Independent review of Individual Advocacy services delivered by Mental Health NGOs

CONSULTATION SUMMARY REPORT

14 July 2023

nous

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This artwork was developed by Marcus Lee Design to reflect Nous Group's Reconciliation Action Plan and our aspirations for respectful and productive engagement with Aboriginal and Torres Strait Islander peoples and communities.

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Introduction

The Mental Health Commission (the Commission) has engaged Nous Group (Nous) to undertake an independent review of Individual Advocacy (IA) services delivered by mental health Non-Government Organisations (NGOs) in Western Australia (WA).

IA services delivered by mental health NGOs are those that seek to represent the rights and interests of people with a mental illness, on a one-to-one basis, by addressing instances of discrimination, abuse and neglect. The ongoing delivery of these services in a contemporary, sustainable and accessible manner is essential to supporting some of WA's most vulnerable populations.

Between January and March 2023, Nous undertook a targeted stakeholder engagement process with service providers, peak bodies, people with lived experience, and funding and commissioning agencies. The purpose of these consultations was to understand:

- *Key strengths of IA services commissioned by the Commission and other Government agencies.*
- *Key challenges, service gaps and unmet needs related to mental health IA.*
- *Opportunities to improve the effectiveness, efficiency and appropriateness of IA services, including through co-commissioning.*

This document is a summary of key themes from the stakeholder engagement process. The themes are organised based on the stakeholder group engaged through the consultation process.

NOUS HAS UNDERTAKEN **16** INTERVIEWS, FOCUS GROUPS AND WORKSHOPS:

- **6** interviews with service providers commissioned to provide mental health IA
- **6** interviews with government agency representatives
- **1** focus group with representatives from peak bodies
- **1** workshop with lived experience stakeholders
- **1** interview with an academic researcher
- **1** full-day workshop with government agency and peak body representatives, and mental health IA service providers

Key themes arising from current state interviews and focus groups

Confusion and uncertainty around IA among government agencies has contributed to gaps and instances of duplication within IA service delivery in WA

Siloed funding approaches have contributed to uncertainty around IA service delivery

Agency representatives recognised that service providers face difficulties in attributing outcomes to specific agency funding.

Agencies expressed that this contributes to uncertainty around what services are currently being delivered, and measuring the effectiveness and impact of IA services.

IA has not sufficiently evolved in line with the changing WA health system

Representatives expressed that IA services have adapted in an ad-hoc way. Many service providers have made changes to how they deliver IA services, but it is not happening in a coordinated way.

Agencies highlighted the need to contemporise the IA service model to better align with the significant changes to the health system, and to better meet the needs of consumers.

There is 'unmet need' for legal advocacy services for people with mental health issues

Representatives from the Department of Justice (DoJ) highlighted that the unmet need for legal advocacy services for mental health tribunal matters is significant.

It was identified that joint Commission and DoJ funding collectively only enables IA services to meet 10 per cent of 'total need' for legal advocacy services for Mental Health Act matters.

The relationship between IA and guardians (i.e. the Public Advocate) is not well understood

There is uncertainty around what IA looks like in matters where an individual has been appointed a guardian to deal with matters pertaining to the mental health tribunal.

Agencies recognised that the roles and responsibilities for individual advocates and guardians need to be more clearly defined and understood.

There is a clear gap and uncertainty in IA for people accessing NDIS supports

Agency representatives recognised that there is a lack of understanding around how IA service providers can effectively support individuals who are accessing NDIS support.

In particular, they highlighted the difficulties in distinguishing between where disability IA and mental health IA operate in the NDIS space.

There is a desire for agencies to collaborate to more effectively commission IA services

It was acknowledged that contracts held with service providers have not been adapted or altered in many years.

Stakeholders recognised the need to gain better oversight into what the other agencies are doing in the IA space. They highlighted the opportunities for collaboration and co-commissioning in the future to more effectively deliver IA services in WA.

> *"The contracts with service providers have been in place for a very long time. There is now a need to contemporise the IA model to align with our current health system"*
>
> **– Department of Health representative**

> *"We are funding the same areas as the Commission. The low-hanging fruit is to work with the Commission to clean up the funding duplication…we should do this before we do anything else"*
>
> **– Department of Justice representative**

Service providers face various challenges when delivering mental health IA due to capacity constraints, under-funding and a lack of understanding of IA within the system

Current funding approaches do not address the needs of consumers

Providers acknowledged how siloed funding from government departments has contributed to fragmented service delivery of mental health IA. Many deliver a relatively 'narrow' scope of services, and in turn are not able to meet the needs of individuals or families holistically.

