



PO Box 668 Rozelle NSW 2039

T 02 9555 8388
F 02 9810 8145
E info@mhcc.com.au
W www.mhcc.org.au

ABN 59 279 168 647

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SECRETARIAT
NATIONAL DISABILITY INSURANCE SCHEME
PO BOX 6555
CANBERRA ACT 2600

NDISengagement@fahcsia.gov.au

Subject: NDIS Rules Consultation paper

The Mental Health Coordinating Council (MHCC) is the peak body representing mental health community managed organisations (CMOs) in NSW. Our members provide a range of psychosocial support programs and clinical services, as well as advocacy, education, training and information services with a focus on recovery-orientated practice. MHCC's membership consists of over 200 organisations whose business or activity is wholly or in part related to the promotion and/or delivery of services for people affected by mental health conditions. We work in partnership with both State and Commonwealth Governments to promote recovery, and social inclusion for people impacted by mental illness, participate extensively in policy and sector development and facilitate linkages between government, community and private sectors in order to shape systemic change. MHCC also manage and conduct research projects and develop collaborative projects on behalf of the sector. MHCC is also a registered training organisation (MHCC LD) delivering nationally accredited mental health training and professional development to the workforce.

MHCC is a member of the Community Mental Health Australia (CMHA) a coalition of eight state and territory peak community mental health organisations whose memberships consists of over 800 CMOs. CMHA was established to provide leadership and direction promoting the benefits of community mental health and recovery services across Australia.

MHCC have had an ongoing involvement at both a state and federal level with the progress of the NDIS since 2010. We have participated in numerous consultations and forums as well as maintaining dialogue with other interested stakeholders such as National Disability & Carer Alliance, People with Disability and the Mental Health Council of Australia and have provided comment on all aspects under review. All MHCC submissions and papers are available from our website link together with news and related events on the progress of the NDIS:

<http://www.mhcc.org.au/current-issues/issue.aspx?issueid=988>

General Comment

MHCC have been given to understand that FaHCSIA have almost completed drafting the NDIS Rules. We are concerned that the time frame given to consider the detailed comments from many stakeholders in response to the Rules Consultation Paper is inadequate to seriously be taken into account in the final development of the Rules. The speed with which the whole process has been undertaken in order to pass legislation and commence the 5 launch sites is worrisome, and we sincerely hope that this objective will not compromise genuine engagement with consultation processes and support best-practice in policy development and implementation.

MHCC find that the NDIS Rules consultation paper questions give rise to more questions. The rules developed subsequent to the legislation draft offer insufficient clarity around how the scheme will work in practice. The rules should have been drafted in tandem to the legislation rather than having to fit into a fixed legislative framework, which will most certainly need to be amended to make possible the functioning of the scheme. Likewise, better coordination across various other inquiries/ consultations would have been beneficial. For example the review of the states' legislation e.g. *Disability Services Act 1983* (NSW) should be more closely associated to the drafting of the Commonwealth NDIS Bill in our opinion.

Where MHCC have experienced most difficulty in providing answers is, for example in circumstances where 'the Agency' will assess services to be more appropriately provided to a participant by mainstream or community-based organisations. We are unclear as to what service types will be considered mainstream, including community managed services, and health funded programs such as HASI. We ask for instance, whether allied health services not currently covered under Medicare such as Podiatry, or Dentistry are considered services that can be accessed under the Scheme, and to what extent is there choice of provider? Similarly, should a person request additional Psychology sessions under the NDIS, would this be considered even if such a service were previously accessed via a Medicare referral?

In our view the NDIS was envisaged as a whole of service approach, but from the work undertaken so far we see ambiguity as to whether in fact the NDIS is better understood as a subsidy approach with services to eventually transitioning from both state and Commonwealth funded services.

Over time the conversation around the NDIS has shifted. At the outset we were led to believe that the scheme was primarily designed to provide additional packages/services to people generally being supported by a plethora of services, but where an additional package of their choice would enhance their quality of life. Much of the discussion now seems focussed on transfer of services to the NDIS and the eventual demise of FaHCSIA/ Commonwealth funded programs, and in NSW for example ADHC funded services. Reference has also been made to provision of services where no other services are being accessed on the basis of need for example for early intervention. However, MHCC agree that transfer to the NDIS may enable a greater potential for consumer choice even when a replacement for a service type.

MHCC also highlight our concern for people with psychosocial disability who may not be considered eligible under the NDIS. Problems may also arise for people with mental health conditions who may feel stigmatised by a scheme that defines them as a person with a disability, which is contrary to recovery principles in mental health practice.¹

Additionally, there are capacity issues for people with psychosocial disability who may experience difficulty accessing services under the new regime whereby a participant has to generate an application (where no substitute decision-making exists). Decision making supports will have to be very well advertised and accessible for people needing such assistance.

We also raise the issue of sustainability of mental health community managed organisations (CMOs) that provide a range of ongoing support services that cannot be easily classified as 'occasions of service' and costed as such.

MHCC envisage that stakeholders' answers to the consultation paper are intended to inform the development of eligibility and assessment tools. In order to assist that process we need to better understand the breadth of holistic/ individualised planning envisaged under the NDIS, particularly if the service applied for is ostensibly unrelated to the difficulty experienced by the person. In the first instance, we need to understand what might fall in and out of the self-directed basket of services available from which a consumer can choose.

