NDIS East Arnhem Co-design Project Evaluation- Final Report

prepared for the Department of the Prime Minister and Cabinet

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Acknowledgements

Thank you to community members in Milingimbi, Galiwin’ku, Groote Eylandt who told us your stories and gave us your time to answer our questions. Thank you to community facilitators who shared your local knowledge and relationships in communities and translated and guided us through interviews with participants and their families. Thank you to our key contacts and service providers who made us feel welcome and hosted us in Nhulunbuy, Milingimbi, Galiwin’ku and Groote Eylandt.

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Disclaimer

The opinions, comments and/or analysis expressed in this document are those of the authors and do not necessarily represent the views of the Department of the Prime Minister and Cabinet.

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Acronyms

ALPA Arnhem Land Progress Aboriginal Corporation

CoS Coordination of Support

DTBI Northern Territory Department of Trade, Business and Innovation

ILC Information, Linkages and Capacity Building

LAC Local Area Coordinator

MJD Machado-Joseph Disease

NT Northern Territory

NTG Northern Territory Government

NDIA National Disability Insurance Agency

NDIS National Disability Insurance Scheme

OoD Office of Disability

PM&C Commonwealth Department of the Prime Minister and Cabinet

POLR Provider of Last Resort

SDF Sector Development Funding

VTEC Vocational Training and Employment Centre

Executive Summary

The National Disability Insurance Scheme (NDIS) is a complex scheme that involves significant change for individuals, communities, service providers and government departments and agencies. The challenges of communication and service delivery in remote communities such as East Arnhem create additional hurdles for the roll out of the scheme. The NDIS East Arnhem Co-Design Project differs significantly from the NDIS in other parts of Australia in its community engagement approach and is guided by specific strategies and special conditions, prioritising face-to-face engagement and a focus on adapting the scheme to local needs and circumstances.

Despite these implementation strategies, 14 months after the commencement of the roll out, there is a lack of awareness and understanding of the NDIS in communities, and low activation and utilisation of plans in the region. Given the complexities of both the scheme and the remote context, it is clear that it is too early to measure significant outcomes from the project and that more time is needed to build understanding, relationships, capacity, and skills for all stakeholders to successfully engage with, navigate and benefit from the NDIS in East Arnhem. In particular, more time needs to be dedicated to ongoing communication with participants, carers, families and communities, using culturally appropriate information and resources in Language, to develop quality plans that reflect participants’ needs and community priorities.

Stakeholders agree that the Co-Design project is incorrectly named as it was designed in the National Disability Insurance Agency (NDIA) head office without their input. They feel the term co-implementation more accurately describes the way in which the NDIA NT office is working with a range of stakeholders, including community members and local service providers, to adapt the scheme to local conditions and needs. Ongoing engagement with local service providers demonstrates that NT NDIA is listening, responding, and seeking flexibility in how the Scheme is rolled out in the region.

The early stages of the transition and roll out have faced a range of challenges and the uptake and transition of clients to NDIS has been slow, as expected, but is increasing. There is a lack of services in the region, particularly in smaller communities, which is impacting on participant outcomes. The current lack of reliable data and market visibility in East Arnhem is impacting on the ability of project stakeholders, including local and potential future service providers, to plan for and develop new services and a local workforce for the region.

Despite the range of challenges and early implementation barriers, processes are improving and all project stakeholders see the potential of the NDIS to benefit the region, are seeking common outcomes and investing heavily in the scheme, planning and developing a range of initiatives. The project is benefiting from strong collaboration between project stakeholders on the ground, in particular local service providers. There is strong evidence of a shared commitment to build sustainable engagement with the NDIS that will bring positive outcomes for East Arnhem communities.

Summary of Key Findings and Recommendations

Following is a summary of the key findings and the recommendations for each of the four overarching evaluation questions. Detailed findings are provided in section three of this report.

|  |
| --- |
| 1. **Before the NDIS**   ***Before the NDIS how did people with a disability and their families participate in and contribute to their community and were their reasonable and necessary support needs met?*** |
| 1.1 In East Arnhem, extended families share the care of relatives with a disability and provide a range of informal supports.  1.2 People with a disability participate and contribute to the community in a range of ways including through cultural activities and events, ‘DJ’ing and playing music, teaching/mentoring, and the football club. Engagement in everyday life is limited when there is no carer available.  1.3 Prior to the NDIS, some clients were case managed through the NT Government Office of Disability, or Office of the Public Guardian, or were part of the Partners in Recovery program. Existing services provided include aged care services, sport and recreation facilities, libraries, community development programs, church groups and school programs.  1.4 There is a lack of services across the region and in smaller communities in particular, this means there is very little choice for people living with disability. Lack of choice in respite services is a particular problem, and lack of equipment maintenance services and services designed for youth.  1.5 People living with disability in East Arnhem want to be able to be a supported to engage in culture and community, including practices like hunting, attending funerals and other cultural events. They want to have access to a range of activities that are interesting and stimulating for them.  1.6 It is too early to see significant changes in East Arnhem communities but some participants and families have received new equipment, are accessing more services and exercising more choice.  1.7 Non-Indigenous participants are demonstrating a higher level of engagement with and outcomes from the NDIS in East Arnhem. People with English as a first language, with stronger computer literacy and who live in townships seem better able to engage with the Scheme and articulate their needs. |
| 1. **The Co-design process**   ***How has the co-design process worked in each community? What have stakeholders identified as necessary to meet the reasonable and necessary support needs?*** |
| 2.1 All stakeholders identified that co-design is not an accurate term to describe the project as they were not engaged in its design.  2.2 Co-implementation would more accurately describe the process of strong collaboration taking place between project stakeholders in the delivery of the project. It is recognised there is a need for creativity and flexibility as community needs vary.  2.3 There is strong evidence that the NT NDIA flexibility is a key strength of the project.  2.4 The NDIA has been responsive and adaptive to local conditions and feedback from service providers throughout the implementation of the project.  2.5 There is strong evidence that collaboration of service providers is a key strength of the project.  2.6 Limited collaboration between the NT Government and the NDIA within the governance structure of the Bilateral agreement has impacted on some aspects of the project. |
| 1. **Establishing Foundations to support outcomes**   ***In the period since the co-design process began in September/October 2016 has it established the foundation to achieve the outcomes stakeholders have identified?*** |
| 3.1 A range of NDIA strategies have been developed to build the foundations for the roll out of the NDIS East Arnhem Project. These strategies reflect an understanding of the complexity of service provision in the region and prioritise community engagement, listening and flexibility.  3.2 Despite the focus on community engagement, there is a lack of understanding about the NDIS in communities and more time is needed to build awareness and engagement.  3.3 Community Connectors are key to engaging communities in East Arnhem with the NDIS. There is evidence that the utilisation of Connectors has increased throughout the roll out.  3.4 A range of challenges in terms of establishing foundations have been experienced by community and project stakeholders, due to the major changes involved with the transition and implementation of the NDIS.   * 1. NDIA and NT Office of Disability have collaborated well on the ground throughout the transition.   3.6 Processes are improving, communication is strong and there is strong of evidence of flexibility,  innovation and collaboration between project stakeholders.  3.7. Funding made available through the Sector Development Funding (SDF) and Information, Linkages and Capacity Building (ILC) grants have been accessed by local service providers for a range of projects. However, this funding could have been made available before the roll out to allow SPs to better prepare themselves and communities for the changes.  3.8. Despite early challenges in implementation and lack of co-design, project stakeholders are positive about the potential of the NDIS to achieve outcomes in the future and are planning and developing initiatives for communities.  3.9 The project is benefiting from shared outcomes across the range of stakeholders, who are committed to sustainable engagement with the NDIS to achieve positive outcomes for East Arnhem communities. |
| 1. **Business and Employment**   [***How has the Co-design Project supported Aboriginal and Torres Strait Islander people to establish businesses and has it increased employment of local people?. 15***](#_Toc507495686) |
| 4.1 It is too early to measure significant business and employment outcomes. Nineteen Community Connector roles are the main employment outcome.  4.2 There are a range of initiatives and plans for new services in the region including a respite centre in Ramingining, a wellbeing centre in Galiwin’ku, and the extension of existing services including those provided by sport and recreation centres, community development programs, and local art centres.  4.3 Training programs and flexible employment models are also being proposed and considered for the development of a local workforce to help deliver the NDIS in East Arnhem. |
| 1. **Recommendations**   ***What has been learned from the pilot project, what can be improved?*** |
| **5.1 Too early to measure significant outcomes in East Arnhem**  **Recommendation One (a):** That the Commonwealth review the implementation and outcomes of the NDIS East Arnhem project in another twelve months’ time.  **Recommendation One (b):** That at least 24 months of implementation be underway before evaluating outcomes from the NDIS roll out in remote Aboriginal and Torres Strait Islander communities.  **Recommendation One (c):** That a monitoring framework be developed using co-designed, effective implementation principles as a guide, to monitor and continuously improve the implementation of the NDIS roll out in remote Aboriginal and Torres Strait Islander communities.  **5.2 More time and communication are needed to build understanding and engagement**  **Recommendation Two:** That the NDIA provide consistent and ongoing communication and consultation with communities, working with Community Connectors and resources in Language, to increase understanding of and engagement with the NDIS in East Arnhem.  **5.3 The importance of good quality NDIS plans**  **Recommendation Three**: That the NDIA provide sufficient time and funding for the pre-planning, planning and review process in East Arnhem to follow cultural protocols and for planners to engage with a range of community and family members. This time and funding are needed to ensure that plans reflect the needs, goals and cultural priorities of participants.   * 1. **Leadership of local Service Providers**   **Recommendation Four:** That the NDIA continue to collaborate closely with and support local service providers who are key to the effective implementation of the NDIS in East Arnhem.   * 1. **Flexibility of NDIS to respond to local needs, conditions and cultural priorities**   **Recommendation Five:** That the NDIA continue to provide flexibility in the delivery of the NDIS in East Arnhem and to develop local solutions in response to community needs, conditions and cultural priorities. For example, the NDIA should work with community and project stakeholders to create opportunities for local carers to be employed as NDIS support workers.  **5.6 More collaboration between government agencies on workforce development**  **Recommendation Six:** That the NT and Commonwealth Governments collaborate closely with the NDIA, share resources and information, in order to better support the implementation of the NDIS in East Arnhem and the development of a regional disability workforce.   * 1. **Collaboration between all stakeholders the key to successful implementation**   **Recommendation Seven:** That the NDIA and government departments continue to support and encourage collaboration between stakeholders throughout the implementation of the NDIS in East Arnhem, providing opportunities for project stakeholders to network, share information, discuss funding opportunities, and identify shared outcomes, challenges and successes.   * 1. **Co- Design NDIS pathways with local communities**   **Recommendation Eight:** That the NDIA use the pathway models included in this report as a base, to take back to communities in East Arnhem, and co-design with local service providers, participants and their families, the NDIS pathway that works best for them and their local community.   * 1. **Consider these recommendations for the roll out of the NDIS in other remote Aboriginal and**   **Torres Strait Islander Communities**  **Recommendation Nine:** That the NDIA consult with each remote Aboriginal and Torres Strait Islander community to consider the application of the above recommendations for the roll out of the NDIS in their location |

1. Background
   1. About the NDIS

The NDIS, established by the NDIS Act in 2013, is the new way of providing support for Australians with disability, their families and carers. The NDIS was first trialled in a selection of sites in 2013, including the Barkly region in the Northern Territory (NT), followed by a staged, national roll out that included East Arnhem in January 2017. The NDIS aims to provide about 460,000 Australians under the age of 65 with a permanent and significant disability with the reasonable and necessary supports they need to live an ordinary life. People who are eligible for NDIS support are called participants. Each participant has their own NDIS plan that identifies the outcomes they wish to achieve, the supports that will be funded by the NDIS and other supports the person requires. Providers are individuals or organisations that deliver a support or a product to a participant in the NDIS. People with disability will choose the providers they engage and can change providers at any time[[1]](#footnote-2).

