how to help the two-year-old son.

We had two staff who worked with her to develop her first plan, and the plan was

implemented. However, what we found once the plan was approved was that the mother was struggling to engage services and start using the funding. We met with the mother—a coordinator met with the mother—a number of times and discussed with her the issues that were preventing her from being able to access the service. She identified that she had two service providers that she was looking at, but each time she made an appointment to see them she would cancel the appointment and not go. In the end, what we did was organise for one of our coordinators to go with her to the appointment with the service provider and develop that connection, to help her understand what the service provider was going to do and the work that they were going to do with the child. I am pleased to say that she is now connected with the provider and the child is receiving the therapy and support that he needs.

THE CHAIR: Thank you very much. My question is about your coordination role. I assume that, similar to the local area coordinator that we have for adults and older children who are NDIS participants and those who are not eligible, you would also have a coordination role in the early intervention early childhood sector. Can you explain what that role is and how you work to build the capacity of those services across the sector and link in with people that come to you?

Ms D’Arcy: Yes. I will say that that is an area of work that we need to do a lot more work on. When we first started, our focus was very much on getting plans done before they expired to make sure that families did not have a gap. As you know, we are based at the child and family centres, which gives us a really good, close relationship with the staff there. We are working with ACT Playgroups to look at particularly what supported playgroups are doing and how we can work in with them to support their work. We meet with people like maternal and child health nurses and educators on a regular basis. I guess at the moment what we do is respond. When we see there is an issue that requires some capacity building, we will work with that agency or organisation to increase their capacity. But that is a huge task that requires a focus almost of its own. About 10 per cent of our work is focused on that community capacity building. We are in the process of engaging a person that will just have that focus across our two regions, and that will further that work.

Ms Elkins: I can add to that a bit. Just this morning, the team had a session with the education department. That was two-way capacity building, with the education department talking about what the expectations were of the education sector from their understanding and asking the team if they had identified any issues so that they could work out jointly if there is a way that they could build that capacity and respond to that. I think the more we do that type of work and look at things jointly to improve the sector, the more we will feel that we are achieving what we want to achieve.

THE CHAIR: Has any market analysis been undertaken, either by the NDIA or by your organisation, in relation to the early childhood early intervention sector in the ACT and what some of those weaknesses or challenges might be?

Ms D’Arcy: Do you mean amongst providers?

THE CHAIR: Amongst providers, but I guess what I am asking is: do you understand the layout of the sector and could you provide some documentation that might help us to understand that a bit better?

Ms D’Arcy: I do not think we can provide documentation at the moment. There is a child and family working group that we are part of with the ACT government and NDIA, and that group is working towards identifying where the holes are, if you like, that we need to put a plug in, and how we then go about doing that.

THE CHAIR: In terms of your referrals and helping children with a disability and their families to implement their plans, you must have a fairly good pathway to services, and that must be mapped out in some way.

Ms D’Arcy: Yes

THE CHAIR: Is it possible to provide that sort of information to us?

Ms D’Arcy: The pathway to services once a child has a plan is that we will sit down and talk with the family about the providers. As you have heard, there are over 1,000 registered providers in the ACT. Of those who have really strong expertise in early childhood, there are probably 20 or 30 that operate within more or less a best practice framework.

It is not our role to actually choose the provider for the family. It is our role to help the family choose a provider, if that makes sense. We would never recommend a particular provider. Where we identify concerns that have come to us because of a family’s experiences with a provider, we will follow them up. But we do not particularly have a map of providers; that is on the NDIS portal. All our staff are certainly aware of the providers that are available and are aware of the different practices within the providers so that they can work with the families to help the families identify a provider that will be suitable for their needs.

Ms Elkins: I will just add to that as well. If our staff are identifying, when they are working with families to implement plans, if they were unable to implement it because there was a gap in the service provider market, which I think is what you are asking, we would be aware of that and we would work on that. I do not think we have come across that problem where there is a complete market breakdown at this stage. I think that all of our families have been able to find providers, though we are aware that in some service provider fields there is less choice than others.

THE CHAIR: In what areas?

Ms D’Arcy: One of the biggest problems is psychology, particularly around early childhood.

