

**Mental Health Carers NSW Inc.**

# **Review of the Anti-Discrimination Act 1977 (NSW)**

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**Mental Health  
Carers NSW**

## Introduction

Mental Health Carers NSW (MHCN) is the peak body for carers of people who experience severe and persistent mental distress in NSW. It is a community-based, non-government organisation that provides systemic advocacy, capacity development and education for the carers, family, friends, and kin of those experiencing mental distress across NSW. There are currently 2.7 million unpaid carers in Australia, 39% of whom provide more than 40 hours of care per week<sup>1</sup>. 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. MHCN also undertakes systemic advocacy for psychosocial disability issues to non-Health state government services under the Disability Advocacy Futures Program funded by the Department of Communities and Justice. We regularly engage carers in a range of different ways. Currently, we convene the *Carers of Forensic and Corrections Patients Network* meetings, held monthly in collaboration with Erika Ballance, Family and Carer Consultant, Justice Health and Forensic Mental Health Network, Ministry of Health. We also hold monthly meetings that are peer led through the *Carer Connections Meetings*.

We are pleased to present our submission to the Law Reform Commission (LRC). In our submission MHCN will address (1) protection against discrimination and harassment, (2) impact of vilification and sensationalist media reporting, and (3) promoting participation.

## Executive Summary

People with experience of serious and persistent mental distress or psychosocial disability are too often victims of 'stigma' resulting in discrimination and exclusion from the life of our community generally. The Anti-Discrimination Act should be strengthened to protect people with psychosocial disability and their families and carers, particularly if they experience legal difficulties because of their distress or disability, when not fully responsible for their actions.

MHCN is gravely concerned that in spite of their diminished responsibility, they are routinely demonised and vilified in the media, if the lack of adequate care and support has resulted in them getting into legal difficulties for committing a serious offense, (often after their families and carers have been futilely warning authorities they might do so for years, to no avail). Furthermore, the media intrusion into the privacy of persons who are unwell creates additional trauma which perpetuates both the stigma of mental illness and the illness itself, causing severe long-term harm to families, carers and their loved ones already experiencing significant distress.

Carers of forensic and corrections patients disclosed to MHCN staff at a recent meeting (September 26<sup>th</sup>, 2023) how sensationalist media reporting had deeply impacted their wellbeing, resulting in trauma and, in some cases, ongoing harassment. We also canvassed the opinions of stakeholders including advocates in the Family and Carer Mental Health Program and the NSW Disability Advocacy Network via a survey. The survey was sent to stakeholders representing disability advocacy in NSW. In total, we received 11 responses to surveys.

In a 2021 submission to the Law Reform Commission on Open Justice Review MHCN strongly argued that the Anti-Discrimination Act be amended to prohibit vilification of people who experience mental

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<sup>1</sup> Barrett, C & Cramer, P (2015). *An Extra Degree of Difficulty*, La Trobe University.

illness and their families and carers, and that this legislation be extended to include prohibitions on the publication of the identity of forensic patients, or identifying details such their addresses, places of incarceration, release or residence, or those of their families and carers. Our recent discussions with carers affirm that protection against stigma and vilification continues to require urgent attention for persons impacted by mental distress and their carers and families.

## 1. Protection Against Discrimination and Harassment

MHCN strongly advocates that mental illness, psychosocial disability, and cognitive impairment become attributes protected in the Anti-Discrimination Act. Majority of stakeholders we surveyed also agreed (90%).