Arrangements for the transition and implementation of the NDIS in the NT are outlined in the Operational Plan Commitment between the NDIA, NT and Commonwealth Governments. According to the NDIA, while the Territory will be the smallest market within the NDIS with around 6,500 NDIS participants, (50% of them Aboriginal and Torres Strait Islander), the growth in people receiving disability services will be one of the highest: 103% once it is fully implemented. East Arnhem is expected to have 500 participants by 2020 with expected annual funding to increase from $5 million in 2017 to $30 million by 2020. [[2]](#footnote-3)

* + 1. NDIS Eligibility

To be eligible to access the NDIS an individual must:

* Have a permanent and significant disability or developmental delay
* Be under 65 years of age
* Live in Australia where the NDIS is available
* Be an Australian citizen or hold a permanent residency visa[[3]](#footnote-4)
  + 1. NDIS Plans

Once eligibility has been established, trained NDIA planners work with the individual, called an NDIS participant, to develop a plan. In most cases, the planning conversation takes place over the phone[[4]](#footnote-5), however for the NDIS East Arnhem Project, planning meetings take place face to face with participants in their communities. The plan is the entry point to the NDIS and the beginning of the relationship with the NDIA. An NDIS plan includes two parts:

* the participant’s [statement of goals and aspirations](https://www.ndis.gov.au/operational-guideline/planning/participant-statement-goals.html), which is prepared by the participant and specifies their goals, objectives, aspirations and personal context (including all informal, community and other mainstream supports already available to the participant); and
* the [statement of participant supports](https://www.ndis.gov.au/operational-guideline/planning/statement-participant-supports.html), which is prepared with the participant and approved by the NDIA, which specifies, among other matters, the supports that will be provided or funded by the NDIS (known as reasonable and necessary supports)[[5]](#footnote-6)

Before any support is added to a participant's plan, the NDIA must be satisfied that the support will assist the participant to pursue the goals, objectives and aspirations that the participant has stated. Support will be funded or provided when the NDIA is able to identify a direct link between it, and the participant’s goals and aspirations.[[6]](#footnote-7) Plans are reviewed and renewed after 12 months unless there is a change in circumstances and the participant requests an earlier review.

Once approved, the participant is then able to choose how they manage the individualised funding in their plan:

* Self-managed – participant or their nominee is paid directly by NDIA and uses the portal to administer the funded supports in the plan
* Agency managed – local registered service providers are paid by NDIA to coordinate and administer funded supports in participant’s plan
* Plan managed – a plan manager is elected by the participant and paid directly by the NDIA to administer the funded supports in the plan.[[7]](#footnote-8)
  + 1. NDIS Portal

The NDIS Portal has two different access points for participants and registered service providers.

Myplace is the NDIS Participant Portal. It is a secure website where self-managing participants or their nominees can view their NDIS Plan, locate service providers with the Provider Finder tool, message with service providers and the NDIS, request payments, and manage services from providers[[8]](#footnote-9).The Provider Portal for registered NDIS service providers includes a range of functions for them to view and manage their services with NDIS participants including managing bookings, making payment requests and viewing referrals made to their organisation.[[9]](#footnote-10)

* + 1. Coordination of Support Services

Coordination of support (CoS) involves supporting a participant to implement all supports in their plan, including informal, mainstream, community and funded supports. Support coordinators work creatively and resourcefully with participants in how they utilise their support budgets to achieve their goals. During the planning process, participants can elect support coordination services from a provider of their choice. The role of support coordination is complex and includes the management of all aspects of the plan while building the capacity of participants to self-manage their plan over time. CoS services are expected to support participants to achieve the following outcomes:

* maximise the value for money they receive from their supports
* genuinely exercise their choice and control
* implement their plan
* have increased capacity to manage/direct their own supports
* have greater opportunities to explore and connect with community and alternative support options
* better coordinate multiple supports and services
* have the capacity of their informal support network strengthened
* be better able to use the NDIS Participant Portal myplace[[10]](#footnote-11)

CoS hours are allocated in all participants’ plans in the NT (this is not the case elsewhere) and the level of hours is significantly higher than in other locations.

* + 1. Local Areal Coordinators

Local Area Coordinators (LACs) are generally local, experienced organisations selected by the NDIA to partner with them in the roll out of the NDIS in a particular region. LACs are responsible for

* Linking individuals to the NDIS
* Linking individuals to information and support in the community, and
* Working with the local community to make sure it is more welcoming and inclusive for people with disability

LACs help individuals and communities understand and access the NDIS and help participants create their first plan. The LACs also work closely with local organisations, often service providers, who have been funded through the NDIA-administered ILC grants to deliver programs in the region[[11]](#footnote-12) (see section 3.3.9 for more details). In essence, the LACs become the local NDIA representatives, an information hub for individuals and service providers to seek information instead of contacting the NDIA directly.

* 1. About the NDIS Co-Design Pilot Project in East Arnhem

The NDIS East Arnhem Co-design Pilot Project, (hereafter the NDIS East Arnhem Project), was established in September/October 2016 by the NDIA to flexibly deliver services to eligible Australians in the region with a significant and permanent disability. These services are to enable them to live an ordinary life through:

* Supporting their independence and social and economic participation by providing reasonable and necessary supports; and
* Enabling people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports.

According to the Modified Monash Model used by the NDIA, East Arnhem is classified as ‘very remote’ with less than 5 participants expected per 100km2 at its peak. East Arnhem is a local Government area in the northeast of the NT and includes nine communities: Milingimbi, Ramingining, Galiwin’ku, Gapuwiyak, Yirrkala, Gunyangara, Umbakumba, Angurugu and Milyakburra and a number of homelands or outstations. The total population of the region is 9026 with 93.5%, or 8439 people identifying as Aboriginal and Torres Strait Islander and 88% of the population (7946)[[12]](#footnote-13) speaking an Indigenous language at home, primarily Yolngu Matha and its dialects: Gumatj, Dhuwaya, Galpu, Rirratjingu, Djapu, Djambarrpuyngu, Gupapuyngu, Golumala, Djinang; and Anindilyakwa on Groote Eylandt and Bickerton Island.

Measuring the rates of disability in East Arnhem is challenging and there is a current lack of research and reliable data about the numbers of people in East Arnhem. This is due to a range of issues including under identification of Aboriginal and Torres Strait Islander people in population surveys, differing views of disability that affect self-reporting of disability, and lack of culturally appropriate survey tools. ABS data from 2015 indicates that nationally, 18.9% of the total population and 23.9% of the Indigenous population are living with a disability. From this total of 4.3 million people with a disability, approximately 460,000 or 10%, will be eligible for the NDIS[[13]](#footnote-14). For East Arnhem, the data shows that 385 (4.6%) Indigenous people stated the need for daily assistance, with similar numbers of males and females, and with 43.5% of those with a disability over the age of 55[[14]](#footnote-15). The MJD Foundation conducted a disability audit in 2013[[15]](#footnote-16) which found 4% of the population in East Arnhem needed daily help with a permanent disability.

The NDIS Project in East Arnhem is significantly different to the NDIS in other parts of Australia and is the first region to deliver services on a community-by-community basis, putting Aboriginal and Torres Strait Islander people with a disability at the centre of the design, delivery and evaluation of policies and services which affect them. It is informed by the NDIA’s Rural and Remote Strategy and is based on the NDIA’s commitment to build enduring and collaborative relationships with Aboriginal and Torres Strait Islander communities as outlined in the NDIS Aboriginal and Torres Strait Islander Engagement Strategy and to ‘listen, learn, build and deliver’ by ‘walking’ and ‘working proper’ with Aboriginal and Torres Strait Islander communities.

NDIA’s community by community approach will involve building community capability and capacity to develop local solutions and a deliberate focus on options to grow the number of Indigenous registered providers of support*.[[16]](#footnote-17)*

* + 1. The NDIS East Arnhem Co-Design Project Working Group

A working group was established to oversee the implementation of the NDIS East Arnhem project with membership from the three key stakeholders in the project, the NT Government, Department of the Prime Minister and Cabinet (PM&C) and the NDIA.[[17]](#footnote-18)

According to the terms of reference, the purpose of the group is, “to serve as a focused, accountable structure to support the implementation of the NDIS in the East Arnhem region. The group will facilitate local Indigenous input from participants and other key stakeholders to maximise the opportunities for employment and build provider capacity in the region”.[[18]](#footnote-19)

* + 1. NDIA Staff: the ‘Purple Shirts’

In East Arnhem, the LAC (see section 1.1.5) role is currently remaining with the NDIA, rather than being outsourced to another local organisation as in other regions of the NDIS roll out. This means that the NDIA is the key contact point and information source about the NDIS for service providers and communities in East Arnhem and that NDIA staff or ‘purple shirts’ are the ‘face’ of the NDIS in the region. ‘Purple Shirts’ is the term that has been given to NDIA staff in East Arnhem communities due to the purple coloured polo shirts they wear as their uniform. The term refers to the Nhulunbuy based NDIA LAC staff as well as the NDIA engagement and planning teams that visit communities. As outlined in Section 1.1.5, LAC staff are responsible for a range of functions including building awareness of the NDIS in communities, engaging individuals with the NDIS, developing participants’ plans, facilitating the engagement of service providers with the NDIS and, in collaboration with the NT OoD, transitioning existing disability clients to the NDIS.

Although not NDIA employees, Community Connectors (see below) are also supposed to wear purple shirts when they are representing the NDIA in communities. Due to a range of staff sharing the Community Connector role part-time, and also due to a lack of shirts, it was reported by three stakeholders that the purple shirts are not consistently worn by Community Connectors.

Throughout community interviews for this evaluation, the term ‘purple shirts’ was used to refer to NDIA staff who visited their communities and did not refer to Community Connectors who live and work locally.

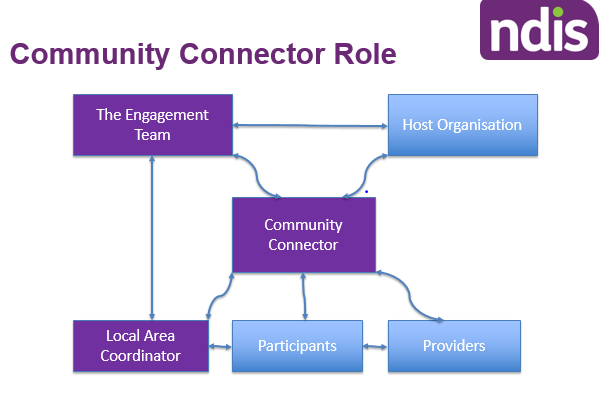
* + 1. Community Connectors

The Community Connector role was introduced for first time as part of the NDIS roll out in the NT to support the pre-access, access and planning conversations between the NDIA and community members. Community Connectors work with participants in their communities to help them access resources and supports, plan for their future, and increase their participation in the community.[[19]](#footnote-20) Community Connectors in East Arnhem are funded by the NDIA NT office and employed in host organisations that are Aboriginal community controlled and well established in the region. The NDIA is responsible for providing ongoing support and training to both the host agency and the Community Connectors.

Community Connectors are local people, who speak Language, and have an intimate understanding and strong relationships with community members. Essentially, the Community Connector is the link between participants in communities and the NDIA, helping to build understanding of the Scheme and facilitate culturally appropriate communication and engagement in the planning process. There are 19 Community Connectors in East Arnhem, most of them existing staff within host organisations who are sharing the role, providing male and female Connectors where appropriate.

Figure one below shows the way in which Community Connectors provide connections and facilitate communication between the NDIA, service providers, and participants.

Figure One: NDIA Community Connectors[[20]](#footnote-21)



Community Connectors play a critical role in identifying people with a disability and, as trusted community members, in assisting them to build relationships with service providers and access the scheme. Their role also involves assisting NDIA staff to develop appropriate and realistic plans to achieve participant life goals. They are a key to ensuring communities understand the NDIS and that local participants connect with planners and LACs.[[21]](#footnote-22)

* + 1. Intended outcomes of the NDIS East Arnhem Project

The Productivity Commission described the NDIS as “An enormous challenge… a major, complex national reform - the largest social reform since the introduction of Medicare.”[[22]](#footnote-23) The NDIS East Arnhem Project, is to an even greater extent a complex and resource-intensive project with relatively few numbers of participants likely to join the NDIS. Numerous stakeholders are involved including: people with a disability, their families, carers and local community; current and potential future service providers; the NT Government, local government, the NDIA and the PM&C. In addition, it is being delivered in a very remote region that experiences extreme weather, lacks infrastructure and does not have access to the variety of services that in other regions enable a choice in types of services or service providers.

