Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000001

NDIS ACCESS

Question Date: 04 December 2020 **Format:** Spoken

Question:

Senator URQUHART: I do. Thank you very much. You've given us some figures here until 31 May, but I'm interested in digging a little bit deeper around those. Can you tell me how many people in total with a diagnosis of FASD have applied for access to the NDIS?
Ms Johnson: In total, we've had 1,606 participants with a FASD diagnosis apply for the scheme as at 30 September 2020, of which 1,100 indicated that FASD was their primary disability; and 506, their secondary.
Senator URQUHART: Okay. And how many of those applications or access decisions have been approved?
Ms Johnson: It's 94 per cent, so 1,514.
Senator URQUHART: Can you tell me how many were approved after the applicant made multiple access requests?
Ms Johnson: I'd have to take that on notice.
Senator URQUHART: If you could take that notice, that would be great. Also—maybe you'll need to take this on notice—how that then compares to other cohorts of disability types that are applying for the NDIS. So I guess the question is: do FASD applicants persist with it or do they give up early?
Ms Johnson: I'll have a look at that. I've got probably just a little bit more information on access. For the nought to six-year-olds, it is 100 per cent of people who have applied who have been given access to the scheme; for seven to 14, it is 93 per cent; for 15 to 18, it is 96 per cent. But, generally speaking, the access rate for FASD across all the age groups is higher than for other disability types. Senator URQUHART: Okay. Of the NDIS applicants with FASD that are rejected, how many of those have made multiple applications?
Ms Johnson: I'll take that on notice.
Senator URQUHART: Thank you. Can you get a breakdown—and you might need to take this on notice as well—of the above response to FASD participants in rural and remote areas and to Aboriginal and Torres Strait Islander people.
Ms Johnson: Yes, I'm happy to take all of those on notice. I'd just make one comment. It's quite a small number that haven't been successful, so breaking it down by remote and very remote Indigenous participants might lead to identifying information. So we'll check what we've got on that. But we'll break it down.

Answer:

As at 30 September 2020, 461[1] NDIS applicants with a primary or secondary diagnosis of FASD had made multiple access requests.

As at 30 September 2020, of the 80 applicants with a primary or secondary FASD diagnosis who had an access not met decision, 34 had made multiple access requests.

The table below shows ineligible applicants split by Indigenous/non-Indigenous and remoteness classification (Modified Monash Model 2019) as at 30 September 2020[2].

Remoteness	Indigenous	Non-Indigenous	Not stated	Total
Major cities	12	20	5	37
Population > 50,000	8	<5	<5	13
Population between 15,000 and 50,000	<5	8	<5	12
Population between 5,000 and 15,000	<5	<5	<5	<5
Population less than 5,000	<5	<5	<5	7
Remote	<5	<5	<5	<5
Very Remote	<5	<5	<5	<5
Missing	<5	<5	<5	<5
Total	**30**	**36**	**14**	**80**

Remoteness	Indigenous	Non-Indigenous	Not stated
Major cities	40%	56%	36%
Population > 50,000	27%	6%	21%
Population between 15,000 and 50,000	7%	22%	14%
Population between 5,000 and 15,000	3%	6%	0%
Population less than 5,000	13%	8%	0%
Remote	0%	3%	21%
Very Remote	10%	0%	7%
Missing	0%	0%	0%
Total	**100%**	**100%**	**100%**

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[1] During the transition of existing State/Territory/Commonwealth programs to the NDIS, where insufficient information was available to contact a prospective participant, the original access request was determined as not able to be progressed. Where an application was received at a later point in time, this is recorded in the ICT system as a subsequent access request.

[2] As at 30 September 2020 of 1,606 applicants diagnosed with FASD, 1,501 have an access met decision, 80 have an access not met decision, 13 have their access revoked/ceased, 7 had their access requests cancelled, 4 applicants had their access request withdrawn, and 1 had their access request in progress.

Reference No: SQ21-000002

PLAN UTILISATION

Question Date: 04 December 2020 **Format:** Spoken

Question:

Senator URQUHART: How much funding are FASD participants using from their plans? What's the average utilisation?
Ms Johnson: The average utilisation as at 30 September for people with FASD is 65 per cent of their plan. I might just elaborate a little bit on that. We know across the whole scheme that participants tend to use more of their plans the longer they've been in the scheme. So for people with FASD who are on a subsequent plan—that is not their first plan—it's 70 per cent. That compares with the overall scheme average of 71 per cent. When you look at it by some of the different age groups, generally speaking it's a fairly similar utilisation rate for FASD as it is for the scheme as a whole.
Senator URQUHART: You might want to do this or notice: are you able to provide a breakdown of plan utilisation from the start of the NDIS according to local government area, age, plan size and then the length of time as an NDIS participant? I think you've just said that the longer they're on it the more likely they are—
Ms Johnson: Yes, it's quite significant.
Senator URQUHART: Are you able to provide that on notice?
Ms Johnson: I will take that one on notice.

