Making Inroads

Addressing the Needs of Consumers and those with Psycho-Social Disability within NDIS/My Way

‘It helps to get to know me if you know a bit about us’
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Consumers of Mental Health WA (Inc)

ABN: 95581286940

**Business Address**: 13 Plaistowe Mews West Perth WA 6005

**Postal Address**: PO Box 1078 West Perth WA 6872

Ph: (08) 9321 4994 or admin@comhwa.org.au

Web: [www.comhwa.org.au](http://www.comhwa.org.au)
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Executive Summary</td>
<td>3</td>
</tr>
<tr>
<td>Feedback</td>
<td>3</td>
</tr>
<tr>
<td>Method and Rationale: Consumer Voice in the Context of NDIS</td>
<td>3</td>
</tr>
<tr>
<td>Case Study- ‘Sarah’</td>
<td>5</td>
</tr>
<tr>
<td>Key Issues and Recommendations</td>
<td>6</td>
</tr>
<tr>
<td>The Social Impact of NDIS on Consumers</td>
<td>6</td>
</tr>
<tr>
<td>Engagement, access and eligibility for people with psychosocial disability in NDIS</td>
<td>8</td>
</tr>
<tr>
<td>Consumer Participation</td>
<td>10</td>
</tr>
<tr>
<td>Safeguards and Consumer Rights to Maximise Self-Direction</td>
<td>11</td>
</tr>
<tr>
<td>Conclusion</td>
<td>12</td>
</tr>
<tr>
<td>Appendix 1. References- Consumer Research and Consultations</td>
<td>14</td>
</tr>
<tr>
<td>Appendix 2. Respecting our Choices- Focus Group Report 2014</td>
<td>15</td>
</tr>
</tbody>
</table>
1. Executive Summary

The Making Inroads report draws on consumer perspectives to identify advocacy issues of concern related to NDIS, in the broader context of self-directed funding, and summarises proposals and strategies that have been identified by consumers for ensuring the needs of consumers are incorporated into the design, delivery, evaluation of NDIS/My Way. Consumer perspectives bring important insights from direct experience into how opportunities for a good life are shaped by the mental health supports available to them, the broader factors at work in their lives, and the choices and opportunities they encounter in their recovery. This Report provides a summary of consumer perspectives for policy makers and services who are interested in how NDIS implementation can best support those with psycho-social disability. Four major areas of need are outlined in this report about self-directed supports:

- The Social Impact for Consumers of NDIS: How NDIS and related systems, such as health, non-NDIS mental health supports, social benefits, housing and employment supports will be reviewed and modified to work in a coordinated way to support good outcomes in people's lives
- The consumer requirements for people to learn about, engage with, access and experience fair outcomes in NDIS requires strong understanding of consumer's unique lives and recognition of the potential impact of changes to a disability model for consumers
- The need for consumer participation in design, delivery and evaluation to ensure NDIS intentions to empower consumers with choice and control and to respond to the distinctive needs of people with psycho-social disability are not undermined by other stakeholder priorities, interests and cultural resistance to self-direction
- The need for a practical and consumer-focused range of safeguards to uphold and further develop capacity for self-direction and self-advocacy, in order that choice and control realised in planning and fund management, with a key role for peer support, consumer capacity building and independent advocacy.

2. Feedback

- NDIS advocacy and practical strategies are ongoing priorities for CoMHWA as it tracks and inputs into NDIS on behalf of consumers from pilot to full roll out (3 year process). We welcome comment and feedback, ideas and discussion of this report and will provide further opportunities to have a say in NDIS.

3. Method and Rationale: Consumer Voice in the Context of NDIS

Consumer Voice is a term developed by the consumer movement, as a user-led movement, to describe a process of "Speaking out about the needs, priorities, and perspectives we share, from the common ground of our lived experience, informed and enriched by the diversity of our experiences." The impetus for Consumer Voice comes, like the Disability Rights movement, of being largely absent from decision-making, and as a result
experiencing limited benefit, or event harm, from services provided to them. Rachel Perkins notes that one of the major challenges to personal budgets in mental health is that “The assumption that ‘the professional knows best’ is firmly entrenched in health and social services - especially mental health services.” Despite some similar origins and influences as the disability rights movement, consumers (without additional disabilities) typically do not identify as having a disability for various reasons. As such their voice is far more strongly present, articulated and understood in the mental health landscape, and more marginal in disability settings. That is, consumer voice speaks to the distinct and unique needs, priorities and perspectives of those with mental health issues, including those understood as having psycho-social disability for the purposes of NDIS/My Way.

CoMHWA exists as a peak body for and by consumers in order to coordinate, promote and support consumer voice. This is achieved through, systemic advocacy, representation, and developing and strengthening capacity for consumers to be self-directing and empowered within their lives and to share this capacity through the peer support, representation and advocacy they may choose to do.

NDIS includes consumers understood to have permanent and severe psycho-social disability within eligibility. Participant numbers at full scheme are estimated at 28,000. However, it is estimated by full scheme that the number of people with mental health issues requiring support will exceed 1 million. There is fundamental uncertainty about what sustained supports will be available to meet this need, as a result of bilateral agreements suggesting the loss of key state and federal mental health programs will no longer be available to those that may seek to access them in future. As a result, CoMHWA is acutely aware of the importance of consumer voice into NDIS, in relation to understanding the challenges required in tailoring disability models and approaches to consumers, and in relation to ensuring that opportunities for good mental health outcomes are available for current and future consumers are adequately responded to as part of NDIS negotiations.

Correspondingly, there are three risks of significant to major consumer concern if consumer voice is not a strong element in the progression of NDIS to full scheme:

- The limited benefit of consumers from NDIS due to the transplanting of disempowering approaches and structures into NDIS from mental health providers, such as the tendency for use of substituted and supported advisors and decision-makers as a matter of routine in a person’s life, rather than as a matter of last resort and minimised through independent safeguarding approaches;
- The limited benefit of consumers from NDIS due to their lack of prior integration within the disability sector and user-led disability rights movement, which limits readiness for focused approaches based on understanding of their needs and identity
- Risk of major and devastating impact on recovery prospects for the broader and growing population of mental health consumers into the future.

