

# NDIS EXPERIENCES

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

November 2015



people with disabilities  
western  
australia



## **Acknowledgements**

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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 trialed in the State. In July 2014 the National Disability Insurance Agency (NDIA) began a two year NDIS trial site in the Perth Hills. At the same time 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.

These trial sites are each being independently evaluated. It is however recognised that inter-governmental negotiations will likely conclude before the evaluations have been finalised to ensure the continuity of funding and a model beyond the June 2016 trial end dates. People with disabilities and their families and carers expressed concern that their voices and experience of the trial sites would not be heard as part of the negotiations, because the evaluation period would not be completed in time to inform the design and delivery of the agreed NDIS in WA. People want to get the best scheme for NDIS in WA and the evaluation has been seen as the mechanism to inform the changes that would need to happen to get the best system, based on the learnings from both trials.

### **1.1 Background**

In August 2015 a number of disability advocacy organisations and consumer and carer representative groups collaborated to collect feedback from people with disabilities and their families and carers about their experiences of the National Disability Insurance Scheme (NDIS) in Western Australia and the WA My Way NDIS (My Way). 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.

The consultation arose out of concern that decisions about the final model for funding care and support for Western Australians with a disability was being made prior to the conclusion of the independent evaluation, and without the direct input, oversight or engagement of people with disabilities and their families and carers directly affected by the changes.

Disability advocacy and consumer and carer representative groups acknowledge that there has been ongoing engagement by both Governments with the disability sector about the reforms. However, our organisations were concerned that the focus of this engagement has been to demonstrate how well the models perform relative to each other rather than providing a qualitative analysis of what is working and not working in each of the models being trialed from the point of view of those whose lives are directly affected by the reforms.

It was for this purpose that our organisations undertook this consultation and developed this report. This report presents feedback on the experiences of people with disability and their families and carers in each of the three trial sites and across both the My Way and the NDIA models. The consultation did not include service provider organisations or staff. This was a deliberate tact to ensure the evidence embodied in this report is based solely on experiences from people participating in NDIS, their families and carers.

## **1.2 Findings**

The information was collated from a combination of responses to an online survey and two focus groups, one in Busselton and one in Perth. Approximately 250 people responded in total. Further information on the methodology and responses is available at section two.

Based on the overall feedback, the consultation was not able to indicate that one model was preferable to the other, but rather that there are strengths and weaknesses in each of the models across the three trial sites currently in Western Australia. There are issues and trends that are emerging as the trials progress which need to be analysed and considered. It is strongly recommended that these are considered in any system re-design.

In broad terms people in the Perth Hills and Lower South West trial sites are experiencing a mixture of issues. There are pockets of good practice and it is recommended that where good practice is evidenced this should be highlighted, shared and replicated.

In general, issues that require attention fall under the remit of the following categories:

*System design issues*

*Experiences of obtaining information*

*Experiences with the planning and plan implementation process*

This report elaborates on these key themes and makes recommendations for change.

Based on survey results, people residing in the Cockburn/Kwinana trial site are experiencing many of the same issues as the other trial sites areas, however there is a distinctly different tone to that feedback with concerns being more prevalent here than in the other sites. The majority of responses indicated areas for improvement rather than highlighting good practice. This suggests that there is something unique to how the trial is being experienced in Cockburn/Kwinana which needs to be more

closely understood. While this report does not make any assumptions as to the causal effect, anecdotal feedback from the region might provide some context and insight. We recommend further investigations and changes be made to resolve these concerns in the Kwinana/Cockburn trial site area.

### **1.3 Key messages for Government**

While this consultation is not exhaustive or representative, it provides no indication that one reform model is performing consistently better for people with disabilities and their families and carers in the trial sites than the other. Given that negotiations are commencing without the independent evaluations being completed, advocacy and consumer and carer organisations believe there needs to be greater transparency for people with disabilities and their families about the basis on which the State and Federal governments will be negotiating the final reform model for Western Australia.

Our analysis points to some critical questions which we believe need to be considered and explored in greater detail in the ongoing negotiations and in the governments' engagement with people with disabilities and their families and carers:

- How well is each of the models meeting the objectives of 'choice and control'?
- How do the diverse population of people with disabilities and their families and carers measure the success of reform?
- How will we determine that the outcome we negotiate is likely to address those measures?
- How well are each of the models enabling people with disabilities and their families and carers to realise broader outcomes such as independence, inclusion, citizenship and social and economic participation?

The following discussion and recommendations are based on analysis of our consultation and highlight the elements that have emerged as important for people with disability and their families and carers. We look forward to working with all stakeholders on ensuring continuing engagement and feedback from people with disability, their families and carers.

## Discussion

Our consultation has given a unique insight into the experiences of people with disability, their families and carers in trialing the NDIS in Western Australia. How these findings can directly influence the negotiations for what happens in Western Australia is part of this discussion.

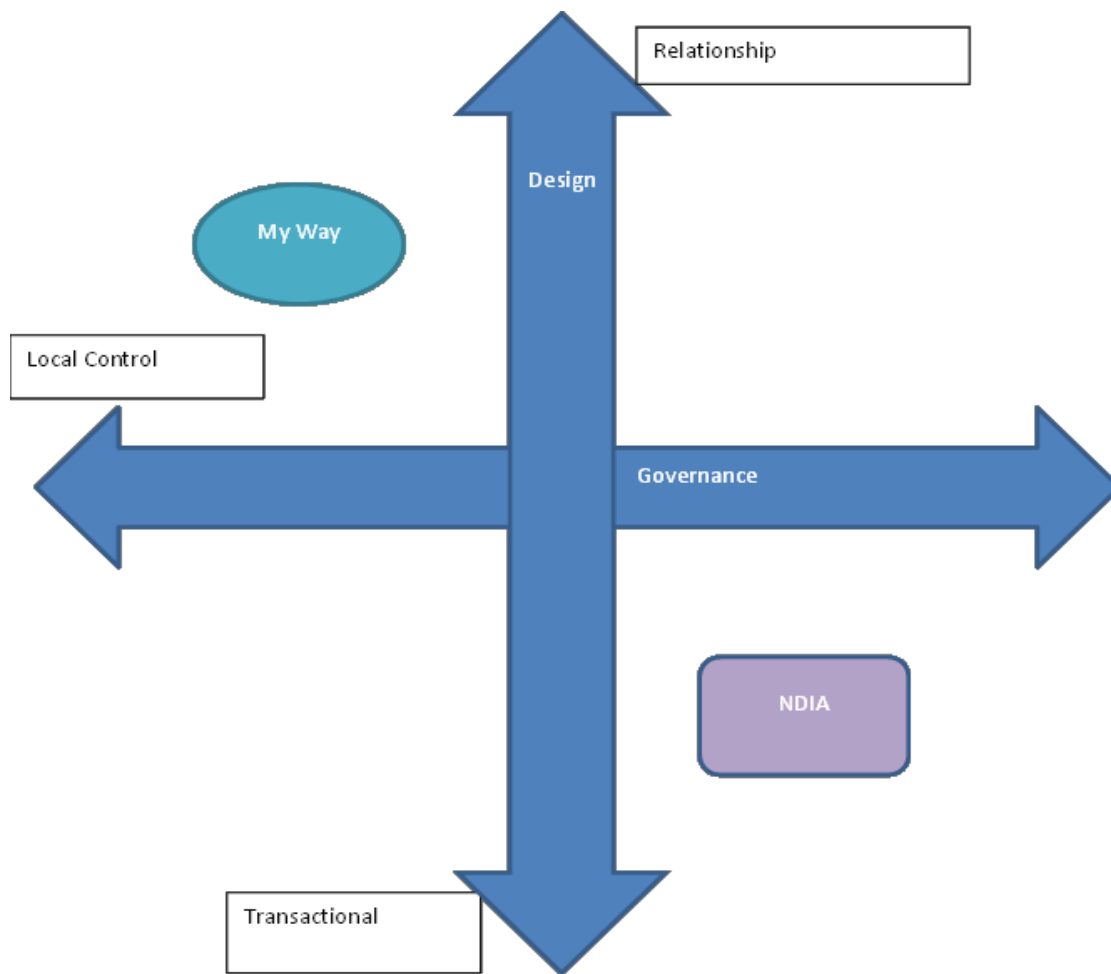
When people with disability, their families and carers campaigned for a national disability insurance scheme they identified three pillars:

- Sustainability - A system which would give people the certainty of getting the funding and support that they needed, and knowing it would be there in the future for themselves and/or their children.
- Rights - A system which would put people with disability in control of their lives and have their rights acknowledged, with a focus on inclusion in community and having the same access to opportunities and choices as anybody else.
- Consistency - A system where funding is portable across the nation and you know that you will get funding based on your needs and not who has the loudest voice or lives in the best area.

As the scheme has been implemented in its trial stage a fourth pillar has also been recognised 'quality'.

- Quality - A system which can provide better services, choice of services and a better quality of life in terms of safeguards as well as opportunities for people with disability, their families and carers.

What our consultation has found is that the diversity of needs of people with disability, their carers and families cannot be met by any one model. The critical question which we raised in the introduction around how the diverse population of people with disability, their families and carers measure the success of the reform cannot be answered by focusing on dichotomies such as a model being either relationship based or transactional, or having governance at a local or national level. In much of the discussion about the two models that have been trialed in Western Australia the notion of one model being relationship based and the other model being transactional has persisted, when the reality of what people need is a combination of both dependent on a person's individual circumstances. Below is a diagram showing the matrix of where the two models might currently be perceived to sit.



What has come from our analysis is that rather than the dichotomous approach, what is needed is a system with the flexibility and responsiveness of approach which allows people to find the right fit for them at the individual and family level.

For example, a person with a disability and/or a family who is clear about their needs and believes that what they require is fairly straightforward may only want very minimal contact with a 'local area coordinator' or government staff member and not wish to go into detailed discussion on their personal life. Examples from the consultation which highlight this perspective included respondents indicating that they really liked *"crosschecking accountability to my portal"*, *"having the option to self-manage. Having more control of my independence."* Others liked that they had support to self-manage but deal with the transactional aspects themselves - *"We are self managing and have had lots of support at our meetings with the finance people and our wonderful NDIS coordinator"*.

Other people with disability and their families and carers may be on a different part of the journey, have more complex needs or situations, or just want a different experience and level of support. Respondents comments which highlighted this



perspective included - *" we have a case manager who represents (our daughter) at school meetings and also talks to all her therapist and specialists. I like the idea of having somebody who is across everything we're doing and can help manage and direct what we should do next"*. For some the role of the My Way Co-ordinator was really important - *"my Co-ordinator has guided me through the process and regularly updates me on new opportunities"*. For others it was about knowing that if they need to purchase support for coordination then they can, *"I have no concerns, my plan has provision for support coordinator to guide and help me through the implementation process"*.

These comments reinforce that flexibility and responsiveness must be built into the system that provides a broad variety of options to reflect and respond to the breadth of experiences, needs and desires of people with disability and families and carers. Further, in order for this system design to be flexible and responsive, requires the intrinsic involvement of people with disability, their families and carers themselves.

The need for greater flexibility and more options came through at many levels in our consultation, ranging from how people get information right through to ways to manage the planning process. Responses to the consultation suggest that the more channels that people have to source information increases the likelihood of their ability to make informed choices than if the information is funneled through a singular source.

A theme which came through in relation to planning was how highly dependent the quality of the planning process was as it relates to the quality of the planner and how much they can engage with the person with a disability and their family or carer in the way that is right for them. Furthermore, having the ability to choose who to plan with and the type of planning process came through as a theme in the consultation. At the time of our consultation none of the trial sites had the option of a person being able to choose who does the planning. This means that it is highly likely that you will not get a planner that knows you or your situation. Although our consultation did not go into what makes a good planner versus a bad planner, it did highlight that where people got good information from the planner and were listened to by the planner it was likely to be a better outcome. It was also very clear that people with disability, their families and carers want to be in control of their own planning process. These are just some areas of improvement that can be pursued during negotiations.

Referring back to the four pillars of a good system, - sustainability, rights, consistency and quality -the consultation results suggest that far more is required in order to adequately embed these four pillars in the system – either My Way or NDIS.

Sustainability must not just be about the financial sustainability of the NDIS as a long term scheme but also the individual sustainability of people's plans and funding for them to be able to achieve their long term vision for their own lives. There were a

small number of people saying that their needs were not being met by the packages they received, due to insufficient funds, plans not being flexible enough, and service costs being too high. It is concerning when average package costs are promoted as a primary factor in measuring the sustainability of the scheme. The notion of value for money, the foundation of any government procurement process, does not solely refer to what is cheaper.

Numerous comments from respondents indicated they felt pressured into decisions about their plan, and their choices compromised due to, for example, having to use only certain service providers and a lack of transparency of process and availability of information. This unduly restricts people's rights to choice and control.

The NDIS is legislated to enact the UN Convention on the Rights of People with Disability in Australia. This is reflected in the strong focus on economic and social participation and community inclusion in the NDIS. The consultation response identifying the extent of difficulty in accessing unfunded services indicates that the vision of inclusion of people with disability and their families in mainstream services needs a lot more work. A focus on informal supports and the mainstream community in people's plans means there must be the corresponding support at all levels for informal supports and community systems so they can take on these roles and responsibilities.

Transport was highlighted, particularly in the Lower South West in relation to informal supports. Informal support from the community needs to be cultivated and there is often a cost involved whether from in-kind benefits, or a contribution of some kind as payment. Informal support from family and carers also must be recognised and supported in the planning process and in plans. Informal supports are an investment that requires input both from the NDIS in funding packages and pricing systems as well as the Information, Linkages and Capacity Building components of the scheme.

Consistency is not explicitly addressed in the consultation however it is important when addressing people's expectation of 'reasonable and necessary'. Transparency is required in relation to how 'reasonable and necessary' is determined in order to ensure consistency.

People with disability and their families and carers will talk to each other about their experiences and will learn from each other. In the current and emerging technological environment it is easy for many people with disability, family members and carers to connect through social media from across the country. There are emerging apps and websites for rating services and sharing experiences. In negotiating future rollout in Western Australia, all parties need to be aware that people will compare across systems and across the country. It is important as the systems evolve that we continue to have the ability to learn from other states and

share our experiences with the rest of Australia.

There must also be opportunities for people to provide peer support as a way of increasing the overall understanding of the system and feeling empowered to think beyond their current boundaries. People with disability, their families and carers in the focus groups we ran, and other peer groups, have appreciated the opportunity to share and hear others experiences.

Evidence in relation to quality will emerge more so during rollout and will be informed partly be people sharing experiences. Acknowledging that it is only at trial stage, it is still notable that some respondents indicated that they are unable to have real choice of service providers, and that there were not enough small and innovative providers. However many people felt that they were getting more opportunities than previously.