Answer:

The NDIA produces a range of reports and analyses by service district and local government area, including participant characteristics (age group, primary disability, indigenous status etc.), plan utilisation and other market indicators. These can be accessed via the NDIS market monitoring page and the NDIS website here:

- https://data.ndis.gov.au/reports-and-analyses/market-monitoring
- www.ndis.gov.au/about-us/publications/quarterly-reports

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000003

RURAL AND REMOTE PARTICIPANTS

Question Date: 04 December 2020 **Format:** Spoken

Question:

Senator URQUHART: Thank you. Senator Askew just asked a question about rural and remote. I think I want to delve a little bit deeper into that. Of the total number of NDIS participants with FASD can you tell me how many are in rural and remote areas? You went around some of the states, but I'm not sure that they were all rural and remote.
Ms Johnson: Yes, I can tell you that. Of the 988 that I mentioned before, at 30 September, with primary FASD we've got 61 in remote areas and 52 in very remote areas. There's also another 94 in populations of less than 5,000 people.
Senator URQUHART: Are you able to then break that down as to where those are?
Ms Johnson: Yes. I'll take that on notice. I don't have that level of detail with me.

Answer:

Number of active participants with an approved plan with FASD as disability, split by state and territory and remoteness (Modified Monash Model 2019) as at 30 September 2020 is below.[1]

State & Territory	Remoteness								
	Major Cities	Population > 50,000	Population between 15,000 and 50,000	Population between 5,000 and 15,000	Population less than 5,000	Remote	Very Remote	Missing	Total
NSW	170	18	131	54	53	<5	<5	<5	430
VIC	72	26	26	12	12	<5	<5	<5	148
QLD	189	132	15	35	46	10	18	<5	445
WA	102	12	16	<5	12	29	26	<5	197
SA	47	<5	6	9	10	<5	<5	<5	79
TAS	<5	19	11	<5	12	<5	<5	<5	43
ACT	12	<5	<5	<5	<5	<5	<5	<5	13
NT	<5	41	<5	<5	<5	36	27	<5	106
OT	<5	<5	<5	<5	<5	<5	<5	<5	<5
Total	592	251	205	110	147	79	76	<5	1,461

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[1] Missing refers to those participants for whom location data is not available.

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000004

PLAN UTILISATION

Question Date: 04 December 2020 **Format:** Spoken

Question:

Senator URQUHART: That's fine. What's the average percentage of plan utilisation for NDIS participants in rural and remote areas?
Ms Johnson: It does differ. Once again, as at 30 September the utilisation in remote areas across the scheme is 67 per cent and the utilisation in very remote areas is 43 per cent. For FASD specifically for remote it's—
Senator URQUHART: Sorry. Do you have any figures on the population less than 5,000?
Ms Johnson: Yes, it's 62 per cent. When I look at it for FASD by itself, we have 63 per cent for less than 5,000, remote is 57 per cent and very remote is 59 per cent, so for very remote it's higher for FASD. I'm actually giving you the stats for people on their second plan or later, just because the first plan is always quite a bit lower.
Senator URQUHART: Yes, great. Do you have a breakdown of how many of those participants are Aboriginal and Torres Strait Islander?
Ms Johnson: I will take on notice the exact figure, but it's roughly half.
Senator URQUHART: Half of those numbers?

Answer:

Number of active participants with an approved plan with FASD as disability, split by Indigenous status as at 30 September 2020 is below.

	Indigenous status			
	Yes	No	Not stated	Total
FASD	737	509	215	1,461
% FASD	50%	35%	15%	100%

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000005

NDIS PARTICIPANTS IN THE JUSTICE SYSTEM

Question Date: 04 December 2020 **Format:** Spoken

Question:

Senator URQUHART: What's the average percentage of plan utilisation for NDIS participants who are in juvenile detention or jail?
Ms Johnson: I would have to take that on notice.
Senator URQUHART: Okay, if you could take that on notice. You might need to take this series of questions on notice then. How many NDIS participants with FASD are in juvenile detention or jail?
Ms Johnson: I'll take it on notice, noting that a lot of our structured data information doesn't always have whether or not a person is incarcerated. We will look at what is available.
Senator URQUHART: Right. Then further to that: how many of those are Aboriginal and Torres Strait Islanders and what's the average percentage of plan utilisation for NDIS participants with FASD in juvenile detention or jail?
Ms Johnson: I'll take that on notice...
Ms Studdert: If I could just jump in there. I think it's important to note that, when participants are in the justice system, plan utilisation is generally very low because the services are then provided by the state as part of the juvenile system—
Senator URQUHART: Do you keep track of the provision of those services once that occurs?
...
Ms Studdert: ...it would be very difficult for us to track what services are being provided in the system. What we really put our effort into is picking up participants as they move in and out of the system. We are expecting low utilisation when they're in and then trying to pick up participants as they exit in a very timely manner so they're back into service support through their plans...

Answer:

In 2015, all governments agreed the ‘Principles to determine the responsibilities of the NDIS and other service systems’, including Applied Principles and Tables of Support (APTOS). The APTOS Principle 9 addresses the responsibilities of the NDIS and Justice systems. It outlines that while an NDIS participant is incarcerated, the justice system is responsible for most disability related supports and associated costs. It is expected that utilisation will be very low during periods of incarceration and/or that the participant does not have an active plan in place.

