Submission to the Joint Standing Committee on the NDIS regarding provision of services under the NDIS for people with psychosocial disabilities.

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February 2017

Introduction

The submission contains three proposals, discussion of the proposals followed by some notes. These are from the perspective of a psycho-social rehabilitation worker, a psychotherapist and someone who has for more than a decade worked with people whose lives have been seriously affected by mental illness (I also bring a broader economic perspective from various executive roles in the commercial sector arising from a forensic accounting background). I make the following proposals in respect to the NDIS:

Proposals

1. That there be a category in the NDIA price list for psycho-social rehabilitation relating to psychosocial disability. Possibly within a support cluster for psycho-social rehabilitation and recovery. (Terms of Reference 1b)

2. That the assessment criteria for clients currently receiving PHaMs (Personal Helpers and Mentors service) support be made transparent and that current uncertainties be removed. (Terms of Reference 1a)

3. That the interface with psycho-social rehabilitation and providers of clinical mental health services become more linked and integrated. (Terms of Reference 1e)

Discussion of Proposal 1

1. **That there be a category in the NDIA price list for psycho-social rehabilitation relating to psychosocial disability. Possibly within a support cluster for psycho-social rehabilitation and recovery. (Terms of Reference 1b)**

PHaMs was carefully designed by looking at some of the most effective mental health services and approaches in Australia and overseas. There are 17 PHaMs units in SA and from early in the inception of these programs the Team Leaders have regularly met together with the funding managers in order to enhance the service delivery. There has been a series of national PHaMs Operational Guidelines that carefully articulate how the service works for people whose life has been seriously affected by a mental illness. The objective of PHaMs is to support these people to increase:

> '*access to appropriate support services at the right time*
> *personal capacity, confidence and self-reliance*
> *the ability to manage daily activities, and*
> *community participation (both social and economic).'*
> Operational Guidelines 2016-17 to 2018-19 page 8

The target groups for PHaMs (70%) include people facing additional disadvantage, such as Indigenous Australians, people with culturally diverse backgrounds, young people and people who are homeless or at risk of homelessness. Eligibility to the service is for people not receiving non-clinical community support similar to PHaMs through state government programs. In SA this would include having an Individual Psychosocial Rehabilitation and Support Services (IPRSS) package. People with an IPRSS package also have a government mental health worker who has a coordinating role; a clinician, who is supported by a multi-disciplinary team including psychiatrists, psychologists, social workers and mental health nurses.

A PHaMs worker in most cases will provide the coordinating role for the participant in order to navigate various other supports such as GP, dental, psychological services, housing support, seeking employment, education/training and often linking with financial support services. This form of service is called psycho-social rehabilitation support. These services operate with a strengths-based recovery-focussed orientation and subscribe to a set of principles that underpin service delivery to PHaMs participants. These are detailed in Attachment A of the Operational Guidelines, and are client centred, that is, the client decides what they want.

The following list of activities that a PHaMs worker attends to will be similar to the tasks that will be required to be provided to the participant once they have a NDIA funded package, ie:

- gather and document the functional limitations utilising the PHaMs Eligibility Screening Tool (EST). This will be relevant to ongoing plans for the participant.

- generate assessments utilising tools such as the Health of the Nation Outcome Scale (HoNOS).

- help participant compete the PHaMs Individual Recovery Plan (example attached as Attachment D from the Operational Guidelines) as the basis for the first NDIA plan and subsequent plans.

- *'support and mentor PHaMs participants to achieve goals in their Individual Recovery Plans, including assisting PHaMs participants to make and attend appointments, manage daily tasks, facilitate transport, address barriers to social and economic participation, secure stable housing, and improve personal, parenting or vocational skill, etc'*

- *Coordinate support and help PHaMs participants navigate the mental health and community sector supports, and*

- *Liaise and work with other stakeholders to make appropriate referrals for people with mental illness.'* (Operational Guidelines page 12 and 13)

What a PHaMs worker *'cannot provide is personal care and domestic help for PHaMs participants, although PHaMs workers may show PHaMs participants how to do things, prompt them to do tasks and help find assistance to undertake tasks they cannot manage themselves.'* (Operational Guidelines page 16)

The funding (cost) for a PHaMs worker is about $70-80 per hour, assuming an 80% worker to participant outcome (which is difficult to achieve), three hours per participant per week and PHaMs target participant numbers. This work is complex, it requires expert supervision and there needs to be a reflective and flexible approaches to participants' needs. The workers in the Adelaide Inner Southern PHaMs team are paid at SACS Level Four . They have a minimum of Cert 1V mental health and most of the team are university graduates.

