Joint Standing Committee inquiry into the provision of services under the NDIS for people with psychosocial disability related to a mental health condition.

Written by:
Nathan Grixti
VMIAC Research

Contributions:
Ella Kingsley
Neil Turton-Lane

Victorian Mental Illness Awareness Council
Building 1, 22 Aintree St, Brunswick East, 3057, Victoria, Australia
www.vmiac.org.au/
Joint Standing Committee inquiry into the provision of services under the NDIS for people with psychosocial disability related to a mental health condition.

Preamble

This paper is written in response to the Joint Standing Committee’s request for submissions relating to the provision of services under the National Disability Scheme (NDIS) for people with psychosocial disabilities.

VMIAC is the peak non-government organisation for people with lived experience of mental health or emotional distress issues in Victoria.

In this report VMIAC brings to notice current issues in the design, development and implementation of the NDIS from the consumer perspective as currently experienced in Victoria. The scope of this submission aims to address those critical issues, providing positive recommendation for realistic and achievable improvements in the current scheme.

VMIAC acknowledges consumer experience of the NDIS has been varied and would like to acknowledge and thank the Joint Standing Committee members, National Disability Insurance Agency (NDIA), NDIS and all key stakeholders for their willingness to receive open feedback and for their ongoing commitment to make positive changes to the scheme which benefit consumers, communities and the Australian populace in general.

A note on language:

VMIAC recognises language is powerful. Specific terminology used to describe individuals and their experiences is of critical importance and continually evolving to better represent and reflect the diverse perspectives and reality of each individual’s experience of psychosocial disability.

VMIAC welcomes ongoing discussion on this matter. For the purpose of this paper the term ‘consumer’ or ‘participant’ is used to describe people with lived experiences of mental health or emotional distress issues.
EXECUTIVE SUMMARY

VMIAC’S submission into the inquiry of provision of services under the NDIS for people with psychosocial disability related to a mental health condition

The National Disability Insurance Scheme represents the most significant mental health reform in Australia since de-institutionalisation, and as such promises both an unprecedented opportunity and concern for the wellbeing and future of people with lived experiences of mental health issues and psychosocial disability.

The 2013-16 NDIS trial offered valuable opportunity for reflection, learning, adaptation and growth. As we progress through the first year of the current national rollout there is an imperative that those issues identified as critical and arising from the design and implementation of the scheme, be addressed and remedied as a matter of urgency if the Scheme is to retain sustainability and deliver on its promise to participants.

Summary of key issues and recommendations:

1. The eligibility criteria for the NDIS are not aligned with the support and recovery needs of consumers and can be experienced as exclusionary and discriminatory for many people.
   
   **Recommendation:**
   (I) Review the eligibility criteria for people presenting with mental illness and psychosocial disabilities to reflect complexity of psychosocial disability, cognizant of research evidence, trends and best practice in mental health.

2. Current transitional arrangements will effectively deny a large percentage of people access to vital community based mental health supports.
   
   **Recommendation:**
   (i) Community based psychosocial services remain available and accessible for all consumers who require or choose to access these supports. Access should not be dependent on level of functional impairment.

3. In the context of the national rollout of the NDIS the development and implementation of the Information, Linkages and Capacity Building (ILC) framework is significantly delayed. Consequently, few consumers are adequately informed about how to access the Scheme and in what way the NDIS will meet their needs.
Recommendation:
(i) That an ILC framework is informed and meets the needs of all consumers in a diverse range of contexts and fully utilises the capabilities of an emerging peer work discipline.

4. The NDIS access and planning process does not meet the needs of people experiencing psychosocial disability. The process is ill-fitting, lengthy and presents a complexity that is extremely difficult to navigate in a mental health context. Availability to meaningful and viable supports is limited.

Recommendation:
(i) That the NDIS access and planning process be reviewed and informed by evidence based models of recovery and best practice in mental health.
(ii) The NDIS release copies of the assessment pro-forma of 140 questions.
(iii) That consumers receive a copy of their completed assessment along with the planning schedule
(iv) That participants with psychosocial disability have access to Peer Support as a provision of choice

5. With the introduction of the NDIS consumers of forensic mental health services are at increased risk of losing access to community-based rehabilitation and support. This has the potential to jeopardise a seamless supported transition back into the community.

