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2. To the people with disability, and families that shared their experiences and allowed this to be part of the report in case studies.
3. The Co-Design team for all your input and dedication to the project.
4. To the service providers across the state that have been so generous with your time and information that has been an integral part of the report.
5. To the other members of the Disability Coalition who have worked in partnership with this project to achieve the responses and report findings.
6. To the Department of Communities who have provided the funding to partake in this project and highlight the voice for individuals and families in this transition.
7. To NDIS and the Local Area Coordination Partners for your willingness to engage in the project and work collaboratively.
8. To the Project Staff and team at PWdWA in the support and collaboration in completing the report and the findings.

Project Overview and Summary

PWdWA provides individual and system advocacy around issues experienced by individuals, their families, and carers concerning the National Disability Insurance Agency (NDIA) and the Scheme (NDIS).

PWdWA provides ongoing advocacy to individuals engaging with the NDIS processes at all levels. There have been continuous requests by individuals and families for advocacy support in relation to NDIS. In 2019-2020 Financial Year, NDIS represented one third of all issues dealt with by PWdWA.

As part of the Western Australian Disability Coalition of advocacy and peak organisations, PWdWA undertook the lead in the systemic advocacy project “NDIS transition and interface issues”.

The focus of the project, over an 18 month period, was to address the systemic barriers arising from the transition to NDIS in WA including issues with the National Disability Insurance Agency policy and practices and other departments/mainstream agencies interface with the NDIS.

The project engaged with people with disability, peer groups, advocacy groups, the service sector, other government departments, Cultural and Linguistically diverse (CaLD) community and the wider community across the metro and regional areas of WA; to obtain feedback and identify the issues and barriers in the NDIS transition. A key part of the information gathering was through a long - running survey on the PWdWA website that gathered feedback from individuals, families and the community on their experiences of the NDIS.

As part of the project a diverse group of people with disabilities were engaged in a Co-Design group that met on a regular basis and looked at solution-focused approaches to the issues both at an individual and systemic level. The Co-Design group partnered with NDIA and NDIS LAC Partners to discuss and Co-Design recommendations to address issues that were raised during the project. This has culminated in the findings that are included in this report.

The findings from the project highlight issues with the flexibility of the scheme to deal with diversity and individual complex circumstances, as well as a lack of supports to navigate and connect people to the NDIS and service systems. The project used the principles from the NDIS Act 2013 as a foundation and found that the NDIA policy and practice does not always align with those principles.

The most important sections of the report are the Co-Design Report, Recommendations, and Case Studies. The case studies show that even when a person and/or family ultimately has a good outcome from the NDIS, the process to get there is stressful, confusing, bureaucratic and clunky.

During the course of the project, the findings have been used to inform submissions to Government Inquiries and the WA State Disability Strategy. Each submission had specific recommendations.

The following are the high level recommendations from the project:

1. The NDIA regularly reviews its processes, rules and procedures against the principles in the NDIS Act 2013 and use those to inform continuous improvement.
2. Co-Design principles and practice be adopted by NDIA and LAC Partners to ensure that lived experience is part of future decisions, solutions, and the future of the scheme in WA.
3. Implementation of Tune review recommendations include a broad focus on increasing flexibility for individual complexity and diversity, decreasing check box responses, and simplifying language.
4. Flexible Community Development approaches are used to connect to people in regional and remote areas, through funding peer support, local organisations, and intentional outreach.
5. NDIA provide funding and support to people with disability, and families, in local community groups to assist with accessing the scheme, accessing pre-planning, for people with disability to train planners, be planners, and be supported to train and be Support Coordinators.
6. Independent Individual Advocacy and Systemic Advocacy are recognised and engaged by the NDIA to inform change and support individuals in complaints, reviews and appeals.
7. Recommendations from the Co-Design report are considered to ensure that a transparent, effective scheme is introduced that reflects the NDIS Act and principles.
8. Recommendations from the CaLD report are considered to ensure that the scheme is applicable to people from different cultural backgrounds.
9. Recommendations from the project to the State Government are supported by the NDIA and put in the State Disability Strategy Action Plan to address the gaps in the system for those not eligible for NDIS, and those areas the State can assist.

The full set of recommendations are on page 57.

An Easy Read version with images and Easy Read text version of the Co-Design report is available on the PWdWA website and printed copies available on request.



people with
disabilities
western
australia



Co-Design Project Report

National Disability Insurance Scheme (NDIS) Transition and Interface Issues

A collaboration of individual people with disability and service providers, to improve the individual experience of the NDIS, and promote better experiences for all.

Co-Design Group

NDIS Users for PWdWA

Co-Design Report

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6. Recommendations to the NDIA

6.1 There are significant barriers to accessing the NDIS.

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6.3 The NDIS lacks transparency.

6.4 NDIA Staff are inadequately qualified, trained or experienced in working with people with disabilities and there are significant inconsistencies across decisions regarding access, plans and reviews, and information provided.

6.5 At present services are not individualised nor holistic and there is a lot to be desired in terms of integration and collaboration amongst government, community services, private sector, and families.

7. Conclusion

8. References

1. Introduction

The Co-Design group for People with Disabilities Western Australia (PWdWA) consists of nine National Disability Insurance Scheme (NDIS) participants with lived experience of disability and the roll-out of the NDIS scheme in WA. The Co-Design group has met together face-to-face and via Zoom (due to Covid-19 restrictions) for the past nine months on a regular basis to explore the National Disability Insurance Scheme (NDIS) Transition and Interface Issues. The ultimate purpose of the Co-Design group was to discuss the issues and Co-Design strategies and solutions, culminating in this report, where we provide recommendations based on the group's prioritisation of the concerns raised with respect to the interface issues experienced across NDIS participants in Western Australia.

2. Co-Design

A knowledge of Co-Design is vital to understanding this aspect of the project. Co-Design involves a collaborative relationship and mutual exchange (rather than filtering information gathered through consultation) between people with lived experiences of disability and organisations (in this case, People With disabilities Western Australia with the aim to establish Co-Design with the NDIA). The shared purpose of a Co-Design group is to either establish, improve, and/or change services and processes and due to this the process is goal-directed. Essential components of Co-Design in this context are: learning about the experience of people, challenging assumptions about people with disabilities, and reframing and addressing the inherent power imbalance between participants and the NDIA.

In this report we gather our recommendations for improvement of the systemic issues participants' face, with a focus on solutions that are functional, usable and sustainable. In-line with PWdWA Co-Design principles, we seek to improve access, inclusion and genuine participation of people with disabilities who are, or seek to become NDIS participants, with recommendations that would lead to better experiences with the NDIS processes¹.

3. Co-Design Group

Our Co-Design group was initiated by People with disabilities Western Australia as part of their National Disability Insurance Scheme (NDIS) Transition and Interface Issues project. The project's collation of experiences across the state through qualitative research (gathered from peer discussions, workshops and forums, case studies, and surveys) informed the issues presented to, and raised by, the Co-Design group. External stakeholders have collaborated with the Co-Design group by participating in face-to-face and Zoom meetings to hear of the

¹ People With disabilities Western Australia [PWdWA], (n.d.a). Connect with Me Co-Design Guide: Co-Design for Organisations Co-Designing with People with Disability. Retrieved from https://www.pwdwa.org/documents/connect_with_me/co-design-guide/index.htm

lived experiences of people with disabilities during the NDIS transition, discuss interface issues in-depth and contribute in a meaningful way to implement improvement. As such, recommendations for changes and improvement have been considered from both perspectives of people with disabilities and service providers.

Below are the stakeholders participating in this Co-Design group:

People With disabilities Western Australia:



Anne Livingston

Project Lead Facilitator



Talitha Mberi

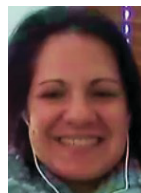
Project Administrator Support Project Officer for Culturally and Linguistically Diverse (CaLD)

NDIS Participants:



Douglas – 47 -year-old male with T6 Paraplegia; A Peer Support Officer for Spinal Life Australia, Volunteer Youth Advocate and Mentor; Studying to become a registered Builder with NM Tafe.

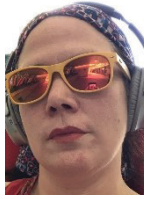
Ella - Young adult female; works at Autism West and a Mental Health Support Worker.



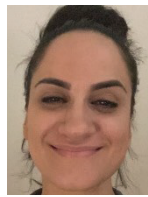
Gemma – 35-year-old Social Worker (previously worked as a Local Area Coordinator for Disability Services Commission); Early Childhood Teacher; Mother of a five-year-old son with Autism Spectrum Disorder (ASD) and Global Developmental Delay (GDD).



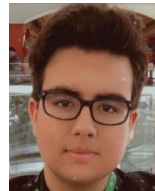
Gloria – Female with Vision Impairment; a strong desire to promote equality and inclusion for people with disability; Worked many years in Disability & Mental Health; Currently working in Supported Employment.



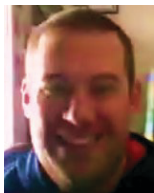
Jennifer – Economist, Artist, Maker, Activist, and Multiply Disabled Person. Passionate about the value of disabled experience in informing resilient social policy, and equally passionate about challenging how we value our endeavour, particularly in social services, resolved to dissolve the difference, challenging the assumptions made about and roles played by those who support and those who are supported, those who are employed and those who volunteer, and those who pay tax, and those who receive tax benefits. Committed to the raw honesty that Co-Design brings into all aspects of this process, as we forge cohesion from lived experience via levelled exchange.



Julie – 42-year-old female; Stay-at-home mother of a 3-year-old with ASD and GDD; Studying to be an Education Assistant.



Justin – 18-year-old male with ASD; Training with Metronet in rail car manufacturing with a focus on train driving; critiquing all WA train stations with regards to accessibility and compiling an informational video to result in strong advocacy.



Kyal – Male with Intellectual Disability; Employed with Perth Convention Centre for seven years and Optus Stadium; Starting a microenterprise for a coffee-making business with Valued Lives.



Lana – Female who has hearing and visual impairment; Enjoys sitting on committees where she can be of some value and contributes openly to the community and needs of others. Pursuing the opportunity of creating her own business with the assistance of Valued Lives.



Peter – Male with Cerebral Palsy; International advocacy with a political background specialising in complex communications; Completed a Peer Mentor program with Indigo for Assistive Technology.

Three external stakeholders participated in the Co-Design project on a regular basis.

Rebecca Bilotft – Community Engagement Facilitator from Mission Australia

Carla Stagles - Team Leader from Advanced Personnel Management Communities (APM)

Hannah Kan – Community Engagement Officer from National Disability Insurance Agency (NDIA)

Other stakeholders from Consumers of Mental Health WA (CoMHWA), Mission Australia (Engagement Facilitator), NDIA (Engagement Team), and Perth Transperth Authority, attended one-off meetings.

4. The Value of Co-Design within the NDIA

Within Co-Design, NDIS participants and nominees are validated as the experts of our own lives and we act as representatives speaking on behalf of NDIS participants. We are a valuable resource of firsthand information and response to how systems, procedures and service delivery impact our lives for good or for bad. Co-Design rightfully places people with disabilities at the forefront of decision-making that substantially affects our lives.

Lived experience of disability provides an advantage that policy makers without lived experience do not possess, allowing for empathic consideration of the experiences of people with different disabilities and backgrounds. By including a diverse group of people, we offer insight into a range of lived experiences with disability and capture a broader view into the range of interface issues that participants experience. We identify underlying and contributing factors, and their impact on participants and participants' support networks across a variety of situations and circumstance.

We identify where systems and service delivery may or may not work. This varies for individuals from different backgrounds, different disabilities, with particular note to the challenge for those who have no informal support, those who are socially or linguistically isolated, and those whose multiple disabilities complicate functional impact and cannot be simply classified under one single diagnosis. We considered the effectiveness of potential strategies and the ramifications of suggested change, as each of our perspectives offer insights into how policy change can affect each of us in disparate ways.

The diversity of our experiences within this Co-Design project highlighted the impossibility of developing a “one-size-fits all” approach to NDIS policy and also that any change in policy can easily affect us disproportionately. Without the flexibility to adapt to individual difference, policy and practices in the NDIS (and how they affect the services sector) will result in improper supports for

participants. This limits the extent, and in some cases completely prohibits, us from achieving our goals. We identified the tension this brings with respect to consistency in the scheme, and highlight that consistency must not be forced in a way that imposes unnecessary burdens, but rather is developed with respect to meeting individual disability support needs.

The participation of external stakeholders enabled a partnership between our experience and knowledge with representatives from the LACs and the NDIA. This was a mutual exchange of sharing and listening so as to gain a better understanding of our experiences with these organisations in the transition to and working with the NDIS and partner organisations. Both sides expressed having gained better insight into what would lead to improvement in how the NDIS is implemented. A system informed by a range of perspectives has the potential to become a more comprehensive, practical, accessible, and effective system.

The external stakeholders who participated in the Co-Design group also felt that Co-Design was, is, and will be essential to informing how we fund and coordinate disability supports, services within the policy and procedures framework adopted by the NDIA and disability sector. According to Carla Stagles, Team Leader from APM:

“In order that supports really be what people with disability need and want – people with disability themselves have to be part of the development of solutions from the beginning.... Co-Design is more than valuable – it is essential. Would Toyota make a car and never do any research on what consumers are likely to buy or what they need?”

Stakeholders noted the empowering nature of Co-Design went both ways, stating “...we have more strength and power to change things together than we do alone”. Both stakeholders and group members noted that an ongoing role for Co-Design within the NDIA would be instrumental in ensuring that the scheme is truly representative of what people with disability want and need.

5. NDIS Transition and Interface Issues

As the issues that were brought to and raised by the Co-Design team over the nine months of our existence were examined in-depth, and in collaboration with the above-mentioned external stakeholders, we discussed what they reflected across all stages of NDIS process. We discussed issues around eligibility, applications, pre-planning, planning meeting, plan’s approval, implementation of plan, and annual review process. We identified problems surrounding NDIS accessibility having a high associated cost that impacts some participants much more than others, greatly impacting the level of choice and control some could have over their plans.

The accessibility of NDIS language, policy and procedures, required high-end user knowledge for participants and providers alike. For example, participants have to learn what service providers are and how to negotiate with them and navigate their procedures, know about the existence of and the distinction between NDIA managed plans, shared or plan management options, and the costs and benefits involved with self-management. Participants have to learn about their reasonable and necessary based funding, what that means in terms of the NDIS price guide, learn about what Support Coordination is and what it can be, learn about assistive technology, health vs. disability, employment pathway options, and that isn't even touching on the complexities of how the NDIS impacts the traditional understanding of the role of therapy. How to manage transport has presented a great many headaches across the board, and generally speaking these things are expected from us with no room for grace.

This is unreasonable; participants are effectively forced to become experts in a complex system while the system is not made to listen to and adapt to participants. In order to resolve this, we need to be heard more than told and Co-Design throughout the scheme on all levels would ensure that our voice is there at the ready for any issue of significance.

5.1. Need for respect for the right to privacy of people with disability

Respect for participant's means that we say we feel respected and heard and that we are well supported in our NDIS journey. When power differentials exist, respect must be prioritised for the participant, not weaponised by the agency, such that any perceived disrespect from participants to agency members or the agency must be taken as a symptom that the participants' needs are not being well met by the agency. Throughout the participants journey and the operations of the NDIS, there must be consistent checks to ensure that the agency is being supportive of the participant. If a participant makes an error, it should be seen as a growth opportunity, not sanctioned in terms of loss of choice and control. This is crucial to the integrity of the scheme.

People with disability have a right to control our own personal information. Information relating to participants held by the NDIS should be accessible to participants without resistance, including Freedom of Information requests, such that all information about us is well managed, readily provided, free from redaction. NDIS practices must be consistent in this respect, and the NDIS must be held accountable for the information that it requires, collects, and stores. The NDIS must develop transparent guidelines around how to handle participants' information.

Particularly, there needs to be accountability around any risk factors involved when requiring compromising information from us by identifying what circumstances would require compromising information to be submitted by

participants, recognising the impact of this kind of intrusion and invasion, and taking responsibility for identifying information that is indicative of a duty to act. When it comes to the mandatory reports at annual reviews, consideration for the associated frictional costs to our lives and therapeutic pathways of requiring these reports must be balanced with how that cost is turned into value for participants in the planning meeting.

The NDIS also needs to develop transparency surrounding how the information will be acted upon. The NDIS must take responsibility for acting on the information that they require in a way that benefits the participant and does not introduce avoidable harm, in consultation with a participant and a participant's nominated support network, including information that is presented to the NDIS that is submitted by participants. That is, if a participant or member of a participant's support network submits information that could put a participant at risk of harm or indignity, the NDIS must take care in how it manages this information.

Importantly, the NDIS must acknowledge the participants' rights and primacy when it comes to maintaining the integrity of any information that is required, submitted, generated, and stored about us.

5.2. Need for respect of individual rights to freedom of expression, self-determination, and decision-making

An overarching principle and attitude within the NDIA should be that the NDIS participant is the expert in our life and disability support needs. As such, it should be common practice that a draft plan is provided to participants, to view and provide feedback, in order to prevent unnecessary reviews for minor adjustments. Participants should sign off on a plan before it is valid in order to preserve the integrity of us being the experts in our lives. Improving upon quality of life according to the participants and relevant supports needs to be the focus of any funded plan.

Many participants highlighted that the notion of capacity building with the view of support reduction over time did not reflect how they viewed capacity building, nor how they would go about designing a reduction in support. For the NDIA to ensure respect for people with disabilities, the operations should model the highest level of respect for individual needs. To minimise the conflict of interest introduced when informal and formal supports are the dictators and validators of a participant's support needs, participant self-advocacy needs to be honoured, promoted, developed and preserved so that participants move from being subjected to the seemingly arbitrary decisions made for them by the NDIS, toward being serviced by the funding body responsible for making sure we are well supported in our disability support needs. We need to have easy access to

initiate conversations with the NDIA, and the NDIA needs to operate in such a way that it is safe to challenge the decisions made.

5.3. Need for empowerment of individuals in terms of choice and control

People with disability have a right to know what our rights are.

Case example: A participant was not informed at their Planning Meeting of their right to self-manage and shared management was put in their plan without a discussion on management options during the planning meeting. In this case, the participant should have been 1) duly informed of their options; presented with the advantages and disadvantages, and responsibilities associated with self-management and shared management, and 2) been given the right to make a well-informed decision.

And these rights must be maintained within the integrity of the scheme:

Case Example: Jan 2019 was my first NDIS plan. It was not a good plan at all, basically a bodged rewrite of my earlier WA NDIS plan so I started the process of reviews trying to get changes made. In July 2019 after a successful review (eventually) I got some increased Therapy funding and some Support Coordination funding. Just before Christmas and with a great deal of work by the support coordinator and myself, we lodged a "proper" Change of circumstances review which after about a dozen interactions with NDIS they accepted my plan didn't reflect my circumstances so I waited another 2 months for a review. Plan 3 came in April this year and was pretty much what I was anticipating except they changed my Support Coordination from Self-Managed to Agency managed which meant no longer being able to use the support coordinator that helped so much in changing my plan. So another review was requested to make the 30 second change to one line item. But they failed to do it within 30 days despite requests from myself, the LAC and the Support Coordinator. After the 30 day limit expired, another Change of Circumstances review was generated which was finally acted on yesterday.

4 plans in 17 months and a huge amount of stress. Sheesh, who said the NDIS is easy

There are many rights that participants are generally not made aware. It is the responsibility of the NDIA to confirm that individuals and their families know and

understand what their responsibilities and obligations are in respect to the NDIS and where to find information relative to the NDIS. This is not always accessible to all applicants depending on their cultural, linguistic and social demographic and access to online content, and where it is not that must be the priority to remedy. Participants must be informed of their right to negotiate, and this begins with the NDIS plan construction and extends into the right to negotiate with providers to make one's own Service Agreement and this highlights the importance of funded support coordination to assist us in knowing and negotiating where we require. Many participants identified Support Coordination as something one is entitled to as a right. Without knowledge and information, informed choices are not possible hence participants are at a disadvantage.

The NDIS system must not have the impact of disadvantage, and yet many participants have expressed that it is not "user-friendly". The complexities of funding - multiple buckets and lines of funding and knowing where everything fits; frustration associated with not being able to get the information needed when calling the NDIA (after waiting a very long-time on hold before speaking to someone); unresolved portal issues due to no-one from the NDIA understanding what is causing the issue...etc. are just some examples.