CoMHWA has undertaken research, consumer consultation, and participation in multi-stakeholder consultative environments, in order to collate and summarise Consumer Voice in relation to NDIS. This includes:

- Literature Scans for key findings from consumer research and consultations - see Appendix 2. Secondary Consumer Research and Consultations
- CoMHWA NDIS Focus Group, 23rd May 2014 – see Appendix 1. Focus Group Report
- NDIS Launch Conference attendance, 2013
- WAAMH Sector Forums- Feb 2014, May 2014
- Advisory Group Participation- NDIA (Hills Launch site) and NDIS/My Way (South-West Launch site)

This Report offers a summary of key concerns, priorities and recommendations raised by consumers with a focus on specific and constructive recommendations, or ways forward, for meeting consumer needs in NDIS/My Way. It commences with a case study in order to highlight how the issues raised in this report can translate directly into people’s experience of support and opportunities for recovery.

4. Case Study- ‘Sarah’

Sarah is a 42 year old woman who became homeless at 13 after she fled from her family home to escape her uncle, who sexually abused her from the age of 6. In her teenage years she had to develop survival skills, and she did. She had contact with the criminal justice system for theft and minor possession, but was able to avoid juvenile detention and, through a chance contact with a member of a local church, was linked in with a youth outreach worker, who facilitated her first job opportunity and safe, shared housing arrangements.

After several years and tired of working casual jobs, she enrolled in a vocational certificate, but found herself feeling more and more overwhelmed by managing both work and study and, most of all, a violent and controlling partner who reinforced the hostile and attacking voices she had started hearing soon after her abuse started in childhood. She started drinking to cope and, three months later, experienced her first admission to hospital after attempting to end her life. She was diagnosed with bipolar disorder and substance-induced psychosis, which was changed to schizophrenia by a subsequent psychiatrist based on a trial of different medication. The impact of flashbacks and the voices, locked ward treatment, and what felt like a life sentence of illness, cause her to lose hope.

10 years on, Sarah resides in a psychiatric hostel and periodically is admitted to hospital. She lives in her inner world and finds it hard to connect with people. She shares a room with 4 others and they frequently quarrel, which has led to her being moved across 4 different hostels over the 10 year period. She has no family or friends to visit her and is comfortable with what is familiar to her. Sarah has never heard of recovery, and certainly does not believe it is possible. Sarah has forgotten her abilities and her independence, as these are distant memories for her.

From time to time, good hearted people have come in and offered to support her, but do not know how to assist. She is referred to NDIS by her long-term public guardian who has clear intentions, and best
intentions, for using a self-directed funding package to improve Sarah’s quality of care within the hostel. The NDIS assessor is legally obliged to follow guardian requirements, but obtains guardian consent to include peer support in the initial plan as an approach that has not been tried and which may help Sarah in having someone to relate to and talk about what has happened in her life.

By the end of 6 months, Sarah has been able to identify some of the things that most bother her about the hostel she is living in as what stands out as most important, how she would know if and when she felt ready to move into her own unit, and the steps she needs to get there. When she learns that she cannot move to a unit for several years, due to public housing wait times, she feels angry and let down. She refuses to see her peer support worker or the NDIS assessor anymore and, after frequent angry calls to her guardian, her guardian asks them to withdraw. Her guardian is also receiving pressure from the hostel, stating that due to limited places and changes to funding of places she will only be able to remain in the hostel on a full fee paying basis. Her guardian withdraws the peer support from NDIS and directs funding to the increase in costs of existing board and lodging arrangements. The balance is allocated to a trust fund for emergency accommodation in the event she is evicted from her hostel in the future.

5. Key Issues and Recommendations

Key Issue 1: The Social Impact of NDIS on Consumers

Discussion

Social impact is a term that captures the way mental health, as a common and significant challenge in society, can not be addressed by one system or service in isolation, but requires understanding and addressing the way multiple systems and sector impact on people’s lives to improve or undermine recovery. Social impact is about new ways of thinking that try to address the macro issues, such as how systems interact and work together, how they are siloed or integrated, and how they create competing or complementary drivers for or against recovery. Consumers seek assurance that NDIS will not be viewed in isolation. This includes two main aspects- systemic issues related to socio-economic circumstances of consumers and, secondly, limited clarity on how consumers not eligible for NDIS will be supported in the future as a result of proposed funding changes. Both aspects involved recognition that the provision of individualised funding is not sufficient for a person to move beyond those issues that are broader systemic challenges impacting their life.

Firstly, recovery is not simply about mental health, but often involves navigating and accessing a range of benefits and programs available to people to address a holistic range of issues that cross sectors but are needed to move from socio-economic disadvantage to socio-economic participation. Social benefits, financial relief, housing and housing assistance, and employment assistance are common benefits sought by consumers as part of moving beyond crisis to recovery and independence. These must be aligned with and work in complementary ways with NDIS if socio-economic participation and recovery outcomes are to be achieved.
Successfully. Examples of roadblocks that have been raised by consumers include Centrelink rules that make Disability Support Pensions difficult to successfully apply for, challenges meeting living costs on income support payments, shortfalls in housing affordability, siloed supports across a range of sectors that do not meet multiple and individual needs, and disincentives to employment that can exist when extended safety nets for transition and maintenance of employment are not available. The aim is to ensure that consumers do not encounter such roadblocks that limit benefit from NDIS, such as service gaps and inconsistencies in eligibility and support thresholds when seeking NDIS in conjunction with social benefits and multi-sectoral supports. Sarah’s frustration with NDIS staff, who planned for her readiness for housing, when housing was not ready for her, is a common example of systemic issues that impact on recovery support. These systemic issues affect not only prospects for living a full and meaningful life, but affect the process of planning, through shaping choices and decisions about how to spend money. NDIS will be experienced as unhelpful and frustrating if it is not able to recognise and respond to consumer spending preferences that address poverty, such as resolution of crises and stabilisation of living related to cost of living and insecure circumstances (e.g. inadequate housing). These elements are necessary to recovery but not sufficient for recovery, and reflect the realities of living below the poverty line. The following diagram illustrates this tension between consumer concerns, and NDIS assumptions about reasonable and necessary support.