The majority of respondents to our survey and focus groups did feel that their access to services and the community had improved due to the NDIS. However, as we have discussed the key areas of communication and access to information, planning, and plan implementation had issues from all trial areas related to accessibility, choice and control. These areas for improvement and highlighted areas of good practice provide the evidence for our recommendations.

## Recommendations

The following recommendations are based on the findings from the consultation, and 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.

Recommendations have been categorised into three sections:

Firstly those that recommend changes to the overall system which express the need for better engagement and collaboration, improved linkages, innovation and quality. The second set of recommendations focus on information. The evidence shows that timely, accurate, relevant information in the desired format greatly improves the person's access to, experience of and involvement in the NDIS process. The final set of recommendations focus on the NDIS process whether this involves pre-planning, planning or post planning options.

### System Design Issues

- 1.1. Whilst it is clear inter-governmental negotiations will commence before evaluations have been concluded it is strongly recommended that preliminary findings from these evaluations are considered. It is also important that other consultation activities such as the NDIS citizens' jury scorecard and 'lessons learnt' from other states are factored in to the process.
- 1.2. 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.
- 1.3. More options to be made available for either small service providers or innovative individualised arrangements within the pricing catalogue, and less bureaucracy with how service providers can be registered depending on their size and business models.
- 1.4. Advocacy to be 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.
- 1.5. 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.
- 1.6. 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 pricing structures and 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 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. Peer and representative groups to be funded to provide information and sharing of experiences.
- 1.9. 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.
- 1.10. 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’.
- 1.11. It is recommended that the notion of ‘management’ is clarified and unified in the WA NDIS approach. Currently the terminology means different things in NDIA and My Way which is often misleading and confusing.

## Planning and plan implementation

- 1.12. People with disabilities and their families and carers 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.
- 1.13. A quality framework to be introduced for Planner/ My Way Co-ordinator

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.

- 1.14. The role of government is better placed to be in determining eligibility to the scheme and endorsing 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 thereafter.
- 1.15. People to be able to choose and purchase support coordination if and with whom they prefer, rather than being automatically allocated a My Way Co-ordinator. Access to support coordination is an important aspect of peoples' experiences and lessons should be learnt from different states.
- 1.16. 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).
- 1.17. A range of fund and plan management options available. There is evidence to suggest 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.

## Methodology

The consultation relied on two mechanisms for collecting experiences from people with disabilities and their families and carers in the three trial sites: an online survey and two face-to-face focus groups.

### 2.1 Process

The online survey, NDIS Experiences, was open for people to provide their feedback on the scheme between 24/08/15 to 21/09/15. 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 My Way 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 the My Way 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 200 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 distribution. DSC posted the survey on the My Way website and alerted My Way Co-ordinators that the survey was available for participants to complete. The NDIA distributed the survey to all participants in the NDIS Perth Hills trial site via e-mail or post where an e-mail address was not available.

In addition to the online survey, two face-to-face focus groups were conducted. A forum was held for participants in the Perth Hills and Cockburn/Kwinana on 12 September 2015, and another forum was held in Busselton on 17 September 2015 for participants in the Lower South West. The forum in Perth was facilitated by an independent facilitator, and the forum in Busselton was facilitated by WA's Individualised Services, one of the collaborating organisations. A copy of the consultation questions and agenda is at Appendix Two.

### 2.2 Survey Profile

As of 30 June 2015, there were 777 individuals found eligible for supports and services in the Lower South West My Way trial site, with 688 having completed a completed WA NDIS My Way plan (*DSC, June 2015, quarterly report to Commonwealth Government*). No data was yet publically available for the Cockburn and Kwinana trial site. In the Perth Hills NDIS trial site, there were 1,199 approved

plans as of 30 June 2015 (*NDIA, July 2015, Report on the Sustainability of the NDIS Quarter 4 of Year 2*).

The survey attracted 200 respondents which equates to 10% of those total participants with a plan as of 30 June 2015. Of the 200 respondents, 25% were participants with disability, and 75% were a family member, friend or carer of a person with a disability who is a participant.

64% of survey responses were from people in the Perth Hills; 21% of responses were from people in the Lower South West; and 15% of responses were from people in Cockburn/Kwinana. The strong representation from the Perth Hills may be attributable to the fact that a higher number of plans have been completed in the Perth Hills Trial Site, and that the NDIA actively disseminated the survey to its participants. The low representation from Cockburn/Kwinana may be reflected in the fact that the trial has only been underway for four months.

Data on Aboriginal or Torres Strait Islander (ATSI) status and Culturally and Linguistically Diverse (CALD) status was collected: 3% of respondents identified as Aboriginal or Torres Strait Islander. 3% indicated speaking more than one language at home. These languages included Dutch, Portuguese, Italian, Akan and Yinjibarndi.

One acknowledged limitation in the survey profile is the lack of information about whether respondents had been receiving supports and services prior to the trial, or whether the trial was their first engagement with the support system. This information might have provided useful contextual background to people's responses. People who are new to the care and support system will have a different point of comparison or 'baseline' experience than those who were already connected to the care and support system. It would be useful to profile each of the three trial sites on that basis. Anecdotal feedback beyond the consultation suggests that this could be a factor in some of the differences in the tone of feedback from the trial sites.

While this was not collected at the individual level, there was a specific question asking people to compare experiences of the care and support system during the trial and prior to the trial.



## Survey Results and Analysis

This section of the report provides an analysis 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. The subsequent sections review feedback on specific aspects of the My Way and NDIS processes including access to information, access to mainstream and community services, the planning process, plan implementation and managing funds and support.

### 1. What's working well and what needs improving

This section of the report provides an analysis of the qualitative feedback collected in questions 10 to 12 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 response rates to these questions by trial site are representative of the response rates to the survey by trial site.

In this report, we provide an overview of the responses and some analysis of our review of the qualitative feedback. A more detailed analysis of this data can be provided upon discussion, and we recommend that government meet with the collaborative group to discuss this in greater detail.

#### 1.1 Good Practice

A total of 62% of respondents provided feedback on what they thought was working well overall in My Way and the NDIS<sup>1</sup>. The main areas that were identified as beneficial include:

- 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

“We have more choices of services we can buy with the funding and in most cases more relevant to his needs or the supports he needs.”

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<sup>1</sup> 67% of responses to this question were by people from the Perth Hills; 21% were by people from the Lower South West; and 11% were by people from Cockburn/Kwinana.

“I like (now I know) that we build the plan around my son not try and get my son to fit around someone else's vision of what he needs”

“The increased choice in service providers. The focus on planning - my plan is more specific and flexible now to my needs than ever before”

## **1.2 Areas for improvement**

62% of respondents provided feedback on what they thought was not working well overall in My Way NDIS<sup>2</sup>. The main areas identified as needing to improve include:

- 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)

## **1.3 Recommendations for change from respondents**

61% of respondents provided feedback on areas that could be improved<sup>3</sup>. The main elements include:

- 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

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<sup>2</sup> 67% of responses this question were by people from the Perth Hills; 19% were by people from the Lower South West; and 14% were by people from Cockburn/Kwinana.

<sup>3</sup> 66% of responses to this question were by people from the Perth Hills; 21% were by people from the Lower South West; and 13% were by people from Cockburn/Kwinana.

## 1.4 The Impact of Reform

Question thirteen 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 regarding things such as choice, control, knowledge, outcomes, supports and flexibility. A total of 150 respondents, or 75%, responded to this question with consistent numbers of people providing responses across the statements.