Currently there is not an appropriate price category for psycho-social rehabilitation support, which would need to be about $70 - 80 per hour for a similar service to PHaMs. Typically, this may translate into an annual NDIA package of $12k per year per participant (three hours per week). In the trial sites for the NDIS, the average in Victoria was $20k and in NSW $30k.

Given that funds from programs such as PHaMs have been designated as 'in-scope' for the current NDIS with price category of about $50 hour, this will lead to significantly inferior services that would not be recovery-focused. The current NDIA rate is based on SAC Level 2, and with a worker to client %

achievement of 85%. This could possibly work for someone coming in to clean or provide basic 'to do for' tasks (domestic support) but would not address what currently PHaMs workers provide to participants. Nor would this approach address the Productivity Commission's target of overall economic benefit if support for people with a mental illness does not address recovery rather than just assistance.

In respect to 'continuity of service' (CoS), this issue is being addressed by the DSS and NDIA in SA, but there is no certainty as to what this will look like. In the *Report of the National Review of Mental Health Programmes and Services, Volume 1 (Contributing lives, thriving communities)* it was noted that:

> *Given that funds from programmes such as Personal Helpers and Mentors (PHaMs) and Partners in Recovery have been designated as "in scope" for the NDIS, if the funding goes into the NDIS and the people do not, then there will be proportionately less funding in the mental health system to achieve the "continuity of service" guarantee to which all governments have committed.* (Main Report page 62)

This represents a significant risk that effective program funding will move to less effective processes for psychosocial disabilities and cross subsidisation to other categories of disability. This will be difficult to monitor as senior executives in various Mental Health Commissions recognise the difficulty of following the money trail for mental health.

Discussion of proposal 2

2. **That the assessment criteria for clients currently receiving PHaMs (Personal Helpers and Mentors service) support be made transparent and that current uncertainties be removed. (Terms of Reference 1a)**

Currently there appears to be considerable uncertainty whether some existing PHaMs participants will be able to successfully access a NDIA package. PHaMs was introduced to provide psycho-social rehabilitation and recovery packages for people whose lives are seriously affected by mental illness having difficulty accessing services. For the purpose of eligibility to receive a PHaMs '*a person with severe mental illness will experience severe functional impairment because of his/her mental illness, denoted by a score of three or more on the functional assessment section in the Eligibly Screening Tool (EST).*' (Operational Guidelines page 25). The guidelines go on to suggest that *'this is generally consistent with the NDIS disability requirements set out in s 24(1) of the NDIA Act'.*

It would be helpful if the NDIA could confirm that PHaMs participants who have correctly met the EST requirement (and the other NDIS criteria) will be able to access an NDIA package which will at a minimum match existing support provided by PHaMs.

It has been suggested that most PHaMs participants will not be eligible for a NDIS package (see below), if this is correct significant on-going funding will be required to ensure continuity of service.

'Personal Helpers and Mentors (PHaMs) and Mental Health Carers Respite (MHC/Respite) are the key Department of Social Services-funded responses designed for the wider group of people dealing with severe mental illness who will not be eligible for the NDIS, and who need intermittent low-to-medium levels of support, from programs designed to be transitional, supporting short to medium term journey to greater independence. Some consumers and carers entering these programs have been found to need the longer term and more intensive supports offered by package in the NDIS, and this will continue to happen. However, with the huge unmet need for these programs, demonstrated by nation-wide waiting lists and low but steadily increasing referral rates from primary health and clinical services, they should be retained at least at the current level of access. Current funding for these programs is in the order of $200 million, which should continue, to ensure no loss of access. The source of these funds should be from outside the NDIS, to ensure adequate resources are available within the NDIS for people who need the more intensive, ongoing supports offered by an IFP. Most providers of PHaMs and MHC/Respite have recently been re-funded for up to three years, with funding tagged to reduce progressively as the NDIS is fully implemented. Given the evidence summarised above, that there will be more unmet need than even full continuation of funding can guarantee, these scaled reductions should be removed from the contracts.'

(Mental Health Australia *Key actions to ensure continued access to community support for people affected by severe mental illness during NDIS transition and beyond* see

https://mhaustralia.org/sites/default/files/docs/draft_position_paper_on_community_support_during_ndis_transition_and_beyond.pdf

Most PHaMs participants have sought help from PHaMs because their functional limitations (resulting from their mental illness) have reached a crisis point. This may be a result of a real risk of becoming homeless, financial emergencies, relational distress and serious suicidal ideation. They may seek PHaMs support because they do not want adult mental health involvement,

which in the past has taken their own control away. Or because adult mental health will not attend to them because their problems have no evident psychosis or delusional thinking associated with the symptoms (axis 1 diagnosis).