Note: So as to make clear to those reading MHCC's submission we firstly identify the Rule and Questions prior to providing comment.

Rule

1. The rule may prescribe matters for and in relation to this chapter (relating to the types of assistance for people with disability provided by the Agency). (Clause 17)

Question

A. What sorts of general information and referral services should the Agency provide for people with disability who approach the NDIS?

The question is problematic because of insufficient clarity surrounding the process or sequence of information provision, assessment, and referral. However, we propose that general information should be available to everyone in the community in the first instance. This may mean that a person seeking initial information is not the person seeking to become a participant, but a carer, service provider or support worker. The first point of call may well be when a person asks how they can initiate a request to access the NDIS for themselves or on behalf of someone else.

Initial information is likely best presented through the existing services and suppliers that a person with a disability already engages with, e.g. Centrelink; primary health care; mental health and other psychosocial/disability services, guardianship and trustee tribunals, etc. Information is necessary concerning eligibility criteria and breadth of services that may be considered for access as well as pathways to planning, approval of plans and methods of payment (direct or self-administered) may be structured. Those accessing services are likely to want to know whether they will be able to self-manage the package or what other methods are available.

Information must also be available concerning supported decision-making and how assistance can be accessed by people unable to undertake their own application. If necessary, they should be referred to supported decision-making processes, and offered a variety of delivery models including in person, by phone, or through home visit arrangements.

Once referred to the agency providing an assessment, a person should have access to a broad range of information concerning services in their area across the taxonomy of service types; direct contact details and information on which services are accredited or are providing informal services. Information should also be available that makes clear which services are considered mainstream or accessible outside of the NDIS. The local agency coordinating the information and referral processes should be able to provide a wide range of information on the services available in the area.

On the basis that many people eligible for the NDIS will currently be engaged with Centrelink and other mainstream health and mental health services, and may be known to a diversity of agencies (e.g. housing) these people should be informed about application processes for the NDIS from wherever they are already connected. The concept of 'No Wrong Door' should be applicable to access to the NDIS.

What is unclear at the moment is at what point an assessment will occur, and whether the assessment is related to the service, or to the disability.

The Agency should provide alternative methods of receiving information including visiting the local agency, being visited at home, online resources, or written information in brail or otherwise accommodating to a range of access difficulty.

Question

B. What guidance should the rules provide the Agency about how to support people in referring them to community or mainstream supports, or to other support systems?

What is unclear is whether this question refers to support for people once they have been assessed relating to a formal referral, or whether this is generalised information. Whilst the Agency is clearly responsible for people who have been assessed as eligible for the NDIS, they also have responsibility prior to assessment for people that may later be deemed ineligible.

There has to be a process in place to enable the Agency to ascertain the level and kind of support a person requires, including whether a person requires supported decision-making support, so that they can then be referred to a person who can assist them .

The Agency should also be able to advise people about how informal supports may be funded under the NDIS.

Question

C. What guidance should the rules provide the Agency about funding of persons or organisations so that those persons or organisations may assist people with disability to realise their potential, and participate in, all areas of life?

Guidance to the Agency must relate to services not currently available through mainstream and other service support systems. It should include lists of more generalised, broad based services in the location and rules concerning self-managed funds and choice of services.

The rules would need to provide the breadth of service provision within the area that the Agency can refer to that are outside of what are considered mainstream services, for example creative pursuits or community based services that are on offer to the general public.

Funding rules should have sufficient flexibility built in so that the Agency can fund a service that is highly sought after with large waiting lists.

It is important that at all points of inquiry or entry that people are aware of supported decision-making assistance available to them should they require support.

Rule

2. Age requirements for specific locations within Australia during launch. Clause 22(1)(2)

Question

D. Should the rule also set out the types of information the Agency will need to establish that a person meets the age requirements?

Comment on this section

The consultation paper states that in becoming a participant (p. 7) the legislation sets out the criteria which will be used to decide who will be eligible to receive support from the NDIS and become a participant in the scheme. In fact what the legislation sets out is the criteria for assessment and not confirmed participation. It is misleading to suggest that that the criteria stated in the legislation leads to automatic participation. It would appear that in the first stage, criteria relates to eligibility for entry (age and residence), thereafter assessment for support needs whilst conducting NDIS assessment process for a package/plan.

MHCC recommend that a variety of documents be specified to choose from to establish age including: a birth certificate, passport, permanent residency, citizenship, drivers licence, & disability support pension card, Medicare card, identity document (if the Agency can access birth dates from those data bases) . If there are some concerns regarding identity, the documents required would need to be those that provide a photo ID.

With regards to people who have no fixed abode, or have no access to documentation, inclusion criteria on the basis of age could be determined by an affidavit or Centrelink data.

Rules

3. What alternative or additional criteria may be used to determine that someone is resident in a launch site. Clause 23(1)(c).
4. On what date or date in a time period should a person need to be living in a launch location to be considered a resident Clause 23(3)(a)
5. How long a person may need to have lived in a particular location to be considered a resident. Clause (23) (3)(b)
6. Whether a person needs to continue to live in a launch site to be considered a resident. Clause 23(3)(c)

Question

E. What factors should be taken in to account in deciding whether a person meets the residence requirements? What types of evidence are appropriate to determine if a person meets the residence requirements?

