Mental Health Carers NSW Inc.

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

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About Mental Health Carers NSW (MHCN)

Mental Health Carers NSW (MHCN) is the peak body for carers of people who experience mental illness in NSW. It is a community-based, non-government organisation that provides systemic advocacy, capacity development and education for the carers, family and friends of those experiencing mental illness across NSW. There are currently 2.7 million unpaid carers in Australia, 39% of whom provide more than 40 hours of care per week.[1] Due to the demands of their full-time caring role, carers are at a high risk for developing mental health issues. We work to ensure the voices of mental health carers in NSW are represented and heard in policy and service reform processes to ensure they are recognised and their rights upheld. We endeavour to empower mental health carers across the state to become champions for mental health reform and advocacy.

As the peak body representing carers and family members of persons experiencing mental health issues and/or distress, MHCN advocates for greater support for carers and family members. We are especially concerned about the inflexible models of supported decision making for people whose capacity to make sound independent decisions varies due to fluctuating mental ill health, and the difficulties faced in accessing NDIS supports.

MHCN engages with families, friends, kin and carers of people experiencing mental health issues through its Mental Health Carer Advocacy Network and undertakes systemic advocacy on their behalf; and for those experiencing psychosocial disability through the Disability Advocacy Futures Program for a better, more accessible system for our community in NSW.

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[1] Barrett, C & Crameri, P (2015). *An Extra Degree of Difficulty*, La Trobe University.

Introduction

Mental Health Carers NSW (MHCN) advocates for carers and friends supporting persons experiencing mental ill health and distress, including psychosocial disability, which is a term "used to describe the challenges, or limits, a person experiences in life that are related to their mental health condition" (MHCC 2021). Persons affected by psychosocial disability usually experience symptoms consistently or are consistently at a high risk of experiencing symptoms, which can cause a range of negative impacts, including social and economic. Consequently, they may experience increased vulnerability to abuse, exploitation, and neglect. Carers and family members provide vital supports, bridging gaps in the system and advocating on behalf of their loved one for access to such services.

Psychosocial disability is a major mental health concern. In Australia 4.4 million people have a disability, 26% of whom have a psychosocial disability (ABS 2018a). 47% of adults with a disability have experienced violence in comparison with 36% of those without a disability after the age of 15 (AIHW 2022). As reported by the ABS (2018a) the rate of psychological disability seems to increase with age, with 27.2% of women and 21.9% of men aged 85 years and over experiencing psychosocial disability. However, identifying whether a person is experiencing a short to medium term illness or disability can be challenging.

Mental ill health and distress increases vulnerability to violence, abuse, neglect and exploitation. The support provided by carers and family is vital in helping to ensure safety and protection. However, significantly better access to information and resources are needed to better support and guide carers and family members in their caring role. MHCN strongly believes that providing such support will help to improve safety and protection of persons with psychosocial disability.

Psychosocial Disability

Psychosocial disability refers to "the experience of people with impairments and participation restrictions related to mental health conditions. These impairments can include a loss of ability to function, think clearly, experience full physical health, and manage the social and emotional aspects of their lives" (Mental Health Australia 2014). While experience of mental health symptoms is typically episodic, a person experiencing psychosocial disability will typically experience symptoms or high risk of symptoms for very extended periods (often involving long term management by medication) and so will face challenges in a range of spheres, including employment, education and access to suitable housing.

For example, Mental Health Australia (MHA) pointed out the significant challenges to social participation and engagement in employment for people with a psychosocial disability, including stigma and discrimination (MHA 2020). A summary of the data shows significant concerns for persons with a psychosocial disability across a range of spheres, including:

- In 2018, 24.1% of people with psychosocial disability experienced discrimination, up from 21.5% in 2015. Service and hospitality staff, family, friends, employers and work colleagues were amongst the most common sources of discrimination experienced by people with psychosocial disability.

- Two thirds of people over the age of 15 with psychosocial disability had avoided situations in the last 12 months because of their disability. This figure is much higher than the 25.2% of people with other disability, and the highest proportion of any disability group. The situations avoided include visiting friends and family, going to shops, banks, etc., public transport, work, and medical facilities. These figures are listed under disability discrimination, and avoidance could be due to social stigma, lack of support and understanding about barriers and access to needs associated with psychosocial disability (ABS 2018a).
- Income – 59.2% of people with psychosocial disability of working age (15-64 year old) had a government pension or allowance as their main source of income, as compared with 28.2% of people with other disability and 7% of those with no disability (ABS 2018a). The median income of people with psychosocial disability of working age is less than half of those without disability.