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

Those responding from the Perth Hills site were more variable across the statements, but had higher levels of agreement across the statements than disagreements. This data should be considered in the context of whether or not people in those sites were already receiving supports or not. Where people had limited experience with which to compare their current experience, then it is reasonable to expect that they would be more likely to agree with statements.

“My coordinator introduced my son to support systems which we had no knowledge of existing prior to us being connected to this coordinator...”

The first statement asks whether people’s packages under the trial better reflect their needs compared to their packages under the previous system. 76% of respondents from the Lower South West agreed that their package better reflected their needs, 53% of respondents from the Perth Hills agreed, and only 16% of respondents from Cockburn/Kwinana agreed their package of support better reflects their needs. In fact, 53% of respondents from Cockburn/Kwinana disagreed that their package of support better reflects their needs.

“The targeted support provided by the service provider has been fantastic. The flexibility of the funding has allowed for the support to be timetabled for appropriately to reflect specific needs.”

The second of these statements referred to people's knowledge of what goals are included in their plan. 72% of respondents from the Perth Hills agreed, 86% of respondents from the Lower South West agreed, however only 53% of respondents from Cockburn/Kwinana agreed with this statement. 21% of respondents from Cockburn/Kwinana neither agreed nor disagreed, and 26% of respondents from Cockburn/Kwinana disagreed that they knew what goals are included in their plans.

The third statement inquired about whether people felt they knew how to make their plan reflect their goals. 79% of respondents from the Lower South West agreed that they knew how to make their plan reflect their goals. In the Perth Hills, 50% agreed and in Cockburn/Kwinana 26% agreed they knew how to make their plan reflect their goals. In Cockburn/Kwinana 42% of respondents disagreed they knew how to make their plan reflect their goals and 32% neither agreed nor disagreed. In the Perth Hills, 19% disagreed and 22% neither agreed nor disagreed.

The fourth statement asked whether people agreed they have more choice under the trial compared to the previous system. In the Lower South West 66% agreed that they had more choice. In the Perth Hills 50% agreed and in Cockburn/Kwinana 32% agreed. 53% of respondents from Cockburn/Kwinana disagreed they had more choice.

On the question of whether people thought they now had more control than under the previous system, 69% of respondents in the Lower South West reported that they did, contrasted with 67% of respondents in Cockburn/Kwinana who disagreed that they had more control.

When considering whether they received more supports now than before, 67% of respondents in the Lower South West agreed and 52% of respondents from the Perth Hill agreed. In Cockburn/Kwinana 42% of respondents disagreed that they received more supports.

The Lower South West also demonstrated a very high level of agreement in regard to the statement that 'I now achieve better outcomes' at 72% of respondents. This compared with only 46% and 21% in Perth Hills and Cockburn/Kwinana respectively.

The eighth statement in the series asked about receiving support in a timelier manner. 68% of Cockburn/Kwinana respondents disagreed with this statement, as opposed to 62% of Lower South West respondents. On the question of flexibility in using funding and supports, 62% and 54% of respondents from Lower South West and Perth Hills respectively agreed, and 58% of those from Cockburn/Kwinana disagreed.

## 1.5 Analysis

The qualitative feedback gathered through these questions provides a detailed perspective on how individual people have experienced the system; what specific aspects have been beneficial to or challenging for them. A number of the responses demonstrate clearly whether people feel they are receiving a better overall outcome than before or not. It is apparent that some people in each of the trial sites believe that the trial has made an improvement for them, and equally there are others who report that their experience under the trial has been adverse compared to their previous experiences.

What is notable in the analysis of the qualitative feedback was a distinct difference in feedback from Cockburn/Kwinana. Where the other trial sites included more of a balance between positive and negative feedback, the respondents from Cockburn/Kwinana were far more likely to provide feedback that was not positive. This is likely attributable to the newness of the trial in Cockburn/Kwinana, and perhaps reflects the time pressures in the early stages of signing people up to the trial and completing plans.

Overall, it appears that there is considerable inconsistency within and across the trial sites by people with disabilities and their families when it comes to the primary reform objectives of choice and control. There are a number of factors which might contribute to this variation beyond the specifics of a model itself, and these must be taken into account in the negotiations so that undue cause and effect is not given to system design aspects unless there is clear evidence that they are the contributing factor – a challenge in an environment where the scope of reform is large, the trial timeframe is relatively short, and independent evaluation has not been completed or been able to be reviewed by stakeholders.

The diversity of the responses to the survey suggest that system design, and therefore differences in the models, might not be the only critical factor in people's experience. Other factors which analysis of these qualitative responses to these three questions appear to point to include:

- The baseline experience of people with disabilities and their families and carers;
- The reform environment – that is, the practicalities of implementing a trial model, the consequent time frames, and the range of factors needing to be in place for a service system to reach its full potential, and the challenges of scaling up in a short period of time;
- The human factor –inconsistent experiences within a human services system where human interactions between consumers and agents of the system are

a critical factor; and

- The different expectations and imperatives for people with disabilities and their families and carers and government agencies.

“At least I was given an LAC who had some knowledge about the trial and he did listen effectively to what my needs are.”

“Funding body (NDIS) lacking intimate knowledge of who I am and what are my needs are. I don't always fit into a box. Relying on my advocate to push my claims outside of the designated box. Not all my needs and the equating required support can be calculated in an hourly rate. Funding support staff at NDIS are limited; extremely busy; and lack comprehensive knowledge of how the funding system works.”

## 2. Access to information

In this section of the report, we describe the survey responses to questions 5 to 9 of the survey relating to access to information. These questions included multiple choice and free text responses.

Overall, approximately 60% of all respondents to the question on how easy it was to get information indicated that it was easy for them, or the person they support, to access information about the trial<sup>4</sup>. Respondents from Cockburn/Kwinana were far less likely to report they found it easy to access information than other respondents. 66% and 56% of respondents from Perth Hills and Lower South West responded that it was easy for them to access information compared to 35% of respondents from Cockburn/Kwinana.

Some 30% of respondents to this question indicated difficulties in accessing information across all trial sites, which they described in a free text response<sup>5</sup>. 50% of respondents from Cockburn/Kwinana indicated it was not easy to access information, 32% of respondents from the Lower South West indicated it was not easy to access information and 22% of those from the Perth Hills. Their responses can be themed into the following:

- Lack of information on the supports and services which can be accessed with the funding;

<sup>4</sup> 73% of people who indicated it was easy to access information were from the Perth Hills; 18% were from the Lower South West; and 9% were from Cockburn/Kwinana.

<sup>5</sup> 57% of people who indicated they had difficulties accessing information were from Perth Hills, 19% were from the Lower South West, and 24% were from Cockburn/Kwinana.

- Staff not appearing to have all the information to adequately support people with accurate information and support;
- No reply or long delays in getting responses to queries;
- Mixed messages and contradictory information given by different staff which caused confusion and delays;
- Feelings of being overwhelmed by all the paperwork and information;
- Information changing and goalposts shifting of what was and wasn't allowed;
- Website confusing and a lack of information in plain English.

Overall, just over half (52%) of respondents indicated that they had sufficient information to make choices about their support needs<sup>6</sup>. Respondents from Cockburn/Kwinana were far less likely to report they had sufficient information to make choices about their support needs than people from the other trial sites, with a significantly smaller percentage – only 24% of respondents from the Cockburn/Kwinana trial site indicated that they had sufficient information to make choices about their support needs.

Respondents identified what further information was needed in order to make informed choices about their support needs. Fundamentally the two dominant issues are to:

- Provide more information on what services and organisations individuals can access for their supports.
- Ensure all staff across all trial sites have a good understanding of what can be funded and what is available in their area.