**Spending Priorities Related to Limited Income in Consumer Lives**

- **Getting out of Crisis**
  - Food, Shelter, essential needs
  - Paying housing and other debts

- **Getting standard of living to baseline**
  - Supplementing basic income to better meet needs
  - Catch up (e.g. new whitegoods)

- **Transformative Spending**
  - Vocational education
  - Substance recovery
  - Travel
  - Pet ownership
  - Complementary therapies
  - Rec classes

Secondly, will there be other options for Sarah if NDIS does not work, in the event she had not been referred to NDIS. Would there be options in the event Sarah’s life is much better but still has steps towards recovery to make? And would there be the right supports available to get back on track, in the event mental health services meet someone like Sarah, at that first point she tried to end her life? The various stages of recovery, the individuality of the recovery process and supports required, requires both a commitment to sustainable levels of funding for those eligible for NDIS funding and those ineligible, to match needs for support with the availability of support, and a commitment to understanding of effective recovery supports. Tier 2 supports, within NDIS, which provide information and referral to non-NDIS services, require and assume the existence of services that can effectively and adequately meet need. This underpins major concerns about the loss of access to mental health programs that are within scope for roll into NDIS, but which serve a wider group of consumers in need. It
has also led to consumer interest in options for expanding self-directed funding approaches beyond NDIS, as a way to support the individual and self-led journey of recovery.

A further and distinct issue relates to awareness of the significant change involved in transferring care arrangements from one sector to another in terms of the experiences of those receiving support. Consumers may experience the many changes this can entail, as confusing, challenging and burdensome. This might include: decisions to transfer a consumer from a current program into NDIS with changes in key supports, use of new language and terminology affecting sense of identity and recovery hopes and expectations, a sense of difference from and deficit relative to their peers, the need to familiarise with new types and approaches to the support they are receiving in order to benefit from them, due to their relocation across sectors (disability and mental health). These are all experiences of discontinuities of care and externally determined changes to their lives. These experiences need to be responded to with service insight and compassion as such changes come into effect, with a central role for lived experience advocacy and perspectives to inform how changes will be facilitated for people to support, rather than hinder, recovery.

**Recommendations**

- Map the interface of mental health, health and disability services from a consumer perspective.
- Clarify how services including welfare, housing and health care interact with NDIS to affect outcomes for consumers.
- Develop and implement a strategy, in partnership with consumers, to manage the change process for consumers and their key supports from receiving support through mental health to Disability Services.
- Ensure reasonable and necessary supports are developed in consultation with consumers, to ensure funding choices incorporate the range of life circumstances and aspirations that shape recovery, and to assist in mapping and responding to service needs that fall outside of fundable supports

**Key Issue 2: Engagement, access and eligibility for people with psychosocial disability in NDIS**

**Key Issues**

Sarah’s life story and her recovery journey is unique, but the circumstances she finds herself in, her experiences of supports, and barriers to recovery, bear similarities across others with significant histories of institutionalisation where late intervention, rather than early intervention, recovery responses are required. Because those with mental health issues who have choice about how they identify are unlikely to identify as having a disability, third party referrals are likely to be more common in the scheme. A further element of psycho-social disability is the close correlation that is implicit between severe functional impairments in areas of thinking, decision-making and communicating (‘psycho’ aspect of psycho-social disability), severe mental illness, and legal incapacity under mental health legislation, which again suggests those with mental illness who apply volitionally are least likely to be eligible for support. Based on this credible assumption about defining out those with less psycho-
social impairments (i.e. substantial choice, self-direction and independence) poses very real challenges for NDIS, in that:

- recovery-focused outcomes require more recovery expertise, strategies and resources than in early intervention
- Maintaining the integrity of the scheme principles of choice, self-direction and control requires thoughtful and adequately resource safeguarding arrangements to address vulnerabilities, and conflicts of interest and disempowering approaches that often arise in the context of vulnerabilities
- In the absence of these elements, high effort for low outcomes may lead to these potential participants being under-served, or served later than other people with disabilities, within NDIS.

The assumption of a correlation between incapacity and severe and enduring ‘psycho-social disability’ is also consistent with the small percentage of participants expected to benefit from the scheme, relative to the number of people likely to be classed as Tier 2. As mentioned previously, it is also of major concern how these needs will be sustainably met, in terms of mental health support options, within the current NDIS context where programs able to respond to Tier 2 are being rolled into Tier 3. While continuity of support is guaranteed for current participants, future participants will be unable to benefit from the scheme.

This fundamental ambiguity of who will benefit, in conjunction with the unfamiliar language of disability, are two factors that limit the likelihood of consumer awareness of and engagement in the scheme. To give an example of the need for tailored communications, the My Access checker is unreliable from a consumer perspective. It asks whether a person has a disability (not if they have a mental health issue requiring support). It also asks, in assessing need for the scheme, the extent a person would achieve participation outcomes based on how much support they received. For a consumer experiencing hopelessness, where no amount of support feels like it would improve an outcome, or where it is the type of support -- not amount of general support-- that makes a difference, this ‘blindness’ to experience as a first encounter with NDIS can be a barrier to further engagement.