- We propose that proof of property ownership, a tenancy agreement and utility bills be accepted as confirmation of residence in a launch site.
- A person should reside in a launch location for 3 months to be considered a resident of the launch site.
- We propose that a person should have lived in a particular address for one week provided they have lived in the launch location for 3 months.
- A person must continue to live in a launch site to be considered a resident.
- Where people are residing informally on an ongoing basis, e.g. at a friend's house or a shelter for example, a letter from the person or organisation concerned should suffice.

Question

F. What boundary issues between launch and non-launch locations are likely to arise and how could these be resolved in developing the rules?

We suggest that the boundary issue most likely to arise will be in relation to people on the border of a launch site who feel that they are being discriminated against based on lack of access and equity. These people should be afforded information and referral to mainstream services where possible.

Another difficulty might present itself where people are accessing services that operate within the launch site, but live outside of the launch site. These people cannot fairly be denied the service. We propose that on that basis, they should continue to have access.

Equally a problem may arise when a person is living in the launch site is accessing services outside of the launch site and wishes to remain with their service provider of choice. We recommend that these people be allowed to continue accessing that service where possible if preferred, or offered suitable transition to another service.

Rule

7. The time period during which the previously existing supports need to have been received, and the programs under which the previously existing supports need to have been delivered, for a person to meet the access criteria and be eligible for the NDIS. Clause 21(2)(b)

Question

G. What factors should be considered in deciding whether the NDIS should provide continuity of support to someone who has been receiving assistance under other programs

In any circumstance where a person will be negatively impacted, for example potentially losing access to a service they currently engage with because ineligible under the criteria for the NDIS, they should be included in the scheme, unless an alternative referral is available and acceptable to the person.

Rules

8. The criteria to be used to determine that the impairment or impairments are permanent or likely to be permanent. Clause 27(1)(a)
9. The criteria to be applied to determine that one or more impairments substantially reduce a person's functional capacity, or their psychosocial functioning, in relation to one or more activities such as communication, mobility, or self-care. Clause 27(1)(b)
10. The criteria to be considered in assessing whether and to what extent social and economic participation has been affected. Clause 27(1)(c)

Question

H. What criteria/factors should be taken into account in determining whether a person meets the disability requirements?

MHCC propose that the draft eligibility statement makes a good start in attempting to describe the people in scope to receive support funded under a NDIS. However, Item 4: *The impairment /s: a) is permanent or likely to be permanent* – sits uncomfortably in terms of the language favoured by the mental health sector in the context of the person-centred recovery orientated approach to mental health service delivery which is considered best practice. We propose the terminology is replaced by “the condition is permanent or likely to be permanent” in preference.

In terms of the criteria to be taken into account to determine whether a person meets requirements, we propose that a valid disability support pension assessment, a recent medical/psychiatric report together with a global assessment of functioning report, or a guardianship order could be used.

Question

I. Should there be any guidelines on people being able to provide existing assessments to meet the disability requirements?

People should be able to provide existing assessments to meet disability requirements provided they are current within the last 3 months. In the case of a person's assessment following a first episode psychosis for example, provision of an assessment within a 12 month follow up post episode should be considered appropriate.

MHCC raise here the matter of ongoing support under the NDIS for people who have been assessed as eligible on the basis of the potential for early intervention (EI) supports to minimise long-term impacts. We highlight the need for the Rules to clearly define the cut-off points between early intervention and ongoing support under the NDIS, and the safety mechanisms in place to ensure care-coordination/referral to mainstream and other services for these consumers.

Question

J. What should be considered in developing a rule on the types of persons who should conduct assessments?

Persons who conduct assessments should be suitably qualified to undertake a disability assessment within the particular area of disability and have appropriate understanding of the functional/ psychosocial impacts of a disability. For example a worker with extensive knowledge surrounding physical disability may well have no understanding of the lived experience of mental health consumers and their carers.

However, the assessor does not need to be a medical practitioner. In the mental health field a global functioning assessment may be completed by a range of people with mental health skills and training including: OTs, social workers, psychologists, and mental health professionals with Cert 1V and above qualifications. In some circumstances for example, the CANSAS Assessment Tool incorporates separately the views of both users and workers about needs. We would consider it inappropriate for a person without mental health expertise to conduct an assessment for the eligibility of someone with a mental health condition.

Question

K. What should be considered in developing a rule on the kinds of assessments that could be provided or undertaken as part of meeting the disability requirements?

As part of any assessment, a self-assessment must be conducted that incorporates the consumer's perspective. Assessment must include a measure of global functioning that considers psychological, social, and occupational functioning from a perspective that is holistic, person-centred, and recovery-orientated.

An aspect of the assessment process which is unclear to MHCC is how the assessment will relate to a request for service. For example, a consumer may request a service that they consider will dramatically improve their quality of life, e.g. attendance at an art class, acupuncture, Reiki, etc. The assessor may consider that the individual assessed would benefit more from access to a fitness program as their health is somewhat compromised by their medication/ treatment plan. We question how such decisions will ultimately be determined.

Question

L. How can we make sure the rules determine disability on the basis of a functional assessment of what a person can or aspires to do, rather than on the basis of diagnosis?