In this context, the NDIS East Arnhem Project supports the following three outcomes:

* People with a disability in East Arnhem Land (both NDIS participants and people who are not eligible) have the opportunity to have an ordinary life;
* Aboriginal and Torres Strait Islander people’s economic participation increases through the creation of businesses to provide services and a subsequent increase in employment opportunities, including employment of people with a lived experience of disability; and
* Implementation of a cost effective co-design framework that demonstrates improved outcomes for people with disability, their families and communities compared to previous models.
  1. Purpose of the evaluation and evaluation questions

In July 2017, PM&C commissioned Social Compass to undertake the Evaluation of the NDIS East Arnhem Project. The evaluation is focused on the first 12 months of the implementation of the project in the following three communities: Groote Eylandt, Galiwin’ku and Milingimbi and was conducted from September 2017 to February 2018.

The purpose of the evaluation is to identify successes, challenges and learnings to date and whether these provide the foundation required to achieve the three outcomes listed above.

Specifically, the evaluation was designed to answer the following key questions and sub-questions:

1. **Before the NDIS, how did people with a disability and their families participate in and contribute to their community and were their reasonable and necessary support needs met?**
2. What has changed, when and how in terms of participation?
3. What is the most significant change as a result of the project?
4. **How has the co-design process worked in each community? What have stakeholders identified as necessary to meet the reasonable and necessary support needs?**
   1. How do stakeholders understand co-design?
   2. What are the co-design aspects/processes of the project?
   3. What are the support needs? How have they been identified?
5. **In the period since the co-design process began in September/October 2016 has it established the foundation to achieve the outcomes stakeholders have identified?**
   1. What were the outcomes that stakeholders identified? When and how were they identified?
   2. What foundation has been established?
6. **How has the Co-design Project supported Aboriginal and Torres Strait Islander people to establish businesses and has it increased employment of local people?**
   1. What businesses and employment opportunities have been generated?
   2. How many have been taken up?
   3. Why or why not?
   4. What have been the challenges?
   5. What are the success stories?
7. **What has been learned from the pilot project, what can be improved?**
8. Methodology
   1. Design

A largely qualitative design was used for this evaluation to allow both a broad and in-depth range of stakeholder views to be captured. This consisted of face-to-face interviews with East Arnhem community members in three locations, service providers in the region, NDIA staff, staff from the NT Government and the PM&C. Quantitative data was also included to provide evidence about project activities and outcomes. Data from stakeholder interviews was coded into key themes and also quantified, in order to provide transparency about the extent to which key views were shared across the range of stakeholders interviewed.

A participatory action approach was utilised throughout the evaluation, with the intention of engaging community members in the research process, to both build their understanding of and input to the research, as well as develop research skills and capacity in the community. The initial plan to train local researchers to conduct community interviews was adapted due to the burden this would have placed on community members in each location, and because of the identified lack of personnel to fulfill the roles.

Social Compass therefore consulted with local service providers in East Arnhem (MJD Foundation, Miwatj Health Aboriginal Corporation and East Arnhem Regional Council in Nhulunbuy, Milingimbi, Galiwin’ku and Groote Eylandt) to identify the most appropriate facilitators amongst their staff in each of the three communities included in the evaluation. These facilitators were then engaged to recruit for, facilitate, and translate all interviews between Social Compass researchers and community participants. Facilitators also advised Social Compass on local cultural protocols and practices and helped develop two key research tools (see Appendix B):

* a culturally appropriate plain language statement to inform community members about the evaluation, its purpose and their participation in it
* a culturally appropriate interview guide for Social Compass researchers to use during community interviews

After community interviews were completed, the facilitators in each community were asked to provide input to the analysis of findings for the community cohort, to ensure that Social Compass researchers had understood and accurately given voice to what they heard during interviews with community members.

When analysis of all data sources was completed and synthesised into findings, a summary of the key findings was sent to all project stakeholders who participated in interviews. Stakeholders were asked to provide feedback and identify to what extent, and around what issues, findings resonated with them. This was another aspect of the participatory action approach of the evaluation and added another layer of analysis to the data.

Teisha Rose, an NDIS participant and advisor to the NDIA, informed the evaluation as a subject expert, providing background and context on the NDIS, and feedback on the findings of the evaluation. Ms Rose’s[[23]](#footnote-24) knowledge and experiences of the NDIS provided additional insight and understanding of the evaluation data in particular in relation to the process of participant engagement with the NDIS and the process of developing and reviewing an NDIS plan.

* 1. Assumptions

The NDIS East Arnhem Project, and therefore this evaluation, is based on a range of assumptions that inform its delivery and intended outcomes including:

* 93.5% of the residents in East Arnhem identify as Aboriginal and/or Torres Strait Islander. Their needs and priorities are therefore at the centre of the NDIS East Arnhem Project and at the centre of this evaluation. All references to community members in this report are to Aboriginal and Torres Strait Islander people, except where stated.
* Aboriginal and Torres Strait Islander communities place priority on building rapport, trust and a relationship of reciprocity. This takes time and ongoing engagement, particularly with non-Aboriginal people and agencies from outside the community.
* Co-design means working with Aboriginal and Torres Strait Islander communities in a process where cultural perspectives and frameworks inform the development of a project and are not only recognised and acknowledged, but fully incorporated in the design, implementation, monitoring and evaluation.
* The NDIS uses a range of terms and definitions including ‘disability’, ‘reasonable and necessary support needs’ and an ‘ordinary life’, which may have different meanings and interpretations in East Arnhem communities.
* The ongoing impacts of colonisation mean that Aboriginal and Torres Strait Islander people experience significant disadvantage in all areas of physical, mental and social determinants of health compared to the non-Aboriginal population.
  1. Data collection methods
     1. Community Stakeholder Interviews

Twenty-seven face-to-face interviews with community stakeholders including NDIS participants, their carers and families were conducted in the communities of Groote Eylandt, Milingimbi and Galiwin’ku. Five of these interviews were with non-Indigenous clients, but the remainder were with Aboriginal and Torres Strait Islander people.

Interviews were facilitated and translated where necessary by community facilitators and explored participants’ and their families identified support needs, their understanding and experience of the NDIS roll out in their community and any changes since the NDIS was introduced. The full interview guide is attached to this report in Appendix B.

* + 1. Project Stakeholder Interviews

Twenty-six interviews with a range of staff from stakeholder organisations were conducted either face to face or by telephone[[24]](#footnote-25). Local staff in the three communities as well as the regional centre Nhulunbuy were interviewed. In total, sixteen different project stakeholders were represented in these interviews including:

* Staff from nine different service providers including Aboriginal community controlled and other organisations providing services as part of the NDIS in Nhulunbuy, Groote Eylandt, Milingimbi and Galiwin’ku (14 interviews in total)
* NDIA NT Regional staff, PM&C and NTG staff (11 interviews)
* VTEC and Community Development Programs operating in the NT (one interview)

The 45-60 minute interviews explored a range of issues including stakeholders’ views and experiences of the implementation of the NDIS East Arnhem Project, the changes the NDIS has brought, their identified outcomes and any evidence of these, and suggested improvements for the project. The full interview guide is attached to this report in Appendix B.

* + 1. Review of documentation and data relating to project activities

A range of documents and data relating to the Co- Design Project were reviewed including:

* NDIA Aboriginal and Torres Strait Islander Engagement Strategy (2017)
* NDIA Rural and Remote Strategy 2016-2019
* NDIA Three Tiered Engagement Strategy
* NDIA Remote Area Servicing Paper
* NDIA ‘Lessons Learnt’, NDIS report on NDIS roll out in East Arnhem and Darwin, July 2017.
* NDIA data on plans in East Arnhem, and engagement with regional service providers
* Data on East Arnhem NDIS related projects funded through NTG and Commonwealth grants

A brief review of literature related to the delivery of the NDIS in Aboriginal and Torres Strait Islander communities also helped inform this evaluation by providing contextual information about the NDIS, and the needs of people living with disability in this particular cultural context.

* 1. Data limitations

The role of community facilitators as translators and facilitators in all interviews with Aboriginal and Torres Strait Islander participants and their families, and the Aboriginal identity of one of the key researchers, helped to maximise trust and understanding throughout the interview process. However, in the presence of external researchers entering communities and asking questions about a government program, it is likely that some Aboriginal and Torres Strait Islander participants in the research may not have felt able to fully disclose their views and experiences. Therefore, there may be limits to the range of views that were expressed.

Due to sensitivities of sharing data from small communities with limited data sets, some NDIA data was not able to be shared with the evaluation team. The evaluation team was unable to see detailed data demonstrating the extent to which plans had been utilised in each community.

1. Key findings in response to the four evaluation questions: What we heard
   1. Before the NDIS

**Before the NDIS, how did people with a disability and their families participate in and contribute to their community and were their reasonable and necessary support needs met?**

* + 1. Families sharing care

Culture and kinship ties are strong in East Arnhem. Extended families are sharing the care of relatives with a disability and provide a range of informal supports including cooking, cleaning, personal care, administering medication and transport. A disability audit conducted in 2013 demonstrated that across East Arnhem, between 15-20% of the population was providing informal care to those with a disability[[25]](#footnote-26).

Interviews with participants, carers and families indicated that community members generally keep an eye on people with a disability when they are in public, but not always. Many family members identified that if the main carer is at work, and other carers are out of the community or receiving medical treatment, there is no one to look after the person with a disability.

Before the NDIS… Families were heavily responsible for looking after them (people with a disability) with no assistance at all. Support may have been respite once or twice a year and maybe some continence products. There was nothing about building capacity*.* (Service Provider)

Some participants and their carers identified that it can be difficult to find an appropriate ongoing carer in communities, particularly for older people with a disability, and two participants we spoke to have no current carer to help them with domestic chores.

* + 1. Participating in community, culture and Country

Participating in community, culture and Country is important for participants and their families that we spoke to. There are ‘everyday’ things like fishing and hunting, caring for younger children and Elders, visiting relatives and attending funerals in other communities that everyone is a part of whether they have a disability or not. People with a disability also participate and contribute to the community in a range of ways including DJ-ing at the Saturday night disco at the local Sport and Recreation Centre, playing music at church and with friends, going to school and the library, teaching or mentoring others, and being part of the football club.

* + 1. Previous services for people with a disability

According to interviews with project stakeholders, some NDIS participants in East Arnhem have transitioned from the NTG Office of the Public Guardian, 140 people with a disability will transition from the Partners in Recovery (mental health) Program[[26]](#footnote-27) (funded by the Commonwealth Department of Health) by July 2018, others have transitioned from the NTG OoD, and some were previously receiving no disability supports.

According to service providers, participants and their carers, before the NDIS, occupational therapists visited remote communities monthly to work with disability clients funded by the NT OoD. Speech therapists visited MJD clients on Groote Eylandt on a regular basis. Other existing services for people with a disability were described during community and project stakeholder interviews. These include local Council-run aged care drop in centres which provide a range of services including meals on wheels, community transport, laundry service and personal care. Other services described include sport and recreation facilities, local libraries where computers can be accessed, local health services, community development programs, church groups, school programs and art centres.

* + 1. Lack of services in the region

All community and project stakeholders acknowledged the lack of services across the region and in smaller communities and homelands in particular. They identified that there is very little choice for people living with disability. This is a common issue for the NDIS in very remote regions.[[27]](#footnote-28) Lack of choice in respite services is a particular problem, and was the most frequently identified gap in participant and carer interviews. Currently, there are only respite services available in Darwin, which the majority of participants and carers indicated is a long way to travel, hard to organise, and more local options would be preferred.

Service providers and carers of young people with a disability also identified the lack of services designed for young people in communities. Most current disability services and drop in centres are provided by aged care providers who are adjusting their programs as best they can to cater to the needs and interests of young people. However, except in Nhulunbuy where youth with a disability were accessing life skills and swimming classes, interviews with participants, carers and service providers revealed there are very few services and activities designed for young people with a disability.

Participants and service providers also identified a lack of equipment maintenance services in the communities which is problematic for people in wheelchairs that need servicing or repair.

* + 1. Support needs of people in East Arnhem

NDIS participants and their families told us they want to be able to be supported to engage in culture and community. This includes practices like hunting, fishing, art and basket weaving, and to be able to attend funerals and other cultural events and ceremonies, including those in other communities.