**Recommendations**

- Useful education on recovery must be accessible and promoted to consumers, their key supports and referrers, in addition to recovery training of NDIS staff
- Understand debates about, and clarify current ambiguities on, eligibility that are arising due to unfamiliarity of consumers and third party referrers about the relationship between different elements of needs assessment in eligibility (psychiatric, disability, and lived experience approaches to needs assessment)
- Design and implement local consumer engagement strategies
- Review and address regulations and rules that present barriers to consumer access and eligibility for NDIS, including criteria of permanence, diagnosis, tier definitions and early intervention.
- Ensure consumer focussed communication to directly reach consumers likely to be eligible, and which enables consumers to understand and make informed decisions about NDIS.
- Develop and communicate clear accountabilities for planning timelines, intentions and consultative processes in relation to the broader impact of NDIS on available supports
- Monitor and evaluate clear and fair targets for PSD uptake of NDIS as part of overall NDIS cohort.
- Map systems and seek mental health consumer feedback to understand the impact of NDIS on eligible and ineligible participants. It is anticipated that the State Mental Health Planning process, and the National Review of Mental Health Services, offer key sites to address the issue of sustainable levels of recovery supports across a spectrum of varying levels and duration of need.
- Identify options for expanding self-directed funding and approaches to areas that are not currently accessible through NDIS, to improve late intervention outcomes and prevent late intervention approaches.

**Key Issue 3: Consumer Participation**

**Discussion**

Consumer participation is enshrined in the National Standards for Mental Health Services in recognition that consumer-focused and recovery-focused services are achieved through consumers being an active component of governance, delivery and evaluation. This ensures that there are points of accountability that are independent of service and can advise on how to align supports with consumer voice. Lived experience perspectives bring unique, valuable and irreplaceable insights into the experience of having mental health issues and of receiving support to improve services and, in doing so, are an essential element in supporting good outcomes for people.

In Western Australia, Peer Support is the most common lived experience role at service delivery level, with Consumer Representative roles offering advocacy input and overseeing service design delivery and evaluation. In other states, Consumer Advocate roles are recognized and supported at service delivery level in addition to Peer Supports to further ensure consumer accessibility, such as ease of navigation and access, and assistance in complaints resolution. For people in Sarah's situation, having people who can easily relate to aspects of her life experience and translate those into priorities, ideas and strategies that could help to build more personal choice, options and capabilities for Sarah, can be a vital and distinct perspective from the many other decision-making perspectives in Sarah's life. Peers have also been found to better able to build relationships of trust, respect and mutuality more quickly to facilitate engagement, planning and action in recovery.

NDIS is a unique and significant development, particularly to community-based mental health providers, because it involves a fundamental change in purchasing and decision-making in the direction of consumer choice and control. Where consumers seeking help within a service-driven environment frequently experience fundamental uncertainty and ‘luck-based’ support when seeking the help they need, due to waitlists, poor information on services, exclusion criteria, or inappropriate supports, service providers will in future face the parallel uncertainties of a customer-driven service environment. Arrangements for meeting the needs of those with psycho-social disability are negotiated in this transformation, power shifting context. This creates opportunities for conflicts of interest, and diluting of scheme elements, if consumer voice is not recognized as distinct from service provider perspectives, and directly consulted as a partner voice, in scheme design. The first example, related to decisions about individual planning, are calls by service providers to input into a consumer’s plan, irrespective of the person’s consent, on the grounds that they have closely supported the person and can offer ‘best interest’ perspectives of their needs. A second example, related to decisions about NDIS preparations,
relate to the very different capacity building requirements of service providers and consumers in preparing for the scheme. Partnerships with service providers to address their advocacy concerns and capacity building must therefore be matched by equivalent partnerships with consumers. Similarly, consumers are not the best reference point for consultation on service provider requirements, nor are service providers the best reference point for consultation on consumer requirements. In addition to a co-production (equal and collaborative, partnership approaches between NDIS/My Way, service providers, consumers and families), it is critical that a key principle of deliberations about NDIS includes mindfulness and management of the tensions and conflicts of interest that can exist between service provider, consumer and key third party decision-makers (carers/families, clinicians, guardians and nominated persons).

Recommendations

Consumer Participation in Scheme Design, Delivery and Evaluation

- Develop and implement a consumer-based rating system of supports as a core component of a quality assurance system.
- Develop and deliver a consumer engagement strategy that ensures NDIS framework, policies and evaluations are consumer reviewed and consumer-focused
- Develop and deliver, as part of a consumer engagement strategy, lived experience workforce arrangements that provide or enable access to independent peer support and advocacy in approaching and navigating NDIS

Key Issue 4: Safeguards and Consumer Rights To Maximise Self-Direction

Discussion

Consumers have a strong and unsurprising preference for self-direction, to lead a life of one’s own, and also recognise that there are times when they may not be able to do this as well. There is also recognition that there is an important, but hard to assess, difference, between needing help with decision-making because mental health challenges are affecting decision-making, and needing help with decision-making because of situational factors. These might be because of lack of confidence or experience about decision-making generally, limited knowledge about the NDIS scheme, access and navigation, or because their decision-making power is limited by legal or social influences. Examples of experiences that can undermine confidence in decision-making include:

Conditional Aid: The experience of receiving supports that carry a personal or moral judgment, such as the requirement to seek financial counselling if someone needs financial support with bills, which assumes a person has problems in financial decision-making, rather than experiences difficult circumstances

Misdirected Aid: The experience of receiving support or assistance that has prescribed purposes that do not align with requests for need, such as payment for work clothing that cannot be used to buy child care. Not having needs listened to or heard can shut down decision-making voice and confidence.
External Decision-Makers: People in low socio-economic circumstances and accessing supports are frequently affected by external decision-making such as rules, criteria, procedures, and responsibilities by agencies, professionals and services that they must follow. This can lead to an ‘other-directed’ rather than ‘self-directed’ life experience in which expressing or attempting to be assertive and independent may lead to negative consequences, such as non-compliant, difficult, or complaining.

Capacity building for consumers in this context is about equipping consumers with information, skills and resources (people they trust, useful tools and information), to be confident, experienced decision-makers in NDIS and effective self-advocates in exercising choice and control. To ensure that decision-making space exists and is upheld for people to exercise that capacity, this is supported by the consumer participation in NDIS design, delivery and evaluation discussed earlier.

As a key capacity building strategy, consumers have expressed a strong interest in being able to learn from peers, such as through lived experience stories, consumer education and peer group learning environments. Consumers thus recognise that decision making can be strengthened through exploring options and case examples, and self-led participation in peer support should be recognised as an empowering approach to supported decision-making, as well as important to in-scheme learning by participants generally.