Case Example: A call to NDIA was disconnected by no fault of the participant however the person she was speaking to did not call her back to resume the phone call so the participant had to call again and explain everything to a new NDIA staff member.

Another way that the NDIS is not user-friendly is NDIS Language, Policy & User Knowledge. Further clarity is needed for the NDIS to understand people rather than expecting us to understand a new language. We should be safe to come as we are and competently and confidently navigate our way through the system because it is built for us.

Participants should be consulted with regards to language and terminology employed by the NDIS. For example, it has been found that people with a disability prefer "mental impairment" as opposed to "psychosocial" for which participants felt invoked notions of "craziness" and reinforced societal stigma. More clarity on what is "reasonable and necessary" with examples and clear protocol and feedback to participants is required. The NDIS is also not user-friendly for people of CaLD (Culturally and Linguistically Diverse) and ESL (English as a Second Language). The funding and options provided to people with disabilities means nothing if there is not the infrastructure to ensure people are equipped with the knowledge, skills, and capacity to implement them and this should be balanced with forgiveness when we misunderstand. There is a need for culturally appropriate and sensitive procedures and practices to be adopted. For example, it has been reported that many participants, particularly people of CaLD background, do not know how to employ our own support workers. There

are many examples of Aboriginal people with disabilities being in the criminal justice system when NDIA support could have prevented this.

Barriers to accessing NDIS need to be addressed or removed to ensure potential participants are empowered to make choices and exercise control. These barriers are significant where financial capacity is limited, indicated by the need for a fixed address and a well-documented diagnosis. This criterion precludes individuals who are homeless, transient or may never have been to a doctor, those who are trapped in domestic violence, as well as individuals in settings such as institutions akin to prisons and hospitals, where the focus is re-entering the community, not providing diagnoses or reports. If people cannot afford assessments and reports, we are prevented from accessing the NDIS. Furthermore, there is a discrepancy in terms of the quality and detail of reports provided by the public health versus private health sector. Thus, the NDIA is perpetuating systematic discrimination, and reinforcing the cycle of disadvantage and poverty for those who experience it whilst accessing the NDIS. To remedy this would be to bring about significant change for our communities.

Empowerment would require reframing a system to operate consistently and wholly from the premise that people with disabilities are the experts of our own lives. This can't be just something we say. For example, with respect to the determination of funded supports in one's NDIS plan, in most (if not all) cases the individual comprehends more than the NDIA planner in terms of the support, services and equipment we need. It needs to be recognised that the NDIA planner employs their qualification and professional knowledge and experience when crafting an individual's plan, but lacks the specific erudition to the individual's case; there must be that respect for, and not resistance made to participants' requested supports, else there will be deficiencies in the effectiveness of funded supports.

That is, we must re-orient the processes and how they impact the culture of interactions between people working for the NDIA and participants. Currently, the process comes across as *adversarial*. The premise of "proving" your disability, impairment and support needs to gain access to the NDIS and to continue to prove deficit and dysfunction to be given adequate NDIS Plans year after year in deficit-focused planning meetings and reviews contributes to the adversarial nature of the NDIS.

The NDIA's sustainability mandate appears to be inappropriately applied to reducing expenditure on a plan-by-plan basis. This propagates the adversarial dynamic between the NDIA processes and imposes upon participants. For example, with every NDIS review participants experience anxiety and angst due to the uncertainty of what supports will continue to be funded and whether supports they rely upon will be arbitrarily cut without deliberation or negotiation.

Most concerning, participants have indicated being made to “play down our abilities” if we don’t want our funding cut. This is widespread and bears significant focus for reform if we expect people with disabilities to live to the best of our ability. There is consensus that participants feel that, were we to convey our strengths, gifts, and positive abilities, we may be perceived as not needing support. The primacy of an individual’s funding requirements should not be centred on what we can’t do, but rather what disability support needs are required in order to do the things we aim to do. This concept is met with strong resistance due to sustainability concerns, but without it we cripple participants’ abilities.

There needs to be acknowledgement of the fact that the NDIS disrupted the disability services and support sector, and that this disruption introduced frictional costs that we bear disproportionately, so keeping funding to the minimum possible amount means that we face significant risks where we are meant to be supported but are not, so the provider-focused transition payments must be mirrored but characteristically distinct within individual plans. Whereas providers were acknowledged to have significant costs of transition, so do participants in the form of not being able to optimally use our funding. Rather than cutting successive plans when our plans are not fully utilised, we should have just-in-case funding put in place to prevent costly disruption to our supports due to mismatches between the market and our needs. For example, if we are made to deal with inconsistently supplied supports, we have to retrain and retrain and retrain our support workers. When a provider fails us, we must seek out suitable alternative providers, and this is a highly costly endeavour in terms of research, investigation, and emotional labour. Never mind actually using our supports to get on with our lives. Sustainability concerns must only be implemented systematically, because as should be clear, not doing so can paradoxically result in increased support needs in individual plans.

A working relationship between the NDIA and participant which recognises our inalienable right to put our strong suit forward would allow participants to live our best lives. Peer programs of mentorship which are consistent with this model could assist the transition from the deficit model to the strengths based model so that people felt safer to be strong without fear of losing that which allows us to be strong. Peer council from established and stable participants who have familiarity with the NDIS would benefit those of us who are scared in a way that could model how to self-advocate effectively rather than having to seek out an advocate to speak on our behalf. This would be especially useful, in the pre-planning stages, as lived experts coach newly formed agency. It seems as though Co-Design would produce these kinds of participants who could assist people who don’t know how to say the words that meet the criteria, despite having real and legitimate disability. It is of note that Peer support may be especially beneficial for people who have developed mistrust due to systemic trauma. This peer-support for self-advocacy produces personal agency which

would assist independence for us as we navigate through other systems such as education, health, and criminal justice systems. The ability to communicate the impact of our disability effectively, in a way that preserves our dignity and is well met with our integrity, particularly within challenging settings, is crucial to our citizenship, and yet it made harder by the current NDIS operations. This is a critical focal point for positive change.

5.4. Need for honesty, integrity, clarity, and transparency in the NDIA - its system and processes

There is a great need for honest and transparent processes within the NDIA. The access process is flawed due to the application process. The process is not transparent and does not provide unsuccessful applicants the feedback to assist us to re-apply successfully, if we in fact meet the criteria but have simply failed to present the criteria in a way that satisfies the requirements of the scheme. This deprives viable participants of supports we are entitled to if we do not persist with re-applying. This lack of communication and transparency also occurs post planning and review meetings.

Case Example: A participant went to a review meeting with APM and never heard from anyone afterwards, nor was there funding or a plan on the portal. The participant then had to apply for an emergency review, waiting a total of 3-4 months for a new plan during which the participant received no funds from the NDIA.

We often do not understand why things are being granted or refused in our plans and this leads to large discrepancies between what the perspectives of participants versus the perspective of the NDIA on what constitutes “reasonable and necessary”. The process should encourage two-way growth and development especially as we are implementing a new scheme, so we are all still figuring things out and we need to be heard to be understood. For example, most participants agree that, broadly speaking, psychological counselling is reasonable and necessary given the comorbidity of mental health issues and disability, however far too often it is resisted and not funded by the NDIA. Ironically, the imposition that the NDIS places upon participants is frequently cited as the reason for the need for psychological support. This highlights how important it is to avoid restricting supports by diagnosis or class. Another example is participants being expected to finance Support Workers’ mileage when this constitutes part of the support they need. There are also many participants being refused ways to spend their funding by NDIA Plan Managers and external Plan Managers, despite the requests being aligned with their goals and supported by therapist reports and the plan manager’s role being limited to financial intermediary.

Another area of the NDIS lacking transparency and accountability and instigating frustration and increased vulnerability from us is the lack of timeframes for resolving complaints, responding to requests for urgent reviews, and change of circumstances. The Co-Design group deemed it important that the NDIA establish clear timeframes and streamlined, supportive pathways, to give participants an expectation that matters will be addressed and resolved and that it will be done by a certain time period. Urgent reviews are urgent for a reason usually to with participants being at risk. Requiring our vulnerability is unfavourable for good outcomes, therefore urgent reviews should be attended to thoroughly and promptly. A system which is transparent about response timeframes and accountable to ensure positive outcomes is also one of integrity and one that can be held accountable when they do not deliver.

In the opinion of most participants the NDIA lacks integrity. There is a perception that less supports than participants need will be provided in a plan and more reports and compromising information is required than is needed to ensure positive outcomes for participants. Participants, families, therapists, and service providers are counteracting this by asking for more than what they feel they need in their plans. It is also widely understood that if participants do not spend all the funding in their plan, it will not be available in the next plan, and/or they may be disadvantaged in some way. The KPI culture of the NDIA does not espouse the values of integrity, transparency, and respect, nor does it promote safety and quality. This perception is easily shifted by simply reframing the internal structure to ensure that people are being supported and are not unduly encumbered. Another example where integrity is amiss is the 10% increase permitted by NDIS during COVID-19 which we report is being absorbed by services rather than going to our employees and yet it comes from our plans. This 10% increase is not being automatically reimbursed to our plans, and this creates a situation where we are being sacrificed for the sake of the service providers.

5.5. Need for safe, fair, and quality processes and services

A “safe, fair and quality service for all” means that NDIA and the partners implementing the scheme must continually be accountable to a measure of experience and expertise. The NDIA must have exemplary processes procedures and have openness with the sector to ensure that we are all setting and challenging the standards for the entirety of the disability sector as well as how society at large is equipped to engage with us. There needs to be a development of resources available to planners and partners and performance indexes must not be set on plan per time interval, but rather set to how well the plan reflects the various contextual factors which may require specialist knowledge or understanding. For example people of CaLD (Culturally and Linguistically Diverse) and ESL (English as a Second Language), people of Aboriginal and Torres Strait Islander descent, people with dual diagnosis or comorbidities such as disability and complex medical needs, youth in aged care or mental health

diagnosis/es, and various familial circumstances will likely require a holistic approach that is experimental, not prescriptive.

Participants report there to be an assumption that they have a carer or informal supports, but many of us are our own carer. This is not always due to a lack of informal supports, either. Recognition for our right to independence is important, but even more important is identifying those of us who truly require that our plans reflect our divergent needs to ensure viable stability. Parents with disabilities who have children, and parents with disabilities who have children with disabilities are at increased risk of loss of autonomy in the current NDIS structure, and this must be addressed to provide the kind of certainty and stability that will allow for us to be just as valid as other parents, to be able to partake in our kids' activities and to have more full lives than simply managing our disability and NDIS pathways.

Additionally, the safety considerations of disabled parents and how support affects our children requires consistency in our supports, and that requires certainty and adequacy in our funding. And the risk to our sense of being a fit parent of even what may seem like innocuous inquiry requires that there be solid cultural development of how to ensure that we are cherished members of society who have the NDIS backing us up, make sure that we are supported to live safely, and that our supports are safe for our children. Sensitivity to the higher support needs must be well understood in this arena, as the pressure to work towards less dependency on formal supports is especially brutal for those among us who have no one to turn to, and who are already under far too much loading. This sensitivity must ensure that the burden of self is never pressed onto us, but rather that we are well supported so that we can be proper caregivers to ourselves and our children.

Support for carers of children with disabilities is not taken into consideration in NDIS plans which negates an ecosystem approach to individuals and the plethora of research indicating that parents of children with disabilities are more prone to stress, health and mental health issues. Supports such as respite are rarely funded, yet the quality of life for a child with a disability is intrinsically linked to its parents' quality of life, health, and capacity. The previous system within Western Australia was much more holistic in approaching the quality of life for the family and individual with disability in terms of the supports needed. Consequently, the transition to NDIS has been anxiety-inducing and stressful for families and carers. If the NDIS will not include carers' needs in individual plans then there should be a pathway for support for carers within the scheme.

Individualised, holistic services for people with disabilities and better integration and strengthened collaboration amongst government, community services, private sector, and families is essential to ensure better outcomes for all. Participants with dual diagnosis of disability and mental health, and/or aged care

and complex medical needs, are increasingly vulnerable because Mental Health and Health services are stating supports should come from NDIS, and vice-versa and thus the burden is shoved onto people who are already overtaxed and who lack the capacity to absorb the strain of this kind of denial of service over critical supports. This is similarly occurring between NDIS and both the Departments of Housing and Aged Care. Examples of gaps in services are people with a disability discharged home from hospital and not having their additional recovery support needs met by either NDIS-funded supports or outpatient hospital and health services, for example medication administration. People who qualify in terms of their disability for NDIS but are in the aged care bracket of over 65 years of age are also neglected because aged care is categorically different than disability support.

Case example: A female who has arthritis and had rods surgically placed in her toes but due to an error on the part of the surgeon, had to have her foot amputated. This qualifies her as having a permanent disability but given she is over 65 years of age, supports can only be accessed through “My Aged Care” which are often not adequate for disability-related support needs.

NDIS and other government departments and services need to collaborate and establish a clear understanding of roles and responsibilities, in terms of what they do and do not provide with regards to funding and services whilst ensuring no gaps in service provisions. The focus needs to be rightfully on the participant and their needs, not “in-house fighting” around distinctions between disability, health, mental health, housing, and age.

Quality and safety of services would operate from a premise of what supports would improve a participant’s quality of life, not a premise of future reduction of supports. There are many case examples where people are told by planners from the NDIA that at their next review, it is expected they will receive less capacity building supports. It can only be deduced that this operates on a presumption that a level of capacity will have been built which contradicts the eligibility criteria for the NDIS that a participant has a **lifelong** disability, thus being of a non-rehabilitative nature and requiring **lifelong** support. The reduction of needed lifelong supports jeopardises the safety of participants, is responsible for unnecessary stress, anxiety and deterioration in health and does not ensure a quality of supports. There is also a consensus that people feel pressured to spend all their money, for fear of receiving less in following year. Yet this does not account for exceptional circumstances, or the fluctuating nature of disabilities with managing their conditions, sickness including hospitalisations may impact the expenditure of funding on supports. There is also an expectation of dissatisfaction with NDIS plans, with participants holding a preconception that they will receive less funded supports than they feel they actually need or were currently receiving via other state-funded services and avenues before accessing

the NDIS. And there is no acknowledgement for the natural capacity building that comes about from having quality therapy rather than assessments, and being well supported to do things that we can do, rather than being made to do things that are the very definition of too hard.

High quality processes and services are underpinned by consistency. Many inconsistencies are apparent within the NDIA and associated services and therefore the quality is not high. These inconsistencies are a common grievance experienced by participants. The only source of inconsistency in funding should be the variability of individuality, and yet we are finding that people experience inconsistency in what we are told and how we are treated.

There is a common perception that a participant's satisfaction with their plan "comes down to the luck of the planner they receive". Participants have noted a lack of knowledge possessed by employees of the NDIS around disability in general including core components or types (mental health, vision impairment, chronic fatigue, fibromyalgia, to name a few) resulting in differing eligibility and plan outcomes amongst different employees viewing or reviewing each case. As such, more comprehensive training packages for planners is recommended to reduce inconsistencies arising from different levels of planners' expertise in the disability field with consideration that this must not toss out the baby with the bathwater. Consistency must come from best practices, not by rigidity in form. Moderation processes are recommended to improve inconsistencies across plan outcomes for participants. With regards to shared management, inconsistency is being experienced amongst plans and outcomes for various people and various conditions. More specific standards of practice need to be asserted across plan managers with moderation processes to ensure consistency.

To safeguard quality, there is a formidable need for more efficient and responsive processes. Prompt action is required for concerns that potentially impact the quality and safety of supports provided to participants. With regards to efficiency, training, and moderation processes of NDIS planners and staff is to ensure consistency of information and decisions around access to NDIS and funded supports in plans.

Case Example: An individual tried on three occasions to access NDIS for vision impairment and was deemed eligible for the scheme on the third attempt. Each time the individual had submitted the exact same application, and no further information was ever requested hence demonstrating discrepancy between assessors.

A feedback mechanism based on the experiences of participants is essential to provide an accurate evaluation of the NDIS, as demand for the scheme does not

equate with satisfaction. It would be valuable if this feedback formed part of the KPIs to help balance the prioritisation of speed.

To guarantee fairness, funding should consider disadvantages and inequalities amongst the general population, for example participants living remotely as opposed to those living in the metro area. With respect to transport allowance, it needs to be individually tailored; for example, participants living in remote areas need to be accorded a greater transport allowance to account for the larger distances covered to access the community and services. This also needs to be considered regarding travel costs incurred for therapists to home visit. Participants should also be allocated a Local Area Coordinator from their nearest office.

Case Example: A participant who has visual impairment and lives in Perth's Northern suburbs being allocated a LAC who works at the Northam Office (approximately 100kms distance) and needing to use taxi service both ways.

Safety needs to be paramount when arriving at travel allowances. Taxi fares are being removed and/or reduced in plans and yet some participants do not have the confidence or feel safe to travel using public transport without a Support Worker.

Lastly in terms of safety, the following alarmingly speaks for itself - there has been a profound increase in suicide attempts since the introduction of the NDIS (according to COMHWA).

5.6. Need for a strong and viable market for disability supports and services

Funding for supports does not translate to participant's being supported without a strong and viable market. Participants have limited choices in WA with the current market, which is even more so for those living in remote regional areas. Without a strong market, there is an inherent power imbalance between service providers and participants because participants are ultimately at the whim of whatever is available. This can also lead to limited (or no) accountability for the quality and ethics of some services. In some cases, charges have not been explained properly to participants resulting in their funding being exhausted early in the scheme of their plan's duration. Some services are also known to claim administrative work at the same rate as therapy rate which is unethical.

There are several gaps in the market, particularly in cases where different psychosocial issues overlap in an individual's life. There are also gaps created by the NDIS pricing model where pre-existing services are no longer financially viable, for example community centres for people with mental illness. This is where the State & Federal government need to identify and examine these gaps

and problem-solve as to how critical support needs can continue to be provided within this new scheme. Also, the NDIS pricing model has caused an increasing inflexibility of agencies and therapy services. Services have been re-examining their provision based on what is considered “financially viable”. Group therapy and supported social groups providing community access and social connection are diminishing so that there is only the option of 1:1 therapy and community access. However, this does not cater to the imperative basic need of social connection for which many people with disabilities need support. Nor does it cater for the need to acquire and practice skills such as social communication with peers. Given this is the case, the NDIA needs strategies regarding integration of people with disabilities into society, without consideration of cost or pressure on participants to do this themselves without necessary supports.

Inflexibility is also reflected in Service Agreements in which clauses are thought to be “aggressive”, “patronising” and supportive of a “profiteering” nature by participants. For example, service agreements with unrealistic cancellation notices required. This is particularly unfair for participants for whom fluctuating health is synonymous with their disabilities. This seems punitive of the disability itself and hence the person with the disability and is another example of a lack of understanding of disability in procedures and policies.

Information about the existing market needs to be readily available and accessible to participants to assist with self-determination. At present, an awareness of the types of services available (especially mental health and wellbeing) is lacking. Support Coordinators assist participants to find supports, but not all people have Support Coordination funded in their plans. Even when they do, support coordination inadequacy must not be an excuse to shirk responsibility or deny a participant the funding they require. It appears that even Local Area Coordinators are not fully informed of the market. It is evident that the sector needs a lot more development in order to ensure competency and proficiency of services.

6. Recommendations to the NDIA

After exploring the above-detailed issues in-depth, the Co-Design group deemed the following issues imperative for improvement. The following outlines the recommendations for functional, usable, and sustainable change and improvement based on these issues to benefit most participants and service providers’ experiences of the NDIS.

6.1. There are significant barriers to accessing the NDIS

Recommendations for Improvement:

1. Remove the need for a fixed address to apply for access to the NDIS. Alternatively have the option of putting the fixed address of a family

member, friend or service provider, and/or an email address or mobile phone number.

2. Provide funded assessments for people applying to the NDIS who do not have sufficient supporting evidence.

Benefits to People with Disability:

1. More people with disabilities would gain access to the NDIS and be deserving and appropriately supported.
2. People with no fixed address, once deemed eligible for the NDIS, may be more able to obtain a fixed address once their disability support needs are met.

Benefits to Service Providers:

1. Service Providers would benefit from a greater demand for services.
2. Service Providers would have the opportunity to specialise according to the unique needs of certain populations.