Ms Elkins: We were invited by the University of Canberra to be involved in a working group when they were trying to identify a way to work with speech therapy. We would work across the sector at a higher level to advocate and try and develop ways to increase the market.

MRS KIKKERT: Thank you both for being here today. How can the ACT government support you in delivering the services that you provide?

Ms Elkins: It is really great that we are able to co-locate. For families accessing services, especially when it is a new development, it is very important that they do not have to try and think about “Where do I go and who do I talk to?” If a family can continue to go to the places they have always gone to, like the child and family development centres, there is no wrong door. Being able to negotiate co-locations has been very helpful.

We continue to talk about the different sectors that sit within ACT government and how we work together. For example, having the department of education come and work with our team is very supportive and helpful. We just need to continue working together so we have a joined-up service system.

Ms D’Arcy: There probably is a need to do a bit more work with Health in the ACT, to have those relationships clearer. I think that would be a useful thing to look at.

THE CHAIR: What work do you do with the education system in early primary school?

Ms D’Arcy: We do not do work in the primary schools; rather, we work with the educators. We work with INSET, for instance, in the department of education. And we would support families who have children who are of a school age or preschool age to make those connections to get their children enrolled in preschool and to look at the options for education.

Once the family is actually with a provider, that is really the provider’s responsibility, not our responsibility. We would not do any individual work in schools; that would be more providers if the child has a plan. As I say, we will work with the family around what sort of education options there are that would be suitable for the child and support them in that if they do not have a plan and as part of our initial supports and early intervention work with families. Otherwise we would not go into schools individually.

MR PETTERSSON: One of the common things we keep hearing is that it takes a long time for the NDIS to respond. Has that been your experience?

Ms D’Arcy: Sorry, a long time for?

MR PETTERSSON: To respond to queries, questions, when you are trying to develop a plan.

Ms D’Arcy: From our point of view, no. We have a really good relationship with NDIA. At the moment we have a process where, if we have put in a plan on behalf of a family and the NDIA delegate has a query about that, they will contact the coordinator who has worked with the family and talk about that to arrive at a solution. Our experience with the NDIA is very positive.

Ms Elkins: Some of the feedback you are getting might be referring to us, because we operate as a partner with NDIA. People might be saying that whether they are contacting NDIA or the partner. They might be describing a delay. We recognise that there have been delays in the start-up of our service, which we think have improved

immensely.

MR PETTERSSON: Sorry, I am thrown for a loop by that one. Are you saying that some of those initial delays were potentially caused by delays internally within each?

Ms D’Arcy: Yes.

MR PETTERSSON: Why was that? It was new; I get that. But you said you have identified the problems and fixed them. What were the problems you identified?

Ms Elkins: It was just having the staff and the responsive system, the same as when you roll out any new system. It is the same as NDIA rolling out, the transitioning to a new system. We are part of the whole system as a partner with the NDIA. We work together. It was, I guess, families understanding that and making sure we were accessible to families. I think having us work as a partner improves the accessibility now for families.

Ms D’Arcy: Also, as I said before, our main focus when we first started was actually around plan reviews, not on new children coming into the system. That was because we were really aware that for families who are already getting a service, we did not want them to have a gap in the service, so we needed to do the plan review before the plan expired so there was no gap in the system. That was very much a focus. It did mean that some new referrals waited for what was probably an unacceptable length of time, but we now have a process to deal with that.

MR PETTERSSON: Can you give me some examples of what you mean by an unacceptable amount of time? Are there clinical consequences for the delays?

Ms D’Arcy: No; more unacceptable in that we do not think any child should have to wait for any level of service, really. Our goal is to get children into early intervention and support families as quickly as we can, because that is what is best for the child and the family. I would say any delay is unacceptable.

MR PETTERSSON: Good answer. Thank you.

THE CHAIR: This is a supplementary. Do you have any numbers that you can provide us about your current benchmarks in terms of timing with plan reviews and new plans being established?