They want to have access to a range of activities that are interesting and stimulating for them, increase their skills and education, and that connect them with others in the community. Carers for young adults with a disability would like more support getting their child to and from school, and while they are at school to help them with their learning and with possible bullying and social issues. Carers would also like to see more services tailored to young people. Cultural activities like hunting and bark painting were suggested as examples of activities that will interest young people and make them want to leave the house because it can be difficult for family members to motivate them to get out and do things.

In NDIS participant interviews, the most common requests included:

* Easier access to and a choice of respite services in communities, including in Nhulunbuy and on Country in the homelands to support cultural connections and priorities
* Modifications to homes, including ramps
* Support in the home to clean, do washing, shop, cook etc.
* Support to accompany people with a disability to do a range of activities like walk to school, walk to the beach, get some exercise, take part in cultural events and activities like hunting (including those in other communities as many people have family and kinship ties to other parts of East Arnhem), and to take medication at the right time every day
* Cover the costs of travel to access services which may be in other locations, including for family members who need to accompany the person with a disability

These needs were similar to those identified by service providers namely, a choice of and greater access to; respite services, the need to support travel costs for participants and their families to attend mental allied health services, home modifications, and support workers in the home.

* + 1. Too early to see significant changes in communities

More than 70% of the Indigenous participants and carers we spoke to reported no change in terms of services, supports or participation in the months since the introduction of the NDIS. In Galiwin’ku and Milingimbi, two participants had requested house modifications like ramps which had not yet been started. Two others had requested new equipment (wheelchair and motorised scooter) which had not yet arrived. One participant reported that they had received a new wheelchair, and one carer is receiving nappies for her son.

The plans are there, but it’s gonna be a long process for the clients to understand how to make sense and use them. If they (the NDIA) stick around and offer a lot more choices, then I think we will see changes in the long run*.* (Service Provider)

On the other hand, NDIA has collected stories from participants who report accessing new services, receiving new equipment and the provision of services to community members who were not receiving supports before the NDIS.

Another service provider in Nhulunbuy reported that participants are accessing a greater range of services and have more choice in services, particularly for young participants, like swimming lessons and life skills. One service provider in Groote Eylandt reported that participants were accessing more allied health services and were receiving more culturally appropriate services. The latter included allied health professionals treating them in their homes and on Country, which eliminates the need to travel to the clinic and go out in the heat of the day. Another service provider working in the homelands also reported being able to provide more services in a culturally appropriate way to participants, particularly through plan management (see section 1.1.2). This approach allows non-NDIA registered community members to be paid to provide support services.

There has been a change – just even access to services, to social relations – people are able to participate in community activities and having someone to assist them in that and going to other homelands to participate whereas previously they may have just sat under a tree all day every day. Exercise in swimming pools every week is happening for some*.* (Service Provider)

A very significant change for one participant was reported by a service provider in one community who described how a young Yolngu woman with a disability in the community had applied for, and secured, assisted housing in Darwin so that she can attend university there.

* + 1. More significant change for non-Indigenous participants

The five non-Indigenous participants and their families reported more notable improvements and stated general satisfaction with their early (at the time of interview) perceptions of the financial support they could now access and self-manage via their NDIS plans. Change was reported by these participants in terms of access to more choice in funded services including physiotherapy and life skills. The non-Indigenous interviewees stated that although they felt that services were scarce, they had enough knowledge and skills to adequately and efficiently navigate their own way through the NDIS and that they were successfully managing their plans. They demonstrated a knowledge of the existing services and programs available to people with disabilities in East Arnhem, and all had been participating in these services and programs since before the NDIS roll-out. All non-Indigenous participants and carers spoke English as a first language, and all were connected to peer supports through the school and other families both locally and in Darwin.

It was clear that self-management of plans was more attainable for non-Indigenous participants and the lack of language barriers meant that their understanding of and engagement with the NDIS, including use of the portal, was much higher than for Indigenous participants.

* 1. The Co-Design Process

**How has the co-design process worked in each community, what have stakeholders identified as necessary to meet the reasonable and necessary support needs?**

* + 1. ‘Co- implementation’, not ‘Co-Design’

It was apparent in interviews with community members and the range of other project stakeholders, that co-design was not an accurate term for the NDIS East Arnhem Project. From high-level Government stakeholders, to service providers and participants, only two interviewees were able to describe elements of co-design in the project and both actually referred to the implementation, rather than the design of the project. These two interviewees were local service providers who described the way in which the NDIA was listening to their suggestions about how to improve the roll out in East Arnhem as evidence of co-designing the implementation of the project. No stakeholders felt or reported being consulted or included in the process of the actual planning and designing of the project. The unanimous view was that it had been designed by NDIA Head Office in Geelong, and was now being delivered by NT people in East Arnhem.

The Issue here is that this project was written in Geelong with no consultation with local people and NT people told to do it(Co-Design Working Group member)

It was agreed by the Co-Design Working Group members and suggested by nearly all service providers, that co-implementation or co-delivery would more accurately describe the processes taking place in the roll out of the project. All local service providers described that despite the lack of co-design, and some ill-fitting elements of the scheme in the East Arnhem context, (including mainstream resources and training for Community Connectors, see sections 3.3.3 and 3.5.5), that they were now in the process of working with the NDIA on adapting and re-designing the NDIS to better fit the region. Although this co-implementation process was reported by nearly all project stakeholders to be working well, it was stated by more than half the interviewees that consultation and input from community and project stakeholders in the actual design of the project could have avoided some of the early barriers to implementation.

In Community, everything run differently than Government areas. You have to be creative and have to get this done ‘our way’*.* (Aboriginal staff member of service provider)

* + 1. Collaboration between stakeholders the key to successful co-implementation

Twenty-three of 26 stakeholder interviews reported that collaboration between service providers was a key strength of the project, and the majority of service providers interviewed reported that existing, local Indigenous organisations were not competing in the NDIS space. These local service providers are playing a key role in the implementation of the project, providing information and support to participants and their carers, while informing the NDIA and government stakeholders of community needs and priorities.

The willingness of the NDIA to adapt and work with service providers to respond to community needs and conditions, was described in service provider interviews as evidence of co-implementation. Nine of fourteen service provider interviewees described the NDIA’s openness to feedback and flexible approach to delivery in East Arnhem as a key strength of the project and crucial to the successful implementation of the scheme.

There is a deep commitment to getting it right from the NDIA local manager (Service provider)

According to project stakeholders, the level of collaboration has evolved and grown stronger throughout the project. For example, two provider expos were co-hosted by the OoD and NDIA in June and September and were attended by 26 and 18 stakeholders respectively,[[28]](#footnote-29) the majority of them service providers in the region. The aim of these expos included the provision of networking and showcasing opportunities for service providers and to provide information about grants available to them as part of the NDIS. Four service providers identified that, although a little late in the implementation process, these expos had a significant impact on the willingness and ability of service providers to collaborate in the roll out of the scheme.

* 1. Establishing Foundations

**In the period since the co-design process began in September/October 2016 has it established the foundation to achieve the outcomes stakeholders have identified?**

Strong foundations need to be laid. “Without foundational work, the fundamental principles the program is founded on fall apart. It’s all being done now retrospectively*.* (Service Provider)

* + 1. Working Group

As outlined in section 1.2.2, a Co-Design Working Group was established with members from the trilateral transition arrangement including the NDIS NT Regional Office, the NT Chief Minister’s Office, the NT OoD, and the PM&C to oversee the implementation of the NDIS in East Arnhem.

In interviews with group members the following strengths and weaknesses were identified.

Strengths:

* The Working Group brought a closer working dialogue between the trilateral stakeholders and exposed some of the challenges and issues involved in the rollout across the agencies/departments.
* Members had extensive experience and understanding of the realities of delivering Government programs in East Arnhem.
* The Working Group gave personnel on the ground a chance to give feedback up to the group members and higher levels.

Weaknesses:

* Lack of ownership of issues, for example around workforce development in East Arnhem. All members have a part to play but no one was leading any joint initiatives and there was no integration of the different agencies’ approach on the issue.
* Lack of decision-making authority and lack of integration with the NTG structure of the roll out of the scheme
* Lack of collaboration and information sharing, for example the NDIA was critical that OoD’s Community Planning Project[[29]](#footnote-30) for the NDIS and the NDIS East Arnhem Project did not collaborate or inform each other. Three members were critical of the NDIA’s lack of data sharing with the group.

Players were overall very committed. In NT everything gets done by relationships so you have to be delicate and it was easier to address issues outside the meeting. The Working Group didn’t take ownership. The Working Group should have had elevated governance and decision making capacity and authority*.* (Working Group member)

The workforce issue was raised in the group - we all said it was a priority etc. but there wasn’t an authorising environment to bring that together. All the funds should have been pooled and managed together*.* (Working Group member)

* + 1. NDIA focus on face to face communication and strong community engagement

As described in the background to this report, the NDIS East Arnhem Project is informed by the NDIS Aboriginal and Torres Strait Islander Engagement Strategy and the NDIS Rural and Remote Strategy. The project has also been informed by the experience of staff at the NDIA NT office in adapting government programs to the region, and learnings from the Barkly trial site. These strategies and processes reflect an understanding of the complexity of service provision in the region and prioritise community engagement, listening and flexibility. The approach is based on face-to-face engagement which means that the NDIA Engagement Team goes ahead of the NDIA planners who visit communities approximately every six weeks. The approach also includes the introduction of the Community Connector role, and the development of a three tiered engagement strategy developed for NT communities and canvassed with traditional owners at a Northern Land Council Meeting in Nhulunbuy in July 2016. The three tiered engagement strategy was members’ preferred approach in order for the NDIA to recognise and work with established frameworks of authority within communities. The three tiers are not in any order of priority of sequence and are outlined below:

* Tier One: Land Councils, regional authorities, traditional owners and regional service providers
* Tier Two: larger service providers, community governance structures and community representatives
* Tier Three: community members, families and participants, advocates, on-the-ground service providers[[30]](#footnote-31)

The NDIA reports that the strategy was followed in all engagement with communities in East Arnhem however there is no specific data to demonstrate this process.

NDIA data on engagement activities demonstrates that communication with a range of stakeholders, including service providers and community members, began in September 2016 with 18 sessions held in Nhulunbuy before December 2016. More than half these sessions were held with individual service providers to inform them about the transition process to the NDIS. Other sessions were for broader stakeholders including participants and their families and provided information about the NDIS, how to access it and how it works. In November 2016, the NDIA visited both Groote Eylandt and Milingimbi for two days each during which time they delivered information sessions for participants and families focused on “What is the NDIS”, as well as information sessions for service providers in those communities.

Throughout 2017, the NDIS continued to host information sessions about the NDIS for participants and their families. They ran workshops and training for service providers with a total of 72 engagement and information sessions[[31]](#footnote-32) delivered across eight communities in East Arnhem from September 2016 to March 2018. Five of these sessions were to provide information to organisations hosting Community Connectors (see section 1.2.3), including a two-day training workshop held in Nhulunbuy in June 2017. Thirty of these sessions were with individual or groups of service providers to provide NDIS information and support and to promote networking between providers. Sixteen of these sessions provided information about the NDIS to participants and their families.

In the three communities that are the focus of this evaluation, five of the above engagement and information sessions were held in Milingimbi, six in Galiwin’ku and one in Groote Eylandt. Some of these were targeted at providers only, and others included providers and participants and their families. Although attendance is not known for all these sessions, two sessions in Milingimbi and Galiwin’ku for participants and providers recorded over 40 attendees. NDIA staff who delivered these large community information sessions noted that the presence of translators was a significant benefit, allowing all verbal material to be translated into Yolngu and increasing participants’ understanding. All NDIA hosted engagement sessions included Yolgnu translators in East Arnhem.

* + 1. Lack of understanding about NDIS in communities

Despite the NDIA focus on face-to-face community engagement for East Arnhem, analysis of the 27 interviews with NDIS participants and their carers in the three communities, it is clear that there is very little knowledge about the NDIS, what it is and how it works. Twenty community members we spoke to said that they didn’t understand what the NDIS was about, except for example, that it was “for people with a disability”, and to “help us get things we might need”. As outlined in section 3.3.7, the five non-Indigenous participants reported better understanding of the scheme. They could identify what supports were described in their NDIS plans and were accessing the portal and self-managing their plans.