In order to determine what a person can or aspires to do, rather than on the basis of their diagnosis, a consumer needs to be asked what their needs are and supported to express these if unable to do so autonomously. Assessments should also be strengths-based rather than focussing on deficits.

It is also imperative that people involved in assessments understand that severity does not necessarily correlate with diagnosis. (See last comment to Q K above).

Rules

11. Criteria for determining if early intervention supports are likely to reduce a person's future need for supports in relation to disability. Clause 27(1)(d)
12. The criteria to be considered in assessing whether a support is likely to mitigate, alleviate or prevent of an individual's function capacity to undertake communication, social interaction, learning, mobility, self-care or self-management. Clause (27(1)(e)
13. Criteria for determining if early intervention supports are likely to strengthen the sustainability of the informal supports available to the participant, including through building the capacity of a carer. Clause 27(1)(f)

Question

M. What criteria would be useful for considering the benefits of early intervention for mitigating or preventing deterioration in a person's functional capacity to undertake activities such as mobility, self-care or self-management?

The benefit/s of early intervention in the mental health field is based on a plethora of evidence found in the literature. A person conducting assessments must understand the prognosis, 'risk of harm' and also be able to assist the individual self-determine what supports they believe will assist them. The expectation is that the person making the assessment has the skills and understanding in the domain they are assessing in order to make appropriate judgment.

Some examples of evidence available supporting early intervention in the mental health field are:

- Catania, L., Hetrick, S., Newman, L. & Purcell, R. 2011, 'Prevention and early intervention for mental health problems in 0–25 year olds: Are there evidence-based models of care?' *Advances in Mental Health* 2011, Vol. 10, No. 1: 6–19.
- Victorian Government. 2008. 'Prevention and Early Intervention Ministerial Advisory Sub-committee Report.'
- Birchwood, M., Todd, P. & Jackson, C. 1998, 'Early intervention in psychosis. The critical period hypothesis.' *British Journal of Psychiatry*, 172 (suppl. 33), 53–59.
- Craig, T., Garety, P., Power, P., et al. 2004, 'The Lambeth Early Onset (LEO) Team: randomised controlled trial of the effectiveness of specialised care for early psychosis.' *BMJ*, 329, 1067.

Question

N. How can the support provided by families and other carers be made more sustainable by early intervention?

Support can be provided by offering information, education and training and counselling as well as by helping carers maintain their own lifestyle and employment; have access to respite, financial planning and income support at an early intervention stage rather than allowing situations to deteriorate towards crisis. Carers must have access to the support mechanisms that provide for different stages and levels of care required. Such support can minimise negative outcomes for a carer, and thereby provide better outcomes for a consumer.

Question

O. How should the rules support innovative approaches to early intervention and balance this with the need to get the best outcomes for people with disability and for the scheme to be accountable and sustainable?

This question asks how supporting innovative approaches to early intervention (EI) need to be balanced with best outcomes for people with disability, suggesting that if EI is one of the criteria under the scheme it will impact on numbers of people eligible to access the scheme who already meet the disability criteria.

In the first instance it is important that the scheme support innovative approaches to EI so that people as less likely to develop a permanent condition and become long-term users of services, at greater cost to the individuals themselves and the community at large.

However, to provide for both ends of the disability spectrum is both a financial challenge and politically contentious. Without the funds originally determined by the Productivity Commission as necessary to support the launch of the NDIS scheme (\$3.9M) the scheme is already compromised where a package of only \$1.1M has been allocated.

The likelihood of a change in Government at the next Commonwealth election in September 2013, together with the knowledge that funding provided by the Mining Tax will not meet that obligation, may well lead to a softening of the cross government commitment to broad based service delivery. MHCC fear that the initially determined launch sites for the NDIS might well become pilots that will be used to test the model but might eventually get lost in the cross party discourse of blaming and shaming that is an inevitable part of the changing government discourse.

The second part of this question asks about how the scheme can be accountable and sustainable, is a related but different question altogether. Sustainability is about the funds being available for the services to operate effectively as well as to ensure workforce capacity-building to develop supported decision-making roles and train assessors and service providers delivering occasions of service. Additionally, for the scheme to be accountable, appropriate evaluation and monitoring processes and data gathering need to be established and embedded into the system with the funding mechanisms in place to support ongoing service delivery, research and monitoring activities.

Importantly the system must support innovative approaches that are evaluated and constitute quality improvement strategies for the future. The services delivered must be dynamic and flexibly constructed so as to better respond to the individuals that engage with services otherwise the whole scheme will be rendered moribund before it even gets off the ground.

Questions arise here in the context of NSW as to the oversight and monitoring role of the Ombudsman. The Ombudsman currently has a role auditing services provided by ADHC but not where services are funded by NSW Health. MHCC advocate for an amendment to *the NSW Disability Services Act 1983* that the Ombudsman's role be expanded and likewise that the role of the Official Visitor could be expanded to include CMOs. This obviously will vary across jurisdictions but must be reflected in the rules

Question

P. What criteria should be included in the rules to assist determining if an intervention strengthens the sustainability of informal support?

