Independent functional assessment for NDIS participants with psychosocial disability

August 26, 2020

Preamble

Instead of only relying on diagnostic assessments, assessing functionality has the potential to be beneficial, but only if:

- (a) Independent functional assessments (IFA) are conducted by adequately trained staff,
- (b) They are voluntary and flexible to meet the needs of the participants
- (c) Assessments are done in a considered manner as part of a comprehensive set of measures aimed at improving the lives of participants

Following is the feedback from the State/Territory Mental Health Peaks on this issue.

Summary of the feedback

The various peaks are in general agreement with their views on the IFAs.

- 1. Impact IFA on people with Psychosocial Disability (PSD)
 - Prior to an assessment taking time before an assessment to develop a trust relation is very important as the nature of the PSD can make it hard for a participant to open up to a stranger.
 - The pressure of the significance of the IFA can trigger the participant with a potential for disengagement.
- 2. Quality of the assessor
 - highly skilled and experienced assessor,
 - Trauma-informed and recovery focussed
 - Cultural aware
 - Proper remuneration and training opportunities are essential
- 3. Quality of the assessment
 - Cultural appropriate.
 - Relevant for people with PSD, an assessment tool(s) that works for people with PSD
 - Adequate time allocated for an assessment and processing,
 - three hours is not enough to assess the often complex needs of people with PSD and write a comprehensive report.
 - Ten hours turn around not feasible
 - o Ability to spread the assessment of multiple days to accommodate the participant
 - Availability of skilled assessors, especially in remote and rural areas
- 4. Other
 - There is a strong argument against making IFA mandatory to avoid disadvantaging people with PSD

- The planned roll-out of IFA over the next 3 years will be of high cost;
 - o Could that money not be invested in service delivery?
 - Is there a need for an additional assessment? Can this not be done by the treatment team of the participant?
- Will the funding be adequate?
 - o To engage highly skilled assessors?
 - o What will be the out of pocket costs for participants?
 - Will there be sufficient funding to enable participants to attend the assessment, especially for people living in remote areas?
 - o Will clinical/medical staff be part of the assessment? If so, who will refund them?
- How independent will the assessors be, if they represent the NDIS?
- Limited information on the impact of IFA on People with PSD
 - o Only 7% of the pilot were people with PSD
 - o No specific details on the outcomes for this cohort
- Concern that more people will fall out of the NDIS and end up in the already stretched state system

Of relevance is Chapter 4 of the <u>David Tune Report</u>: Evidence to support decision making and the MHCT report <u>Removing barriers on testing for the NDIS</u>, 2020.

Collated detailed feedback

Mental Health Victoria

- Receiving a compulsory functional assessment from someone who does not know the
 person well may not provide accurate evidence of the individual's functional capacity and
 associated disability support needs.
 - People with Psychosocial Disability often report that a trusted relationship built up over time is essential in building trust and allowing for open conversation about their past and present mental health challenges. If assessments are done by someone whom the person has no prior relationship with, there is not only a risk that the assessment won't be accurate, but a risk that the person undergoing the assessment may be adversely effected by the experience of being "assessed" by someone they have never met.
 - If the assessment is for the purposes of NDIS access, this is already fraught with anxiety for many people. Being assessed for access by someone unknown to the participant can only add to this anxiety.
 - 3 hours for the assessment and the report is not adequate to allow for: communication around and collection of previous reports and background information on the client; reading the information provided; rapport building; a thorough assessment session/s (more than one is probably necessary) and a report detailed enough to provide benefit to the participant in service planning and support provision.
- There may be a cohort of people who due to complexity/distrust of government agencies refuse to undertake the assessment and thereby are not be able to gain access to the NDIS.
 - If access to the NDIS is reliant on this assessment it will certainly be a barrier to many people who may be eligible but who refuse the assessment.
- People who should be eligible for the NDIS may be denied access or have their plans reduced, resulting in service gaps and increased demand and pressures on Victoria's mental health system.
 - As it stands, the assessment is not pitched or aimed at enhancing supports for people with psychosocial disability, but more so as a gateway for access.
 - o If people who are eligible for NDIS supports do not make it through this 'gateway' it will fall to the state mental health and health system to support them.
- Further demand will be placed on clinical services who may be required to provide clinical information/ treatment history as evidence for the assessments.
 - For an assessment to be comprehensive and as accurate as possible the assessor should be seeking detailed background information on the client and their interactions with past services – this places demands on other parts of the system without a funding plan to support this demand.
- Where is the stated role of carers and family members in this process?