Ms D’Arcy: Yes. What we are working on for plan reviews is that the plan is submitted within two weeks. All the work that is done for the plan is finalised so that the plan can be submitted two weeks before the plan expiry. We are working on notifying families that their date for their plan review is coming up 12 weeks prior and letting them know what information we will need—that we will need reports and assessments from their current providers or from anybody else who has been involved with the child—and then to have a meeting with them at least four weeks before the plan has expired.

THE CHAIR: And then with new plans, you contact them within two days of referral but you—

Ms D’Arcy: That is our aim. I am not saying we are there yet. That is certainly what we are working towards—that we contact families within two days, that we have an appointment within two weeks of that contact and that where they do go on to require funded supports, once they have met access, we develop the first plan with them within two weeks. That is certainly what we are working towards, yes.

MRS DUNNE: You said in response to Mr Pettersson’s question that there were not clinical implications. We have heard from the Shepherd Centre that the delays in referring babies to hearing services may—it is probably too soon to tell—have a clinical impact because these children need to have the speaking part of their cerebral cortex stimulated in a way that hearing children do not and that if they do not get that service early the long-term prognosis is not as good. Can you talk us through what has happened with children with hearing impairment in the ACT that prompted the Shepherd Centre to make the submission to us that it did?

Ms D’Arcy: I think that was addressed, in part, by NDIS yesterday. Certainly, the only thing I can say is that, if we have a child with a hearing impairment that comes to us, we would treat that as an urgent case and we would process it as quickly as we can.

MRS DUNNE: It was put to us that children with hearing impairments get a downgraded classification disability. I have had this experience. I have two children with cystic fibrosis. It was put to us that when being assessed for a disability—they have a medical disability—they were asked things like, “Can they sit, can they grasp, can they reach out,” et cetera, so that it is a musculoskeletal test, which is irrelevant to children who have hearing impairment. It was put to us that as a result they do not get a large amount of money in their program because they do not have musculoskeletal difficulties and it makes it difficult for families to buy the services they need up-front in an early intervention. What they need is early intervention that goes on for three or four or five years, and then possibly not much intervention after that.

Ms D’Arcy: Which is the whole goal of early intervention, that children do receive intervention early in life that then allows them to have much improved outcomes later in life. In relation to the Shepherd Centre, I do not really know enough about this. They have not raised their experiences in the ACT with us directly; so I am really not quite sure what they are talking about.

What I would say is that some children with hearing impairment do not only have hearing impairment, they may have a whole lot of other things. What we do is approach the child as a whole. We are actually developing an arrangement with the Shepherd Centre and other specialist hearing impairment providers in the ACT to build up the expertise of our staff and to make the process with us as smooth as possible.

However, it is still really important for us to consider all aspects of the child, not just the hearing impairment. It is important for us to ask the family about what issues the child has with muscle development or with tone or with behaviour. That all helps us form a picture of what supports the family needs. While we will certainly expedite hearing impairment where there is a clear need, we still need to look at the child as a whole and to discuss with the family what the child as a whole needs, not just one

aspect of it, if that makes sense.

MRS DUNNE: Yes, I understand that, but—

Ms D’Arcy: Good.

MRS DUNNE: what we were told was that the reference to Hearing Australia was not expedited; it was, in fact, delayed and that, when it came time to allocate an amount of money to a package for a deaf child, they were saying, “They are not really very disabled because they can grasp and sit and do all these things,” and therefore the amount of money being given to parents of deaf children did not match the therapeutic demands of those early four to five years.

Ms Elkins: Our understanding is that the referral to Australian Hearing should be expedited and that is the pathway—

MRS DUNNE: Yes, we all agree that it should be expedited. What we are hearing is that it is not.

Ms D’Arcy: We are not the ones who make the referral to Australian Hearing.

MRS DUNNE: We have been told that you are a part of the process, that people have to go to you and you are the gatekeeper to Hearing Australia—

Ms D’Arcy: No.

MRS DUNNE: and that the old system, with the audiologist being the gatekeeper to Hearing Australia, is no longer the case and that the NDIS are saying that they have taken six months or so to contemplate how to improve this. I thought it would have been pretty simple but I am no longer a bureaucrat. What we are hearing from the hearing specialists is quite different to what we are hearing from NDIA, and what you are saying is something different again.