As at 30 September 2020:

- 1,244 NDIS Participants were known to be incarcerated. Of these 1,127 had an active plan in place.
- 403 (32%) incarcerated NDIS Participants identified as Aboriginal and/or Torres Strait Islander.
- 27 (2%) incarcerated NDIS Participants had a primary disability of FASD.
- 23 (2%) incarcerated NDIS Participants both identified as Aboriginal and/or Torres Strait Islander and had a primary disability of FASD.

- The table below reports the average committed supports and average utilisation for NDIS Participants in custody with an approved plan.

	Identifies as Aboriginal and/or Torres Strait Islander	Primary disability of FASD	Both Aboriginal and/or Torres Strait Islander AND primary disability of FASD	Total NDIS Population
NDIS Participants likely to be incarcerated (total)	403	27	23	**1,244**
NDIS Participants likely to be incarcerated (with approved plan)	368	25	23	**1127**
Average annualised plan budget	$86,501	$114,546	97,234	**81,582**
Average utilisation	38%	54%	53%	**46%**

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000006

NDIS PARTICIPANTS IN THE JUSTICE SYSTEM

Question Date: 04 December 2020 **Format:** Spoken

Question:

Senator URQUHART: Ms Studdert, can you tell me how many registered NDIS providers provide support to participants with FASD?
Ms Studdert: I don't have that number at hand. I might just ask Ms Johnson how we would access that.
Ms Johnson: We can provide that on notice. We'd have to have a look at the participants with FASD and their plans and then the providers who have drawn down against those plans.
Senator URQUHART: Okay, if you could provide that on notice. How many registered providers support participants with FASD in rural and remote, so if you can give us a total number, then break it down into those rural and remote? How many providers provide support to Aboriginal or Torres Strait Islander participants with FASD?
Ms Johnson: I'm happy to take that on notice.
Senator URQUHART: I guess just breaking it down.
Ms Johnson: Yes.
Senator URQUHART: You've already said that you don't have providers who provide support to participants with FASD who are in juvenile detention right now.
Ms Johnson: No, we won't have that information.
Senator URQUHART: Maybe, as part of that information, you could talk about what the NDIA is doing to address those, because we would think they'd be clear. You've already indicated there are thin markets in some areas. What is the NDIA doing to ensure that people with FASD can use funding in their NDIS packages—how that gets utilised?
Ms Studdert: I think we recognise there are thin markets, a range of different thin markets in a range of areas, and the trials we are doing are not 100 per cent covering those. But we can certainly give you a bit more information about those that would be largely addressing utilisation rates for people with FASD. Chair, I notice Senator Urquhart has been referring to data tables that were at the back of our submission; that's May data. If it would help the committee, we could give you an updated set of numbers from our September quarterly report.
Senator URQUHART: That would be helpful.

Answer:

Summary of providers who ever delivered supports to participants with FASD by remoteness classification (Modified Monash Model 2019) as at 30 September 2020[1][2] is below.

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[1] The column of the two tables below cannot be summed up to obtain the total number of providers on national level as providers may deliver supports to multiple groups.

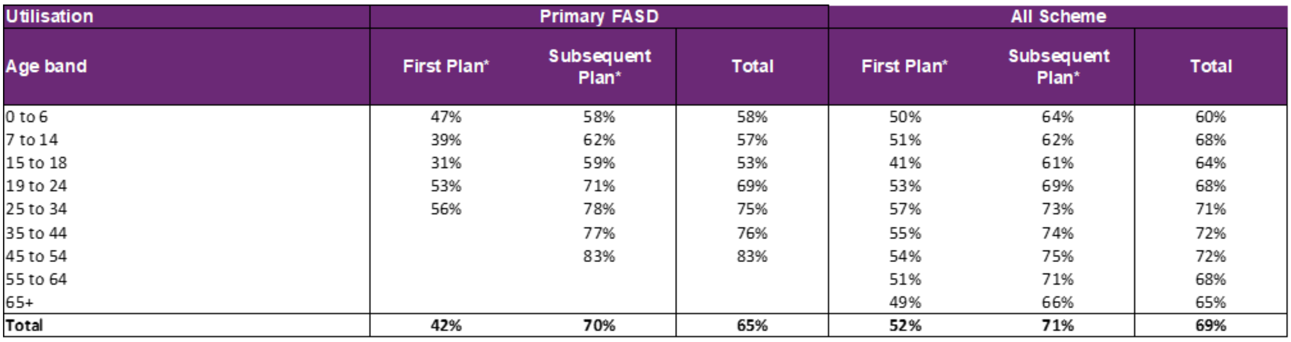
[2] The number of providers in this analysis consists of those that have received a payment for supports provided to Agency managed participants. Plan managers (who are registered providers) make direct claims from the participants' budgets to pay the ultimate providers for supports on their behalf, and the number of ultimate providers in this analysis is not identified. Self-managed participants also directly claim from their plan.

