



Melbourne Disability Institute

# **African Australians with disability and the NDIS: Exploring support and service needs**

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# Table of Contents

<b>ACKNOWLEDGEMENTS .....</b>	<b>3</b>
<b>EXECUTIVE SUMMARY .....</b>	<b>4</b>
Project background.....	4
The research approach and participants .....	4
Research findings .....	5
<b>METHOD OF APPROACH.....</b>	<b>7</b>
Data collection and analysis.....	7
Our research participants .....	8
<b>AWARENESS OF THE NDIS .....</b>	<b>10</b>
Limited awareness of the NDIS .....	10
Gaining awareness of the NDIS.....	11
Challenges of raising NDIS awareness .....	12
Raising NDIS awareness in the community.....	14
<b>APPLICATION FOR NDIS SUPPORT .....</b>	<b>19</b>
Experiences of delay .....	19
Unfamiliarity of required supporting evidence .....	21
Insufficient supporting evidence .....	22
<b>CHALLENGES AND BARRIERS ACCESSING NDIS SUPPORT .....</b>	<b>25</b>
Language barriers and the role of interpreters .....	25
Shame and stigma associated with disability .....	28
Issues of trust and anxiety .....	31
<b>RECEIVING APPROPRIATE NDIS SUPPORT .....</b>	<b>34</b>
Suitable housing support .....	35
Meaningful employment opportunities .....	37
Family and community support .....	39
Issues of family violence .....	41
<b>RECOMMENDATIONS FROM THE COMMUNITY.....</b>	<b>45</b>
Sustainable funding for specialist community organisations .....	45
NDIA appreciation of community challenges .....	47
NDIA employment for community members .....	49

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The views expressed in this paper are those of the authors and are not necessarily those of The University of Melbourne.

We acknowledge the Australian Aboriginal and Torres Strait Islander people of this nation. We acknowledge the Traditional Owners of the lands on which our university is located and where we conduct our research and teaching. We pay our respects to Ancestors and Elders, past, present, and future.

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# EXECUTIVE SUMMARY

## Project background

This project emerged from growing anecdotal evidence from within the community sector about the challenges facing African Australian communities when seeking access to the NDIS. These anecdotes indicated that while African Australians with disability share many of the experiences and challenges other Australian's with disability have faced when seeking access to the NDIS, for African Australians with disability, these shared experiences also often intersect with the migration and settlement experiences that are specific to African Australian communities. At the time of writing this report, little to no research has been undertaken to document the range of experiences and challenges facing African Australians seeking access to the NDIS. This report seeks to address this gap in both documentation and understanding by reflecting on the findings of a pilot research project which received seed funding from the Melbourne Disability Institute. The aim of the project was to explore the experiences of African Australians with disability seeking access to the NDIS, with a particular focus on the gaps that form between the support and service needs of African Australians with disability and the coverage and accessibility of the NDIS.

The project brought together a research team of interdisciplinary academics as well as an experienced community leader. The project builds on a collection of earlier work conducted by the team, including Dr Spivakovsky's earlier work on the service and support experiences of people with disability, Dr Onsando and Dr Johns work on the experiences and perspectives of African Australians involved in the Victorian criminal justice system, and Dr Vaughan's work on the role of settlement and multicultural services in responding to violence against women.

## The research approach and participants

The findings of this project are informed by twenty semi-structured interviews with African Australians. Thirteen of these interviews were conducted with African Australians seeking access to the NDIS, all of whom happened to be South Sudanese. A further eight interviews were conducted with African community workers who support African Australians with disability. Recruitment of interviewees for this project was facilitated by the key partner for this project: Mr Deng Kor, Program Director of Community Abundance.

The vast majority of our research participants with disability were currently unemployed, and had limited education. Approximately half of these participants (six of thirteen) were women, many of whom were single mothers, raising five or more children.

## Research findings

The findings of our research appear across five chapters within this report. In the first we report findings concerning the awareness of African Australian communities in Victoria of the NDIS. Here we outline some factors that may limit awareness of the NDIS within African Australian communities, including the limited reach of mainstream NDIS awareness raising approaches. We also report on some of the community-led initiatives that have worked to raise awareness of the NDIS within African Australian communities, and the challenges associated with facilitating these initiatives.

In our second findings chapter we bring attention to the experiences of African Australians with disability when applying for the NDIS. Here we report on the lengthy delays some African Australians with disability have experienced between submitting their application to the NDIS and receiving a decision on their application. We also report on a common issue recounted in our interviews, that is: having an initial application to the NDIS rejected as a result of not providing sufficient evidence. As this second findings chapter details, this problem of insufficient evidence occurs for some people due to a lack of clarity around what evidence is required, but for others, it occurs because the evidence required is not easily accessible for people from refugee backgrounds.

In the third findings chapter we delve further into some of the challenges facing Australians with disability from refugee backgrounds and bring attention to some of the key cultural and linguistic tensions facing African Australians with disability when attempting to access NDIS support. Here we attend to challenges such as language barriers and the significant role that some interpreters are playing in the lives of African Australians with disability. We also discuss other challenges such as issues of trust, and anxiety about the actions of government, and how these challenges create barriers for seeking support.

Our fourth findings chapter then draws attention to a common concern that emerged from our interviews. Specifically, it reports on the broader supports and service needs facing African Australians with disability at this time which the NDIS is unable to address through its coverage. Here we consider issues of housing, employment, and holistic family support.

The final chapter of our report then considers the question: what more could be done to both reduce the barriers and challenges facing African Australians with disability seeking access to the NDIS, and to better support their services and support needs? Here we listened to the South Sudanese community, as one group of African Australians, and report three key recommendations from this community.

First, there is a need for specialist, representative community organisations such as Community Abundance to receive sustainable funding in order to undertake the multifaceted and significant work

they do to support the needs of African Australian communities. Indeed, as this report illustrates throughout the first four findings chapters, specialist, representative community organisations such as Community Abundance play a fundamental role in both reducing barriers and challenges facing African Australians with disability seeking access to the NDIS, and better supporting their services and support needs.

The second key recommendation proposed by South Sudanese community members was that the NDIA needed to increase its appreciation of the needs and backgrounds of African Australians with disability. Specifically, the NDIA needed to ‘come and see’ the community. For the African Australians with disability we spoke with, this desire for the NDIA to ‘come and see’ the community emerged from specific concerns about the application process, and the desire, for example, for the NDIA to see that the person has a physical disability, even if they are unable to provide the paperwork surrounding their disability because of that paperwork. In contrast, for African community workers who support African Australians with disability seeking access to the NDIS, this desire for the NDIA to ‘come and see’ the community emerged from a broader desire to create more culturally sensitive processes and practices.

The final key recommendation to emerge from our project was that there was a desire for increased opportunities for African Australians to work at the NDIA. Like the previous recommendation for the NDIA to ‘come and see’ African Australian communities, this request for increased opportunities for African Australians to work at the NDIA also stemmed from a desire to increase the cultural sensitivity of the NDIA, and would complement the culturally safe approaches of specialist, representative community organisations such as Community Abundance, which are irreplaceable.

## **METHOD OF APPROACH**

This project was undertaken in partnership with the community organisation, Community Abundance. The aim of the project was to explore the experiences of African Australians with disability seeking access to the NDIS, with a particular focus on the gaps that form between the support and service needs of African Australians with disability and the coverage of the NDIS. The key research question the project examined was: what are the experiences of African Australians with disability seeking access to the NDIS, including transition experiences? The project employed a qualitative, exploratory research approach to data collection and analysis which is outlined in further detail below.

### **Data collection and analysis**

Data for the project was collected via semi-structured interviews with the two participant groups. The first participant group comprised African Australians, aged over 18 years, who have a physical disability and/or chronic health condition, or who provided care for a child with a disability and/or chronic health condition, and who have sought access to the NDIS within the past two years (2018-2020). The second participant group recruited for this study were African community workers who have supported African Australians who sought access to the NDIS within the past two years (2018-2020). The community workers we interviewed were all aged over 18 years, and worked at the community organisation Community Abundance. Our interviews with these two participant groups focused on exploring participants' experiences of and perspectives on accessing the NDIS.

Recruitment of both participant groups was facilitated by Mr Deng Kor, Program Director of Community Abundance. Potential participants were provided with a plain language statement that outlined the research process, including the purpose and objectives of the study, details of what the research study involved, details of how participants' interests and concerns were to be addressed, and issues of privacy and confidentiality during and after the study. These key pieces of information about the project were then reiterated verbally to each participant upon first meeting with a member of the research team, and where appropriate, translated by an interpreter. Only after the prospective participants indicated full understanding of the procedures explained by a member of the research team were they requested to sign an informed consent form.

Interviews were conducted at the premises of Community Abundance in Dandenong. This location was selected because Community Abundance premises is a community-owned and culturally sensitive organisation which is easy and familiar for participants with disability to access, and which offered a private room for interviews to be conducted. The majority of interviews were conducted by Drs Spivakovsky and Onsando in a 'paired-approach'. This approach enabled Dr Spivakovsky to draw on her expertise of working with people with disability, and Dr Onsando to draw on his expertise in working with people from African backgrounds. Interview participants were provided with a \$50

Woolworths voucher as a token of appreciation for their time.

Interviews lasted from 20 to 60 minutes, and interpreters were made available for participants when needed. With participants' permission, all interviews were recorded using a digital voice recorder. Recorded interviews were then transcribed verbatim by an external transcription service. The qualitative data gathered through the interviews was then analysed thematically.

## **Our research participants**

A total of twenty African Australians were interviewed as part of this research project. Thirteen participants were African Australians who had sought access to the NDIS for either themselves or their child, and a further eight participants were African community workers who have supported African Australians seeking access to the NDIS. While Community Abundance provides services to Ethiopian, Kenyan and other African ethnic communities, all thirteen of our participants who had sought access to the NDIS for either themselves or their child had migrated to Australia from South Sudan. Eleven of the thirteen had migrated to Australia as a refugee, via countries such as Kenya. All had now resettled as Australian citizens or permanent residents, and the majority of these participants had been in Australia for over 15 years.

The vast majority of our participants who had sought access to the NDIS were currently unemployed, and had limited education. Just under half of the African Australians with disability we interviewed (n=6) were women. Four of these women were single mothers, raising between five and nine children on their own. Of the seven men we interviewed, four were living alone, with three speaking of having to leave their wife or broader family in Africa. Most participants were actively engaged with their communities in Australia. Only three participants identified as being 'not active at all' in their communities in Australia.

Table 1 presents a summary of some of the characteristics of our research participants. Each participant was given a pseudonym to protect their identity and ensure confidentiality.