Functional assessments may be useful for providers of NDIS supports if they:

Are done voluntarily by the participant with transparency of their use and aims

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- Are not done for the purposes of access to the Scheme or ongoing access to the Scheme, but to enhance understanding of a participant's needs and supports.
- Are done with an outcome that will benefit the participant (i.e. for improved service planning)
- Are done by professionals with skills, qualifications and experience in mental health and psychosocial disability.
- Are done comprehensively considering the input of the client / participant; carers and family (with consent); previous clinicians and support workers (with consent)
- Are done having built trust and rapport with the participant
- Consider and make recommendations not only around NDIS supports but for other services or supports outside of the NDIS
- Are shared (with consent) with NDIS service providers to enable better service planning and provision

Mental Health Council of Tasmania

- In December 2019/January 2020, MHCT conducted a consultation with consumers in regards to
 the barriers to applying for the NDIS. Barriers included costs, access to health professionals to
 gain evidence and the ambiguity between disability and recovery. Findings from the report may
 also be relevant to the barriers for utilising an IFA approach.
 http://mhct.org/wp-content/uploads/2020/02/MHCT-Removing-Barriers-to-Testing-for-the-NDIS-31012020.pdf
- A standardised approach to assessing NDIS applications would be beneficial in terms of consistency in decision making within the NDIA and potentially in the development of plans. However, in selecting an IFA approach there are several issues that would need to be addressed:
- What are the out of pocket expenses for the assessment? Particularly if the IFAs are mandatory in testing eligibility to the NDIS. The costs involved would be a significant barrier for consumers.
- Allied health workers appear to be the targeted workforce that may tender for the assessment
 work. In Tasmania we have significantly lengthy waitlists to access allied health services such as an
 OT. That is on top of finding an OT or other allied health professional that is registered via the
 NDIS to make these assessments.
- How will IFAs address the concept of recovery and the episodic nature of psychosocial disability?
 MHCT has heard that when consumers are collating evidence to apply for the NDIS, they are told
 to describe their 'worst day', which can be a depleting experience. Work would need to be
 undertaken to identify particular assessments that are relevant to the episodic nature of
 psychosocial disability.
- MHCT has heard that it takes time to collate evidence along with retelling the person's story. How would the assessment take into consideration a trauma informed approach?
- The trial of IFAs only included 7% of people with psychosocial disability, it would be helpful firstly to understand the outcomes from the pilot of that particular cohort. But also recognising that 7% is a very small sample size. It may be advisable to undertake a larger trial of IFAs for people with psychosocial disability before making any decisions about mandatory IFAs.

Northern Territory Mental Health Coalition

In proposing an assessment system involving a functional capacity assessment process, David Tune (2018 https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf Chapter 4) identifies that potential disengagement (i.e. refusal to interact with NDIA-approved providers) is a high risk for those with a psychosocial disability, particularly among Aboriginal and Torres Strait Islander and CALD backgrounds. We also believe those most severely impacted by mental illness are at risk.

Tune argues that the NDIA-approved panel of assessors must be sufficient to mitigate engagement risks, and other issues relevant in specific locations, communities or for particular disability types. He concedes that it may not always be possible to source an appropriate provider, or there may be individual circumstances where it is more appropriate for non-NDIA providers to undertake assessments. We also believe there should be a mechanism for people to be granted exemptions from participating in functional assessments if they are made compulsory. Otherwise people are at risk of losing the support that they are entitled to due to the very nature of their illness or their cultural background – either of which is discriminatory.

It seems likely that potential (and existing) NDIS participants in the NT (and other remote areas) with psychosocial disability are more likely to fall into Tune's 'at risk' category than in other regions of Australia. A higher proportion of the NT population is Aboriginal and Torres Strait Islander than elsewhere and nationally (25.5% vs 2.8%, 2016 ABS Census).

When assessing the FAQ relating to the pilot, we could see the LSP-16 and Vinelands 3 where the most likely instruments used for functional assessments of people with psychosocial disability. We have concerns in regard to the cultural appropriateness of questions. For example, from the LSP-16

- "Does this person wear clean clothes generally, or ensure that they are cleaned if dirty?"
- "Does this person generally maintain an adequate diet?"
- "Does this person generally have problems (e.g., friction, avoidance) living with others in the household?"