All survey participants agreed that people with experience of mental ill health, psychosocial disability and / or cognitive impairment experience vilification and discrimination in New South Wales. One respondent stated:

*"Yes, the discrimination is often subtle and builds through the increase in contacts to services. It [sic] becomes more apparent and appalling when the behaviour of the person exacerbates [sic] and the general population including general practitioners want "them out of our service" with often a reference to, "it's a mental health team issue".*

Over 70% of respondents agreed that harassment for mental health issues or psychosocial disability; or for being a relative, friend or supporter of someone who experiences mental health issues should be banned. Several respondents were unsure, agreeing that individuals should not be harassed while also recognising the complex interface with the right to free speech (but one which is routinely navigated in other areas of discrimination). **This is reflected by only 45% of respondents agreeing that harassment for mental health issues or psychosocial disability should be a *crime*, (although this was still by far the most popular option with only 18% disagreeing).**

Two thirds of survey respondents believed the system for letting people with psychosocial disability or cognitive impairment make complaints against discrimination or exclusion was inadequate. One survey respondent commented that,

*"It's a hidden agenda with governments to keep people in the dark about any complaints or investigation into treatment and care for people with mental illness or disability and their families".*

One respondent highlighted a key example of this as the lack of awareness around NDIS complaints reporting systems, and that families should be informed and made aware how to competently and confidently report any concerns, abuse, and risk. The respondent stated that a paid NDIS component was needed to ensure this, along with a focus on whether there was sufficient scope for communication generally, as well as protection (not just for complaints).

Regarding complaints mechanisms, over 65% of survey respondents agreed that our system to let people with mental distress, psychosocial disability or cognitive impairment, (or their families or carers), make complaints against discrimination or exclusion was inadequate. One respondent asserted that NDIS should fund a small component for family-carer education for first time participants, as carers do not receive any education about how to navigate complex systems. Two respondents were not sure, with one respondent stating they had a lack of experience in this area.

One respondent highlighted inadequacy around multicultural assessment tools:

*“Yes, I believe there is insufficient attention given to the multicultural assessment tools currently available for use in health, mental health, Aboriginal, disability encounters. The impact of legislation on people's lives ought to be part of how does this overcome any discrimination experienced or perceived. Toward Zero Suicide means using multi-cultural assessment Tools in assessing and listening to families”.*

## 2. Impact of Vilification and Sensationalist Media Reporting

Stigma may manifest as vilification (see Katterl 2023) which may be seen in biased and inaccurate reporting. Carers of forensic and corrections patients recounted to MHCN staff the inaccuracy of reports and lack of context provided, as well as the damage caused by such reports. As stated by one carer:

*Sensationalist media reporting further stigmatises mental illness, perpetuating a vicious cycle. Such media reports deem that the person is worthless and destabilise recovery.*

A strong majority of respondents agreed that the identity of people who come before the courts or Mental Health Review Tribunal because of behaviour related to their mental distress should be protected, including from media. The comment by one survey respondent indicates the distressing and ongoing trauma experienced because of media exposure and suggests the need for training of media about the Mental Health Review Tribunal and courts:

*“The complexities behind major cases involving mental health appearances before the Courts, often needs to be preserved from overexposure in the media. The personal and family history of some cases is traumatising, lifechanging and deeply distressing. Often there are many staff involved, if media gives a human rights portrayal, then maybe Media needs some training about MHRT and Courts.”.*

The respondent also highlighted that, *“while these Tribunals are open, the consent of all parties is required”.*

Such media reporting is indeed traumatising, with one carer recounting that even after moving interstate the media had somehow managed to find their new place of residence, waiting outside for them to leave their home, even decades later. Carers were deeply concerned about how their details and other personal details were leaked to the media, and felt harassed by the ongoing media reporting and strongly felt stronger prohibitions on Health, Police and Corrections staff on disclosing such information should be strengthened significantly. A letter recently written by a carer to ministers shows the real and long-term impacts of media reporting (see Appendix 1).

One carer recounted how the media report lacked any regard for context and the impacts of mental illness experienced by their son. The carer stated that the report was derogatory and available for their entire community, including their son's school, friends, and sporting team. However, the report omitted that at the time of the crime their son had been under the care of a treating team and had been seeking support for mental illness over many years, including hospitalisations. Another carer, while grieving loss and shock, recounted how a journalist knocked on their door for an interview the day after a distressing incident involving their family member. Though 10 years had passed, the carer was still very much impacted by this invasion of privacy, particularly at such a difficult time for their family. In a third case, subsequent family law matters were impacted when false media reports of the incident were repeatedly cited in unrelated proceedings, impacting on the outcome.