The qualitative data indicated the following trends in the comments provided across all trial sites:

- More information on what services could be funded through My Way and NDIS;
- Flexibility of services which can be funded through My Way and NDIS;
- Staff who have sufficient time to support individuals and families through the planning process and implementation of the plan;

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<sup>6</sup> 69% of respondents who indicated that they had enough information to make choices about their support needs were from the Perth Hills site, 24% were from the Lower South West, and 7% were from Cockburn/Kwinana.

- Time for individuals, families and carers to consider information and options in order to make choices and decisions about their support needs and the plan;
- The need for a go-to person or place to get the information and support you need. Examples included Local Area Coordinators and Area Supervisors;
- A clear step-by-step process so individuals, families, carers and staff in the trial sites all have an understanding of the process and who is responsible for what steps;
- Clear, precise information in plain English;
- Ability to include other people in the planning processes, such as service providers;
- Staff with a good understanding of what services are available.

In response to the question asking what sources of information were the most useful, approximately 50% of respondents indicated that the My Way Coordinator or NDIA Planning and Support Coordinator were the most useful source. Other useful sources of information included:

- Service providers (20%);
- Other people with disability, families or carers (20%); and
- Website/information session/advocacy organisation (10%).

Based on the breakdown of these responses, it would appear that respondents from Cockburn/Kwinana were less likely to indicate that it was easy to access information and more likely to report that they had difficulties in accessing information. They were also less likely to report that they had sufficient information to make choices about their support needs than respondents from the other regions. This would appear to be consistent with the different tone of feedback from Cockburn/Kwinana discussed earlier in the report, and might be attributable to particular issues in the timing and implementation of My Way in that location.

On the basis of these survey responses, there is nothing to indicate that either of the trial models performed better at providing information to people with disabilities and their families and carers to make choices about their support needs. The three overarching issues regarding accessing information appear to be:

- Consistency in information from staff within the trial sites;
- Timeliness of information; and



- Making generic information meaningful for people who need information and answers that is specific to their individual circumstances.

It is recognised that a number of initiatives have been supported to provide targeted and customised information to specific populations, and while it is not possible to account for the impact of those in this survey the responses do indicate that people have accessed information from multiple sources. Some of these experiences can be attributable to the fact that it is in a trial phase, but it is also likely that even in an ongoing system ensuring information is consistent and timely will continue to be an issue.

Further discussion on access to information occurs later in this report regarding survey responses on planning process, where information emerged strongly as a theme in the qualitative feedback.

### **3. Access to mainstream and community services**

Questions fourteen to seventeen asked people to provide feedback about their access to mainstream and community services. Respondents were asked how easy it is to access services that are not funded but in their (or the person they support's) plan.

These questions are of importance because of the strong focus of the disability support reforms on maximising access to mainstream and community services and informal supports in order to make those services more responsive. This is in order to contribute to better outcomes and possibly reduced need for disability specific care and support, as well as to moderate the demand on the disability care and support system to meet people's other service needs. These services are often included in a person's plan, but are not funded through the plan.

Also included in this section were questions on whether or not people's equipment needs were met within their plan.

Question fourteen invited people to reflect on how easy it is to access services that are in their plan but not funded. 70% of survey respondents answered this question and the level of responses by region was consistent with the survey sample. There was an overwhelming response across the trial sites that people did not find it easy to access unfunded services, but there were also differences between the trial sites. *No respondents* to this question from Cockburn/Kwinana found it easy to access unfunded services, 61% said it was not easy and 39% were unsure. In the Perth Hills, only 16% of respondents indicated it was easy and 30% of respondents that it was not easy. The greater percentage of respondents from the Perth Hills (54%) said that they were unsure. In the Lower South West an equal number of respondents found that it was easy to access unfunded services and that it was not

easy (29%). A greater percentage of people were unsure (43%).

In determining which factors made it easier to access services not funded in the plan, respondents indicated the following across all trial site areas:

- Access to information
- Help from Coordinator/Planner
- Informal family support
- Support organisation
- Deciding to pay for private services
- Already in place before NDIS Plan

Factors which made it difficult to access services not funded in the plan include:

- Lack of information
- Lack of help from Coordinator/Planner
- Being passed between government departments who are unclear who has responsibility for the service
- Inability to use internet to research
- Exhaustion

A number of factors were particularly prominent in the Lower South West. These included:

- Lack of services in the area
- High costs / ill-affordability
- Transport

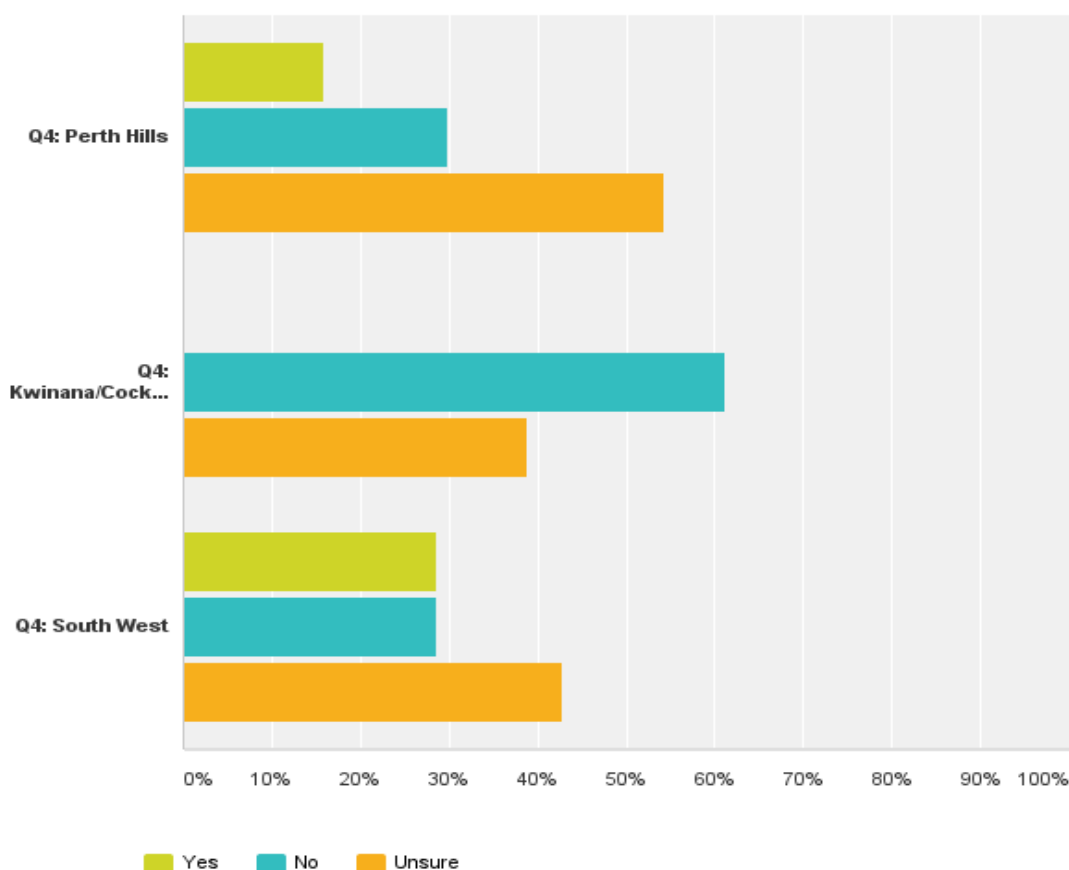
A lack of services and transport can be attributed to the delivery of services in a regional area, and the fact that trialing the reforms in a regional site requires a scaling up of the system and related services and support, resulting in a lag between supply and demand.