There are two aspects to this question to be addressed in the rules, determining if an intervention strengthens the sustainability of informal support. One is from the perspective of the consumer receiving the service, and the other is from the perspective of the carer (in relation to the support they receive to undertake their informal support role). An important rule should be that the carer providing informal support is nominated by the consumer/participant or that the consumer has clearly determined their choice in this matter. Where necessary a consumer must be assisted by decision-making support to ensure that they are able to maximise self-determination in the decision as to who provides informal support.

Determining whether an intervention strengthens sustainability may be subjective but by measuring ongoing engagement with this type of support where other services have been offered or might be requested would provide an indication. However, the most conclusive evidence is to determine outcomes from consumer/ carer feedback surveys. This also enables a system of flagging when issues arise that might need to be followed up.

Question

Q. What criteria should be applied to determine 'evidence-based' assessment of the benefits of early intervention?

In the case of assessment of benefits for people with who have been in receipt of EI services, an assessment tool needs to be developed that measures good outcomes from the perspective of the individual receiving the service as well as measuring the individual's health and wellbeing as assessed by their regular health provider/ case manager or support worker.

Rules

14. The methods or criteria for deciding which supports will be funded or provided. Clause 35 (1)(a)
15. The supports that will not be funded or provided under the NDIS. Clause 35(1)(b)
16. The supports that will not be funded or provided under the NDIS for certain participants. Clause 35(1)(c)
17. The methods or criteria for assessing the supports that will be funded may also include methods or criteria relating to the manner in which the supports are to be funded and by whom these supports will be provided. Clause 35(2); 35(3)
18. The methods or criteria for providing supports may also include methods on how to take in to account compensation payments. Clauses 35(4); 35(5)

Questions

R. What methods or criteria should be used to determine those supports that would not be provided or funded by the NDIS, based on the criteria set out in clauses 34 and 35 of the Bill?

We suggest that the NDIS must clearly define what its aims are. The rules consultation paper states that: "People with disability should be able to determine their own best interests, exercise informed choice and engage as equal partners in decisions that will affect their lives, to the fullest extent of their capacity; and address the effect of an impairment or impairments on their capacity to undertake everyday activities, including by enabling them to participate in and contribute to social and economic life to the extent of their ability; and allow them to achieve their goals, objectives and aspirations, to the extent possible." Therefore a person should be able to access a service that will enable them to meet their goals and aspirations even if those goals may be viewed differently by others. For example a consumer may want to access an alternative or spiritual activity or engage in leisure activities, artistic pursuits or sexual activity that may be otherwise unavailable to them because of financial or social limitations, believing that these will be the services that will make a real difference to their health and wellbeing.

MHCC suggest that any activity that is legal and is not assessed as harmful to the individual and which is available and within the limits of the person's individual package allocation should be considered.

We question at this point the assessment of a person's support needs. "These assessments will use a consistent set of tools for identifying a person's needs and any potential risk or need for safeguards. Where people already have existing assessments, including people who are already receiving disability supports under other systems, they may wish to provide those assessments to the Agency." If as the rules suggest the NDIS is more than just about support needs but is about life enhancement, goals and aspirations, the basis on which an assessment tool is developed and used is very different. If the assessment is about the degree to which someone can function in the world and what supports they need to better engage and be more self-supporting, that may be quite different from their goals and aspirations to access services outside of what might be assessed as 'need.'

Question

S. Are there any issues that are not covered by these proposed topics for determining reasonable and necessary supports that should be?

MHCC propose that until the parameters of criteria for inclusion/exclusion of 'supports' are determined that it is difficult to make recommendations concerning the development of assessment tools, or comment on whether the tools that exist are appropriate for the people being assessed with mental health/ psychosocial disability, or can be adapted to fit an aspect of NDIS assessment.

If an individual is assessed against a NDIS tool measuring a person's reasonable and necessary support needs - can this be called self-determining? As we have already stated, this is very different to a consumer identifying what in their view will improve their quality of life and choosing who may supply that service.

Rules

19. Criteria for determining whether a participant managing a matter would present an unreasonable risk to the participant. Clause 44(3)

20. Particular matters within a participant's plan that must not be managed by the participant. Clause 44(2)(b) 18

21. Circumstances which would require a review of a participant's plan to be automatically triggered. Clause 48(6)

Question

T. What criteria should be used by the Agency in deciding whether there is an unreasonable risk for the participant in self-managing funding?

The criteria for determining whether managing a matter would present an unreasonable risk to the participant could be determined by whether they have similar matters already under the management of a Guardian or Trustee, with the option for appeal under the NDIS system.

Since Guardianship or matters determined by the Trustee are decision-specific the capacity assessment must take into account whether the decision or management of a matter is one that a participant lacks capacity to determine or undertake.

Question

U. What flexibility should a person have in making changes to their support arrangements without requiring a review of the plan?

Making changes to support arrangements should be situation specific e.g. whether services that require accreditation (a health service for example) could be transferred to another suitably accredited service type. It is important recognise that if services of a certain type require accreditation that this will narrow the opportunity for consumer choice in some instances.

Question

V. What circumstances should trigger an automatic review of a person's plan?

- A review should be conducted if the consumer wishes to alter the type of support provided.
- Set periodic review times.
- Notification of a complaint or changes to service offering, e.g. place, provider etc.
- Change in consumer circumstance/s.
- Where other mandatory service providers have offered input concerning changes to consumer's treatment plan (under a CTO) for example
- Requested change to type of support because a consumer has tired of the activity

MHCC comment at this point that a flexible approach is necessary, particularly with regard to cross subsidization where appropriate.

