NDIS EXPERIENCES 2016

A report detailing survey and forum feedback about peoples' experiences of the National Disability Insurance Scheme (NDIS) in Western Australia.

October 2016

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Introduction

Western Australia (WA) is in the unique position of having two models of the National Disability Insurance Scheme (NDIS) being trialled in the State. We are now over two years into that trial, with the trial having been extended to June 30, 2017.

The purpose of having two trials in Western Australia has been to test different ways of implementing the NDIS given that the Western Australian government has had a long experience of implementing an individualised system. The state government has been clear that it supports having the NDIS in Western Australia but that it believes a better system will be provided to people with disabilities and their families when the state retains control of the administration and governance of the NDIS. There are a number of pros and cons to whether a national scheme that is governed and administered at the state level is the best option for people with disabilities, their families and carers. It is not the purpose of this report to explore those reasons, although we do believe that many of the issues raised in this report may be addressed differently depending on the governance that is put in place. The purpose of this report is to ensure that the voices and experience of people with disabilities, their families and carers in all trial sites are heard, and those experiences are considered in intergovernmental negotiations and ongoing development and evolution of the scheme in Western Australia.

People want to get the best scheme for NDIS in WA. The results of the independent evaluation commissioned to inform the changes required to get the best system, based on the learnings from both trials has not yet been made public. As such this is one of the few mechanisms that has been available that crosses all trial sites. The purpose of this survey and report is not to compare the two models that are being trialled in WA, but rather to raise the issues of where improvement is needed and where changes need to be made to have a model which will work for people with disability, their families and carers in WA.

Background

In July 2014 the National Disability Insurance Agency (NDIA) began a two year NDIS trial site in the Perth Hills. At the same time the Disability Service Commission (DSC) began a trial of My Way NDIS in the Lower South West. A further My Way NDIS trial site began in July 2015 in Cockburn and Kwinana.

In August 2015 a number of disability advocacy organisations, and consumer and carer representative groups collaborated to collect feedback from people with disabilities, their families and carers about their experiences of the National Disability Insurance Scheme (NDIS) in Western Australia (WA). Feedback was gained from participants in both the National Disability Insurance Agency (NDIA) trial in the Perth Hills, and the WA NDIS My Way trials in the South West and Cockburn/Kwinana. The purpose of this consultation was to provide a direct feedback mechanism from the trial sites to decision makers to inform the pending negotiation of the final reform arrangements for Western Australia.

A report was produced as result of the feedback from NDIS trial sites in WA entitled "NDIS Experiences" (available at http://pwdwa.org/). The report was presented and considered by senior officers of the National Disability Insurance Agency (NDIA) Commonwealth Department of Social Services (DSS) and State Disability Services Commission (DSC).

In July 2016 further consultation was undertaken to consider the experiences of people in the NDIS in WA at a later stage in the trials. The method for consultation was the same as the previous approach, an online survey and focus groups; and participants again self-selected, with advertising of the survey going through the NDIA and DSC. In addition, case studies and feedback from advocacy agencies and other surveys that have gathered information directly from participants have been noted. People from non-trial sites were invited to provide feedback and this data has been captured separately.

At the time this survey was being completed, there was a lot of tension and stress in the disability community as the end of the trials were soon approaching. Originally the trials were going to be finished in July 2016, and many people were unclear as to what would be happening next. In June 2016 there was an announcement that trial sites would be extended in Western Australia for another year, to June 2017. It was also announced that the governance arrangements for WA would be expected to be finalised in October 2016 and an announcement made then. This report is now being analysed in the context of another period of stress and tension amongst the disability community as there is still no clear direction on how the governance of the NDIS will work in WA into the future.

Findings

This report follows on from the previous report with a discussion section which explores the context of the NDIS in Western Australia currently and how findings from the survey fit within that context. A number of recommendations have also been made, many of which are the same recommendations that were made in our first report. Analysis of the survey responses has then been done on a question by question basis with quotes and case studies to highlight particular points.

Many of the findings in this report echo those that were found in our 2015 report. There is no clear indication that one model is preferable to another, but rather that there are strengths and weaknesses in each of the models across the trial sites. Many of the areas that require attention are still the same and fall under the same categories:

> *System design issues*

> *Experiences of obtaining information*

> *Experiences with the planning and plan implementation process*

Notable changes in the findings are that the participants in the Cockburn/Kwinana trial site were reporting greater satisfaction this time compared to the issues that were being raised from our previous survey. However, despite greater satisfaction rates, many of the core issues as previously identified remain unchanged. These related to flexibility in the planning process, use of funding, choice of service providers and coordinators, as well as access to good information and transparency. On page 18 of the report there is a table which shows what participants of the survey identified as working, not working, and recommending for improvement from our 2015 survey and this survey.

Key messages for government

Our consultation is not exhaustive or representative and provides no indication that one NDIS model is performing consistently better for people with disabilities, their families and carers in the trial sites than the other. The questions raised in our first report are still entirely relevant now with no clear indication from State or Federal government on what the final reform model for Western Australia will be. In particular, we would point to the principles that are enshrined in the NDIS legislation and ask that all aspects of the system that are put in place for Western Australia are measured against whether they are meeting those principles. This is not something which we believe government is able to do objectively and must be done in collaboration with the representative organisations of people with disability, their families and carers. Those critical questions which we believe need to be considered and explored on an ongoing basis are:

- How are all aspects of the system meeting the objectives of 'choice and control' and the principles enshrined in the NDIS legislation?
- How do the diverse population of people with disability, their families and carers measure the success of the NDIS reform?
- How well does the system enable people with disability, their families and carers to realise broader outcomes such as independence, inclusion, citizenship, social and economic participation?

Discussion

Our consultation has given a unique insight into the experiences of people with disability, their families and carers in trialling the NDIS in Western Australia. This discussion is primarily influenced by the information gained from the 2015 and 2016 surveys and forum feedback. Part of this discussion is also as a result of direct client feedback from our advocacy work and conversations we have had with Federal and State Government agencies.

Our 2015 report discussed the findings from the perspective of those things that people with disability, their families and carers were looking for in the NDIS – sustainability, rights, consistency and quality. The need for a system which is flexible and responsive has again been a highlight of the findings from our consultation. An added element which has also been raised is transparency for the person with disability, their family and carers.

As people have been waiting for a decision on what the arrangement will be for the NDIS roll out in WA, stress has increased for those within and without trial areas. Below are the key areas which we believe need further consideration for how the NDIS will roll out for people with disability living in WA. Although many in the disability community are concerned that Western Australians with disability are not disadvantaged, we also hope this feedback may go to improving the NDIS as a whole and that learnings from WA will always be important to the national scheme.

Principles in Legislation – People both in and out of trial sites are still not confident that WA will have the NDIS, or that a WA model will have the same principles, eligibility, and portability. The principles in the NDIS legislation were developed through consultation and clearly connect to the UNCRPD and National Disability Strategy. They especially highlight the principles of choice, control and impact on consistency of the scheme across regions such as the interpretation of reasonable and necessary, and the appeals process. There is concern that these principles are not being met with comments from participants about lack of consistency in interpretation of reasonable and necessary, lack of flexibility in use of funds, lack of responsiveness when wanting to change services, lack of transparency and supports for appeals processes. Any need for separate State or Commonwealth legislation to enable the NDIS in WA will need to ensure these principles are mirrored, and more importantly that the system is continually evaluated against those principles to ensure quality of the NDIS in WA.

Engagement with people with disability – Our recommendations again highlight the need for people with disability, their families and carers to be involved in feedback and engaged in design and governance of the scheme. The governance structure in WA needs to include people with disability on any Board *and* in an advisory capacity. There also needs to be a commitment to co-design and an inclusion of people with disability and their representative organisations in policy development and evaluation. Both in our survey and in peer support groups' people have commented that they haven't felt heard and wanted a culture of listening and learning to be evident in the scheme. It is particularly concerning when issues which are raised by more than

one person or group are dismissed, or when policy may be in place but is being incorrectly implemented in practice, for example.

