Arafmi Qld Inc.

Submission to

Joint Standing Committee on the NDIS

The provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition

Introduction

Arafmi Queensland Inc. is a community organization providing support for families, carers and people with a mental health issue or psychiatric disability. Commencing as a carer self-help group in Brisbane in 1977, Arafmi Brisbane became incorporated in 1986 and since then has provide a broad range of services to support families and others caring for people experiencing mental illness. These services were initially developed in the Brisbane region and have gradually been extended and adapted to provide support for Arafmi groups and carers in regional areas of Queensland. Arafmi support services include: Emotional support for carers – support groups, counselling and telephone support; Education for families and carers; Respite – four locations in greater Brisbane; Lifestyle support – for people living with mental illness; Carer Connect – one on one support for carers; Information and referral; Mental Health Carer Hubs. Arafmi services are funded by the Department of Social Services, Department of Communities, Child Safety and Disability Services and Queensland Health.

Submission

Arafmi Qld Inc. recognises that the NDIS is arguably the biggest social reform in Australia in a generation (Mendoza, 2013). Through consultation with its constituent base and a review of the National and International literature recognises the accumulated wealth of knowledge of the lived experience of carers and persons with mental illness and information on the implementation of disability schemes in Europe can inform implementation in Australia.

Arafmi QLD Inc. understands that National evaluations of self-directed support pilots in England (Glendinning, et al, 2008) found significant higher quality of life amongst consumers in the pilots than those in control groups, furthermore that self-directed supports has not resulted in any increase in cost, and in some cases reduced it (Glasby and Littlechild 2009; Tyson, 2010).

However, the clear message from international experience of disability support schemes and mental health is that 'one size does not fit all' (Williams, 2014). Countries like England have retained 'services as usual' options for persons living with mental illness (Carulla, 2016). In Australia, the focus on outcomes for individualized funding for people with psychosocial disability has been minimal (Brophy 2015) and aspects of disability associated with psychiatric conditions have not been given the attention they need in the design phase of the NDIS scheme (Nicolas, et al, 2014).

Arafmi QLD Inc. recognises and understands that there are particular impediments for carers and people living with mental health issues with regard to the uptake of the NDIS scheme (Larson, et al, 2013) as such just how the NDIS will operate in practice for people with psychosocial disability is of particular interest for Arafmi Qld Inc. and the carers families and friends of people with mental illness, who often bare the primary responsibility or care and support for persons living with mental illness. Arafmi Qld Inc. fundamentally acknowledges the view that carer needs are separate from those of the care recipient and therefore services need to be designed and funded specifically to meet carer needs. Arafmi QLD Inc. supports the view that there is a risk that without adjustments to the NDIS scheme that there will be poor uptake of support packages by people with psychosocial disability which may result in people missing out on necessary support and assistance (Larson, et al, 20120). Furthermore Arafmi QLD Inc. shares concerns with regard to the inclusion of mental illness within a scheme fundamentally designed by the specialist disability sector (Williams 2014).

Of particular concern is the fact that the current NDIS eligibility criteria may exclude people living with mental illness and the loss of the recovery-oriented services for people with sub-acute support needs (Koop, 2014) may have unintended consequences and outcomes for carers and people living with psychosocial disability (Brophy and Grigg, 2015).

Arafmi Qld Inc. believes that access and equity concerns will be compounded by issues of 'identity' as many people living with mental illness do not view themselves as being 'disabled' (Williams 2014) and by extension will not identify with the NDIS scheme. This has been borne out by both current research evidence and present day anecdotal evidence of early experiences in Toowoomba of mental health consumer's non-identification with the NDIS scheme and their associated non-engagement.

Arafmi Qld Inc. supports the view that engagement with the NDIS may also be constrained by notions of permanent functional impairment which conflict with consumer and carer-led principles of recovery (Slade, 2015; Nicholas, et al, 2016; MHCA, 2013). Furthermore that functional assessment approach to NDIS is not congruent with psychosocial disability and the notion of permanent disability incongruent with the episodic nature of mental illness which requires a capacity to tailor supports rapidly to meet fluctuating variations in need.

Arafmi QLD Inc. equally shares concerns with regard to an insurance scheme predicated on individual capacity for participation and an emphasis on personal responsibility (individual choice and control) and its capacity to further alienate marginalized groups with recognized problems with cognition (Springgay and Sutton, 2014) motivation and engagement (Flawcett, 2014). Fluctuations in lived experience of psychosocial disability, has the potential to make annual assessment planning and review complex, and may require flexibility in the individual planning process and service provision to respond to changing needs of individuals (Brophy 2015).

Arafmi QLD Inc also supports the view that assessment of disability in mental illness is more complex than in other disability groups due to the difficulty of differentiating symptoms from functional impairment (Wakefield 2009).

In England only 9% of eligible adults with a mental health issues received self-directed support as opposed to 41% of eligible adults with a learning disability (Royal College of Psychiatrists 2013). Both Germany in 2010 (Buscher, et al, 2011) and Spain, in 2014 (Ochoa, et al 2014) opted for revised eligibility criteria for mental illness as a result of consequent problems in the eligibility system for people with serious mental illness (Carulla, 2016).

These findings are consistent with early findings and experiences from NDIS Trial sites in Australia, which indicate lower levels of market navigation skills than expected (MHCC, 2015) The NDIS has not been able to link participants with disabilities to services as effectively as the productivity commission expected when it designed the NDIS., and there appears to be have been an under-estimation of the level of assistance required by people with psycho-social disability to register for the NDIS and undertake the planning process (Nicholas, 2015).