**Recommendations**

- Plan and deliver an effective consumer capacity building strategy for NDIS.
- Develop definitions and resources for reasonable and necessary supports in ways that maximize consumer choice in their personal recovery journey.
- Design and deliver an education program on self-directed planning and self-directed funding to consumers and their key supports.
- Establish framework to maximise self-direction in decision making.
- Implement transparent and easily negotiable complaints/advocacy appeal mechanisms.
- Implement a local consumer support network to build capacity for self-direction and recovery, in the NDIS My Way trial areas.

**6. Conclusion**

*Making Inroads* has explored many of the key issues identified in consumer research and consultation regarding personal planning and budgeting in the context of NDIS. Consumers clearly seek self-directed arrangements, with safeguards that maximise choice and independence. This is a stronger call than a request for individualised or person-centred arrangements where the consumer has just one say, among others, about funding and support options that shape their lives. Correspondingly, the power shifts necessary to realise self-directed approaches require that policy makers and service providers are cognisant to the ways in which choice and decision-making is challenged through the multi-stakeholder considerations of NDIS, and to hold as a top priority a commitment to listening and responding to consumer voices in order to share NDIS design and
implementation for maximum self-direction, as intrinsic to choice, control and recovery. Consumers require capacity building support to enhance the experience of accessing NDIS My Way, and a comprehensive commitment to consumer participation in all aspects of NDIS design, implementation and evaluation. For those interested in or directly involved in NDIS, the equal rights of consumers in scope for NDIS funding, and those who will not benefit, to receive high quality, recovery-focused and empowering supports needs to be in the forefront of the broader conversations about how NDIS can work in conjunction with the bigger picture of recovery options for all West Australians.
Appendix 1. References- Consumer Research and Consultations


Appendix 2. CoMHWA Focus Group Report

Respecting our Choices

Findings from the NDIS Mental Health Consumer Focus Group (WA)
Summary

Respecting our Choices provides a summary of a focus group run by and for mental health consumers in Western Australia about NDIS in May 2014. Seven participants took part in the focus group, which identified advocacy concerns and strategies for NDIS design that could improve the experiences of mental health consumers in NDIS.

The report is titled Making Inroads as a key metaphor for progress on the journey of NDIS trial and roll out. Based on focus group responses, there are four elements where inroads can be made:

- Advocacy, progress and action is needed to ensure that mental health consumers can be adequately responded to, and do not sit at the margins, of NDIS design
- Advocacy, progress and action is needed in order to ensure that NDIS works within the context of interrelated systems of support (e.g. welfare, housing)
- Progress is needed on development of pathways and strategies that facilitate awareness of, access and navigation of NDIS by potential participants, with a particular importance given to the socio-economic circumstances of consumers and their requirements for ease of access and advocacy support.
- Progress is needed to ensure consumers have inroads into the decision-making process. Focus group participants want to see a co-production process within NDIS, with consumers being equal partners and contributors to NDIS design, trialing and implementation, in order to ensure the first two messages are received, understood and translated into action.

Feedback

NDIS advocacy and practical strategies are ongoing priorities for CoMHWA as it tracks and inputs into NDIS on behalf of consumers from pilot to full roll out (3 year process). We welcome comment and feedback, ideas and discussion of this report and will provide further opportunities to have a say in NDIS.

Background

NDIS provides self-directed funding for eligible participants to receive reasonable and necessary supports, over a lifetime if required, on an insurance model. Mental health consumers may be eligible for NDIS if they have a severe and permanent psycho-social disability as a consequence of a mental illness, which represents a much smaller group of mental health consumers. However, all mental health consumers are potentially affected by NDIS due to terms of bilateral agreements rolling existing mental health program funding into NDIS, and due to
most consumers being able to access the supports other than funding packages that will be determined for Tier 2 participants. Both launch sites in WA, NDIA Hills and DSC-MHC My Way (South-West) will commence from July 1-2014. CoMHWA has therefore been taking an active role in increasing consumer awareness and knowledge about NDIS to date through regular newsletter communications, promotion and scholarships to advocacy and educational events about NDIS, and responses to member enquiries, since the official launch of NDIS last year.

Method

Despite CoMHWA’s activities to support interest in NDIS, consumer participation in sectoral NDIS events has been limited, compared to more familiar topics such as recovery and consumer participation. For this reason, it was assumed a survey method would not have high response rates, and would yield limited data due to limited awareness. NDIS, particularly the issues surrounding how mental health consumers will be affected by NDIS, can seem complex. Focus groups present a ‘snapshot’ of experiences, ideas and perspectives, to complement and inform further enquiry on complex topics. CoMHWA therefore chose a focus group method for consumers that assumed limited or no prior knowledge of NDIS, with education about NDIS instead provided as part of the focus group, and in a peer group environment. This method has been chosen by others consulting with consumers on NDIS nationally.

Focus group participants addressed two main areas of enquiry:

1. The perceived advocacy priorities of consumers
2. Strategies, including self-help and peer supports, that can improve:
   I. planning that supports recovery
   II. consumer access and uptake of NDIS
   III. supporting self-management of funding by consumers
   IV. supporting self-direction (decision-making rights)

The education component of the focus group provided an overview of NDIS aims, key dates, funding levels and numbers of the population targeted (federal and WA), tiered supports, the application process, and basic eligibility criteria. A range of advocacy issues were briefly summarised to encourage ‘new and additional thinking’ to build on advocacy issues that have already been identified.

Structure of this Report

The main Report provides Summary Results and a Discussion of the overall findings, with full data included in the Appendix. The Next Steps section focuses on CoMHWA intended activities with consumers, NDIA leaders and other stakeholders, to progress the report findings.

Summary Results
1. Key Advocacy Messages to NDIS on Behalf of Consumers

Each participant provided their 3 top priority advocacy messages to NDIS on behalf of consumers. These have been grouped into 4 overarching messages, with participant ideas incorporated.