**Table 1 Demographic characteristics of African Australian research participants with disability**

<b>Pseudonym</b>	<b>Sex</b>	<b>Age</b>	<b>Year of Arrival</b>	<b>Refugee/Citizenship Status</b>	<b>Employment Status</b>	<b>Family Connections/Living situation</b>	<b>Level of Community Engagement</b>
Kulang	M	55-60	2006	Refugee → Citizen	Unemployed	Lives with wife and multiple children	Active
Gatluack	M	35-40	2016	Refugee → Permanent Resident	Unemployed	No family in Australia.	Not active
Bigoa	F	35-40	2003	Refugee → Citizen	Employed	Single mother, lives with multiple children.	Active
David	M	45-50	2002	Refugee → Citizen	Employed	Lives with wife and multiple children	Very active
Adau	F	40-45	2007	Partner Visa → Citizen	Employed (P/T)	Lives with husband and a few children	Very active
Aluel	F	30-35	2001	Refugee → Citizen	Employed (Casual)	Lives with husband and multiple children	Very active
Bol	M	30-35	2002	Refugee → Citizen	Unemployed	Lives with friends in shared accommodation.	Sometimes active
Nyamach	F	35-40	2006	Partner Visa → Permanent Resident	Unemployed	Single mother, lives with multiple children.	Sometimes active
Nhial	M	50-55	2005	Refugee → Citizen	Unemployed	Lives with friend.	Very active
Nyakoang	F	35-40	2002	Refugee → Citizen	Employed (Casual)	Single mother, Live with a few children	Sometimes active
Ayen	F	35-40	2003	Refugee → Citizen	Unemployed	Single mother, lives with multiple children.	Sometimes active
Abraham	M	40-45	2005	Refugee → Citizen	Unemployed	No family in Australia.	Active
Jacob	M	60-65	2010	Refugee → Citizen	Unemployed	No family in Australia.	Not active

## AWARENESS OF THE NDIS

One of the key barriers facing African Australians with disability who are eligible for the NDIS is a lack of awareness of the Scheme. In the sections below we describe some of the circumstances and experiences contributing to this lack of awareness, as well as some of the approaches undertaken by Community Abundance to facilitate greater awareness of the NDIS among African Australians communities.

### Limited awareness of the NDIS

The most straightforward accounts of how our participants became aware of the NDIS came from two participants who had backgrounds of either working for, or informing the work of, state and local governments. In the case of David, he was working for the Victorian Government, and had learnt about the NDIS and the application process through his work. David explained:

*'Cause I'm working with the [...] Victorian Government [...] So, when the NDIS came out, we are the first people who have been contacted about NDIS because the disability sector is going to be transferred to the NDIS [...] This is how I heard about NDIS [...] so to do the planning for the client and do consultations, meeting with the families and talk to them about NDIS, the benefits.*

A similar account was provided by Abraham who was actively involved in his local council, and had learnt about the NDIS through his involvement in local council groups and committees, as Abraham explained:

*I heard before it [the NDIS] was launched, when it was in the initial stages, I heard a lot about from the [...] Council. [...] I am a member of this group. We do come for meetings, conferences and conventions. So they told us about this [NDIS]. Before it rolled out, until when it rolled it, it rolled out in some places, others followed. [...] So that's how I heard about it.*

As the above excerpts from the interviews with David and Abraham suggest, these participants' connections to the work of state and local governments meant that they were aware of the NDIS even before it was rolled-out in their local area. They also understood how the roll-out of the NDIS would occur, and what was involved in the planning process. This level of awareness and depth of understanding of the NDIS, was not common among the participants we interviewed. Rather, the vast majority of people we interviewed had not been aware of the NDIS until such time as they were

directly encouraged to apply for it by either formal or informal supports and services in their local community. We explore these support pathways to the NDIS in greater detail below.

## Gaining awareness of the NDIS

For many of our interview participants, awareness of the NDIS did not occur until the NDIS was rolling-out in their local area, and they were directed to apply for it by formal, mainstream supports and services in their community. For example, in the case of Ayen, information about the NDIS came during a visit to her doctor. As the interpreter for Ayen outlined to us:

*She said when she heard from the doctor because she have a disability, and then they told her everything been stopped because everything used to go through government and then they told her that this thing will stop because she have [...] to go through the NDIS. That's when she heard that. And then she came and then she did the application because they need a new one, she need a new one.*

Bigoa also found out about the NDIS from her doctor, as she explained to us in the context of her child:

*I found out from the doctor, and my child he doesn't talk. And then I get worried and then I took him to the family doctor and then sometimes I get worried when he doesn't eat. He doesn't eat soft food, he just only eat the dry food and then I get worried because up until age four, he doesn't talk. They forced me to go to doctor and then when I took him to doctor, doctor said he got, what is it? ... autism.*

*Doctor said yeah and then doctor told him that and then doctor give her the report so he can give it to NDIS.*

As these two women's accounts indicate, local doctors can be a key starting point from which African Australians with disability, or their carers, can be directed towards the NDIS. These doctors not only raise awareness of the NDIS but also often provide the necessary reports for participants to make their applications, as was the case for Bigoa. It is important to clarify, however, that local doctors are not alone in directing people towards the NDIS.

For Aluel, it was her child's school that made her aware of the NDIS, and further provided connections to NDIS personnel. As Aluel detailed:

*I hear about NDIS in the school. She'll call us like family and then they tell us about it, [...] They said there is something called NDIS and they're helping when he finishes school,*

*something like that. Then they just call on that family and they tell us. Then one day, the NDIS come and all of us, we're there in this school [....] and they explained to us everything about it. Then they give us all the forms and say, "Okay. We have some offers here. You can come". [....] For everyone there [not just African families], meet NDIS, yeah.*

*[...]Then we made appointment and then we see them. Then they give us that appointment.*

*[...] Yeah, we done it. Yeah, approved last year, yeah.*

In the case of Gatluack, it was Centrelink who began the process. As the interpreter for Gatluack outlined for us:

*the first time when he heard that one, it was through Centrelink. Centrelink told him about NDIS for disabilities, for people, they can provide you. And then they fill the form first. They talk to them, and then it was referred to the agent. So from that, this is where we got the information, is from Centrelink. [...]*

Yet, while formal supports and services in their community such as doctors, schools and Centrelink have clearly played a role in raising awareness of the NDIS for African Australians with disability, many of the African Australians with disability we interviewed, along with our African community worker participants, felt that there may be many others in African Australian communities who still did not know about the NDIS. Below we explore some of the reasons that were outlined to us for this broader lack of awareness of the NDIS within African Australian communities.

## **Challenges of raising NDIS awareness**

As indicated above, many of the African Australians with disability we interviewed, along with our African community worker participants, felt that there were a number of African Australians who still do not know about the NDIS. One of the reasons for this lack of awareness that was repeatedly raised with us by our interviewees was isolation. To be precise, people were unaware of the NDIS because they had not been provided with sufficient disability support to be involved in their communities. As Aluel put it:

*Like sometimes, no one can help. They stay at home for a long time, they can't go out, like father and mother.*

A similar account of isolation and insufficient support was reported to us by David, who said:

*...there's a lot of people who never heard about NDIS. Like, yesterday, I talked with one of the ladies. She have a son and that son have a delayed development in his speech. He's got a*

*male autism. This lady, she didn't know anything about NDIS. She doesn't have any support and then, I tell her, this is what is happening. If you go, you can see NDIS and then they will support you. I had to bring him to them and they will support him with application and all this stuff.*

*[...] I brought a few people. Like, one of my cousin. She's disabled, but she's staying in the family, nobody knows about NDIS. So, I have to advocate on her behalf, talk to the family, explain to them what the NDIS is, what they do and all this stuff, and I talk to them, then, they said, "Okay". So, we did application, so just waiting for the result.*

As David's account indicates, there are still many people who have never heard about the NDIS, and who need people to go to their homes and make the connection for them. This need was something that Gatluack also spoke to us about. As Gatluack's interpreter translated for us:

*He's talking about some people who are now disabled who are at home. This one is not willing to go out, just want to stay in that home there. So that is a difficult situation, it makes it worse. If he doesn't go out, to socialise or whatever. So for himself that person can be sitting in one place, it's not a good thing. But if there is someone from the community come and take him. This is your way, what is the decision, why are you not going out? And then see link in and see if that person is okay, you can get help from NDIS. Yeah, if you go around and socialise whatever, it is something. So that is a community members need to be having more knowledge about it.*

The accounts by Aluel, David and Gatluack highlight the lack of support that surrounds some African Australians people with disability, and their carers, in the community, and how this lack of support can lead to isolation of African Australians people with disability. Their accounts also indicate one of the ways that this gap in support and connection can be at least partially filled: through outreach activities. However, as Kulang further outlined for us, these outreach activities need to be performed by people from African backgrounds. They said:

*What NDIS is doing is very helpful [but] many [in the] community they don't know [...] So it needs people from African and African Australians background to be in the program so that actually they compare and then tell the people what is the benefit and then they let others who don't know what is actually, where is the help. Yeah so he's talking about the people are very few who are delivering the message to the community. We need ... more people actually just from the community background to be there.*

Notably, as Staff member 5 further clarified for us, one of the reasons it is so important for African

community members to make these connections for other African community members is because of issues of trust:

*Yeah, there's a lot of effort to go, and the question is, yeah, now people, they say, okay, it's not by community background, they don't trust much. So, that when you, maybe the program is not communication or whatever, but they say it another way. That they don't concern because it's not from the background.*

These are issues that Community Abundance has been actively attempting to address, and below we outline some of the successful approaches Community Abundance has taken to raise awareness of the NDIS within African Australian communities in Victoria, Australia.