Data and Technology – Data needs to be collected and analysed consistently, creating not only State-wide parameters but also National indicators. It is important there is consistency in recording and analysis of data, and measurement of outcomes against the same criteria using the same methodology. As evidenced in our survey, different design aspects mean potentially responses are not accurate for example the role of Local Coordinator in the WA NDIS is not the same as the Planner in the NDIA.

Although there were issues with the NDIS Portal during the change of the National scheme to a full roll out, it was still seen as a beneficial tool by those surveyed and in forums. A key point made about the portal was the ability to keep track in real time of expenditure and funds used by services and when self-managing.

> *"Self -managing funds through the Portal is excellent and I have done away with all service providers and control my son's supports..."*
>
> *"The Portal is good for keeping an eye on what the agencies charge for services. Keeps them honest. We need this to be available in the State WANDIS."*

Technology such as the portal and e-market needs to be available to all. They can be an extremely useful tool for participants retaining control and there being transparency in funding. A lot of money has been and is being spent on the technology available and, despite current problems, there should not be a duplication of systems. Whatever system eventuates there need to be recognition that many people with disability and their families do not have access to the internet or smart phones and so there must be alternative on offer, and funding to support access to technology.

Flexibility and services – How can the systems increase flexibility over time? There is concern that there is too much emphasis on developing markets and competition, rather than empowering demand. There are concerns that the principals are being watered down to maintain current providers, reduce prices through competition that, in turn, reduce the choice and control of individuals and families.

Our survey and forum responses questioned the impartiality of Local Coordinators and Planners. This then goes to having multiple options - for example independent planners and service coordination (brokers) rather than only government agency employed staff. We specifically asked people if they would prefer an allocated coordinator or would like to choose their own and the majority indicated they would prefer to choose their own. Where a person has a Local Coordinator who listens and is responsive in their support, they are very happy with that support – *"it rests on a very skilled planner/coordinator, my experience is that I have had both,"*. However,

there were also many indications that getting a good coordinator was highly variable and often the coordinator took choice away – "*Not being listened to and missing out on important things needed for my daughter.*" "*Lack of correct info from the MyWay coordinator*".

The key concern with the model of a Local Coordinator doing the combined responsibilities of planning, recommending funding, and supporting coordination is that influence and control of the process and its outcome is centred on one person or role. The survey found that in the WA NDIS sites information was more likely channelled through the Local Coordinator, and although this potentially gives consistency, it is also limiting in exploring different or innovative ideas and learning from others. With both systems the planning is done by people in a role which has a clear line back to funding decisions. This leads to the Local Coordinator and Planner roles being gatekeepers of what can go into plans. It may not be a conscious bias but the system has put them into a role where there is an underlying expectation that they must do planning that is going to meet funding parameters rather than meet the needs of the participants.

> "*Planner is never clear as to why support is not being provided. Usually it is said "I have to ask my superior""*
>
> "*more flexibility would make better sense. DSC tend to guide us towards the large, Perth based providers over the smaller, more experienced locals.*"
>
> "*It seems the LAC model has now changed to be purely 'funding assessment/planners' there is very little in support/information now*"

If people are experiencing psycho-social or decision-making disability and/or do not have strong informal supports, they may need more intensive one on one support to test their eligibility for NDIS and go through the planning process. Currently service providers are working with people in this way under existing block funding but as this changes (is reduced or ceased) and programs such as Partners In Recovery, PHAMS & Better Start have funding moved into NDIS, it will potentially expose a gap in the capacity of Local Coordinator's to support people in the ways they may need. This links to the point about the viability of the role of Local Coordinators in an already overstretched service. People need alternatives that are independent, skilled and resourced to ensure that people's plans are achieving their optimum value.

In our previous survey we highlighted that people wanted flexibility and choice with planning and coordination. In addition to the consultation we have done, current research also supports this view. The work of Dr Tim Stainton, a recent 'Thinker in residence' at DSC, analyses the international progress on the implementation of personalisation and individualised funding. His work strongly advocates a number of positions that form part of our recommendations in relation to person-centred planning, these include:

- The need for separation between planning, funders and providers

- People who self-manage their funding requiring both fiscal and management support (choosing to self-manage not equating to taking on sole responsibility for all associated tasks)

(Stainton, T & Askerova, S. (2013) A comparison of cost and service utilization across individualised and traditional funding options through community living British Columbia.)

> *I self- manage our daughter's funds, to do this I **need** part of the funds to cover accounting advice staff wage/tax & super obligations, funds to provide computers, paper, ink/other office requirements to ensure the smooth working and reporting of the plan, I supply my labour fee to run the program approx 3 days per week.*

Although we are hearing that at a policy level there is supposed to be increased flexibility with people not limited to purchasing at the level of the line items, when the survey was conducted this was not evident. We were also hearing that in order to get the flexibility people are looking for they are choosing to self-manage.

> *We are constrained by the funding brackets – it's a nightmare.*

Self-management of funding requires support and is not as simple as handing money over. The survey and forum responses made reference to the NDIA paying people who choose self-management similar hourly rate as providers, which allowed recognition of time spent in self-managing, flexibility, and the opportunity to pay for some administration support. In WA NDIS we have heard people self-managing get a lower rate with no recognition of the work load as highlighted in the quote above. This inconsistency across the two systems need to be rectified when a decision is made.

There is also concern that aids and equipment programs may remain in kind or limited to assessments by one provider which can reduce choice and efficiency in spending.

Appeals – The appeals processes in WA needs to be a truly independent process with decisions that feed into the ongoing interpretation of reasonable and necessary. The data on page 27 of this report illustrates the main reason for complaints and appeals. A higher proportion of respondents received advocacy support in the Perth Hills site than in WA NDIS trial areas. Although the resolution varies between trial areas it is clear from the feedback received that people find the process stressful and time consuming.

> *'even though we had a mediation session to resolve the issues, I felt it was only done so I wouldn't take things further'*
>
> *'It's long, painful and in some cases, degrading'*
>
> *'it was hell, wouldn't wish that to happen again or to anyone else.'*

People deserve an appeals process that is transparent and independent, and to have access to independent support. Advocacy funding which is tied to the appeals process has worked well in ensuring more people are supported in the Perth Hills trial.

Policy development – Both the State and Commonwealth have done policy work in different areas. This work needs to be shared and continued. In the policy work on housing and accommodation innovation, WA should consider using use the information and learning from work done on the Specialist Disability Accommodation policy by the NDIA. There are still group homes and hostels with more than five people with disability living together in WA. The policy work on innovation and transition in this area should be shared nationally. For example, in a forum consultation where there was discussion about housing, a query was raised that with a seven to ten year wait list for housing how will people who want to move out of the family home and have the supports through NDIS to live independently, or with support, actually achieve this.

> *if you want to purchase a home for a family member with a disability there is no help, no guidance …. If you purchase a place that will suit your son/daughter & live in support worker, you might not get the funding. So you cannot run the home without correct funding…*

Conversely, WA has done a lot of work engaging with the Department of Education and the Department of Health which should be shared and some of the models of engagement such as the Disability Health Network are ideal for working on the NDIS interface with mainstream agencies. People in WA want to be able to access and influence policy development nationally and innovation that occurs in other states. How this is built in, alongside engagement and co-design of local people with disability, their families and carers is extremely important for the ongoing evolution of the scheme.

Quality and Safeguards – WA will need to align with the national safeguarding framework, and a means is required for the quality of services needs to be maintained during the transition period. Standards audits are important but the costs of running a quality service and meeting the standards need to be recognised. People have made comments about choice of services and the difficulty of accessing services that are not registered with the NDIS. This is a tricky area as there is still a responsibility to ensure services are providing quality supports and have transparent, accountable systems in place. Research has shown that the best safeguards for people with disability is having multiple people in their lives and being connected to non-disability specific activities, for example, friends and groups; as well as knowing where to go to get help and speak up if needed. A number of people raised issues of being limited in accessing supports due to funding and finding it difficult to access mainstream community services.

