

Research of the Models of Advocacy Funded under the National Disability Advocacy Program

Proforma for Submissions by Disability Peak Bodies

This proforma is provided for peak bodies in the disability sector. These organisations include those representing people with disability, the parents, families and carers of people with disability and disability service providers. The proforma is designed to guide those who wish to have input to this research project. The proforma will also assist the researchers to make the best use of the information you provide in answering the research questions.

About the National Disability Advocacy Program and the Six Models of Advocacy

The National Disability Advocacy Program (NDAP) assists people with disability to overcome barriers (for example, physical access, discriminatory attitudes, abuse or neglect) that impact on their daily life and their ability to participate in the community. Currently over 60 disability advocacy agencies are funded through the NDAP to assist up to 24,000 people with disability.

Six models of advocacy support are used in NDAP funded advocacy agencies¹. A general description for each of these advocacy models is presented below.

Model of Advocacy	General Description
Individual Advocacy	<p>Individual advocacy seeks to uphold the rights and interests of people with all types of disabilities on a one-to-one basis by addressing instances of discrimination, abuse and neglect. Individual advocates work with people with disability on a short-term and issue-specific basis.</p> <p>Formal individual advocacy is undertaken by a paid advocate employed by an advocacy agency. Informal individual advocacy is undertaken on a voluntary basis by a family member or a friend.</p>
Systemic Advocacy	<p>Systemic advocacy seeks to influence or secure positive long term changes that remove discriminatory barriers to ensure the rights and interests of groups of people with disability are upheld.</p> <p>Systemic advocates and policy officers employed by advocacy agencies and peak bodies undertake this advocacy.</p>
Self-Advocacy	<p>Self advocacy supports people with disability (predominantly people with an intellectual disability) to advocate on their own behalf or on a one-to-one or group basis.</p> <p>The advocate is paid by the advocacy agency to support people with disability to advocate on their own behalf.</p>

¹ These six models of advocacy have been set out in the 'National Disability Advocacy Program (NDAP) Quality Assurance Consultations Report'. This report is available on the FaHCSIA website.

Citizen Advocacy	<p>Citizen advocacy seeks to support people with an intellectual disability by matching them with volunteer advocates on a one-to-one basis. Citizen advocates are encouraged to represent the interests of a person with a disability as if they were their own and be free from conflict of interest.</p> <p>Citizen advocates are supported by a paid coordinator who manages the citizen advocacy office. Some of the matches made may last for life.</p>
Family Advocacy	<p>Family advocacy works with parents and family members to enable them to act as advocates on behalf of a family member with a disability. Family advocates work with parents and family members on a short-term and issue-specific basis. Family advocates work within the fundamental principle that the rights and interests of the person with disability are upheld at all times.</p>
Legal Advocacy	<p>Legal advocacy seeks to defend the rights and interests of people with disability on a one-to-one basis through the Australian legal system.</p> <p>Legal advocacy is undertaken by a lawyer or individual with appropriate legal knowledge</p>

Around 90 per cent of NDAP-funded agencies use a combination of two or more of the six advocacy models. The most commonly used advocacy model is individual advocacy with 82 per cent of NDAP funded agencies reporting some use of individual advocacy.

This research project is investigating issues such as:

- how the different advocacy models can best achieve positive outcomes for people with a disability
- what strategies can be used to overcome any barriers to achieving positive outcomes
- how advocacy models contribute to systemic change
- how the advocacy models feed into public policy
- whether the current models of advocacy are appropriate for meeting current and future needs and how the models could be improved or developed
- collaboration between models of advocacy i.e. how different models of advocacy can work in combination or complement each other to provide a more whole of life response to the issues that people with disability encounter.

Topics and questions for your submission are presented on the following pages.

About Your Organisation

This information will help us to describe the profile of organisations that provide submissions for this research project and to identify key issues for particular groups.

Who does your organisation represent?

The Mental Health Council of Australia (MHCA) represents the Australian mental health sector, with members including national organisations representing consumers, carers, special needs groups, clinical service providers, public and private mental health service providers, researchers and state/territory community mental health peak bodies.

Does your organisation have national coverage or is the organisation based in a particular state or territory?

The MHCA is a national organisation with members in each state and territory. MHCA members are either national bodies or state/territory peak bodies. Associate membership is available to state-based bodies.

What involvement or interaction does your organisation and its members have with advocacy agencies funded under the National Disability Advocacy Program?