We would welcome clarity surrounding how the HASI program will operate within the NDIS scheme and how referrals might be established both to and from HASI.

Question

W. What matters within a participant's plan must not be managed by the participant?

Matters that relate to the interface between the NDIS and mandatory treatment plans (CTOs) including e.g., visits to community mental health to receive medication, required blood tests, case manager and psychiatrist appointments, compulsory drug and alcohol/rehabilitation etc.

Some people with mental health conditions experience coexisting problems such as substance abuse, gambling and other problems that may exacerbate their difficulties in managing their own financial affairs. This may require that money allocated to a support plan be directed to the service provider rather than the individual taking responsibility for payment.

Whilst the ideal is that consumers manage their own funds related to the NDIS, the additional stress financial problems can create for people with mental health problems must be acknowledged. However, it is important that information and decision-making support for people with regards to budgeting must be high on the agenda for the NDIS Rules so as to maximise consumer autonomy.

Question

X. How can the concept of 'dignity in risk' inform the development of these rules?

Dignity of risk is a term used to describe the right of individuals to choose to take some risk whilst engaging in life and is an important concept that mental health service providers should be mindful of. It is essential that people with mental health conditions are not overprotected, or coerced into care and treatment.

Following a diagnosis many people feel or are subject to negative attitudes concerning their capacity to function autonomously and be self-directing. In the process of receiving treatment they frequently are deemed to have given up their 'right' to make risky or potentially self-defeating choices without intervention from authorities, clinicians, service providers or family members wishing to protect them.

Every endeavour has an element of risk, and every opportunity for growth carries with it the potential for failure. All people learn through a process of trial and error, often learning as much from their mistakes as from their successes. When people living with a mental illness are denied the dignity of risk, they are being denied the opportunity to learn and recover. Dignity of risk places an emphasis on personal choice and self-determination - two concepts central to 'recovery'.

Anthony (2000)ⁱⁱ states: the notion that one has options from which to choose is often more important than the particular option one initially selects. Likewise Deagon (1996)ⁱⁱⁱ writes: Self-determination, or taking responsibility for one's own recovery, is the core component of recovery. Part of that responsibility involves the self-management of wellness and medication, autonomy in one's life choices and the willingness to take informed and planned risks in order to grow.

What keeps us from encouraging people to make choices? What stops us from allowing people living with a mental illness the dignity of risk? One of the biggest barriers is fear of the unknown, and the legal ramifications of failure. Mental health service providers are often concerned that if a consumer takes a risk and fails that it implies they are failing in their duty of care. We need to encourage workers to see the positives in risk and allow consumers to take control for their choices and actions. Failure can be used as a learning opportunity and supporting people through failure can assist them to develop resilience.

Hope is central to recovery. Every choice involves both the possibility of failure or success. Paternalism can lead to learned helplessness, which is often more debilitating and disabling than any illness itself (Petersen, Maier & Seligman, 1995).^{iv} By supporting dignity of risk and encouraging people to make choices and take chances, service providers help to combat learned helplessness and bolster self-esteem, self-respect, empowerment, hope and support recovery.

The development of rules for the NDIS must minimise interference in people's decisions. The rules must identify what the risk is and for who and must be based on what is acceptable for the community in general i.e., normal expectations in terms of making decisions for people without disability as opposed to substituted decision-making except where lack of capacity has been established. Nevertheless, supportive decision-making processes must be utilised to maximise autonomy.

Rules

22. Prescribing State or Territory laws under which a person would not be required to provide information to the Agency. Clause 58(2)
23. Making provision for the Agency to disclose information in the public interest. Clause 66(2)
24. Making provision for the Agency's CEO to disclose information to the head of a Commonwealth or State or Territory authority. Clause 67

Questions

Y. Under what circumstances would you consider it reasonable for the CEO of the Agency to disclose information to a Commonwealth or state or territory authority?

- De-identified data collection/ reporting.
- De-identified evaluation/outcome measurement.

- With consent from the service user for research purposes, publications and presentations.
- Complaints, legal proceedings, subpoenas.

Question

Z. Are there any other protections for information that are not covered?

There are several protections that have not been identified:

- Participant consent forms and protocols in the Rules
- Nominee or Guardian consent forms and protocols in the Rules
- Issues around mandatory reporting e.g. criminal issues or risk of harm to self or other
- Complaints mechanisms to be identified
- Appeals processes.

Question

AA. How do we strike the right balance between making sure people don't have to repeat their story and personal information, and making sure people's' privacy is respected at all times?

MHCC suggest that there are two separate issues posed in this question:

1. A service user having to repeat their story and provide information rather than the Agency accessing information already gathered by an existing or previous service provider /agency can only occur if the consumer or nominated substitute decision-maker provides consent to information being made available, and that the information sought is specific to the information required, rather than blanket access to all personal/health related/ criminal history.