“New service providers coming that don't have any idea of what the access issues are here. They are doing away with the Regional Therapy Team who have worked with us for years and understand ways around the access issues for equipment and services.”

These figures would appear to indicate a relatively low level of confidence by people with disabilities and their families and carers across the models about accessing mainstream and community services and other informal and unpaid supports. While there is certainly some notable variances by location in relation to 'ease' of access, the overall responses to this question indicate that more guidance and support is needed to assist people in this regard in both models.

**Q14 Is it is easy to access services that are not funded but in your (or the person you support) plan?**

Answered: 140 Skipped: 60



Respondents were also asked in this section if they were able to get their equipment needs met in their plan. Approximately 45% of the respondents indicated that this question was not applicable. A further 30% indicated that they did get their equipment needs met, with 25% of respondents indicating that they did not get their equipment needs met.

Factors that helped respondents in getting the equipment they need include:

- Assessment and approval process
- WA DSC Equipment team
- Support from Coordinator/Planner

Factors that stopped respondents from getting the equipment they need include:

- Process being too long and too complicated
- Limitations of scope of what is included
- Lack of evidence as to the benefit of the equipment
- Waiting on assessment/complexity of assessment
- Lack of information
- No follow up contact
- Inadequate funds
- Lack of suppliers
- Fear of asking

“The initial flexibility of the scheme has changed. Shift in focus back to the big service providers who only provide a standardised/inflexible care arrangements. Lack of block/seed funding for smaller service providers to do innovative work. Lack of information from DSC on what could be provided in a plan. Those who had never received anything under old system, had no knowledge of what's available. Loss of DSC officers' ability to be an advocate”

## 4. Planning process

Questions eighteen to twenty-three 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.

### 4.1 *Role of Planners and Coordinators*

Question eighteen asked respondents to reflect on the role and impact of planners and coordinators. It posed a series of five statements and asked respondents to indicate whether they agreed or disagreed with these statements across a scale. 70% of survey respondents responded to these statements, and responded to all statements. 66% of the responses were from respondents in the Perth Hills, 20% from the Lower South West and 13% from Cockburn/Kwinana.

Similar to question thirteen, which used the same approach to gather comparisons between the previous system and the trial, the responses to this question showed distinct variations across the sites. Responses in the Lower South West showed higher levels of agreement on most of the statements than Cockburn/Kwinana. Perth Hills again showed more variability in responses but respondents were more likely to agree with statements than not. Against each of the statements some people from each trial site responded that they neither agreed nor disagreed. For the purposes of finding points of comparison we've focused the discussion on where people agreed or disagreed.

The first statement referred to planners and coordinators helping people to develop their plan. 78% of respondents from the Lower South West, 65% in the Perth Hills and 50% in Cockburn/Kwinana agreed that their planner/coordinator had helped them. In Cockburn/Kwinana, 33% of respondents disagreed, compared to only 15% and 7% in Perth Hills and Lower South West respectively. The next question asked people to reflect on whether they believed their planner/coordinator had listened to them. This also received a higher level of agreement in the Lower South West (82%) and Perth Hills (77%) than in Cockburn/Kwinana.

On the notion that planners and coordinators provided adequate information, Perth Hills recorded a 67% agreement with this statement. Levels of agreement to this in the Lower South West were lower than on the previous statements - only 57% of respondents from the Lower South West agreed that their planner/coordinator had provided information. In Cockburn/Kwinana 39% agreed and 33% disagreed. The fourth statement invited people's views on whether they felt their planner/coordinator gave them adequate time to develop their plan. In the Lower South West 61% of

respondents agreed, as did 56% of those in the Perth Hills. In Cockburn/Kwinana only 28% of respondents agreed and 50% disagreed with the statement.

“It is very slow to get things done, we are still waiting for some equipment to be issued, there appears to be too many duplications.”

“[I] feel as if I'm being pushed by the system to hurry up and select a new service provider so I sign off on my plan. Feel as if I'm being rushed into doing this as well. Because I didn't have any choice but to be in the My Way trial, there's the constant worry and fear that my current HACC funding will be removed if I take too long to come to any decisions. Feel as if my choices are being taken away.”

The final statement referred to planners and coordinators helping people to implement their plan. This statement featured the lowest level of agreement and highest level of disagreement from each of the trial sites - 54% and 29% respectively in Lower South West; 46% and 20% in Perth Hills; and 17% and 44% in Cockburn/Kwinana.

Analysis of the qualitative feedback indicates that some respondents report very positive experiences in both the NDIS and WA My Way NDIS planning processes, while others describe that they have been overwhelmed by the planning process. Positive experiences with the planning process appear to be strongly dependent on the individual and family or carer having access to a “good planner” or My Way

Coordinator, such that people who felt that they were listened to and that their plans reflected what they needed and accurately interpreted planning conversations tended to report a more positive planning experience.

Overall, survey participants felt that planners needed to listen more to what families and carers were saying during planning conversations. In the Lower South West there was a strong indication that planners were listening to what carers had to say about their needs. In other areas this was not the case and people indicated they would like much more carer recognition and support within the planning process. It was recognised that the focus on NDIS and My Way is on the person with a disability; however the impact on the family and functioning of a family unit needs to

be a key consideration as the scheme develops.

The main concerns that respondents have when implementing their plan include:

- High turnover of NDIA planners
- Influx of new My Way Coordinators who have limited knowledge of the person

The implementation of plans appears to be one of the areas where people are least satisfied.

#### **4.2 Access to information to support the planning process**

While information was a focus earlier in the survey, it emerged clearly as a theme in response to questions related to the planning process. Respondents cited the following issues as important to help them plan and prepare:

- Access to timely and accurate information;
- Pre-planning information sessions to gather information;
- An effective and accessible website; and
- Facebook Groups or Peer Support groups

Respondents from the Perth Hills reported that the NDIS website, although somewhat difficult to navigate, provides significant information. The NDIS Portal is generally well received and respondents reported that they like the fact that they can see where funds are being spent and that they can track payments.

In contrast, respondents from the My Way sites reported that the DSC website is limited in terms of providing people with good information and that currently there is no way for people to see how or where their funds are spent.

Where respondents felt confident that they had good information moving into the NDIS planning process they were much more likely to have positive planning experiences. However a trend in qualitative data indicates that many respondents feel that they have to “find” information as it is not readily available through the sources currently in place.

Respondents stated that they need to feel in control of their own planning process and the system needs to adapt to enable people to take control and plan in their own way.

Respondents indicated that they should be able to access support for planning in various ways. NDIA Planners and My Way Coordinators are very well placed to

support the development of NDIS plans however there should also be alternative options available to assist people to develop their own plans. The respondents suggest that this may be through family and friends as well as service providers with long standing knowledge of the person or through peer networks offering independent advice about ways to develop plans.

### ***4.3 Recognition and Support for Families and Carers, and psychosocial disability***

Question nineteen specifically sought feedback on the recognition and support of families and carers in both the planning process and the plan itself. 69% of survey respondents responded to this question, and responses were representative across the trial sites.

This question also elicited varying responses by trial site. In the Lower South West, 64% of respondents indicated that carers and families were recognised and supported. In the Perth Hills, 46% agreed, and in Cockburn/Kwinana only 22% agreed. In that trial site, 67% of respondents indicated that they believed carers and families had not been recognised and supported in the process or the plan.