Carers have told us how distressing it has been to find out, for the first time, details, and significant information about their loved one's offence through media reporting. One carer was even advised by authorities to find information about her son through searching media reports.

Biased, ill-informed and false reporting exacerbates the significant issues that carers and families are already facing. The vilification of carers and their loved ones occurs in a context of ineffective support and services, particularly early intervention, and seemingly impossible navigation of a complex mental health system. Frequently, carers are left feeling burnt out and experiencing mental ill health themselves while also seeking to advocate for better outcomes for their loved one.

Even respondents in our survey who were unsure as to whether the identity of people who come before the courts or Mental Health Review Tribunal should be protected, including from media noted that (while) "*communities need to be aware of the risk and what the community is doing to support any risks or factors*", and stated, "*However, the person should be protected as in having their name withheld from being reported unless there is a serious indictment...*".

One respondent who disagreed, still recognised the need for truthful and balanced reporting, and that media should be held accountable for providing "*incorrect, hearsay or incomplete information to the general public*".

### 3. Promoting Participation

In our survey, almost 100% of respondents agreed government and business should be obliged to take steps to promote better community participation by those with disability, including psychosocial disability, in things such as employment and education. As stated by one respondent:

*"We are seeing more and more specialisation in the area of supported training, community engagement with disability providers - Sydwest Multicultural Services - clients with psychosocial- disability who can work, as well as young people who need a NDIS employment component to help them move on from youth - psychosocial disability and lack of opportunity".*

This is critical as the median income of people with psychosocial disability of working age is less than half of those without disability. About 60% 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 2018).

Furthermore, as has been extensively reported, stigma and discrimination severely impact the participation of persons experiencing mental health issues, including social participation and employment (Mental Health Australia 2020). Fluctuating capacity associated with psychosocial disability is associated with vulnerability in various spheres, such as employment. In addition, there is evidence of increasing discrimination against people with a psychosocial disability. In 2018, 24.1% of people with psychosocial disability experienced discrimination, in comparison with 21.5% in 2015 (ABS 2018).

Furthermore, the lack of support and understanding about barriers and access to needs associated with psychosocial disability may be a factor leading to an avoidance of situations among people experiencing psychosocial disability, including using public transport, work and going to the shops (ABS 2018). It is therefore vital and urgent that government support programs to promote employment and training for people experiencing mental ill health.

## Recommendations

MHCN reiterates and expands upon its recommendations made in the Open Justice Review submission to the LRC in 2021:

- Amend the Anti-Discrimination Act to include vilification of people who experience mental illness and their families and carers, and that this be extended to include prohibitions on the publication of the identity of forensic patients and their addresses, places of incarceration or residence or release and those of their families and carers.
- The law empowers institutions including the health services, Mental Health Review Tribunal, and police to implement a binding Code of Ethics and Code of Confidentiality upon staff to prohibit the publication of the identity of Forensic patients and their families and carers.
- Protect the identity of forensic patients and their families and carers in the same way as the identify of children are protected in legal matters, by empowering and obliging the courts to consider orders do so in such cases of their own responsibility.
- To improve the safety of the community and the wellbeing of Police service itself, a significant investment needs to be made into:
  - addressing mental health stigma among Police and in developing the inherent capacity of Police to work with mental health services, and
  - in how they can respond to people experiencing mental health crisis and their families and carers, as well as,
  - in a significant investment in addressing stigma in health services and the capacity for mental health services to respond to people in crisis in the community *instead* of Police).

These changes would be most effective if implemented alongside the implementation of broader community awareness programs to reduce stigma, and programs to support participation in employment are important in effectively challenging vilification and discrimination associated with experiences of mental illness, psychosocial disability, and cognitive impairment.