Many of these PHaMs participants can be supported to achieving a 'contributing life' within twelve months at a package cost of $12k, followed by a very low level on-going support, particularly if they have access to group activities that can lead to 'normal' community engagement, volunteering or paid work. This common experience is congruent with NDIS (Becoming a Participant) Rules 2016 s 6.5, *'An impairment may be permanent notwithstanding that the severity of its impact on the functional capacity of the person may fluctuate or there are prospects that the severity of the impact of the impairment on the person's functional capacity may improve.'*

Discussion of Proposal 3

3. **That the interface with psycho-social rehabilitation and providers clinical of mental health services become more linked and integrated. (terms of reference 1e)**

It is surprising that after seminal reports like the Burdekin Report (1993) and one of the most recent compressive reviews by Alan Fells et al (2014 *Contributing lives…*) that they have only been implemented in limited and piecemeal ways, sidestepping some of the fundamental recommendations and the need for systemic change. This may be because medical services have been un-willing to embrace psychosocial solutions and focus on pharmaceutical solutions that address clinical symptoms and bring unwanted side-affects. Some positive change has been incrementally made. These ought to be promoted and embedded, but there are concerns that the NDIS will adversely affect some of these gains. The notion that suicide, teenage (and adult) self-harm and serious mental illness, has its solution in acute mental health services and pharmaceutical prescriptions is common place and ignores many other factors.

Evidence based research informs us that trauma, dysfunctional family and relational experiences contribute to most mental illness (psychotic disorders and the like may fit a different paradigm but can be linked to the same issues). Evidence based solutions to these problems do not appear to be at the forefront of current interventions. These therapies include family therapy, Open Dialogue and various sensorimotor (body mindfulness) therapies. These therapies have a strong evidence base, but are not explicitly included in Medicare and ATAPS funded focused psychological therapies.

Many reviews relating to mental illness services identify a siloed approach. From the perspective of a PHaMs client this results in participants finding it difficult to access the appropriate therapeutic support prior to a catastrophic event resulting in hospitalisation and/or suicide or suicide attempt.

While PHN's have funds for special needs groups anecdotal evidence shows that these groups are not accessing PHN services. This could be addressed by LAC (and PHNs) funding agreements specifying % numbers from target populations not supported by State funded clinical mental health services. Such agreements could also specify directions to PHN to address mental health problems resulting in functional limitations that are being addressed by NDIS packages and Local Area Coordination (LACs) services.

The specialist services provided via PHN should provide evidence based trauma treatments (and family therapy) recognising that traditional CBT (cognitive behavioural therapy) is not appropriate when cognitive functions are compromised by trauma or when problems primarily relate to dysfunctional behaviour within families or relationships. These services can be provided by psychologists, social workers and OT's who have the appropriate training and accreditation, and should be available to be accessed through an NDIA package if not available through time limited Better Access or PHN programs.

Notes for proposal 1

Video Eddie Bartnik regarding provision of services under the NDIS for people with psychosocial disabilities

see https://www.youtube.com/watch?v=5Vw_kwNm4ZI

Video about NDIS service examples for people with psychosocial disabilities

see https://www.youtube.com/watch?v=9X-ea-O50Vg

DSS National Disability Insurance Scheme Transition - Personal Helpers and Mentors Operational Guidelines 2016-17 to 2018-19
Health of the Nation Outcome Scale (HoNOS). The Australian Mental Health Outcomes and Classification Network (AMHOCN) has an interactive reporting function from assessment instruments utilised by all state and territories funded mental health services https://data.amhocn.org/dst/web/#/. National data for HoNOS indicates a range most of people getting community based mental (state funded) health services have a score at intake of between 5 and 20 (mean of 11.6) and at discharge a mean of 8.1.

Contributing Lives, Thriving Communities - Review of Mental Health Programmes and Services, Alan Fells et al 2014. Systemic problems and silos page 62.

NDIA report on the methodology of the efficient price July 2014

Disability Care and Support Productivity Commission Inquiry Report Vol 2 page 941

Notes for proposal 2

Section 7 – Functional Information

34 How often does the applicant need personal help or supervision with activities or participation in the following life areas?