**Think, plan and act about ‘NDIS and what else’** Recovery requires a holistic and population based approach that is more than NDIS. Consumers are concerned about living below the poverty line, housing and income stress, and a culture of ‘conditional choice-giving’ in which people’s choices are limited by both professionals, agencies and providers. NDIS needs to be understood in the context of, and coupled to evolve holistically with other systems of support, in order to support every Australian to have full life opportunities. This includes expanding self-directed approaches and funding beyond NDIS where it can lead to better outcomes, and ensuring baseline social benefits, community supports and housing are sufficient to meet needs and designed to support recovery.

**Our Advocacy Rights - Make them Real**

There is evidence of low uptake and benefit of people with psycho-social disability in other schemes and also high levels of nominal rather than self-directed funding and decision-making arrangements for mental health consumers. These experiences should not be repeated in Australia. Independent advocates with relevant skills, lived experience and independence from NDIS need to be funded for and incorporated as a core resource alongside NDIS. This is important for enabling consumers to engage with, access, navigate and have optimal self-direction within NDIS.

**Make the process fair and helpful from a consumer perspective.** Consumers have rich experiences to draw on about service barriers and helpful, versus unhelpful, approaches to promotion, engagement, assessment and support. NDIS needs to work harder to reach out to consumers who may be eligible, and to listen and respond to consumer knowledge about effective strategies that can support access, uptake and benefit.

**Implement Co-Production into the NDIS Scheme.** Co-production is the formalised recognition and embedded practice of policy, reform and service delivery in partners with consumers and their key supports, based on the equal value and complementarity of lived experience of mental health issues, and professional skills. Co-production is essential to:

- Designing and embedding recovery approaches
- Enhancing trust and engagement by consumers through the presence of peers who can relate to, understand and advocate for them
- Providing a source of meaningful and quality workforce contribution by consumers
- Ensuring those most impacted by services have most say into what services look like and how they are improved.

3. A Path Forwards for Consumers: Design Elements in NDIS
Consumers undertook small group work to explore strategies that could improve consumer experiences of NDIS in 4 areas (‘themes’) and to consider the role of peer support and self-help across these themes. These are summarised below.

### Theme 1: Recovery Planning
- Non-Time limited
- Open to change and mistake making
- Holistic- centred on good life goals
- Can start before NDIS with peers
- *LEARNING is as important as planning:* examples, stories, trial and error, research

### Theme 2: Engagement and Access
- Make the access and assessment process *EASY*
- Consumer led, targeted promotion and outreach
- Wide and basic education- eligibility, the process
- Advocates/Peer staffing

### Theme 3: Supporting Self-Managed Funding
- Peer Group Sharing and Lived Experience Examples
- Learning and skills building (long term planning, fund self-management, decisions, money pressures, confidence, acquittal)
- Advocacy in decision-making

### Theme 4: Decision-Making Rights
- Charter of Rights
- *Independent* education, advice and advocacy
- And peer advocates part of NDIS office staffing
- NDIS Staff need to be recovery-focused: have trust, accept dignity of risk, attitudes

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<table>
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<tr>
<th>The Role of Peer Support and Self-Help Across the 4 Themes</th>
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<td><strong>Example Models</strong></td>
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<td>- Learning Circles/Local Meeting Groups</td>
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<td>- Participant Conferences</td>
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<td>- Lived Experience Libraries</td>
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Limitations and Discussion

The Focus Group results importantly reinforce emerging ideas around how consumer capacity building in NDIS can be supported by self-led and peer approaches, and some clear messages and strategies NDIS planners and the mental health sector can take forwards in ensuring mental health consumers needs are understood, respected and responded to in NDIS. There was high alignment between the advocacy issues raised (part 1 of the focus group) and the themes explored in part 2, which suggests CoMHWA has effectively identified and worked in alignment with consumer priorities in it’s advocacy efforts to date. The unique contribution of the Focus Group was to reveal three areas in which further consumer feedback and exploration is required. These are also key limitations of the focus group, which was constrained by time and limited numbers in the extent to which issues could be comprehensively addressed.

- A sophisticated NDIS that is connected, integrated and works well within the context of interacting systems of support (non-NDIS components of the mental health system, but also key additional support systems of welfare, housing, health care etc. that are equally essential to ‘get right’ if a good life for consumers is to supported by NDIS). The vision of consumers within the focus group was not just of how NDIS can be modified to respond to constraints within related systems, but how NDIS can transform related systems through self-direction, norms about government support, and innovative approaches
- Consumer understandings of reasonable and necessary supports, which were typically discussed in this context of interacting systems of support
- The rationale and roles for lived experience advocacy and peer support, and the difference that can be made by these support elements, as a key element consumers see as important to a fair and accessible NDIS.

In response to these areas, our Discussion Paper *NDIS in the Context of Consumers’ Lives*, has been co-released with this report and is open for feedback, comments and suggestions. In the interim, clear capacity building activities have been outlined by participants, that can be progressed effectively if co-production guides their development.

Next Steps- CoMHWA

- Undertake further consumer research on items for further discussion (NDIS in the context of other support systems, consumer perspectives of reasonable and necessary supports, the potential for differences made for lived experience advocacy and peer support)
- Publication and circulation of results to key stakeholders
- Written request for response/intent based on findings (WA Hills, My Way)
- Explore and progress opportunities for co-production with key agencies
- Explore and progress opportunities to undertake consumer-led activities that can enhance recovery, self-direction, self-advocacy and general readiness for NDIS, with a focus on pilot regions commencing 2014
- Regularly report to members on progress and NDIS Updates relevant to focus group findings
Conclusion