Ms D’Arcy: And I cannot answer that, as I say, because the Shepherd Centre have not talked to us directly about that. I am not aware of what the issues are. I would need to follow that up and find out more.

MRS DUNNE: It might be an idea if you had a look at the evidence.

Ms D’Arcy: Yes, and yet we do have regular contact with the Shepherd Centre; so I am intrigued as to where that has come from.

Ms Elkins: If we have a child who comes to us with a hearing impairment, we would expedite the referral to Australian Hearing, and we will do what we can to ensure that the pathway that was there in the past is still there.

MRS DUNNE: People do come to you; you are the means by which people are referred to Hearing Australia?

Ms D’Arcy: No. My understanding is what is supposed to happen is that from the

hospital the referral is made to Hearing Australia, and from there, if the child needs a plan, that goes directly to NDIS. So I am not—

MRS DUNNE: NDIS or to EACH?

Ms D’Arcy: No, NDIS is my understanding. I think that was explained yesterday at the hearing.

MRS DUNNE: I do not think so.

Ms D’Arcy: Right.

MRS DUNNE: I am just putting it out there.

Ms D’Arcy: Yes.

MRS DUNNE: It is something that this committee thinks needs to be dealt with, and it is not being dealt with.

Ms D’Arcy: Absolutely, yes.

MS LE COUTEUR: The NDIS people explained to us that, in fact, they did not do advocacy, they do not fund advocacy. That was not part of the NDIS. You obviously are not an advocacy organisation but clearly you would be interfacing with all the kids’ advocates, who are primarily their family, I imagine.

Ms D’Arcy: Yes.

MS LE COUTEUR: Are you finding that families, generally speaking, have enough capacity to do this? I certainly feel, and I think the rest of the committee would agree, it would appear the people who did best out of NDIS were people who had someone who could advocate for them, whether it be themselves or a family member, but people who were not good at advocacy were less likely to get an adequate package out of the NDIS. How is this working for your clients—for kids who obviously cannot be their own advocates?

Ms D’Arcy: No, the families are the advocates, and they are the people that we work alongside, really. We work in partnership with the family. In terms of advocacy, I am just thinking of a situation that we have had with a childcare centre where the childcare centre basically would not take a child because of their developmental delay, and our coordinator has advocated with that centre about the need for inclusion for that child and reminded them of their responsibilities in relation to that.

In terms of that individual advocacy with individual organisations, we will do that. We do not advocate for the family but we work alongside the family, if that makes sense. I guess one of the concerns that we have is that the families who are particularly vulnerable are those who are not articulate and who do not have a voice. And that is where I see that the work that we are doing with the child and family centres is particularly important because that is the group that they work with.

They can, if they have a family now, walk down the corridor to see our worker and introduce a family to us so that we can then work with them. Our role is to understand what the family needs. So to some extent, yes, they can have an advocate if they need to but generally they do not because we will work with them in all sorts of ways to help to understand what their needs are and how we can best support their needs.

Ms Elkins: But it is everyone's right to have access to an advocate.

Ms D'Arcy: Yes.

Ms Elkins: So there is a role for advocates in a system like NDIS.

MS LE COUTEUR: It is people's rights but, presumably, from what we have heard, that is not NDIS funded; it would be a right that would only be available to some families. Am I correct in saying that?

Ms Elkins: There are funded advocacy services that people can access separate to NDIS that will support them.

MS LE COUTEUR: But we have also heard evidence that they were turning away half of their potential clients; it is not a freely available service. I am tending to imagine that the people who fall through the cracks are the people who usually fall through the cracks.

Ms D'Arcy: I think that is really important to actually recognise and I see part of our work is to actually find those people who are falling through the cracks and work with them, not necessarily as advocates but to work with them to ensure that they can access the same services as everybody else.

MS LE COUTEUR: One particular group who would appear to be falling through the cracks is the multicultural community. We heard evidence earlier that—I cannot remember the figures—they are grossly under-represented in terms of NDIS participants. Is there anything that you are doing so that children from multicultural communities actually do get into EACH, into the services, because it does not appear that is happening equitably?