Lack of Access to Suitable Housing

Lack of access to suitable housing can increase vulnerability to violence and exploitation. Moreover, attaining stable housing has been identified by people with a psychosocial disability as important for living their version of a good life, alongside health, economic, social connection and family and relations (Brophy et al. 2015). As reported (ABS 2018a) most people with a psychosocial disability lived in households (87.4%), while one in eight or 12.7%, lived in cared accommodation, such as hospitals and aged care facilities.

However, the participation of people with primary psychosocial disability in the NDIS is low. Just over 308 000 people as at 30 June 2019 meet NDIS access requirements (NDIA 2019), though 26% of the 4.4 million people with a disability have a psychosocial disability (ABS 2018a). The National Mental Health Commission (2019: 14) reported that as at 30 June 2019, “25,192 people with psychosocial disability (9% of all NDIS participants) were accessing and receiving support through the NDIS. It was expected that by full scheme, 64,000 participants (or 14% of all NDIS participants) would be people with a psychosocial disability as their primary disability.”

It is important to better understand the experiences of people with psychosocial disability living in supported accommodation. We hope greater understanding can be facilitated through the *Own Motion Inquiry into Aspects of Supported Accommodation in the NDIS* by the NDIS Quality and Safeguards Commission. While persons with cognitive disability might need consistent support with housing, this may be different for persons experiencing a psychosocial disability. Because of fluctuating health, flexible supports that are sensitive to the needs of persons with a psychosocial disability is needed. One issue, for example, is the loss of accommodation while being in a mental health ward. While experiencing ill health, people should be supported to maintain their housing.

MHCN has done little work around supported independent living arrangements and group homes for people with a psychosocial disability, although when we have done consultations with carers it was an area that several carers were highly interested in seeing MHCN respond to. Brophy and colleagues (2014) identified preference for following types of supports and funding among people with psychosocial disability: financial advice and assistance, moving and relocating, a housing worker, and a sense of home.

Some specific challenges which are noted with people who have a psychosocial disability with regards to living arrangements include limited access to supported independent living arrangement due to:

- Limited funding to the Housing and Accommodation Support Initiative and Community Living Supports and other similar programs which provide support for independent living outside of the NDIS.
- Limited or no options for supported independent living available through the NDIS in some areas, particularly regional and rural areas

Stigma and Workplace Discrimination

People with psychosocial disability of working age (15-64 year old) are more likely to report restrictions to employment due to their disability (84.6%) than those with other disability (60.2%). Discrimination in the workplace against people with a severe mental illness is a factor leading to exclusion from employment (Mental Health Australia 2020). The submission by MHA (2020) to the Disability Royal Commission on employment highlights well critical issues affecting employment for persons experiencing psychosocial disability, including stigma and workplace discrimination. Of concern, people with disability experience have higher levels of economic disadvantage and unemployment compared with other members of the population, while people with psychosocial disability experience higher unemployment rates at 7.9%, in comparison with 4.5% and 3.9% for people with other disability and with no disability respectively (ABS 2018a).

Similarly, the Our Turn to Speak survey of the National Stigma Report Card, completed by 822 participants, found that stigma and discrimination is indeed a major barrier to employment (SANE Australia 2020). For example, on average 56% of participants experienced stigma and discrimination in employment, while 60% indicated that they anticipated these issues in employment. Furthermore, about 70% decided against participating in employment (SANE Australia 2020). Over one third (37.9%) relied on a government pension or allowance as their main source of personal income, and only 59.7% has their assistance fully met (ABS 2018b).

Changes to the disability pension have reduced access for people with a psychosocial disability. The assessment criteria were not suited to people with a psychosocial disability in the first place**.** In addition, recent evidence questions the impact of Disability Employment Services (DES) in promoting consumer choice among people with a psychosocial disability (Devine et al. 2021). Specifically, the ability to exercise choice and control within the marketisation of DES may be constrained by a range of challenges, including lack of adequate information to guide and enable choices (Devine et al. 2021). Ensuring access to support employment programs and services can enable economic participation. Furthermore, the submission by Mental Health Australia (2020) to the Royal Commission provides important recommendations for improving and addressing major concerns affecting employment for people with a psychosocial disability.

Carers and Family Members Bridge Gaps in the System

Families are often a crucial source of support and advocacy for people with a psychosocial disability. Families can intervene to report and stop violence, abuse, exploitation and neglect when it occurs, and family involvement may also deter violence, abuse, neglect and exploitation in a variety of service settings. The majority of people with psychosocial disability need some form of assistance: 95% need assistance or have trouble with at least one daily activity, most commonly with regards to cognitive or emotional tasks (85.5%), mobility (54.9%), and health care (51.5%) (ABS 2018a).