Remoteness classification	Total providers (ABN)
Major Cities	926
Population greater than 50,000	520
Population between 15,000 and 50,000	319
Population between 5,000 and 15,000	228
Population less than 5,000	291
Remote	94
Very Remote	59
Missing	5
Total	**1,765**

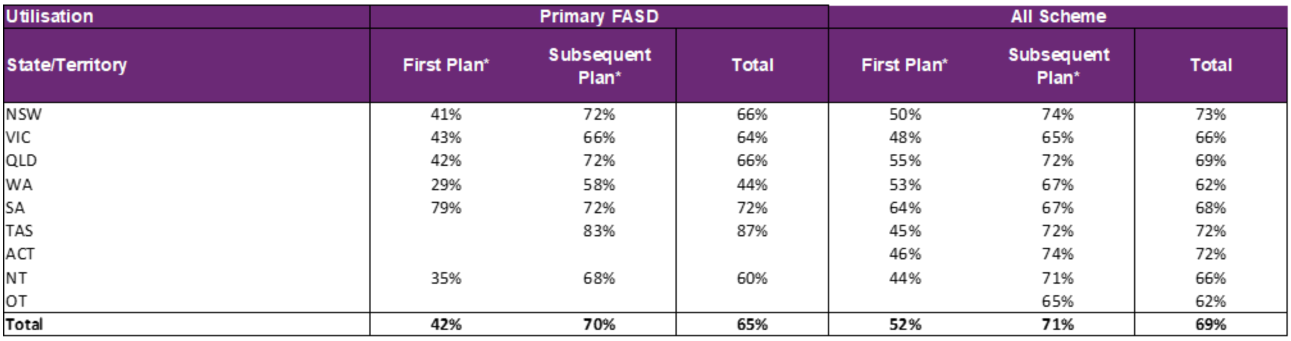
Summary of providers who ever delivered supports to participants with FASD by Indigenous status as at 30 September 2020 is below.

	Total providers (ABN)
Indigenous	942
Non-Indigenous	973
Not stated	552
Total	**1,765**

Plan utilisation – by age group, state and territory and remoteness[3]



Utilisation	Primary FASD			All Scheme		
Age band	First Plan*	Subsequent Plan*	Total	First Plan*	Subsequent Plan*	Total
0 to 6	47%	58%	58%	50%	64%	60%
7 to 14	39%	62%	57%	51%	62%	68%
15 to 18	31%	59%	53%	41%	61%	64%
19 to 24	53%	71%	69%	53%	69%	68%
25 to 34	56%	78%	75%	57%	73%	71%
35 to 44		77%	76%	55%	74%	72%
45 to 54		83%	83%	54%	75%	72%
55 to 64				51%	71%	68%
65+				49%	66%	65%
Total	**42%**	**70%**	**65%**	**52%**	**71%**	**69%**



Utilisation	Primary FASD			All Scheme		
State/Territory	First Plan*	Subsequent Plan*	Total	First Plan*	Subsequent Plan*	Total
NSW	41%	72%	66%	50%	74%	73%
VIC	43%	66%	64%	48%	65%	66%
QLD	42%	72%	66%	55%	72%	69%
WA	29%	58%	44%	53%	67%	62%
SA	79%	72%	72%	64%	67%	68%
TAS		83%	87%	45%	72%	72%
ACT				46%	74%	72%
NT	35%	68%	60%	44%	71%	66%
OT					65%	62%
Total	**42%**	**70%**	**65%**	**52%**	**71%**	**69%**

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[3] Utilisation, as at 30 September 2020, for supports provided between 1 January 2020 and 30 June 2020. Utilisation is not shown where there are fewer than 10 participants. *Since in-kind and YPIRAC payments cannot be allocated to individual plans, first plan and subsequent plan utilisation rates are for cash only.

Utilisation	Primary FASD			All Scheme		
Remoteness classification	**First Plan***	**Subsequent Plan***	**Total**	**First Plan***	**Subsequent Plan***	**Total**
Major Cities	50%	74%	67%	55%	72%	70%
Population > 50,000	33%	74%	71%	49%	72%	70%
Population between 15,000 and 50,000	46%	71%	63%	50%	71%	68%
Population between 5,000 and 15,000	36%	63%	62%	45%	67%	66%
Population less than 5,000	41%	63%	57%	45%	62%	60%
Remote	38%	57%	53%	46%	67%	61%
Very Remote	17%	59%	48%	30%	43%	39%
Total	**42%**	**70%**	**65%**	**52%**	**71%**	**69%**

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000007

DATA SHARING

Question Date: 04 December 2020 **Format:** Spoken

Question:

Ms Studdert: I'll just add something there, also. I'll stand corrected by my colleagues, but I don't think we necessarily capture data that would tell us that a participant had been in the justice system—particularly the juvenile justice system, where stays are quite often short term—from one plan to the next. I don't think that would necessarily be a data point that we would have.
CHAIR: Given the very real situation we face in this country of the number of people, particularly First Nations people, with FASD who end up connecting with the justice system, why haven't you done that and would you reconsider that?
...
Ms Johnson: It is something that we're looking into. At the moment we rely quite heavily on address information to understand the extent to which a person may be in the justice system at a point in time. Ms Studdert's right: if it's a short stay they may not have picked up a change in address. But that is what we're looking out at the moment to estimate the number of people in the justice system. Over time, we do need to look to include a flag in our system which is updated as best as it can be when people are in the justice system.
CHAIR: What do you mean by 'over time'? Why isn't it happening now? Why can't it start immediately? Why can't you ensure that that's part of the process now?
Ms Johnson: I'll take it on notice. It requires a change to our IT system, and I need to take on notice that the extent to which that's feasible and the time that it would take. I don't have that at hand.
CHAIR: Okay, thank you.