There is a strong perception of 'under-funding' in the sector by all service providers.

Service providers have varying interpretations of what IA is

The role of mental health IA services is not well understood. The MH IA services differ significantly in the nature of services delivered, eligibility criteria, and staffing model.

Some providers (i.e., Carers WA and Helping Minds) deliver a carer-focussed service, while others (i.e., Health Consumers Council) provide issue-specific support in relation to health system issues only.

Few providers deliver IA that somewhat reflects a 'pure advocacy' model

There is varying appreciation of the role of IA services in protecting human rights – in addition to just healthcare rights.

Many services noted that the scope of their service delivery is limited to advocacy in the context of mental health treatment. Others, like Multicultural Futures provide a truer model of individual advocacy, in addressing issues related to housing, disability and employment.

Most services do not promote or market their service due to capacity constraints

Most providers expressed that they do not actively promote their service, reflecting that they would not have the capacity to support the demand that would follow.

Some providers reflected that they have had to close waiting lists and stop talking calls due to capacity constraints. As a consequence, it was recognised that the existence of IA services is not well known by consumers, and the broader community.

Advocates experience consistent challenges engaging with clinicians

Providers raised several examples of barriers advocates face in supporting individuals, specifically identifying challenges with clinicians either mis-understand, or not respecting their role.

Some examples raised include clinicians refusing to share client information with advocates, and limiting an advocate's ability to be in a consolation room or on a phone call with the person they are supporting.

IA services have an essential role in working with service providers to build capability, and broader systemic advocacy

Providers emphasised that individual advocates play a critical role in building the capability of the broader system in understanding and protecting human rights.

Providers also recognised the critical role of IA in informing broader system advocacy, but recognised that the two roles being delivered by separate organisations is appropriate.

> *"Many GPs don't really know what we offer, therefore when we have to speak to GPs on behalf of an individual, it is always a challenge"*
> **– Service provider representative**

> *"The demand for the service greatly exceeds what we are able to meet. Typically the waitlist is 6-8 weeks, but right now it is at 6 months"*
> **– Service provider representative**

Mental health IA can be more effectively delivered to support individuals holistically, particularly those with alcohol or other drug (AOD) issues and culturally and linguistically diverse (CALD) communities

The importance of 'human rights' as the basis for IA is 'lost' in current IA services

Peak bodies emphasised that while they broadly understood the role and purpose of current IA services, the core purpose of IA in the protection of 'human rights' is largely lost in current service delivery.

It was specifically noted that the disability advocacy model provides a useful case study in how IA services should work to protect the human rights of vulnerable persons holistically – not just a person's rights as they relate to a single issue or service.

There is significant under-delivery of IA services in regional WA

Peak bodies stressed the significant gap that exists in the accessibility of IA services for people with mental health issues in regional and remote WA.

It was identified that while each service is notionally a 'statewide' service, there is no physical presence anywhere outside of Metropolitan WA. It was re-emphasised that the ability to meet face-to-face is critical to the building of a strong relationship between an advocate, and a person being advocated for.

Actual and perceived 'independence' of individual advocates is essential

Peak bodies emphasised the importance of both actual and perceived 'independence' of individual advocates. It was noted that individual advocates should not be part of the same organisation or service that they advocate to.

The need for independence from funders was also identified. Participants raised examples of IA services in other sectors that perceived that their loss of funding was a response to advocacy directed toward the funding body, on behalf of clients.

There is a critical gap in IA for people with AOD issues, Aboriginal people and CALD communities

Stakeholders emphasised that the IA sector has significant gaps. Key gaps include:

AOD advocacy. People with AOD issues experience profound human rights challenges, yet are not included in eligibility criteria for existing IA services.

Aboriginal-specific services. IA support should be culturally appropriate, and trauma-informed. Aboriginal people should be able to access Aboriginal-led services, that provide a holistic, family-centred approach.