Support systems designed to respond to the challenges faced by families may act to prevent violence, abuse, neglect and exploitation. While the focus of this submission is on the experiences of people with psychosocial disability of violence, abuse, neglect and exploitation, we acknowledge that family members also experience violence or abuse by people with psychosocial disability. People experiencing mental illness are far more likely to be a victim of violence or abuse than to perpetrate it. Our experience is that most family members and people with a disability are not violent or abusive. However, as the Royal Commission has already noted, in some circumstances families can also become a source of violence, abuse, neglect and exploitation. Often, family members are a key source of supportive and dedicated relationships for people with a disability.

Family Focused Practices are Needed

Family focused practices require support services to focus on and address the relational context of individuals experiencing disability and/or mental illness. By implementing policies and processes that require a focus on families across disability, health, education and justice settings, services are more likely to:

- Identify, include and listen to supportive family members as partners in care
- Identify and address caring and relational challenges by providing empathy, education, referral and support
- Be held accountable to families' expectations for quality and timely care and support
- Identify and respond appropriately to instances where violence, abuse, neglect or exploitation is occurring within families.

Family focused practices uphold confidentiality and support the independence of a person with a disability. Services and professionals often cite confidentiality and right to independence as a barrier to family focused care and this reflects the need to address common misconceptions and cultural beliefs about families within services.

A systems approach to implementing family focused practice requires decision makers to drive top-down cultural change and mandate the implementation of family focused practices in all service settings. It also requires robust sustainable funding for direct carer and family services so that carers are able to independently access support for their own needs.

The Right to Choose Living and Caring Arrangements

The Royal Commission should uphold as a principle the right of people with a disability and their families to choose their living arrangements, caring arrangements and relationships. This choice is often contingent upon access to quality formal caring and housing arrangements. Choice allows for people with a disability and their families to end harmful or abusive family situations.

People with a disability should be able to define, enjoy and participate in relationships (whether partner, parent, child, kin, family or friend) without also needing to rely on those people as carers and housing providers. Choice means that people with a disability can leave abusive family situations. Choice means that untrained family members are not required to either leave their family member to fend for themselves without adequate care or provide care when they are overwhelmed or stressed, or when they do not have the skills, knowledge, financial, physical or emotional capacity to do so.

"The choice not to care for and live with each other" also provides dignity for people with a disability and for their families. This choice allows for individuals with a psychosocial disability and their families to define their relationships. While many families take joy and pride in their caring, many families do not want a "carer and caree" relationship. For some families a "carer and caree" relationship is not compatible with their personality or lifestyle. Some people with a disability may feel a loss of dignity when they have to rely on close relationships for care. Family members often value their relationship with the person who has a psychosocial disability as a source of support and happiness and some feel that being a "carer" diminishes the contribution of the person with a psychosocial disability to their relationship. The "carer and caree" relationship can sometimes become a source of grief, loss of control and resentment in families. For these families, having choices can enable full enjoyment of the happiness, support, care and affection that they have in their roles as parents, siblings, children, relatives, friends or kin without needing to tackle the complexities of the "carer-caree" relationship.

Carers experience various stressful circumstances. Systemic inaccessibility of quality and timely care and support for people with psychosocial disability across a variety of settings often results in loss of choice for families and individuals with psychosocial disability with regards to their living situation and caring arrangements. Many families and carers of people with a psychosocial disability have told MHCN that they provide care and housing for a family member because they have no other acceptable options which would provide adequate care and independent housing to their family member.

Provide Supports for Carers

Carers and family members provided support and advocate on behalf of people with disability. As stated by Carers Australia (2021:4) in their submission to the Disability Royal Commission information and training for carers is needed:

> Carers of people with disability regularly come into contact with the disability, health, education and legal service systems that people with disability may use throughout their lives. For example, they may help to navigate complex systems such

as the NDIS or Centrelink, attend health appointments or be present when support workers visit at home. They may be the ones to raise concerns about service quality or make complaints. As such, the Royal Commission could consider ways carers could be supported to learn about formal safeguards and the role they could play in supporting those formal safeguarding mechanisms.

There are very limited options for carers and families to access meaningful assistance and support when a person refuses treatment due to the symptoms of mental illness, unless that person is a significant risk to themselves or others. Mental Health Carers NSW is aware of families that have cared for people with severe mental ill health for many years without access to any support services because the person they care for does not want treatment. Carers in these situations may not be aware that they are carers or that some limited carer supports are available to them.