Question twenty two asked if people with a mental health condition or psychosocial disability had any issues with the planning process. A very small number of people made a specific comment about accessing the NDIS with a psycho-social disability. Those that did comment said it was hard to get clear answers from NDIS staff. Notably, people in all three trial areas said they had increased anxiety going through the process.

### ***4.4 Plan Implementation***

Questions twenty and twenty-one provided the opportunity for people to share their experiences regarding the implementation of their plan. In question twenty-one, people responded to whether or not it was easy to implement their support plan. 68% of respondents answered this question, representative across the sites. In the Lower South West and Perth Hills, 52% and 44% of respondents respectively indicated that it was easy to implement their plan. In Cockburn/Kwinana the response was only 22%, with 50% of respondents indicating that it was not easy to implement the support plan. In all samples, approximately a quarter of respondents indicated they were unsure – 28% in Cockburn/Kwinana, 26% in the Lower South West, and 24% in Perth Hills.

Respondents felt that they should be able to exercise choice and control right from the start of entering My Way or the NDIS with a person or organisation who knew them well and with whom they felt confident would deliver the best outcomes.

In Perth Hills, people who were allocated funding for “coordination of supports” for

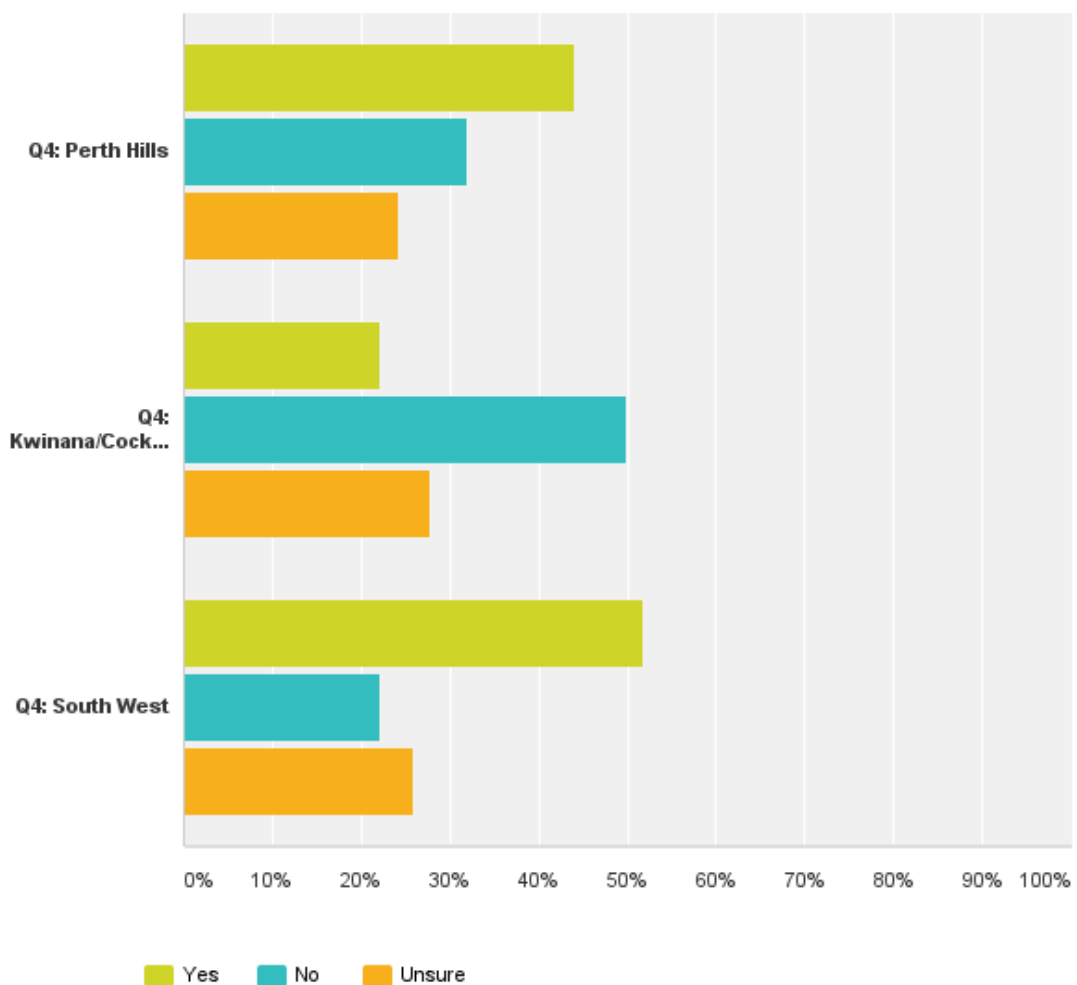


plan implementation felt that having the choice of who assisted them to implement their plans was really valuable; although the hours dedicated to this was sometimes inadequate, particularly for people with complex needs.

Individuals and families did not always feel that they needed to develop a 'relationship' with a My Way Coordinator or Planner particularly if they were not known to them previously. If people are provided with good access to information and a person of their choice to develop and implement their plan such as a service provider with longstanding connection with the person or an organisation or person independent of government they indicated they would feel more comfortable.

### Q21 Was it easy for you (or the person you support) to implement your support plan?

Answered: 136 Skipped: 64



## 5. Managing funds and support

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

Question twenty-four asked if respondents could choose how they managed their funding and support. 68% of respondents addressed this question, representative across sites. Across the trial sites, 74% of respondents stated they are able to choose the way they manage their funding and support. 21% indicated they were unsure and 3% indicated they were not able to choose. There was, however, variation across the sites. The Lower South West and Perth Hills showed high levels of agreement – 75% and 68% respectively. In Cockburn/Kwinana this dropped to 41%. No respondents from the Lower South West said they were unable to choose, but 25% were unsure.

Some of the reasons given for not being able to choose 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.

Question twenty-five invited people to indicate what were their preferred management options. Overall, 35% of respondents prefer self-management, with the next highest preference being a combination of self-management with another option (23%). The preference for self-management over other models was consistent across trial sites, but was most popular in the Lower South West where 46% of respondents indicated it as their preference. In Cockburn/Kwinana there was a preference for a combination of self-management and other options with 53% expressing this as their preferred option. Plan management was the option of least interest with only 7% choosing this option. A notable comment from a respondent indicated that they had “*not decided yet but no incentives to self-manage as you can include a management fee but not admin time for a carer to manage*”.

## 6. Meeting Needs

Question twenty-six of the survey asked people whether their plan and funding package was meeting their needs. 66% of survey respondents answered this question, representative across trial sites. Overall, 47% of respondents indicate that the plan and funding package are meeting their needs. Overall, 27% of respondents indicate that the plan and funding package are not meeting their needs.

The remaining 26% are unsure at this stage. This was not consistent across the trial sites. In both Perth Hills and Lower South West, approximately half of the respondents said their plan and package met their needs – 54% and 52% respectively. 19% of those in the Perth Hills said it did not meet their needs, and 26% were unsure. 33% of those in the Lower South West said it did not meet their needs, and 15% were unsure. In Cockburn/Kwinana, only 5% of respondents indicated their plan and package met their needs whilst 59% indicated their needs were not met.

The main reasons 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.

## 7. General comments

Respondents were asked to provide any additional comments about their NDIS experience. 70% of the respondents replied from the Perth Hills with the majority of comments praising NDIS with comments such as *'At first I was a little worried but now I am happy with the extra help and support both given and offered to me'*. *'NDIS is making a tremendous difference to all our lives'*. The main negative issues raised include, *'it being too stressful'* and *'respite not being available to family members'*. Many of these issues were mirrored in the 20% of respondents who replied from the My Way Lower South West region.

