



Submission to the Improving the NDIS Experience Discussion Paper

Settlement Services International

Settlement Services International (SSI) is a community organisation and social business that supports newcomers and other Australians to achieve their full potential. We work with people who have experienced vulnerability, including refugees, people seeking asylum and culturally and linguistically diverse (CALD) communities, to build capacity and enable them to overcome inequality. SSI recently merged with Access Community Services Ltd in Queensland which significantly extends our service footprint and reach.

SSI and Access provide a range of services in the areas of humanitarian and migrant settlement, services to people seeking asylum, employment support, enterprise facilitation and social inclusion initiatives and programs in the area of disability. In 2017-18, SSI provided direct services to almost 27,000 people across NSW. These programs are mainly funded by the Australian, Queensland and NSW governments.

SSI delivers a range of NDIS supports in Queensland through Access Community Services (ACSL) and Harmony Place. ACSL is registered to deliver a range of NDIS supports. Harmony Place delivers support coordination, therapeutic supports and group and centre-based activities. Both ACSL and Harmony Place work closely with external stakeholders and community leaders in order to upskill and advocate for choice and control; leading to better outcomes for clients.

Until recently, SSI was one of the largest providers of Ability Links NSW, funded by the NSW Department of Family and Community Services. Under Ability Links, intermediaries called 'Linkers' supported people with disability, their families and carers to identify their goals and connect with their community and mainstream services. SSI delivered Ability Links in parts of metropolitan, regional and rural NSW.

SSI's FutureAbility Project develops strategies aimed at ensuring CALD communities achieve better access to the National Disability Insurance Scheme (NDIS). FutureAbility is a multiphase project managed by SSI, originally funded by the NSW Government, which has also implemented initiatives with Information, Linkages and Capacity Building (ILC) funding under the NDIS. For example, the nation-wide Multilingual Disability Hub is a multilingual hotline and website that provides relevant and accessible information on disability and the NDIS to CALD communities in 14 languages. Similarly, SSI conducts community information sessions to provide CALD communities with information on disability and the NDIS to help improve their quality of life and increase community participation in the NDIS.

In the area of employment and enterprise services, SSI is a 5-star Jobactive provider and is the lead agency in a consortium that delivers Disability Employment Services. SSI's self-funded IgniteAbility facilitates the establishment of enterprises by people with a disability. The Ignite Small Business Start-Ups works in a similar way with migrants and refugees. SSI also delivers a number of other programs funded by the Australian and NSW governments.

SSI is well placed to contribute to this discussion paper. In doing so, we draw on our extensive experience engaging with and delivering services to people with a disability, their families and carers, particularly those from CALD backgrounds, in NSW and Queensland.