As described in section 1.1.2, the NDIS East Arnhem project recognised the need for the planning conversation to take place face to face and NDIA planners in East Arnhem meet with each participant in each community. Despite this face-to-face interaction and the presence of Yolgnu translators in planning sessions, NDIS participants and their carers reported that they understood very little of what the NDIA planners talked about during the meeting. Twenty reported that they were unsure about what was in their plans, what services they were entitled to and how the NDIS program was going to work. Four interviewees described how the dollar figure on plans confused participants and carers who assumed a lump sum was to be paid. More than half the community interviewees in Milingimbi and Galiwin’ku stated that the NDIA ‘purple shirts’ staff should be more visible in communities, visit more often, or even be based there so that participants and carers could access information about the NDIS more easily.

The purple shirts need to come and explain it better, and stay longer*.* (Aboriginal Staff Member, Service Provider)

Other project stakeholders supported these community views. Despite the range of engagement activities outlined in the section above, all service providers bar one, and 19 of 26 project stakeholders interviewed, described the early implementation of the project as rushed and lacking adequate communication and consultation with communities and service providers. Seven interviews with service providers stated that, in the early stages of implementation, NDIA staff did not coordinate with local staff for community visits and therefore communities were often unaware of planned visits and when staff arrived, there were no participants to see them. Eight service provider interviewees stated that Community Connectors were initially underutilised by NDIA staff when engaging with communities, were not notified of NDIA visits to communities, and not included in the planning process with participants and families. Training for Community Connectors was not held until June 2017 and one host organisation reported that the first contact between NDIA and Community Connectors was in July 2017.

They (the NDIA)just came and told us the program that one time. Now, it is helping – little bit better. We’ve been going around explaining to people that NDIS is for helping ‘’later on’’, it’s not money straight away. So, Balanda[[32]](#footnote-33) gave me story, and I can explain to my people what it does. (Aboriginal staff member, Service Provider)

NDIA ground staff also acknowledged that, “engagement activities needed to commence earlier with greater provision for the time required by community governance structures and community organisations’ boards to become familiar with the NDIS and adapt accordingly”[[33]](#footnote-34). The Productivity Commission’s ‘Costs’ Report came to the same conclusion based on the transition process around Australia, and in Recommendation 5.2, states that the NDIA should, “ensure that Local Area Coordinators are on the ground six months before the scheme is rolled out in an area and are engaging in pre-planning with participants”[[34]](#footnote-35). Engagement in communities in East Arnhem began in September 2016, but was clearly not sufficient to build awareness and prepare communities for the NDIS.

Based on Australia-wide submissions, the 2017 Productivity Commission Report also found that “the NDIA must find a better balance between participant intake, the quality of plans, participant outcomes, and financial sustainability. Greater emphasis is needed on pre-planning, in-depth planning conversations, plan quality reporting, and more specialised training for planners.”[[35]](#footnote-36)

The lack of resources about the NDIA in Language was reported by 12 of fourteen service providers to have significantly hindered the ability of East Arnhem communities to understand and engage with the NDIS. The significantly improved understanding of and engagement with the NDIS by non-Indigenous participants (with English as their first language) interviewed for this evaluation supports that finding. It was also suggested by service providers that more diagrammatic resources, using relevant local images would aid understanding of the NDIS. Language and cultural barriers issues affecting participants’ awareness of and engagement with the NDIS have been researched[[36]](#footnote-37) and reported by a range of stakeholders[[37]](#footnote-38) who have identified a range of factors including different cultural concepts of disability and a focus on community rather than individual needs and goals that need to be taken into account by planners.

There is no Yolngu word for disability, and challenging to translate “what is wrong with you” and identify needs and issues when Yolngu don’t see it that way - cultural translation*.* (Service Provider)

Community and service provider interviews for this evaluation asserted that NDIS planning also needs to consider kinship care structures in communities. These structures require that NDIS information be communicated with a range of family members who may be sharing the care of a person with a disability. Three interviewees described the need for several family members to be directly involved in the planning and ongoing communication process with CoS (see section 1.1.4) services for NDIS participants, and Miwatj has included the broader family in their communication flowchart for the role of Community Connectors. The MJD East Arnhem disability audit in 2013 also recognised this need and advised the NDIA to provide time and funding for this to take place[[38]](#footnote-39).

Eight of the 14 service provider interviewees reported difficulties understanding and using the portal and they and another two project stakeholders reflected that the high digital literacy needed to use it would preclude many participants and their families in the region from accessing it. NDIA staff also acknowledged that many participants and providers would need ongoing support to use the portal effectively.[[39]](#footnote-40) None of the Aboriginal and Torres Strait Islander participants and carers interviewed had accessed the portal, in fact none of them reported knowing about it or its purpose. This lack of access to the portal reflects the lack of understanding in the community about the NDIS in general, and how Plans can be self-managed in particular. In contrast, four of the five non-Indigenous participants interviewed, reported success using the portal to self-manage their plans.

It is unrealistic for individuals to work out how to access service providers, how to get on the portal etc. and draw down on funds, and navigate all the logistics of the scheme to manage their plans. Even businesses can’t navigate it yet.(Service Provider)

There is unnecessary complexity around terminology and lack of consistency - we need a common language for the region, for providers and participants so we know who is doing what, what the intended outcomes are.(Service Provider)

NDIA staff reflected on the first six months of implementation in East Arnhem and, similar to service providers, identified that “Stronger communications, role clarification and on ongoing investment into learning and development is needed to improve consistency of messaging throughout the planning process and better support participants”.[[40]](#footnote-41)

Community needs to understand they have a voice and can inform the process. At the moment choice and control is non-existent because COSs or planners are making decisions and there are limited services to choose from.(Service Provider)

* + 1. Current NDIS plans in East Arnhem

As stated in the background section of this report, uptake of the NDIS was expected to be slow in East Arnhem. The NDIA NT Regional Office states that the focus has been on quality rather than quantity of plans and fixed targets were not set for the early implementation stages. According to NDIA data, the following number of plans have been approved and activated[[41]](#footnote-42) in East Arnhem as at 31 December 2017.

Table One: Number of participants with approved plans and percentage of plans that have been activated in East Arnhem.

|  |  |  |  |
| --- | --- | --- | --- |
| East Arnhem Community | Approx. pop with disability[[42]](#footnote-43) | Approved NDIS plans | % of plans activated |
| Galiwin’ku | 85 | 20 | 20 |
| Groote Eylandt | 64 | 15 | 33 |
| Milingimbi | 49 | 19 | 21 |
| Other East Arnhem | 159 | 122 | 40 |
| Total | 357 | 176 | n/a |

The data shows that the numbers of plans in each community are low and that activation rates for the three communities included in the evaluation are considerably lower than those for the rest of East Arnhem. The activation rate for the rest of East Arnhem is higher, likely due to the higher access to services and awareness of the NDIS in the larger community of Maningrida, and the regional centre Nhulunbuy.

The above data on activation rates is consistent with community and stakeholder interviews which indicate that the awareness of and access to plans is still low in communities across East Arnhem. It also demonstrates the low demand for services (in terms of numbers of plans) in these communities at this stage of the NDIS implementation. The Productivity Commission’s report acknowledges that underutilisation of plans for a range of reasons, including supply shortages, may continue for some time, particularly in ‘thin’ markets like East Arnhem.

Figure two below, shows the cumulative total of participants with approved plans by quarter, for both the three communities at the centre of the evaluation, and for other communities in the East Arnhem roll out. This data shows that a significant number of plans were approved in the early stages of implementation, before communities and service providers felt aware of and prepared for the changes the NDIS brought and before Community Connectors were utilised to facilitate engagement with participants in communities.

Figure Two: Cumulative total of participants with approved plans


2016-17 quarter 2: communities of interest: 0; other East Arnhem communities: 0
2016-17 quarter 3: communities of interest: 20; other East Arnhem communities: 29; total: 49
2016-17 quarter 4: communities of interest: 46; other East Arnhem communities: 61; total: 107
2017-18 quarter 1: communities of interest: 54; other East Arnhem communities: 68; total: 122
2017-18 quarter 2: communities of interest: 54; other East Arnhem communities: 68; total: 122


* + 1. Community Connectors and the importance of relationships and trust

There are known barriers to Aboriginal and Torres Strait Islander people accessing government services and different cultural concepts around disability that may affect their access to disability services.[[43]](#footnote-44) The crucial role of Community Connectors in overcoming these barriers was discussed by nine of the 14 service provider interviewees, and by another eight stakeholders, who stated the importance of having a trusted community person to facilitate the relationship building and engagement with NDIA staff and understanding of the scheme more broadly.

Families don’t know what’s going on at plan meetings – we have to ‘clean it up’ later.(Community Connector)

In addition, the Aboriginal community controlled organisations hosting Community Connectors in East Arnhem have been working in these communities for some time, (for example, Miwatj who hosts the Connectors in Milingimbi and Galiwin’ku has been operating since 1992), employ local staff, and have established relationships and trust with community members.

Community Connectors are working in both Milingimbi and Galiwin’ku, however a host organisation could not be secured for Groote Eylandt so there are no Connectors operating there at this point. In their absence, service providers in Groote described how they are working closely with the NDIA and participants, providing CoS (see section 1.1.4) and other services and acting as NDIS information sources for local participants and carers.

Training for the Community Connector roles was delivered by the NDIA in Nhulunbuy in June 2017. The training was recognised by Community Connectors and other staff at their host organisations to be in need of further adaptation to make it relevant and appropriate for the East Arnhem context. Therefore, some of the content and resources of the training are undergoing further development. The position duties and processes are also being adapted by host organisations to better suit local protocols. For example, Miwatj, who has up to twelve staff working in Community Connector roles, has developed a nine-point pathway which outlines the steps involved in the Community Connector’s engagement with family members, participants and the NDIA in the planning process alone.

The importance of having the position as a bridge between the community and the NDIS cannot be under estimated*.* (NDIA NT Staff Member)

A vital aspect of the Community Connectors’ skill base is their ability to speak both Language and English and they often act as interpreters in planning meetings. The value of this skill is appreciated by the NDIA who is introducing further training for Community Connectors to enable them to register as interpreters with the Aboriginal Interpreters Service and thereby significantly increase the rate they can charge per hour for their work as Connectors.

Interviews with Community Connectors themselves indicated that there are some challenges with their work. The three Community Connectors we spoke to described how the role becomes an additional ‘hat’ which they need to wear, learn about and adjust to. Two local service providers indicated that this can also create some confusion in the community about their roles, as sometimes they are working in their Community Connector roles wearing their NDIA ‘purple shirts’, and sometimes in other capacities. Community Connectors are motivated by a strong sense of responsibility to support positive outcomes for their communities but indicate that they themselves are still learning about the NDIS and how it works.

* + 1. Transition — ‘a unique and challenging period in the life of the scheme’

The newness of the NDIS is a steep learning curve for participants, providers and government staff. As such, roles and responsibilities can at times be unclear. This can create challenges for staff collaborating during transition, [as well as] participants and providers at each stage of transition.[[44]](#footnote-45) (NDIA staff)

A range of challenges have been experienced by all stakeholders due to the major changes involved with the transition and early implementation of the NDIS. The Australian Productivity Commission outlined the challenges of the transition period Australia wide because of the following factors, unique to the transition:

* the number of new participants entering the NDIS over such a compressed timeframe
* so many disability support service providers facing the challenge of transitioning from a block-funded model of support to a fee-for-service market-based approach
* so many new scheme participants learning how to navigate a new scheme where they change from passive recipients of supports to informed consumers through having choice and control over the disability supports they access. [[45]](#footnote-46)

Other significant challenges identified by stakeholders that have impacted on outcomes of the NDIS East Arnhem Project to date, are outlined below:

* Service providers identified that a lack of resources in Language, high turnover of NDIA staff and subsequent lack of knowledge transfer, inconsistent cultural and community knowledge of NDIA staff, and underutilisation of Community Connectors (see section 1.2.3), were factors which resulted in a lack of awareness of the NDIS in communities. Ten of fourteen service provider interviewees reported that these factors created lower quality Plans in the early stages.
* For service providers, the shift from block funding to fee for service, the move into the new and complex administrative CoS service delivery (see section 1.1.4), and hosting and managing the Community Connector roles which they feel are underfunded, has created challenges. Many are now also providing new services outside the scope of their usual delivery. Thirteen of 14 service provider interviewees felt underprepared for the transition, would have appreciated more engagement and support from NDIS, (including access to funding) before the roll out in order to prepare themselves and communities for the changes.