Answer:

The known number of NDIS participants in custody is likely under-reported. When aware, NDIA captures some data on incarceration, however this is reliant on a participant informing the NDIA of their situation.

Improved interface and data sharing between NDIS and State/Territory Justice systems are being negotiated and defined, in line with Commonwealth, state and territory disability ministers’ agreed timeframes.

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000008

JUSTICE LIAISON OFFICERS

Question Date: 04 December 2020 **Format:** Spoken

Question:

CHAIR: Is it not part of the justice liaison officer's role to ensure that the participant is actually getting the support that they need in those centres?
Ms Studdert: I don't believe that is part of their role. Mr McNaughton, can you confirm whether that's the case?
Mr McNaughton: Yes, that's correct. Once the participant is in the justice setting, the justice setting is responsible for the majority of the support. We will work with them primarily around exit and making sure that the exit and step-down arrangements are appropriate. But, once they're in the justice setting, we don't have a lot of visibility about any ongoing supports that are being provided in there.
CHAIR: Are you aware of any circumstances where the care providers that were providing care have, in any form, been able to continue to provide either support to the participant or advice to the state or territory authorities on someone's ongoing support needs?
Mr McNaughton: I'd have to take that on notice to see if I have any examples of that but, to my knowledge, I'm not aware of any.

Answer:

The NDIA does not have structured data to answer this question.

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000009

EXECUTIVE STAFF TURNOVER

Question Date: 04 December 2020 **Format:** Spoken

Question:

CHAIR: If you could take it on notice, that would be appreciated. In terms of your answer to Senator Hughes about staff turnover, are you able to take on notice to provide us with details for the last three years of who's been in the senior roles and the time lines that they've been in those roles? It's so that we can see how it's changed. Could you also provide details in terms of the contact people for the organisation. For example, you'll be aware that we've heard evidence that in Central Australia there was concern around the different contacts changing. In terms of the contacts for organisations and the people who are responsible for the states and territories, can you provide an overview of how long they have been in their positions and how often they have changed?
Ms Studdert: I'm happy to try to be helpful, but if I could just make sure we scope that question to address your concerns. So for senior roles—you said our state and territory managers?
CHAIR: Yes. I'd like the overall executive and the senior managers in the states and territories, because the concern mentioned about the change in contacts is not from one organisation; it comes up a lot.
Ms Studdert: Yes, okay. We'll give you data on the turnover in staff from the executive and the state and territory managers over the last two years. Is that what you would like?
CHAIR: Let's make it two years, yes.
Ms Studdert: Okay, so state and territory managers and the executive team for 2019 to 2020.
CHAIR: From 2018-19 and then up to date—if they're still in that position.
Ms Studdert: Sure, happy to do that.

Answer:

The number and turnover of executive and state and territory managers is below.

State/Territory Manager roles	2018-19	2019-20	2020-21 (YTD to 21 December 2020)
Number of positions	8[1]	8	8
Staff Turnover[2]	0	3	0

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[1] A restructure in September 2018 resulted in 14 previous regional management positions being consolidated into 8 specific State and Territory Manager roles of which 6 continued to be performed by previous regional management personnel. There were no further changes to State and Territory Manager personnel during 2018-19.

[2] Staff turnover includes the number of staff who permanently vacated the role during the period.

Deputy Chief Executive Officers	2018-19	2019-20	2020-21 (YTD to 21 December 2020)
Number of positions	4	4	4
Staff Turnover[3]	0	3	0

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[3] Staff turnover includes the number of staff who permanently vacated the role during the period.

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000010

NDIS PARTICIPANTS WITH FASD

Question Date: 04 December 2020 **Format:** Spoken

Question:

Senator SIEWERT: Thank you. The overall number was 1,606, wasn't it?
Ms Johnson: Yes, that's correct. At 30 September there were 1,606 participants with a FASD diagnosis who had put in an access request and had a decision made.
Senator SIEWERT: Just then you gave us figures for remote and very remote. For those 1,606, are you able to provide us with a broad breakdown—or did I miss it?—of metropolitan versus remote and very remote?
Ms Johnson: I'll specifically take that on notice. In the data I've got at hand I have it for our current active participants, but I'll take on notice to split that 1,606 up, noting that that's primary and secondary FASD.
Senator SIEWERT: Yes, and if you could provide it in that breakdown that would be great—the primary and secondary diagnosis. Ms Johnson: I'd be happy to.

Answer:

Summary of all access requests by remoteness and FASD diagnosis[1] is below.

Remoteness	Primary FASD	Secondary FASD	Primary or Secondary FASD
Major Cities	436	208	644
Population > 50,000	187	94	281
Population between 15,000 and 50,000	162	64	226
Population between 5,000 and 15,000	78	41	119
Population less than 5,000	106	56	162
Remote	70	19	89
Very Remote	60	24	84
Total	**1,100**	**506**	**1,606**

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[1] There are a small number of participants that do not have a remoteness classification, and have been removed from this table.

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000011

ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

Question Date: 04 December 2020 **Format:** Written

Question:

The committee has heard that the NDIA is too rigid in its approach to working with Aboriginal communities, and that it would be far more effective if the NDIA employed local Aboriginal people to deliver NDIS services in their communities so that they can understand what it is and how the system works.