6.2. The NDIS is not user-friendly

Recommendations for Improvement:

1. Peer Support employed by NDIA, possibly enriched by a pool of long term Co-Design placements, to support people with disability (PWD) apply for access and with pre-planning, planning meeting, familiarisation with the NDIS and implementation of their plan.
2. Clear communication lines established between people with disability, service providers and the NDIA.
3. NDIS language, policy and procedures reviewed to make more accessible to people with disability and cater to all cultural backgrounds.
4. Funding buckets of lines of funding to be simplified, for example all funding to be claimed from “one bucket”.
5. Support Coordination to be funded in all first NDIS plans.
6. NDIA equip or fund the equipping of people with disability with self-advocacy skills.
7. Communication from the NDIA advising of upcoming reviews with web links to recommended preparation to be taken by participants, for example inform therapists and ask for reports, consider whether you would like Support Coordination, reflect on how you have found shared or self-management and what you would like for the new plan...etc.

Benefits to People with Disability:

1. People with disability would be equipped with knowledge, skills, and capacity to understand the NDIS, operate within it and self-advocate.
2. People with disability would be supported relationally with Peer Support and/or Support Coordination to familiarise themselves with the NDIS and implement their plan to ensure best outcomes.
3. With a more accessible and user-friendly system, more people with disability would receive funding to support their quality of life and achieve their goals.
4. A more user-friendly system with simplified funding procedures may encourage non-NDIS providers to become NDIS-registered, thus increasing the market and choice for people with disability.
5. With simplified funding procedures, self-managing would be less anxiety-provoking. Decreasing the deterrent to self-managing would enable more to self-manage and receive the benefit of increased choices and flexibility to suit their individual needs.
6. Were more people with disability to self-manage, the competition would be increased meaning NDIS providers would have to increase their quality of service and competencies to match that of non-NDIS providers whom more people with disability would have access to utilising.
7. People with disability would feel more supported by the system with the delivery of timely, relevant information.

Benefits to Service Providers:

1. Service providers would become more competent and provide more quality of service.
2. Service providers' service provision would be able to align more with the funded goals in people with disabilities' NDIS plans were people with disability to be adequately supported by Peer Support and/or Support Coordination for matters relating to liaising with the NDIA, the NDIS portal, policies, procedures and process.
3. Service providers would be able to access NDIA with more ease and obtain timely, accurate and relevant information.
4. Service providers providing shared management would be able to claim more efficiently, allowing more time for direct service provision.

5. Service providers would be able to better understand the needs and wants of people with disability, were the former upskilled in self-advocacy.

6.3. The NDIS lacks transparency

Recommendations for Improvement:

1. NDIA establish clear timeframes to give participants an expectation of when their matters will be addressed and resolved.
2. NDIA to provide clear feedback when people are deemed ineligible for the NDIS and with regards to funding decisions and claim rejections.
3. NDIA to be transparent about feedback received and active responses to feedback.
4. NDIA to make an accessible, transparent policy regarding privacy, confidentiality, and Freedom of Information that is respectful of the agency's role in servicing and supplying funding to people with disabilities in a way that is with integrity to our vision of self.

Benefits to People with Disability:

1. Clear timeframes will give people with disability a sense of security, foster faith in the NDIA, and empower them to keep the system accountable if, and when it does not deliver.
2. Clear feedback regarding ineligibility, funding decisions and claim rejections will enhance participants' knowledge of the system and hence empower them, as well as give them the choice to re-apply for access with the information required, appeal decisions they are dissatisfied with.
3. Transparency around feedback and response will improve the quality and integrity of the NDIS, from the perspective of participants, and enhance participant choice and control with the option of providing feedback potentially resulting in improvement.
4. An accessible, transparent policy emphasising our primacy over our personal and compromising information and how it is handled and utilised, which highly regards our privacy and confidentiality, and reduced resistance from the Freedom of Information branch will likewise increase participants' sense of control.

Benefits to Service Providers:

1. Improved relationships with participants to support us with deference respect that it is our lives at stake would clarify the role and would reduce unnecessary invasion in the name of duty, which would reduce the conflict

of interest in having to document things that may not be in the best interests of the client.

2. Clear timeframes will allow service providers to advocate on behalf of people with disabilities, with our consent, with a confidence in timeframes which will enable them to plan accordingly.
3. Transparency around what information is actually used and what has been of no significance will also enable service providers to develop a greater knowledge of the NDIS which will result in greater consistency regarding information provided across the sector.
4. The development of a transparent policy regarding privacy and confidentiality would assist service providers to adopt similar, also resulting in consistency across the sector.

6.4. NDIA Staff are inadequately qualified, trained or experienced in working with people with disabilities and there are significant inconsistencies across decisions regarding access, plans and reviews, and information provided

Recommendations for Improvement:

1. NDIA to employ people with relevant qualifications such as Allied Health Professionals, people with lived experience of disability and or substantial experience working in the disability sector.
2. More comprehensive training packages for planners is recommended to reduce inconsistencies arising from different levels of planners' expertise in the disability field.
3. Moderation processes are recommended to improve inconsistencies across eligibility for NDIS, plan outcomes for participants and amongst plan managers.
4. NDIA to provide training and efficient information dissemination to the disability sector (NDIA employees, carers, support workers, agencies...etc.), other government Departments and related services such as GPs and hospitals so that everyone is receiving consistent, accurate, relevant information.
5. As much as possible, participants to have the same planner for consistency and relationship (unless a different one is requested by the participant due to personal issues).
6. NDIA to employ Peer Support workers (people with lived experience with disability and the NDIS) to support potential participants to apply for

access to the NDIS and participants with pre-planning, plan meeting, implementation of plan and reviews.

Benefits to People with Disability:

1. There would be less cause for confusion, as People with Disability will benefit from consistent, accurate and relevant information from all stakeholders in the disability sector.
2. Having the same planner would alleviate the burden of participants (and/or their family and carers) needing to “retell their story”. Were a strong rapport and trust to be built between a planner and participant, this would be of significant emotional, psychological, and practical value to the participant.
3. Consistency will assist participants to build a trust of the NDIA - the information provided, and decisions made. A reliable system will also alleviate a lot of anxiety, concerns and fear experienced by participants in the current state.
4. Peer Support Workers would provide a trustworthy, empowering relationship for participants to learn to navigate through the NDIS. In Mental Health, the utilisation of Peer Support Workers has improved hope, increased self-esteem, and improved advocacy skills in the people they support.

Benefits to Service Providers:

1. They will be more confident in the NDIS and confident in their delivery of information to participants.
2. Frustrations towards anomalies in plans and significant funding cuts after reviews...etc. will be reduced with increased consistency resulting from enhanced training and moderation of planners.
3. More consistency across Plan Managers would enable a reliable working knowledge of how Plan Managers operate, what is considered “reasonable and necessary” ...etc., which would benefit service providers and participants.

6.5. At present services are not individualised nor holistic and there is a lot to be desired in terms of integration and collaboration amongst government, community services, private sector, and families

Recommendations for Improvement:

1. NDIA to strengthen existing collaboration amongst government, community services, private sector, and families.

2. NDIA to collaborate with state government departments to establish a clear understanding of roles and responsibilities, in terms of what they do and do not provide with regards to funding and services whilst ensuring no gaps in service provisions.
3. NDIA to provide or fund training for carers and people with disabilities to understand the roles and boundaries of different services such as the NDIA, and Departments of Health, Transport, Housing, Education, Mental Health and Aged Care.

Benefits to People with Disability:

1. People with disability would feel their needs are catered to, rather than discovering what needs can be met and cannot be due to policies, boundaries, and limitations of services.
2. People with disability would be supported according to their needs, rather than according to what can be met by current boundaries and limitations of government departments.
3. Participants and their families and/or carers will know how they can be supported by different State Government Departments, which will empower them to make decisions and access the services and supports they require.

Benefits to Service Providers:

1. Increased collaboration would create good working partnerships amongst the sector and co-existing departments, resulting in better outcomes for participants and service providers.
2. There would be less cause for confusion and frustration, as service providers would know how the different State Government Departments operate and will benefit from consistent, accurate and relevant information from the NDIS and Government Departments.

7. Conclusion

By using the Co-Design process the Co-Design team have outlined the NDIS transition and interface issues experienced by NDIS participants and make recommendations for improvement to the NDIA, it is hoped that these recommendations will be acted upon to improve the individual experiences of people with disability as NDIS participants, and promote better outcomes for all. It is also the strong belief of the Co-Design group that Co-Design should form an integral part within the NDIS. A fixed role for Co-Design within the NDIA would:

- 1) Rightfully acknowledge people with disabilities as the experts of knowing their lives and knowing their own needs;

- 2) Enable the active participation of people with disabilities in decision-making, and
- 3) Implement continuous improvement in the Scheme and Disability sector and thereby support better experiences and outcomes for all NDIS participants.

8. References

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people with
disabilities
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National Disability Insurance Scheme (NDIS) Transition and Interface Issues

Systemic Advocacy Project Report and Findings

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Systemic Advocacy Project Report and Findings

Introduction

As part of the Disability Coalition, PWdWA undertook the lead in the systemic advocacy project “**NDIS transition and interface issues**”. The focus of the project was to research and address the systemic barriers that have been identified from the transition to NDIS in WA including issues with the National Disability Insurance Agency policy and practices and other departments/ mainstream agencies interface with the NDIS.

The project was completed over an 18 months period and included research and analysis of statistics provided by advocacy groups across the state which identified the increase in the issues arising from the transition to the NDIS in WA. Extensive engagement with individuals and families was undertaken across WA both in metro and country to gather feedback and identify issues and concerns as people transitioned into the NDIS. This also involved a running survey on the PWdWA website that gathered feedback from individuals, and the community on their experiences of the NDIS, there were over 350 responses to the survey.

As part of the project a Co-Design group of people was formed representing a broad range of disability and lived experience. The group looked at issues that were identified about the NDIS transition and co-designed recommendations and solutions to address these. The group met on a monthly basis and then weekly via zoom during the COVID19 restrictions. The Co-Design groups’ work has been used to inform submissions, reports and opportunities for feedback to relevant parties in the NDIA, Joint Parliamentary Standing Committee on the NDIS, the Minister and feedback to NDIS and the NDIS Partners. In December 2019 representatives from NDIS and the NDIS Partners were invited to be part of the Co-Design meetings and continued to be part of the regular meetings until project end in June 2020. This provided the opportunity to discuss and understand the issues and experiences being raised by families and individuals and be part of problem solving. The Partners and NDIA staff involved passed on feedback to their management.

This report highlights the disparity between the General Principles which guide the NDIS in the NDIS Act, and what the experiences have been of some participants in the National Disability Insurance Scheme. Over the 18 months it has been clear that some of the early issues identified by people have been addressed and this was particularly evident during the changes adopted because of COVID19. There are still common themes that have yet to be addressed; these will be highlighted in this report and demonstrate the inequity, power imbalance and areas that contravene the general principles of the NDIS Act.

Engagement

The project objectives were to engage with people with disability, peer groups, family, advocacy groups and the community, and gather feedback to identify the issues that are contributing to the barriers in the NDIS rollout and transition in WA. A variety of mechanisms were used for engagement including:

- A survey on the PWdWA website
- Meetings with peer groups across the state across multiple areas
- Focus groups with specific topics
- Interviews and feedback from key stakeholders
- A survey of advocates
- Meetings in person and by phone in regional areas
- A Co-Design group for recommendations

Survey

Over 350 people responded to the survey, with 35% being individuals with disability, 45% a family member or informal carer supporting an individual, and 20% being a family member or friend.

Diverse representation was achieved with 5% from regional areas, 4% identifying as Aboriginal, and 9% of people with English as a second language. 12% of people who completed the survey said they needed support to communicate.

We asked people where they were on their NDIS Journey and 16% were in the process of applying or pre-planning, 37% had their first plan, and 32% were on their 2nd, 3rd or higher plan.

The feedback and information gathered has produced common areas/ themes providing feedback and concerns that are supported by similar information gathered from the focus groups.

Peer Groups and Focus Groups engaged

The focus of the project engagement was to get feedback from individuals, families and community across a diverse group of people involved with the NDIS in WA. This included individual meetings with people with disability, and with people with their families and hearing their stories. The willingness from people to be engaged with the project demonstrated the high concerns and anxiety that people were experiencing as the NDIS transition was rolling out. In the regional visits people were specifically contacting the systemic project officer to request meetings to share their experience and express their concerns.

In all interactions with people whether individually, family settings, small groups, peer groups or larger community forums the intentions have not only been to hear people's feedback but also provide them with the resources available from PWdWA, and provide information and advocacy. The project officer took

resource packs to each regional trip and peer group meeting which included information on:

- NDIS Access requirements
- Advocacy
- Planning and pre-planning resources.

Engagement activities often provided the ability for individuals and families to gain greater peer support and join together to seek local solutions.

There was an intentional focus on ensuring that a diverse group of people were reached. This included the engagement of Cultural and Linguistically Diverse (CaLD) families. To do this PWdWA engaged a systemic CaLD officer whose main role was to engage with people from CaLD backgrounds. She was successful by contacting multicultural specific services and using personal interviews with people to offer the opportunity for them to be part of the survey and also share their stories (see CaLD Issues Report at Appendix 2). This report demonstrates the challenges and experiences that families who are not adequately supported have of the NDIS, and the resulting anxiety and fear that could be avoided.

The regional areas covered through the project have been Kalgoorlie, Esperance, Geraldton, Wheatbelt and Bunbury. The initial first visit to Geraldton occurred prior to them rolling out into the NDIS in July 2019. People came to a community event that was hosted by Carers WA, with representatives from the NDIA also presenting. The feedback from attendees was that people felt overwhelmed and could not understand the terminology or how the funding categories related to them or their family member. PWdWA provided resources and support to the families during this visit to help them understand how to translate the changes from the state system to the NDIS. In the systemic officer's return visit to Geraldton in February 2020 many of the families that were supported in the first visit made contact and provided feedback about their experience entering into the NDIS. See Case Study 6, this was a family that was supported from the first visit by the systemic officer and through the journey eventually had a positive experience.

There was a challenge to engage with Aboriginal people and their involvement with the NDIS. A visit by the systemic project officer to Esperance highlighted the lack of engagement from the Aboriginal families living in Nulsen area, (suburb that has a large population of Aboriginal people) with the NDIA. One of the issues is that the NDIA is based in the Centrelink office in the centre of Esperance. This is also the case in Kalgoorlie. Discussion with other services in the community highlighted the possibility of NDIA planners going to the community facility in Nulsen to provide better access for people to engage with the NDIS. The project officer had further discussion with BEGA Aboriginal services in Kalgoorlie who

had been engaged by NDIS as rural partners. Once provided with information about this issue, they made a commitment to ensure that when they went to Esperance, they would base themselves in Nulsen.

Engagement with community has also identified the community challenges in delivering support. In Esperance it was evident from people requiring services that local service providers were limited especially in provision of therapy. The two visits to Esperance provide the opportunity to mobilise the community when bringing people together and realising common issues. Conversations started with initially identifying the lack of therapy providers outside of WA Country Health Service (WACHS), then moved to looking at how therapy could be accessed. The results of these discussions have been that a therapy provider has opened services in Esperance and that there are now therapy providers coming from Perth, Albany and Kalgoorlie to support individuals and their families with services.

The other area that has been a focus in engagement is the cohort of complex needs. This is often an area that gets put into the “too hard basket”. The project officer has intentionally connected with families who have children that fall into this area to ensure their voice is heard. This is historically the cohort of families that don’t have a “voice”.

Speaking to Merger of Minds families, they say their experience and engagement has been very challenging because there is nothing typical in their lives. In speaking with families their feedback is that planners “don’t have the experience to understand”. These families are only just managing and the stress of the NDIS can be enough to tip families over the edge and give up, without support. (**See Sadie Case Study 1**)

Over 20 peer groups have participated to date and provided feedback across the state. The peer groups that have been involved in the discussions have been smaller groups consisting of individuals and families. Peer support groups and community groups ranged from 5 -30 people. These groups cover the metro area from Joondalup through to Rockingham and Midland. These groups include:

- Kalparrin families
- Peer groups from Valued Lives
- EDAC
- Musability
- Senses Foundation- Peer support
- Carers WA
- CoMHWA

- Merger of Minds
- Ability families
- Deaf Blind Community
- DDWA - Young leaders
- Families in Esperance - Esperance Homecare/BOICO/Escare
- Geraldton families - through Cares WA workshops
- Hyden families - case study
- Individuals with spinal injury
- School parent groups North and South of the river (Canning College, Mirrabooka Senior High School, West Coast Senior High School)
- Community forums - North and South of the river
- Individuals' families in Kalgoorlie - through Hope and Salvation Army.

The meeting with the peer groups have been to gather feedback about the experience of peoples' engagement with the scheme and any barriers incurred. These discussions have been an opportunity for people to discuss openly about the understanding of the NDIS processes. Some discussion topics covered have included, but were not limited to:

- Gaining access to the scheme
- Understanding the planning process and pre planning preparation
- Understanding the actual plan and how to implement the plan
- Negotiation with service providers and getting services in a slim provider market especially in complex supports
- Understanding the review processes
- How to have an early plan review or changed if it is not what is needed or expected
- Oversights in the plans
- Quality and skills of the planners
- The appeals process

The intention was to ensure that the project captured voices across a broad range of people with disability with diverse individual circumstances.

An art project was undertaken with the Deaf/Blind community. The focus was to provide people the opportunity to express themselves through art and to express their concerns moving into the NDIS. Over 30 people attended the event at which DADAA delivered a workshop in print art. People printed art work that was an expression of how people were feeling about the changes across to the NDIS. Some of the final artwork was framed and presented to the NDIA and the State Ministers Chief Advisor at the PWdWA Annual General Meeting on the 30th of October 2019. What this artwork particularly highlighted is the anxiety and fears the transition has caused to many people.

The Individual Advocates of PWdWA were also engaged through a survey and provided information on trends in advocacy. A number of individuals that attended focus groups then came to access individual advocacy as they learnt of their rights through the engagement process.

Co-Design group

The Co-Design group of people was formed to have a range of disability and NDIS experiences represented.

The group consists of 10 people with disability and family members that include:

- people with physical disability – congenital and acquired
- people with sensory disability
- people with intellectual disability/autism
- parents of children with autism
- parents of children with developmental delay

The group was selected via an expression of interest which was circulated across the community. The initial Co-Design meeting was held on the 23rd of September 2019 with a training session conducted by Alison Blake of Strategic Support that provided a solid platform for the group's understanding of Co-Design principles and process.

The purpose of the group was to design practical solutions that were shared with the Co-Design partners from NDIA and NDIS LAC Partners.

The group met initially on a monthly basis to discuss the issues raised from individuals/ families, the peer groups, and community. Once the COVID 19 restrictions were enforced the meetings were held weekly via Zoom.

These meetings and discussions have then been used to inform submissions, reports and opportunities for feedback to the relevant parties in the NDIA, Joint Parliamentary Joint Standing Committee on the NDIS, the Minister and any other groups currently looking at the NDIS Transition.

The Co-Design report included in this report demonstrates the importance of having a Co-Design process included in any future decisions and continuing to implement the NDIS across WA.

“Planning for the people by the people”

General Principles of NDIS Act 4.4.2 section4 (8)

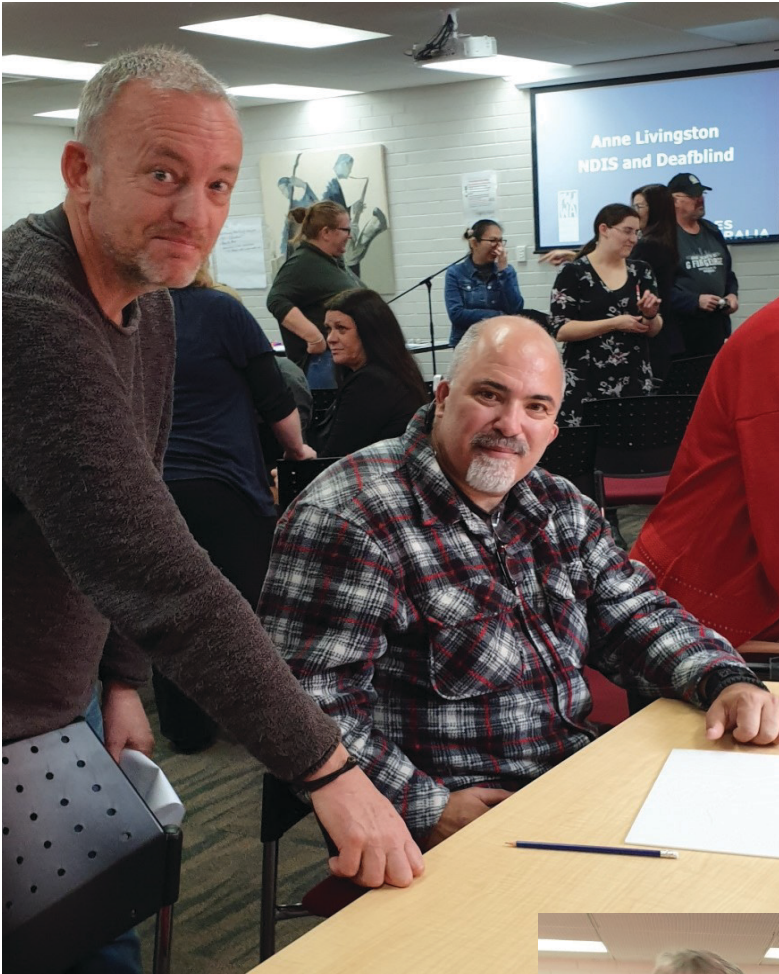
People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity.