In effect the NDIS will remove the last remaining Community Mental Health Supports currently accessed by transitioning Forensic patients. The specialist skills of CMHS workers who currently support Forensic patient’s integration into the community have been devalued. The absence of community connections may significantly impact on the decisions of the Courts with regards to discharge planning into the community.

Recommendation:
(i) That the NDIS be cognisant of and adhere to Statutory Legislative requirements.
(ii) That access to community-based supports continues for consumers under forensic services.
(iii) Commitment to provide Forensic patients with a consistent and stable platform to enable a safe, holistic rehabilitation back into the community.

6. It is unclear how the scheme intends to make provisions for consumer-led initiatives that value Lived Experience and Peer Support Work and whether these will be funded support items for participants.

Recommendation:
(i) That NDIS gain a thorough understanding of consumer-operated initiatives which enhance the capacity of the NDIS to meet the needs of people with a psychosocial disability
VMIAC submission to the Joint Standing Committee on the NDIS – Mental Health

(ii) That drawing on an extensive international and local body of knowledge informing the Peer Work and Lived Experience discipline the NDIS makes resource commitment to the growth and development of sustainable Peer work.

7. Advocacy services are integral supports to vulnerable people experiencing psychosocial disabilities, particularly in the context of community services where provisions for advocacy are recognised as necessary inclusions to support services. Three year’s post NDIS implementation, the position and commitment to funding of independent advocacy services remains outstanding.

Recommendation:
(i) That culturally appropriate Independent Advocacy Services be resourced to safeguard vulnerable people. This includes hard to reach and engage populations including Aboriginal and Torres Strait Islanders, CALD and LGTBI communities ensuring that the National Disability Standards underpin and inform all NDIS activities.
(ii) That Independent oversight of the issues encountered by people with a Psychosocial Disability occurs at a national level. This may be achieved through the resourcing of a National Coalition of Independent Psychosocial Advocacy Services.
(iii) That the role and importance of independent advocacy in the context of mental health be acknowledged and understood in relation and contrast to other areas of disability advocacy.

8. Choice and Control is promoted as a fundamental tenant of the NDIS. Predetermined reference packages and inflexibility of service provisions relevant to consumers with psychosocial disabilities leave consumers with little choice and control. Many consumers in rural and hard to reach areas are disadvantaged in achieving access appropriate supports.

Recommendation:
(i) That a range of culturally appropriate conceptual paradigms such as Peer Support, Yarning and the Hearing Voices Approach, which frame experiences in helpful, positive and often life changing ways are incorporated in NDIS consumer options of provision.
(ii) NDIS commission a co-designed Rural Gateway Initiative to address specific needs of rural and hard to reach communities to identify and deliver applicable services.
(iii) That the NDIS support Independent Advocacy to mitigate power imbalance.
VMIAC submission to the Joint Standing Committee on the NDIS – Mental Health

VMIAC REPORT  set against terms of reference

1. The eligibility criteria for the NDIS for people with a psychosocial disability

**Findings**

(a) Eligibility criteria that have a focus of functional impairment do not align well with the psychosocial disability support and recovery needs of mental health consumers. The current Eligibility criteria fail to reflect the complexity of the lived experience within psychosocial disability.

(b) Existing eligibility criteria based on a medical model fail to take into consideration that mental health diagnoses and prognosis are contestable across the range of medical expertise and lived experience. The task of proving level of fluctuating impairment to function is problematic and a barrier to inclusion.

(c) Access criteria requires people have a definitive label with a particular diagnosis and notions of permanence in order to access entitlements.

(d) When eligibility criteria are based on a purely functional model of assessment the complexity and impact of biopsychosocial disability is denied. The mind impacts functions in all domains. Severe, enduring and fluctuating mental illness has potentially catastrophic effects on all areas of life expectation and opportunity.

(e) People with lived experience of mental health issues face incredible barriers, not least discrimination and stigma. A permanence label impacts identity and carries with it diminished expectations of achieving an [extra] ordinary life.