No-one has sat with us and explained it to us or helped us develop strategic plan/service. It was like they came to us and expected us to help them navigate the region*.* (Service provider)

* More than half the stakeholders interviewed described funding problems created by the NDIS remote pricing guide[[46]](#footnote-47) and its inability to reflect the actual costs of service delivery in East Arnhem.
* For a range of stakeholders, including potential future service providers, the lack of reliable data and market visibility is hindering the ability to invest in and plan services for the NDIS and develop the workforce in the region.
* The exclusion of the NDIA from the NTG’s Community Planning process and the lack of involvement of the NT Department of Trade, Business and Innovation (and its administration of the Innovation Grants for NDIS providers) in the Working Group. These two factors were seen by the NDIA to limit the opportunities to effectively work together on workforce development for the NDIS East Arnhem project.

For the NDIA, difficulty recruiting to local roles, and the challenge of stretching funding to cover the resource-intensive nature of the NDIA work in East Arnhem impacted on their ability to provide consistent communication and support to service providers and communities. Whilst some weighting is given to remote locations, NDIS regions are funded based on the numbers of participants and do not take into account geography or population demographics such as English as a second or third language.

The COSs need to be better established, the mechanisms of the scheme need to be fit for the region, and everyone needs to be more familiar with the scheme to use it and make the most of the money and the opportunities. Then we can create quality Plans for services to draw down on and create income and jobs in the local areas. Quality Plans will create visibility of the needs for everyone to know, and move forward in response to them.(Service Provider)

* + 1. Collaboration between OoD and NDIA on the ground

The collaboration between OoD and NDIA staff in the transition process was reported by NDIA staff and OoD staff to be generally strong. To ensure a smoother transition experience for existing clients, and to build on existing OoD relationships in communities, time limited NT Government funding allowed OoD and NDIA staff to attend early engagement and planning sessions in communities together. This provided ‘warm handovers’ with the aim of providing peace of mind and continuity of supports for participants. OoD participant profiles provided NDIA staff valuable information about the participant and the supports already in place. These profiles also highlighted different terminology that needed to be taken into account to improve consistency of messaging with the NDIS. NDIA and OoD staff reported that when challenges on the ground arose in the transition period, they were able to be quickly addressed by both agencies.

A workshop held in July 2017, brought together NDIA and OoD staff who had been engaged or were soon to be engaged in the East Arnhem and Darwin Urban projects, to reflect on challenges and successes of the transition with the aim of taking the shared learnings and making improvements to future processes.

The relationship between NDIA and OoD at most levels is very strong. My staff communicated well with NDIA staff. Tension on the ground has actually improved processes. Has worked well because we are both looking at outcomes for individual participants*.* (OoD staff member)

* + 1. Things are getting better, ‘we’re learning together’

All stakeholders interviewed agreed that processes are improving and that some of the early challenges of the project are being resolved with strong communication, collaboration and a focus on flexibility in the delivery of the scheme. The cooperation, skills and established relationships of experienced stakeholders and the openness of the NDIA to adapting the scheme were the most commonly cited strengths of the project. These strengths can be seen in the following actions:

* Engagement between the NDIA and service providers is increasing understanding and building strong collaboration
* Funding made available through the Sector Development Funding (SDF) and ILC grants have been accessed by local service providers for a range of projects
* Resources have been developed in Language incorporating Yolngu concepts and worldviews and will soon be workshopped with service provider staff and community members.
* Local service providers are developing and adapting NDIS processes in ways that are relevant and responsive to local needs and conditions
* NDIA is responding to feedback from service providers and communities and considering ways to adapt the scheme to better respond to conditions and needs in East Arnhem. For example, ‘pooling of funds’ is a concept that has been put forward by service providers in East Arnhem as a way of maximising the value of external services brought into communities and NDIA is helping iron out the practicalities of this process
* Despite early challenges presented by the complexities of the CoS role (see section 1.1.4), NDIA staff have noted that some CoS providers are now displaying strong practice in CoS service delivery which is demonstrating and leading the way for others.

We are learning as we’re going and one size doesn’t fit all. Senior Leadership are aware of that and open to a different approach. We are able to notice what is working well and stop what isn’t working well and equip us for what to do next.(Government stakeholder).

* + 1. NDIS Funding opportunities and funded projects in East Arnhem

There are two main grant funding opportunities from the NT and Commonwealth Governments which have been utilised by service providers to support their engagement with the NDIS and build capacity in communities.

* National ILC funding of $131 million per annum is administered by the NDIA with a focus on community inclusion. Open grants support personal and community capacity building to achieve greater inclusion of people with a disability in the community. Funded projects in East Arnhem include:
* MJD Foundation, Arnhem Land Progress Aboriginal Corporation (ALPA) and Miwatj are running support groups in communities for participants, carers and families
* Miwatj and ALPA are working with ARDS Aboriginal Corporation to develop NDIA resources in Yolngu Matha
* SDF - NTG Innovation Grants: Total funding available under the Innovation Grant Program is approximately $2 million. Round 1 of the Innovation Grant Program was completed in December 2017, where approximately $1 million of funding was granted to organisations across the NT for projects up to $100,000. These include an Integrated Service Hub in Ramingining, the establishment of a Wellbeing Centre at Galiwinku, and a feasibility study for short-term accommodation for NDIS participants with a psychosocial disability in Nhulunbuy (more details on these projects are provided in Section 4 of this report).

Four project stakeholders identified that the timing of the funding was an issue, given that the grants were only made available once the roll out had begun, and earlier availability would have enabled service providers to better prepare themselves and communities for the NDIS.

ILC grants came at the same time as the roll out and needed to come 2 years earlier. For example, to get resources in Language running because there is no choice for clients until they understand what is on offer and they need language resources to do this*.* (Service Provider)

* + 1. Stakeholders see the potential of the NDIS and are working towards common outcomes

Across the range of project stakeholders, common outcomes were clearly identified. Twenty-one of twenty-six interviewees stated their desire and commitment to creating positive, long-term outcomes from the NDIS for East Arnhem communities. These outcomes included access to more culturally appropriate services, capacity building for individuals and communities, increased choice and participation for people with a disability and more local employment opportunities. All project stakeholders are focused on both outcomes for individuals, and outcomes for the broader communities. In particular, each of the local service providers stated that they are involved in the NDIS, to ensure that local Indigenous needs and priorities are represented and that the best possible outcomes from the scheme for local participants and broader communities are realised. All Aboriginal Organisations we interviewed stated that their boards are strongly supporting their engagement with the scheme and see it is imperative that they are key stakeholders in the NDIS in the region.

NDIS is good because we put on an NDIS coordinator (funded internally) and rolled it out into the homelands. We did this because we knew services wouldn’t be provided unless we did something. All our participants have received occupational therapist assessments and are now getting equipment. We get coordination of support funding*.* (Service Provider)

East Arnhem Land Regional Council is the largest provider of CoS services (see section 1.1.4) with a range of other organisations including Miwatj Health, ALPA, MJD Foundation, Anglicare and Laynhapuy Health providing programs and services in the communities included in the evaluation.

The leadership of local service providers has been amazing. They are committed to positive outcomes for participants. (Working Group member)

Other project stakeholders including NT Government Departments, the PM&C and VTEC training organisations have a particular focus on workforce development. This includes business and employment outcomes for local people in East Arnhem.

A shared commitment to common long-term outcomes, across the range of stakeholders in East Arnhem, has enabled the high level of collaboration in the implementation of the NDIS which has been documented throughout this report. Despite early challenges in implementation and lack of co-design, stakeholders are positive about the potential of the NDIS to achieve outcomes in the future and are planning and investing in initiatives for communities. The section below will provide more detail on planned projects and initiatives.

* 1. Business and Employment

**How has the Co-design Project supported Aboriginal and Torres Strait Islander people to establish businesses and has it increased employment of local people?**

* + 1. Too Early to measure significant business and employment outcomes

There is little evidence of outcomes in terms of increased business and employment at this stage of the project. For a range of reasons described in this report, the transition and early implementation stage of the NDIS East Arnhem Project is still building foundations and more time is needed for business and employment outcomes to be realised. Project stakeholders are aware of this, and of the need to work collaboratively to achieve outcomes over the longer term. Therefore, this section will outline the small number of current jobs for Aboriginal and Torres Strait Islander people created by the NDIS, planned and funded projects being delivered by service providers on the ground, and a range of other collaborative initiatives that have potential to generate Aboriginal and Torres Strait Islander NDIS-related employment in the region.

* + 1. Successes

New jobs for local people

Currently, the main employment outcome from the NDIS East Arnhem Project is through employment of 19 Community Connectors across six communities in the region. These roles are all filled by local people, many of whom were already employed in a range of roles by the host organisations.

Some other small employment opportunities have been created including:

* NDIA Indigenous employees based in Nhulunbuy including an Assistant Director of Engagement and an Indigenous Planner.
* Two local personal care workers are being trained and employed by Laynhapuy Health who can be employed for participants that are ‘plan’ managed rather than ‘agent’ managed. Plan management allows non-registered providers to be paid for NDIS services.
* Miwatj has employed two Yolngu trainees and has plans to take on another four across the three communities.
* On Groote Eylandt, a local woman has taken on a part-time role with the local physiotherapist who has registered as an NDIS provider. There are other part-time roles available.

Twenty-two of 26 project stakeholders interviewed see the creation of local jobs as key to the success of the scheme in the region. Interviewees identified that this requires creativity and flexibility and the development of localised training and workforce development.

There was little evidence, however, of stakeholders creating employment opportunities for people with a disability themselves. This is a key objective and intended outcome of the NDIS. There were, however, comments made by both service providers and carers, about increasing the life skills of NDIS participants, including plans to train participants to engage in food and drink preparation as part of a “café” at the proposed Galiwin’ku Wellbeing Centre.

Discussion, Planning and Developing New Initiatives

Project stakeholders including the NDIA, other government agencies, service providers, and registered training organisations are engaged in the planning and development of new projects and programs through a range of collaborative initiatives. Some examples include:

* The NDIA is having discussions with service providers and community members, around the best way to engage family and kinship carers in the provision of NDIS services. This would recognise prior skills, include locally delivered training, and provide opportunities for local employment, bringing cultural safety and appropriateness to the delivery of services. Local service providers are working with communities to identify suitable candidates for these roles.
* Flexible, pooled labour hire models are being discussed (similar to those currently used in other industries by ALPA) to best support a sustainable local disability workforce.
* Funded by SDF, the NT Department of Trade Business and Innovation (DTBI) is delivering a Remote Workforce Development Program with the Industry Skills Council NT who is working with training organisations and local service providers to identify NDIS employment opportunities and training needs, in order to adapt, develop and deliver appropriate training and support transition into employment of local people.
* The DTBI also funds a Business Readiness program which includes four organisations in East Arnhem who are engaged and completing programs. Three more organisations have also expressed interest.
* A recent contract with PM&C has been confirmed for a VTEC to service the Nhulunbuy region. The VTEC will collaborate with local service providers and community stakeholders to develop and deliver culturally appropriate training for industry and organisations including NDIS related jobs for East Arnhem.
* Other funds and programs available in workforce development (e.g. NTG Local Jobs) have been quarantined for East Arnhem but not yet accessed, in some cases due to the uncertainty about the level of need for training and the lack of defined jobs at this stage of the NDIS roll out.