## **Raising NDIS awareness in the community**

As indicated in the previous two sections, our participants believe there are still many people in African Australian communities who are unaware of the NDIS, and who require outreach activities, such as having a friend or someone they know from their background speak with them in the community. This is an issue that Community Abundance has been actively attempting to address, as Staff member 3 explained:

*So, from the Community Abundance, we were focusing to close the gap between the mainstream and the community in general. Until then, they came in and started focusing to provide information about how the people can access the mainstream services.*

One of the key ways that Community Abundance attempts to close this gap is through running regular and repeated community workshops. These workshops were the reason that Jacob first heard about the NDIS, as Jacob's interpreter translated for us:

*He said when he first came to notice about NDIS when [Community Abundance] the NDIS, he went around to the community calling meetings, briefing people about the NDIS, making some workshops about NDIS, and then, "That way I heard about NDIS and then from there, people came and tell me that, you need to go and see what NDIS is doing. How they can help you. What they can do for you". That is how he get to hear [...] I come and learn because we're running around and I was going to the community session, the community gathering, consultation, community workshop, I learn about NDIS.*

These workshops were also the reason that Nhial gained the support for his application to the NDIS, as Nhial outlined:

*Yes, we hear about NDIS through our office here [at Community Abundance] because is the one give us the information within the community. There are so many people that you can see. There's many people now [in the foyer of Community Abundance]. They have come in because of the information that have been passed on by the community, and the community also run some information sessions.*

*For the process, after I learn about that NDIS can help, I was given a form and the process was that you are given a form, you fill it in and then they schedule you for an assessment, and within that assessment, whatever they ask you, that's what can determine whether your application is successful or not. So, I just applied once because they have seen my situation, so that what make it maybe successful, one application. After an assessment I came back and then I receive a letter later on that said, "Your assessment been successful," so that's how now I'm given support. So, now many, many people within the community, they don't have an information about NDIS before without this office. Yeah, so through them, through the other office which is Federation, these are the one who now pass on the information to the community, and now you can see many members they have come, they are benefitting from this.*

Importantly, while many of the community workshops run by Community Abundance are focused on the NDIS at this time, this is not their sole focus or purpose. Rather, these workshops run in order to raise awareness of a number of issues of relevance to African Australian communities, and to provide people with access to relevant services. Indeed, in addition to workshops focused on the NDIS, Community Abundance runs similar workshops in relation to issues such as family violence and suicide. They also attempt to cater to any emerging or express needs of the local community by asking people attending the workshop what they would want to hear more about next, as Staff member 8 explained:

*I think most of the time, they bring people with experience from different areas, mostly the NDIS and from those sectors, or family violence sector, who have experience who has worked in the field for a long time. Then they come and portray and explain the whole account of the whole mission and the reason for NDIS and how to access the services and how to approach. We tell disabilities are eligible. I've been to a couple of workshops. It's interesting because you start learning a lot about this type of service that you can access, there's this and there's that. So it's kind of like an information session for everyone. We set up and I think Deng, with his government, he connects, and he brings a guest who knows more about that, who have the information to give. Then we also take the views of people who came, and we ask them, "Okay what do you want us next to discuss", or "What do you want next to be talked about"*



*or “Do you understand” or “Which area for like is left out”. So that’s what happens at most of the workshops.*

*Yeah. I think it’s kind of like an eye-opener. Now they’ll be like “Okay”. If you say if you have a friend, tell a friend, you telephone them and they’re “Okay”. Now I think even the numbers goes like this, they start doing the workshops and the workshop the more they see for themselves and they’re more, they be like this is the right place I have to, that’s why you find like the workshop before, people were coming here. We are finding a number of them are coming here, because then they’re curious and they can understand more.*

Notably, as the second part of staff member 8’s account indicates, one of the benefits of running these workshops for the community is that they not only raise awareness and provide important connections to services for those who attend the workshop, but they are also able to reach others in the community by ‘enlightening’ those who come to the workshops (as staff member 5 put it). This flow on effect from running the workshops was nicely captured in our interview with Aluel, who said:

*Yeah, I feel so happy. When I hear about it and I see a lot of people, they already done it, so I feel free and that I want to tell everyone to do it because it's different. It's different. My daughter have problems, the leg. They need someone to help her exercise, put it outside, need someone to talk with and know people, something like that. It's a different case. ... everyone have it different.*

*It's hard before, but now I learn a lot of things from it. Easy to tell anyone, if you see someone have a problem, you can say, your problem, you can get someone to help.*

And by David, who explained:

*[...] when I see somebody that has a need, who was in the community, I will talk with that person and I will do the connection, with somebody that can support their family.*

However, as Staff member 1 explained, while the workshops are an important tool for communicating key information to African Australian communities, not everyone in the community understands why they should attend. Other, complementary outreach approaches are therefore also needed to raise awareness of the workshops, and explain why they are important. One such complementary approach is the use of Facebook Live. As Staff member 1 outlined:

*Yeah, so that what we do, so we do it live and people ... You just invite people. ... Yeah, you invite people on the page. When you’re doing live everybody will see it, your friends and everyone will know what happening, yeah, and then you will get some people who be like,*



*yeah, have a few friends, I think I might join you next time. It is a big number but it is not the number that we expect from the community that they can come. Because sometime lots of people they think that they are wasting their time, I think they would hear the message. Yeah, they think maybe it is just a community celebration, so they don't get it.*

The other, primary way that awareness is raised about the workshops and their importance for people in African Australian communities to attend them is through church. Indeed, many workshop sessions are held at a local church, with the pastor and church leaders inviting people to join the session. As staff member 5 explained:

*[...] we do the plan, then set it out, then tell the pastor in church, then the community that this day on Saturday, people have given out this venue, so we can meet from 10 up to 3 or to 4 or something like that. So, you call your people to come to the session and then yeah, this is the work of NDIS, just to help. So, we need people to understand the one who are entitled to get that one, they can come and discern actually, if they will get an access for that one. So, the pastors and the people who are in that church actually just, they accept us for that day, they call people and then they come. Then the NDIS staff come and with the people who are supporters, and then the NDIS, they do the session. So, this is how we do it. So, we send out the flyer. As the one who are just doing interpreting, also we get that flyers and then we can go to the people are nervous to you or in other sections of the community, [...]tell them, that area to come to the session. Yeah, to send out information.*

Notably, one of the reasons why these workshops are so important and successful for connecting African Australians with disability to the NDIS is because they are able to overcome language barriers. As Staff member 5, who provides interpretation services at these workshops put it:

*When I came here, we got a lot of information that people don't know. So, at home, people stay with disabled, whether the elders or the children and instead that they can get help, that in term of the NDIS, but they didn't know. There also, even for our community welcome, because Deng is, from what I said, when we are in South Sudan, he's very far away from there, [...] but we speak one language. That's all. We speak Dinka. We speak Arabic. [...] So, people knew a lot and then some people now got help also from the NDIS. So, now they are ... because some of people got tired at home and staying with the disabled. So, exactly is, we say, if there is a help and is a national and have a body who have got a right, who is disabled to the level that has got a right can join. Yeah, no one actually just, because they come to Deng, sometimes when they go to other people who doesn't speak their language, there is a language barrier. They don't know ... because there's no session. They've not been*

*enlightened. They're not been interpreted in full. But when these sessions came, now people are start to come, and then the case is now they are informed and going to be assessed according to their level.*

In the next chapter of our report we explore some of the experiences African Australians with disability have had of 'going to be assessed according to their level'.

## APPLICATION FOR NDIS SUPPORT

Many of our interview participants spoke to us about the process of applying for the NDIS. The vast majority reported significant issues such as having long delays between when they submitted their application and when they heard an outcome, as well as issues when they did hear an outcome of being told their application was rejected. In the sections below we describe some of the circumstances and experiences that surrounded these issues of delay and rejection.

### Experiences of delay

The majority of the NDIS applicants we interviewed spoke about experiencing lengthy delays. Sometimes the reasons for the delay were known. For example, in the case of Abraham, the person responsible in the NDIS had gone on holiday, as they explained:

*Yeah, yeah. It was delayed. When I look at why I wasn't called, their letter says my support, who was there, the LAC, went for a holiday to Bangladesh and didn't put a note that someone should contact me for.*

Most other participants we interviewed, however, did not receive any indication of the reasons why their application had been delayed. As a result, many were left feeling unsure about when an outcome might occur. As Nyakoang explained:

*Yeah. So I don't know what next is going to happen. We started last year. It take me a long time, yeah.*

*[...] they told me it's not, it should be like three weeks, two weeks, but mine is take long. When I talk to one of the NDIS, they told me like it not happen. And I feel like if I am on your, but now I can go to NDIS and tell them what you guys did, it were wrong. And I can't wait longer than this. So what you guys did is not right, so shouldn't be that long.*

Bigoa shared a similar account through her interpreter, they said:

*[...] we just put the application in, but we waiting for the approval. [Interviewer: Okay so how long ago was that?] Last year. In November last year. Almost two months or three months ago.*

*[...] They told me a month. [...] She just told me that when the, just give me the concession reference, and then when it's here, and then we'll just go from there. So she doesn't know when exactly the time.*

*I just want my application to get on the process now to being approved. So I'm sure when it*

*gets approved, I will get more help. And I don't know anything at the moment until I get it ... so I can have more knowledge and information.*

Adua also experienced delays, and was frustrated by both the length of time taken, and the difficulty involved in navigating the process. Adau told us:

*It's long. So long. I didn't know because my husband is the one, he did online, so he has to submit papers until, wait maybe nearly six or something months. Then they said after, you can come and meet somebody, somewhere. So, that person, I think, everything will come to them there and they will do interview.*

When interviewing staff at Community Abundance, it became clear that Adua, Bigoa and Nyakoang's experiences of delay were not uncommon. Indeed, as staff member 5 explained, the average wait for an outcome on an application was six months:

*Yeah, in average, you can say, sometimes that is up to six months, yes, following the application. That is average. It might be less than that [...] and it may be more than that, and some are still waiting, it's more than one year. So, the average is six months. And then people hear when they keep coming always. They look at us.*

As the conclusion of staff member 5's account begins to detail, while applicants are left waiting to hear back from the NDIS for several months to a year, they turn up to Community Abundance asking for answers and for support. As a result, the community organisation has had to take on the role of providing NDIS applicants with reassurance and support while they wait to hear back from the NDIS. Often this reassurance comes in the form of repeatedly telling people to be patient, as staff member 8 explained:

*The issue I think will be like they just – most people, like I said, they want to rush into it. Like most of the people, the clients, they just want – when you start, they just when you come and we help them out, they just want it to happen like straight away.*

*Well it doesn't work that. Also you can't do the paperwork and all that. I think that will be a problem but yeah.*

*We just explain it. You've got to be patient with people, explain to people, and they understand because everyone has to play a role. You can't write it. You can't write it. Even if you write it, it's not like if you write anything's going to happen, so definitely you've got to get there with the amount of time.*

But as staff member 5 explained, sometimes the reassurance that Community Abundance is being asked to provide while people wait to hear from the NDIS comes in other forms too. For example, clarifying for people the reason why they are being made to wait so long by the NDIS. As staff member 5 told us:

*they expect to be in a certain period, so they get frustrated. This is main thing. It's not actually just [the NDIS] understanding us and doesn't want to give anything. This is what they think, these ones [the community]. So they don't get help very fast. This is what they think. [...] so, we tell them, "Be patient, the program is new" [...] to come to you from your tongue, and the one who is talking actually in your tongue, to tell you, you are ignorant about that one.*

Further problems then emerge when people finally receive the result of their application. In particular, if they find out their application has been rejected after waiting for so long. We outline the issue of rejection and how it often came about in further detail below.