Answer:

The NDIA works collaboratively with Aboriginal communities and wherever possible employs local Aboriginal people to deliver NDIS services. The NDIA invests in Remote Community Connectors (RCC) and Evidence, Access and Coordination of Planning (EACP) programs to support remote communities to engage with the NDIS. The NDIA also works with state and territory governments, and health and educational services to support Aboriginal and Torres Strait Islander children with developmental delay or disability and their families to understand the services and supports under the NDIS.

RCCs are, where possible, local community members with strong understanding of their community, strong Indigenous language and reasonable English skills. The primary strengths of RCCs are their knowledge of community, language and culture, and their ability to broker effective interaction between the NDIS and community.

The NDIA is also working with the National Aboriginal Community Controlled Health Organisation (NACCHO) to support local Aboriginal Community Controlled Health Organisations (ACCHOs) to register as NDIS providers and provide NDIS services locally in their communities.

Connectors Branch within the NDIA has primary responsibility for working with remote Aboriginal and Torres Strait Islander communities. Almost 24% of staff in this branch identify as Aboriginal or Torres Strait Islander.

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000012

EARLY CHILDHOOD SUPPORTS PROGRAM

Question Date: 04 December 2020 **Format:** Written

Question:

The committee has heard about the success of the NDIA's Early Childhood Supports (ECS) Program in the Kimberley, Pilbara and Goldfields region. Can you describe how this program has been operating, what aspects of it have been successful, and whether the model can be implemented in other regions?

Answer:

The remote Early Childhood Supports (ECS) Program is intended to address the need for initial supports in remote communities.

The ECS has been implemented through Aboriginal Medical Services (AMSs) in Western Australia, who have been engaging allied health therapy teams regionally to support children under 7 years of age with developmental delay to receive early NDIS supports and services. Progress has been negatively impacted by COVID-19, however, it has also been hampered by difficulties in recruiting staff to work in regional centres.

The NDIA is currently undertaking a review of the Early Childhood Early Intervention approach, which will inform the future approach in remote areas. In addition, the NDIA will undertake a review of the Remote Early Childhood Services, including the ECS program, to review the lessons and best practices, and inform the ongoing models for NDIS early childhood approaches in remote areas.

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000013

REMOTE COMMUNITY CONNECTORS

Question Date: 04 December 2020 **Format:** Written

Question:

Can you confirm that the NDIA's Remote Community Connectors (RCC) program is employing local, community-based people, employed by Aboriginal Community Controlled Organisations to promote understanding and awareness of the NDIS.

Answer:

Yes. At 30 November 2020 the RCC employed 230 Remote Community Connectors, covering 297 rural and remote communities across NT, SA, WA and QLD.

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000014

RESPITE

Question Date: 04 December 2020 **Format:** Written

Question:

You note in your submission that a specific respite line item for short-term accommodation was added to the NDIS support catalogue in December 2019.

How many participants have applied for respite support as a result of this change? How is the NDIA promoting this respite support to participants and their families or carers?

Answer:

The NDIA does not currently have structured data on applications (approved or denied) requesting respite.

The NDIS website page titled ‘for families and carers’ provides information about how the NDIS can help carers, including through the provision of funding for respite. The website also provides links to external websites, including the Carer Gateway, where carers can access respite, counselling and other support services. See: www.ndis.gov.au/understanding/families-and-carers for further details.

In addition, every participant planning conversation with an ECEI partner, Local Area Coordinator (LAC) or NDIS planner includes discussion of a participant’s informal supports. LACs, ECEI Partners and NDIA planners can provide information to NDIS participants and their families or carers about how to flexibly use core supports to purchase additional paid care support in the family home and short-term accommodation.

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000015

CHILDREN AND YOUNG PEOPLE IN DETENTION

Question Date: 04 December 2020 **Format:** Written

Question:

The committee has heard that access to NDIS continues to be sporadic and uncoordinated for children in detention, even though the prevalence of FASD in youth detention centres is extremely high. Can you explain how the NDIA is addressing this problem?

Answer:

While an NDIS participant is incarcerated, the state/territory justice system is responsible for most disability related supports. The NDIA has Justice Liaison Officers (JLOs) working with each state and territory jurisdictional Points of Contacts (POCs). The JLOs support justice staff to assist people with a disability to better navigate the NDIS pathway and assist participants' transition out of the justice system.

The POCs help JLOs to build connections and provide virtual support to a number of justice staff in adult and youth custodial facilities. The JLO role is complemented by Community Connectors who add a trusted, culturally capable resource for support where required.

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000016

DATA SHARING

Question Date: 04 December 2020 **Format:** Written

Question:

You have previously told the committee that the NDIA is working with the Department of Social Services and states and territories to develop formal data sharing arrangements to improve the experience of participants moving into and out of justice settings. Can you explain more about these arrangements and how they will help people with FASD?

Answer:

The NDIA and the Department of Social Services are continuing work on data sharing arrangements between the Commonwealth, state and territories. The data sharing arrangements are intended to assist NDIS participants, including those with FASD, by facilitating more timely access and planning processes, including where participants are moving into and out of justice settings.