Information, Linkages, Capacity Building (ILC) – A query in relation to the negotiations between the State and Commonwealth is - will WA use the same policy framework, outcomes and principles already being developed through extensive consultation on Information, Linkages and Capacity Building? There are practices in WA that can be considered and adopted by the NDIA and other States like the need for Disability Access and Inclusion Plans to improve access and inclusion. The emphasis on peer led and disabled person's organisations in the ILC framework should be widely promoted and used as a catalyst for future development. There is a huge concern from people with disability that the funding attributed to the WA ILC framework will be used to supplement the role of the Local Co-ordinator. It is important to recognise that the intent of the ILC is to build capacity and networks for those individuals in the community who are not accessing NDIS and as such the funding should be directed to organisations, networks and projects that work in this arena.

Overall the survey and forums have raised the same issues as in 2015, however there has been an increase in people stating that the process is stressful and not as flexible as it should be. It is not seen to be lining up with the NDIS principles. The recommendations indicate that greater flexibility and more responsive options are required in the system for it to meet the diverse needs of people with disability, their families and carers.

Recommendations

The following recommendations are a based on the findings from the 2016 consultation, our understanding of the two models in WA, and direct experience working with and advocating with people with disabilities, their families and carers in all trial sites in WA.

What is evident is that many of the recommendations expressed as a result of the 2015 consultation are still relevant as issues raised in the 2016 consultation. However, the 2016 consultation has resulted in new recommendations and illustrated two additional elements:

- It identifies where governments have considered and acted upon our 2015 recommendations. For example, it is evident that in Kwinana/Cockburn the number of respondents who are satisfied overall has increased significantly and some of the recommendations in the original survey about information and engagement have been addressed.
- It highlights ingrained systemic areas where further consideration needs to be made due to evidence of where the system is not supporting people.

A number of recommendations are presented in bold. These recommendations are either related to issues emphasised in the 2016 data as important, or a new recommendation as a result of new data.

System Design Issues

1.1 People with disability, their families and carers to be represented at all levels of governance arrangements of the NDIS in WA through to co-design of system policy and evaluation, and representation to include the diversity of disability in WA.

1.2 An independent external appeal and merits review process to be available with specific funding for associated advocacy support. This independent appeals process should have a final decision-making authority.

1.3 The NDIS interface with other systems needs to be articulated and a collaborative approach implemented. People are now experiencing a reduction in service and or funding because it is perceived by other systems that the NDIS will provide funding for that service, but in reality this is not happening - this is particularly relevant in services that cross into health, housing and education.

1.4 More options to be made available for either small service providers or innovative individualised arrangements within the pricing catalogue, and a graduated registration process for service providers depending on their size and business models.

1.5 Advocacy to be offered and made available at all times and to be promoted from first contact as an available option - this is particularly important for consumers with complex needs.

1.6 Projects and services that may require grant funding to support community inclusion need to be identified. The funding may be a combination of funding from partnerships between local government, the ILC, state government etc. but can be provided for things like shared community transport options.

1.7 Informal supports to be clearly recognised in planning. Allowance should be made to recognise in-kind and alternate supports for informal support such as contributions to travel costs.

Information and engagement

1.8 A version of the online portal of the NDIA to be made available for all participants in WA. It is important that this portal can be accessed for a variety of purpose including dissemination of information, payment processing, allocation and management of funding enabling people to clearly understand funding transactions and availability of services. Strategies must also be in place for people who do not have access to or use the internet. For these people it is important that they receive monthly mail-outs of funding statements and up to date information.

1.9 Peer support groups and representative groups to be funded to provide information and promote sharing of experiences.

1.10 A comprehensive communication strategy to be developed with explicit requirements that a diversity of channels and formats for access to information is created particularly ensuring there are always options in Easy English. This should include multiple channels for information and planning options to be provided not just through government agencies and their representatives.

1.11 Education, awareness raising and consistency in the use of terminology in the NDIS. Individuals and families require consistent information and transparency of process particularly around "in kind' support and "reasonable and necessary" supports. Many people are not able to understand what the system means by this and there appears to be a continual shift in 'the goal posts'.

Planning and plan implementation

1.12 The role of government is better placed to be in determining eligibility to the scheme and endorsing and reviewing funding allocations. It is recommended therefore to reframe the role of planner/coordinator as a funding negotiator. There then needs to be a range of options available to people to develop their plans with support from those they choose.

1.13 People to be able to choose and purchase support coordination if they wish and with whom they prefer, rather than being automatically allocated a Local Co-ordinator. Access to support coordination is an important aspect of peoples' experiences and lessons should be learnt from different states.

1.14 Plans ought to have greater flexibility and reviews able to occur more frequently than 12 months. For example, some people have indicated various options for the review process, with some preferring a trial period of three to six months to ascertain if their plan is meeting their needs. Other people have preferred a light touch at twelve months with a full plan review at three year intervals where implementation is running smoothly (subject to indexation increases).

1.15 A range of fund and plan management options available. There is a strong preference for self–management but for many this requires adequately funded support to the same degree as service providers, which in turn is an incentive to self-manage. The benefits and services of shared management (as understood in WA) should be extended to people who self-manage.

1.16 People with disability, their families and carers are enabled to choose who does their planning with them as well as pre-planning including from people based in the community such as multicultural or indigenous groups, peers, friends and family.

1.17 A quality framework to be introduced for Planners/ Local Co-ordinators which incorporates standards for training, skills and knowledge, and an appropriate value base that can be used by planners in the community. This could incorporate a code of practice and encourage a community of practice to develop.

Methodology

The consultation relied on two mechanisms for collecting experiences from people with disabilities and their families and carers in the three trial sites: by an online survey and two face-to-face focus groups to provide opportunities for people in all trial areas to participate. An additional question for people not in trial sites was added to the survey.

Process

The online survey, NDIS Experiences, was open for people to provide their feedback on the scheme during May and June 2016. The survey was widely posted on social media by the collaborative group and distributed amongst their membership and networks. The online survey invited participants of NDIS WA and the NDIS and their families and carers to comment on their experiences of the trials. The survey was constructed to capture people's experiences in a sequential manner as they would have moved through NDIS WA and NDIS processes: general information; access to information; general experience; access to mainstream and community services; planning process and managing funds and support. The survey used a combination of multiple choice and free text responses. A copy of the online survey is at Appendix One.

A total of 215 survey responses were received. A breakdown of this sample is provided below.

The Disability Services Commission (DSC) and the National Disability Insurance Agency (NDIA) provided assistance with advertising the survey distribution of the survey link. DSC posted the survey link on their face book page and alerted local co-ordinators that the survey was available for participants to complete. The NDIA advertised the survey in the newsletter provided to all participants in the NDIS Perth Hills trial site.

The survey responses were a self-selected sample so there was more likelihood that respondents were those who wanted to give feedback. The number of respondents compared to those in the scheme has meant that the representative sample is a smaller percentage for this survey.

In addition to the online survey, two face-to-face focus groups were conducted. A forum was held for participants in the Perth Hills in June 2016, and another forum was held in Busselton on May 2016 for participants in the Lower South West. A copy of the consultation questions and agenda is at Appendix Two.

Survey profile

The table illustrates that the number of people completing the survey in 2016 is consistent with that in 2015.

November 2015	July 2016
200 people completed survey	215 people completed survey.
22% people with disability 22% family member or friend of a person with a disability 56% family member or friend who cares for/supports a person with a disability	29% people with disability 22% family member or friend of a person with a disability 49% family member or friend who cares for/supports a person with a disability
64% Perth Hills 15% Kwinana/ Cockburn 21% South West region	29% Perth Hills 23% Kwinana/ Cockburn 38% South West region 10% not in trial site

There was a big drop in people from the Perth Hills Trial site responding to the survey, but a more even spread across all three trial areas. A small increase was seen in the number of people with disability who responded directly. No one identified as Aboriginal or Torres Strait Islander, and seven people identified as being from CALD backgrounds with languages other than English spoken at home. Three people identified specifically as using Auslan.

A further question was added in 2016 to establish at what stage of the NDIS process respondents were at.

	Checking Eligibility status	Pre planning stage	Planning stage	Post plan sign off	Review stage	I am not in a trial site
Q4: Perth Hills	8.33% 5	0.00% 0	5.00% 3	35.00% 21	31.67% 19	0.00% 0
Q4: Kwinana/Cockburn	2.08% 1	4.17% 2	14.58% 7	47.92% 23	16.67% 8	2.08% 1
Q4: South West	1.18% 1	2.35% 2	5.88% 5	27.06% 23	38.82% 33	2.35% 2
Q4: Not in a trial site area	4.55% 1	0.00% 0	0.00% 0	0.00% 0	0.00% 0	86.36% 19
Total Respondents	8	4	15	67	60	22

As the table indicates, the majority of respondents were at the post plan sign off. A higher proportion of respondents were at the review stage in the South West trial site area.