## Unfamiliarity of required supporting evidence

Many of our interview participants had their first applications rejected by the NDIS. Often this rejection occurred because applicants did not know what evidence would be required. As the interpreter for Nyamach recounted to us:

*Interpreter: She applied first, and then they rejected her, and then when she apply the second one, and then Deng help her [...] and then they have to give the medical report and then they accept it.*

*Interviewer: So the first time they rejected because there were not medical reports? or was another ...*

*Interpreter: Yeah. Before, she doesn't know anything, the first time she fill in the form. And then she just went to the family doctors and they give her some evidence, but there were not enough, and then after that, they give her evidence and then they accepted.*

As staff member 5 explained, this is a known issue to Community Abundance, and it is one that the organisation has been trying to address:

*[...] some cases have been applied for it twice, and then for the third time, got accepted. It's just to protocol, this one. That is one. [...] So, we try actually, just to say, "Okay, all the support things, support documents and all these ones, bring them. Bring them and then people*

*will like you".*

The problem for some people, however, is that it remains unclear exactly what kind of evidence the NDIS may require for their application to be successful. For example, Nyamach, who, as previously indicated, had her original application rejected because she had not provided sufficient evidence, attempted to speak with the NDIS about what evidence would be required for her application to be accepted. The response she received made her feel uncertain and concerned about what she should do next. As Nyamach's interpreter relayed to us:

*She was on the phone with them, the NDIS people, and then they told her, "This evidence that you provide, if you got it, this child, she doesn't have any disability, so you can go jail" or something. [...] They said because she's the one call to, because she was asking for application, and then they have to tell her that it's anybody from NDIS have to go through that, so that they have to ask her that, "If you give us a false document, later on you can go somewhere else", "if it's true, and it's okay."*

And as staff member 2 further clarified, applicants are not the only ones who are unclear about what kind of evidence the NDIS requires in order to approve an application. They said:

*We do not know what are the categories used by the NDIS head office, whenever an application reaches them. We do not know what they use, what is their model, and how this person would be successful.*

Connected to the issue of people having their applications rejected because they do not know what evidence is required is a second issue of not having access to the evidence that is requested. This second, connected issue is considered in further detail below.

## **Insufficient supporting evidence**

What was apparent from a few of our interviews was that sometimes it was not possible to provide all the support documents that are required. This situation often occurs if the person seeking access to the NDIS has come from overseas and either does not have access to such documents, or has never been provided them in their home country. This issue was made clear to us by Nyakoang, as they explained:

*And then I apply for, when NDIS, when it started, and then I try to apply. When I apply I been rejected. They said they need proof. And I don't know what kind that they need. And then I apply some of, from my doctors. Because this is the background that, it's happening overseas,*

*not in here. So I give them some proof but they still reject it. And I don't know what kind of proof exactly what they need from me. If they want me to go to them and then can walk and then they can see me, or they want to see my leg, or what exactly what it is, so I don't know.*

Another interview participant who also raised the issue of having different documentation depending on where the person was born, or in which country the disability developed, was Adau. In their case, they raised this issue of documentation when discussing the different outcomes for her two children and husband when they applied for the NDIS, as Adau explained:

*My son, he got already, he's now through, but my husband, they rejected his. ... Yeah, he did all together ... Both of them. Even with my daughter, she got problem with her leg, yeah, so hers too they rejected and my husband together [ ...]*

*[My son] he was born here. So, maybe yeah, that's why he went through straight away. So, with my husband it's difficult. With my daughter, because I came with her when she was three months old, from back home, yeah. So, the problem with her leg is started here, not from back home. So, she got operation on her legs... So, I think, maybe, yes, those who are born, maybe can benefit first then who are coming from overseas. Of course, you can see the person physically, he's already disabled. Without even doing interview, you know already that person is struggling. So, you just have to, he straight away do the paperwork will make it easier, but it's hard sometimes, yeah. Yeah, it's hard.*

Yet even when our interview participants were able to provide what they believed to be sufficient evidence, they still experienced problems with their application, which often resulted in them being rejected (at least initially) from the NDIS.

Being rejected by the NDIS was something that was feared by many African Australians with disability who came to Community Abundance for help. It was also something which many were frustrated about. As staff member 1 explained to us:

*They're worried about their rejections, when they put the application, because most of them, they've been rejected and then they have to do appeal and then the appeal would be accepted. So that's the point that a lot of people concerned, why they're rejected people, and this is, should be, 'cause they put it there to help the disable people and they still, if you disabled, they will still reject it, people get frustrated, sure.*

However, as staff member 1 continued to explain, being rejected had other consequences for African Australians with disability too, such as diminishing people's sense of hope:

*And they will do the plan here [at Community Abundance] to do the application and then they've, when they put the application in then they reject that's where people. I had just one of the ladies she just came here last week, and then they rejected her, ... and she was just break down. ... Because you will not know when the, when they tell you that you've been rejected you think that maybe, there's no hope, that's what you feel, yeah.*

Being rejected also had consequences for some people's sense of self. Nyakoang, for instance, who had had her original application rejected because she was unable to provide documentation for her disability because it had never been provided in her country of origin, spoke to us about the impact of this rejection on her self-esteem:

*[...] Because a person like me, I know I have disability. I will never lie about it. I have some proof, even if it's not here but you can see it from my personal disability, you know. You will know that person, she is. So that's what I think because I didn't get any help since I came to Australia here. But when the government provide the help so I can be one of, among this people and instead rejected me and making me feel really bad about myself. So yeah.*

*[...] It's making me like, you know, it give me a low esteem. Yeah. Because when they have that application, I had it with the confidence that I might get help, but it didn't happen. I thought maybe because I came from background that they don't know. It's like discrimination.*

These experiences of delay and rejection, as well as the related issues of frustration and uncertainty that surround the NDIS application process, and in particular, surrounding the experiences of providing the evidence required as part of the NDIS application process, remind us of the broader immigration and resettlement context facing African Australians with disability at this time. In the next section of this report, we bring into view this bigger picture surrounding African Australians with disability, and consider the implications that this bigger picture holds for the experiences of African Australians with disability seeking or gaining access to the NDIS.



## CHALLENGES AND BARRIERS ACCESSING NDIS SUPPORT

The majority of the African Australians with disability we interviewed as part of this project required an interpreter to participate in our interview. A number of our interview participants also spoke about the broader issues of shame and stigma that affect some African Australians attempts to access services and supports. In addition to these concerns, some African Australians with disability are also concerned about the consequences of needing to speak with others beyond their community about their disability-related support needs. In the sections below we consider the implications of these bigger picture dynamics that African Australians with disability have to negotiate.

### Language barriers and the role of interpreters

The majority of the African Australians with disability we interviewed as part of this project required an interpreter to participate in our interview. This tension of needing interpreters to be present in order to participate is, of course, repeated in many other contexts as well, as Kulang explained:

*We need support everywhere. To go to hospital you need support, the interpreter. You come to NDIS office, interpreter. You go to the job network, interpreter. Wherever you go, where people only speak English, they need interpreters. So if, would you be able to provide someone to give me some classes at home? ... Just interpreting ...from English to Dinka, yes and English to Sudanese Arabic ... if you've got health condition overnight and then to talk and looking for the interpreter as well they are not there. So that is difficult sometimes, so it's better if you have someone near to you, checking you, yeah so you can know what is your condition.*

Or as Nhial told us:

*Even the government who brought us here doesn't know the kind of quality life that we are living. They don't know that. They just throw us down there and that's it.[...] we try to reach also the wider community service [but] they don't even listen to us, because when we came, there is no any language. We do know there is a barrier there. No one even show us. No one even give us information.*

*[...] Even me, as I said it before, when I kick out from my house, and the government didn't even care about me, and they knew I am an illiterate person, I don't know how to read and write, there will be no way to access the information. There will be no way to reach the other services. And some of the services, when you go there, also they ask you, "How long have you been here?" If you say more than a time that may be in their [indecipherable speech], they say, "You are not eligible." How do we be eligible? How do we be not eligible when we don't*

*have any information or right directions where to go?*

*And that's why you have seen so many people come in here [to Community Abundance], because now the community have learned that people will give us right information, they don't reject us, they do all these things for us.*

Yet as the conclusion of both Kulang's and Nhial's accounts appear to suggest, interpreters do more than just translate information from one language to another: they also provide another form of outreach support in the community.

The additional support roles that some interpreters play for African Australians with disability were further outlined to us by the interpreter for Jacob, who explained:

*He's pointing at me because I sometimes help him, because he's my countryman, but I'll sometimes take him to the appointment. He's pointing at me because I'm the one sometime he call upon and say, "Come and help me with this please?", but I'm not a permanent member. He telling that the one he can come and see, any people for me, then something the doctor written, "You come and read for me?" and if there anything the doctor want to tell me, the one who can talk and listen to what the doctor is saying.*

*He's saying that, "Most of the time I'm the one to assist him to calling appointment and taking him somewhere. He's not driving. When he go for radiotherapy, he needs someone to drive him around. If he want to go to another appointment, he has to go around with somebody and if there's something, like going to Centrelink, if he has no interpreter found there, sometime I take him there". So, he need assistance from somebody close to the family.*

*Of course, I've [the interpreter] been doing that. I've been going with him, during the operation, I was there. Even when they were doing the radiotherapy, I have to be there with the doctor. Who's putting everything on, and when it is finished and then, we clear the room and then, we all go out. That is how we will continue. So, he's saying that you're the third person in the family, them and the family and then I'm the friend. I'm outside helping wherever he goes because he cannot explain himself. Yeah, a friend.*

This need to rely on interpreters to not only participate in medical and other appointments, but also to establish those necessary appointments in the first place was something Staff member 1 outlined to us as well. As Staff member 1 said:

*[...] if they want anything, so they have to come to me, and then I talk to them, and, yeah. If they need appointment to talk to them or they need to make, because most of people they don't speak English. So, I have to make them, I have to make call and then with appointments and*

*then, yeah, organise all this and I answer a lot of calls.*

It is important to understand, however that these dual issues of language and access barriers do not simply occur because some African Australians are only able to speak or read limited English. Rather, these language and access barriers also occur because some mainstream services do not make efforts to bridge these gaps. As staff member 2 clarified for us:

*Our people have an issue of their wider service providers. Because when they go there, first of all they look at them with their limited language, and say "oh yes, what do you want? what services? Okay, how long you have been here? Five years? Sorry, we can't talk to you." So even to get the information, they don't get this. So the community gets frustrated.*

Moreover, as staff member 2 further explained, it is because of this frustration and the lack of efforts by mainstream services to bridge communication gaps in order to service the needs of this community, that so many people come to places like Community Abundance to seek support:

*[...] we speak to them in the same language. We it make it easy for them to understand what the service is for, and what is needed from them by the service. And what is their contribution that is needed. So it is easy to be put to them easily within their language. And then also they come here, they feel comfortable.*

Or as staff member 5 outlined:

*[...] I guess, for the interpreting, they really talk about me, it's just to interpret what has been said to them and the question from that one to the NDIS staff, but even the application can be explained. This is the application to apply and then also, if you've already been accepted, this is the application for review also. If your time is going to finish, so this is what you do. This is what you do. But looking to the application to fill it, yeah, that is one who is accredited one then. Yeah. Is one filling that one. Yeah, so they come to the office in a different way when they learn that there are someone who can fill the application, help you and all these ones, they come to the office. Yeah. Some people applied somewhere, they got the difficulty, they come to seek some advice also. Then also they go to that other agent. If they fail, they come here also.*

Yet as Gatluack further explained, the reason why some African Australians rely so heavily on the services of community organisations such as Community Abundance is not just because these organisations can bridge communication and other supports and services gaps, but also because of issues of shame and stigma within some parts of African Australian communities. As the interpreter

for Gatluack outlined:

*This [Community Abundance] is the only place. He comes here. Because he is new in Australia also. [...] Because sometimes meetings [with Centrelink or the NDIS] to go from here, need driver's licence and be driving also. [Gatluack says:] "I can get there with another person." [...] so it's not he's reluctant, because it's always, he needs someone to come for that one, but there is nothing. No one. [...] So he is saying that sometimes you need to ask one of the community leaders or other one to help you if you are sick or other conditions and out of the community you don't have anything completely. But if you are, yes, have something like what I have now, given by Centrelink, and you go to ask other person, so if that is shameful, it doesn't work. So we don't have anyone.*

Gatluack was not the only interview participant we spoke with who raised issues of shame and stigma as affecting their attempts to access services and supports related to their disability. Accordingly, we explore these issues of shame and stigma in further detail below.

## **Shame and stigma associated with disability**

As indicated above, a number of our interview participants spoke about the broader issues of shame and stigma that affect some African Australians with disability attempts to access services and supports. It is important to understand, however, that these issues of shame and stigma that are associated with having a disability are not new, and pre-date the roll-out of the NDIS, as Staff member 8 explained:

*Because most of the time, you find African that are in our society, we keep – like have someone with a disability in the family, it's kind of like a forbidden thing to talk about outside the society.*

*[...] So you've got to actually – you've got to support the normal way about it, it's not a caste, or like our people used to think back in the day, but now it's a different time. It's a very big issue that people need to deal with, because that's when you're like – you're causing them more harm, and your like taking away part of their rights, part of their human rights because if there's a way that can be help, and you're not giving them that care or allowing them to access that, you're doing them more disadvantage to them and to yourself as a parent or a guardian or a person who is surrounding them.*

For Nyakoang, these experiences of stigma from 'back in the day' (as staff member 8 put it), result in ongoing feelings of shame and a lack of confidence, as they explained:

*[...] because the background that I came, sometime is you know, it feel like shame. I feel, and sometimes I don't have confidence to talk about it since I came, until now. I am growing and now it's a time for me that I can speak up for myself. [...] Because in my background that African Australians, especially like my mum, when we was there, we have to be at home, you know, because it feel like she have a shame. Two kids have that disability, the same thing. It's like there is a curse in the family. Yeah. And then we brought up with, you know there is no confident that I can be even around the families or around community, I get just frustrated and not confident.*

While Nyakoang and staff member 8 both spoke of the broader experiences and implications of these issues of disability-related shame and stigma within African Australian communities, other interviewees we spoke with drew connections between these broader experiences of shame and stigma and the specific process of applying for the NDIS.

Staff member 2 for instance, reflected on the connection between the perceived 'taboo' associated with being diagnosed with a disability, and the requirement to have evidence of a disability in order to gain access to the NDIS:

*Some of them maybe they would say well, I can't go to my doctors. Because most of them, especially young people, the kids, there are only their mothers, and the mothers don't want to take them to the doctors where they can be diagnosed. And then they would be given a good result which can help them with their kids. They pretend, they say no, I don't want my, it might be a taboo or something like that. So, there are a few things there which really also push people back.*

Adau also saw these issues of shame and stigma as holding people back from gaining access to the NDIS. As Adau simply put it:

*Yeah, some of them, they don't want to talk, and maybe they just close themselves. So, they won't get that benefit or yeah.*

Yet as David further clarified, while these issues of shame and stigma are perceived to be holding back people with disability in African Australian communities, these issues are not wholly insurmountable, and can be addressed (at least to some extent) if approached in the correct way, by the correct people. As David put it:

*There's one problem in our community, are the Sudanese. Our people they shy away from things. If you have a problem, you don't want to disclose it to other people. Maybe other*

*people they may bullying you or they may laugh on you, or they may say something. Like, disability in our communities is like a curse. Somebody did something wrong in your family, or you did something wrong, that why this thing happen to you and the reason sometimes, a lot of people, they don't want to disclose their problem to other people.... [so]some people now, they just taking care of their loved one, they're persuaded, without no support.*

*This is what I'm seeing. What they [the NDIS] are doing now is good, but it's needed more. There's not a lot of people come out. A few come, but most of the people we need to reach them out and we need to ask if there's somebody in the community who cannot come out, we'll come into their home.*

*You know, there are trusted people, like priests and counsellors, case support workers, those who are involved in this kind of things, and their close family friends, so you need to ... find out the needs of that person. So, if you go there in a cultural way, you can approach the situation.*

*People they need the right information. If you don't give the right information, people will not open up to you. So, you need to give them the right information and let them have a choice. Leave it to them, give them information and leave it to them to think about it and then, later on you remind them.*

These various tensions identified by David around stigma, coming at things culturally, and needing to reach out to people form yet another set of reasons why Community Abundance have been running their outreach-based workshops in the community for the past year. And, as staff member 8 reflected, these community-based outreach approaches appear to be helping people 'open up':

*[The workshops are] helping a lot because it's opening people's eyes, and it's making people to understand [...]. This is the time that also these people, the disability, they have a right, a human right. So they also have a choice to make. That's why the NDIS, the government put it in place or if the services are there, why can't you access them? I don't see a reason [why] with NDIS.*

*So I think like, most of them know [about the NDIS], as there's more workshop and with giving out information and doing workshop and all that, I think now they're like about to open up some more. So when they come here [to Community Abundance] they're like – they want to get more information about it [the NDIS], because most of them, they may have a disability, and because end of the day, NDIS is growing, and if there is help somewhere, why can't you just access it? We leave this kind, "it's not right to do that" or "it's not good to tell everyone" [...] I think that's why most of the time they're trying to engage and get more*

*information on what we do, and they can access, if they have anyone who is disadvantaged or who has disabilities. I think that's why they're here.*

Yet, as the end of staff member 8's account begins to suggest, one of the issues holding some African Australians back from seeking access to the NDIS is not only the shame and stigma that surround issues of disability within some parts of the community, but also the consequences of speaking with other parties beyond the community about disability-related support and service needs. Below we consider this additional, often intersecting issue of the feared consequences of speaking with others beyond the community.

## **Issues of trust and anxiety**

As indicated above, in addition to the concerns some African Australians with disability have about the stigma associated with having a disability within their community, some are also concerned about the consequences of needing to speak about their disability-related support needs with others beyond their community. As David explained to us, for some African Australians this reluctance to speak with others has been informed by some of the broader issues of trust and acceptance between African and non-African Australian communities in Australia over the past few years:

*Yeah, the other thing is this: our community is not fully integrated into mainstream and that is the reason a lot of people, they lack information [about the NDIS]. They don't receive information, 'cause participation has become very limited. You can tell people, "This thing is going to be done", and the participation is not that good. Maybe a few people went and majority of people they don't attend. This is the reason they need to be brought into the level of community by those who they trust.*

*So, now, a lot of people with this, rumours been going on in Melbourne, for three years or four years now, about African gang and all this stuff, and it has brought a lot of opinion for people and that trust has made a barrier. That barrier need social workers who is in the community, their own people, they will go in and do this.*

Yet as Nyakoang explained to us, for other African Australians, this reluctance to speak with others also stems from fears about the consequences of divulging such information about support needs. In particular, a fear that if they speak about their disability-related support needs to the NDIS, the government might take their children away. Nyakoang spoke to us in greater detail about this fear of the government taking children away from people who disclose their disability and disability-related support needs to the NDIS. As Nyakoang explains:

*But most of the people that I know, they know about their disabilities, it's the people that have*



*young kids that grown are here, they have a different disability, like they have autism. So those people, most of the people that I know, yeah. And a lot of community people are scared of if I say that I need help, maybe they will take my kids away from me. People are afraid. Yeah, they will not tell you a lot, you know, in case of turn off they will say maybe Child Protection will be involved. Or will say oh you can't take care of your kids so let's take them. Yeah, you will not be able. That's what I think when I said when I have kids I'm like okay, if I apply [to the NDIS] maybe, you know, they'll take my kids away from me. And because I'm not able to help them so I had that thought first.*

This fear that the government might take children away from people who disclose their disability and disability-related support needs to the NDIS is a significant issue, and one which is very difficult to address. Indeed, it is relevant to note that while Nyakoang was the only interview participant to speak directly with us about this fear, we were later informed by staff at Community Abundance that when interviewees had completed their interview with us, they would mention to staff at Community Abundance that they were worried that if they said too much to us (the research team), we might get them in trouble and take their kids away. The presence and effect of this fear about the research team - despite our efforts to both obtain informed consent, and to clarify the independent nature of our research project - is both saddening to us as a research team, and illustrative of the significance of this issue for African Australians with disability who are seeking access to the NDIS.

At the same time, this anecdotal evidence is also indicative of the significant levels of trust that staff from Community Abundance has been able to foster with African Australians with disability. That is to say, while our interviewees may worry about the government taking their children away from them if they disclose their disability and disability-related support needs to people outside the community (including to a research team), they remained comfortable raising these fears with staff of Community Abundance. As staff member 3 explained to us, this is a common occurrence – that people will raise this concern about the government with staff at Community Abundance – and it is an issue which Community Abundance is actively attempting to address. As staff member 3 explained:

*The other services who came in [to talk about the NDIS], even when the people came here [to the community] some people, they went out and they say, "Oh, I did not talk because I don't want to tell all my feelings towards those people. Maybe they'll come and take my kid," [laughing]. I say, "No." I tell them, "No. They don't have power."*

The work Community Abundance has undertaken to not only raise awareness of the NDIS for African Australians with disability but to also establish trust and rapport with African Australians with disability who might otherwise avoid seeking access to disability-related services and supports due to



issues of stigma and shame, is necessary, important and positive. As we will show in the next part of our report, these are not the only challenges facing African Australians with disability seeking access to the NDIS, nor the only fundamental roles that Community Abundance has come to play in relation to facilitating this access.