The MHCA has no direct contact with advocacy agencies funded under the NDAP, although some of these agencies might be members of our national or state/territory member organisations (for example, the Victorian Mental Illness Awareness Council, which receives funding under the NDAP, is a member of Psychiatric Disability Services of Victoria, an MHCA member).

Few of the agencies currently funded under the NDAP appear to address mental illness, focusing rather on physical disability, intellectual disability or brain injury. The advocacy needs of people with a mental illness will in most cases differ from the advocacy needs of these other groups.

Achieving Positive Outcomes

From the experience of your organisation and its members:

What positive outcomes have been achieved for people with a disability as a result of advocacy support provided by NDAP-funded agencies?

As noted above, the MHCA has no direct contact with advocacy agencies funded under the NDAP, and we are therefore unable to respond to this question.

Are there circumstances where a particular model of advocacy has achieved positive outcomes?

Model of Advocacy	Circumstances where this model has achieved positive outcomes
Individual Advocacy	
Systemic Advocacy	The MHCA's own work is based on systemic advocacy and has achieved positive outcomes through this approach. One example of this is our advocacy work relating to employment policy – more information is below.
Self-Advocacy	
Citizen Advocacy	
Family Advocacy	
Legal Advocacy	

Please continue here if you need more space for your comments

In 2007, the MHCA launched its *Let's Get to Work* report, which provides a strategy to improve employment outcomes for people with a mental illness in Australia. This document was followed up with the establishment of the Welfare to Work Reform Collaboration involving a range of groups assisting people experiencing disability or social disadvantage. This collaboration published a document outlining the key shared priorities on reforming Welfare to Work legislation. Since the publication of these two documents, significant changes have been made to disability employment policy, including the implementation of a new Federal Mental Health and Disability Employment Strategy.

Are there any barriers or issues that prevent advocacy agencies from achieving positive outcomes for people with disability?

An issue that is regularly faced by advocates for people with a mental illness – regardless of the model of advocacy – is that mental illness is often not seen as a disability in the same way as physical or intellectual disabilities. Unlike other disabilities, the symptoms of mental illness are largely 'invisible', and people with a mental illness

may have no obvious impairment. This does not mean, however, that they are not facing significant disabilities that can have enormous impacts on their ability to work, maintain social relationships and live a normal life.

An example of this perception at the Federal, systemic level appears in the application forms for Centrelink's Carer Payment and Carer Allowance. The questions on these forms that address the type of care required have a strong focus on physical disability, asking, for example, whether a person can feed, bathe and toilet him/herself. The care required by a person with severe mental illness is a different sort of care, but is no less demanding and draining.

This perception is a major barrier for those who provide advocacy for people with a mental illness.

Another barrier that is faced by all advocacy agencies, particularly those engaging in systemic advocacy, is that the agency's advocacy priorities might not be shared by those who currently benefit from existing systems (in our case some health professionals, State governments, acute care settings, etc.). In this case a clear message must be presented about why current arrangements do not meet clients' needs, how proposed changes will benefit people, the costs and the outcomes.

Preparedness to acknowledge the existence of a mental illness is also a barrier because many people believe they will experience some form of discrimination or disdain if they disclose a mental health disorder.

Are any of these barriers or issues associated with a particular model(s) of advocacy?

See above.

What strategies could be used to overcome these barriers or issues?

The MHCA encourages those who are able to promote policy changes and effect systemic reform to recognise the importance of our priority issues through research and reporting that demonstrates the urgent need for change in these areas. This includes the use of statistics that indicate the extent of the problem, as well as personal stories from consumers and carers, that provide insights into the issues that people face 'on the ground', including how they are being failed by existing systems.

The level of disability experienced by people with a mental illness is largely dependent on the way systems and individuals respond, so encouraging systems and individuals to move beyond stereotypes and address real needs is a core strategy in Australia and internationally.

Advocacy and Systemic Change

Can you describe any examples of advocacy contributing to systemic change? (e.g. changing organisational cultures, improving disability service practices and procedures)

The MHCA is involved in ongoing work with the life insurance industry that involves advocating for change in life insurance outcomes for people with a mental illness. While this collaboration is ongoing and there is still significant work to be done, work over the past five years has seen increased acceptance rates of life insurance applications from people with a mental illness, whereas in the past most applications from people with a mental illness were rejected.