Select just one of the following response categories of level of support needs for each life area:

Personal Capacity Activities:

34a Interpersonal relationships—i.e. forming and maintaining social and interpersonal relationships with family, friends, and other people, and interacting with other people in social situations

- ☐ Unable to do or always needs help or supervision in this life area
- ☐ Needs help or supervision most of the time in this life area
- ☐ Needs help or supervision some of the time in this life area
- ☐ Does not need help or supervision in this life area

34b Learning, applying knowledge and general demands—solving problems, making decisions, paying attention, organising daily routines and handling stress

- ☐ Unable to do or always needs help or supervision in this life area
- ☐ Needs help or supervision most of the time in this life area
- ☐ Needs help or supervision some of the time in this life area
- ☐ Does not need help or supervision in this life area

Section 7 – Functional Information cont'd

34c Communication—for example, participating in conversations and discussions, and expressing ideas clearly

- ☐ Unable to do or always needs help or supervision in this life area
- ☐ Needs help or supervision most of the time in this life area
- ☐ Needs help or supervision some of the time in this life area
- ☐ Does not need help or supervision in this life area

Community Participation Activities:

34d Working and Employment—undertaking activities to obtain and retain paid employment or self-employment

- ☐ Unable to do or always needs help or supervision in this life area
- ☐ Needs help or supervision most of the time in this life area
- ☐ Needs help or supervision some of the time in this life area
- ☐ Does not need help or supervision in this life area

34e Education—i.e. participating in school, college or any educational activities

- ☐ Unable to do or always needs help or supervision in this life area
- ☐ Needs help or supervision most of the time in this life area
- ☐ Needs help or supervision some of the time in this life area
- ☐ Does not need help or supervision in this life area

34f Social and Community activities—i.e. participating in social and recreational activities, and engaging in religious, political and other community life

- ☐ Unable to do or always needs help or supervision in this life area
- ☐ Needs help or supervision most of the time in this life area
- ☐ Needs help or supervision some of the time in this life area
- ☐ Does not need help or supervision in this life area

Independent Living Activities:

34g Domestic activities—undertaking activities such as caring for children and for other family or household members, shopping, preparing meals, housekeeping and maintaining a home

☐ Unable to do or always needs help or supervision in this life area
☐ Needs help or supervision most of the time in this life area
☐ Needs help or supervision some of the time in this life area
☐ Does not need help or supervision in this life area

Section 7 – Functional Information cont'd

34h Transportation and mobility—activities in getting around, such as moving around or leaving your home, accessing public transport; driving your car

☐ Unable to do or always needs help or supervision in this life area
☐ Needs help or supervision most of the time in this life area
☐ Needs help or supervision some of the time in this life area
☐ Does not need help or supervision in this life area

34i Self-care—activities in taking care of yourself, such as maintaining reasonable levels of hygiene, standard of dressing, nutrition, managing diet and fitness, administering medication and managing general health

☐ Unable to do or always needs help or supervision in this life area
☐ Needs help or supervision most of the time in this life area
☐ Needs help or supervision some of the time in this life area
☐ Does not need help or supervision in this life area

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35 Functional Limitation Score. *(automatically generated by the Eligibility Screening Tool)*

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Bessel Van Der Kolk *The Body Keeps the Score – Mind, Brain and Body in the Transformation of Trauma 2015*

Ogden and Fisher *Sensorimotor Psychotherapy* 2015

Notes for proposal 3

Contributing Lives, Thriving Communities - Review of Mental Health Programmes and Services, Alan Fells et al 2014. Systemic problems and silos pages 38 – 39.

Contributing Lives, Thriving Communities - Review of Mental Health Programmes and Services, Alan Fells et al 2014. PHN and mental health issues pages 76, and 78.

Childhood sexual abuse and mental health in adult life.

P E Mullen, J L Martin, J C Anderson, S E Romans, G P Herbison

The British Journal of Psychiatry Dec 1993

Childhood Sexual Abuse and Adult Psychiatric and Substance Use Disorders in Women An Epidemiological and Cotwin Control Analysis

Kenneth S. Kendler, MD; Cynthia M. Bulik, PhD; Judy Silberg, PhD; et alJohn M. Hettema, PhD, MD; John Myers, MS; Carol A. Prescott, PhD

Arch Gen Psychiatry. 2000;57(10):953-959. doi:10.1001/archpsyc.57.10.953

The impact of child sexual abuse on mental health

Research has established a strong, albeit complex relationship between child sexual abuse and adverse mental health consequences for many victims

See https://aifs.gov.au/cfca/publications/long-term-effects-child-sexual-abuse/impact-child-sexual-abuse-mental-health

Conclusions This prospective study demonstrates an association between child sexual abuse validated at the time and a subsequent increase in rates of childhood and adult mental disorders.

See http://bjp.rcpsych.org/content/184/5/416

2015 Trauma in Patients with Serious Mental Illness: The Acceptability and Impact of a Brief Psychoeducational Intervention for Trauma in the General Acute Inpatient Psychiatric Setting Kevin E. A. Giangrasso Philadelphia College of Osteopathic Medicine,

Relationships between trauma and psychosis: an exploration of cognitive and dissociative factors

Authors

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First published: 15 September 2005