How might these questions be interpreted in a remote context where people live in overcrowded housing with a large number of adults in a 3-bedroom house and food security cannot be assured. The questions are not necessarily appropriate and are open to the assessor's own bias, especially when assessing within a cultural context.

Culturally safe and trauma-informed practice for all people with a psychosocial disability requires potential/existing participants to interact with assessors that they are familiar with, and to have the option of being supported by family, carers and people who have good knowledge of their care needs. The assumption that this can be achieved in 2.5 to 3 hours is unrealistic.

The approach of using a national panel of independent and appropriately skilled and qualified assessors is likely to cause disadvantage to people in the NT. It is therefore important that this scheme does not become mandatory, and that the voluntary arrangements to be in place from October are rigorously evaluated, particularly in a cultural and remote context.

The evaluation should also take into account local market structures. NT service providers in regional and remote areas are struggling to provide services at the prices set in the NDIS Price Guide. Barriers to entry are high as a result of a low value of funding flowing into regions, the diverse needs of participants, large distances, and the scarcity of appropriately trained workers (especially mental health professionals).

For example the population of Katherine is approximately 10,000 people and there is no bulk billing GP for people to even generate a mental health care plan. There is an Aboriginal Community Control Health Service, but this service is for Aboriginal and Torres Strait Islander people only. It is worth noting that Aboriginal Medical Services have largely not engaged with the NDIS. It's difficult to imagine how

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'independent' assessment services will be found in regions like Katherine when there are already thin NDIS markets and a scarcity of health service providers.

Finally, compulsory assessment prior to plan reviews or even as part of access requests may be extremely problematic for people who are the most functionally impacted by their illness. We believe an individual's insight into their illness and their preparedness to interact with people they don't know are both likely to be diminished with the severity of a person's illness.

A well individual may not have full insight into how significant their functional impact is when they are unwell and may not be able to respond as realistically as a family member or support worker who has supported them while unwell. There will be people who will potentially disengage from the scheme entirely instead of having to do an assessment with someone they do not know or trust. See two case studies below.

Case Study 1: Person gives carer consent to make NDIS access request after 2 years of discussion and refusal. Consent is provided only 2 months before state government supports cease as part of the NDIS roll out. Carer does all liaison with acute mental health services who have provided services for 15 years. Person is too unwell to have ever engaged with a psychosocial provider even though fully treated (has high level of paranoia, persistent hallucinations and delusions, high anxiety and communicates with only a handful of people, will kick family out of house when overwhelmed). This person accessed the NDIS and was able to transition previously state funded supports into the NDIS without ever speaking to the NDIS. The persons carer completes all NDIS Plan reviews and orchestrates services. They would not participate in a compulsory Independent Functional Assessment.

Case Study 2: Person experiences persistent religious delusions and frequently articulates being rewarded by god in the near future as part of delusions. If feeling uncomfortable about participating in an upcoming IFA, the person would self-exclude, justifying that the assessment is not necessary because they will be very wealthy in the near future and won't need their NDIS supports.

Mental Health Coordinating Council (NSW)

There are four main issues on which feedback is being sought:

1. The impact of IFAs on people with psychosocial disability

- The IFA represents another hoop that a person with psychosocial disability (PWPD) will need to navigate
- Distrust of government services may pose a barrier to a person agreeing to undertake the
 assessment, this may lead to them not receiving services, when they clearly would otherwise
 be eligible
- People who would otherwise be receiving services would likely require enhanced public mental health and human services. This may well lead to increased use of EDs and admissions to MH facilities, and more use of general health and human services
- The process of assessment is 3 hours, undertaken by someone unknown to the PWPD. Having little time to build trust may result in some people not getting the supports they need; or none at all.
- Since presentation may vary because of episodic unwellness, and lower or better functionality, may result in inequities.
- People may feel unduly humiliated by the assessment questions and attempt to answer questions in a way that puts them in a 'less disabled' light. They may lose out as a consequence

2. The impact of IFAs on people who may find it harder to engage with the Scheme or who are vulnerable:

IFAs may result in the following:

- Deterioration in mental and physical health, social and emotional wellbeing
- Further social isolation
- Risk of homelessness
- Reduced service eligibility will impact on carers and families and result in increased pressure in other parts of the system
- Relationship and financial pressures
- 3. The assessment tools:
 - A range of assessment tools should be considered
 - None listed are necessarily appropriate for people with a psychosocial disability **see list below of assessment tools (Proms & Prems)**
- 4. The assessment process:
 - The time will not allow for adequate assessment of paperwork, reports as well as engaging with the person, who may well be distressed by this process.