## RECEIVING APPROPRIATE NDIS SUPPORT

While many of our interview participants had experienced delays or rejection when attempting to access the NDIS, some had been successful in their application, and were enjoying the benefits of the Scheme. The benefits of the NDIS were especially clear for participants who had a physical disability, and who required either a piece of equipment or some other tangible form of support in order to more fully participate in their daily life, as explained by the interpreter for Kulang in relation to Kulang's hearing aid:

*The part of the NDIS that is a good thing ... [is] being given equipment [like this hearing aid] [...] So he's saying that this is the good side of NDIS.*

A similar account was provided by the interpreter for Gatluack in relation to Gatluack's walking frame and boots:

*Actually yes, NDIS is very helpful [...] This is] all the equipment he's got now. That's his chair there. And over here he's got all the walking boots [...] and also got all the equipment that they can get him. [...] Like if he does sit in there, and he's not making communication with the Centre of the NDIS, they don't do anything. So there is an understanding between the agent who is like them, and then the NDIS Centre, to see people like him. And that actually does benefit him now. [...] Yeah, sometimes just when they get a planning, so his need to choose the things that would fit him and then NDIS go and buy this one. Yeah, from the providers [...] Then the NDIS pay that one.*

And, as further detailed by Nhial in relation to receiving funding for a carer:

*And also my teeth, they all came out because another fall. And the third fall is that I broke my broken leg. I broke it again, and that's when now, the NDIS came in, and they give me the support, and I went to the hospital and have an operation. So, now, I would say, really, the life on the other side is really changed because there is somebody who can give me service, the carer. Like, if it rain, I can call someone and that person would come and take me. So, that will prevent all these falls because I would have someone who would care for me. This is a good thing.*

Yet as Nhial went on to explain to us in some detail, while being provided with funding for a carer was 'a good thing' - something which really changed their life - other supports and services were still needed in order to fully support their participation in daily life and the broader community. In this section of the report, we outline the additional supports and services needs which face African

Australians with disability but which are not necessarily being addressed by the NDIS, including housing, employment, and holistic family support.

## Suitable housing support

One of the key challenges facing some African Australians with disability is secure housing. As staff member 2 explained to us in the context of the limited reach of the NDIS into some people's lives:

*There is so many people. We have a larger number within our communities. Some of them, they're even homeless. They are disabled. They are not really getting the service they're supposed to. And very few people, their cases went through. We still have a long way to go, and that's why we are pushing very hard to say no, you'd better have another look into the situation.*

A number of the African Australians with disability we interviewed had experienced periods of homelessness, or insecure housing, and many were now relying on others from the community to support their accommodation needs. Kulang, for instance, was living in accommodation that had been provided to him by his church; the church was also heavily subsidising the accommodation. As the interpreter for Kulang explained:

*... So in the church where he is, one of the pastors was working with him here, so he went and bought the house when he got the situation is difficult. So he bought the house and then he told him just to move in. In that house with his family, paying a little bit, not too much.*

In the case of Ayen, she was living in temporary, emergency accommodation with many children. This housing situation was problematic on two fronts. First, there were insufficient rooms for such a large family, and second the accommodation was only temporary, and Ayen was being asked to move on. As the interpreter for Ayen explained:

*Yeah because at the moment she doesn't have a settled place that she live. They put her on the accommodation, [...] emergency [...] and [a large number] of them in the same house. So even if they have someone to help her [through the NDIS] there's no place, that the problem that she's facing at the moment.*

*They just put her there for temporarily but she said they ask her to go and look for the rent and now she is but there's no, they're not accepting her.*

Notably, when we spoke with Ayen, she already had an NDIS plan in place, so we asked her if her support plan had any accommodation-related considerations. The interpreter for Ayen explained:

*She said if it's by herself it [the NDIS] can help her to find somewhere, but because she have her kids, so will be government issue to help her.*

*[...] She said the help that came from NDIS it's like they're going to help her leg for sure, they will pay for it, and then if she have a government house, they can help her to extend the house if there is, she's going to use a wheelchair. So they can help her there, they can pay if it's a government house. That's where they can get the help from.*

Other people we interviewed, like Nhial, had moved from place to place over the years due to a complex situation where they were forced to move out of their home. Nhial was unclear how the government could allow people with disability to live this way, as he explained to us via an interpreter:

*Yeah, my concern really is, which is I don't feel ease about it, which maybe the community are not aware or even the government, or maybe the government don't have attention to that, is that when I was asked to leave the home, [...] they just left me like that and I'm a disabled person. There is no proper accommodation. [...] So, I don't feel ease about this. They should have a concern about me too. If they don't want me in that house, they should find me a place to stay. Or if they don't want me here, they could maybe send me back home to Africa. This has really made me annoyed. That's the only thing that I could say. If the NDIS have a way of supporting me in that because maybe that is a part of the government, that would be okay, because that is real concern, I don't have a place to stay.*

*[...] So, the things really we need to be done in addition to this would be that if NDIS could provide us, or me, an accommodation. Because accommodation you can settle; you know now I have a permanent place. And then from there also, we could ask also NDIS could provide us some skills, training, so that we can get the skills. We would not just be independent, do anything, or dependent on whatever. We want to be independent. Things that can be done on the table, fit for us, for my situation or whatever situation of another disabled person, it would be good so that we are not just idle. We could be active, do things, participate within the larger community as well. [...] When you are working, you are engaged, psychologically you are clear. So, instead of thinking I'm down here and all this, so that will take away all these things that you will be thinking of because you will be busy, you will be engaged with something. That will be good, of course. Even being disabled doesn't prevent someone to participate in larger community.*

As the above excerpt from our interview with Nhial suggests, there are several issues confronting African Australians with disability at the one time; there may be issues with housing as well as issues

with employment. Notably, this additional, often intersecting issue of employment was raised repeatedly in our interviews with both African Australians with disability and staff at Community Abundance. In the sections below, we draw out and describe this additional and at times intersecting issue affecting African Australians with disability, and we explore the connection between these broader issues and the provisions of the NDIS.

## Meaningful employment opportunities

Like Nhial, many of our interview participants spoke about difficulties finding employment. As Abraham explained:

*I am registered with a job network, job service provider, specialising in getting jobs for people with disabilities. But they've never got a job for me. More than two years. Returning from one to one. Yeah.*

For many of the people we spoke with, there was a hope that gaining access to the NDIS would help them secure employment, and avoid situations like the one described by Abraham. Here, the NDIS was seen as a facilitative tool; it was viewed as enabling them to gain access to supports and services for addressing their impairment, with their impairment viewed as something that was stopping them from work, and hence, once they had funding to put supports in place around their impairment, they could return to work, or find a different job. This view of the NDIS as a facilitative tool for employment was captured in our interview with Bol, who responded in the following way when we asked how he thought the NDIS might change his life:

*He said maybe he will get a good price, and then he will get more help because of his hand [which has impaired function due to shrapnel being lodged in his upper arm]. He's not doing anything, and then maybe he'll get different job or anything. [...] Yeah, he said he can work and he can support his family back there.*

A similar sentiment was shared by Kulang who had already had his application to the NDIS approved, and was awaiting being sent a hearing aid as part of his plan. As the interpreter for Kulang explained:

*...what he has been promised is actually just to be given help, like the hearing one [he had received two hearing aids, and was waiting for a third], and then to look for the job.... a job that he can do in his capacity. [When the NDIS funding comes through for the third hearing aid] there will be a change ... my hearing will become good. Then some work, sometimes need instructions, [...]. So ... I will be happy, getting a little bit of work...*

Staff member 5 also saw the NDIS as a facilitative tool which could support people with disability to find work:

*These people who are disabled, they can't have a work because they aren't being supported, to get some job in their capacity, what they have actually, so a particular job that they can do it. To get employed. Because they are disability agents, they are disability agents there. We see some people, they say, "Okay. I've been given to do the cleaning or do whatever. Yeah, I can work". In other communities, these people, they've got pushed a little bit. That helped. So, one year, two years, they see improvement. But now here, as if they don't get help, then they get, they're tied down in that way. So, disabled people, they need to be employed also, and then they need to be employed, they should have any supported by the NDIS, given the equipment, whatever they can make them able to do. Then they can be looking for future. Things become okay, it will improve the disabled people to get a job. Getting the equipment, all these one and everything so then they can be looking for work. Actually, just to look for the job to support themselves. That relieves things because, from their job, they even can return some of the money through tax, that will come to the NDIS.*

Yet while Bol, Kulang and Staff member 5's accounts provide indication of how the NDIS may be able to play a facilitative role in supporting African Australians with disability to find employment, others viewed the situation as more complicated. For example, for staff member 2, it was both the NDIS and the government which needed to do more to empower African Australians to find work, as they explained:

*The community actually needs a lot of support, and we need some funding, so that those who can be able to, be also empowering the community. So there will be an employment, and then people can reach out to those who are unreached. This is what also we need from NDIS to consider funding that would be good funded. And also the government, because they are not, they are giving the funds to other organisations which really have nothing to do with the community.*

Notably, as the second part of staff member 2's account suggest, for some of the people we interviewed, a concern was not just that the NDIS was not seen to be doing enough for some African Australians in relation to employment. Rather, there was a perception that the NDIS was directing its funding to the wrong people and organisations. This was a view that was shared by Adau who spoke about this tension in the direction of funds in this way:

*It's just NDIS, yeah, this is what I was thinking, they brought that system to give some other*

*people job is what I was thinking, yeah. This, they create another job for other people, but it's not supporting family, really the issue, they are not supporting it. This job, application for physio, for speech, for yeah. Because now when you go there, 45 minutes, a lot of money, like \$300 or something just for that visit. Yeah, just for visit, and a little bit play, or showing something to do with that child. Then you come home, and you have to practice that thing with that child at home. [And they] will claim money, yeah, they claim the money from the government. So, this is what I just conclude at the end: is job creations for the others through our families that need support. Yeah, this is what I was thinking.*

Indeed, as the second part of Adau's account suggests, another tension African Australians are experiencing with the NDIS, is that while the NDIS provides funds for some items or services that directly support or attend to the impairments of the person with disability, there is a desire and need for more support to be directed to the families and carers that surround that person. We explore the tension between the needs of the person with disability as an individual, and the needs of the person with disability as a member of a family and community in further detail in the next section.

## **Family and community support**

As indicated above, one of the issues raised through our interviews with African Australians with disability, was the tension between the support needs of the person with disability, when viewed as an individual, and the support needs of the person with disability, when viewed as a member of a family. This tension was particularly flagged by two sub-groups within our interview cohorts, both of which were only made up of mothers, many of whom were raising children on their own: mothers with disability, and mothers of children with disability.