2. During any communication, information retrieval and information sharing, privacy must be respected at all times. Staff whose responsibilities touch on these matters must have knowledge and understanding of the relevant national and state legislation such as:

- NSW Health Records and Information Privacy Act 2002
- NSW Privacy and Personal Information Protection Act 1998
- NSW Mental Health Act 2007
- Cth Privacy Act 1988
- Cth The Healthcare Identifiers Act 2010
- Cth Personally Controlled Electronic Health Records Act 2012

Staff must practice ethically and workplace orientation must include education and training that covers matters concerning information sharing and maintenance of appropriate boundaries around information sharing.

Rules

25. Criteria for registering or revoking the registration of a service provider to deliver supports or a class of supports, including whether compliance with safeguards or quality assurance standards and procedures or qualifications of employees is required. Clauses 70(1)(d); 72; 73(1)

26. Prescribing the consequences of registered providers failing to comply with the NDIS Act, regulations or rules. Clause 73(2)(a)

27. The requirements for registered providers including governance, business and accounting practice. Clause 73(2)(b)

28. The obligations of registered providers in relation to the monitoring of compliance, complaints handling and auditing requirements. Clauses 73(2)(c); 73(2)(d); 73(2)(e)

Question

BB. What would be appropriate criteria for registering a service provider to deliver different types of supports?

Any registered service provider in the disability /health sector/s will be subject to state or government quality management standards, key performance indicators and accreditation processes. They may also require specific qualifications for their workforce according to the roles undertaken. There will be no 'one-size fits all' registering mechanism applicable.

Service providers must be able to demonstrate quality standards (WH& S) and accreditation is a clear way to understand that a service has the capacity to provide a service. However, this may limit consumer choice where they judge their needs may be better met by a service that does not normally undergo accreditation. For example a consumer may wish to access a massage provider rather than a physiotherapist, or chiropractor in their local area because they know and trust them. There must be mechanisms within the NDIS assessment processes to ensure that the Agency fairly determines who is an appropriate provider for the individual concerned.

Where some difficulty arises is in services which provide more informal support and in the area of personal care services, and where the participant self-selects an informal carer.

We assume that it will be necessary that those providing formal or informal support complete the normal police/criminal/ working with children checks and other formalities considered appropriate to their role.

MHCC understand that in terms of guardianship a criminal check is not an automatic part of the nomination process - the Tribunal will not investigate criminal history. However, it is possible for a party to present any information that they see as relevant to the decision (i.e. existing criminal record) which will then be taken into account and may influence the decision. It is entirely up to those involved to present information they deem as relevant.

Question

CC. How can the Scheme ensure that providers don't have to go through a lot of red tape, while also ensuring that services are of a standard and quality to best support people with disability?

It is necessary that providers conduct appropriate quality assurance processes / accreditation processes for health and personal care in order to ensure best practice.

Providers of informal services that are offered generally to the community would be subject to the appropriate WH & S standards and oversight as appropriate to that service as generally provided in the community. For example a person/ business providing a fitness class would be expected to have appropriate qualifications and suitably approved premises to undertake that function. However, they may for example not be able to offer certain disability access features.

Question

DD. What registration information should the agency collect from registered providers of supports that will promote the policy objectives of the NDIS Act to enable people with disability to exercise choice and control?

This depends on the type of service or support that is being provided. Any registered service accessed under the NDIS must provide information in relation to data gathering, process and outcome evaluation, and importantly gather information that records user evaluations.

Registered providers should also provide evidence of their capacity to support decision-making processes to maximise consumer self-determination.

All aspects of a registered service should be transparent so that consumers can assess information concerning and organisations governance structures, insurance and WH&S policy, quality management and fees for service/s.

Question

EE. What registration information should the agency collect from registered providers of supports that will build data for public evidence based decision making?

Dependent on the service provision type, information may concern affiliation to industry or professional associations, workforce accreditation or qualifications, quality management accreditation, ISO, insurance, funding bodies, complaints mechanisms, legislation, standards and guidelines governing certain organisations' operations, etc.

To build a data base requires data gathering from entry to exit, fee structures and consumer/ carer evaluation of service delivery.

NOTE: MHCC is not addressing the questions in Rules 29-33.

Rules

- 34. Criteria to be considered in deciding to appoint a nominee. Clause 88(6)(b)
- 35. Requirements and matters to consider in the appointment, suspension or cancellation of nominees. Clauses 93(a); 93(b)
- 36. Prescribe who must not be appointed as a nominee. Clause 88(6)(a)
- 37. Prescribing additional duties of nominees to support decision making by the participant personally or to give appropriate weight to the participant's views. Clauses 80(4)(a); 80(4)(b)

Question

FF. What criteria should guide the decision to appoint a nominee?

- Substitute decision-maker assessed as necessary (decision-specific) maximising supported decision-making processes
- Existing nominated carer or guardian in place
- User consent
- Advance directives

Note: The NDIS rules will need to take account of differing arrangements for assisted or substituted decision making across State and Territory jurisdictions.

Question

GG. What criteria should be used to select an appropriate nominee?

- Consumer choice and consent
- Advance directives
- Capacity of nominee to undertake the role
- Note – peer workforce must be recognised and valued

Question

HH. How can a nominee demonstrate thorough knowledge and understanding of the participant's wishes, goals and life aspirations?