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Executive Summary

- The uptake of the NDIS by people of culturally and linguistically diverse (CALD) backgrounds is much lower than we would expect, despite people of CALD backgrounds having rates of disability similar to the rest of the Australian population.
- We must not lose sight of the fact that it is the responsibility of the National Disability Insurance Agency (NDIA) and Local Area Coordination (LAC) providers to be accessible to all people with a disability. The underutilisation by CALD communities and other groups in the NDIS is not inevitable. While there are barriers, there are also enablers that can improve outcomes for people with a disability from CALD backgrounds.
- Potential and current NDIS participants experience challenges across the NDIS service journey and so it is important to adopt both tailored and systematic approaches to address these challenges.
- NDIS Participant Pathways could be improved for people from CALD backgrounds through ‘soft’ entry points or community connectors to the NDIS. These community connectors can effectively engage and build trust with CALD communities and organisations. LAC providers have not played this role effectively as they often lack the cultural and linguistic skills to work with people from CALD backgrounds; are not sufficiently connected to CALD communities to build trust and rapport; and often have insufficient capacity to engage the mainstream service system (e.g. allied health, GPs, etc) that is an important conduit for CALD people with a disability to the NDIS.
- While support coordination is available under the NDIS, people from CALD backgrounds are often unable to access this support as part of their plans. The provision of support coordination for at least 12 months after an NDIS plan is in place would assist people of CALD backgrounds activate, access and review the supports they require.
- Our consultations have indicated that the NDIA and LAC providers can improve the effectiveness of Participant Pathways by responding to the barriers facing CALD communities, specifically:
 - The importance of in-language information and support has been demonstrated through the launch of SSI’s national Multilingual Hub which delivers a culturally responsive service to address barriers faced by people of CALD backgrounds.
 - The importance of community connectors or intermediaries has been demonstrated by the success of SSI’s delivery of Ability Links NSW which, in an independent evaluation, showed that almost two-thirds of SSI’s Ability Links individual outcomes were with CALD people, which represented three-quarters of the statewide program outcomes for CALD participants in NSW.
- The NDIA should develop and implement a multilingual and culturally diverse workforce strategy to ensure that the NDIA and LAC providers are able to meet the diverse needs of CALD communities and enhance Participant Pathways. The workforce strategy should include mandatory training for NDIA and LAC staff in culturally responsive practice.
- The Participant Service Guarantee and Service Standards should be enhanced with additional principles around culturally responsive services, in-language information and support, and ongoing monitoring and feedback while a participant is accessing, activating or reviewing an NDIS plan.

Recommendations

SSI recommends:

1. Enhancing Participant Pathways through:
 - a. **Culturally responsive connectors** or intermediaries to address issues around uptake and access to the NDIS for people from CALD backgrounds.
 - b. The provision of **support coordination for at least 12-months as part of NDIS plans** to enable participants, particularly those from CALD backgrounds, to receive support in activating, accessing and reviewing supports under their plan.
 - c. Responding to the **barriers facing CALD communities** highlighted in this submission.
2. Improving the cultural responsiveness of the NDIA by implementing workforce strategies:
 - a. Focused on **recruiting multilingual and culturally diverse staff** to better 'connect' with CALD communities.
 - b. That **include a requirement for culturally responsive practice training for staff at the NDIA**, and potentially LAC providers, **to ensure they understand and respond** to the intersectional needs and aspirations of people with a disability from CALD backgrounds. In doing so, the NDIA could leverage the expertise of organisations such as SSI which have deep knowledge and experience in working with people from CALD backgrounds.
3. Enhancing the **NDIS Participant Service Guarantee and Service Standards** to enable underserved populations in the NDIS, such as people with a disability from CALD backgrounds, to achieve social and economic inclusion. This involves modifying the current principles and including additional principles around **culturally responsive services, in-language support, and ongoing monitoring and feedback**.

General Comments

The uptake of the NDIS by people of culturally and linguistically diverse (CALD) backgrounds is much lower than we would expect, despite people of CALD backgrounds having rates of disability similar to the rest of the Australian population.

Population data indicates that people from CALD backgrounds have rates of disability, and profound or severe disability, similar to the rest of the Australian population. ABS data shows that the proportion of people born in a non-English speaking country who have a disability is the same as the rate of disability for all Australians [1]. Similarly, six per cent of all Australians have a profound or severe core activity limitation, and the rate of profound or severe limitation is also six per cent for people born in a non-English speaking country [1].

An estimated 23 per cent of the Australian population are from a CALD background by the NDIS definition of cultural and linguistic diversity [2]. By the end of 2017, only seven per cent of NDIS participation plans across Australia were being delivered to people identified as being from a CALD background [2]. By the end of 2018, the proportion had increased slightly to eight per cent [3]. This is approximately one-third of the 23 per cent of potential NDIS participants who could be expected to be from a CALD background.