We work a lot in business development in remote areas and know the longer timeframe and risks for micro enterprises etc. We need to look at it in terms of a job creation perspective and look at labour hire models, like ALPA’s labour pools being used in other industries and apply them to the NDIS.(Project stakeholder)

NDIS Projects being delivered by local service providers

Below are some planned and funded projects for East Arnhem which include the three communities at the focus of this evaluation as well as other locations:

* ALPA NDIS Integrated Service Hub – Ramingining in collaboration with Carers NT and Carpentaria. This project involves the upgrade of an existing facility in Ramingining to create an integrated NDIS Service Hub, which will be accessed by multiple providers to deliver a variety of services including allied health. The shared space will be used to offer day respite and a variety of individual and group-based supports such as daily activities and social participation. This project will create opportunities for local employment and create a community owned and culturally safe environment for service delivery
* Miwatj Galiwinku Wellbeing Centre in collaboration with ALPA. The focus of this project is to repurpose and upgrade the old clinic at Galiwin’ku to establish a Wellbeing Centre which will be utilised to provide community participation, social inclusion and the upskilling of Galiwin’ku mental health/NDIS participants. With a focus on mental health, services will include physical activity, mental stimulation, participation, socialisation and clinical treatment. The centre will create long-term employment opportunities for the community.
* TEAMHealth, Keeping Families Strong in East Arnhem. TEAMHealth will conduct a feasibility study that investigates the cost and development of a viable service model for short-term accommodation based in Nhulunbuy for NDIS participants with a psychosocial disability. Utilising a collaborative approach, including consultation and workshops with key local organisations, it will develop a workforce plan that supports employment of Yolngu support workers and Aboriginal peer workers to create a safe environment and ensure a culturally appropriate approach.
* Respite centre in homelands: Laynhapuy Health Aboriginal Corporation
  + 1. Challenges

Lack of market visibility

A lack of reliable data around the level of disability in East Arnhem and the corresponding need for services in the region has been identified by a range of project stakeholders as a key challenge. More than half the interviewees identified that without market visibility, there is too much risk for smaller organisations to register as service providers. The lack of data presents barriers for all project stakeholders to understand community needs and plan and develop appropriate services and initiatives. Four project stakeholders were critical of the NDIA’s lack of provision of clear and reliable data for East Arnhem.

The NDIA is not getting down to the granular data and not sharing market information to inform providers. If you don’t know what that market is - you don’t know whether to invest. (Project Stakeholder)

Issues with market visibility in the region were known and expected and have been experienced in other parts of Australia during the NDIS roll out. The particular challenges in East Arnhem have been identified by the Productivity Commission which found that in terms of provider readiness, “in a market based model for disability supports, thin markets will persist for some groups”,[[47]](#footnote-48) including those living in very remote areas, and who are of Aboriginal and Torres Strait Islander background. To address the issue, the following recommendation was made:

The NDIA should address thin markets by:

* considering a range of approaches, including block-funding
* publicly releasing its Provider of Last Resort (POLR) policy and Market Intervention Framework discussed in the NDIS Market Approach: Statement of Opportunity and Intent as a matter of urgency
* collecting and making publicly available disaggregated data, feedback and reports on thin markets, including when POLR arrangements are used.

1. Synthesis of Findings
   1. NDIS Pathways of Change

Based on the key findings, two NDIS Pathway of Change models have been developed to demonstrate the cultural context, needs, key inputs and processes needed to effectively implement the NDIS in East Arnhem and achieve identified outcomes. Figure three - *NDIS Pathway of Change* is an overarching program implementation model representing perspectives of all stakeholders.

Figure Three: NDIS Pathway of Change

The NDIS Pathway of Change (Figure three) is an overarching program implementation model, representing the perspectives of all stakeholders. There are six elements in this model and include:
Element 1, titled Context (Cultural Landscape), positioned at the bottom of the page has three boxes, including:
1. Strengths: Culture, Kinship and language are strong in East Arnhem. Yolngu and Anindilyakwa families are sharing the care of relatives with a disability. Existing services include Aged Care, Sport and recreation centres, libraries, art centres, health clinics and schools.
2. Challenges: When family members who are carers go to work or need to go out of the community, no one is left to care for the person with a disability and it’s hard to find a suitable ongoing carer. Many communities and outstations are very remote and have few services. There are no local respite services and Darwin is the nearest option and carers do not receive much support.
3. Engagement: Aboriginal people in East Arnhem are happy for Balanda (white East Arnhem people) to support with English skills and work skills and to work together with local people, but not to tell them how to do things or make decisions for them. New people and programs must invest in building relationships, understanding and trust over time with people in East Arnhem and appreciate that things may be different in these communities.
Element 2, titled Need, positioned above Context has three boxes, including:
1. People with a disability in East Arnhem want to be able to do things that interest them and participate in culture and community
2. People need to know and understand more about the NDIS and what it offers
3. In East Arnhem communities, there are gaps in services for people with a disability and for their families and carers.
Element 3, titled Inputs, positioned above Need has eight boxes, including:
1. People with a disability, their carers and families
2. Culture, country and community
3. Knowledge and skills of Community Connectors (CC)
4. New Service Providers (SP) 
5. Expertise and established community trust of local SPs providing CoS and other services
6. NDIA resources for NT eg. Community Engagement Strategy
7. NDIA, NTG, PM&C staff
8. NDIS and other NTG and Commonwealth funding for East Arnhem.
Element 4, titled Activities, positioned above Inputs contains seven boxes, including:
1. NDIA collects and shares data to increase market visibility and inform planning for new services
2. Community Connectors facilitate communication about the NDIS and the planning process, between people with a disability and their carers and NDIA staff when they visit communities
3. SPs develop and workshop with communities, NDIA information and resources in language that make sense and are useful to people living in East Arnhem
4. Develop and adapt training to build skills of community members in disability support and other roles
5. Local SPs work together with communities, NDIA and NTG and Commonwealth government to maximize funding opportunities and co-design and develop the right solutions and strategies for the region
6. NDIA responds to feedback about the needs of people in East Arnhem with a disability and the challenges of providing services there, and provides flexibility in the way NDIS works in the region
7. Local SPs work together and with new SPs to access resources, and develop new services to respond to the needs of people with a disability in East Arnhem.
Element 5, titled Outputs, positioned above Funding has seven boxes including:
1. Good quality NDIS plans
2. Local culturally appropriate training
3. Reliable data about the needs for services
4. New jobs and labour hire models for Indigenous people providing services for people with a disability
5. NDIA resources in language
6. Effective communication and strong relationships between NDIA staff and community members
7. Expansion of existing services and development of new services for people with a disability.
Element 6, titled Outcomes positioned above Outputs sits across the top of the page and has six boxes including:
The first three boxes are the short to medium term outcomes and include:
1. Understanding and trust are developed between NDIA and communities
2. People with a disability in EA have and use NDIS Plans that reflect their needs
3. Increased and ongoing collaboration between stakeholders.
The final three boxes are the medium to long term outcomes and include:
4. An increase in local, sustainable training and employment opportunities
5. People with a disability in EA have the supports they need to live an ordinary life, participate in the community, connect with culture and Country and do the things that interest them
6. The needs and priorities of carers, families and communities are supported.


Figure four focuses on community stakeholders, demonstrating the perspective of community members with a disability and their families. These models are intended to be a guide and should be taken back to communities in East Arnhem and co-designed with community and project stakeholders.

Figure Four: East Arnhem Community Best NDIS Pathway

Figure four titled East Arnhem Community Best NDIS Pathway model looks at three stages that move from a state called ‘Rough water’ through to the state of ‘Calm water’. There are five steps with outcomes identified to assist with the process of moving from stage 1 through to stage 3.
At stage 1: The community is disempowered. There is a lack of understanding of and engagement in the NDIS. Services are overlooked and navigating complex systems occur with limited resources.
This is the ‘Rough water’ stage and includes: Living with a disability in a remote region. Very few or no local therapy services. A health system which requires high aptitude for mainstream service, utilisation and participation.
Progress begins and moves away from the ‘Rough water’. Client needs are identified. A good NDIS Plan is developed. The family of the client understands the process, and is aware of the capacity of the program.
At stage 2: The community is included in all program aspects. Needs are being identified, local knowledge is utilised and Culture is central. Local Aboriginal businesses are emerging and delivering services. Local services are well resourced. They are staffed and led largely by locals. They receive strong leadership, guidance and collaboration from NDIS. Local cultural engagement is best practice.
Progress continues and moves further away from the ‘Rough water’ stage: There is consistent, reliable, and clear communication coming from the Purple Shirts. Community questions and concerns are addressed quickly.
Further progress continues: The client and their family are receiving support and access to resources that are improving their lives. The plan is useful, and the processes are not burdensome.
(During stage 2 the community is able to self-determine their support structures, and grow their collective capabilities. Local services and Aboriginal businesses able to apply local best practice standards and unique local approaches).
At stage 3: The community is empowered. Locals understand, engage with and benefit from the NDIS. Services are strong. Local Culture and needs are central to programs and messaging.
‘Calm water’ is reached. Needs being met, having choices and access to services that give them the ability to participate in the community. Having a developed trust and faith in the health system. Being empowered.

* 1. Effective implementation principles

Based on the implementation activities described in the NDIS Pathway of Change Model, the evaluation has identified several effective implementation principles which may be used to guide and monitor the roll out of the NDIS East Arnhem project. These principles are intended as a guide and should be taken back to community and project stakeholders and adapted and co-designed with them.

Table Two: Effective implementation principles and activities

|  |  |  |
| --- | --- | --- |
| **Effective implementation principles** | **Implementation Activities** | **Qualitative Rating of NDIS East Arnhem Project** |
| 1. Service Providers (SPs) work collaboratively | Local SPs work together and with new SPs to access resources, and develop new services to respond to the needs of people with a disability in East Arnhem | **Strong evidence of this principle**  Collaboration of service providers is a key strength of the project |
| 2. NDIA resources are adapted to local language and culture | SPs develop and workshop with communities, NDIA information and resources in Language that make sense and are useful to people living in East Arnhem | **Currently in development.** Earlier availability of funding would have allowed better preparation. |
| 3. Community Connectors are consistently utilised in the communication and planning process | Community Connectors facilitate communication about the NDIS and the planning process, between people with a disability and their carers and NDIA staff when they visit communities. | **Increasing evidence of this principle.** Utilisation of Community Connectors has increased throughout the roll out. |
| 4. Implementation is co-designed with all stakeholders and collaboration between stakeholders is supported by the NDIA and Government Departments | Local SPs work together with communities, NDIA, and NT and Commonwealth governments to maximise funding opportunities and co-design and develop the right solutions and strategies for the region | **Increasing evidence of this principle**  Stakeholders are working together on the implementation to create shared outcomes for communities.  Service providers collaborating well with communities.  Further collaboration between the NDIA and NTG would strengthen this principle |
| 5. NDIA provides flexibility in delivery of the scheme | NDIA responds to feedback about the needs of people in East Arnhem with a disability and the challenges of providing services there, and provides flexibility in the way NDIS works in the region | **Strong evidence of this principle.**  NT NDIA flexibility is a key strength of the project |
| 6. Training is culturally appropriate and relevant to local needs | Develop and adapt training to build skills of community members in disability support and other roles | **Not yet developed**  Recent VTEC contract in Nhulunbuy will work with local stakeholders to develop and deliver training |
| 7. Reliable data is collected and shared | NDIA collects and shares data to increase market visibility and inform planning for new services | **Little evidence of this principle**  A range of challenges to data collection have been identified and need to be addressed |

1. Discussion and Recommendations: What have we learned and what can be improved

Based on the key findings, the implementation processes demonstrated in the Pathways models, and the performance of the NDIS East Arnhem Project against the effective implementation principles, the following recommendations are made:

* 1. Too early to measure significant outcomes from the NDIS East Arnhem Project

It is clear that after 14 months of implementation, it is too early to measure significant outcomes for individual participants and their communities as a result of the scheme. All stakeholders are aware that the NDIS involves changes for community members, service providers and government agencies and that it will take time for measurable results to be achieved.

**Recommendation One (a):** That the Commonwealth review the implementation and outcomes of the NDIS East Arnhem Project in another twelve months’ time

**Recommendation One (b):** That at least 24 months of implementation be underway before evaluating outcomes from the NDIS roll out in remote Aboriginal and Torres Strait Islander communities

**Recommendation One (c):** That a monitoring framework be developed using co-designed effective implementation principles as a guide, to monitor and continuously improve the implementation of the NDIS roll out in remote Aboriginal and Torres Strait Islander communities.