10% of respondents replied from the Cockburn/Kwinana trial site. The majority of the comments were negative and includes comments such as *'it has been the most stressful and frustrating process,' 'it is all about cutting and not the person', 'I don't feel empowered to look after our child in the ways that I think are important or particular to our family needs.'*

## 8. Easy English Survey

An Easy English version of this survey was hosted by Down Syndrome Western Australia (DSWA). In total 19 people responded to the survey with approximately 85% of respondents being parents of a person with Down syndrome. The geographical split between NDIS sites was 40% from the Perth Hills and 30% respectively for Lower South West and Cockburn/Kwinana.

The results from this survey broadly reflected the findings of the larger survey. Flexibility and choice was indicated as strength; however, as with the larger survey this was also cited as a concern. The main concerns can be categorised into:

- Communication with Planners/My Way Co-ordinators
- Lack of information
- 'Uncertainty' with the process
- Inflexible plans

Recommendations for change also mirrored that of the larger survey and included:

- Provision of information that is easy to understand
- More regular meetings and ongoing support
- Creation of a data bank of available support workers and host families in the area.

Respondents were asked about the different channels to accessing information. Results were similar to the larger survey, the 4 main channels being:

- My Way Coordinator
- Other people with disability and families
- Service provider
- NDIS website and social media.

## 9. Forum Feedback

Two face-to-face forums were held in September in Perth and Busselton.

Fourteen people attended the Perth forum from Cockburn/Kwinana and the Perth Hills. The majority of participants were from the Perth Hills with twelve people from

the NDIS trial site and only two from the My Way site. The Busselton forum also had fourteen attendees. With an imbalance between the numbers of people from each site across the forums we are unable to draw too many comparisons between the sites and as such, the feedback is not categorised by site.

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.

### **The NDIS program is an improvement in planning**

Many of the issues identified mirror those of the survey results and include:

- Poor quality or lack of information
- The quality of the Planner/My Way Co-ordinator determines the effectiveness of the planning process
- Equipment being managed through 'prescription' makes simple things more complicated
- The length of time to receive funding

### **The NDIS program is an improvement in accessing services**

Overall people felt they are able to access the services they need. This is due to an increase in funding and an increase in service provision. In the Lower South West, it was stated that less than half the registered providers are physically present. There were also concerns about the following:

- Choice being compromised due to pressure to use only certain service providers
- Loss of innovation due to smaller providers being unable to operate in the NDIS system as funding rules are creating more limits and reducing what is

possible

- More transparency required on what is available

### **The NDIS program is an improvement in accessing the wider community**

Overall people said NDIS has improved their access to the wider community, and the plan allows for people to have a better influence on the activities they do. Importantly, funding is highlighted as the key to be able to access the wider community.

There were concerns expressed by participants about the planning interface with other government agencies particularly education. There was also concern about respite and that support for carers is no longer considered as necessary.

### **Life is better because of the NDIS**

Overall people were positive about the NDIS because they have had an increase in funding, better access to services and better choice. Some people re-iterated that the planning process needed improving however once the plan was approved and implemented, life was better.

Factors that people said needed to improve their quality of life include:

- Feeling confident about and access to independent complaints process when things are not going right
- An easier system to use – this was particularly pertinent to people with an intellectual disability who sometimes did not understand the information/process
- Reduce stress levels – people are tired of a bureaucratic system and a process that takes a long time to achieve results.

## **Conclusion**

This report highlights that the NDIS is providing a level of flexibility and choice to people with disability and where the process has been working well people experience 'a better life because of the NDIS'. However, the evidence suggests that there are flaws in the system. At the transactional level, 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 are concerned about. At a transformational level, peoples' experiences are significantly affected by the quality of the support provided by their Planner/My Way Co-ordinator. 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. We have learned much from the experience of people in the different trial sites and we will endeavor to continue to engage with all levels of government to get the best outcomes for people with disability, their families and carers in WA.

## Further Information

To obtain a copy of the survey results or more detailed forum notes please contact [info@pwdwd.org](mailto:info@pwdwd.org) or phone 9485 8900.

## Appendix One

**This survey is for people with disability, families and carers who are participants in the NDIS Perth Hills and NDIS My Way in WA.**

### **1. Introduction**

**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. 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

### **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.**



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

Yes

No

Unsure

6. If no what difficulties did you have?

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

Yes

No

Unsure

8. If no what further information do you need?

9. 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.**

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

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

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

13. 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.**

14. Is it is easy to access services that are not funded but in your (or the person you support) plan?

Yes

No

Unsure

15. What has made it easy or not to access those services?

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

Yes

No

N/A

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

### **5. Planning process**

18. 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

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

Yes

No

Unsure

20. What are your concerns with implementing your plan?

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

Yes

No

Unsure

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

23. 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.**

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

Yes

No

Unsure

If no why?

25. 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)

**7. Are your needs being met?**

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

Yes

No

Unsure

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

28. 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 November it will be available.

29. 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 Two








Both forums used the same format.








Perth Consumer/Carer Forum Saturday 12<sup>th</sup> September 2015

South West Consumer/Carer Forum Thursday 17<sup>th</sup> September 2015

Time	What	Process Notes
2:00 pm 10min	<b>Welcome and Introduction</b> <ul style="list-style-type: none"> <li>Welcome from host organisation</li> <li>Purpose of this session</li> </ul>	Joel Levin
2:10 pm 10min	<b>Time to gather your thoughts</b> <ul style="list-style-type: none"> <li>Using the points below as a guide and talking with one other person next to you, give your own score.           <p><b>PWD</b></p> <ul style="list-style-type: none"> <li>The NDIS program is an improvement in planning for my needs</li> <li>The NDIS program is an improvement in accessing services</li> <li>The NDIS program is an improvement in accessing the wider community</li> <li>My life is better because of the NDIS program</li> </ul> <p><b>Carer</b></p> <ul style="list-style-type: none"> <li>The NDIS program is an improvement in planning for the person I care for</li> <li>The NDIS program is an improvement in accessing services for the person I care for</li> <li>The NDIS program is an improvement in accessing the wider community the person I care for</li> <li>The life of the person I care for is better because of the NDIS program</li> </ul> </li> </ul>	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	<b>Exploring views and options</b> <ul style="list-style-type: none"> <li>Discussing 4 x Themes</li> </ul>	15min per theme to explore the reason for each score
3:20 pm 40min	<b>Most Significant Change</b> <ul style="list-style-type: none"> <li>Table discussion of the changes that have been most significant for each person as a result of the NDIS program</li> </ul>	15min to discuss at tables (might be good to have a scribe)  15min plenary sharing
3:50pm 40min	<b>Closing</b> <ul style="list-style-type: none"> <li>What happens with this information</li> <li>Thank you for your time</li> </ul>	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

<b>Consumer Score Card</b>	<i>Strongly Disagree</i> 1 	<i>Disagree</i> 2 	<i>Somewhat Disagree</i> 3 	<i>Neutral</i> 4 	<i>Somewhat Agree</i> 5 	<i>Agree</i> 6 	<i>Strongly Agree</i> 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							

<b>Carer Score Card</b>	<i>Strongly Disagree</i> 1 	<i>Disagree</i> 2 	<i>Somewhat Disagree</i> 3 	<i>Neutral</i> 4 	<i>Somewhat Agree</i> 5 	<i>Agree</i> 6 	<i>Strongly Agree</i> 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							