(f) Current eligibility criteria disadvantage people who for various reasons are disconnected from the mental health system. There is a range of valid reasons. Cultural, health, family, environmental or locational access. Traumatic experience of deprivation of liberty; negative, unhelpful and disabling experiences of mental health services, including harmful and iatrogenic effects of medical treatments and pharmaceuticals.

(g) Consumers not viewing their disability from a medical model are disadvantaged. Alternative and culturally appropriate conceptual paradigms such as Peer Support, Yarning and the Hearing Voices Approach, frame experiences in helpful, positive and often life changing ways.

(h) A consensus exists within contemporary mental health literature and research that language which focuses on deficits, functional impairments, disability and
permanence acts to not only impede recovery but also contributes to a culture of low expectations and poor prognosis which extends beyond medical treatment into how individuals are treated more broadly across society.

(i) Medical models of disability overlook or discount the experience of adverse life experiences, including the effects of violence, sexual abuse and trauma on an individual’s psychosocial functioning

(j) The eligibility criteria create barriers for consumers who do not identify for a variety of reasons with psychiatric labels, this includes: young people, members of the LGBT community, people with dual disabilities, dual diagnosis and people from CALD backgrounds, including Aboriginal, migrant and refugee communities.

(k) Critical concerns have been raised that the current eligibility criteria fail to adequately delineate impairments from health conditions. This situation is complicated by the complex individual and fluid nature of mental functioning and in particular casts doubts about the scope and funding potential for early interventions within the evolving NDIS

**Recommendation:**

(i) That NDIS review the eligibility criteria for people with a diagnosis of mental illness and psychosocial disabilities to reflect the complexity of a lived experience in conjunction with current evidence, trends and best practice

(ii) That NDIS develop or modify the eligibility criteria to better reflect existing evidence based recovery models and programs, including biopsychosocial models of mental health, and

(iii) include provisions for eligibility that support participation based on experiences, identity, presentation and representation

(iv) That NDIS assessment allows and gives sufficient weight to assessments and opinions from Psychologists, Social Workers and Peer Support Workers as an acceptable adjunct or option to Psychiatrists and G.P report

(v) That reasonable review periods for ongoing eligibility replace the focus on permanence

(vi) That eligibility criteria are developed cognizant of the subjective and contested nature of psychiatric diagnoses, respecting individuals’ experiences, diversity and cultural perspectives, including provisions for consumers to state if they identify with formal diagnosis

(vii) Early Intervention criteria should include specific provisions for instances where clinical mental health treatments and supports may not be suitable or sufficient.
2. **The transition to the NDIS of all current long and short term mental health Commonwealth, state and territory Government funded services**

**Findings**

a) Inclusion of all Commonwealth, state and territory funded services into the scheme does not represent an equitable transition.

b) The NDIS is targeting a different cohort of consumers than existing programs and services traditionally provided support services to. Following cessation of transitional arrangements, a large percentage of consumers will be denied access to vital community mental health support services.

c) Current estimates suggest that up to 502,000 adults and 123,000 Australians under age 18 have a severe mental illness. The scope of the NDIS includes provisions to support up to 64,000 people with psychosocial disabilities.

d) Additionally, approximately 209,000 consumers currently need some form of community support; be that individual, group or non-acute residential care.

e) The actual number of people with severe mental illness presenting with significant permanent functional impairment is unknown though generally accepted to be a much larger cohort than earlier estimates. The figures indicate that under current funding arrangements a substantial number of people who meet eligibility criteria will fail to gain access to NDIS supports.

f) Programs and services being transitioned into the NDIS scheme (e.g. PHaMs, D2DL) are based on decades of recovery research and best practice. The programs were instituted to address identified gaps in current service provision. Removing these schemes whilst denying many participants access to the NDIS effectively amounts to a significant downsizing of community psychosocial service provision for Australians.

g) Denying people with mental illness and psychosocial disabilities access to appropriate levels of support is in effect a denial of the Human Rights accorded to every Australian and ratified in the United Nations Convention of Rights for People with a Disability to which Australia is a signatory.

h) Consumers require assurance that the NDIS understand the context, role and services currently provided by the community mental health sector.