Ayen, a single mother with disability, spoke to us about this tension when we asked her about the kinds of support she was receiving from the NDIS in relation to her and her children, her interpreter explained:

*She said when we start it, they ask her about that, and they told her that we're not going to help you with the kids, and then when she explain the situation that she need it, and then they told her that we can help you if you go out with the kids because she said if I go out with the kids, and then I'm in play zone with the kids, and the kids involve her that they need someone to run after them so she can't run, so then they will find someone, and then to help her, or otherwise if she's taking them to park, so that's where, but there's not much for the kids.*

Importantly, while Ayen's account highlights some of the practical implications associated with seeing the person with disability not simply as an individual, but also as a member of a family who plays particular roles in that family (e.g. needing support to be able to 'run after the kids'), our

conversation with Nyakoang further highlighted some of the broader, sociological impacts associated with not seeing the person with disability as a member of a family.

Like Ayen, Nyakoang was a single mother raising several children. Like Ayen, Nyakoang had a physical impairment that made it harder, at times, for her to 'run after the kids'. Yet as Nyakoang, explained, the issues she faces in her everyday life as a result of being a single mother with disability are more complicated than only having some difficulties running after the kids in a park. As Nyakoang outlined to us:

*So now, when I say the struggle, when I had kids, so that's when it gets tough on me. Yeah, so I'm not in relationship, I'm a single mother. And then we didn't get a chance to actually live with man and all this, it was only by my own I had my first child. [...] And the thing what's so tough, I was so stressed, depressed, and then even I was on the medication when I had the first because I didn't know what to do. And the struggle was beginning until now. So it's tough, yeah.*

Of course, Nyakoang and Ayen's experiences of needing greater support as single mothers do not occur simply because they are living with disability. These are experiences that are shared by mothers without disability too. Indeed, our interviews with mothers who did not have a disability, but who have children with disability, raised very similar concerns about the desire for greater support from the NDIS for *families* with disability. This was a desire that Bigoa spoke to us about.

For Bigoa, the hope was that the NDIS would provide her with more time to attend to all the other components of her busy lives. As the interpreter for Bigoa explained:

*She said yes, it will affect my life very well, because now I am very, very busy mum. I have other kids, and if been approved [by the NDIS] I know that I will have more time. So I will get someone to help him and then even to go to visit the doctor, [...] even today if, because I didn't put him in childcare, I wouldn't be here [at the interview]. [...] so it's very tough yeah. So I will have more relieve things.*

Yet as Aluel explained, although she too had hoped for more holistic support from the NDIS - such that it would not only provide support for her child with disability, but also for her as the person directly involved in the life of her child - these hopes had not come to fruition. As Aluel explained:

*No, no, no. You can't get all of the things that you want. It's hard. NDIS now, they help only the child, they're not help the family. [...] they will say, "that is your responsibility to do that". Yes, so, they just pay maybe for physio or speech or care. They'll sign a thing that they just dealing with, but they don't deal with other issues around. If this child need physio, they*



*will provide, need speech, they will provide, need carer, they will provide. If they got some special supplement, they give that person, they will provide nappies. Yeah, those are the items, but the others are not included. You, you're not included in that, yeah, so you have to struggle even with the, yeah. [...] A lot of money, but nothing, family, they can't get anything. They support the person not the family.*

Importantly, while our interviews with African Australians with disability and African Australians caring for people with disability highlighted the need for the NDIS to not view the person with disability as just an individual with specific impairments, but also as a member of a family within which specific dynamics of care operate, our interviews with staff drew attention to the importance of another dynamic within families that affect people with disability: family violence. We explore this dynamic in further detail below.

## Issues of family violence

As indicated above, while our interviews with people who were applying for the NDIS highlighted a desire for the NDIS to take a more holistic view of individuals and families, our interviews with staff from Community Abundance drew attention to another dynamic within families that affect people with disability: family violence. Staff member 1 spoke about family violence in African Australians communities in this way:

*Family violence, all the time because what community been through especially the background that I came in, there is all the violence and people they don't have, especially women, they're going through a lot of violence and then they don't have a voice, they don't know that they are in the, they are in the country that people are free but it's still, yeah. ... There is still a lot of violence.*

It is important to clarify, however, that the dynamic of family violence raised by staff should not be seen as wholly separate from the previously described dynamics of care raised by the mothers we spoke with. Rather, as staff member 3 explained, experiences of family violence can directly shape the dynamics of care for some families, as staff member 3 outlined in the context of the limits of one woman's NDIS plan:

*I know the woman that I was telling her story, she's got a good plan with the support worker to go and help her two hours in the morning and two hours in the afternoon, her kids' meal and all these kind of things, and shopping and all this community access. [many] kids in [not enough] bedrooms.*

*So, they're healthy but to implement it, no good, [...] That is, being [many] kids with one leg*

*and a single mother experiencing extreme violence, I mean, [...]. If you put yourself in that kind of thing, it's terrible.*

*She's a single mother. [...] No single support since she arrived to Australia [...] So, we need to do more work to develop a case [for the NDIS] at least to have something from our team, from clinical psychologists, from others. So, from there she can, but before that she is sitting there in the house, feels isolated, no interaction with anyone and it's stressful for the family. [...] So, when you see those kinds of things as a clinician person, you feel there's something they need to work on. We are in Australia.*

Yet as staff member 5 acknowledged, while it is important for the NDIS to support people with disability who are experiencing family violence, and the various effects this dynamic has on both family and care relationships, other organisations need to play a role too:

*So, when you come from the different country or you are staying there, you don't know what the government decided this is the rule, and do the program, like if there is family violence. So, what do you expect, if you are the one wrong, or what do you expect from your family and where the children goes, this is where the child protection come and whatever you lose ability. We included that one also [in the community workshops run by Community Abundance], and that need also for the people to do the finding. [...] People want to know them.*

*[...] Yeah. So, here, this information they need, actually just to be well informed. This is what they need. So, that information fully to get, we need a lot of things, not NDIS itself. Yeah, there are a lot.*

A very similar account was provided by staff member 3, who spoke about some of the broader dynamics which surround women with disability experiencing family violence, and the role Community Abundance attempts to play in primary prevention through awareness raising:

*Yeah. When you are in the war zone, ... being in a refugee world and being a war zone witness, death, and came to a stable country where you don't know the difference of intersection that you're talking about, yes, potentially that is a high link there because in the refugee life and the war zone life, violence is normal. It's acceptable. So, you can exercise it the way you want. With Australian contact, no. And if someone doesn't give you orientation to differentiate, you can still exercise the power that you have here and you end up with Intervention Order for seven years like what he did.*

*He was filing up another case where the woman, she was really violent almost for eight years.*

*She's disabled physically. His husband abused him to the maximum level. He struck her down, [...], sits on her stomach, tied her hands up and beat her. So, when she was telling me the thing some time I cried, and I questioned this myself, because it was too much. So, all this sit together with a big link.*

*So, the role when, and this is where we established Community Abundance, to try to provide a list of primary prevention [...] and we say in the community leadership that we need to provide at least some information to the community at least to let the people step back and be aware about normal behaviour and try to take a journey of advocacy and lead the people, we could minimise the level of young people going to the prison.*

As the second and third parts of staff member 3's account suggest, Community Abundance not only provides support for women with disability who are experiencing family violence, but also works to provide information to African Australians who perpetrate violence. While it is both important and beneficial that Community Abundance responds to both of these needs within African Australian communities, it is worth considering that this one organisation does this while also responding to the community's need for greater employment opportunities and housing, as well as while raising awareness of the NDIS within the community, and while supporting African Australians with disability to collect the evidence required for their NDIS application, submit their application, and wait (for extended periods of time) for an outcome on their application. In other words, Community Abundance plays a number of important roles within African Australian communities, including facilitating access to the NDIS for African Australians with disability, and this means that in practice, there are now a lot of people from African Australian communities who are now solely reliant on the services, support and compassion of Community Abundance to participate in daily life. While it is both admirable and valuable that an organisation like Community Abundance has come to play this very significant role for its local community, it is may not be sustainable in the long term, as staff member 2 explained:

*Some of them, they open up with us. When there is someone like me or [the CEO] or anyone of the employees attending a meeting with them, they are better help. They are better help. Because also, we lack the employees, because we don't have money. Not everybody will do all this just voluntarily. Travelling time also time consuming, all this distance. So no one really would take all this. Only us if I'm there, or [the CEO], we are the only one who are accepting the situation, because we want the, wanting to care the community that is there is these services, if you come together and you want to be served, this is how you can be served. And we are struggling to get funding. Because even ourselves, we need some money to make move. To make us, you know, the facility, the work. But we are doing it voluntarily, and it is burning out.*

In the next and final part of our report we consider what else might be needed in order to both better support African Australians with disability who are seeking the NDIS, and to sustain the invaluable work of Community Abundance.

## RECOMMENDATIONS FROM THE COMMUNITY

As part of our project, we asked the people we spoke with if they thought there were any approaches the NDIA could take to better support people with disability from African Australians communities in Australia. Our participants repeatedly flagged three potential approaches: increased funding for Community Abundance so it can continue to provide the invaluable support it does for African Australian communities; increased appreciation by the NDIA of the needs and backgrounds of African Australians with disability; and increased opportunities for African Australians to work at the NDIA. We explore these three recommendations from our participants in greater detail in this final section of the report.