Survey Results and Analysis

As with the November 2015 results, the results from the July 2016 consultation do not compare the trial sites but illustrate good practice, and make recommendations for improvement. Where there is an issue with a specific trial site this is identified.

This section of the report provides the results of the survey responses. The first section of the analysis considers overall feedback from respondent on areas of good practice, areas for improvement and recommendations for change. It also identifies the main characteristics identified in the 2015 survey to those of the 2016 survey. This section also illustrates feedback on specific aspects of the NDIS WA and NDIS processes which includes:

- access to information
- access to mainstream and community services
- the planning process
- managing funds and support
- complaints and appeals
- non trial site area

The following information shows the results of the survey and, where possible, reflects the findings from the November 2015 survey to those collected in the July 2016 consultation.

What's working well and what needs improving

This section of the report provides an analysis of the qualitative feedback collected in questions 11 to 13 of the survey. These questions were open ended, text responses asking people to share from their experience what things are working well, what things are not working well, and what could be improved. The data provided shows the main elements from the 2015 survey and the survey conducted in 2016.

What is working	
• Communication with Planners/ My Way Co-ordinators • Support co-ordination • Better choice of services • Level and flexibility of funding available • Access to and regular assistance of support workers • Easy access and use of NDIA portal for both information and payment process	• Choice and control of services • Variety and flexibility of services • Communication with WA NDIS coordinators • Different management options (particularly self-management in Perth Hills) • Integrated Services • Improved relationship with service providers • NDIA portal (Perth Hills area)

What is not working	
• Communication with Planners/ My Way Co-ordinators • Length of time to make things happen • Information not being easy to understand • Lack of engagement with service provider • Inflexibility or ability to quickly change plan • plans being rushed • Self-management being too hard • Lack of available services (in Lower South West trial site)	• Time taken to complete plans • Communication with Planners/ Coordinators • Lack of information • Cuts in funding • Lack of engagement with service provider • Inflexibility • Too much paperwork • Lack of experience and understanding of staff • Support for carers • Stress • Time taken to receive funding • Lack of available services (in SW region)
Recommendations for change from respondents	
• Less bureaucracy and a streamlined service • Better targeted, relevant and current information being available • Ability to review plans at more regular intervals not just 12-month stage • Clear guidance of the process • More consultation with families • Advocacy support	• A simpler and easier planning system with less paperwork and a reduction in the length of process • Better communication, education and information about NDIS and accessing funding (needs to be tailored to WA in Perth Hills) • Increase the number of Local Co-ordinators • Better training for planners in Perth Hills • More support with planning; more support co-ordination • Improvements and more support for self - management option • Include support for carers • Devise an app for the portal • Ensure there is an independent body for overseeing decisions • Pay providers so they can service their customers

The impact of reform

Question fourteen of the survey invited people to reflect on their experiences in the trial compared to their experience of the pre-trial system. Respondents were invited to indicate their level of agreement with nine statements:

- The support package I now receive better reflects my needs
- I know what goals are included in my plan
- I know how to make my plan reflect my goals
- I now have more choice
- I now have more control
- I now receive more supports
- I now achieve better outcomes
- I now receive support in a timely manner
- I have more flexibility in how I can use my funding and supports

The responses in 2015 show some distinct differences across the trial sites. People in the Lower South West were much more likely to agree across the statements that the WA NDIS had a positive impact for them. In contrast, respondents from Cockburn/Kwinana were much less likely to agree and far more likely to disagree.

In 2016 however, comparative data suggests that people in the Cockburn/Kwinana area are more likely to agree with the statements than in 2015. In contrast in 2016, people in the Perth Hills trial site and the Lower South West are less likely to agree with these statements than in 2015.

This trend is consistent across all nine statements. Of significance is that over 60% of respondents agreed with all bar one of the statements in the Cockburn/Kwinana area. The statement 'I now receive support in a timely manner' received the least support at 58%. This statement also received the lowest support in the other trial site areas, 42% in Perth Hills and 47% in South West region.

Over 50% of respondents in the South West region supported the remaining statements.

Respondents in the Perth Hills area were least likely to agree with the statements with the majority of responses in the range of 54% to 40%. However, people in the Perth Hills were more likely to answer 'neither agree nor disagree' than disagree. It is likely that respondents from the Perth Hills were those who have had issues with the system as a smaller number of respondents came from that trial site area.

Access to information

Overall 62% of respondents reported that they had sufficient information to make choices about their support needs. This is 10% higher than the 2015 survey. However, as the table illustrates there are noticeable differences between trial sites.

	Survey 2015	**Survey 2016**
Perth Hills	66%	50%
Kwinana/Cockburn	35%	68%
South West	56%	68%

The types of issues reported were very similar to those highlighted in the 2015 survey and include:

- Lack of information on the supports and services which can be accessed with the funding;
- Staff not appearing to have all the information to adequately support people with accurate information and support;
- No response or long delays in getting responses to queries;
- Mixed messages and contradictory information given by different people which caused confusion and delays;
- Information constantly changing and the shifting of goalposts of what was allowed and wasn't allowed.

The table shows where people have indicated the most valuable source of information is obtained. The table shows the top 3 sources

	Survey 2015			**Survey 2016**		
	NDIS Planner/LC	Family member /carer	Service provider	NDIS Planner/LC	Family member /carer	Service provider
Perth Hills	37%	17%	22%	19%	22%	16%
Kwinana/Cockburn	26%	26%	22%	34%	19%	12%
South West	40%	18%	15%	65%	11%	10%

As the table suggests, a higher proportion of respondents in the Kwinana and Cockburn and South West areas are receiving their information from NDIS Local Co-ordinators, which has increased since the 2015 survey was conducted. The opposite has happened in the Perth Hills with a broader mix of sources including advocacy organisations (14%), information sessions (10%), and the NDIS website (10%).

Access to mainstream and community services

People were asked if they needed support in areas of their life which were not covered in their plans. Over 55% of respondents indicated that they did. The main areas in their life where support is needed greatest are Health, Education and Recreation/Social activities which is seen in the survey results.

People in the Perth Hills were less likely to be able to access support in the areas they identified. People in Kwinana/Cockburn were more likely to be able to access supports whilst there was an even mix for those people living in the South West region.

People were asked what has made it difficult in accessing support. The main issues identified include:

- Lack of funding
  '*Supports provided pre-NDIS not covered to same extent under current plan. Now need to financially cover costs of these services outside of NDIS.'*
- Payment of services upfront
  '*I simply cannot afford after school activities and club membership that would benefit my child. I have been told I can set up an account and be reimbursed but I cannot afford to do this.'*
- Lack of information about what is available
  '*We have not been made aware of how we can be supported with these items.'*
- Lack of coordination between agencies
  '*Disagreements as to what is health related and what is related to disability. The thought that a young child needs no help accessing social support because the parents do it anyway*.'

A specific question was also asked about equipment. For those that had requested equipment there was a consistent response across trial areas that the process was time consuming and there were lengthy waiting periods. Another issue was lack of clarity as to what could be funded that was necessary for disability/communication support that is not a specialist item, as well as whether funding could be used flexibly for small items.

> *"We have struggled to get equipment needs met within our Plans. A physiotherapist assessing communication supports is a major stumbling block. We needed to get our psychologist and occupational therapist to write up thorough letters of support in order to have equipment funded (we don't currently have a speech pathologist, the therapy banding doesn't stretch far enough)."*
>
> *"Was unaware that recommended equipment plan had to go to another funding agency for approval"*

Planning

Questions twenty-one to twenty-seven invited respondents to provide feedback in relation to the planning process. Questions covered the experience of planners and coordinators, recognition and support of families and carers, and people's experience with the implementation of plans. Additional questions specifically asked people with psychosocial disabilities and families and carers to provide feedback on what issues they have experienced in the planning process.