i) Current programs and services include specific provisions for outreach into the community which target ‘hard to reach’ consumers who may have multiple and complex needs and have not achieved access to the NDIS whilst in transitional phase. These outreach services are themselves at risk post
VMIAC submission to the Joint Standing Committee on the NDIS – Mental Health

transition. Retaining the role of outreach in continuing to meet the needs of vulnerable and at risk people needs to be a priority regardless of people’s eligibility for the scheme.

j) As essential existing community supports become inaccessible to a disproportionately high number of vulnerable and marginalised consumers left without any provision for support to exist outside of the NDIS, significant emerging service gaps will place societal and financial pressure on other services.

k) This anticipates an increase of consumers needing to access clinical supports as the only option and will lead to overload of a critically under resourced system. People will be unable to access clinical supports with potentially devastating impact to individual, community and societal wellbeing.

l) The Intergovernmental Agreement (IGA) commitment to the principle of ‘no disadvantage’ only includes provisions for consumers currently accessing community based supports for the duration of the rollout period. People who qualified to access supports but remain on waiting lists will not be covered by transitional community provision arrangements.

m) There is a consensus based on Human Rights and ‘fair go’ principles that Commonwealth and state/territory funded services continue for people who are either not eligible for NDIS funding or who are not participating in the scheme.

Recommendation:
(i) That the NDIA acknowledge the vital contribution community mental health services play in the health and wellbeing of society and evidence commitment to preserve and resource Mental Health services.
(ii) That essential community based mental health services remain available and accessible for all consumers who require or choose to access these supports.
(iii) That outreach supports for consumers who are hard to reach or experience multiple and complex needs continue for consumers considered to be both eligible and ineligible for the scheme.

3. The scope and level of funding for mental health services under the Information, Linkages and Capacity Building framework

Findings
(a) The ILC holds enormous promise and potential for its stated goals of building the capacity of consumers and the broader community in tandem with creating unprecedented opportunities.
Achieving these aims presents critical challenges particularly in a mental health context where a significant number of consumers already experience isolation and disconnection from the community as well as specific psychosocial disability related issues which often prevent people from accessing existing supports and mainstream services.

(c) Unique challenges also exist for communities living in isolated and rural settings and regional areas of wide cultural diversity and socio-economic disadvantage.

(d) The pace of the rollout combined with the ongoing development of the NDIS means that very few mental health consumers are properly informed about the schemes intentions and processes. Being informed about the scheme, accessing and navigating the scheme currently remains the province of the well networked.

Recommendation:

(i) NDIS commission a co-designed Rural Gateway Initiative to address specific needs of rural and hard to reach communities.

(ii) The NDIS publish localised information for consumers on community support provisions

(iii) Providers and other consumer access points e.g. GP surgeries, libraries and meeting places receive directories of NDIS local provisions.

4. The planning process for people with a psychosocial disability

Findings

(a) There remain several high-level concerns in relation to appropriate planning for people experiencing a psychosocial disability.

(b) Planning remains a lengthy, complicated process for all participants

(c) In stark contrast to existing models and programs, access to the NDIS is a lengthy multi-stepped process requiring consumers gather evidence, attend meetings and complete invasive assessments which will be ongoing.

(d) Concerns have been raised about the recent shift from face to face planning sessions to the NDIA preferred method of phone contact by a Local Area Coordinator which can include lengthy assessments of up to 140 questions, not previously shared with the consumer to enable preparation.

(e) Telephone assessment in the context of psychosocial disability is of critical concern as it fails to encompass the elements of a holistic face to face assessment excludes those who do not have the means due to engage on the telephone.

(f) Feedback from Barwon indicated an overwhelming majority recommended individuals seek ongoing advocacy support.

(g) Reports of lengthy wait times for assessment are particularly problematic in the context of mental health. Anecdotal reports from consumers and services in Barwon indicate a wait period of up to eight months before plan approval.

(h) Of concern are indications that consumers accessing step-up/step-down style services, such as PARCs have been told a wait of at least one month between exiting the service and commencing community based supports is to be expected.
VMIAC submission to the Joint Standing Committee on the NDIS – Mental Health

This totally compromises consumer’s health and wellbeing and impacts the value and efficacy of these services in providing integrated and seamless transitional support into the community through existing collaborative partnerships and referral pathways with community services.