## References

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## Appendix 1 – Recent letter by a carer to Ministers

### **Re: Support for Carers of Forensic and Corrections Patients**

My name is Colleen Kosowicz, and I am a carer and mother of a son with a mental illness in the forensic system. I also work in the mental health system supporting other carers and families with Mental Health Carers NSW (MHCN), 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.

MHCN strongly values the lived experience of carers and families in creating a just mental health system. 20 years ago, my son committed a very serious crime: he was found guilty but not responsible due to mental illness. Prior to committing his crime, he had many admissions to hospital. It was well known by the mental health system he could be a danger to himself and others and yet all this was ignored. 2 weeks prior to committing the crime he had presented himself to his local emergency department asking for help. They assessed him as not being suicidal. HE WAS TURNED AWAY. WHERE WAS THE DUTY OF CARE?

For years prior to his crime, we had begged the local hospital for help and assistance for his mental health only to be told he is now not a danger to himself or others.

Due to the nature of his crime, media was involved. We, the parents, had no idea and no indication of his crime. We were only informed by me knowing the police officer who arrested him. This officer suggested we leave our premises as quickly as possible, as media will be stalking us (**which they did**). The media splashed our address all over the news - as a result, media were stationed outside our home for quite some time.

Moving on 20 years later, families are still being stalked by media.

My son has had 20 years of rehabilitation and is now in a better place but still media stalk us. Over the past 4 years, media have invaded our private lives - once at our local supermarket, as well as identifying our private residence. They have stalked my son at his supported residence causing his support network to employ security for his safety. We have had our lives splashed all over Facebook and YouTube. This is not acceptable with media using false and misleading information just to achieve ratings.

WHY CAN THEY GET AWAY WITH THIS? Media needs to be accountable for destroying families, friends and even the workplace, as was my experience.

Do you really know what it is like to have people turn their back on you or have your work locker written obscenities all over it?

**I DO**

Do you know what it is like to be afraid to go to the local shopping center to buy groceries?



## **I DO**

Do you know what it is like to have to hold your head **down** when out in public, for fear someone will recognise you?

## **I DO**

Media must be stopped from persecuting families. **We** do not deserve this. **Where is our privacy**, do we not have the privilege of privacy, families are open to ridicule and condemnation from community and media.

The families are not to blame and yet we are persecuted. Not every family is of low socio-economic background as media presents to the community. Media sensationalise everything to sell papers. The real truth never comes out. Consequently, the community have no idea of the fight and struggle families have had to go through.

I work in mental health and have done so for the past 20 years, supporting families in similar circumstances - each have had much the same experience as myself and my husband and this is 20 years later.

## **TELL ME WHAT HAS CHANGED.**

Our journey as carers over the past 20 years plus has been one of suffering, guilt, stigma, criticism, isolation from family and friends as well as NO understanding from governments. Our pleading to government bodies to have a better mental health system has gone on deaf ears. Sure, you can throw money into mental health as you say you have done and then boast about how you support mental health. **In fact, you have no idea what is needed to create a better mental health system.**

Speak to carers who have been through this - carers who are still going through this and will continue to go through this.

What is needed is more supported accommodation with dedicated staff to help prevent these tragedies from occurring.

Stop throwing money away. The solution is prevention in the form of supported accommodation as with **HASI plus** in the forensic system. Prevent it before consumers need to enter the forensic system (Long Bay Hospital) which in fact is just another way to say **asylum**.

The lack of support for families and carers who have someone in the family suffering from chronic mental illness has, for years, gone on deaf ears from government bodies. The general lack of training, education and/or knowledge provided to police officers, lawyers, judges, media, and the general public is appalling.

Unless you have walked in our shoes one can never understand that you become a carer for life, it's a 24/7, 365 days a year job without pay. Should carers be paid it would cost the government \$1,000,000,000's if it was to be paid out of government taxes.

When will you listen to the carers, the one's who know best? A carer and mother of a son with a mental illness in the forensic system.

Yours Sincerely,  
Colleen Kosowicz

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