There is an ongoing paradox within recovery, in which the characteristics of recovery that focus on non-linear, uniquely individual, and transformative journeys, co-exist in consumer’s lives with common experience and determinants that shape our recovery prospects. It is the latter that underpins consumer voice and the evidence that informs our systemic advocacy. The characteristics of recovery we promote are normative and create a new world for consumers, which gives us back a right to self-direction, as experts of our experience. It is then advocacy on the common experience and determinants that help us to realise that right, by political voice over the determinants that affect those rights, such as disadvantage, discrimination and stigma. What this in turn means is a consumer voice that both respects the individual, and is mindful of the shared elements of our journeys, which include the bigger picture of systems and bureaucracies on the paths and options we take. Respecting our Choices therefore calls for Consumer Voice into NDIS, which would progress an agenda that recognises and responds to the ways NDIS and other systems interact to impact on our lives, and the access, engagement and advocacy implications of these interactions. It is not our essential difference, but common determinants, that give mental health consumers a stake in NDIS, and that equip them with the lived experience needed to make a major contribution to right design. With one month's launch to NDIS, close to one year's trialing of NDIS in Australia, and a general sense from stakeholders that learning from participants, advocates and local sites has not been well coordinated or integrated into NDIS arrangements, it is timely that co-production is considered in the way forwards.

Appendix 1. Focus Group- Full Results

1.Key Advocacy Messages to NDIS on Behalf of Consumers

Participants provide their 3 top priority advocacy messages to NDIS on behalf of consumers. These have been grouped into 4 key themes:

Recovery Requires A Holistic and Population Based Approach that is More than NDIS

- Give maximum funds to consumers for self-directed funding [self-directed funding can be used in other initiatives, not just NDIS; and people may have very different priorities for use of funds to NDIS ‘ideas’ of what they should use it for]
- Understand our financial crisis circumstances and make sure quick funds are available for emergencies, such as housing crisis- don't lock up funding when it's needed
- There should be the same eligibility test for Centrelink and Homeswest. That is, assessment once only paid for by taxpayer for a person to receive all three types of supports, with linked and aligned safety net arrangements.

1 This comment is referring to the gap in Western Australia where Department of Housing and Centrelink are not linked, so that you become ineligible for Homeswest on lower earnings and sooner than you do for DSP, but consumers need a good safety net for both in order to be able to return to and stay in work.
• Housing can be self-directed too.
• Flexible funding for what consumers need shouldn’t be medically focused or dominated - it should be for a social and emotional good life.
• There needs to be proper consideration for our youth issues and funding, e.g. early intervention. Foyer is a good example and should be within every TAFE.

Our Advocacy Rights - Make them Real

• Fully trained advocates must have lived experience - either as a carer or consumers, and there must be support for their professional development of advocacy skills.
• Create a rational criteria of the advocacy needed to shore up decision making rights, ensure responsibility can be debated where the person wants to self-directed, and which sets out clear accountability (e.g. rights and responsibilities of all parties, right and process of appeal, and transparency and appeal about funding decisions made).
• Advocates should have legislated and guaranteed independence for those who access them, with sustainable and independent funding sources.

Make the Process Fair and Helpful from a Consumer Perspective

• There needs to be more work done to build consumer awareness of NDIS and to help consumers engage and understand their eligibility.
• Makes sure the process for consumers to access funds is easy
• Clear message on how we get in contact with NDIS and which raises awareness of NDIS and how it can benefit
• NDIS should be based on where the consumer is at the time (level of interest in NDIS, types of needs, other options)
• There needs to be transparency through open disclosure and discussions about NDIS with consumers.
• We need a psycho-social model that allows flexible assessment
• Commit to meaningful and maximised self-direction in the scheme through capacity building for self-advocacy and self-managed planning and budgeting, a strengths and recovery approach to consumers approaching NDIS, and consumer access to advocates and peer supports as neutral third parties.

Implement Co-Production into the NDIS Scheme

• Reasonable and necessary support should be defined by consumers as they have direct experience of the diversity of ways that funds can support recovery. An example is a living library of experiences that any participant can contribute to (not ‘hand picked’ by NDIS).
• ‘Do it but do it right’ - ensure that careful, thoughtful and considerate planning is undertaken about NDIS, in partnership with consumers

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1 The participant felt that transfer of public housing stock to community independent housing, with NGOs or cooperatives, and linked to self-directed funding eligibility, could increase safety and recovery for people who are trying to recover.
- 50% of decision-makers for My Way/NDIS must have lived experience (as consumers, people with disabilities)
- The needs of consumers must be paramount, not overtaken by providers
- The Recovery model needs to be clear and embedded within NDIS, including eligibility criteria, skills of staff in working with consumers etc.

2.A Path Forwards for Consumers: Design Elements in NDIS

2.1 Planning in Recovery

*Key elements NDIS needs to consider to make sure planning is empowering and useful to consumers*

- Advocates and peers supporting consumers to develop plans – including *prior to NDIS*
- Kontiki tour through what's out there – dreams [to assist with understanding how to turn dreams in reality, and explore what is practical and feasible]
- Reassessment for redirection [planning enables people to change their plans as goals change]
- Allow stretchy time for planning, e.g. 1 year. Self-agency is unknown and very new for many people. Rachel Perkins: Planning is like planting a garden and seeing what works
- Support to meet consumer's goals: food, housing, education, work, transport
- Ensure support and education to self-manage funding is part of the planning process

2.2 Consumer Uptake of and Access to the Scheme

*Strategies that could help consumers to:*

2.2.1 *Know about NDIS*
- Approaching potential consumers, face to face outreach (for homeless people etc.)
- CoMHWA advertising
- Informational presentations, range of newsletters (e.g. NGOs), local papers, Consumer Advisory Groups
- Medicare Locals, GP's
- Educate providers too
- Webpage FAQs

2.2.2 *Choose to Apply for NDIS*
- Paid Peer advocates
- Via shopfront
- Linking people up
- Information focuses on easy practical step
- Consumers are educated about the eligibility process and criteria

2.2.3 *Experience fair and equal access to NDIS*
- Consumer participation conferences
- NDIS Advocates
- Consumers approach eligibility ‘as if it was their worst day’ [i.e. mental health consumers eligibility processes should be able to build up an accurate picture of need, and ‘blindspots’ in eligibility tools
need to be addressed by NDIS, or by educating/supporting consumers about the blindspots so they aren’t disadvantaged. The ‘worst’ day is about the blind spot of eligibility that can happen when consumers have their ups and downs, and on an ‘up’ day may be assessed as ineligible.