Ms D'Arcy: Yes. Perhaps I could use what we are doing in Ipswich as an example of that. We do not do it here because we have a much smaller team here, but we actually employ up there two, what we call, bi-cultural workers who have experience of both working in multicultural communities and working with those with disability.

Our team here is quite diverse, which is always helpful. It is an area that we are aware of and we use interpreters when we need to. We have also worked really hard to make sure that families feel culturally safe when they come to us. In terms of looking at how we keep appointments, how we invite people into our space, or they invite us into their space, we work very hard at that. We have not had a particular strategy, I guess, if that is your question.

MS LE COUTEUR: Partly because it—

Ms D’Arcy: We have not had a particular strategy to target core communities but that is certainly in our plan, yes.

THE CHAIR: My question is in relation to children with autism, undiagnosed or diagnosed, and how you support them through your service.

Ms D’Arcy: We support children with autism in the same way as we support all children with developmental delays and disability. There is a saying that if you know one child with autism you know nothing about autism. Autism covers a huge spectrum. We work with each family individually and we approach each child as being unique and having unique needs and the family as having unique needs for supports. We work with the families to identify what is important for them, what their goals are and what they want to achieve.

THE CHAIR: And what do the supports available in the ACT include for children with autism?

Ms D’Arcy: Sorry?

THE CHAIR: Are you concerned about any gaps for children in that category?

Ms D’Arcy: Not that have been raised with us directly, no.

THE CHAIR: What are the typical supports that you would be helping families to access?

Ms D’Arcy: The most common form of support under an early childhood package would be what we call capacity building, which covers a broad range of supports—actually supporting a family to access a trans-disciplinary approach so that they can access people for behavioural issues, for speech and communication, for sensory issues. Does that make sense?

THE CHAIR: Yes. And the availability of group-based early intervention supports for those children in the ACT, what is—

Ms D’Arcy: Group-based early intervention?

THE CHAIR: Like playgroups and other services where groups of children can come together, is that—

Ms D’Arcy: There are a range of groups and groups aimed at supporting families as well as playgroup-type groups that are operated by NDIS registered providers.

THE CHAIR: You are not concerned about any gaps in that area?

Ms D’Arcy: When you work in early childhood you can always think that there would be a lot more things that you can do and there would be a lot more supports that could be available for children and families, but generally what we find is that we are able to match up families with the supports that they need.

THE CHAIR: And that includes children who are undiagnosed?

Ms D’Arcy: Yes.

MRS KIKKERT: You do not have any volunteer workers?

Ms D’Arcy: No.

MRS KIKKERT: I am just looking at your web page and it says “volunteer work”.

Ms D’Arcy: That is EACH generally.

Ms Elkins: You are looking at EACH. We do not have any volunteers in the ACT at all. And all our team are skilled workers.

MRS KIKKERT: But your other jurisdictions have volunteer workers?

Ms Elkins: Yes.

MRS KIKKERT: Is it just ACT that do not have volunteers?

Ms D’Arcy: In the early childhood early intervention program we do not have volunteers. Ipswich and ACT, neither of them has volunteers.

MRS KIKKERT: Are you in need of volunteers or are you quite right?

Ms D’Arcy: No, we do not.

MR PETTERSSON: I just wonder if you could clarify something for me. You are funded per participant?

Ms D’Arcy: No.

MR PETTERSSON: How are you funded?

Ms D’Arcy: We have a contract. I will let you talk to that.

Ms Elkins: We have a grant that is a block funded that we need to deliver certain functions under. Marg described the number of functions that we deliver.

MR PETTERSSON: And is that determined on the number of participants in—

Ms Elkins: We do have a target number of participants that we will work with, and it also includes working with the community as a whole.

MRS DUNNE: On that, you have a grant. Does that cover the therapy that might be delivered to an individual on their individual plan?

Ms D’Arcy: No.

Ms Elkins: No.

MRS DUNNE: That is NDIS funded?

Ms Elkins: Yes.

Ms D’Arcy: Except we do—I would not call it therapy—some initial work with families who come to us.

Ms D’Arcy: Whether they end up getting a plan—

MRS DUNNE: But your grant does not cover a package that an individual would receive?