The Co-Design group and partners believe that:

“To understand what people with disability need there needs to be a commitment to have people with disability involved in the decisions and rollout of the NDIS.”

The Report of the Co-Design group has been written by them based on their 9 months of working together and hearing all of the information gathered.

The full project findings are based on the information gathered through all of these mechanisms.



Deafblind Art workshop



Hand and Heart Artwork



Deafblind Art workshop - the results



Art work on NDIS



Karen Wickham - Senses, Rita Klienfeld-Fowles - Deafblind Group, Louise Holding - Ministers Office at PWdWA AGM



Karen Wickham - Senses, Rita Klienfeld-Fowles Deafblind Group, Tim Fettis - NDIA, at PWdWA AGM



Artwork - Feelings on NDIS



1Artwork - Feelings on NDIS Planning

Findings

These are the common areas of concern, and consistent themes from the focus groups, survey, and Co-Design group. Case studies to show impact have been noted throughout the findings. All case studies are in full at Appendix 1.

Gaining access to the scheme

The general feedback from participants entering the scheme, accessing the scheme and navigating the scheme has been that the processes and procedures are bureaucratic, complicated and “clunky”.

Feedback from **Consumers of Mental Health WA** (CoMHWA) in consultation with the people with a psychosocial disability has been that participants who may be eligible need support to go through the accessibility process. CoMHWA noted that those individuals that reported positively of the NDIS, were those individuals that had intensive support to learn about the NDIS and had dedicated support to help them to apply and navigate the whole process. Those individuals that struggled and were challenged by the NDIS process, were those who lived independently and had few family members or carer supports.

For all participants who have applied, there is no system in place to monitor the progress of the application, with some applications taking months and others being processed seemingly quickly. This causes anxiety and stress for the participants. The feedback has been that this has resulted in people becoming unwell both mentally and physically.

The language used in the NDIS is very bureaucratic and while easy English guides are available these assume people have access to technology and know how to use technology. People from cultural and linguistic diverse (CaLD) backgrounds, families with limited capacity, and people living rough or homeless are excluded from accessing the scheme without external supports.

This is highlighted in **Case Study 10 - Abi**. Abi's parents from Sudan do not read or speak English arriving in Australia as refugees. NDIS posted letters to the family asking them to complete access request for Abi. The parents did not understand the letter. The therapy provider fortunately was shown the letter and the family were supported to apply for access.

Consultations with families and community group **ESCARE** in Esperance raised concerns about people who were slipping through the gaps and the lack of support in the Esperance community to assist people to gain access to the scheme. The community groups like **ESCARE** and **BIOCO (Bay of Isles Community Outreach)** who are not funded to support people to apply for access are assisting people where possible. The Aboriginal community who mainly live in the Nulsen area where not able to seek support due to distance to get to the centre of Esperance (Centrelink where the NDIS planners are based) and/or

people were unable to get the documentation required to provide evidence for eligibility.

WA Country Health Services (WACHS) raised concerns about the number of people that they support who have not the capacity or support to access the NDIS. Although WACHS will continue to provide in-kind support this will be basic support only until the full roll out in June 2020 thereafter services provision is unknown to these families. This has been escalated as a concern by the Executive Director of WACHS who has escalation pathways to NDIS service provider team.

The Planning Experience

The consistent feedback from individuals, families and carers has been the stress and anxiety for participants and their families around planning meetings.

The consistent response from all the peer groups has been that the planning experience from pre planning to the actual planning meeting and then receiving the plan is extremely stressful and difficult for most individuals and families. Even when it a second or third plan. This has been a main topic of conversation in all discussion groups.

Meetings with the families in the schools at Mirrabooka SHS, West Coast SHS, Burbridge Education Support Centre and Cannington SHS highlighted how families felt ill-informed, unprepared, and unsure of what they can ask for, and felt unsupported. Those families that had a connection to Local Coordination (LC) (DOC) when they transitioned from the state system to the NDIS felt more supported, but many were still very unsure during the meeting as most people did not bring their LC with them to their planning meeting. Most people had been to the information session provided by NDIS roadshows but felt this did not provide clarity - in fact it was more confusing.

This anxiety and confusion is demonstrated in **Case Study 5 - Pam.**

*“I was extremely anxious and spent weeks preparing documentation, filling in the NDIS book2, researching the literature from the NDIS it was not helpful to our situation. Felt like there was a lot of duplication and this increased my stress”
(Father)*

In particular concerns were raised by the schools about the lack of support for students transitioning from school. The feedback from the schools was that they were in the dark as to how to support families through this transition time and that the previous State System provided a pathway for school leavers to apply for support for transition from school. Families reported that the response from NDIS planners and Partners was plans would not be developed for transition until the

student was at the end of their final year. This was a huge area of concern for families.

The peer group with **Valued Lives** raised concerns that the information sent to the planners or partners providing reports and the evidence to support the requests for the plan, were often not read. This meant that families had gone to enormous lengths to gather this information to support their requests and this was very stressful for families who assumed that the person they were meeting would at least have read the background information provided.

The peer groups from **VisAbility** and **DeafBlind** Community raised concerns about the lack of consideration and understanding about the need to set up the environment for the meeting, not receiving information in an accessible format and/ or having the necessary interpreters. The **DeafBlind** peer group said that they were advised that they could only have interpreters from a particular service provider even though that provider could not provide appropriate interpreters who could sign for people who are deafblind.

See Case Study 3 - Ben

“The engagement with NDIS from our perspective has been an utter debacle” (Father)

The experience, expertise and qualifications of planners

The feedback from individuals and families has been that the quality, experience, expertise and qualifications of the planners varies markedly from planner to planner. This includes professionalism of the planners in engaging with people from the very outset of the planning session. Planners often came to planning meetings unprepared, and are under a very tight time schedule.

The planners often use NDIS speak that people do not understand, and the person leaves thinking they have been understood by the planner, but end up with a plan that looks completely different. This very common theme is reported as an issue, with 45% of survey respondents saying they did not feel heard by the planner and 48% saying they did not know what they should be asking for.

Individual Advocates supporting individuals commented that the planner did not seem to understand the needs of the person with a disability, especially where they were complex. They find that what is being discussed in planning meetings regarding supports is not what ends up in the plan. While the NDIA have ‘disability guides’ which indicate the kinds of supports a person with a particular disability might need there needs to be better recognition by planners that people’s needs are diverse and circumstances just as diverse.

Many people felt that planners make assumptions about what is and is not required and that the planners are not prepared when meetings occur. Often

people submit a number of therapy reports and evidence to demonstrate reasonable and necessary supports and planners have not read this information, or state they do not have time to read them. People will bring copies of evidence submitted before planning meetings to the meeting and planners say they have never seen it before. It is concerning that planners are making recommendations about supports or decisions about approved supports without having read, and considered the available information.

Planners and NDIS language. Planners are using legislation and "work speak" in planning meeting with individuals. There is a huge gap in understanding. I was in a meeting where I said three times - "I don't understand" and the Planner offered nothing, nor do the Support Coordinator. They just talked to each other. I felt excluded"

NDIS Transition and interface survey 2019 - 2020

There is a feeling amongst participants that planner's roles are to provide the least amount of supports possible, rather than exploring all the possible support options available. Individuals and families are preparing for planning meetings going in with the worst-case portrayal of their family member for fear that they won't get the supports that are required.

Case study 4 - Mrs W is a clear demonstration of this issue.

"I felt scared going into the meeting and felt I needed to ask for more help than required in case I didn't get my employment funding" (Mrs W)

Quality and knowledge of planners

Feedback from individuals and families has been that planners did not seem to understand the needs of the person with a disability, especially where there were complexities. The breadth of people accessing the scheme with various disabilities, unique needs and individual challenges is varied and vast. In speaking with the families from the peer group **Merger of Minds** who are families who support family members with complex and unique needs, the general feedback was that they did not feel that the "Planners" have the basic knowledge of understanding of disability or complex needs. Often they were encouraged **not** to bring in the individual into the planning meeting and time for planning was capped at 1.5-2 hours.

The NDIS planners' understanding of complex appears often to be limited and finite. Although NDIA has a "complex support needs pathway" that supports people with more complex support there is little acknowledgement that

complexity for clients can be more than the pointy end situations that may involve mental health, homelessness or justice interface.

Complex supports could involve:

- Multiple service providers
- Co-occurring disabilities or health issues
- Parent or carer capacity
- Families who have other members in the same home with disabilities or mental illness
- Refugee families who have experienced trauma
- Individuals and Families with English as a second language from CaLD backgrounds
- Individuals who have complex needs with communication or behaviour
- Multiple areas of support within a plan

Planners have also stated to people that “what is being discussed in planning meetings regarding supports is not what ends up in the plan”. This makes it very unclear about the purpose of planning. Lack of transparency leads to a feeling there are secret rules about what can and can’t be funded. The NDIA ‘disability guides’ don’t seem to assist planners to recognise people’s individual capacity to manage or their diverse circumstances.

The impact on families with this lack of understanding and trained planners is highlighted strongly in **Case Study 1- Sadie**.

“I know for a fact that they pushed go on our plan without being properly implemented and left us absolutely at the mercy of me trying desperately to get it reviewed as it was completely inadequate” (Mother)

Other concerns raised by participants is planners having little or no understanding of unique or complex communication needs for participants. The deaf/blind community expressed their challenges in the transition to NDIS. The feedback was greatly concerning in that the majority of people felt they were not understood by the planner. The need for specific interpreters was often denied. People had turned up to planning meetings and interpreters were not booked. Planners suggested plans could progress by writing down questions and answers on paper.

“Anxious and feeling unprepared for the planning meeting. Would have preferred it not to be at the NDIS office but no option given”.

NDIS transition and interface survey 2019 - 20

Other areas of concern were that the plans were mirrored. A family reported that they had two children with same diagnosis of autism, both children very different and requiring individualised plans. The planning meeting was set on the same day for both children with no gap between the planning meetings. The planner had not had time to read the reports provided by the family. The result was the plans were a basic mirror image of each other and very inadequate and requiring an internal review.

Planners are minimising the complexity by changing the goals people are wanting in their plans. e.g. 6 clear goals are condensed down to one goal and there is limited funding provided. Participants are meant to have full control over the goals included in their plans and this is in clear violation of the *NDIS Act 2013*.

“When explaining how my mental health issues affect my physical disabilities I was told that as this plan focuses my physical disabilities (primary) and my mental health issues are irrelevant”

NDIS transition and interface survey 2019 - 20

The ongoing training and professional development of planners.

It is evident from the general feedback from individuals and families that the quality and expertise of planners varies tremendously across the state. The professional knowledge, preparation, interaction and engagement from planners with people sets the scene for a successful planning meeting.

If this could be addressed it would minimise the need for internal reviews, reduce the stress to families and individuals and the ultimate break down in family units.

See Case Study 1- Sadie

“I have to go into battle every single time to be heard” (Mother)

The survey to date conducted by PWdWA around the “NDIS transition and interface” clearly demonstrates this as a common theme. Of the feedback provided by the survey participants 45% of people felt that they “didn’t feel heard by the planner”.

There is a need for planners to have ongoing training to understand the changes that are happening within the NDIA and maintain a consistent quality of interaction. The key job of the planner is to support and assist families and individuals at the planning meeting to ensure that everything is captured in the plan that meets reasonable and necessary support for the person. People should not feel penalised because their planner has less experience, however that is what is occurring when in peer groups they hear from a friend who has a great outcome from a plan done by a more experienced planner. Consistency, transparency, knowledge, understanding, are all words that families use to express how they feel a service from a planner should be delivered.

A family member suggested in a community Peer group meeting that perhaps the families and individuals should be provided with the option to give feedback directly after their planning session through a survey to NDIA rating their experience and satisfaction of the planning meeting and process, and again after then seeing the plan

The current demands on planners and partners.

There is immense pressure on planners in WA currently to get plans done in a timely manner. KPIs of numbers of plans seem to be the priority, not quality plans, and this is seen across both the NDIA planners and LAC Partners.

In a number of cases across advocacy organisations in WA, there have been unacceptably long delays between access being granted and planning meetings taking place. Planner fatigue is evident with the turnover of staff and with the number of planner errors that are seen by participants. Things that have been discussed in the planning meeting have been left out of plans resulting in light touch reviews or internal reviews needing to be requested. This creates bottlenecks in the process, unnecessary stress for families and is not effective or efficient.

Additionally, because of the pressure on planners to get plans done they are not giving participants the time required to create a quality plan. Planning meetings are limited to 1-2 hours which means there is little time for the planner to 'unpack' and ensure that all possible requirements for support are considered. The planner should be the person with knowledge about the types of supports available, and what supports a participant may require based on their disability – the onus should be on them, not the participant, to ensure all reasonable and necessary support are explored.

A family that was supported to attend their child's planning meeting was ushered out of their planning meeting after 1.5 hours as there was another planning meeting booked. This participant has extremely complex needs with multifaceted supports required and the family was told the planner would use the documentation to complete the plan. There was no consideration to the wealth of knowledge that the family could provide as well as the therapist who has attended the meeting to support the participant. The final plan had the participant portrayed as able to do a number of things independently, which was completely incorrect and resulted in an internal review. This review process was undertaken 3 times before a plan was developed to reflect the child's complex needs.

"Planners are untrained, and /or have zero knowledge or experience of disability and what we BATTLE with every day.

NOBODY at the NDIA/NDIS listens or cares about us or our needs!"

NDIS transition and interface survey 2019 - 20

Participant involvement in planning processes.

Feedback from families has also highlighted the uncertainty of whether their family member should attend the planning meeting. Some feedback from families has been that they take their child into the meeting in the hope that they will not cope so that the planner can see and acknowledge their supports.

Effort should always be made to ensure the participant is at planning meetings, even if it is a child and this may require meetings to take place at the person's home. In many cases where the younger person has complex needs, better results would be seen if planner could meet the younger person face-to-face. This also ensures that the younger person's needs and preference are taken into account as they can often differ from the needs and preferences of the family.

The other side to this issue of participant being present in a planning meeting is the planner directing all questions to the participant exclusive of the parent or guardians' input. An example was a young man with Down syndrome attending his planning meeting with his parents. The planner directed all question to him and busily typed his responses. At no point were his parents asked their opinion etc. Even though documentation was provided by psychology reports demonstrating this young man had inappropriate sexualised behaviours whilst in public towards females the plan received did not reflect the need or support to address this issue and had minimal supports built into the plan. This resulted in an internal review.

“Especially don’t know who to bring to the meeting. As a parent of a person with an intellectual disability I felt sidelined in the process. Planner said I need to have Guardianship to participate but I have been told that isn’t the case, I can be appointed Nominee for NDIS purposes.

My child isn’t able to communicate effectively with the Planner so my input to the process is critical.”

NDIS Transition and Interface survey 2019 - 20

Access to draft plans

In regards to making draft plans available – this would eliminate many common issues identified by participants and their families:

- Wrongly categorised supports
- Funding discussed in planning meetings which are accidentally left out of plan
- Issues with the way funding management has been allocated
- Issues with transitions from WANDIS to NDIS which is guaranteed to be like for like but which is often not occurring

Individuals and families reported they are leaving planning meetings with the expectation that what was discussed in the meeting was captured by the planner and will transfer into the plan this is often not the case. This is a common theme that is being reported by people which results in the internal review. The other alarming message to people from planners is that if they are not happy with the feedback the planner is providing in the meeting, the planners are saying “if you’re not happy when you receive the plan you can request an internal review” not explaining how long this process can take.

“The plan is approved and the way it is delivered to the participant is not acceptable. I think you should be able to read it as a document (as you would any other legal document) and have sufficient time to check it and ask for amendments if possible”

NDIS Transition and Interface survey 2019 - 20

Case Study 2 – Stephanie

“I didn’t understand the plan... then I realised that it was significantly short! No one at NDIS helped me to sort this out! I didn’t understand the process to get a review” (Mother)

The review processes and the impact

The feedback from individuals and families regarding the reviews and change of circumstances has highlighted the continued concerns and dissatisfaction by large numbers of participants. The consistent feedback from individuals and families is that the time it takes to get responses about all processes within the access, planning and review stages from NDIS is inconsistent, frustrating, stressful and bureaucratic.

Many responses from participants has highlighted that supports are often left in limbo whilst waiting for an internal review because people are too frightened to use their funds for fear of running out before a review has occurred. In the **EDAC** peer families group, one parent explained that she had a critical component of therapy left out of her son’s plan. She requested an internal review but did not use any of her therapy budget because she thought she couldn’t until the internal review process had be completed putting her son’s therapy on hold for 4 months.

The general feedback from participants and their families is that they are fearful going into the review process based upon the feeling that they will have their supports reviewed. This is often reinforced by comments made by planners and LAC partners to participants at planning meetings. Comments such as “well this year you will have this support to build capacity and next year it’s likely not to be included in the plan”. There have been a number of participants and their families state that they are as nervous about their review meeting 2nd / 3rd/ 4th plan as they were at the initial planning meeting.

Individuals and families have strongly stated that if they had the option to view a draft plan that many of the planner errors and things omitted within the plan as discussed at planning meetings could be addressed prior to approval.

“Planning /Review meeting focused on what can be cut back on rather than on what’s required for progressing the next 12 months. Supplying funding for services that is requested by specialist that is 1/3rd of my budget that goes on report writing with support not funded!”

NDIS Transition and Interface survey 2019 - 20

Understanding and implementation of plans

The feedback from individuals and families has been that once receiving their plans they have no understanding of how to interpret the plan and implement the plan. The feedback has been that people have not received services because they don't know what services they are entitled to receive. The way that the plans are written in the various areas and the funding is "lumped" together people don't know what they can spend the funding on.

The language in the plans is so confusing and the resounding request from individuals and families is, if the language was simplified and user friendly the general understanding of each plan would be easier.

The introduction of LACs does not necessary solve this issue because the same quality and demand concerns exist and there is the added potential for information to get 'lost in translation' between the LAC and the NDIS delegate who approves the plan.

At the **Community Forum** held in Success, a young single mother of four children, two with a disability, stated that she had no support to start to implement the plans other than being given a list of service providers to call by the LAC Planner. She was advised that they could not make any suggestions or provide her any guidance to source a suitable provider. She didn't know what she was asking for or what she could receive and it was left up to the service providers to help her interpret her plan. She is still unsure what exactly she has in the plans for her children.

The general feedback from individuals and their families is that because they don't understand their plans they feel they don't have full choice and control because they are relying on LAC planners, Support Coordinators, Service Providers and other informal contacts to advise them on what they can access in the plan. This is further complicated if people are from CaLD or Indigenous backgrounds. See attached report Culturally and Linguistically Diverse Background Engagement with the NDIS at Appendix 2.

Support Coordination in people's plans can assist with getting plans implemented, however there are growing issues with the capacity and quality of support coordinators. Advocates stated that they are getting increased requests from Support Coordinators for information or to support participants with issues that should be done by the Support Coordinator. It is unclear at times what the boundaries of the role are and what best practice Support Coordination looks like. People often do not have enough hours for Coordination of Supports in their plan and must go through review or change of circumstances to get extra hours before the year is through.

Challenges for individuals living in rural and regional areas

The rural and regional areas in WA have their own unique issues in regards to the planning process in the NDIS. The distance to travel to planning meetings, gathering the necessary documentation required for planning meetings and the understanding of the planners about the barriers to receiving supports within small rural towns are only a few of the issues.