> *IA services can bring a discourse around human rights and viewing practice through a human rights lens*
> **– Peak body representative**

> *Their [service providers'] experience is that they get a lot of queries seeking IA services outside their area. Housing, finance, education etc. is often where these people need help*
> **– Peak body representative**

The academic researcher particularly noted the importance of system navigation, as well as peer advocates in the delivery of mental health individual advocacy

The academic researcher highlighted seven key points:

- There is a significant need for a 'navigation' component of individual advocacy services, noting the continued complexity in how the mental health system is configured, and the challenges associated with system navigation.
- It is important to have a more psychosocial model approach to both individual advocacy, and all of mental health care, that recognises that people with mental health issues are highly likely to be experiencing a number of other health and social issues that have either contributed to, are a result of, or co-occur with mental health.
- The small scale and disparate nature of individual advocacy services means that establishing a clear, universally accepted path forward is difficult. It is clear however, that it is a very reactive model.
- A no-wrong-door approach is essential. Evidence shows that people who are turned away from a service are very likely to never search for that support again.
- The role of the Health and Disability Services Complaints Office in this space is currently very understated – it is estimated that only 3% of clinicians know what it is.
- Individual advocacy should include, or at least inform systemic advocacy.
- Peer workers are seen as the panacea of the mental health sector because they represent the needs of consumers with no other motive (i.e., as distinct from the biomedical model of mental health care). However, there are not enough peers to satisfy the workforce demand, and a real risk of burnout and re-traumatisation.

> *An advocate should act as a navigator for someone who doesn't understand the system. However, when you don't have a map on how health, social services, justice and education interact, then it is very difficult to help someone navigate.*
>
> **– Academic researcher**

> *The advocate needs to be truly independent and there needs to be a level of permissions from the system to let the advocate engage with the system on behalf of another person.*
>
> **– Academic researcher**

> *Each service should provide advocacy in its role, even if it is not an advocacy service. They shouldn't be turning people away because it is very unlikely that person will come back to seek support.*
>
> **– Academic researcher**

Key themes arising from workshops

Lived experience stakeholders had inconsistent experiences when accessing IA services and often faced various barriers when accessing support

The experience of consumers with IA varies not only across services, but within the individual services

Participants noted that advocates have varying levels of training and qualifications. This has resulted in inconsistent experiences for individuals, despite accessing the same IA service. For example, some of those who had accessed an IA service noted that the advocate was able to address their needs, where as others commented on the inexperience of the advocate.

Experienced advocates are being used most frequently, resulting in high caseloads and burnout

Lived experience participants recounted that the quality of service was often dependent on the efforts of an experienced advocate going beyond what was required of their role.

These staff in particular appear to be stretched thin across several consumers and unable to sustain their high caseload.

Capacity constraints in services have led to narrowing access to some services based on severity of need

Consumers reflected that they faced challenges in accessing IA services because providers prioritised individuals in crisis and high-risk cases due to capacity constraints.

As a result, many people needing IA support often find themselves at the bottom of wait lists. One participant raised an example of feeling 'shamed' for trying to access a service when not in a crisis.

Peer advocates provide significant benefit to consumers, but experience several significant challenges

Participants stressed that peer advocates are uniquely impactful in drawing on their lived experience to empower and build capability in others.

However, peer advocates face challenges. Examples were raised of peers being asked to "get coffee or tea" when joining consultations and feeling unsafe to advocate to clinicians in the same organisation.

An IA standard of practice should be developed, including formal training and accreditation to ensure consistency

Many workshop participants expressed that all individuals with mental health issues accessing IA should have positive and consistent experiences with services.

Participants believed that formal training and an IA standard of practice, which clearly articulates the core competencies of an advocate, should be established.

There is a lack of accountability for services respecting the rights of people with mental health issues

Stakeholders felt that there is limited recourse against services if an individual's human rights have been deprived. They reflected that too often, rights are disregarded until an advocate is involved.

Participants believe that in the future, advocates could play a role in building the capability of services to ensure human rights are appreciated and respected.

> *All good experiences I've had with advocacy have been down to luck*
> **– Lived experience representative**

> *Advocacy services aren't advertised at all – no one knows what's out there*
> **– Lived experience representative**

> *Just because you're old and in a nursing home, doesn't mean you no longer have any rights*
> **– Lived experience representative**

Stakeholders highlighted further strengths and challenges that are present within current mental health IA service delivery in WA

Service providers have established effective referral pathways for individuals requiring further support

Stakeholders highlighted the strong relationships held by mental health IA service providers with clinical mental health services and other community services.