The low level of access seen in population data is consistent with the findings of the evaluation of the trial of the NDIS by the National Institute of Labour Studies (NILS). The NILS found that while the NDIS has improved the lives of people with disability overall, it has left several minorities, including people from CALD backgrounds, no better off or even in a worse situation [4]. In addition, the evaluation found that “some design aspects and implementation outcomes are not as person-centred as originally desired, and several outcomes are not attained at the speed that was originally expected” [4]. The evaluation identified several issues, including in service supports, workforce, choice and control, participation, and equity and access [4]. Similarly, the Productivity Commission’s 2017 NDIS Costs – Study Report noted that “... not all are reporting improved outcomes under the NDIS” and identified groups, including those with a psychosocial disability, complex and multiple needs, language and cultural barriers, transitioning from the criminal justice system, the homeless and socially isolated as being at risk of having poorer outcomes [5].

Access to the NDIS by people from CALD backgrounds is also affected by thin markets. The Department of Social Services recently engaged in a consultation process on these market constraints. SSI made a submission [6] and made a number of recommendations including:

- Market facilitation through the use of culturally responsive connectors or intermediaries which provide ‘soft’ entry points to the NDIS system and address the lack of awareness of the NDIS among people of CALD backgrounds; and
- Market deepening through the NDIA placing a stronger emphasis on diversity in its workforce strategy and implementing workplace training in culturally responsive practice for its staff.

Potential and current NDIS participants experience challenges across the NDIS service journey and so it is important to adopt both tailored and systematic approaches to address these challenges.

The NDIS service journey involves participants engaging with numerous parties (e.g. NDIA, LAC providers, etc) who have different roles and requirements across several stages of the NDIS service journey. Participants who are not supported through this process can find it difficult to engage and manage relationships with the different parties and understand the processes involved. The NDIA recognises the need for tailored approaches and to evaluate “the quality of experience at different points in time including when accessing the NDIS, during the planning and plan implementation; and when using a particular support or service” [7].

The NDIS requires participants and their families to navigate the complexity of the NDIS to have their needs met. However, disadvantaged groups are less able to do this for themselves. The NDIS evaluation noted that the NDIS was considered to be working best for articulate, English-speaking participants, and that participants from disadvantaged groups such as people with intellectual disabilities, Indigenous people and participants from CALD backgrounds were “at risk of being allocated lower levels of funded supports” [4]. The evaluation also noted “the need for equity and fairness is a fundamental ethical underpinning of the NDIS” [4]. Working towards making this equity a reality points to the need for more systematic changes in the delivery of the NDIS across multiple levels.

A consistent theme for people with disability from CALD backgrounds in the evidence base is the intersectionality of multiple issues that heighten vulnerabilities and compound the barriers and challenges they face [2]. The NDIA *Cultural and Linguistic Diversity Strategy 2018* [7] is a welcome step in the right direction for the agency, but a much stronger commitment to CALD participation is required. In SSI’s view the NDIA should adopt and implement a cultural competency framework across all parts of the agency and the programs that it funds (e.g. Local Area Coordination). A good example of a systematic framework was developed by the National Health and Medical Research Council with the four levels of action across systemic, organisational, professional and individual domains [8].

Examples of the kinds of initiatives that could shift the needle towards a more culturally competent NDIS that support choice and control for CALD people with a disability at each of these levels include:

- a workforce strategy in the NDIS that embeds cultural and linguistic diversity and is supported by training on culturally responsive practice in the disability sector to NDIS providers (systemic);
- requiring LAC providers to develop and implement CALD community engagement plans, especially in areas of high cultural and linguistic diversity (organisational);
- actively seek to recruit bilingual professionals at the NDIA and at LAC providers (professional); and
- ‘flag’ CALD NDIS participants who require language interpreting so that this is the routine method of all communications with the NDIS participant (individual).

People from CALD backgrounds need culturally responsive connectors or intermediaries to the NDIS that can effectively engage and build trust with CALD communities and organisations.