(i) Current community programs have been designed to have a collaborative, relational approach to support which focus on consumers and agencies working together directly to establish recovery plans and goals. A model where networks and services take a competitive role in planning potentially negates the purpose and efficacy of community supports.

(j) Increased visibility, recognition and referral rates to community services by clinical mental health services have indicated a growing and unmet need for community support services.

(k) Communication and referrals between services are now required to go through the interface of the NDIA rather than direct communication and agreement between services and consumers.

(l) This raises concerns that the implementation of the scheme risks compromising collaborative relationships and approaches which have and should continue to be formed between the clinical and community sectors.

(m) The expectation for clinical mental health services, GPs, and other allied health professionals and primary health networks to take a lead role in supporting consumers to access the scheme places increased strain and burden on an already under-resourced sector without necessary and additional provisions to support such a shift.

(n) High level concerns have been raised that GPs and other health professionals are unfamiliar with the Scheme and not engaging with the NDIS. There is a general lack knowledge of NDIS entry and assessment requirements. Many view psychosocial disability as a specialism they do not all feel equipped to report on.

Recommendation:

(i) That the NDIS planning process is reviewed to more appropriately meet the needs of consumers.

(ii) The planning process be reviewed to ensure consistency with current and emerging evidence based models of recovery and best practice in mental health community services considering the efficacy of community mental health services.

(iii) The NDIS release copies of the assessment pro-forma of 140 questions.

(iv) Peer Support is accepted as a primary and vital part of recovery planning in collaboration with consumers.

(v) That consumers receive a copy of the full completed assessment along with the planning tool.

(vi) GP and allied health information and training from NDIS in collaboration with consumer focus groups.
5. **The provision, and continuation of services for NDIS participants in receipt of forensic disability services**

**Findings**

(a) For prospective participants currently in the forensic mental health system requiring access to community based supports as part of conditional leave entitlements and rehabilitation planning, the NDIS presents a potential barrier.

(b) Legislated practices in forensic mental health services which often require extensive multi-disciplinary planning directly with community supports prior to approval of leave requests and discharge to community based rehabilitation do not appear to have been integrated in the NDIS provisions.

(c) Concerns have also been raised in relation to participant experiences of increased stress, anxiety and frustrations related to the impact of NDIS processes and contact with the NDIA, as well as reports of extensive wait times.

(d) In the context of consumers in the care of forensic services this is of particular concern, particularly when individuals face serious penalties or have leave entitlements revoked as a consequence of behaviour which is considered inappropriate or in breach of agreements between individuals and services.

**Recommendation:**

(i) That NDIS legislation be reviewed to support seamless processes, marrying the raft of current legislative directives on which the Forensic system relies.

(ii) That the NDIS ensure robust safeguards and quality assurance systems which do not place participants at increased risk of being incarcerated longer than necessary.

(iii) That NDIS acknowledge and demonstrate commitment to maintain access to vital community based supports for consumers in the care of forensic mental health services, regardless of eligibility for the scheme.

(iv) That specific supports and advocacy be made available to patients of Forensic services to assist preparation for application to the NDIS.
VMIAC submission to the Joint Standing Committee on the NDIS – Mental Health

Other related matters and areas of concern

6. Peer Support

Findings
a) Peer Support, the lived experience workforce and consumer led initiatives in the context of the NDIS is an emerging, evidence based discipline. Peer Support has long been recognised as a valuable resource which reflects established evidence based principles and best practice.
b) As a capacity building support line item in the NDIS guide, Peer Support focuses on volunteer arrangements and community assist. This fails to represent the diverse and established community of practice both in Australia and internationally and devalues Peer Support in the mental health and psychosocial disability context.
c) It remains unclear how the NDIS will make provisions for consumer led initiatives and in what way this provision will be funded under support items for participants with approved Individual Funding Packages.