- Advance directives
- Previous history and knowledge of consumer choice and what has been beneficial in the past
- Close personal relationship to consumer
- Knowledge of wishes, consumer goals and aspirations recorded in another support plan

Question

II. How can we test that the decisions of a nominee are reasonably those the person would have made if they had the capacity to do so?

- There should be more emphasis on how to support people to maximise capacity, rather than how to manage a situation when they are deemed not to have capacity
- The whole framework needs to be strengths based/ focused

- Decision making seems to be understood as having capacity or not, rather than on a continuum with an emphasis on supporting people to make decisions where possible

Question

JJ. What should be in place to allow these arrangements to change?

- Consumer request
- Nominee availability
- Service access
- Change of consumer circumstances

Question

KK. Who should not be appointed as a nominee?

- A person the consumer has rejected as a potential nominee
- A person the consumer has complained about who was a nominee in the past
- A service provider
- A nominee with any conflict of interest
- Someone with potential financial gain, or financial interest in particular services being used
- Someone who makes it clear they do not have the capacity to undertake the role
- Someone with a criminal record

Question

LL. Other than duties to support decision making by the participant personally or to give appropriate weight to the participant's views, what additional duties should be prescribed to nominees?

- General information provision and support in accessing information
- Keeping the consumer's support network informed where appropriate
- Assisting with paperwork where required
- A nominee **SHOULD NOT** be made responsible for advocacy this should be a separate service accessible to the consumer

Question

MM. Should the appointment of nominees be for a fixed period or should there be a regular review of the arrangements to ensure the person with disability is satisfied with their nominee arrangements?

- There should be a fixed period for review of a nominee's role which should involve consumer feedback and evaluation of role provided
- Where necessary support must be provided to assist a consumer make their wishes and feedback understood

Question

NN. How can we ensure that the nominee arrangements continue to build the decision making capacity of people with a disability.

- Education and information provision, helplines, and nominee training and support

Rules

38. The treatment of compensation payments in determining reasonable and necessary supports provided by the NDIS. Clause 35(4)(5)

39. Criteria for taking into account other amounts that a participant (or prospective participant) did not receive by way of compensation payments because they entered into an agreement to give up their right to compensation. Clause 35(5)

40. The Commonwealth, State or Territory laws to be set out in the NDIS rules that need to be considered in determining what if any, past NDIS payments can be recovered from a compensation payment made after the NDIS amounts were paid. Clause 106(5)(b)(iv)

Question

OO. How should compensation payments for care and support be treated in working out how much care and support should be provided by the NDIS?

- The amount of care and support provided by the NDIS should be in direct relationship to a compensation payment. That is that a person eligible under the NDIS should not be able to 'double dip.'
- If a compensation payment is less than what would otherwise be available to a consumer under the NDIS, the unmet balance should be made available to the eligible person under the NDIS.

Additional Comment

- If under the NDIS any general asset test is applied, this should only be based on individual assets **NOT** including primary dwelling and **NOT** including the assets of a family/parental/partner.
- Information concerning the NDIS should be made available to people transitioning out of the criminal justice system (CJS). Referral should be part of release / discharge processes. Centrelink and court-based programs should act as information providers, as well as Community Visitors, the Public Guardian, Ombudsman, Public Advocate, Official Visitors etc.
- Supported decision-making processes must be made available to assist people exiting the CJS so as to assist them with referral post release/discharge.

- Eligibility for the NDIS should not cease as a consequence of a person entering the criminal justice system. Corrections and Justice Health do not provide specialist disability services in goal and a person should be able to access a number of services in goal. They also should not have to make another application on exiting gaol and reapply if already assessed.
- People referred to post release services run by government departments such as the Justice Health Connections Program, and NSW Interagency Support Program (ISP) should be points of referral to the NDIS.
- MHCC are interested to understand how the ISP program in NSW would operate in the context of the NDIS. The ISP is currently funded by ADHC but offers intense support plans to people with complex needs often with mental health, co-existing substance abuse, and co-occurring disability such as cognitive or ABI problems. How this program might transition from ADHC to a NDIS self-determining package when most generally ISP clients are compulsorily cared for seems highly problematic.

MHCC thanks the Department for the opportunity to provide comment to this inquiry and would welcome any questions concerning this submission and any other aspects of the NDIS to be directed to Corinne Henderson, Senior Policy Officer at E: corinne@mhcc.org.au or T: 02 9555 8388 #101.

Yours sincerely,



Jenna Bateman
Chief Executive Officer

ⁱ National Standards for Mental Health Services. 2010. Principles of recovery oriented mental health practice. Commonwealth Government. Available: [http://www.health.gov.au/internet/main/publishing.nsf/content/DA71C0838BA6411BCA2577A0001AAC32/\\$File/servpri.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/DA71C0838BA6411BCA2577A0001AAC32/$File/servpri.pdf)

ⁱⁱ Anthony, W. 2000, A Recovery oriented service system: Setting some system level standards. *Psychiatric Rehabilitation Journal*, 24(2), 159-168.

ⁱⁱⁱ Deegan, P. 1996, Recovery as a journey of the heart. *Psychiatric Rehabilitation Journal*, 11, 11-19.

^{iv} Petersen, C., Maier, S.F., Seligman, M.E.P. 1995, Learned Helplessness: A Theory for the Age of Personal Control. *New York: Oxford University Press*. p 241-242.