The NDIS model assumes an awareness of the NDIS and the supports which are available in the NDIS market. While the role of the LAC providers is an integral part of the NDIS structure and planning process, people from CALD backgrounds are not effectively engaging with the LAC providers. To be effective, LAC providers need to work with people with a disability within their cultural and community context to leverage existing formal and informal networks. For example, in SSI's experience, people from CALD backgrounds learn about the NDIS through trusted community members or 'CALD-friendly' service providers. The barriers to engaging effectively with the NDIA and LAC providers include:

- **The NDIA and LAC providers often lack the cultural and linguistic skills to work with people with a disability from CALD backgrounds:** People with a disability from CALD backgrounds experience an intersectionality of multiple issues that heighten vulnerabilities and compound the barriers and challenges they face. In our experience, the NDIA and LAC providers often lack an understanding of this intersectionality of disability and cultural and linguistic backgrounds.
- **The NDIA and LAC providers are not sufficiently engaged with CALD communities to build trust and rapport with people with a disability of CALD backgrounds:** While the NDIA and LAC providers have professional capabilities, they often lack the necessary connections and rapport with CALD communities to tap into the networks of support used by people of CALD backgrounds.
- **Accessing the NDIA and LAC providers requires a degree of self-advocacy and agency:** People of CALD backgrounds are often unaware of what services could address their needs or what services the NDIS offers. This is compounded by difficulties communicating with the NDIA and LAC providers or accessing information through the portal or other means. These difficulties in the planning stages can result in people of CALD backgrounds receiving lower levels of support and serves to entrench the social disadvantage that the NDIS is working to address.
- **The LAC providers often have insufficient capacity to engage the mainstream service system (e.g. allied health, GPs, etc) that is an important conduit for CALD people with a disability to the NDIS:** In our experience mainstream services that are accessed by people from CALD backgrounds with a disability have a poor knowledge of the NDIS and LAC providers have insufficient capacity to address these gaps.

The barriers to engaging effectively with the NDIA and LACs accentuate the importance of culturally responsive connectors to act as intermediaries and assist CALD participants navigate the NDIS planning process and the NDIS supports they require.

Based on SSI's experience, there is an urgent need for 'soft' entry points that can serve to link people from CALD backgrounds to information and services available under the NDIS. The soft entry points can also actively engage CALD community organisations, mainstream services and businesses to become more inclusive of people with disability.

An example of these kinds of 'soft' entry points was Ability Links NSW. Under Ability Links, individuals called Linkers supported people with a disability, their families and carers to identify their goals and connect them with their community, the NDIS and mainstream services. Linkers also supported community organisations, mainstream services and businesses to become more inclusive of people with disability. An evaluation of the state-wide Ability Links program found that it was generating positive outcomes, including for Aboriginal participants, and reported a 3:1 ratio of benefits to costs [9]. The independent evaluation of SSI's delivery of Ability Links found that almost two-thirds of SSI's Ability Links individual outcomes were with CALD people, which represented three-quarters of the statewide program outcomes for CALD participants in NSW, which provided vital pathways to potential and existing NDIS participants [10].

The FutureAbility program is another example of a culturally responsive program which aims to increase awareness of disability and the NDIS in CALD communities. FutureAbility uses innovative methods and channels that are better suited to specific CALD communities such as SBS in-language radio education campaigns. Other successful examples include conferences, theatre plays, in-language education sessions, regional roundtable discussions and workshops, with more than 5,000 attendees across these methods [11].

Another example, illustrating the importance of in-language services, is SSI's national Multilingual Hub. The Multilingual Hub includes a multilingual hotline and website providing relevant and easily accessible information on disability and the NDIS in 14 languages. People wanting to access information in their preferred language have the choice of calling the hotline, which is operated by trained bilingual staff, or visiting the website, with accessible in-language information about disability and the NDIS.

SSI recommends enhancing Participant Pathways through culturally responsive connectors and programs to address issues around uptake and access to the NDIS for people from CALD backgrounds.

While support coordination is available under the NDIS, people from CALD backgrounds are often unable to access this support as part of their plans. The provision of support coordination for at least 12 months after an NDIS plan is in place would assist people of CALD backgrounds to activate, access and review the supports they require.