- Consumers need to know what entitlements are possible
- Use lived experience employees in NDIS
- Lived experience advocate supports consumers through application process
- Make assessment eas, e.g. like an ‘above the line’ not a ‘below the line’ on a voting card
- Easy access to shopfront by public transport
- Brochures and posters at all key services

2.3 Self-Managed Funding

**Things that can be done to assist consumers to feel ready to self-manage their funding**

- Independent and sympathetic financial development
- Peers- sharing examples and ideas
- Education
  - A list/guide and example plans to provide people with ideas of what they could spend the money on
- Help to understand the value and potential of money: Example of 25 years of poverty- didn’t understand how much of a difference that money could make and how to spend to my best advantage. I was reluctant to spend it as I didn’t have experience spending. When I started spending it, I realised how easily and quickly problems can be fixed when you have money.
- Have to allow practice and mistakes as part of learning how to manage funding
- Budgeting, financial counselling should not just be focused on the ‘short term’ but includes the longer time financial planning and advising as to best value for money across time. Likewise, goal planning is not ‘short term’ but is about life planning which links to financial planning. Example of affordable home ownership schemes under Department of Housing, and how longer term planning could get you there.

2.4 Decision-Making Rights

**What ideas do you have about how a person’s right to control and self-direct their life can be upheld in NDIS, particularly when other’s say they know ‘what’s best for them’?**

- Independent education and advice
- NDIS Charter of Individual Rights
- Feedback from consumers, advocates and carers aiming towards transparency of goal negotiations [with NDIS]
- Built in flexibility- life can sometimes be chaotic and change day to day.
- Advanced health directives
- NB Big planners did *not* acknowledge unsafe housing was negating wellness or any other good outcomes. Self-directed funding is not just being able to buy a haircut [it needs to be linked to other systems and might only be of benefit if it is occurring within a broader environment in which the wellbeing of Australians is supported across sectors/components of living]
• Trusting consumers, in combination with education [helping to develop skills to self-manage]
• Must teach consumers how to do funding acquittals and if employing a person directly must learn about basic employee obligations

2.5 Thinking about the Role of Self-Help and Peer Support Across the Four Areas

Additional strategies to do with consumers coming together and helping each other, that you would see as useful to these areas? Examples provided included peer support workers, self-help groups, consumer advocacy, consumer education, meetings and resources.

2.5.1 Planning in Recovery

• Step by step prioritising with peers
• Learning from, but not being defined by, other people’s lived experience [of recovery and planning]
• Group meetings/afternoon tea discussions to share examples
• Self-supporting localised groups

2.5.2 Consumer Uptake of and Access to NDIS

• Listening to mutual narratives and encourage mutual narratives [sharing experiences of NDIS between peers]
• Shopfront
• Information docs- ‘how to sheets’ developed for and by consumers
• Guidance with filling in forms
• NDIS helpline with lived experience advocacy staffing

2.5.3 Self-Management of Funding

• Self-help and peer support can be used in budgeting [the notion of peer support being used to assist transition from negative budgeting (budgeting to make ends meet) to positive budgeting (budgeting that makes life different). Examples would be peers exploring and prioritising goal setting across hobbies, health, material possessions so they have peace of mind they have made the best plan in terms of using money to make the biggest difference in their lives

2.5.4 Decision-Making Rights

• Advocacy
• A bill of rights based on eligibility education. Make sure person knows what ‘self-directed’ means [i.e. know the different levels of decision-making control people can have, ranging from substitute, to supported/person-centred, to self-directed]
Appendix 1. Questions

**THEME 1: Planning in Recovery (5 mins)**

**Fact:** Planning can be useful to clarify our aims in recovery and what it takes to get there, or it can be, in worst case, a frustrating process. If you were in NDIS, you would be planning around your goals, how funding goes to each goal, how your funding is managed, and what support you will get with turning your goals into reality.

| Question 1: What are some key elements NDIS would need to consider about planning to make sure it was empowering and useful to consumers? |

**THEME 2: Consumer Uptake & Access (~15 mins)**

**Fact:** In the UK, they found that benefits of self-directed funding were high for mental health consumers, but consumers were not strongly accessing the scheme relative other groups..

| Question 2: What are some strategies that could help consumers to:  
2(a) Know about NDIS  
2(b) Choose to Apply for NDIS  
2(c) Experience fair and equal access to NDIS |

**THEME 3: Fund Self-Management (~ 5 mins)**

**Fact:** People accessing NDIS will have the option to have funds managed by NDIS, by a third party, or to self-manage. Past research has indicated consumers are sometimes concerned about whether they feel ready to self-managed funding.

| Question 3: What things could be done to help consumers feel ready to self-manage their funding? |

**THEME 4: Decision Making Rights (~ 10 mins)**

**Fact:** Decision making can be done in three ways: independently, through jointly deciding with others also having a say in the decision, or by someone else making a decision completely on another’s behalf. The challenge is that when others are involved in decision-making with us or instead of us, what we want can easily be lost.

| Question 4: What ideas do you have about how a person's right to control and self-direct their life can be upheld in NDIS, particularly when other's say they know 'what's best for them'? |
**THEME 5: The Role of Self-Help and Peer Support Across 4 areas… (≈ 10 mins)**

**Fact:** Today we have explored strategies helpful to consumers across 4 themes: recovery planning, consumer uptake and access, fund self-management by consumers, and our rights to self-direct our lives being upheld. Consumers supporting each other has also been identified in other consumer focus group as a key way forwards in ensuring NDIS meets consumer needs.

**Question 5:** Are there additional strategies, to do with consumers coming together and helping each other, that you would see as useful to these areas? Examples include peer support workers, self-help groups, consumer advocacy, consumer education, meetings and resources. Please list specific ideas you have about the role that consumers helping each other could play as strategies, for each of the four questions you have answered.