A family in a remote area reported they have two sons both with NDIS plans and the planner had no understanding about the distance required for her sons to access the activities that they wanted to pursue or the distance that support workers had to travel to work with her sons. This was completely left out of the plan and therefore an internal review was required.

Meetings with families in Geraldton gave feedback that the lack of service providers for the more remote areas has meant that families have to travel to Geraldton to receive services. This was requiring parents having to stay overnight due to distances travelled. The outer remote areas have participants with plans that they can't implement because there are no services.

The advocacy service in Geraldton reported that they spend all their time supporting people to get the documentation together to gain access to the NDIS.

A participant from Blind Citizens Group reported that she was requested to travel from her home in Pinjarra to a meeting at the NDIS office in Mandurah at 4pm on a week day. When she explained that she was blind and used public transport and that buses did not run at this hour, the planner was dismissive and made her feel very uncomfortable. Eventually the planner agreed to come to her home, however the communication about the date and time was not clear and the participant was not at home when the planner came to her home and again made to feel uncomfortable.

The feedback from Esperance individuals and families has highlighted the slim market place with no therapy providers in the community. Therapy had to come from Albany, Kalgoorlie or Perth. Many people in Esperance with therapy in their plans was not implemented. After meeting with families and service providers in Esperance the result has been that a service provider has now opened in Esperance. This was overlooked by NDIS despite the roadshows from the NDIS Community Capacity Building Team.

In recent meeting with families in Kalgoorlie the issues raised by families were extremely concerning. People are expected to attend meeting at the Centrelink office. Families from remote areas like Coolgardie and Lenora are just not able to attend planning meetings and are slipping through the gaps. There is very little understanding of the trauma associated with Centrelink or the lack of flexibility in assuming people will come to an office in work hours. In a recent community

consultation with people in Lenora people were not having their basic equipment need met like access to wheelchairs for mobility.

See case study 5 – Ken

“Mrs F felt that things to be considered in rural areas is travel and distance. For us to access any services there is a 2-3 hour round trip.” (Mother)

Interaction with other systems

In consultation, concerns were raised that Health, Child Protection and Justice Staff are finding it difficult to navigate at the individual level and assisting with coordination and pre-planning when they can because they have to assist individuals to enter the scheme. WACHS feedback from Esperance and Kalgoorlie has been that it is an extremely difficult system to engage with for families and that people are now coming back to the health system and being hospitalised because services are not available.

Kalparrin peer supports stated that there is an increase in people bringing their children in to the hospital to provide respite to the family because the NDIS plans do not provide respite breaks for families. The family support workers at Kalparrin advised that they spend 90% of their time supporting families with the NDIS plans and accessing services.

Other feedback included people losing access to healthcare cards, mobility allowance and respite services.

The housing project by Carers WA and Foundation Housing as part of the Disability Coalition Systemic Advocacy goes into more detail about issues with housing, however a lack of any housing options in the category of Robust build was noted. It is also important to note people did not know where to go to address housing needs or seeking greater housing options.

Advocacy

The impact on Individual Advocacy Services of the NDIS has been huge with around 35% of all advocacy and information provided by advocacy services being about NDIS. This is significantly more people than previously who accessed advocacy services. Advocates have also reported great difficulty in being recognised by the NDIA at call centre level when trying to support or access information on behalf of participants. People with disability not eligible for NDIS are being left without advocacy services as waiting lists are now in place.

A project such as this Systemic Advocacy project, has been able to engage and educate participants while actively using mechanisms to raise issues for change to higher levels. Systemic advocacy is unfunded generally.

Submissions

Throughout the project the findings have informed submissions and input into advisory group and consultations. This has allowed the direct experiences of individuals and families to be heard in these forums. Three submissions have been made to Federal Government inquiries with detailed input from this projects findings and from the individual advocacy experiences.

The Joint Parliamentary Standing Committee on the NDIS: The Inquiry into the NDIS.

NDIS Act Review and Participant Service Guarantee (Tune Review)

The impact of changes to service delivery models on the administration and running of Government programs

The full submissions can be found on the submissions page on our website under 2019:

https://www.pwdwa.org/our_campaigns/our_submissions.html

PWdWA also had the opportunity through the Disability Coalition to present recommendations to the State Government for potential inclusion into the State Disability Strategy Action Plan. These are detailed in the Recommendations section of the report.

Each report has detailed recommendations for improvements which have also been provided to the NDIA through a variety of mechanisms and key elements are highlighted below.

Meetings/presentations on issues raised through the project

- Presentation to Minister Dawson 2019
- Issues raised through Tim Fettis – Director, Community and Mainstream Engagement – Western Australia
 - Planners knowledge and interactions
 - Issues with LAC partners
 - Planners engagement with community in regional areas
 - Interaction with health issues
- Issues raised at *NDIA Industry Reference Group*
 - Thin markets in regional areas
 - Travel in regions
 - Community development approach required in regional and remote areas
- Issues raised at *Housing Advisory Roundtable* in conjunction with Shelter WA
 - Policy and Local Planning issues limiting housing

- SDA being built in appropriate areas with more information for participants.
- All issues and submissions have been raised with the WA representative to raise at the *NDIA Independent Advisory Council (NDIA IAC)*
- Issues regarding review process, misinformation, and planning clarity have been raised directly with NDIA Deputy CEO's.
- Information, case studies and issues raised have informed input into the *Self-Management Reference group* and the *Contemporary and Innovative Approaches Reference Group* of the NDIA IAC.

Recommendations

Report Recommendations

Based on the findings and the recommendations from previous submissions and the Co-Design group for the NDIS Transition and Interface Issues Project, PWdWA makes the following high level recommendations to the NDIA:

1. The NDIA regularly reviews its processes, rules and procedures against the principles in the NDIS Act 2013 and use those to inform continuous improvement.
2. Co-Design principles and practice be adopted by NDIA and LAC Partners to ensure that lived experience is part of future decisions, solutions, and the future of the scheme in WA.
3. Implementation of Tune review recommendations include a broad focus on increasing flexibility for individual complexity and diversity, decreasing check box responses, and simplifying language.
4. Flexible Community Development approaches are used to connect to people in regional and remote areas.
5. NDIA provide funding and support to people with disability, and families, in local community groups to assist with accessing the scheme, pre-planning, to train planners, be planners, and be supported to train and be Support Coordinators.
6. Independent Individual Advocacy and Systemic Advocacy are recognised and engaged by the NDIA to inform change and support individuals in complaints, reviews and appeals.
7. Recommendations from the Co-Design report (below) are considered to ensure that a transparent, effective scheme is introduced that reflects the NDIS Act and principles.
8. Recommendations from the Cal report (below) are considered to ensure that the scheme is applicable to people from different cultural backgrounds.
9. Recommendations from the project to the State Government are supported by the NDIA and put in the State Disability Strategy Action Plan to address the gaps in the system for those not eligible for NDIS, and those areas the State can assist.

Co-Design group Recommendations

Recommendations for Improvement:

1. Remove the need for a fixed address to apply for access to the NDIS. Alternatively have the option of putting the fixed address of a family member, friend or service provider, and/or an email address of mobile phone number.
2. Provide funded assessments for people applying to the NDIS who do not have sufficient supporting evidence.
3. Peer Support employed by NDIA, possibly enriched by a pool of long term Co-Design placements, to support people with disability (PWD) apply for access and with pre-planning, planning meeting, familiarisation with the NDIS and implementation of their plan.
4. Clear communication lines established between people with disability, service providers and the NDIA.
5. NDIS language, policy and procedures reviewed to make more accessible to people with disability and cater to all cultural backgrounds.
6. Funding buckets of lines of funding to be simplified, for example all funding to be claimed from “one bucket”.
7. Support Coordination to be funded in all first NDIS plans.
8. NDIA equip or fund the equipping of people with disability with self-advocacy skills.
9. Communication from the NDIA advising of upcoming reviews with web links to recommended preparation to be taken by participants, for example inform therapists and ask for reports, consider whether you would like Support Coordination, reflect on how you have found shared or self-management and what you would like for the new plan...etc.
10. NDIA establish clear timeframes to give participants an expectation of when their matters will be addressed and resolved.
11. NDIA to provide clear feedback when people are deemed ineligible for the NDIS and with regards to funding decisions and claim rejections.
12. NDIA to be transparent about feedback received and active responses to feedback.

13. NDIA to make an accessible, transparent policy regarding privacy, confidentiality, and Freedom of Information that is respectful of the agency's role in servicing and supplying funding to people with disabilities in a way that is with integrity to our vision of self.
14. NDIA to employ people with relevant qualifications such as Allied Health Professionals, people with lived experience of disability and or substantial experience working in the disability sector.
15. More comprehensive training packages for planners is recommended to reduce inconsistencies arising from different levels of planners' expertise in the disability field.
16. Moderation processes are recommended to improve inconsistencies across eligibility for NDIS, plan outcomes for participants and amongst plan managers.
17. NDIA to provide training and efficient information dissemination to the disability sector (NDIA employees, carers, support workers, agencies...etc.), other government Departments and related services such as GPs and hospitals so that everyone is receiving consistent, accurate, relevant information.
18. As much as possible, participants to have the same planner for consistency and relationship (unless a different one is requested by the participant due to personal issues).
19. NDIA to employ Peer Support workers (people with lived experience with disability and the NDIS) to support potential participants to apply for access to the NDIS and participants with pre-planning, plan meeting, implementation of plan and reviews.
20. NDIA to strengthen existing collaboration amongst government, community services, private sector, and families.
21. NDIA to collaborate with state government departments to establish a clear understanding of roles and responsibilities, in terms of what they do and do not provide with regards to funding and services whilst ensuring no gaps in service provisions.
22. NDIA to provide or fund training for carers and people with disabilities to understand the roles and boundaries of different services such as the NDIA, and Departments of Health, Transport, Housing, Education, Mental Health and Aged Care.

CaLD Report Recommendations

1. NDIA support the development of a culturally appropriate case management support system
2. NDIA develop a comprehensive culturally competent framework and a trauma informed disability framework.
3. NDIA fund and support a culturally appropriate disability and family awareness and self-advocacy training program
4. NDIA recognise the need and include Support Coordination in most CaLD NDIS plans.
5. NDIA support Cultural competence/responsive training for workers in the disability field
6. NDIS and service providers to increase their CaLD background staff
7. Create a CaLD engagement and communication strategy to encourage greater awareness and utilization of disability and other support services

Recommendations to WA State Government

1. Provide planning and funding for service access to people living in WA who are New Zealand Citizens, people on 459 Visas and working visas, people who are unable to provide the necessary documentation and evidence due to mental health, comorbidity or familial background, to ensure that there is no disadvantage into the future, until or unless the NDIS includes this cohort in future eligibility.
2. The Department of Health, Department of Communities and Local Government develop pathways and funding for access to equipment and home help support for people not eligible for the NDIS under 65 who have a disability and or chronic health condition.
3. The State develop and support Specialist Disability Accommodation (SDA) building generally and in the robust category specifically with provision of expertise in design and demonstration homes in this area. Specifically that Metronet in the public housing build program include two demonstration homes of a robust build design.
4. The State Department of Communities develop a comprehensive working plan through Child Protection and Family Services and Disability Services to address service gaps for children with disabilities with complex needs and challenging behaviours at risk of relinquishment or in the child

protection system. The plan includes continuation of core operational funding for specialist short stay accommodation that can also be registered for NDIS individual payments.

5. Advocacy services in WA to receive ongoing funding to ensure that people with disability, vulnerable people and their family receive the support they require to understand and navigate the various government systems and sector.
6. The State plan for further opportunities for sector development in the area of complex needs and high support needs, such as current highly skilled workers being supported to become trainers, and provision of specialist training in positive behaviour support through TAFE, to ensure there is a skilled workforce developed in WA.

Conclusion

The findings from this project have clearly identified that there are issues in the scheme that need to be addressed to ensure that people get the best outcome and can benefit from being a participant in the NDIS.

It is evident that people feel that they are having to navigate a complex system that does not appear to be fair and equitable across the board for people with disability, their families and carers. The project has also highlighted the stress and anxiety that the system imposes on people with disability, and families and is causing families to break down and creates stress.

It would appear that the scheme can be made more flexible and easier to use for participants. This has been demonstrated by the changes implemented during COVID19.

The aspects of the NDIS that participants say are working well are generally when they have flexibility and choice in their package. Individuals and families need to be recognised as whole beings with a range of unique circumstances.

This project took place over an 18 month period which is too short a time to see any broad change in systems. The project did achieve many small changes along the way. Every time the project officer went out to meet with people she took resources, information, and a willingness to listen. This in itself had the effect of providing individuals and groups with more confidence, more information, and better outcomes. In regional visits this approach brought individuals and families together with local organisations to see issues that were common and find solutions.

The NDIA WA Engagement team and the LAC Partners have joined in with the Co-Design team willingly and wanting to learn and improve. This project has demonstrated that engagement with participants and looking at the gaps is imperative to being transparent about success of the scheme. It has also highlighted through the Co-Design process that people with disability need to be at the table when decisions are being made to ensure that planning and implementation of the scheme meets the needs of the participants.

This relationship of people with disability, families, and the representatives of the system working together is a legacy we hope continues.

Appendix 1

Case Studies

Case Study 1 - Sadie

Sadie aged 9, has a very rare syndrome, called Rubinsten-Taybi Syndrome (RTS), along with Intellectual Disability and a diagnosis of Autism. Her needs are extremely high, she requires 24/7 one to one support and at times two to one support in all areas of her life. Coupled with her intellectual disability she has sensory processing disorder and displays extreme uncontrollable, impulsive and violent behaviour.

Sadie is loved dearly by her parents and two sisters.

My family's experience of moving across from the State based services into the NDIS has been extremely stressful and traumatic. The 13 month journey of constant fighting NDIS for Sadie's rights and needs has been horrendous. Many nights of lost sleep unimaginable worry this is something that no parent should have to endure. We were simply asking for what our child required and desperately needed. The experience has taken immeasurable toll on my marriage, which is now over, my relationship with Sadie and my two other daughters.

29th April 2019 was our first plan, the plan was significantly less than Sadie's' needs and the supports we had been receiving for Sadie in the state system. It was only after I laid a complaint with the office of the CEO that we granted a review with a promise for us to see the plan before it was rolled out. However, via post I received the new plan which was implemented without us knowing on 29 October 2019 by a senior manager who has since left the organisation.

“I know for a fact that they pushed go on our plan without it being properly implemented and left us absolutely at the mercy of me trying desperately to get it reviewed as it was completely inadequate”

After another complaint to the Office of the CEO, we then had a new plan in December 2019, and were put into the “Complex pathways” to receive specialised planning support for Sadie's plan. The complex care planner arrived at our first meeting having not read Sadie's case file and was rude, condescending and ultimately extremely unprofessional. Her manner was beyond unacceptable. I did not know who she was and she had been introduced as someone that had worked with very complex cases before and could assist in the planning. When asked, she admitted she had not read any of Sadie's file. We stopped the meeting immediately and requested the meeting to be rescheduled so that she could at least read the information provided about Sadie. After a further meeting a plan was developed however it was also substantially short of the funding we needed for Sadie to be supported out of the family home.

“A further battle”.

After asking for the complex care planner to be removed from Sadie’s case, we have had the Associate Director step in from NSW. We are still on that current plan and are working to build a new one with a senior planning supervisor in Wollongong for Sadie that will be implemented once she is fully transitioned into 24/7 care.

The experience has a huge impact on me and my family. It has been fraught with challenges dealing with planners and supposed complex care planners that have no idea what they are doing, that are rude, dismissive and disrespectful. We were not asking for more than Sadie was already getting through Department of Communities but were made to feel that we were being excessive in our requests. We were left at the mercy of the planner pushing go on our plan, who told us that we would not have the supported out of home short stay accommodation (STA) included in the plan. Sadie was attending STA 5 – 6 nights a week at that stage. This support was essential for our family to survive.

I was told “no child under the age of 12 was entitled to respite or supported accommodation”.

I was told that “it is a parent’s responsibility to look after their own child” despite presenting substantial documents from Sadie’s team that monitor her, that clearly explains the complexity of Sadie and her needs.

I had had major surgery and was (and still am) unable to physically care for Sadie. I had just that day arranged with my LAC that we were able to get 96 hours help in the home as Sadie’s Dad and I had separated and he was away with work constantly. With the plan being rolled over, I asked about that support and I was told that it was no longer able to be accessed. I asked what I was supposed to do over the weekend (this meeting was at 3 pm on a Friday) with 24/7 care booked and I was told to talk to an organisation that could help. I rang them and was informed that because I had an NDIS plan, I was not able to access their services.

“I was left, unable to pay my carers and unable to physically care for my child with no avenue of any assistance over the weekend.”

At this time of crisis I was told by NDIS staff:

“To use the money in the plan I had been given to prove what we needed”

“That it was a good sum and better than other people had been given”

“We’ve all dealt with disability Lynley, we’ve all had experiences of being bitten and hit (this was a team leader), I’ve had this happen and I’ve had that happen and that is how it is”

“I have had to go into battle every single time to be heard”.

In regards to using the portal for Sadie’s plan, I had to wait 6 weeks before I was able to access it to pay my providers that was after around a dozen absolutely frustrating calls to the call centre most of which was while I was in NZ, saying goodbye to my sister who was terminal with Breast Cancer. Still nothing changed, only the story as to why it was not working each time. Despite the complex care planner being aware of it, her response was I’ll get back to you. It was only resolved after the Associate Director in NSW becoming aware of it - that something was done so that I finally got access. The financial stress that put us under as we were unable to pay carers that we desperately needed cannot be underestimated, and if I did not have strong relationship with Sadie’s respite provider, they would have been quite within their right to have refused us service.

The support I have received was from Specialised Support Coordination walking alongside me through this process and having contact with the complaints team in the Eastern States. I managed to form a relationship with a NDIS Complaints Officer who actually was the first person in the NDIS to listen to me and reassure me that we would get it sorted. It was only through him that I had a glimmer of hope that someone understood what we were going through and that we might be able one day get what we need for Sadie.

From my dealings with the NDIS as it was implemented into WA, I was put in a position where I was unable to look after my daughter and it began to affect my other two daughters.

We have not been able to access the correct supports for Sadie in over 13 months, this is due to the instability around her plan, and she has regressed in areas that she may have been able to start to develop in if she had had the right intervention.

Planners need to be retrained and have an understanding of complex needs not just quote the policy line they need to be aware of the impact of this process on families and their lives.

The complex care planner needs someone in that role who has a high level of knowledge and skill, empathy, understanding and can support families who are in this pathway because their loved one has complex needs and often they are in a critical situation.

I firmly believe the challenge for families supporting our loved one with complex needs can be traumatic enough, that having to repeat our trauma is detrimental to our wellbeing, our families and ultimately our loved ones with special needs.

Case Study 2 - Stephanie

Stephanie is my daughter, she is young 20 year old woman she lives with us in the family home. Stephanie has autism and severe epilepsy. Stephanie is a vibrant engaging young woman who loves to get out and about enjoying life. She is dearly loved by the family and extended family and is a very valued part of the family unit. Stephanie is nonverbal and communicates using facial expressions and body gestures. It's very important that Stephanie has people around her who know her and who can understand her communication.

Stephanie has received supports in the State System for many years and as her mother I developed a good support network of paid supports around her that assisted her and us as a family. We were very well prepared for the initial meeting when moving across to the NDIS from the State System. I spend an enormous amount of time with my Local Coordinator (LC), therapy providers and support team developing the information, reports and articulating Stephanie's needs.

“I was very nervous about the meeting with the NDIS- didn't know what to expect”

The initial meeting was held with the NDIS in March 2019. I was very nervous going in to meeting unsure of what to expect but I was well prepared with information about Stephanie. Stephanie attend the meeting for about 15 minutes with a support person to introduce her to the planner so that he could have the opportunity to meet her and get a sense of who Stephanie is and what her needs are. I was supported in the meeting by my LC, therapist and community access provider. The meeting seemed to go well.

“I felt heard by the planner”

It went wrong after the meeting, I don't think the planner who met with us built the plan. The plan we received was significantly short and meant that Stephanie could not access her community access services as she required 1:1 support and this was not included in the plan.

“When I first received the plan it looked like a lot of money”

I didn't understand how to read the plan, no one called to go through the plan with me, and I had no guidance at all. There was no support coordination only support connection, in the plan which was not helpful.