The NDIS system is based on the concepts of choice and control which requires participants and their families to independently identify and access the support they require after a plan is in place. Support coordination is designed to assist participants who have less capacity to actively manage their plans including those with high and complex needs.

In SSI's experience, people from CALD backgrounds require support coordination to better understand how their plans work and the plan review process. In our consultations, SSI has identified multiple examples where people with a disability from CALD backgrounds have difficulties activating the supports identified in their plans without support coordination. The absence of such support coordination has resulted in people of CALD backgrounds underutilising the support available to them and being at a disadvantage to address these issues in the 12-month plan review.

SSI recommends that at least 12-months of support coordination be universally offered to CALD participants as part of NDIS plans. This would enable participants to receive support in activating, accessing and reviewing supports under their NDIS plan.

Our consultations indicate that the NDIA and LAC providers can improve the effectiveness of Participant Pathways by responding to the barriers facing CALD communities.

The kinds of initiatives that could shift the needle towards a more culturally responsive Participant Pathways in the NDIS include:

- Continuing to promote the use of interpreters at different points of the Participant Pathway which, while covered by the NDIA as per a recent announcement, may not be widely known or accessed by NDIS service providers;¹
- Allowing more time for planning meetings;
- Ensuring that if a participant requests an interpreter, that this support is ‘flagged’ and is routinely provided by NDIA and LAC staff in every future interaction without requiring the participant to self-nominate each time;
- Ensuring that easier-to-read plans include a one-page summary that has been translated into the preferred language of the CALD participant; and
- Ensuring that there is a single point of contact with the NDIA and/or LAC provider.

The NDIA should develop and implement a multilingual and culturally diverse workforce strategy to ensure that the NDIA is better able to meet the intersectional and diverse needs of CALD communities and enhance Participant Pathways.

People from CALD backgrounds have a range of intersectional needs and barriers when interacting with the NDIS system. These often result in people from CALD backgrounds being under-represented among disability service users [2].

SSI’s experience delivering the Ability Links NSW² and FutureAbility³ programs indicates the critical need for bilingual and multilingual staff to proactively engage and ‘connect’ with CALD communities and support them to access information about the NDIS and disability [10-12]. An independent evaluation of the Ability Links NSW program commissioned by SSI found that the successful outcomes achieved by SSI with CALD participants were driven in large part by the bilingual, culturally diverse and community-connected staff, called Linkers [10]. These individuals were vital to building rapport and trust which minimised cultural and linguistic barriers to the NDIS [10].

SSI recommends the NDIA develop and implement a workforce strategy focused on recruiting multilingual staff from CALD backgrounds. While the NDIS *Cultural and Linguistic Diverse Strategy 2018* seeks to enhance cultural competency within the NDIA [7], SSI recommends also ensuring that the NDIA workforce represents the cultural and linguistic diversity of its participants.

¹ NDIS, *Language interpreting services for providers*. 24 May 2019. Available at: <https://www.ndis.gov.au/providers/essentials-providers-working-ndia/language-interpreting-services-providers>.

² Ability Links NSW was funded by the NSW Department of Family and Community Services until June 2019. Under Ability Links, intermediaries called Linkers supported people with disability, their families and carers to identify their goals and connect with their community and mainstream services.

³ SSI’s FutureAbility Project aims to develop strategies to ensure that CALD communities achieve better access to the NDIS. FutureAbility is a multiphase project managed by SSI, originally funded by the NSW Government, which now has some national initiatives funded under the NDIS.

The NDIS Participant Service Guarantee and Service Standards should be enhanced to enable underserved populations in the NDIS, such as people with a disability from CALD backgrounds, to achieve social and economic inclusion.

SSI supports the Government's commitment to introduce a new NDIS Participant Service Guarantee (PSG) designed to reduce wait times and increase monitoring of the NDIA's performance against specified timeframes. However, a stronger emphasis is needed to promote access by underserved populations. As such, the PSG service standards should enable greater access and inclusion by underserved populations such as people with disability from CALD backgrounds.