Question twenty-one asked people about their NDIS planner/coordinator experience. The question followed the same format as the 2015 survey in that it posed a series of five statements and asked respondents to indicate whether they agreed or disagreed with these statements across a scale. These statements were:

- My planner/coordinator helped me develop my plan
- My planner/coordinator listened to me
- My planner/coordinator gave me information
- My planner /coordinator gave me time to develop my plan
- My planner/coordinator helped me implement my plan.

In NDIS WA all the responses show an increase in satisfaction with over 70% of participants strongly agreeing with these statements. This is a significant increase for the Kwinana/Cockburn area which in the 2015 survey barely achieved a 50% satisfaction rate in any of the statements.

The Perth Hills trial site has however had a reduction in satisfaction from the first survey in four of the five statements. The biggest reduction was in the statement "My planner helped me implement my plan" which 20% of respondents strongly disagreed in 2015. This rose to 48% in the 2016 survey. It should be noted that under the NDIA it is not the planner's role to assist in implementing the plan and people can purchase Support Coordination to get this service, so it is unclear if disagreement was due to the different roles in the scheme.

People were asked about plan coordination, 56% of respondents said they would like to choose the coordinator themselves as opposed to the government appointing a coordinator. 34% of respondents had no preference.

Respondents were asked if carers and families are being recognised and supported in the process and in the participant's plan. In the NDIS WA 55% of people said they were supported, 20% saying they weren't, 25% were unsure. In the Perth Hills, 30% said they were supported but 43% said they were not, 27% were unsure.

People were asked how easy it was to implement their support plan. The main concerns with implementing plans included:

- Length of time to complete the plan
  'the length of time it has taken to get anything happening, some parts of the plan have not been implemented yet, lack of information how to get some of the plan implemented'

- Lack of or inconsistency of information
  '*there are so many hoops to jump through it is very time consuming and causes worry unnecessarily in addition to the requirements of caring for somebody with a disability.*'
- Concerns with self-management being too hard
  '*The legal aspects of tax/superannuation and the time required to do all the planning, staff activity/research/management, payroll and paperwork*'
- Lack of flexibility once the plan has been created and the time it takes to amend things.
  '*once it's set you can't change it*'
  '*I want to be able to move my funding from one goal to another if things don't work as planned*'
  '*Life does not always go according to any plan, it's almost discriminatory that people have to implement one to receive support, this takes away our right to a choice.*'
- Lack of support for carers
  '*when it comes to children with disabilities the plan shouldn't be just about them, other family member's needs should be taken into account, for example parents should be supported so they can go to work.*'
- Process is too 'stressful'

> '*I am concerned that some of the goals in the plan will not be implemented simply because I am too exhausted to make it happen.*'
>
> '*To be stress free as this affects my condition*'

Carers and family members were specifically asked what issues they experienced in the planning process. The following information indicates what the main issues were across all trial sites.

- Length of process. The time taken to implement the plan was too slow and in some responses resulted in service provision being interrupted.
- Lack of knowledge/understanding/empathy of planners/coordinators
  '*Planners are guessing your needs not listening*'
- Delays and turn-around of staff
  '*I have had 5 planners since the beginning of last year but only met one of them.*'
- Lack of information
  '*Knowing what to ask for, remembering what is needed, making decisions.*'

> '*Took a long time – difficult to know what is available. The time taken means things changed by the time the plan was actually commenced. I already am time and energy poor and the amount of time this took out of my life was hardly worth it*"

People with psychosocial disability were asked about the issues they have experienced in the planning process. A large proportion of respondents cited an increased level of anxiety and 'emotional stress' because of the process. The length of time taken to process the plan for approval is increasing peoples' anxieties. '*Especially not knowing if we are going to receive the support we need. When we didn't receive that support, the stress grew.*'

Other issues experienced by people with psychosocial disability include:

- Lack of support, understanding and knowledge of staff - *'they don't listen'*
- Having to remember lots of information and attend lots of meetings - '*there is way too much meetings and decisions required. It is highly stressful to have to spend the many hours required to think about, read, correct update and implement the plan.*'
- Conflicting information

'*The whole planning process can be very confusing. Things are changing to fast. I found the coordinators themselves tired and in some cases misinformed.*'

Funding support

This section of the survey asked people to reflect on the management of their funding and supports.

Question twenty-eight asked if respondents could choose how they managed their funding and support. Across the trial sites, 74% of respondents stated they are able to choose the way they manage their funding and support. This was the same as the 2015 survey. 19% indicated they were unsure and 7% indicated they were not able to choose. These results are fairly consistent with the 2015 survey with the exception of   Cockburn/Kwinana where the percentage of respondents indicating they are able to choose rising from 41% to 71%.

Some of the reasons given for not being able to choose in the 2015 survey included:

- My Way NDIS not offering organisational management as an option;
- Lack of information as to what is involved in self-management;
- Lack of information as to what other options are available; and
- Wanting Shared Management, but NDIA not understanding this as an option.

In 2016 many of the reasons were associated with self-management and the difficulties with managing this option. There was also a number of concerns about the flexibility of funding and that funds are fixed to a support definition and not allowing for alternative options. Many sited that the funding brackets are a constraint and are limiting people's choice.

Question twenty-nine asked people to indicate what their preferred management options were. Overall, 34% of respondents prefer self-management, with this option being consistent across all three sites. In Perth Hills, the next preference was organisation managed with 20%, in Kwinana and Cockburn is was shared management with 18% and in South West it was a

combination of self-management and other options 15%. Plan management was the option of least interest with only 4% choosing this option.

> *'During planning there was "encouragement" to self- manage so we would get more hours - I was keen on the other advantages - being able to select staff, train staff, manage staff/activities, flexibility. Without choosing self-managed we know for sure there would have been a LOT less hours..........but now we realise what a huge burden the administration of it is!!'*

Meeting needs

Question thirty-one of the survey asked people whether their plan and funding package was meeting their needs. In 2015, 47% of respondents indicated that the plan and funding package were meeting their needs. 27% of respondents indicated that the plan and funding package were not meeting their needs. The remaining 26% were unsure at that stage.

In the 2016 survey 51% of respondents indicated that the plan and funding package are meeting their needs. 31% of respondents indicated that the plan and funding package are not meeting their needs. The remaining 18% are unsure at this stage.

Although the data shows a fairly consistent pattern from 2015 to 2016 it should be noted that the Perth Hills has seen a substantial decline with 54% of respondents in 2015 indicated their plan and package as meeting their needs is only 36% in the 2016 survey with a much larger proportion of respondents indicating their needs have NOT been met, a rise from 19% in 2015 to 41% in 2016.

The main reasons in 2015 for indicating that their plan and package did not meet their needs included:
- Funding – insufficient funding means not enough hours can be purchased; lack of funding for respite for family carer; funding for certain services not being approved; and, not enough funding for school to work transition.
- The Plan – not responsive enough to changing needs; not what they requested or agreed; not flexible enough; and, the whole process is taking too long.
- Services – inability to find services required; service costs too high so unable to purchase enough hours.

These reasons were again cited in the 2016 survey, however, there was a greater emphasis on the inflexibility of funding for example, 'the plan does not reflect my goals and lack of funding allocated to my goals, but huge allocation of funding has been made for further assessment and support coordination.'
'it restricts which services I can access – for example I don't need a speech pathology but have access to one, but I do need a chiropractor but don't have access to one.'

People were asked if they had encountered any issues in engaging, paying or changing services. A major concern for people is the time taken to get a plan changed and some participants pointed to their experience of during that time funding being suspended. In particular, the issue of trying to change service providers which are in a participants plan in the WA NDIS was raised.

'*Once engaged with a service provider, if it is found not to be a good fit, it is a long and difficult process to change providers.*'

Another concern is not being able to engage a provider of choice because they are not registered with NDIS. Some participants felt that they could only get choice and flexibility if they chose to self-manage and were then able to use non-registered providers.

Complaints and appeals

In 2016, questions thirty-four to forty-three of the survey relate to complaints and appeals. The percentage of complaints is illustrated below.