* 1. More time for communication and consultation to build community awareness and engagement

A key finding of this evaluation is that more information and communication with service providers and communities before the commencement and in the early stages of the East Arnhem NDIS roll out, would have improved processes and outcomes in the first twelve months of implementation. It is clear that the Regional NDIA team has made substantial engagement efforts, (including development of the three tiered engagement strategy) and has understanding of the complex cultural and remote context of the project. However, the level of awareness, understanding of and engagement with the NDIS in communities is still low. In order for this to increase, ongoing and consistent communication and consultation with communities by the NDIA is needed, utilising Community Connectors and newly developed NDIS resources in Language.

**Recommendation Two:** That the NDIA provide consistent and ongoing communication and consultation with communities, working with Community Connectors and resources in Language, to increase understanding of and engagement with the NDIS in East Arnhem.

* 1. The importance of good quality plans

This evaluation has demonstrated that the early implementation of the project in East Arnhem resulted in rushed and poorly comprehended plans that are being underutilised by participants. Service providers and other community and project stakeholders have identified that NDIA planners need to be consistently skilled both in NDIA processes as well as cultural protocols. Planners need to engage in pre-planning in communities and work closely with, and listen to service providers, Community Connectors, community leaders, families and participants. They also need to provide adequate time for all appropriate people to be informed about and participate in the planning and review process so that plans can effectively reflect the needs and goals of participants.

**Recommendation Three:** That the NDIA provide sufficient time and funding for the pre-planning, planning and review process in East Arnhem to follow cultural protocols and for planners to engage with a range of community and family members. This time and funding are needed to ensure that plans reflect the needs and goals and cultural priorities of participants.

* 1. Leadership of local Service Providers

Many local service providers in East Arnhem are well established, (often Aboriginal community controlled organisations) and are experts at adapting new Government programs to local conditions and needs, in order to create positive outcomes for their communities. These service providers have long-standing relationships with communities built on cultural safety, understanding, trust and reciprocity. In the roll out of the NDIS in East Arnhem, these service providers are working hard to adapt the scheme to fit better in communities. They are the key connection between community stakeholders and the NDIA, providing information and support to participants and their carers, while informing the NDIA and government stakeholders of community needs and priorities. They are collaborating extensively with each other and other project stakeholders, accessing funding opportunities and finding innovative ways to maximise the potential outcomes from the scheme in the region.

**Recommendation Four:** That the NDIA continue to collaborate closely with and support local service providers who are key to the effective implementation of the NDIS in East Arnhem

* 1. Flexibility of NDIS to respond to local needs, conditions, and cultural priorities

The willingness of the NT NDIA to consider adapting and providing flexibility in the delivery of the NDIS in East Arnhem has been a key strength of the implementation of the project. In order for the NDIS to achieve outcomes at an individual and community level in the region, this flexibility must continue. Feedback from local service providers, participants and their carers must be considered and local solutions and adaptations developed. For example, given the level of informal supports being provided by family and kinship care arrangements to people living with a disability in East Arnhem, and the acknowledged lack of services in the region, flexibility is needed to find the best way to include local carers as paid service providers. Alternatives should be explored in order to recognise carers’ prior skills, build capacity, create more local employment opportunities and provide support services for participants.

**Recommendation Five:** That the NDIA continue to provide flexibility in the delivery of the NDIS in East Arnhem and to develop local solutions in response to community needs, conditions and cultural priorities. For example, the NDIA should work with community and project stakeholders to create opportunities for local carers to be employed as NDIS support workers.

* 1. More collaboration between government agencies on workforce development

There are a range of identified challenges to achieving workforce outcomes as a result of the NDIS in East Arnhem. The NDIS context provides an opportunity for the NT and Commonwealth Governments to work more closely with each other, and with the NDIA, particularly in the area of workforce development. Working collaboratively would promote more information sharing and the collection and publication of reliable data. In turn, this would support high level decision making that further facilitates the delivery of the project and the achievement of its intended outcomes.

**Recommendation Six:** That the NT and Commonwealth Governments collaborate closely with the NDIA, share resources and information, in order to better support the implementation of the NDIS in East Arnhem and the development of a regional disability workforce.

* 1. Collaboration between all stakeholders the key to successful implementation

A key strength of the NDIS East Arnhem project is the level of collaboration between project stakeholders in the roll out of the project. This collaboration is enabled in part from the common long-term outcomes sought by stakeholders committed to creating benefits from the NDIS for East Arnhem participants and communities. Collaboration has also been supported by NDIA and OoD workshops that have facilitated networking and information sharing and the opportunity to access funding for joint projects through the ILC and SDF.

**Recommendation Seven:** That the NDIA and government departments continue to support and encourage collaboration between project stakeholders throughout the implementation of the NDIS in East Arnhem, providing opportunities for them to network, share information, discuss funding opportunities, and identify shared outcomes, challenges and successes.

* 1. Co- Design NDIS pathways with local communities

Based on the analysis of data provided by community and project stakeholders, Social Compass has developed two pathways of change to outline the identified elements needed to effectively implement the NDIS in East Arnhem; one from the perspective of community members with disabilities and their families, and one from an overarching program perspective as shown in Figures Three and Four.

**Recommendation Eight:** That the NDIA use these pathway models as a base, to take back to communities in East Arnhem, and co-design with local service providers, participants and their families, the NDIS pathway that works best for them and their local community.

* 1. Consult with community and project stakeholders in each location to consider these recommendations for the roll out of the NDIS in other remote Aboriginal and Torres Strait Islander communities

The above recommendations have been developed in response to evidence collected about the roll out of the NDIS in three East Arnhem locations, and learnings apply to how implementation of the scheme can be improved in these particular Aboriginal and Torres Strait Islander communities. Some of these learnings and recommendations may also be relevant to the roll out of the NDIS in other locations. However, in order to maintain its commitment to a “community by community approach”[[48]](#footnote-49) in the delivery of the NDIS in Aboriginal and Torres Strait Islander communities, the NDIA must consult with both community and project stakeholders in each location to determine the applicability of these recommendations to that particular community as needs, conditions and cultural priorities may vary.

**Recommendation Nine:** That the NDIA consult with each remote Aboriginal and Torres Strait Islander community to consider the application of the above recommendations for the roll out of the NDIS in their location.

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Appendix A: List of project stakeholders interviewed

Active Performance Physiotherapy Groote Eylandt

Arnhem Land Progress Aboriginal Corporation

Anglicare

Commonwealth Department of the Prime Minister and Cabinet

East Arnhem Regional Council

Groote Eylandt Aboriginal Trust

Groote Eylandt and Bickerton Island Enterprises Aboriginal Corporation

Group Training Northern Territory

Laynhapuy Homelands Aboriginal Corporation

Machado Joseph Disease (MJD) Foundation

Miwatj Aboriginal Health Aboriginal Corporation

National Disability Insurance Agency

Northern Territory Department of the Chief Minister

Northern Territory Department of Trade Business and Innovation

Northern Territory Office of Disability

Northern Territory Office of Public Guardian

Appendix B: Data collection tools

**Stakeholder Organisation – Interview Guide**

*The purpose of the questions set out below is to provide a guide for discussion rather than the questions being asked verbatim as they appear.*

1. Please tell me about your organisation and your role in it?
2. What are your impressions of the NDIS roll-out in this community/East Arnhem Land generally?
3. Broadly, what are your interests in the NDIS roll-out in this region/community?

**Evaluation Question 1 to be answered:** Before the NDIS, how did people with a disability and their families participate in and contribute to their community and were their reasonable and necessary support needs met?

* 1. How did people with a disability and their families participate in and contribute to their community before the introduction of the NDIS? (What were the issues)
  2. What were people’s support needs? (How were people’s support needs met and by who?)
  3. A key feature of the NDIS is the provision of ‘reasonable and necessary support needs’. What does this mean to you? What does it require?
  4. Since the introduction of the NDIS, what has changed, when and how for the region/community/those living with a disability?
  5. What is the most significant change and for whom as a result of the project?
  6. What has been learnt – by you personally, your organisation, for the community?
  7. What can be improved further?

**Evaluation Question 2 to be answered:** How has the co-design process worked in each community? What have stakeholders identified as necessary to meet the reasonable and necessary support needs?

* 1. What do you know about the Co-design approach being taken?
  2. How have you/your organisation engaged in it?
  3. What does co-design mean to you?
  4. What are the co-design aspects/processes of the project?
  5. What are the support needs? How have they been identified?
  6. What have you learnt about co-design? What improvements can be made for the future?

**Evaluation Question 3 to be answered:** In the period since the co-design process began in September/October 2016 has it established the foundation to achieve the outcomes stakeholders have identified?

* 1. What were the outcomes your organisation identified?
  2. When and how were they identified?
  3. What foundation has been established?
  4. What would have made it easier for you to know more about the NDIS and for you to engage?
  5. Do you think you have contributed to the successful roll out? What could have made that better?

**Evaluation Question 4 to be answered:** How has the Co-design Project supported Aboriginal and Torres Strait Islander people to establish businesses and has it increased employment of local people?

* 1. Do you know of any business and employment opportunities that have been generated as a result of the introduction of the NDIS?
  2. What businesses and employment opportunities have been generated?
  3. How many have been taken up? Why or why not?
  4. What have been the challenges?
  5. Do you have any success stories?
  6. What has been learnt? What improvements can be made for the future?

****

**The purpose of this document is to provide Milingimbi and Galiwin’ku NDIS participants and their families and carers information about the visit from the Social Compass in the first week of February 2018.**

A mob called Social Compass has been asked by the Government to talk to your community about the way the National Disability Insurance Scheme - NDIS (the people wearing the purple shirts who are the new disability people) has been talked about and started up in your community. We want to know about the things that are working well for you and the things that are not working so well for you with the NDIS*.* This mob want to talk to you because:

1. You are a going to be a part of the NDIS and have a plan for your disability care (someone with a purple shirt has spoken to you before) or you are a family member of someone who is going to be a part of the NDIS.
2. You are a community Elder or Leader and so you can talk for your family or community about the NDIS and the way it is being started up in your community.

Here are the people that are coming to visit:



**Lucy McGarry Nathan Leitch**

This mob want to talk to you about how happy you are with the government’s work with the NDIS. You will be asked to think about what has happened to you or people that you know with the start-up of the NDIS in your community. You will be asked to talk about the things that have worked and the things that have not worked so well with the start-up of the NDIS in your community.

This mob understands that maybe you are tired from speaking to visitors and so won’t talk to you for too long. You will be offered a gift when you talk to the Social Compass mob.

****

**Community Interview Guide**

* Please tell me a little bit about your community and its strengths – what are the good things about your community?
* What are some of the challenges for this community – especially for you and your family

1. What things are most important to you and your family?
2. What do you know about the NDIS (the people with the purple shirts) in this community? What do they do?
3. What do they talk to about? How have they helped you?
4. Has this way been different to normal government way or the same way?
5. Since the people with the purple shirts came (NDIS) to this community has anything changed? If so what was life like before? Is it better or worse now?
6. Do you have an NDIS Plan?
7. Are you using your plan? How?
8. Can you do more things now [participation in community – more involved, easier to participate in life/work, with family, activities etc]?
9. What has been the most important change since the people with the purple shirts started their work here?
10. What more can happen here to help you, what services and supports would help you?

Appendix C: East Arnhem NDIS Rollout Context[[49]](#footnote-50)

This chart shows the roles, relationships and flows of information between the Northern Territory Transition Implementation Group, the East Arnhem Project Team, the National Commonwealth Reference Group and the Local Implementation Team. The Local Implemtation Team establish a relationship with the East Arnhem Project Team. This team is responsibile for the on the ground action, making things happen, building connections and alignments. The team includes the NDIA Chair, PM&C, NT Chief Ministers, NT Office of Disability, 2 East Arnhem representatives (rotating and outreach to other forums), PwC's Indigenous Consulting (Action Learning). They provide status reports to the Northern Territory Transition Implementation Group (NT TIG). This group is responsible for decision making and problem solving and includes the NDIA, DSS, Mental Health, NT Chief Ministers, NT Office of Disability. The East Arnhem Project team also share information between the National Commonwealth Reference Group which is the Commonwealth issues resolution and includes the NDIA, PM&C, DSS, Health and Employment. This group also shares information between the Northern Territory Transition Implementation Group.  


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40. Ibid (p3) [↑](#footnote-ref-41)
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