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000017

BEHAVIOURAL SUPPORT

Question Date: 04 December 2020 **Format:** Written

Question:

The committee has heard from a carer of a person with FASD that, in her case, the NDIS assessor was using a form designed for people with autism, and did not have FASD-specific resources or tools. She commented that the NDIS is designed for people with physical or intellectual disabilities, but not someone with a behavioural disability such as FASD. However, in your submission you note that NDIS support is likely to be needed for a range of FASD-related impairments, including behavioural support.

How does the NDIS provide behavioural support to FASD participants and their families or carers?

Can you provide details of the level of NDIS support provided for behavioural support since the Scheme commenced?

Answer:

The NDIA and its Partners in the Community use a broad range of assessment tools and approaches to determine the functional impact of a participants' disabilities. Assessment tools do not necessarily need to be diagnosis-specific, as it is a participant's functional capacity, and not their individual diagnosis, that the tools are intended to capture. The NDIA has developed practice guidance to assist NDIA planners and Partners in the Community staff to prepare for meeting with participants with FASD and their families.

Where a participant has a demonstrated need for behavioural supports as a result of the functional impact of their disability, funds for behavioural supports can be included in their plan. Behavioural supports the NDIS may fund include (but are not limited to):

- psychological, communication, sensory and environmental assessments
- individual skills development and training for participants
- training for carers or parents
- specialist behavioural intervention supports for assessment and development of a Behaviour Support Plan
- training in behaviour management strategies
- individual social skills development
- higher intensity core supports.

The NDIA does not support the assertion that it is not designed for people with 'behavioural disability' such as FASD. The NDIS provides a broad range of supports, including behavioural supports and a high level of psychosocial supports for participants.

The NDIA does not hold structured data on payments made for behavioural supports to NDIS participants since the start of the scheme.

Payments made for behavioural supports to NDIS participants from 1 July 2020 to 30 September 2020 are detailed in the table below.

Payments for Behavioural Supports

Item Name	All participants
Specialist Behavioural Intervention Support	**$22,955,633**
Behaviour Management Plan	**$11,936,067**
Individual Social Skills Development	**$305,377**
Total Behavioural Supports	**$35,197,077**

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000018

CHILDREN WITH FASD

Question Date: 04 December 2020 **Format:** Written

Question:

We have heard that the approach to NDIS funding is often piecemeal and fractured, and does not provide for the complete care of a child with FASD. For example, a child may be funded to see a speech therapist, but not for transport to get there or a support worker to assist them. In addition, there is very little communication between the primary healthcare team and providers of NDIS packages in relation to supporting children with FASD.
Is the NDIA aware of these problems in delivering NDIS packages?
Given that people with FASD are likely to have other health issues as they get older, would it make sense for the healthcare provider to also coordinate the NDIS care?

Answer:

In October 2019 the NDIA commenced a campaign to support improved access to the NDIS. The campaign was developed in partnership with Royal Australian College of General Practitioners (RACGP) and focused on educating General Practitioners (GPs) about eligibility criteria, and the access process. The NDIA launched new resources to help GPs better support their patients when applying for access to the NDIS. These included a dedicated page for GPs on the NDIS website, RACGP Training module, GP and assessor lead information videos, who else can help brochure, and an eligibility checklist. These products were promoted by RACGP to members, the Public Health Network and through various medical magazines. These resources are available on the NDIS website www.ndis.gov.au/applying-access-ndis/how-apply/information-gps-and-health-professionals.

Children and young people with FASD often access and require support across multiple systems of care. Under a best practice approach, a coordinated, multidisciplinary and multisystem approach should be maintained between family, out of home care and child protection organisations, school and other education institutions, work, and community and support services and therapists to ensure consistency in the participant’s environment.

Coordination of NDIS supports with mainstream services is currently undertaken by NDIA staff, Local Area Coordinators, Early Childhood partners or NDIS-funded support coordinators, who work with participants to ensure the supports in their plans, including mainstream supports, are meeting their needs.

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000019

HEALTH INTERFACE

Question Date: 04 December 2020 **Format:** Written

Question:

You note in your submission that the NDIA is not the lead agency on FASD, but rather operates alongside other mainstream services.
Given that the Department of Health is responsible for raising awareness and reducing the prevalence of FASD in the community, how do the services and programs administered by the NDIA interface with those provided by Health?
Would having a lead agency for FASD-related services help to promote a holistic needs assessment and plan development across the multiple agencies involved, and is the NDIA best placed to be the lead agency?

Answer:

The NDIA is not best placed to be the lead agency for FASD-related services as the impact of FASD is variable, and not all people with FASD are NDIS participants. The Australian Government has endorsed the National FASD Strategic Action Plan (the Plan), a sub-strategy of the National Drug Strategy, which provides a clear pathway of priorities and opportunities to improve the prevention, diagnosis, support and management of FASD in Australia. Responsibility for responding to the priorities and objectives identified and outlined through the Plan is shared between the Commonwealth and state and territory governments, with the Department of Health the lead agency for the Commonwealth.

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000020

NDIS WEBSITE

Question Date: 04 December 2020 **Format:** Written

Question:

The NDIA undertook to consider providing resources about FASD when updating the NDIS website, but this has not yet happened. Why is promoting an understanding of FASD and explaining the process for determining NDIS eligibility not a priority for the NDIA?