With primary mental health carers providing an average of 36 hours a week of care, with additional estimated 59 hours on standby in case of mental health crisis, it is concerning that 35% did not know of services available to carers and only 24-35% were receiving payments or assistance to support their care work (Diminic et al. 2016). Despite contributing an estimated 208 million hours of informal care work per year equivalent to 173,000 FTE formal support workers, primary mental health carers have lower levels of employment and education, which may be due to the significance of their caring responsibilities (Diminic et al. 2016).

Carers and family members who support someone with moderate to severe mental illness need access to carer supports in their own right. Carers and family members living with someone who has moderate to severe mental illness who refuses mental health care often require a high level of support, education and case management.

Access to carer supports can reduce carer stress and may increase carer engagement in self-care activities:

- Provide carers with education on psychosocial disability and mental health services
- Provide carers with education and coaching which improves their skills to provide care and support to their family member with a disability
- Provide a source of support and connection to carers and reduce loneliness
- Facilitate access to other services including services for families and for the person with a psychosocial disability
- Provide respite from the caring role by restoring services equivalent to the former Commonwealth Respite Schemes, only greater in scale to cope with increased population and demographic changes (Carers NSW 2021).

NDIS Must Support more Flexible Models of Supported Decision making

As a consumer directed scheme, more flexible models of supported decision making are often required for people participating in the NDIS whose capacity to make sound independent decisions varies due to fluctuating mental health. People living with psychosocial disability often experience impairment in relation to communication, decision making and life skills which can render them especially vulnerable to violence, abuse, neglect and exploitation in a variety of settings. The Commission’s focus on cognitive impairment/intellectual disability in various areas such as health care and criminal justice is admirable, as legislation in NSW has recently broadened the scope of its forensic system to explicitly cover cognitive impairment, as well. This is because many people living with psychosocial disability and cognitive impairment can experience impaired communication and decision-making capacity due to their symptoms, and so it was thought the support needs might be similar. However, many people with cognitive impairment have a dual diagnosis with psychosocial disability; increasing the complexity of their support needs, (and seemingly the frequency of their incarceration).

It is important to note that key differences between psychosocial and cognitive disability mean that solutions which work well for cognitive disability may need to be adapted to be effective or replaced completely for people experiencing psychosocial disability and vice versa. For example, more flexible models of supported decision making are often required for people whose capacity to make sound independent decisions varies due to fluctuating mental ill health.

Supported decision making frameworks for people who have fluctuating capacity are needed. Persons can fall through the gap when they are struggling, and when they are doing well they should be supported to make decisions. A framework is needed for this, along with advocacy and other support services. Issues pertaining to guardianship must be redesigned to recognise the fluctuating capacity associated with psychological disability and to allow for an enhanced decision making participation and initiation by the person under guardianship, with a greater emphasis on quality of life over purely financial outcomes.

Challenges in access to quality, timely care for people living with psychosocial disability include:

- Chronic underfunding of the mental health care system which results in a lack of available care and opportunities to discharge people to appropriate levels of support in the least restrictive environment (Eagle et al. 2020).
- Limited availability of specialised mental health supports through the NDIS in some areas due to market failure, in particular for the management of disturbed behaviour for discharge from custodial or in-patient settings.
- The complex interface between physical health, mental health, AoD, homelessness and disability services which results in poor transition between different types of care and different levels of care.
- The symptoms of mental illness which can result in individuals choosing to disengage with or refuse care systems when they are very unwell.

Recommendations

1. Ensure carers are supported:
    a. Provide carers with education on psychosocial disability and mental health services
    b. Provide carers with education and coaching which improves their skills to provide care and support to their family member with a disability
    c. Provide a source of support and connection to carers and reduce loneliness
    d. Facilitate access to other services including services for families and for the person with a psychosocial disability
    e. Provide adequate, frequent, routine, respite from the caring role in a variety of forms for heavily engaged carers.
2. Support family focused mental health literate practices and direct support for families and carers, particularly of people at risk of disturbed behaviour.
3. Provide support for flexible models of support decision making for service navigation, which appropriately include and engage with families and carers, but are also independent of all conflicts of interest including commercial conflicts.
4. Engage with the mental health sector to support persons affected by psychosocial disability - the Royal Commission has done excellent work in engaging people with a disability in a respectful, accessible, and inclusive manner. Targeted messaging towards individuals experiencing psychosocial disability and mental health organisations may aide in engagement (e.g., publishing an issues paper on healthcare for people experiencing psychosocial disability).
5. Support improved access to NDIS, including making it easier for people to get the right support through NDIS - Issues related to the design of the NDIS result in the scheme being less accessible for people with a psychosocial disability with regards to applying for and maintaining access to NDIS supports.

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