Perth Hills   9%

Kwinana/Cockburn 12%

South West   6%

The top 4 type of complaint were:

- Communication
- Staff
- Length of time
- Choices of options

The other complaints were regarding inflexibility of supports, and funding choices.

60% of the Perth Hills site had unresolved complaints while 40% had resolved their complaints. The Kwinana/ Cockburn site had 50% resolved complaints and 50% unresolved complaints. The South West site had 100% unresolved complaints. The majority of people reported that they did not receive support when making a complaint.

Overall, 8% of respondents have used the appeals process.

The highest use of appeals was in the Perth Hills at 13%. 100% of these appeals was regarding level of funding. Kwinana/ Cockburn appeals were mainly about eligibility to the scheme and secondary, the level of funding. The South West appeals were regarding goals and strategies.

In Perth Hills, 17% of respondents had no support with the appeals process. 33% had advocacy support and 50% had support from service providers. In Kwinana/Cockburn 66% of respondents had no support, 34% had support from service providers. 100% of respondents had no support in the South West region.

The appeal resolution was satisfactory for 100% appeals in the Kwinana/Cockburn site. In the Perth Hills site there was 33% satisfaction of appeals resolution and 67% of unsatisfied appeals resolution. The South West site had no satisfactory appeals resolution.

Non trial site area

In 2016 a question relating to non-trial sites participants was added. The number of responses was small partly due to the fact the survey was promoted in NDIS trial site areas. The main points that respondents raised include:

- Changes are being made and services are being discontinued for respondents with very little information as to the reasons why provided.
- Lack of information about the NDIS and what will happen in the interim for people not in NDIS whilst the rollout continues.
- Respondents receiving incorrect information, for example, a respondent was told they would '*no-longer receive LAC support because NDIA was taking over.'*

Important features of NDIS

In 2016 we introduced a question which asked respondents 'what are the most important features too you for the NDIS in WA?'

The top 4 most important features for people using NDIS in WA are:

- **Choice of Service provider**

- **Easily accessible information**

- **Ability to have control of funding**

- **Ability to change services**

Forum Feedback

Perth Hills Area

A forum was held at Brown Park Recreation Centre, Swan View from participants and families in the Perth Hills Trial Site in June 2016.

Participants were asked to provide their experience based on the following four key themes:

How much do you agree or disagree with these statements?

The NDIS program is an improvement in planning

The NDIS program is an improvement in accessing services

The NDIS program is an improvement in accessing the wider community

Life is better because of the NDIS program

Based on these four themes a summary of issues can be drawn.

Planning

Most of the people in the group had experienced both the NDIA initial planning and then the review plan process in the NDIA Perth Hills Trial site.

Key points

- First plan experiences were often better than plan reviews. People felt that it was critical that they have an ally in their corner to assist with NDIS planning, this was typically a Support Coordinator or Therapist.
- This ally was important in assisting to understand the rules, translate NDIS language and codes into how it could look on the ground. People did not feel that they got this from NDIA Planners and they felt that the language of NDIS was complex.
- Many people felt that the planning process was rushed and that planners had simply not read or could not find relevant information, reports etc.
- A light touch phone review may be suitable for some people with simple plans but members of this forum all opted for face to face reviews all with different planners to whom they developed initial plans with.
- Consistency remains an issue across planners and the interpretation of "reasonable and necessary supports"
- Difficult to work out the costs in the plan because people have to break down into codes for claims so are second guessing the actual hourly amount.
- Some plans are funded for 52 weeks' others are for 48 weeks – seems to vary and not well documented.

- The group felt that there were lots of errors and incorrect costings and codes in plan reviews and the sense is that it is about getting plans signed off quickly and getting the numbers in as opposed to spending time getting the right plan for each participant.
- The group felt that innovative supports in WA had been stifled under the rules of NDIS, for example a very flexible home share arrangement that was working well had to be revamped as NDIA would not pay the shared rental component. (Resulted in a higher cost plan and more formalised support)

> *'At review time you need to be asked at the start if you want a "face to face" or "Phone review" not set the date & time first & be told you will get a phone call, then have to go through the whole process again to find suitable time for both (this was a 1/4 hr phone call).'*

Plan Coordination

Most of the group have had experience of the Local Area Coordination (LAC) programme in Perth Hills prior to NDIA rolling into the area. LAC is not available in the Perth Hills trial site and all people in this group described being in receipt of funding for Support Coordination (SC) or Support Connection.

Key Points

- The Support Coordination role is a vital component in the NDIA Perth Hills to assist navigating the maze of supports and services.
- Support Coordination and Local Coordinator role works best when they work alongside you and have a deep understanding of your needs. *'You have to "Click"'.*
- You must be able to have choice about who delivers support coordination
- Being "allocated" a Local Coordinator denies people choice and control and a level of independence.
- The right skills, knowledge and experience of the Support Coordinator/ Local Coordinator are critical to the success of the NDIS.

Accessing Services

All participants agreed that they have greater choice and control over the supports and services that they receive. The group discussed their experiences and everyone reported being better off in terms of funded supports and services under the Perth Hills NDIA Scheme than the previous state funded system.

Key Points:

- Getting information about service providers is difficult, long lists of names of services is not particularly helpful, same goes for Support Coordinators.

- We get to pick and choose the services that we want and having multiple providers is easy in the NDIA system.
- Liaising between service providers and NDIA is an issue, there seems to be long delays in the quoting procedures from both NDIA and Providers
- The NDIA provides transparency for participants which is much needed.
- Provider registration is less flexible in WA because the state system requires people to have a panel contract and go through a tender process.

Comments

"The agencies have had a big wakeup call in the NDIS, some are responding well with better relationships and communication and others aren't. They need to be able to show that they can deliver what we need or we can go elsewhere."

"We have the information on the portal, so we can see where service providers are making claims. We definitely have more control over seeing where the money is being spent"

"Self -managing funds through the Portal is excellent and I have done away with all service providers and control my sons supports. However, my Support Coordinator is vital so that I have someone to go to for help."

"The Portal is good for keeping an eye on what the agencies charge for services. Keeps them honest. We need this to be available in the State WANDIS."

> *'We are concerned about the big price discrepancy for people who choose to self -manage with both systems. Nominally $43/hr allocated for both self & agency managed with Perth Hills NDIS, but State based NDIS is about $25/hr for self & $53/hr agency – where is the incentive for someone to self-manage in the state system?'*

Accessing the wider Community

Key Points

- Access to Information is vital as there are so many changes happening all the time.
- A range of different avenues to get information is required.
- Peer Support needs to be acknowledged as a great way of getting information directly from each other, without the "Spin".
- Community needs to be accessible and welcoming – who is going to do this work?

Comments

- *Our Peer Network has been invaluable, we have more knowledge and we have supported each other with planning, getting plans actioned and reviewing plans.*
- *Not everyone wants to or has the time to meet up each month so people are welcome to join us when they want. We connect with people through email, Facebook and people are always happy to help each other out and come up with helpful ideas."*
- *We feel more confident as a result of our group.*
- *The NDIS general communication needs to be improved at all levels. We usually hear of all the changes through our Peer Support Network, what about all the people who don't connect well, how do they hear about what is going on in the NDIS?*

South West Area

A forum was held in Busselton for participants in the Lower South West. 8 people attended. 4 people were participants. 2 people were family members. 2 people were paid support persons supporting participants at the meeting.   Therefore, feedback was from 6 of the 8 people in attendance.

2 participants were either still in planning or only just commenced with services, therefore, very new to the system.