Recommendation:
(v) The NDIS extend the suite of accessible line options to provide a range of essential services relevant to consumers of mental health services and those experiencing psychosocial disability.
(vi) That NDIS actively supports the development of Peer Support Work through a dedicated capacity building initiative, along with other consumer developed and led initiatives in ways which embody the expertise of this discipline.
(vii) Consistent with a body of academic research, emerging trends and evidence based best practice; the NDIS embrace provisions for co-design and co-production of both community mental health services and services offered through the NDIA.

7. Negative and potentially harmful impacts on consumers

Findings
a. Feedback to VMIAC from participants of the Barwon test trial brought anecdotal reports of increased stress and anxiety along with instances of suicidal ideation. These experiences were cited as being a response to NDIA contact and rejections for support from consumers of both mental health services and functional disability services.
b. Many consumers reported concern of elevated stress levels in support workers which impacted in them not wanting to create additional burden by seeking support for their own needs.
VMIAC submission to the Joint Standing Committee on the NDIS – Mental Health

c. Feedback from consumers in public forums and directly to VMIAC indicated many people to be experiencing confusion, distress, and a sense of hopelessness about the scheme and the impact it will have on their lives.

d. Key stakeholders were heard to describe implementation of the scheme as analogous to building a plane in mid-flight, acknowledging that such a feat would have teething problems. Received as an insensitive and insulting slight against consumers, these descriptions speak to an unprecedented lack of considered planning of the Scheme and the real impacts the NDIS is having and will continue to have on the lives of thousands of vulnerable and at risk people in the community experiencing mental health issues.

e. A number of consumers who chose to self-manage report instances of feeling coerced to relinquish control and management of plans to their services.

f. A lack of transparency has cloaked the Scheme from inception with the option to raise critical issues regarding negative impacts, harm and coercive or unethical practices going largely unreported due to a chaotic lack of robust processes. To date no information is made available to the public regarding incidents that the NDIA has been made aware of or has actively investigated.

Recommendation:
(i) That the NDIS Scheme evidences commitment to develop clear strategies to address potential ongoing harmful impacts for consumers at individual and systemic levels.

(ii) That consumers are fully informed and provided appropriate supports to mitigate negative or harmful consequences and risks.

(iii) That NDIS engage meaningful consultation with consumers at all levels of scheme design, implementation and governance.

8. Advocacy

Findings
a) It is still unclear how advocacy services will continue to be funded or what role they will take in relation to the implementation of the NDIS. In the context of current community mental health services, provisions for advocacy are included and recognised as essential support services. A decision not to fund Advocacy services for participants potentially creates a service gap.

b) A majority of consumers will be unable to advocate for themselves due to their ongoing experience of mental health issues and conditions.

c) A large majority of mental health consumers lack skills and confidence to navigate the NDIS or to self-advocate and engage an Advocacy service.

d) Consumers in Barwon overwhelmingly recommended consumer access advocacy for assistance navigating and communicating with the NDIA and NDIS processes.

e) Anecdotal evidence from Barwon consumers and services indicate support workers are often unable to effectively advocate with participants in matters relating to contact with the NDIA or NDIS processes due to the Agency citing
conflict of interest as rationale. The rules of the scheme clearly state participants have a right to an advocate of their choosing.

f) Advocacy services are of crucial importance for people experiencing psychosocial disability, particularly in the context where diagnosis is contestable and consumers have experienced coercive and restrictive practices such as compulsory treatment, seclusion and restraint.

g) At a national level, independent oversight of the issues encountered by people with a Psychosocial Disability needs to occur.

Recommendation:

(i) Culturally appropriate Independent Advocacy Services are needed to safeguard vulnerable people including hard to reach and engage populations; Aboriginal and Torres Strait Islanders, CALD and LGTBI communities ensuring the National Disability Standards underpin and inform all NDIS activities.

(ii) That NDIS make a commitment to fund Independent advocacy services which can operate effectively in areas of individual, community and systemic advocacy in ways which do not compromise the integrity or capacity of services to maintain safeguarding, consumer visibility, consumer voice and perspective.

(iii) That a National Coalition of Independent Psychosocial Advocacy services be established to provide a robust overview and reporting of issues.