Ms D’Arcy: No. We will work with people when it is not clear whether they will go on to have a plan or when they are waiting for a plan, and while we are still trying to assess them or if they might need some short-term intervention from us instead of going onto a plan. We do not get additional funding for that. That is part of our grant agreement.

MRS DUNNE: If a child is sent to you and you are told they do not have a great grip, they need fine motor skills—a two, three, four-year-old, something like that—once upon a time they used to go to Therapy ACT and they would get a bit of OT and they would be sent home with some exercises and stuff like that. Do you do that?

Ms D’Arcy: In that case, if that is all it was, no. We would probably refer them to the child development service drop-in clinic. If that is all it is it probably just needs a little short-term intervention and that will be right. If they had that plus some communication and language issues or some sensory or behavioural issues, then yes, we might bring them in and we would do some short-term work with them.

MRS DUNNE: How do you know where to draw the line?

Ms D’Arcy: Basically, what you just said. If it is a very mild delay in one domain—a very mild delay in communication or in sensory issues or whatever—then we would generally refer them to the child development service. If it is something that is a little more complex or that crosses over a number of domains, we would bring them in and we would do a bit more work and a bit more observation and assessment to try and decide whether the initial supports that we can provide will be sufficient. Part of that initial support also means linking them into things that are happening in the community like playgroups, activity groups and libraries—all sorts of things like that that are out there that will all help a child and a family with bringing the child’s development up to speed, if you like. I have lost my train of thought.

MRS DUNNE: I think that probably answers the question.

Ms D’Arcy: Good.

MS LE COUTEUR: I guess this is a bit of a follow-on from the questions the chair asked you. What do you do in terms of finding the list of other groups that you were

talking about—playgroups and the libraries? I assume there is more than that. Do you actually devote resources to finding those other groups?

Ms D’Arcy: Yes.

MS LE COUTEUR: And do you put any resources into developing them to meet the needs that you are seeing?

Ms Elkins: It is really important that we work with mainstream organisations and help them have a more inclusive approach. If there was a need and families were feeding back that there was a gap in that, we would work with them to skill up their capacity in being more inclusive. One of the first things our staff did was scope out what other services were available to build a directory of services they could link the families into. And that is an ever-growing list of services.

THE CHAIR: Another question I had was about interface with the commonwealth-funded childcare subsidy system, including the new system that starts on 1 July, and particularly how many of the children that you see through the plans that you help develop will be accessing the additional childcare subsidy and those sorts of supports. What preparation has your organisation done ready for the transition on 1 July and linking parents in, who, I understand, have to sign up to get those subsidies? Many have not in the lead-up to 1 July. And how is the transition being prepared for?

Ms D’Arcy: It is not a core part of our work. It might be something that we get involved with because a family has a child in child care and they are concerned about the child continuing in child care. Child care can be a really useful thing for children who have developmental delays in developing social skills. But we would not work with families specifically around child care. We might support some individual families around that but not as a whole. We would not do that.

THE CHAIR: Even where they have a 24-hour worker that comes into the family home as part of in-home care? You do not work with those families?

Ms D’Arcy: It would be very rare with families that we work with. Those really intensive, complex cases would go directly to NDIS or someone who has 24-hour care.

THE CHAIR: Are there any non-mainstream early childhood services that you work with, that is, services that are not funded by the childcare subsidy and not CCB eligible, that support children with disability in the ACT?

Ms D’Arcy: We do not work directly with childcare centres or childcare providers. Our contact with them would be more through the families that we work with who have that contact. And we would work with them around that.

THE CHAIR: You are really only working with mainstream early childhood services, not any specific, dedicated services that support children with a disability.

Ms D’Arcy: We work with services that support children with a disability all the time.

THE CHAIR: But in mainstream services?

Ms D’Arcy: No. The NDIS providers are people who work with children with disabilities and developmental delays all the time.

THE CHAIR: I mean early childhood educational care services. Are there any non-mainstream early childhood care services that you work with in the ACT?

Ms D’Arcy: No, not directly.

THE CHAIR: On behalf of the committee I would like to thank you for attending today. A proof transcript will be forwarded to you once it is available to make any corrections. I now formally declare this public hearing closed.

The committee adjourned at 2.56 pm.