Planning

Key Points

- Brilliant relationship and process with Coordinators.
- Easy to communicate with them and responsive. Couldn't fault it.
- Provided participant with access she did not have before.
- Coordinators great support in designing a responsive accommodation arrangement.
- Plan has been easy to be tweaked if small changes occurred.
- Participant felt he was not listened to at all, nor his partner. The proposed plan is what the Coordinator has decided, not him. *"They don't care what I want".*
- Family member felt she was inadequately informed and supported through the planning process. Plan does not meet her brother's needs.
- Plan needs to be amended with an OT assessment requested. Family member was advised they had to wait until the one-year review point.
- Benefits of planning limited when there are limited choices of providers.
- Concept of 'you don't know what you don't know' discussed. Belief that if you are in the know and know what to ask for and who to go to, you benefit. Otherwise, it's a real struggle and you are heavily reliant on the Coordinator for adequate and appropriate information in order to make an informed choice.
- *Some of the attendees were not aware of some of their options (note by facilitator)*

Accessing Services

Key Points

- Very limited services to choose from, so limited choice.
- One family member informed they were given no choice, just one option on offer.
- Two participants stated that it was not possible for them to get support on the weekend or evenings.
- One participants stated that she has very limited choice of when to have support and for how long – told they have to be 2 hour blocks or more and only limited time slots available.
- One family member stated that she has had 40 years of experience in the sector, therefore, knew where to go.
- Sense of feeling they have to compromise.
- One participant felt she was not able to self-manage despite wanting to as she would have to top up out of her own money for the service she requires.
- Self-management is a big job for people.
- Sense of it is not "my way" but "their way".
- One family member indicated she had limited understanding of how a family member can direct the supports for her brother.
- One service provider referred to as very rigid and inflexible in its approach.
- Concern about psychosocial disability and supports not being adequate. Difficulty finding a provider that will be able to provide support in response to both physical and psycho social disability.
- Self-management the only option for one participant in order to be able to access out of business hour's support.

Accessing the wider Community

Key points

- One participant happy with his access to the wider community and what he does.
- One family member very happy as son has not had life as good as it is now under the WA NDIS.
- One participant wants to be able to live independently again and get out and about more. Currently this person is not receiving support to be able to do this. One participant stated they were hoping to have more activities to choose from.

Life is better because of the NDIS program

Key points

- Self-management has made life much harder with the amount of work that has to be done for it. *Wish I didn't have to, but I feels it is the only option available to be able to get the support required for my child.*
- With limited choice of providers, sense by participant that if they like you, you get a good service and if they don't like you, you don't.
- Not able to get the right support for a participant's psych social disability therefore she remains isolated.

Additional comments from forums

- Consultation 'fatigue' – people are becoming disillusioned with the amount of feedback being asked particularly when it is similar questions but for different agencies. There is a consensus that supports a drawing together of all the feedback currently available on the trial sites from the various sources. If there are still gaps in information, then have forums based on the missing detail.
- Role of Local Area Co-ordinator in WANDIS – In other jurisdictions this role is performed by the not for profit and peers support groups. It does not sit within Government. If WA Government Local Coordinators are charged with all aspects of planning/purchasing and providing supports in the WA NDIS where will the level of independence will come from? How can the advocacy role in LAC work into the future? Is the WANDIS Local Coordinator role even achievable with additional workloads, less staff and more customers?
- The reduction in funding in second year plans. Many people are experiencing a reduction in funding on review of their plans, this is a worrying trend in the NDIA trial site.
- Housing - What is going to happen in the housing area in WA? If you don't have personal wealth to provide for your own housing needs and public housing has a 7-10-year waitlist – how will people who want to move out of the family home and have the supports through NDIS to live independently or with support actually achieve this?

> *"Catch 22 - if you want to purchase a home for a family member with a disability there is no help, no guidance on the number of bed or bath rooms to purchase. If you purchase a place that will suit your son/daughter & have a live in support worker, you might not get the funding. So you cannot run the home without correct funding, but you cannot find out what the funding will be before the home is purchased. This is silly, you need a preliminary meeting to get consensus with the NDIS on what is "reasonable & necessary" before committing a large expense."*

Conclusion

Based on the feedback from the consultation process, this report shows that when NDIS is meeting the needs of the individual it 'provides a better life' because of the NDIS. However, the 2016 evidence coupled with the feedback received from a similar exercise in 2015 suggests there are still flaws in the system. Issues such as the method and availability of information, access to and availability of services, length of and experiences with the planning process, are all areas that people still are concerned about. In 2016, the feedback highlights the pressure people are experiencing, stress and overload are key concerns for people with the system. Many people are reluctant to complain or appeal to decisions and those that do, it appears to be an arduous and overwhelming process.

It is still evident that peoples' experiences are significantly affected by the quality of the support provided by their Planner/Local Co-ordinator and there is a growing fear that the relationship building element of the Local Coordination role is being eroded away as the focus on performance indicators takes precedence. It is important to recognise that in negotiating the future of the NDIS in WA, the learning from peoples' experiences of the trials are acknowledged, valued and actioned upon.

The recommendations indicate that greater flexibility and more responsive options are required in the system for it to meet the diverse needs of people with disability, their families and carers. The recommendations do not favour one trial site over another but provide solutions that ensure the people living in WA are at NO DISADVANTAGE to people in other areas of Australia. We have learned much from the experience of people in the different trial sites and we will endeavour to continue to engage with all levels of government to get the best outcomes for people with disability, their families and carers in WA.

Appendix 1 – Survey Questions

1. Introduction

This survey is for people with disability, families and carers who are participants in the NDIS Perth Hills and NDIS My Way trial sites in WA. If you are not currently in a trial area we would also like to hear from you about how you have been affected.

This is your opportunity to say what has worked and what hasn't; what you like or don't about the process; if your needs have been met; and how you think the system in WA should work.

We ran a similar survey in 2015 and we want to be able to use the information from both surveys to see what has improved and tell the governments what are the challenges before full rollout, and   what needs to change.

Advocacy, peer support and individualised service organisations have joined together to make sure that people with disability, their families and carers voices are heard and are influencing what the NDIS will look like in WA. The information gathered will be used to tell the WA state government and the Commonwealth government what needs to be in the NDIS system in WA. It may take between 15 to 20 minutes to fill in the   survey.

* 1. Please tick any boxes that apply to you. Are you:

☐   A person with a disability

☐   A family member or friend of a person with a disability

☐   A family member or friend who cares for/supports a person with a disability

2. Do you identify as Aboriginal or Torres Strait Islander?

◯   Yes

3. Do you use one or more languages other than English at   home?

◯   Yes

◯   Which Languages?

* 4. Which NDIS area you are a participant?

○ Perth Hills

○ Kwinana/Cockburn

○ South West

○ Not in a trial site area

* 5. At what stage of the NDIS or My Way process are you currently at?

○ Checking Eligibility status

○ Pre planning stage

○ Planning stage

○ Post plan sign off

○ Review stage

○ I am not in a trial site

○ Other (please specify)

[   ]

2. Access to information

In WA information about how the NDIS and NDIS My Way works has been provided through many different sources. We want to know how you accessed that information and if it was useful.

6. Was it easy for you (or the person you support) to access information about the NDIS?

○ Yes

○ No

○ Unsure

7. If no what difficulties did you have?

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8. Do you (or the person you support) have enough information to make choices about your support needs?

○ Yes

○ No

○ Unsure

9. If no what further information do you need?

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10. Where did you get the most useful information from?

☐ My Way Coordinator

☐ NDIA Planning and Support Coordinator

☐ Disability Services Commission website

☐ NDIS website

☐ Advocacy organisation

☐ Other people with disability, families or carers

☐ Information session

☐ Service provider

Other (please specify)

3. Your experience

Whether you are in the NDIS or NDIS My Way we want to hear what has worked well for you and what hasn't. We need your direct experience of the scheme to tell government what's important.

11. From your experience of the scheme what are the things that are working well?

12. From your experience of the scheme what are the things that are not working well?

13. From your experience please tell us what could be improved in the scheme?

14. Thinking about your (or the person you support) experiences in the scheme compared to the pre-NDIS system, to what extent do you agree or disagree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	n/a
The support package I now receive better reflects my needs	○	○	○	○	○	○
I know what goals are included in my plan	○	○	○	○	○	○
I know how to make my plan reflect my goals	○	○	○	○	○	○
I now have more choice	○	○	○	○	○	○
I now have more control	○	○	○	○	○	○
I now receive more supports	○	○	○	○	○	○
I now achieve better outcomes	○	○	○	○	○	○
I now receive support in a more timely manner	○	○	○	○	○	○
I have more flexibility in how I can use my funding and supports	○	○	○	○	○	○

4. Access to mainstream and community services

The NDIS (through NDIA and NDIS My Way) provides funding for a person's disability specific support. Your plan may include services that are not funded and are meant to be available from other service systems. We want to know if you can get those services and supports that are not funded by NDIS. Mainstream services include recreation, health, education, housing and any other service that any person in the community should be able to   access.