Answer:

The NDIA did consider whether it would be appropriate to include information about FASD on the NDIS website, but made the decision that including information about FASD would be inconsistent with the approach taken with respect to other conditions. The NDIS website does not contain information about individual diagnoses, except as part of participant stories or where these may be listed in documents such as the NDIS Rules and Operational Guidelines.

Promoting an understanding about FASD is the responsibility of the Department of Health.

The NDIA is constantly updating its advice to prospective participants on NDIS access requirements through local NDIA and Partners in the Community staff and the NDIS website.

In addition, in October 2019 the NDIA awarded $825,000 to NOFASD Australia Incorporated through the National Information Program (the Program). The grant was awarded to NOFASD for the development of high quality information regarding FASD, including NDIS specific information, online learning modules and a communications and promotions plan.

Details about the grant to NOFASD Australia are available here:
www.ndis.gov.au/community/information-linkages-and-capacity-building-ilc/funded-projects#national-information-program-grant-round

The information resources produced under the grant are available here:
www.nofasd.org.au/parents-carers-and-families/ndis/.

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000021

FASD ADVISORY GROUP

Question Date: 04 December 2020

Format: Written

Question:

You have told this committee that the NDIA does not support creating a FASD advisory group. However, given the complex nature of the NDIS, and the many difficulties people with FASD are continuing to have in accessing the scheme, why does the NDIA not support a FASD-specific advisory group that could help find solutions to the barriers people are experiencing?

Answer:

The National FASD Strategic Action Plan 2018-2028 (the Plan) was developed to provide a clear pathway of priorities and opportunities to improve the prevention, diagnosis, support and management of FASD in Australia. Consistent with the Plan, the NDIA is working to develop solutions for people with FASD and their families and carers through a number of forums, including the FASD National Working and Consultative Group (FASD Group), the Independent Advisory Council and through engagement with the broader disability sector. As such, the NDIA does not believe a separate NDIS FASD advisory group is necessary.

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000022

CHILDREN WITH FASD

Question Date: 04 December 2020 **Format:** Written

Question:

You note in your submission that the current data shows that the NDIS is not engaging with or supporting many very young children with a likelihood of FASD at an early enough stage, and acknowledge that many people with FASD will not have access to diagnostic services to meet the current NDIS requirements.

- How is the NDIA addressing this problem?
- How is the NDIA dealing with the sensitivities and stigma for very young families with a child that may have FASD?
- What are the culturally appropriate strategies being adopted by NDIA and how effective are they in engaging with very young families affected by FASD?

Answer:

The NDIA is currently consulting on Independent Assessments (IAs) and the Early Childhood Early Intervention (ECEI) Reset, to determine how best to support young children and their families. Because young children grow and change rapidly, the NDIA is considering how best to use the IA process to inform the services and supports young children need in their NDIS plan. Feedback received during consultations will help to inform the final design of the ECEI pathway and IAs for the younger cohort.

The NDIS ECEI Reset has a strong focus on pre-access engagement with families and communities in a sensitive and supportive manner. Through Early Childhood Partners and NDIA staff, proactive strategies to find these families and ‘meet them where they are’ is an important principle. Through the ECEI Reset the NDIA will work with and through multiple community partners to ensure the NDIS is accessible and culturally appropriate for very young families of children with FASD.

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000023

ABORIGINAL AND TORRES STRAIT ISLANDER ENGAGEMENT

Question Date: 04 December 2020 **Format:** Written

Question:

What has the NDIA learnt from its work with Institute of Urban Indigenous Health (IUIH) program, and how is it helping to strengthen its engagement with Aboriginal and Torres Strait Islander communities affected by FASD to help them better understand and access the Scheme?

Answer:

The pilot with the Institute for Urban Indigenous Health (IUIH) in South-East Queensland supported over 350 Aboriginal and Torres Strait Islanders to access the NDIS. The pilot confirmed the importance of Local Area Coordinators in helping NDIS participants understand and use their plan, including connecting them with supports in the region.

The pilot also reinforced the importance of the connection between the LAC and the local community. The National Community Connector Program is focussed on continuing to develop and strengthen the relationships between hard to reach cohorts and the NDIA.

Senate Community Affairs References Committee
Answer to Question on Notice

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Reference No: SQ21-000024

ACCESS AND PLANNING

Question Date: 04 December 2020 **Format:** Written

Question:

You list the types of support likely to be required by a participant with FASD and their families and carers and note that they require individualised support. Can you describe the projects underway for improving the process of assessing NDIS eligibility and developing personalized plans?

Answer:

The NDIA has released two papers on the implementation of Independent Assessments (IAs) for public consultation. The introduction of IAs will ensure NDIS participants are treated equitably by providing a consistent, transparent and equitable way to capture information about a person’s functional capacity, without making assumptions based on disability. Assessing a person’s function has always been part of the NDIS planning process, however current arrangements can be complex, costly and inconsistent.

By making IAs free, the NDIA is removing the financial burden of evidence gathering, needed to access the NDIS. Independent assessments will allow prospective participants to have quick access to internationally recognised tools and qualified health professionals no matter where you live, or what your circumstances.

The introduction of IAs will also support development of individualised plans through efficient and consistent and transparent decision making in the planning process to develop quality personalised plans.