Other comments:

- The cost of 527,000 assessments over 3 years will be significant. Could these funds be better spent on actual service delivery?
- Would like to see an actual example of an assessment for a person with a psychosocial disability
- If the aim of this initiative is to meaningfully improve access to and appropriateness of packages, the assessment will need to be:
 - Voluntary
 - Clearly intentioned to benefit the person and assist a better understanding of their needs, care coordination and planning, rather than a method of reducing access
 - o An effective appeals process that supports a person make presentations when refused
 - A diversity of well qualified assessors with expertise in mental health conditions and living with psychosocial disability and coexisting conditions; and a thorough understanding of trauma and its impacts on people across the lifespan
 - o A comprehensive assessment undertaken with a person's chosen support persons, carers and family
 - The time frame of the assessment to be gauged according to the needs and capacity of the person. Some people may require several meetings to build trust, create safety and be able to tolerate the process
- Will IFAs reduce the need to collect and present other evidence in order to access the scheme?
 Many participants have raised the difficulty and expense of collecting the necessary evidence to access the scheme.

Patient Reported Outcome Measures (PROMs)

- CANSAS Clinician completed. The adult Camberwell Assessment of Need (CAN) is used to
 understand the health and social needs of adults who have severe mental health problems. It
 covers 22 domains of life, such as accommodation, food, self-care, daytime activities, psychotic
 symptoms, childcare, money, psychological distress, physical health and relationships.
- LCQ Clinician completed. The Living in the Community Scale is designed to measure social inclusion of consumers in five areas: participation in employment by people with mental illness of working age; participation in education and employment by people aged 16-30 who have a mental illness; community; participation more broadly; stability of housing; and access to a GP.
- HONOS –The Health of the Nation Outcome Scales (HoNOS) is a clinician rated instrument comprising 12 simple scales measuring behaviour, impairment, symptoms and social functioning for those in the 18 64 years old age group.
- LSP16 is a clinician tool which assesses basic life skills and general functioning.
- VI SPADAT a coordinated assessment to more efficiently allocate scarce housing resources based on the support service needs of single adults, youth, and families experiencing homelessness. It is an assessment of their mental health, medical, and social vulnerabilities. Based on scores, individuals are triaged to housing services offering varying levels of support services, and centralised waitlists for housing resources in the community are prioritised accordingly.
- K10 The K10 is a self-report measure of psychological distress based on the previous 4 weeks.
- PQ9 Self reported. The PHQ-9 is a multipurpose instrument for screening, diagnosing, monitoring and measuring the severity of depression: It incorporates DSM-IV depression diagnostic criteria with other leading major depressive symptoms into a brief self-report tool.
- Lifestyle Plan Clinician completed The Life Skills Profile 16 (LSP 16) assesses a consumer's abilities with respect to basic life skills. Its focus is on the consumer's general functioning and disability rather than their clinical symptoms.
- WSAS Self- Reported. The Weinberg Screen Affective Scale (WSAS) is designed to screen for symptoms of depression in children and young adults ages 5–21. It can be used as an initial treatment scale and can be used to follow up on treatment efficacy.
- The Recovery Star is a consumer completed outcomes measure which enables people using services to measure their own recovery progress, with the help of mental health workers or others. The 'star' contains ten areas covering the main aspects of people's lives, including living skills, relationships, work and identity and self-esteem. Service users set their personal goals within each area and measure over time how far they are progressing towards these goals. This can help them identify their goals and what support they need to reach them, and ensure they are making progress, however gradual, which itself can encourage hope.
- RAS Regional Assessment Service is a consumer completed Home Support Assessment

Patient Reported Experience Measures (PREMs)

- The BASIS 32 is a consumer rated tool designed to cover a range of symptoms and functioning difficulties experienced by the consumer.
- Process of Recovery (QPR) Tool Co-designed with Consumer
- YES/ CMO Your Experience of Service is a questionnaire designed to gather information from consumers about their experience of care.