15. Do you need support in areas of your life that are not covered in your NDIS / My Way plan?

○ Yes

○ No

○ Unsure

16. What other areas in your life do you need support with that are not covered in your plan?

☐ Health

☐ Education

☐ Transport

☐ Housing

☐ Recreation/social activities

☐ Other (please specify)

[   ]

17. Have you been able to access support in the areas you identified?

○ Yes

○ No

○ Unsure

18. If you answered No to question 17, what have been the difficulties in accessing support?

[   ]

19. Have you been able to get your equipment needs met within your plan?

○ Yes

○ No

○ N/A

20. What has helped or stopped you from getting the equipment you need?

5. Planning process

21. Thinking about your (or the person you support) experience with your NDIS or NDIS My Way planner/coordinator to what extent do you agree or disagree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/a
My planner/coordinator helped me develop my plan	○	○	○	○	○	○
My planner/coordinator listened to me	○	○	○	○	○	○
My planner/coordinator gave me information	○	○	○	○	○	○
My planner/coordinator gave me time to develop my plan	○	○	○	○	○	○
My planner/coordinator helped me implement my plan	○	○	○	○	○	○

22. If I need assistance to get my plan in place ('plan coordination') I would prefer:

○ the government to appoint me a coordinator

○ I would like to choose the coordinator myself

○ I have no preference

23. Are carers and families being recognised and supported in the process and participant plan?

○ Yes

○ No

○ Unsure

24. What are your concerns with implementing your plan?

25. Was it easy for you (or the person you support) to implement your support plan?

○ Yes

○ No

○ Unsure

26. If you have a mental health condition or psychosocial disability what issues have you experienced in the planning process?

27. If you are a carer or family member of a person with disability what are the issues you experienced in the planning process?

6. Managing your funding and supports

In both trial sites there has been developed some different ways people can manage and control their funding and/or the supports they use. This is part of the core principle of the NDIS to give people more choice and control.

28. Can you (or the person you support) choose the way you manage your funding and support?

○ Yes

○ No

○ Unsure

○ If no why?

[   ]

29. What is your (or the person you support) preferred management option?

○ Self-management - you purchase services directly and manage your funding

○ Shared management - you employ or purchase supports but negotiate management level with a service provider who holds the money and can do some or all of the paperwork if you wish

○ Plan management - you manage your support but a plan management agency (not a service provider) holds the money and does some of the paperwork

○ Organisation managed - your funding goes to the service provider you choose who provides or purchases supports

○ Agency managed - the NDIA holds the funding and purchases supports on your behalf

○ A combination of self management and one of the other options

○ Other (please specify)

[   ]

30. Do you have any preferences on how service providers are paid?

○ When the agreement or contract is signed (before services commence)

○ After I have received services (eg. fortnightly invoices)

○ I have no preference

Other (please specify)

[   ]

7. Are your needs being met?

31. Is your (or the person you support) plan and funding package meeting your needs?

○ Yes

○ No

○ Unsure

32. If it is not meeting your needs why not?

33. Have you encountered any issues in engaging, paying or changing services? If so what have they been?

8. Complaints

The Perth Hills Trial site uses the National Disability Insurance Agency complaints processes and has an Independent External Merits Review for appeals. My Way NDIS has its own complaints processes and uses an Independent Panel for   appeals.

34. Have you made a complaint?

○ Yes

○ No

9. Complaints

35. If you made a complaint, what was the complaint about?

☐ Communication

☐ Staff

☐ Length of time

☐ Choices and options

Other (please specify)

[blank text box]

36. Did you get support to make your complaint?

○ No

○ From a family member or friend

○ From an advocate

○ From a service provider

○ Other (please specify)

[blank text box]

37. Was the complaint resolved to your satisfaction?

○ Yes

○ No

If No why not? (please specify)

38. Is there any comment you wish to make about the complaints process?

10. Appeals

39. Have you used the Appeal process?

○ Yes

○ No

11. Appeals

40. If you have made an appeal what was the appeal about?

◯ Eligibility to the scheme

◯ Goals or strategies not included in your Plan

◯ Levels of funding

Other (please specify)

[text box]

41. Did you get support to make your Appeal?

◯ No

◯ From a family member or friend

◯ From an advocate

◯ From a service provider

◯ Other (please specify)

[text box]

42. Was the Appeal resolved to your satisfaction?

◯ Yes

◯ No

If No why not? (please specify)

43. Is there any comment you wish to make about the Appeals   process?

12. People who are not in trial site areas

We would like to know how you have been affected by the introduction of the NDIS trial site areas. Has your support remained the same or has it changed since the introduction of the trial site areas. If it has changed is your support better or worse?

44. How is not being in the trial site affecting you?

13. Any other comments

45. What are the most important features to you for the NDIS in WA?

- [ ] Portability of funding around the state and interstate
- [ ] Choice of planner
- [ ] Choice of coordination support
- [ ] Choice of service providers
- [ ] You having control of funding
- [ ] Ability to change services easily
- [ ] Support from an LAC
- [ ] Availability of advocacy
- [ ] Easily accessible information
- [ ] Independent information and pre-planning support
- [ ] Quality assurance of service providers
- [ ] Independent Review and Appeals process through the Administrative Appeals Tribunal
- [ ] Local review and appeals process
- [ ] Consistency with other states

Other (please specify)

46. Do you have any other comments about your experience in the NDIS/ NDIS My Way?

Thank you for taking the time to share your experiences. The results from this survey will be part of a report to government from advocacy and consumer organisations to highlight what needs to be in the NDIS for Western Australians and to share nationally. Early July it will be available.

47. If you wish to be sent details of the final report please provide an email address, address or phone contact.

Name

Address

Address 2

City/Town

ZIP/Postal Code

Email Address

Phone Number

Appendix 2 – Forum Agenda and Questions

Forums used the same format

Perth Hills Forum – June 2016

South West Forum – May 2016

Time	What	Process Notes
2:00 pm **10min**	**Welcome and Introduction** • Welcome • Purpose of this session	

2:10 pm
 	
10min
	Time to gather your thoughts
	
	• Using the points below as a guide and talking with one other person next to you, give your own score.
	
	  PWD
	
	  - The NDIS program is an improvement in planning for my needs
	  - The NDIS program is an improvement in accessing services
	  - The NDIS program is an improvement in accessing the wider community
	  - My life is better because of the NDIS program
	
	  Carer
	
	  - The NDIS program is an improvement in planning for the person I care for
	  - The NDIS program is an improvement in accessing services for the person I care for
	  - The NDIS program is an improvement in accessing the wider community the person I care for
	  - The life of the person I care for is better because of the NDIS program
		7min with an individual score card
		
		(see next page example)
		
		3min - Posters around the room for PWD and Carers to add their scores

2:20 pm **40min**	**Exploring views and options** • Discussing 4 x Themes	15min per theme to explore the reason for each score
3:20 pm **40min**	**Most Significant Change** • Table discussion of the changes that have been most significant for each person as a result of the NDIS program	15min to discuss at tables (might be good to have a scribe) 15min plenary sharing
3:50pm **40min**	**Closing** • What happens with this information • Thank you for your time	10min per theme to explore the reason for each score
4:00pm	**END**	

Individual Score cards are 1/3 A4 given as a hand out

Consumer Score Card	Strongly Disagree 1	Disagree 2	Somewhat Disagree 3	Neutral 4	Somewhat Agree 5	Agree 6	Strongly Agree 7
- The NDIS program is an improvement in planning for my needs							
- The NDIS program is an improvement in accessing services							
- The NDIS program is an improvement in accessing the wider community							
- My life is better because of the NDIS program							

Carer Score Card	Strongly Disagree 1	Disagree 2	Somewhat Disagree 3	Neutral 4	Somewhat Agree 5	Agree 6	Strongly Agree 7
- The NDIS program is an improvement in planning for the person I care for							
- The NDIS program is an improvement in accessing services for the person I care for							
- The NDIS program is an improvement in accessing the wider community the person I care for							
- The life of the person I care for is better because of the NDIS program							