### Sustainable funding for specialist community organisations

This report has illustrated many of the vital roles that community organisations such as Community Abundance play in supporting African Australians with disability to gain access to the NDIS. From running workshops which raise awareness of the NDIS, to reassuring people that they can and should gain access to the NDIS even if their first application has been rejected due to misunderstandings of what is required, to supporting people to collect the evidence needed to complete their applications successful, and to being a welcoming and supportive place where people come to sit and wait on the outcome of their application, sometimes for months at a time. It is perhaps of little surprise then, that the first, consistent recommendation for the NDIA provided to us by our interviewees was to better fund community organisations such as Community Abundance to perform these vital roles. As Abraham put it:

*[they] should be given more funds to conduct maybe awareness, and support them during their reviews, because every business has their own language. Not everyone knows the language that need it.*

Yet as this excerpt from our interview with Abraham clarifies, it is not just that community organisations should receive better funding to perform the vital roles that they do for their communities, but that Community Abundance, as a specific community organisation serving African communities in Australia, should receive more funding for the work that it does with these communities. The need to ensure that funds are directed to representative community organisations, like Community Abundance, who provide supports and services for the specific needs of African Australians was an issue that staff member 5 also raised in their interview with us, as they explained:

*That they [other generalist organisations] don't concern because it's not from their background. [...] The people there on the top, a lot of people are complaining that they are*

*not African background, and they are not focusing the issues actually in the community. They don't know what is going on there, but they are the one there. High salaries. And this also, this money they got for, nothing done for it.*

*[...] They [other generalist organisations] say about other people, but they [other people] don't go to the session. They don't see the community, so what is the number of that community? What is the number of actually the concern of the several people? [...]*

*Yeah, they start doing preparation, and all this one, these bodies, and then they don't go to the background of these people, the list of the disabled people are just being called. [...] So, that is misusing the name. The different people hide here, can misuse this money for the name of the African background. The problem has not been solved yet. People can be employed whether from another community, but need to focus what is actually this money intended for? [...] Now, you see, now they don't benefit from it, and the community who was intending to get this one is not benefitting from that one. So, these are some issues there, down here.*

This disjuncture between which organisations are seen as being provided with funds to deliver supports and services to migrant and refugee communities, and which organisations are engaged with by specific migrant and refugee communities, was an issue that staff member 2 also raised in their interview with us. They explained:

*We are here dealing with a community, and we want that money to be given to us, in order to really give the services that the community wants. They are not given to us. They'd be given to [other organisations that support a number of migrant and refugee communities in Australia, not African Australians specifically], and [these other organisations] would say "okay, yes, Community Abundance, come. I have funds here, do this for me."*

*We can't do it for you. Because if you are given funds, you go to the community and give the service. When they call for the community, community don't go to them, don't come. So it means, that is to us. We see it as unfair. We need our organisation to be empowered, so that also we can grant the services to the community, in a good way, and enrich the un-rich person which would really bring a good change to the community.*

*To me, this small office has brought a lot of change and a lot of understanding of the community of the services out there, and how people can work and generate jobs, and do many things. Through here, really we have a good network, good connections, and we connect people. But we do it voluntarily, which is unfair.*

While this report has outlined many reasons why African Australians may continue to come to Community Abundance for services and supports even when other, generalist community

organisations are available to them, we found the following excerpt from our interview with staff member 8 to be indicative of some of the key reasons:

*We understand, like we are a part of the community, we know the experiences, and we make sure whichever people, all the kind the way they deserve. So it's kind of more like we keep track of everything. [...] I think what you know about Community Abundance, one thing I've realised, among all our employees, among all the staff members, they are compassionate and are driven. They understand how to connect with their clients, and they just genuinely open to the people. Like they treat them, like I think they're positive, they see them like family. It's not like got a business down with this, "I'm just doing this because I'm getting a pay cheque". It's just given in place, and I think that's one of the unique things about them was the pure happy about it. All the clients are happy about it, and you find they even with the client, they will have a good relation. [...] a family, they're related but they're not, they're just – that's one of the unique thing I found about that.*

While it is beyond the scope of this report to determine the funding arrangements surrounding the services and supports that organisations such as Community Abundance receive, it is clear that these services and supports are invaluable to African Australian communities, and would benefit from sustainable funding.

## **NDIA appreciation of community challenges**

The second recommendation from community members that emerged from our interviews was that the NDIA needed to increase its appreciation of the needs and backgrounds of African Australians with disability. To do this - our interviewees proposed - the NDIA needed to 'come and see' the community. For many of the African Australians with disability we interviewed, this call for the NDIA to 'come and see' was primarily raised in the context of the application process, and typically in the context of the challenges some African Australians with disability face when asked to meet the evidence expectations of the NDIA. As Nyakoang explained:

*They need to know because I'm not Australian born, I came from Africa, that there's no system that will give me papers that will say that [this person] had this [disability] since you were a child. So, but because when I come here I have doctors that will approve, will say that this is true and they will be written on the system. Even if there's no more evidence you can see it from my physical, if I'm walking you will know. Yeah. So that's what.*

Jacob had experienced a similar challenge when he had applied for the NDIS, and like Nyakoang, wished that the NDIA would consider other forms of evidence, such as physically observing a

person's disability, as the interpreter for Jacob put it:

*He is saying, "Even myself, I'm telling them most of the time that if there is any complication with the application and they're not looking at it as serious as I needed it, maybe I would come in front of them and tell them that, come and look at me, I'm not physically fit. I'm not someone who can do it to myself. But I have a feeling that if somebody will come and sees me, I will come in front of you and tell you, this is how I look. This is what happened to me. Take a statement from how you look at me. That how I can approach the NDIS if one of them is around. So, see physically and how not fit I am because I just came from hospital, I'm walking with a stick and I can't go anywhere. I can't walk around. I can't go and look after myself. I can't go and do job for myself."*

This desire for the NDIA to 'come and see' people as they are was also shared by Nhial, who had been successful with their own application, but saw many others in his community who were still struggling to gain access to the NDIS. They said:

*We need you because there is so many other people still suffering within the community. So, you look into the application of our people carefully because sometimes when you see them you will say, "Okay, this is not, that is not." No. Look. Come closer to us. See us exactly because we have really need. [...]. So, this is what I would tell them, "Please pay special attention to our community."*

Notably, while the African Australians with disability we spoke with primarily emphasised the need for the NDIA to 'come and see' the community due to specific concerns about the application process, the staff members we spoke with wanted the NDIA to 'come and see' the community to address a broader concern about the concepts, decisions and processes of the NDIA. Specifically, staff we spoke with perceived some of the concepts, decisions and processes of the NDIA to be misaligned to the needs of African Australians communities, and potentially culturally insensitive. As Staff member 2 explained:

*First of all, they need to understand the community, and the community needs. What kind of community of African Australians is. It needs to be understood well, culturally, because this is one of the things maybe the, or whatever happens in the media you know, portrays us also in a negative way. People think all this before they, whatever you want to do with them maybe it will not be, they didn't see the positive things that are coming from the community. Yes, they need to also revise their way of doing things, the way they are, is it, what do I determine this is.*



Similarly, as staff member 5 put it:

*Yeah, the change actually is that they [the NDIA] don't come and attend, see things on the ground. That's the problem, yeah. [...] but you don't get information without coming to see it on the ground, because if you don't know anything, much about it, you don't see from the second end, but different thing in your mind, you argue, according to your concept. That, it will influence their, what is needed. Yeah, and you support yourself there, actually just to be a boss, [...] but that you are deciding, you don't know about it much. Yeah.*

As these excerpts from our interviews with staff member 5 and Staff member 2 suggest, there is a perceived gap between the NDIA and African Australian communities in terms of both the concepts and processes of the NDIA ('their way of doing things'), as well as in relation to understandings of the needs of African Australians, and what communities requires from the NDIS. It is for these reasons that David, like so many of our other participants wished the NDIA would 'come and see' communities, in order to increase appreciation of what is needed by communities at this time. As they put it:

*They need to have that flexibility with the African communities 'cause there's a lot of thing that are not going with our culture or our way of life. So, they need to see and find out, "Okay, you can do this".*

It is clear that there is a real desire and potential benefit to be gained from the NDIA working closer with African Australian communities.

## **NDIA employment for community members**

The final key recommendation to emerge from our interviews was that there needed to be increased opportunities for African Australians to work at the NDIA. Like the previous recommendation for the NDIA to 'come and see' African Australian communities as they are, this request for increased opportunities for African Australians to work at the NDIA also stemmed from a desire to increase the cultural sensitivity of the NDIA, as staff member 5 explained:

*Yeah, yeah. So, the system of NDIS is okay, and that NDIS, we need it to continue, but need people to understand also, and then this community, the NDIS need actually, just to get the community involved with the experience also. The people who have got an expertise in there, to go there, analyse the issues and then see also, to know all the program. So, if some people get employed, they are also, these are the ones, actually, just we let the NDIS come and show that community who doesn't know that and the community access it. Yeah, in the right way.*

*So, NDIS itself is not a problem. That is the solution, but the people. [...] The opportunity to be decision-making position. Need some people there. [...] Yeah, where the application goes there, and when you apply, even for the fund also, yeah, to help the people, we need someone there also. [...] Yeah, because, actually just, if you employ people who knows, from the community, what's the problem actually and with a skill [...] They are knowledgeable, yeah. [...] Yeah, even down here. Actually just, when someone come there and then talk in their language, the same culture, he knows what is going on here, yeah, at the ground, and then you can say in a correct way. So, we need people there, and we need it from there.*

Abraham was of a similar view, and elaborated on what might be gained if more people from African backgrounds were employed by the NDIA in a range of positions. As they explained:

*So some people are fed up with the stigma and if you an African and you are employed there and working there, I will call you brother, and I'll tell you everything that's affecting me. But when you go in and meet with them, you just want to answer the question and you answer. But if it's your brother, you can just be open then. Feeling well with my language can also make it understand.*

Notably, while the NDIA has some initiatives in place for employing people with disability, these initiatives are not seen as capturing African Australians with disability, as Abraham further explained to us:

*I don't know. I really don't know. The NDIS. Yeah, one thing I would like to talk about NDIS has an employment side where you can register your interest. But they are not considering African people with disability to the pool.*

*Yeah. Yeah. Yeah, and interviewed, and it's rare for African people. I applied a couple of times, couldn't get into that. A friend of mine also came to – I made him and notified last week, he also applied, especially in the LAC roles. Yeah. The Local Area Coordinators. People like myself, which I think I'm qualified enough to.*

*Yeah, we are not being given such opportunities. For NDIS to reconsider their employment plans or strategies. Mind you, I'm told by Centrelink it's a matter of finding the right job. And this is the right job for me. And I can't get into it.*

While it was beyond the scope of this project to determine the employment opportunities for African Australians within the NDIA, it is clear from our interviews that there are benefits associated with increasing the number of people from a range of African backgrounds employed by the NDIA, including greater cultural and linguistic sensitivity for a range of African communities. However, as

staff member 2 clarified for us, increasing the number of people from African backgrounds employed by the NDIA is just one step towards increasing the access to the NDIS for African Australians with disability. Indeed, what this final section of this report has attempted to demonstrate is that there are three key steps that need to be taken in conjunction in order to increase the access to the NDIS for African Australians with disability: increasing funding for specialist community organisations, increasing understandings and appreciation of African Australian communities by the NDIA, and increasing employment of African Australians within the NDIA. Or as staff member 2 put it:

*Through our organisation, Community Abundance, they [the NDIA] can come and attend as we normally invite them to give lectures or presentations about the NDIS to community. And they can see the community also, can understand the community background, how they live life in a cultural way. Because there is a lot of barriers here. There is a big gap, and that gap, to close that gap, it needs a lot of work. NDIS, to understand that, they need to employ some people from the community, who would really help them. That would be one thing. If they employ people from South Sudan community, or African community, that would be the best things.*