As a peak body for the provision of psychosocial care and support to both Carers and Consumers Arafmi Qld Inc. is acutely aware of the 'sector impact' issues affecting access and equity. How the State and Federal Governments, existing public and NGO providers and the emerging NDIS Market

responds and adapts to the new operating environment under NDIS will be critical to limit fiscal impacts, public distress and anxiety, and negative health outcomes and impacts for persons with mental illness.

Arafmi Qld Inc. recognises and understands the significant and very real concerns and challenges which have been identified for existing service providers which go to limit and constrain current and future sector and market responses. While the key changes occurring for service providers have yet to be fully researched and evaluated (Mendoza 2014), initial findings from trial sites in Australia are indicating significant impact and challenge for existing service providers (MHCC, 2015; Mendoza, 2014).

Existing business and service models (along with established public and NGO service delivery partnerships) are being de-constructed at the same time new business, service and practice models are being developed for entry and transition into the NDIS Market. The community managed mental health services sector is moving from top-down (block funded) business models to a bottom-up demand-driven transactional models resulting in unstable revenue streams (Mendoza, 2014). Whilst overall disability sector funding levels have increased, operating margins are being significantly reduced as a result of fixed service price setting and transactional purchase funding models.

Furthermore, over its 40 years of service to carers and people with lived experience of mental illness Arafmi QLD Inc. has come recognise that in a liberal market economy such as Australia, the individual NDIS participant is constructed as an informed consumer with the capacity to exercise choice and control. However, should individuals and their support systems fail to navigate the NDIS scheme the outcomes are likely to reflect the structural disadvantages and access and equity outcomes evident in the current wider free market, e.g. family breakdown, homelessness, unemployment, reduce life expectancy, increase burden of disease, acute public mental health bed pressures and high-rates of engagement with the custodial and forensic systems.

Given NDIS policy construct of people living with psychosocial disability as ‘consumers with purchasing power’, and its reliance on an engaged and responsive provider market (Flawcett, 2014) issues of ‘access and equity’ combined with a viable community mental health sector is of critical importance. Arafmi Qld Inc supports the concerns raised with regard to the deconstruction of the community managed mental health sector in Australia; the need to insure the financial sustainability for existing service providers and future capacity of existing skilled workforces to provide evidence based recovery-oriented services, that there is a risk that the ‘market’ will not deliver the required services (Flawcett, 2014) and outcomes for carers and consumers.

In acknowledging that individually ‘priced’ services is the new market driver for service delivery options and innovation, Arafmi QLD Inc. is concerned that as financial viability of existing service providers becomes paramount that the new emerging NDIS ‘market’ is under no-obligation to respond to the wants and needs of the individual (and the broader mental health policy imperatives of Commonwealth and State Governments) and will only do so if it is economically viable to do so (Flawcett, 2012).

Central to answering the question of whether or not existing service providers such as Arafmi and be able to deliver the required services for people with psychosocial disability will depend on a) How well can it transition from traditional business and service models into the NDIS Market.

Existing Community Managed Mental Health service providers will need to

A. adapt business and services to reflect lower operating margins and bottom-up demand driven individual funding for itemized support items
B. b) transition their workforce from a fixed, supervised and trained workforce to semi-autonomous teams and a casualised workforce staff who have flexibility to tailor their services to participant needs and local context
C. create high quality services on a foundation of lean corporate and management support;
D. recruit and retain a low paid rostered staff, who will be required to provide skilled, flexible and customer and service focused support
E. reduce overhead costs and over-investment in fixed infrastructure costs; (eg offices, salaried staff, motor vehicles, supervision, education and training)
F. manage multiple service-user contracts and rapid invoicing and debtor management
G. Market NDIS service into non-traditional referral points to open up new customer supply chains
H. compete against new market entrants and 'start-up' company and services without infrastructure overheads or organizational legacy issues (historical models and embedded culture and practice)
I. compete against franchise models emerging which incentivizes franchisee profit-seeking and need to succeed, whilst firewalling systemic financial losses

Arafmi Qld Inc. recognise the expectation that the staged rollout of NDIS will enable service provision to be planned and improved overtime, however, without adjustment, current pricing and implementation issues may drive many service providers from the market with potentially negative consequences for people living with psychosocial disability, further compounding access and equity issues associated with NDIS implementation.

The resultant consequences may well be an increase care and support burden on both mainstream 'public' mental health services and carers, family and friends of persons with mental illness. Consequentially this may result in increased fiscal pressures on state government funded services and increased carer dissatisfaction over the loss of services, lack of access to support and concern for potential negative health outcomes for the people they care for.

The scheduled transition of Commonwealth funded Carer programs combined with the shift of carer supports to the NDIS means that future carer support will be dependent on the NDIS eligibility of person they care for and the capacity to have their support needs recognised and include in the NDIA plan. The lack of clarity to which State Governments will engage with an fund carer support during and following the NDIS transition impacts upon agencies role to provide support and/or information and clarity for carers regarding their capacity to maintain their carer role and function.

Recommendations

1. **That psychosocial disability is removed from the NDIS scheme**

2. **Carer needs are separate from those of the care recipient, and therefore services need to be funded specifically to meet the needs of carers.**

3. **Commonwealth Mental Health and Carer Respite Program funding should be maintained and not cashed out to fund NDIS Scheme.**

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