SSI's specific comments on the PSG service standards are as follows:

- ***Engaged:** Increase the breadth and depth of consultation on NDIA processes and policies*

While SSI supports the NDIA working with people with a disability and other affected populations during the design phase of processes and policies, SSI recommends continuous engagement with affected populations from the design phase through to operationalisation. Organisations that specialise in working with CALD populations could be leveraged to enhance the breadth and depth of participation in consultations.

- ***Expert:** NDIA staff should be trained to recognise and plan for the different needs of participants with similar disabilities.*

SSI supports NDIA staff being trained on the impact that particular impairments have on people's lives. As part of this, NDIA staff should also recognise the different choices and aspirations of people with similar disabilities arising from cultural influences. NDIA planners should demonstrate flexibility in the planning process to ensure that plans reflect individual participant needs, choices and aspirations. For example, SSI has identified multiple examples where people with a disability from CALD backgrounds have difficulties accessing the supports they require. NDIA planners should be able to recognise when underserved populations, such as people from CALD backgrounds, require support coordination to better understand how their plans work and how to access culturally competent providers in their local area.

- ***Connected:** Collaboration should be extended to groups and organisations that serve as formal and informal networks to underserved populations.*

In SSI's experience, people with a disability from CALD backgrounds are typically linked to information and services available under the NDIS through CALD community groups and specialist CALD service providers such as SSI. As such, SSI recommends extending engagement and collaboration with these organisations which may not work directly with people with a disability but that offer formal and informal support networks to underserved populations.

- ***Valued:** Performance measurement against this service standard should be focused on the level of understanding of participants, their families, carers and other support persons.*

While the description of the principle refers to participants, family members, carers and other support persons, the service standard is broadly referring to understanding of the NDIS by the broader community. In SSI's view, the service standard should be measured by regularly surveying the level of

understanding of the NDIS among participants with a disability, family members, carers and other support persons. This will ensure that the service standard is more specific and measurable.

- *Accessible: The means and methods of information dissemination is an important part of ensuring accessibility.*

SSI sees the provision of information to meet the needs of groups such as people of CALD backgrounds as just one step towards accessibility. However, accessibility is also determined by the means and methods used to disseminate such information. For example, and as noted earlier in this submission, SSI has found that 'soft' entry points are the most effective means to link people from CALD backgrounds to information and services available under the NDIS. Further, as noted earlier, the provision of information to people from CALD backgrounds could be enhanced by ensuring that if a participant requests an interpreter that this support is 'flagged' and is routinely used in every future interaction by any NDIA or LAC staff member without requiring the person to self-nominate each and every time.

- *Monitoring and feedback: An additional principle on NDIS' capacity and capability to monitor feedback and respond flexibly to participant's issues during or post plan-implementation.*

The NDIS system is premised on market principles in which participants represent customers who purchase products and supports. Participants who are unsatisfied with their products and supports should be able to raise their concerns with the provider and the NDIA. The NDIA's ability to respond flexibly and resolve participant's issues is a key part of a functioning market.

SSI recommends an additional principle on the NDIA's ability to respond flexibly and resolve participant's issues. The NDIA's performance could be measured against the number of complaints resolved and/or the number of participant plan reviews requested.

- *Culturally responsive and in-language support: An additional principle based on NDIS' Cultural and Linguistic Diversity Strategy [7] providing culturally responsive services and offering in-language support as a standard part of its service delivery.*

As noted throughout this submission, people from CALD backgrounds experience intersectional barriers when accessing disability supports and government services and this is noted in the NDIA's *Cultural and Linguistic Diversity Strategy*.

SSI is of the view that the NDIA's commitment to supporting people with a disability from CALD backgrounds would be strengthened with a principle that seeks to measure the cultural responsiveness of the NDIA's services and its provision of in-language support to participants from CALD backgrounds.