“I felt lost- no one to guide me”

At the time of the planning meeting I provided the nominee form and my bank details. When I tried to access the portal these details were not on the system. I

had to go back and forth to the Joondalup NDIS office to get this rectified. This hold up meant that I couldn't access any of Stephanie's funding.

“I didn't know where to start, I had to teach myself to access the MyGov NDIS and the portal”

When I spoke with the NDIS nothing changed quickly it just took so long. No one advised me to link accounts and authorization to access Stephanie's funding. I have always self-managed Stephanie's funding in the state system and consider myself to be capable but access to the NDIS system took multiple phone calls, in the end I had to delete my MyGov account and create a new account to get things working.

“No one at NDIS helped me to sort this out!”

Once I was able to understand the plan better and realized the funding in the plan was insufficient for Stephanie to access her community supports I attempted to contact NDIS and explain the problem. I called numerous times. Sent emails received a generic response. Never a return phone call or email. I then had to engage People with Disabilities WA (PWdWA) advocacy services to support me with the issue.

“I didn't understand the process to get a review”

Eventually I was told an internal review would be quicker. In April I was told by NDIS I would have an internal review. This did not happen until October 2019- 7 months later! PWdWA provided advocacy however the advocate found it very difficult to get any information for me. The advocate also assisted me to do a changed circumstances and submit that as my mother was extremely unwell and dying at the time.

“Didn't change anything”

Not only was I worried about Stephanie not having the supports she required but I was also trying to be there for my mother who was dying. I was really worried about using the funds in Stephanie's plan because I thought we may run short if the internal review didn't happen.

“I was denied the right to be at my mother's bedside as she was dying”

Then the NDIS called me doing a survey as to my satisfaction about the internal review process. I explained that the review process had not occurred and told her my story. She escalated this internally and I received a call within days from a planner and all that I required was to put into a new plan.

As a family this whole process has been extremely stressful. I was denied the time to spend with my mother before she passed away. I had no one I could call

in the NDIS every phone call was a different person. The email responses from NDIS are generic with no names no contact details.

“I am just a number”

The old system had its flaws but at least people cared. No ounce of care has come from the NDIS. I miss having the relationship and the connections provided by the old state system. I had someone to call, who knew Stephanie and my family. The major events in my family over the past 12 months including losing my mother have taken its toll on us. Life still has to go on. Supporting my daughter with a disability is a big part of my life but I have other obligations. NDIS has too much procedure and red tape.

Case Study 3 – Ben

My wife and I are 83 years old and have dedicated the past 35 years to the care of our son Ben who has Down Syndrome and complex needs. Ben is a valued part of our family, he has siblings and nieces and nephews who are a part of his life however they have their own life to live. Ben is fully dependent on myself and my wife who are Bens Guardians, and Administrators as well as his main carers.

Ben is nonverbal and requires people around him that know him well and can engage him in meaningful activities, connect with his community in Albany and remain healthy and well. Ben lives with my wife and me in the family home in Albany and stays with a host family arrangement for part of the week. All of Ben’s team of care support workers are members of extended families that have known Ben for years. In our struggle and journey as a family, we have brought together the necessary network of skilled and specifically trained group of people around Ben that understand him and are able to assist him to have a good life. It would be a tragedy for Ben, and us, if the NDIA force this to discontinue, and instead return to the “new” system that duplicates the worst aspects of the old State Disability Services Commission (DSC).

Under the W.A. state system we developed and registered Ben’s own business “BAC” in order for us to have the control to develop the supports that meet Ben’s needs. Through that business we were able to access State funding as a “provider” to the State DSC. It was an incredible battle and required changes at policy levels to allow this to happen. We had to comply with all the accounting and administration and Australian Tax Office, and Centrelink requirements in the same way as other service providers to the Disability Services Commission. We have successfully accomplished this for more than 10 years.

As the transition across to the NDIS started to roll out across WA my wife and I have spent copious hours studying the NDIS Act 2013 and attended many

information sessions in Albany and Perth to try and gain a better understanding as NDIS rolls in to WA.

The engagement with NDIS from our perspective has been an utter debacle. There is a distinct possibility Ben will have to be cared for 24/7 by us, his 83 year old parents until we drop. We do not want to have make that our “fall-back position” but the lack of transparency and communication is so unsatisfactory leaving issues unresolved, we just may have to take that fall-back position until all matters are fully resolved. The daunting problems ahead in dealing with NDIA cause us to reconsider if in fact it is really worth the trouble of lodging an insurance claim with the NDIA. We have engaged a highly qualified accountancy service to act as a joint “nominee plan manager” with me, but the lack of communication appears a non-acceptance of a professional service “outside” the “market” of acceptable accountancy services the NDIA want.

The time consuming difficulties of having to deal with this type of unnecessary complications tend to make the whole exercise of lodging an insurance claim with the NDIA unviable. This is particularly evident after a claim is “activated” without advising the “participant” the conditions of using that claim. NDIA insurance claims have to be repeated less than a year later as a condition of use have the appearance “**None of that is worth the cost in time and money**”.

Our “fall-back” position appears the more attractive option to just ignore the NDIA. That is a position one of our friends have already taken. When we have no capacity to deal with this or we die, the Public advocate can deal with the endless problems set up by the NDIA.

As evidence that the above is no exaggeration I refer to the 2019 published review of the 2013 NDIS Act by Mr. David Tune repeated many times all over Australia. It should be noted that the review of the NDIA Act was to find out why so many participants were not fully accessing their claims.

In summary the review highlights the complicated language and ambiguous meanings in the NDIA Act. It also highlights the dependence of the whole system on an even bigger cohort of people who provide up to twice the hours of unpaid (informal) services to support the system than those employed by the system. These are family, age pensioners, employed and unemployed parents, siblings and relatives.

Our experience to date has been less than transparent. On the 23/4 2020 we were advised that we were participating in a pre- planning meeting phone interview with a planner. We were also assured that when the “draft plan” was completed the Geelong office of the NDIA would call us for a second meeting to discuss the proposed plan and agreement to activate the plan. No contact from Geelong.

On the 21/5/2020 we received notification from NDIS that as Ben's guardians we needed to sign the nominee form and provide bank details. These were hand delivered to the Albany NDIS office on the 2/6/2020 and office stamped to acknowledge receipt.

On the 5/6/2020 we received an email from the State System advising that Ben would be exiting that system because he now had an activated NDIS plan. We have neither received the plan nor had phone contact from NDIS advising that there is a plan activated for Ben. We have no idea what was put in the plan, how we can pay for supports. We don't know how to log onto the MyGov site we have no activation code.

We are now in a situation feeling like we have been ambushed into signing documents that have activated a plan that we have had no knowledge existed.

“Any future phone meetings with NDIA need to address the question- Is this a clever ambush or is it an elaborate scam? How will we cope with dealing with the NDIS into the future? Is it all about ownership, control and marketing? And how does this apply to our family?”

For the experience with the NDIA to improve, the system and staff need to be honest and open with people.

Give people time to consider options and the right of freedom for open and honest choice instead and to discontinue the policy of controlled and manipulated choices to fit the heavily controlled marked creation of selected "providers" that the "participant" must use.

Case Study 4 – Mrs W

I am 58 years old and have a vision impairment which is a hereditary condition and my mother, grandmother and great grandmother had the same condition. I was brought up by my parents to believe in my strengths and capabilities. My mother, grandmother and great grandmother all worked in the mainstream occupations.

Where I attended primary school I learnt to read braille and learnt skills to help me manage my limited vision. In upper primary I we had some integration into mainstream classes and I finished my education in a mainstream high school. I then went to Business College and completed a course as a receptionist.

In my work career I have had a number of jobs including both mainstream and supported employment. I owned a clothing business with my father for three years two of those years I did on my own as my father had passed away.

I worked for 22 years for Royal WA Institute for the Blind (now Senses Foundation), 16 years as a supported employee and 6 years on award wages. I held various positions during the time that I worked there including admin assistant, clerk, receptionist and sales assistant.

During the last two years of my employment at Senses Foundation I successfully completed further study in Community Services Certificate III and IV at Mt Lawley TAFE and after completion of my practicum in a mental health organization I was employed as a support worker.

After leaving my job in mental health I went on to complete both a diploma in counselling and a diploma in community mental health.

I am a very independent person and although I have had challenges both in trying to find employment and in work places that have been around discrimination because of my disability; I feel very proud of my achievements.

I currently work in supported employment with Workpower and this is of my choosing. I know I don't need to work in supported employment but it is my decision to do so.

Entering into the NDIS was not of my choosing. I was told that I had to get an NDIS plan if I wanted to continue to work at Workpower because of the changes to funding. I had some assistance from Workpower to prepare for the planning meeting and received a call from the planner who was to meet with me. He asked if I needed any additional support during the meeting to allow me to participate fully. I advised this was not necessary. When I came to the meeting the planner had changed and was not the person I had been speaking with on the phone. However the lady planner was pleasant enough.

“I felt scared going into the meeting and felt I needed to ask for more help than I required in case I didn't get my employment funding”

I felt that the planner made the assumption because I have a disability that I am not capable of managing in my daily life. I have never had any help prior to the NDIS and don't want any help other than funding to work. When the planner sent me a participant statement to read, I was made to look like I was more disabled than I am in what she wrote. She kept writing “.....**as best she can**....will “. I was so upset that I emailed the planner and asked her to please take that out of the plan. She never did and I received the plan with these statements in it. I was so very hurt and upset.

I never mentioned in the planning meeting that I need a cleaner I have never had a cleaner and I don't want a cleaner. It was added into my plan that I needed cleaning support. I also had gardening included. I am more than capable of paying for a gardener if I need one although I really enjoy gardening and do most of it myself.

“There is an assumption that if you have a disability that you are poor and you can’t afford to pay for things....this is so insulting”

I feel like I was backed into a corner and had to accept NDIS just because I wanted to keep my employment. I feel like I have no control over the process.

I do want to keep my job and I do appreciate the work funding and transport allowance from the NDIS, but that is all I need.

Why do I have to be interrogated about my own life? I am a private person and don’t appreciate having to share my story with a complete stranger. I feel that I should be able to go into my planning meeting and let them know that all I require is transport funding and employment funding and that should be acceptable, I don’t like people questioning me further and trying to talk me into adding services which I neither need nor want.

Although I understand more now about NDIS I am still scared and nervous about the next plan review as I feel that NDIS have the upper hand and I will still need to participate in something I never wanted to do in the first place.

Case Study 5 - Ken

Ken is a 53 year old man who lives in a rural area in WA. Ken has autism and apraxia catatonia. He has lived with his family on the farm for most of his adult life until recently when his parents purchased a home for him in the country township. Ken’s parents are both elderly and are big part of his life. He also has a brother who lives in the township who also has a disability. Ken and his family are well known in the township and well supported by the community and the church to which he belongs.

Ken’s mother Mrs F is his main carer and has been very involved in developing the supports paid and informal around Ken to meet his daily support needs. Ken is reliant on support in all aspects of daily living and care. He has limited language and communicates his needs in a number of different ways. Mrs F managed Ken’s supports in the state system and was very involved in his transition across to the NDIS.

Mrs F stated that **“I was very apprehensive we had worked very hard to get the supports for Ken. I didn’t know what the outcome would be so I was very worried about the change”**

Mrs F explained that the meeting with NDIS went well because she had supports from an advocacy service (PWdWA), WAIIS, and OPA Guardian. She said that she felt like the planner understood Kens supports needs and she felt listened too and respected. Once Mrs F received the plan she found it very difficult to

interpret. Mrs F did not understand how to access the portal and was glad that there was support coordination in the plan to be able help her to understand this. She said it was very different to the state system and she found it very complex and confusing at first.

Mrs F said “it’s a very complicated system and I don’t understand why it has to be that way”

Mrs F said that once she understood the plan and the way the funding works, she has been very happy with the outcome. Ken now has the 24/7 support that he requires to live independently in his home and the family feel relieved that he now is well supported. Ken has also been able to get the OT and therapy support he requires which was always a struggle in the state system because of the distance. As she self manages Ken’s plan, she has been able to develop support workers from local people in the town and had the flexibility to look at private therapy providers.

“What has worked is having the funding- not having to worry about not having enough funding”

Mrs F felt that things that could be considered to improve the NDIS would be the acknowledgement of distance for people living in the country. For Ken to receive any services or participate in activities there is often a 2 -3 hour round trip involved. Consideration for the travel costs should be included in the plans. Also she said if she has to come to Perth for any meetings or appointments for Ken there is also accommodation required and this can be very costly as she needs to bring Kens carer with them and the means that a minimum of two rooms are required for accommodation.

Case Study 6 - Pam

My daughter’s name is Pam and she is 47 years old. Pam has Angelman’s syndrome which means that she requires support in all aspects of her life. My wife and I have been Pam’s primary carers all her life I am 73 years old and my wife is 68 years old.

Pam is a bubbly engaging person and loves music, playing, open space and getting out into the community. She has complex needs and requires support from people who know her well, she has a unique communication style which mainly is different ranges of screams and squeals. She is very routine orientated and ensures that people around her understand when she is not happy or needs something. Due to Pam’s condition and her epilepsy she is less able move and requires the use of a wheelchair and will be needing to use a hoist in the near future.

As Pam's parents we made the decision to move to Geraldton from Perth a few years ago to be closer to our other children. This was one of the best things we have done. We now live in Geraldton on a large block and Pam enjoys sitting on the verandah looking out across the fields and bush.

Pam had been in the state system for many years and we always had to be careful about how the state funding was spent because we were constantly concerned about not having enough. My wife and I although we had paid support had to do a lot of the care for Pam ourselves.

Leading up to the transition to NDIS we were very concerned.

"I was extremely anxious and spent weeks preparing documentation, filling in the NDIS book 2, researching the literature from NDIS was not helpful to our situation. Felt like there was a lot of duplication and this increased my stress" (Father)

Eventually we had a phone interview with the planner, we spent a lot of time being really clear about Pam's needs and clarifying with the planner to ensure he understood this. The meeting felt tense because of this.

Pam's plan was approved very quickly and we received everything that we asked for. We are very happy with the plan. The process of moving across to the NDIS seemed on reflection as being seamless. The plan reflects the flexibility, supports her health and wellbeing, and increases our capacity as her carers to continue to support Pam with adequate supports.

We are very happy. We have direct contact with the planner who has shared his details so we know we can go back to him if required. We have support coordination in the plan so we now have that support to implement the plan and the self-management give us the flexibility.

"We are very happy with the experience and the results of transitioning into NDIS".

Case Study 7 – Jordan

I am the mother of Jordan who is 4 years old he has a diagnosis of Autism and Global Developmental Delay. I was a new mum coming into the system. My experience has been mixed in regards to the NDIS planning processes.

I had to wait a long time to be contacted by NDIS to begin with as Jordan was not on the system. Once he was gained access there was another long waiting period to be contacted by NDIS. When we finally had our planning meeting that seemed to go quite well but I was never notified of Jordan's plan approval and being available for us to use.

“I accidentally stumbled on it being approved when I was looking for something else on the NDIS app.”

Apart from not having notification that the plan was live and available to use for Jordan I found the transition to NDIS went well and we received a plan that met Jordan’s needs.

What helped with the planning process was having a planner who was an OT.

“Not only was she understanding but also knowledgeable. This helped in making sure Jordan received adequate amount of funding to his overall needs.”

I would impress on NDIS in regards to improvements that communication is really important. I should have had some form of notification that Jordan’s plan had been approved and was available to use.

Case Study 8 - Ben

Ben is a three-year-old boy with Autism who lives with his family. Ben’s parents are originally from Vietnam. Although Ben’s parents can speak English, but they need some English words simplified for them to understand. Ben’s development is hindered by his disability and he also is in and out of hospital regularly as he requires various surgeries because of his disability. Ben receives speech therapy, occupational therapy and physiotherapy. Ben is currently on a 6-month interim NDIS plan. The family isn’t happy on how the meeting was conducted.

“I got a phone call from the NDIS planner who asked some questions which I thought were pre-planning questions, but I was surprised to get the plan in the post the following week. I was hoping that I was going to get a phone call to arrange for a face-to face meeting, but this did not happen.” said Ben’s mother.

Ben’s mother is happy and grateful that Ben got the funds for his therapy, but she said that she has no idea how many sessions will be covered. Ben did not get any support coordination therefore the family has no idea where to get help about how the plan will be implemented.

The plan states that the funds will be plan-managed, but the family has no idea on what plan management is.

“I was trying to explore on the internet but it’s not making sense. I am waiting for the plan manager to call me so that I can get help in what I am supposed to do with the plan, just like how the Local Coordinator for Disability Services used to do”, said Ben’s mother.

The family had no idea that a plan manager only helps in managing the funds and that they were the ones who were supposed to search for the plan manager. The family said they are confused about how the NDIS process is going.

Case Study 9 – Kate

My name is Kate, and my 7-year-old daughter Mia has Global Developmental Delay. I am originally from China and I was married to a 'white' Australian man who unfortunately passed away of cancer when my Mia was only 2 years old.

I do not have any informal support as I do not have any family here and I do not have close friends that I can share my story with. My family live in China, but I haven't told them about Mia, and I will never do so. I would rather stress by myself than telling my family that my child has a disability. They want to come to visit me to see my child, but I avoid that. I am scared that they will judge me. A few years ago, I married an Australian against their wish so they will obviously say that God punished me and brought a curse upon my life because I disobeyed them.

I have also stopped participating in my cultural groups because the last time I did, my child displayed some behaviours which they said that it was my fault that she behaved in that manner. They said that I have failed as a mother to discipline my child. The other parents did not want their children to play with my child because they think her disability is contagious.

I am grateful that Mia gets funding for her therapies because I would have never afforded it by myself. I am scared that Mia is not going to develop her social skills quickly as I am sceptical of going into the community. I pray every day to God that my child can become normal like other kids.

Case Study 10 – Abi

Abi is an eight-year-old girl with Autism. Abi lives with her father, mother and her two siblings. Abi and her family are originally from South Sudan and they arrived in Australia as refugees a few years ago. Abi's parents do not speak or read English, they only understand a few words.

Abi attends a school at an Education Support Centre and she receives therapy to improve her communication skills, social skills, his physical strength and she also had incontinence issues. Towards the end of 2019, the NDIS posted letters to Abi's parents asking for the completion of the access request for NDIS. Abi's parents saw the letters but they did not know what they meant they thought they were one of Abi's paperwork that were just to be kept.

It was fortunate that the therapist continued to ask Abi's parents whether they had received any message from the NDIS and one day they decided to show the therapist the file with Abi's paperwork. The therapist then realized that Abi was on the final letter and only a week was left to beat the deadline of responding to the NDIS.

The Local Coordinator and the therapists then assisted the family to fill out the paperwork and gather all the documents that were needed to go together with the access request form. The Local Coordinator got in touch with the NDIS and explained to them that Abi's parents needed a translator all the time for communication.

Abi later on got her plan and the NDIS funded support coordination for her even though she was in the LAC area because NDIS realized Abi's parents needed someone to walk side by side with them throughout the course of the plan.

Case Study 11 – Jay

Jay is a 10-year old boy with autism. Jay lives with his parents and two younger siblings. Jay's parents are originally from Syria. The family felt overwhelmed about preparing for the NDIS meeting because they were not sure whether the reports they had were adequate.

“We are really grateful about our Local Coordinator who walked with us step by step to prepare for the meeting and she attended the meeting with us.”

The family were happy with the planning process how the plan was done as they felt heard by the planner. The plan came out after a month which was ok but the family hoped that they were to get a draft first to look at before the final plan, but they were surprised that they were not given the opportunity to look at the draft plan.

The family, however, are happy with the funds that Jay got although they did not get enough funding for a support worker to take Jay out. “We were told that we can apply for a review, but we are grateful that he got something, and it is our responsible anyway to take care of our son”. The family self-manages the funds and are happy with the way the portal works.

The funds that Jay got covers his therapy sessions, but he was denied funds for a support person to take him into the community. The family understands that Jay is only 10 years and it is the family's obligation to take him into the community, but Jay has high support needs and he needs 1:1 support when he is in the community.

“It is very challenging to take Jay into the community together with his siblings because he requires constant support which leaves the other siblings with little

support. This is affecting the siblings as we most of the time end up not going out because of the amount of support Jay needs”, said Jay’s father. The family hopes to get funding for community engagement in the next plan.

Case Study 12- Andrew

Andrew is a peer leader in the amputee community known as the One-Legged Sax Player. This is his NDIS Journey (So Far):

“I had my first planning meeting with a delegate from the NDIS in January 2019. The Meeting was held at the NDIS Office in Joondalup WA, in a very inaccessible building and with no accessible carparks anywhere close to the office.