9. Privacy

Findings

a. High level concerns were fed back to VMIAC by participants in the Barwon test trial in respect of providers being requested en-masse to provide confidential and personal identifying information. This occurred not only without obtaining informed consent from individuals, but also without knowledge of whether those consumers would choose to apply to the NDIS. To this effect, Barwon consumers experienced serious breaches of privacy and confidentiality.

b. Reliable anecdotal reports were received from participants who were not engaged in support activities during, or immediately prior to the trial period and were unaware when they received direct contact from the NDIA making enquiry regarding the submission of an access request, how contact details had been obtained by the agency.

c. This action was publicly celebrated as a means of expediting the transition process for individuals and services in Barwon during the phase-in period, which enabled the Agency to perform a function which overruled privacy laws.

d. Consumers experienced these breaches as being an unethical use of power, representing a clear breach of privacy for many who may had disclosed personal information in the context of therapeutic relationships where confidentiality is assured.
VMIAC submission to the Joint Standing Committee on the NDIS – Mental Health

e. People experiencing psychosocial disabilities also experience disempowerment and marginalisation in society. Consumers need to be able to trust the administration of the NDIS. A display of power without ethical regard to a person’s basic rights does not engender trust.

Recommendation:
(i) The interface between equitable principles, existing legislation and the newly drafted NDIS legislation be reviewed with regard to maintaining privacy rights
(ii) Consumers receive assurance of governance commitment to transparent accountability mechanisms in relation to service standards and quality assurance
(iii) NDIS evidence a robust commitment to obtaining informed consent to access and share personal information and data.

10. Centrelink payments affected by becoming participant of the scheme

Findings
a) While it is largely reported becoming a participant of the NDIS does not negatively impact welfare payments, it is known that the Centrelink Mobility Allowance will cease and instead reasonable and necessary transport costs will be funded.
b) Mobility Allowance is a payment that many consumers utilise flexibly to cover their mobility living costs
c) Some individuals report fears they will unable to financially survive if they access the scheme for support with their mental health needs.
d) Concerns are raised that people are fearful of the intentions of the NDIS and will be pressed to choose between community supports, basic income and essentials.

Recommendation:
(i) The design of the NDIS take into account the likelihood that marginalised and at risk people may opt out of the scheme and forfeit access to vital community based supports if they feel that becoming a participant places them at greater financial disadvantage.

11. Choice and Control

Findings
a) In terms of ‘an ordinary life’ Australians currently have option and opportunity to choose Private Medical Insurance or utilise the public system with consequential tax deduction.
b) Australians also have the legal right to choose what information they share with others.
c) In the mainstream, Australians have autonomy of choice and this includes the right to choose providers of services that have evidenced health benefits for their condition; this may include accessing alternative therapies.
d) For people experiencing mental health and emotional issues choice in employment, housing and social inclusion is significantly impacted.

e) Rural communities are particularly disadvantaged in options of choice. Locality and population demographic impacts commercial viability for providers.

f) For many consumers being transitioned into the scheme access to community supports could occur directly via services of choice, and often through a ‘no wrong door’ approach.

g) Voluntary services which grew in a spirit of community are now in a climate of competition, reducing choice and control of community inclusion for many consumers.

h) Consumers experiencing psychosocial disability need choice and control in options of dialogue that reflect and respect the context of their cultural and diverse lives.

i) In an ordinary life, contact with government departments is relatively minimal. Participants engaged in the NDIS face a potential lifetime of assessments. Choice and control are often lost in an authoritative insurance model that, without due consideration and strong governance would restrict options of choice and control. People with psychosocial disability do not have a voice in this model.

j) Choice and Control is promoted as a fundamental tenant of the NDIS. With predetermined reference packages and inflexibility of service provisions relevant to consumers with psychosocial disabilities, consumers have little choice and control.

**Recommendation:**

(i) The NDIS promote alternative and culturally appropriate conceptual paradigms such as Peer Support, Yarning and the Hearing Voices Approach options which open dialogue and frame experiences in helpful, positive and often life changing ways

(ii) NDIS commission a co-designed Rural Gateway Initiative to address specific needs of rural and hard to reach communities undertaking localised and collaborative research analysis to identify requirements

(iii) That the NDIS support Independent Advocacy to mitigate power imbalance.