SSI suggests that performance against the principle could be assessed using measures such as staff who have completed culturally responsive training; numbers of bilingual or multilingual staff; numbers of staff from culturally and linguistically diverse backgrounds; and monitoring in-language support requested and provided through, for example, interpreter usage data across the NDIA.

Case Studies

The following section outlines case studies from our internal consultations.

Case Study 1 – The key role of connectors or intermediaries

“My name is Cecilia and I am a single mother with mental health issues related to stress. I have three young children, one of whom has autism. I wasn’t aware of the NDIS because people in my community haven’t heard of it and there was no information provided through my community. I’m not good with written information and websites and I don’t speak much English.

I was lucky enough to meet a ‘linker’⁴ who spoke my first language and provided me with information on the NDIS. However, I had difficulty understanding the application process, the time needed, the forms and the funding. I spoke to my linker who invited me to an NDIS workshop conducted in my first language. The workshop was very helpful and I received help to complete an NDIS application for me and my son. While my application was refused, my son’s application was approved.

Preparing for the planning meeting was very stressful. I was stressed because I was told that the planning meeting is important in determining whether I would receive adequate funding for my son. My stress and anxiety preparing for this meeting was unbearable and was made worse by my mental health.

I reached out to my linker for support. My linker connected me with a support organisation that worked on boosting my confidence by role-playing the planning meeting and talking through the planning process.

Although I went to the planning meeting feeling confident, my meeting with the planner did not go well. Speaking through an interpreter took longer than expected and the planner did not provide me with sufficient time to communicate my son’s needs. More time is needed when using an interpreter but my planner was unwilling to be flexible or allocate more time.

Afterwards, my linker assisted me with questions I had regarding my son’s approved plan. I was confused about how to use the funds to help my son, which service providers would be able to provide in-language support, why the funds were at the given amount and how to seek a review of my own rejected application. My linker connected me to an organisation that assisted me to seek additional support coordination funding for my son and request a review of my rejected application.

The most important part of my journey was connecting with a linker who was part of my community and could communicate with me in my language. Otherwise, I would have never been able to access the NDIS.”

Case Study 2 – The importance of support coordination

“My name is Jamal and I live with my wife and two young daughters. I have autism and my youngest daughter has Aspergers syndrome. My wife has an intellectual disability and suffers from depression.

The process of applying to the NDIS, understanding the web portal and photocopying all the documents caused my wife to have a breakdown. She went to a mental health service to get additional help. We did

⁴ Under the Ability Links NSW program, connectors were known as ‘linkers’ and worked closely with people with disability, their families and carers.

not have enough help from one single source and it was even more confusing when different providers told us different things.

After many months, our plans were approved. We also asked for support coordination and domestic assistance but these were not approved. Balancing the pressure of domestic work, our combined disabilities and navigating the NDIS was immensely difficult. We did not understand what to do, where to get help and how it all worked. When we asked different people and organisations, we were given conflicting information.

The NDIS is too complex. There needs to be a single point of contact that can provide us with support through the whole journey.”

Case Study 3 – Degrees of vulnerability

“I am Safana and I am a refugee living in regional NSW. I was settled as part of the Humanitarian Settlement Program funded by the Australian Government. I have three children with hearing impairments and so I applied for the NDIS.

Even though my English was low, I did not receive any support or interpreter services. In my discussion with the planner, I could not communicate about the support I needed. I also could not understand the plan that I agreed to. I felt like I had no choice but to take what was given to me.

In my plan, I have to take each of my children for regular hearing appointments in the closest metropolitan town. This means I have to travel long distances with my three young children and pay for costs like train tickets, food and accommodation in the city. As I have arrived recently as a refugee, I do not have any family who can help me or any savings from back home.

SSI has helped me attend my appointments as much as possible. But I have had to miss many hearing appointments because of the travel and looking after my children. If I request the hearing specialist to come to me, my plan states that this will reduce the level of support I receive.

I am very stressed because of my financial situation, how far I live and my responsibility to look after my three children.”

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