The delegate had never done a plan for an amputee, so I spent quite a lot of time explaining to him why I had asked for things such as socks and the difference between a day leg, a sports prosthetic and a water limb. The planning meeting went for well over three hours. Way too long.

I was pleasantly surprised at the plan that was given to me. It had all that I had asked for in it. I had asked for a new socket for my day leg, a complete water leg and a new wheelchair.

I didn’t ask for any Core Supports as I wouldn’t use them. He didn’t question this either. I had all my funds agency managed, especially the Capital Supports, which were all “quote required supports”.

Here is where the fun began. It took 3 months from the time the quote for a new socket for my day leg was put in to the NDIS. In that 3 months I had to go back into my old wheelchair as I couldn’t walk using my old socket. After much backwards and forwards with the NDIA it was finally approved. My prosthetic provider started the new socket build and I suggested that it would be good to get the quote in for the water leg as it would take about 6-9 months minimum to get it approved.

We put the Assistive Technology request together, submitted it to the Assistive Technology Team and 6 days later got an email saying it had been approved 100%. Exactly as I wanted. Two weeks later I had a brand-new water leg.

My wheelchair was similar. My OT got me an appointment at Motum. We went there and tried out a bunch of chairs. My OT wrote up an Assistive Technology assessment and request for the agency, including a second set of off road wheels and a Free Wheel. These were put in as separate Assistive Technology requests just so if they knocked them back, we would still get the new chair. Now, being as though I am not a fulltime chair user, and the NDIS had just funded me

\$13000 for a new water leg, we were not confident that they would approve what we had requested. A week later my OT had an email from the Independent Living Centre, as the Assistive Technology Assessment Team, asking her if I still needed the chair. She replied yes he does. A week after that we get an email from the Assistive Technology Team at NDIS saying the fund for the chair, the second set of wheels and the Free Wheel will be in my account tomorrow. So, the whole process was done and dusted in about 4 weeks. The new chair is awesome.

First plan complete. Second plan, January 2020.

I attended my planning meeting at APM in Warwick. The Local Area Coordinator had never worked with an amputee so similar situation to NDIA Planner.

The planning meeting went on for about 3.5 hours. I felt I was listened to and validated.

Predominantly my plan was about maintenance of my current Assistive Technology and the ability to have repairs and minor rebuilds done as required. I also asked for Home Modifications to be placed in the plan so I could start the process of having my house made accessible. With this in mind I gave my Local Area Coordinator the Functional Capacity Assessment that my OT had completed. This Functional Capacity Assessment had all the photos and requirements we wanted for the Home Modifications.

The plan was approved on the 19 January 2020 and on 20 January 2020 went to S100 Review. The NDIA Delegate decided that the Home Modifications were not reasonable and necessary.

Two and a half months later I get a call from the Assistive Technology Review Team wanting to know why I hadn't put any quotes or building designs in for the Home Modifications. I had to explain to him the process, being they open the line item in my plan, fund me to get the quotes and designs, I send it back, they review and say yes or no. This seemed a very hard concept for him to grasp.

Two weeks later, end of April, I get a letter from the NDIS stating that they are going to stick to their original decision of my Home Modifications not being Reasonable and Necessary, BUT, they will give me 15 Capacity Building hours to get another OT report and to complete the Complex Home Modification Form, \$500 to engage a builder to do some plans and an extra \$5000 in my Assistive Technology budget for Level 1&2 Assistive Technology.

At the end of this process they have asked me to put in for another S100 review for them to look at. As I write this, I have engaged a specialist OT who only does Home Modifications, and she has completed the Complex Home Modifications

Form for the NDIA. I am waiting to hear from the builder she has recommended, and I haven't spent any more of the Assistive Technology funds.

So that brings us up to date. As I write this, I have an issue with my socket and am in my really nice NDIA Funded chair. The issue is though, I cannot get said chair out of the house, due to steps at the front and the back and I can neither shower, nor use the toilet, as the chair doesn't fit into those rooms. So much for my Home Modifications not being reasonable and necessary and being told, in writing, that the Home Modifications request was not effective. “

Appendix 2

CaLD Experiences Report

Culturally and Linguistically Diverse Background Engagement with the National Disability Insurance Scheme

Background – Disability and Cultural Diversity in Western Australia

The population of Western Australia is drawn from a wealthy and heterogeneous cultural, linguistic, and historical traditions and is becoming the most diverse state in Australia. According to the 2016 Census, 32.2% of people living in Western Australia were born overseas and the larger number were from non-main English-speaking countries. This population represents more than 200 countries, about 170 languages and more than 100 religious' faiths. The census recorded that 17.7% of Western Australians spoke a language other than English at home (OMI, 2016).

This report focusses on people with disabilities from Culturally and Linguistically Diverse (CaLD) backgrounds, that is people born overseas in non-English speaking countries and their immediate families who may be Australia-born. Therefore, the report excludes issues relating to Aboriginal and Island Torres Strait people. As of the 30th of June 2019, The NDIS reported that there were 24,023 participants (Australia-wide) from CaLD backgrounds in the NDIS, making up 8.4% of all Scheme participants (NDIS report, April 2020). “While the rates of disability amongst people from CaLD backgrounds are similar to Australian-born people, the uptake of disability services in CaLD communities is significantly lower”, (Australian Centre for Community Services Research, Flinders University 2017).

The purpose of this report is to highlight the findings and feedback on the experience of CaLD background individuals in accessing and implementing the NDIS. The information was gathered through surveys from participants and from discussions that were held with multicultural agencies. CaLD people with disabilities or their families participated in the primary research for this part of the project and some of them provided their stories as case studies. The following agencies and groups provided feedback on the NDIS issues arising amongst the CaLD people they are supporting:

- Ethnic Disability Advocacy Centre support group
- Valued Lives support group
- The Metropolitan Migrant Resource Centre (MMRC)

The roll-out of the NDIS is presenting several disadvantages and challenges for individuals with disability together with their families, and service providers. Evidence shows that even though the NDIS has a Cultural and Linguistic Diversity Strategy in place, people with disabilities from the CaLD backgrounds are facing additional challenges to effectively engage with the NDIS as well as fully participating in the community. The implementation of the NDIS across the WA state has potential room to improve the lives of CaLD people with disabilities, if these current challenges are addressed. The information provided by the MMRC highlighted that there has been a rapid and unprecedented increase in complaints and poor outcomes subsequent to NDIS determinations and processes. MMRC reported that there is a considerable number of dissatisfied refugee clients with a disability and for the first time “EDAC advised that due to the demand of its advocacy services they now have a waitlist of 6 weeks for clients with 70% of them NDIS related issues.”

The main themes that emerged from the key findings were as follows:

- Language and Literacy Barriers
- Cultural Barriers
- NDIS limitations
- Cultural awareness and Financial Capacity of Organisations.

Key Findings

Language and Literacy Issues

CaLD communities face difficulties in understanding the NDIS model from access, planning through to the implementation stage. The MMRC highlighted that there has been an increase of NDIS related queries from the CaLD people they support. These enquires displays low awareness of what exactly the NDIS is and how it operates, hence these individuals require a professional that will take them step by step to effectively and efficiently access the NDIS. The larger percentage of this population requires assistance in understanding and filling out of the forms for NDIS and gathering evidence documents required for the justification of why they need support from NDIS. These large volumes of paperwork required for completion and ongoing paperwork required by NDIS tend to dissuade this group of people who have low literacy.

The multicultural support groups pointed out that it is intimidating to prove eligibility that is required by the NDIS. They stressed out that they do not have relevant skills and knowledge and fluency in English, informal support and confidence to pursue additional resources required to prove their eligibility. This group rely on each other for information, which is already scarce within this

cohort. This group highlighted that they get confused of various information that they hear from other people as some of it is conflicting.

Other findings related to literacy are that most CaLD people struggle to understand the terminology that is used by the NDIS. Examples are words like “goals” and “respite” that may seem straight forward but may not be understood properly. NDIS does not offer further explanations of such terms to help people who have English as a second language understand what such words mean. Plan management is another term in particular that one of the participants in the survey indicated that she had a different understanding of what it meant. Her understanding was that the plan manager was someone who was to manage the whole plan for her like what the ‘Local Coordinator’ in the previous system did **(See Case Study-8)**.

Cultural Barriers

Cultural barriers were highlighted by communities and organizations as some of the factors that are hindering CaLD people from effectively accessing the NDIS services. Some families conceal the disabilities of their children because they fear that they will be judged and discriminated by their communities. There is lack of understanding on legal confidentiality, so there is fear that people in their cultural community will become aware of their personal situation. This fear of disclosure prevents people from seeking NDIS supports for themselves or their family members. Psychosocial disability is an example of a very sensitive matter for CaLD background people as they will be highly discriminated from their community if this is known. There is high chances of a person with a disability to experience discriminated and avoided due to social unease or the uncertainty that surrounds behaving appropriately as a “good person”. Heneker K et al, (2017), in their research also noted that there is high rates of psychosocial disabilities within the CaLD people but they are reluctant to share and seek help because “if you say you have a mental problem, people start to be scared of you. . .so I swallow it and keep it to myself”. One of the participants’ family said that they were not comfortable to share their story through a video to make sure that the matter remains concealed within the family.

The findings also revealed that the cultural norms and values of most CaLD background people is such that the family has a responsibility for care for their family members, so they tend to refuse support from the government. A family originally from the Middle East indicated that accepting government funding/formal services is a sign that they have failed to take care of their child which is not a good feeling as a parent. “My husband will work hard to raise the funds that we need for the therapy of our child, and my husband’s family will also help with funds from their business”.

The stigma that is attached to disabilities greatly hinder CaLD background people in accessing the NDIS. A disability is associated with curses or punishment from God because of a past wrongdoing or sin against God. The responses and discussions indicated that some cultural communities perceive that people with a disability cannot undertake education or employment and this can hinder the outcomes of their NDIS plans. In most multicultural settings, disability is highly associated with negativity such that people's easy way out is to conceal it, and refuse support and choose to manage it privately to hide it **(See Case Study 9)**.

Responses were also that CaLD people do not generally attend information sessions especially about disability because they are usually in denial because of the shame disability brings to their families. Autism has the largest percentage of people who deny it exists because in the countries of origin, autism is not spoken about. Some of the people believe that the children will outgrow the autism and normalize as they grow. Other cultural groups believe that God will heal the disability, some rely on natural remedies and other traditional rituals, so they opt not to seek NDIS supports.

NDIS systemic limitations on CaLD people with disabilities

The responses of some of the other people indicated that there is a gap in the NDIS communication system with its participants. When a plan is approved, it the responsibility of the participant to search for their own service providers which is challenging for most people from CaLD backgrounds who usually hesitate to shop around for services. One family shared how they almost missed accessing the NDIS because they received access request letters from NDIS but they never read them because they do not know how to read. The NDIS had no idea that the way they were communicating with the family was not suitable as this family had no skills to read, speak or write. The NDIS had not taken note of the information the Disability Services had provided to them, that this family required interpretation in all circumstances. **(See Case Study 10)**. MMRC's report highlighted that CaLD background people lack skills to self-advocate hence they miss out on services and underutilize the resources available to them. It is difficult for them to create options and choices for themselves to be able to participate in this current market based NDIS era.

The respondents demonstrated that there is a gap in CaLD background people in understanding the Australian disability service system because most of these individuals' countries of origins do not have disability services systems. Indications are that there is lack of socio-cultural literacy of the Australian systems, as there is unfamiliarity with available disability supports for their family members.

MMRC indicated that there is insufficient or non-existent support coordination included in CaLD NDIS participants' plans and therefore there is no assistance

available to help them unpack the NDIS plan or to choose service providers or assist in negotiating with service providers for fair charges on the services. There are indications that CaLD individuals with approved NDIS spend some weeks before starting to receive the services because they struggle to get into the market to search for the services.

MMRC further indicated that self-management is not the best option for some of the CaLD people. There is indications there is a fraction of this cohort who agree on self-management but not understanding what it means, then only to seek help throughout the course of the plan because they struggle to understand how to claim payments from the portal. The three options of fund management are not easily understandable by some people who has English as their second language.

There are also cases where CaLD participants are allocated with lower levels of funded supports because they do not have the knowledge, skills, confidence and fluency on how to ask for the supports that they need. Some of them do not go for an internal review because they are “grateful that they are at least getting something” as it is their responsibility to care for their family members with a disability (**See Case Study 11**).

The Valued Lives multicultural support group highlighted that one meeting of one and half hours is not adequate to build rapport necessary for having a cultural appropriate plan. A planning meeting with an interpreter means more time required for the meeting but this is usually not factored in.

The general summary of the respondents was that there is confusion in the NDIS planning process, from rushed phone planning conversations, inadequate support for participants and a lack of effective communication with both participants and the service providers.

Cultural Awareness and Financial Capacity of Organizations

The MMRC indicated that even if they would love to walk side by side with CaLD NDIS participants, they do not have enough funding/capacity to cover this service. The reduction in the capacity of key CaLD organizations like MMRC to assist NDIS CaLD participants in meeting NDIS documentation, application requirements and implementation is having adverse impacts for refugees to effectively access the NDIS. EDAC provides advocacy, it does not provide case management support and those agencies that currently provide case management services or support coordination for CaLD people with disabilities typically fail to engage refugees and are not trauma informed or cultural appropriate.

MMRC noted that most of the service providers that they refer their NDIS CaLD clients to clearly lack cultural competence and this negatively affect the outcomes of the participants in reaching their goals.

Recommendations

Developing a culturally appropriate case management support system

- This may be achieved through providing funding to agencies that are already working with CaLD people or creating more agencies so that there is enough support for CaLD people with disabilities.
- Such agencies will be responsible for coordinating NDIS multicultural strategies to make sure that CaLD people have someone on the ground walking side by side them, guiding them through the NDIS process.
- It is important to have people who are properly trained to understand cultural issues that affect effective NDIS engagement for CaLD people.
- It is vital to have people on the ground who will build meaningful connections with CaLD people and to have a chance of encouraging CaLD people about the importance of attending information sessions and workshops so as to have enhanced knowledge and skills about the NDIS and service providers.
- Creating a cultural brokering, that is, developing a link or bridge between NDIS and cultural groups to reduce inequality and improve access and outcomes for CaLD people living with disabilities.

Developing a comprehensive culturally competent framework and a trauma informed disability framework.

- It is important that there is culturally appropriate service delivery and preferences for CaLD people with disabilities while understanding that their way of life is affected by the trauma that most of them have gone through in their countries of origin.

There is need for a culturally appropriate disability carer training program

- There is a huge need for CaLD communities to be provided with education to enhance their knowledge and skills with regards to how the disability system works here in Australia, with huge focus on the benefits of early intervention programs for children, how ignoring or refusing supports will negatively affect individuals and their families in future and emphasizing that the NDIS is a professional body that observes confidentiality of participants.

- Training workshops also helps to build capacity for self-advocacy for CaLD people – for them to develop skills to be able to articulate their needs with confidence and fluency.
- Providing simplified training about how NDIS works, from access right through to implementation. There is need to simplify some of the terminology used by NDIS, clarifying the fund-management options in a simplified way and explaining the available services.

Support Coordination is necessary in most CaLD NDIS plans.

- Additional funding for Support Coordination is very crucial for CaLD participants who face communication, language, cultural and systemic barriers to self-advocacy. It is important that the participants have someone they can build a rapport and trust in order to effectively navigate the system.

Cultural competence/responsive training for workers in the disability field

- A cultural competence training program is important to increase greater access and inclusion of CaLD people and increasing their engagement with the NDIS.
- NDIS service providers should be encouraged to build partnerships with multicultural groups/agencies who already have experience of effectively working with people from CaLD backgrounds.

NDIS and service providers to increase their CaLD background staff

- Recruiting staff with targeted language skills and cultural knowledge.
- Creating a team that can meet CaLD participants more regularly, having monthly or weekly meetings with families to create ground for building rapport which will be necessary for the NDIS staff to understand the cultural views of the family they are working with and understanding the strategies that work for the families.

Creating a CaLD engagement and communication strategy to encourage greater awareness and utilization of disability and other support services

- It is important to develop an easy-read format to de-mystify the terminology around disability, explaining medical tests, and diagnoses to family members.

- Developing marketing material specifically for CaLD background people and including contacts of a CaLD team which is within the NDIS.
- Creating a team that can help building a rapport with CaLD people through attending their cultural events.
- Providing training programs for cultural communities on the importance of including their own people in the society even when they have a disability, for them to understand the difference social inclusion will make in a family with a person living with a disability.
- Creating a flexible plan on how and where meetings are held. Most of CaLD people are comfortable to have meetings at their homes.
- Creating partnerships/connections with cultural leaders will enhance entry points of information to the wider CaLD communities.

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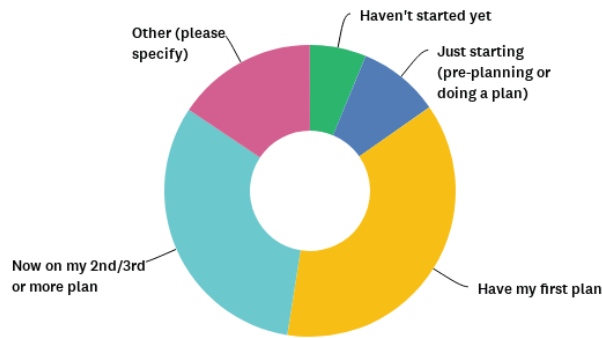
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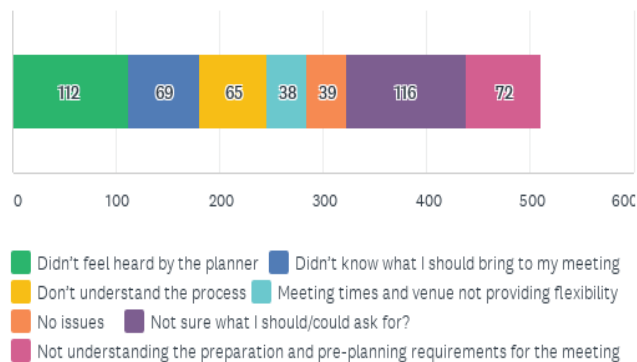
Appendix 3

Survey Graphs

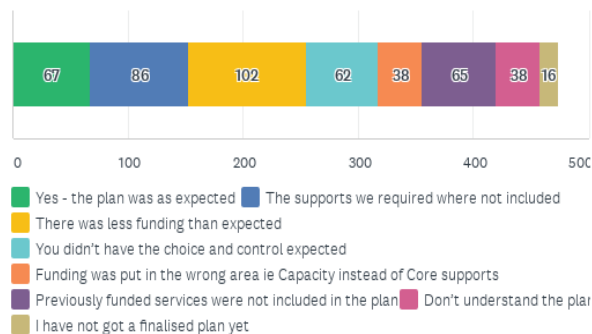
Q6 Where are you on your journey with the NDIS?



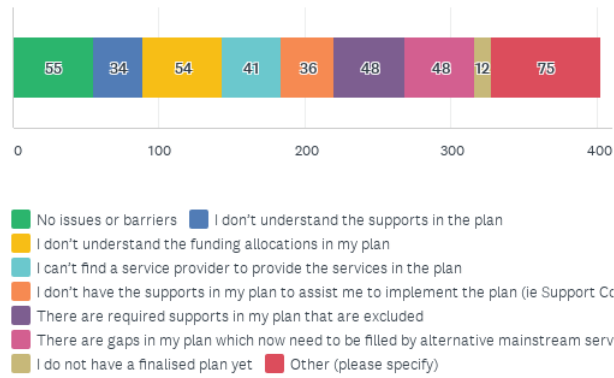
Q7 Have you experienced any of the following issues with the NDIS planning process? (please tick as many answers as applicable)



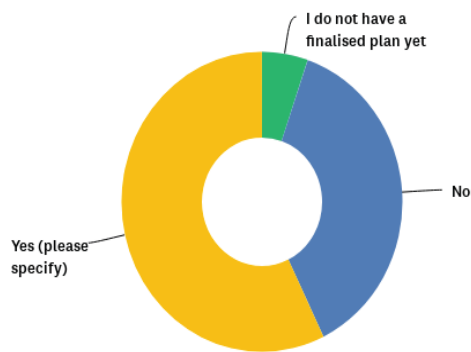
Q10 Upon receipt of your NDIS plan was it what you expected? (please tick as many answers as applicable)



Q13 Have you had any issues or barriers implementing your NDIS plan? (please tick as many answers as applicable)



Q14 Have you had to make changes to your plan before the end of plan review date?