These relationships have allowed for consumers to be referred to other mental health supports (i.e., treatment, counselling or other one-to-one supports) when it is required.

There is too little integration of legal and non-legal advocacy

For guardianship and mental health tribunal matters, the role of the advocate is to interpret the legislation in various ways.

Stakeholders noted that, in these matters, individuals are often represented by an advocate without a legal background (i.e., from the Mental Health Advocacy Service) who would not be as effective as an advocate with a legal background.

Stakeholders called for greater collaboration and integration between legal and non-legal advocates.

The remit of many IA services often diverges from the types of supports that are typically considered a part of IA

Stakeholders identified that current mental health IA services do not deliver 'pure advocacy'.

Examples raised were Health Consumers Council, which provides issue-specific support for health system issues and complaints; and Helping Minds and Carers WA which provide support and capability building to carers. While addressing a clear need in the community, they do not represent 'individual advocacy' as it is defined in literature.

There is little awareness and understanding of the existence and role of individual advocacy service by the community

Stakeholders reflected throughout the workshop that the awareness and understanding of current services is poor – both for members of the community, and for those that work in the system. As a consequence, many people who might need individual advocacy fall through the gaps.

Service representatives felt that there was not enough outreach undertaken by services to inform community members of the supports available to them.

> *"We need specialist services equipped to provide support to people with unique needs"*
> **– Services representative**

> *"There needs to be an increase in access to legal services for individuals and advocates when discussing ethical concerns"*
> **– Service representative**

> *"There needs to be a clear mechanism for the advocate to escalate concerns where a person's rights are not being upheld"*
> **– Service representative**

Participants in the stakeholder workshop developed solutions to the challenges faced in delivering mental health individual advocacy

The role of individual advocates should be 'professionalised' through training and development, and accreditation

Service representatives noted that there is no universal code of ethics, qualification requirements, or accredited course for individual advocates.

Service representatives highlighted the need to 'professionalise' the role of individual advocates and in doing so, ensure that there is a clear set of skills and competencies that all advocates should possess, and consistent expectations for anyone who becomes an individual advocate.

There are opportunities to streamline and simplify how consumers access IA services

The most consistent solution identified by stakeholders was a 'one-stop-shop' approach for IA. Stakeholders strongly supported the idea of a 'single front door' to accessing information about rights, finding IA services, and how to access services.

Stakeholders identified that innovative service delivery approaches are needed for regional WA, including co-locating staff, providing mobile advocacy, and Telehealth.

There is a need for a more proactive mental health IA model

Stakeholders reflected on how there are IA models in other jurisdictions across Australia which work to *proactively* identify cohorts of people who may need IA support (i.e., at risk of their rights being impacted).

Stakeholders suggested that WA should explore opportunities to deliver a more proactive IA model, where through collaboration and information sharing services can identify people at risk, and offer different types of support.

A broad, state-wide education campaign to educate the community and service providers about human rights

Stakeholders stressed that a poor understanding of 'human rights' for consumers and service providers is a significant barrier to be addressed.

It was suggested that a broader education campaign is needed to build awareness and understanding for all people in the community about their human rights, how those rights should be protected, and what they can do if they fear their rights are being impacted.

The role of IA in building the capacity of consumers and carers to self-advocate should be better emphasised

Stakeholders urged that individuals with mental health issues and carers need to be equipped with the tools to self-advocate, or advocate for those that they care for.

It was emphasised that a critical element of IA services is that they are time-limited, and focus on progressively building the capability of consumers to advocate for their own rights, which will in turn lessen demand pressures on IA services in the long-term.

> *"We need integrated service models which give broader scope to provide assistance outside of 'funding silos'"*
> **- Services representative**

> *"With an understanding that mental 'health' isn't just illness or diagnosis, IA in this area needs to encompass everything that impacts our mental health and a person's rights"*
> **- Services representative**

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Nous Group is an international management consultancy operating across Australia, New Zealand, the United Kingdom, Ireland and Canada.

We are inspired and determined to improve people's lives in significant ways. When our strengths complement yours and we think big together, we can transform businesses, governments, and communities. We realise a bigger idea of success.

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PEOPLE	PRINCIPALS	COUNTRIES