Appendix 4**Evaluation Report**NDIS Transition and Interface Issues Project
Evaluation Report

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Introduction

PwD (WA) engaged a diverse group of people with disabilities to participate in a co-design group, using a solution-focused approach to consider NDIS related issues at an individual and systemic level.

The evaluation considers whether the project achieved all its deliverables and met outcomes based on the key performance indicators identified in the Grant Application. The evaluation considers the satisfaction of project participants, the project outcomes have been progressed or achieved. It examines whether the principles of co-design were effectively applied by the project, whether the model was adhered to and whether the project resulted in increased capability of project participants to effectively participate in co-design.

1. Project Delivery

Evaluation methods

- Interview project lead.
- Email questionnaire from PwD Executive Director.
- Minutes (6) October to March, including issues paper.
- Copies of submissions and mid-project report.

Analysis

PWd considered the project achieved its objective to engage with people with disability and families, identify issues and ensure those issues are heard through submissions and meetings.

The project engaged with stakeholders in a number of ways:

- Online survey with a reach of more than 345 people.
- Consultation with more than 20 peer and/or advocacy groups in metropolitan and regional centres and engaged with more than 350 people in metropolitan and regional centres. This included people from Aboriginal or CaLD backgrounds and people with intellectual or cognitive disability or their family members or carers in metropolitan and regional centres.
- Meetings and presentations to high level stakeholders.
- Co-design team including people with physical, sensory or intellectual disability and autism as well as parents of children with a developmental delay or autism.

An issues register was used to record intersections with particular groups. For example, engagement in Esperance led to families and services banding together on the issue of attracting therapy services to town, which increased awareness and resulted in interest from local therapy services in becoming a provider.

Inputs from focus groups, engagement activities and the co-design team formed the basis of submissions to the Joint Parliamentary Standing Committee on NDIS, the Tune Review and the NDIS Joint Standing Committee, as well as an interim report, which was also given to the NDIA. These submissions and reports were also informed through PWd's advocacy work outside of the project.

The interim report and submissions with recommendations were provided to the Minister's office for consideration and representation at COAG meetings and to independent member of the NDIA IAC, Kerry Allen-Zinner to take the Committee. Case studies and issues raised at focus groups were provided to reference groups on self-management, innovation and the Industry Reference group by PWd's Executive Director.

PWd recognises it is difficult to influence national policy without connecting to the work of national peaks or through national advisory and reference groups, given the complexity of the issues and that the NDIS is a national system. However, the broad engagement gave the organisation 'a good picture of the impact on people on the ground'. PWd considers the scope of the project was too broad and despite good inroads in some regional areas and with some Departments, there was insufficient time to work closely with a wide range of departments regarding mainstream interface and ongoing challenges for people with disability seeking supports, who find themselves at the intersect of government systems.

2. Building Co-design Capacity

Evaluation methods

- Project participants complete pre-project self-assessment.
- Project participants complete post project self-assessment independently, via phone or in a Zoom meeting.
- Four interviews with community members (optional).
- Project participants focus group (via Zoom due to COVID-19).
- Interviews with NDIA and NDIA partner representatives (four).

Analysis

PWd used an expression of interest process and approached relevant individuals to invite participation in a co-design team as part of the project. Ten (10) community members were recruited. A member of the NDIA's WA Community Engagement team and representatives from NDIA partners Mission Australia and APM attended some of the co-design meetings. Stakeholder representatives were not members of the co-design team. They saw their role as listening and providing advice.

The role of the co-design team was to provide lived experience and broader perspectives to the project. PWd used detailed input from the project to inform three submissions regarding NDIS Planning.

- The Joint Parliamentary Standing Committee on the NDIS: The Inquiry into the NDIS.
- NDIS Act Review and Participant Service Guarantee (Tune Review).
- The Impact of Changes to Service Delivery Models on the Administration and Running of Government programs.

The Project Manager felt that in this regard the co-design team had been very effective and that community members had grown in the knowledge and self-confidence to be able to contribute to co-design processes.

In times of direct change, attributable to the project, one of the stakeholder representatives changed their community engagement strategy in response to concerns expressed by the group regarding the ability to get information over the phone. The stakeholder representative introduced weekly casual drop-in information sessions in their local government area as a result of attending meetings. The other two stakeholder representatives provided information back-up through their organisations to ensure issues raised in the group reached decision makers. They did not identify any direct change or result of being involved.

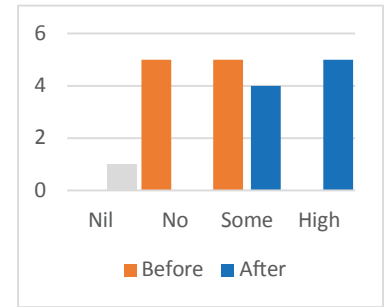
The evaluation found that some co-design team members wanted the group to be able to effect rapid changes in NDIA policy. Other co-design team members felt the group had limited capacity to do this. A minority of community members expressed frustration that the NDIS was unlikely to be improved directly by the group's input.

One stakeholder representative felt that at times this frustration dominated the group and prevented opportunities for collaborative problem solving. "The group dynamics impacted on the effectiveness of the whole group at times. If the group was more cohesive it could have been more effective." The same stakeholder representative said that on occasion, not all community members applied the principles of respect, compromise and mutual exchange that form part of the Connect with Me Model.

All stakeholder representatives found the process was well managed and worthwhile. They valued being involved and hearing directly from people with disability and their experiences of the NDIS. All three organisations agreed they would welcome the opportunity to participate in similar projects in the future.

The Project Manager received feedback from the partners who participated that their involvement would act as a catalyst for them to ensure they bring people together when exploring issues related to the NDIS and transition.

In terms of building individual and community capacity to participate in co-design, the project was effective. Ten (10) community members completed a self-assessment prior to the project commencing and nine members repeated the assessment at the project's conclusion. Four (4) team members requested an interview and nine (9) participated in an online review discussion. One (1) team member did not participate in the evaluation.



Understanding of co-design before and after the project

In terms of co-design practice, prior to the project just two of the community members had previously been involved in co-design. Half of the group reported they had no understanding of co-design and half reported having some understanding of co-design before the project. After the project everyone considered they had at least some understanding and five people considered they had high understanding.

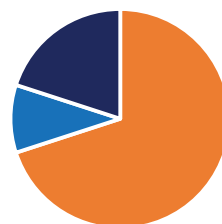
For some people their confidence to participate and confidence to contribute to co-design grew as a result of the project, whilst for others their confidence was tempered. The majority (5) of people considered reported high confidence to participate in co-design after the project.



Some High Very High



Nil Some High



Some High Very High



Nil Some High Very High

Confidence to participate and after the project

Confidence to contribute before and after the project

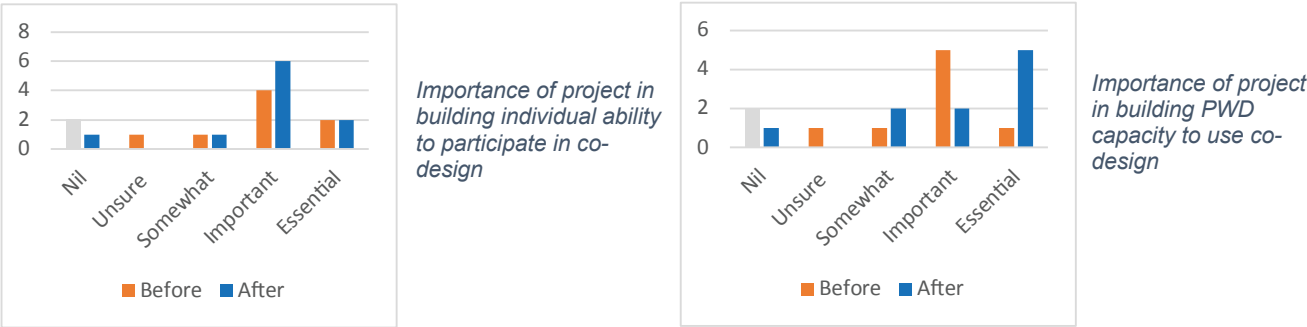
Team members were asked whether the eight principles of the Connect with Me co-design model of co-design were applied throughout the project.

- All respondents agreed (nine) Principle 4: Listening Approach was always applied.
- The majority of people (six) agreed all principles were always applied.
- One or two individuals considered some of the principles were applied some of the time.
- One individual considered the Principles 2: Common Goal and 3: Mutual Exchange were never applied.

Connect with Me Co-design Principles

1. Engage people with disability and involve them in the process from the very beginning and throughout the whole journey.
2. Ensure everyone understands the common goal.
3. Make sure the process includes mutual exchange and is more than consultation.
4. Use a listening approach and be empathetic, flexible and supportive.
5. Be prepared to compromise.
6. Commit to working together in collaboration as a team.
7. Be professional and respectful.
8. Look for solutions that are functional, useable and sustainable.

Community members self-assessed the importance of the project in building their own ability to participate in co-design and PwD WA’s capacity to use co-design. Community members reported an increased sense of ability at an individual and organisational level after completing the project.



The community member self-assessment and interviews found a range of views about the particular co-design process that was used and varied understanding of the purpose and role of the group. Based on their experience, the majority of team members (8) would participate in a codesign process again, although for one person it would depend on the topic. One other person said they were unsure at this time about whether they would participate in co-design again. Qualitative feedback in summarised in Appendix 1.

While all team members were glad to have participated in the project and most considered the use of co-design had benefited the project (8), most were unable to say if the project had been successful, with a strong preference to wait and see what the final project report shows and how the NDIS responds.

For PwD, the project highlighted some process issues regarding establishing co-design and the need to be more intentional about the principles to keep people on track. The Project Manager recommended the development of a guideline for the facilitation of co-design.

The evaluation process identified many practical suggestions for continuous improvement which are attached at Appendix 2. A copy of the questionnaire and questions for interview prompts are included at Appendix 3 and Appendix 4.

Conclusions

PwD achieved its objectives to effectively engage with a large number of people with disability across metropolitan and regional WA. The inputs provided through the consultation were used to identify key themes and issues and were used to directly inform a number of submissions as well as communication with government stakeholders.

PwD had set out to ensure the voices of Aboriginal people with disability and people from culturally and linguistically diverse backgrounds were consulted. However, due to the complexity of the issues, there was insufficient time within the project to establish the links into communities to gain deep engagement. While individuals participated in several sessions, not as much was achieved in this space as PwD would have liked.

PwD considered more needed to be done to engage with Aboriginal people using specific and targeted strategies. The Project Manager reported that while the project allowed for exploration of local issues, more time was needed to build connections and put intentional effort into engaging with Aboriginal people with disability.

The project was effective in establishing a co-design team that built the capacity of individual community members and PWd staff to meaningfully participate in co-design. The project provided a practical opportunity for PWd to also refine its co-design process and identify opportunities for continuous improvement.

Through these processes, PWd captured the NDIS experience of people in WA, for example, the issues of draft plans and flexibility of funds usage. Issues of NDIA planners in regional areas not engaging where First Nations people live, and the need for community engagement in regional areas to drive local solutions to thin markets. These issues were presented to State and national representatives and inquiries in a bid to ensure people with disability are represented, heard and responded to in the national scheme. The longer-term nature of the changes required means those potential outcomes cannot yet be evaluated.

Appendix 1: Summary of Qualitative Feedback from Community Members

Did the project achieve its objectives?

- I don't think we will know until the project is completed.
- I'm looking forward to the report.
- I think it's coming together.
- The objectives moved a few times. It felt like the group has to accommodate the NDIA. We didn't have that decision making where it led to forging a path ahead. I thought we were meant to be able to say what we think.
- Yes, as people who have lived experience at making contribution to what is affecting them directly.
- This can only really be realised once the report findings from the co-design have been implemented and there will always be members who may be less than happy with outcomes as it is very personal and confusing for some.

How would you describe your experience of co-design?

- It has been very beneficial to come together and hear different perspectives and experiences of disability and the challenges that arise from NDIS, and to be able to think beyond the personal experiences in the group to that of the community at large with disabilities, to give feedback to NDIS and related service providers.
- Having service providers attend meetings and be a part of ongoing discussion has also been a valuable exchange. It has been a privilege to contribute to something greater.
- It has been an interesting and informative experience.
- I was very happy to be part of it and to have the experience and understand different people's points of view. Everyone was given plenty of time to have an opinion and present suggestions they had and hear what other people thought. I was glad to be part of it. I have a sense that they all have input but really it was just meetings where we talk about stuff.
- The way the project was constructed didn't allow for true co-design. The co-design process wasn't really well-established as to what we were meant to be doing.
- I wasn't as involved as deeply as I would like to have been. The purpose was unclear.
- We were expecting to have input and provide advice but I had limited access to information. At times it felt like I was being shut down.
- It has opened up my eyes to issues that other people with disability are going through

- Overall, I'm glad to have been a part of it. I'm probably more positive than negative, but we have a long way to go.
- Definitely a learning experience, especially looking from other points of view.
- It was very enlightening for me to learn about the experience of others and how they required support within the community, and discussing how each participant was affected by the rollout of the NDIS and how it could be improved in a balanced way.

Key learnings: When you reflect on the project what would you do differently?

- There was resistance in using online formats prior to COVID-19. My ideal model of co-design is consumer-led. Consider use of gift cards rather than cash to suit individual circumstances.
- I would have liked to have seen the project budget and seen what could have been done. It would have been nice to have co-designers attend consultations to maybe broaden the feedback that might have been provided.
- Unfortunately, it is unavoidable, but the coronavirus restrictions have made it more challenging to Zoom or attend Zoom meetings as a stay-at-home mother with no available babysitters during this time. If there were a few participants with children, a child-minding option would have made my participation in the project much easier.
- It took too long to get there but maybe that's the process we needed to be patient with it.
- Sometimes it felt like we were going over the same ground week after week. We were following the process, but it seemed to go for ages.
- Provide more clarity on interface with NDIA. The idea that there is participatory voice is hugely important to me and though nobody did anything bad. I don't have any satisfaction that what I said matters.
- Give more responsibility to the co-design team with respect to outcomes and broader issues.
- More research so that I am able to contribute more to the group.
- Have the chance to properly challenge some of the responses of the guests as they did at times contradict themselves, leaving us with information that didn't quite answer the question or sometimes just didn't make much sense.
- Attempt to follow the co-design format more closely within the group environment, including the categorisation of all individual responses of situational representations as recorded within the minutes (a time-saving thing).
- I was interested to know the full project budget so I had an understanding of what is possible.
- The gap between meetings was too long to maintain focus. It would be good to catch up in between, perhaps online.
- Yes, there were times when we could not be there in person and those people were able to communicate and participate via other means. Minutes were provided for each meeting so we could all keep up with the co-design group.

What skills/knowledge or personal attributes made you an effective co-designer?

- Ability to engage with people.

- I think my ability to listen, empathise and consider situations from a range of perspectives and to also come up with practical strategies to improve service provision.
- To be an effective co-designer you need to be prepared to learn, read, listen. You need to be patient, interpret information, contribute and ask questions.
- Bravery, curiosity, ability to listen, determination.
- I am an extremely good listener and am willing to learn more about how others are affected by the system and its professionals, I always attempt to conduct myself in a professional manner with integrity and have experience in supporting and mentoring others.
- Listening to other people's points of view. I had some positive NDIS experiences that I could share with the group.
- I have the ability to abstractly think out a situation and am able to view the same thing from many points of view.
- I also have some knowledge of how parts of the disability sector operate and I love to listen to what people have to say and express myself in ways to ensure everyone can understand.

Appendix 2: Recommendations to Improve Co-design Process

1. Set expectations and document the shared goals when using a co-design process.
2. Be clear about whether PwD is using organisation led or peer/consumer led co-design and whether that extends to co-production of resources/materials.
3. Provide role description including role of facilitator/Project Officer.
4. Share the constraints and the full scope of projects where co-design is one component.
5. Communicate constraints to involvement at the outset and be clear about how inputs will be used.
6. Provide the agenda earlier to give people time to think about it and offer supports to people outside of meetings to prepare for meetings and to get across any materials.
7. Refer back to the model and principles throughout the co-design process to provide clarity and track progress in using co-design. Community members reported the process was very fluid and, sometimes, they “didn’t really know the direction” of the project.
8. Provide more time for co-designers to get to know each other and understand their knowledge so the group can see where there are gaps and who needs to be represented.
9. Consider interim online meetings to support co-design team members to remain focused and connected.
10. Conduct a mid-project health check using an independent person, to get feedback on how the project is progressing and identify any issues that can be readily addressed.
11. On complex issues, community co-designers independently nominated a preference to work in smaller groups rather than as a single larger team.
12. Consider broader role for co-designers in designing and implementing the project itself e.g. undertaking consultations.
13. Consider whether there is scope for the co-design team to be established as an ongoing advisory group to PwD on NDIS matters.
14. Provide a broader range of payment options.
15. Provide clarity around future pathways for the project when they become apparent.

Appendix 3: Self-Assessment

People with Disability WA :Post project Self-Assessment

1. How would you rate your understanding of co-design after this project?

No understanding	Low understanding	Some understanding	High understanding	Very high understanding
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2. Were the principles of co-design applied? Please answer Yes, No or Sometimes for each principle.

	Yes	No	Sometimes
Engage people with disability and involve them in the process from the very beginning and throughout the whole journey			
Ensure everyone understands the common goal			
Make sure the process includes mutual exchange and is more than consultation			
Use a listening approach and be empathetic, flexible and supportive			
Be prepared to compromise			
Commit to working together in collaboration as a team			
Be professional and respectful			
Look for solutions that are functional, useable and sustainable			

Comments

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3. Did the project achieve its objectives?

Yes	No	Some
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Comments

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4. Did the use of co-design benefit the project?

5. Yes	No	Some
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Comments

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6. How would you describe your experience of co-design?

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7. Key learnings: When you reflect on the project what would you do differently?

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8. How confident are you today to be able to participate in co-design processes?

No confidence	Low confidence	Some confidence	High confidence	Very high confidence
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9. How confident are you today to be able to contribute to a co-design project?

No confidence	Low confidence	Some confidence	High confidence	Very high confidence
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10. How important do you think this project has been in building your own ability to participate in co-design processes?

Not important	Little importance	Somewhat important	Important	Essential
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11. How important do you think this project has been in building PwD's capacity to use co-design?

Not important	Little importance	Somewhat important	Important	Essential
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12. What are skills, knowledge or personal attributes that made you an effective co-designer?

Please list

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13. Based on your experience of this project, would you participate in other co-design projects in the future?

Yes	No	Some
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Comments

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14. Would you like to provide further comment through a one-to-one conversation with the evaluator? Interviews will be held over the phone on either 16, 17 or 20 of April. The interviewer will email you to agree a time and then call you at the agreed time and date.

If yes, please provide your email address and phone number below.

Email:

Phone:

Preferred date:

If you don't want to provide more feedback, thanks for your time in completing this self-assessment.

Appendix 4: PwD Evaluation Questions

Questions for Executive Director

Did the project achieve its objectives?

How do you know that?

How were the inputs from the engagement events/activities utilised in the project?

How has the project contributed to the removal of barriers to collaboration, or co-design with the NDIA and People with Disability?

Do you expect that to have a lasting effect?

What was your main learning arising from the project?

Do you consider the project increased collaboration with mainstream organisations? If yes, provide examples. If no, why not?

What do you consider to be the critical next steps to maximise the outcomes from this project?

Questions for Project Officer

Do you consider the project increased collaboration with mainstream organisations? If yes, provide examples. If no, why not?

How many people participated in the survey?

How many -rural communities/remote communities participated in the survey?

How many engagement events/activities were there during the project?

How many people were involved in the engagement events/activities?

Which community groups were represented in the engagement events/activities?

What range of disabilities were represented at the engagement events/activities?

What are the deliverables required of the project and were they delivered?

How did this project impact on individual project participants?

How did this project impact on project partners?

How were the inputs from the engagement events/activities utilised in the project?

How would you describe the level of collaboration or co-design utilised in this project? What was the role of the coordinator/Project Officer in this project?

Questions for group Zoom discussion

What did you think of the project?

What do you think about the process?

How did you contribute to the overall solution?

What worked for you?

What did not work for you?

What did you learn?

What impact did the project have on you?

Would you participate in a similar project again?