Another example is the improvement in levels and recognition of consumer and carer participation following advocacy from the National Mental Health Consumer and Carer Forum (NMHCCF), which is auspiced by the MHCA. In 2004, the NMHCCF published its *Consumer and Carer Participation Policy: a framework for the mental health sector*. This document outlines best practice in consumer and carer involvement in the mental health policy debate. This document, combined with ongoing advocacy from the NMHCCF and the MHCA, has contributed to increased levels of consumer and carer involvement in mental health policy discussions, as well as policy initiatives such as the National Register of Mental Health Consumer and Carer Representatives funded by the Department of Health and Ageing. Increased consumer and carer recognition is reflected not only in the increased involvement of consumers and carers, but also in financial recognition such as sitting fees for representatives who provide their time and expertise on a voluntary basis.

Have any of the models of advocacy (i.e. individual, systemic, self, citizen, family or legal) been particularly effective in contributing to systemic change? In what way(s)?

The MHCA's focus is on systemic advocacy and we are therefore not in a position to comment on the efficacy of other advocacy models as defined in this document.

Individual, self, citizen, family and legal forms of advocacy are more challenging in the mental health area because of the perceived stigma and discrimination.

Without the recourse to legal sanctions or some form of penalties for non compliance with agreed standards, these forms of advocacy are always going to be somewhat limited.

How could the models of advocacy and the way these models work together be strengthened to promote positive systemic change?

Please see comments below addressing 'Collaboration between Models of Advocacy' and 'Meeting Present and Future Needs'.

Use of Advocacy Resources

Do any of the models of advocacy demonstrate an advantage in terms of the duration and/or intensity of support required to achieve a positive outcome for consumers?

As noted above, the MHCA's focus is on systemic advocacy, and we are therefore not in a position to comment on the efficacy of other advocacy models as defined in this document. We comment below on the efficacy of a different model of advocacy, involving individual consumers and carers contributing to advocacy on systemic issues, that we consider should be added to the existing models of advocacy.

Are there any ways in which the use of advocacy resources could be improved?

While the MHCA favours systemic advocacy and would emphasise the importance of ongoing resourcing for systemic advocacy organisations, we also recognise the benefit of the other forms of advocacy identified in this document. We would now like to see better resourcing of organisations providing all forms of advocacy services for people with a mental illness. As noted above, few of the agencies currently funded under the NDAP address the advocacy needs of people with a mental illness, which differ significantly from the advocacy needs of people with physical or intellectual disability or brain injury. The NDAP should recognise and address the advocacy needs of all people with disabilities, including people with mental illness, who are currently marginalised within the disability sector.

Collaboration between Models of Advocacy

Are there practical ways in which the different models of advocacy interact, link or complement each other to achieve positive outcomes for people with disability?

As noted above, the MHCA currently manages the National Register of Mental Health Consumer and Carer Representatives (the Register). This Register brings together more than 50 consumers and carers who are successful at individual advocacy, and provides training and support to enhance their skills so that they can become systemic advocates at the national level, while still drawing on their individual experiences and expertise. The Register provides consumer and carer representatives to a range of national groups and bodies, and increases recognition of the importance of including consumers and carers in national consultations.

Consumer and carer involvement in systemic advocacy is essential, and their involvement should be recognised and compensated appropriately. Key principles of consumer and carer involvement, as noted in the NMHCCF's *Consumer and Carer Participation Policy*, include that consumers and carers have a right to participate in discussions and decisions about policies and processes that affect their lives; that consumer and carer participation needs to be adequately resourced and supported to enable their effective participation; and that consumers and carers should be remunerated for their involvement and should not be expected to bear the costs of participation and representation expenses.

Is there a particular combination of models of advocacy that achieves more positive outcomes than either model used alone?

Please see comments under the next question.

Could collaboration between models of advocacy be improved and if so, how could this be done?

The success of any form of advocacy should be monitored so that systemic issues can be identified and addressed. The collection of data on advocacy issues and outcomes should be used to support systemic advocacy if the volume of concerns about a particular issue indicates a systemic problem. The MHCA's work on insurance discrimination, discussed briefly above, provides an example of how individual concerns resulted in advocacy on a systemic level. The work commenced due to repeated inquiries from mental health consumers and carers concerned about their inability to access appropriate insurance products. Monitoring of complaints received identified a large volume of complaints, indicating that there was a systemic issue, and the MHCA commenced advocacy on this issue on a systemic level.

In other words, where the same issue is addressed repeatedly for different people, this indicates that the issue should be addressed more broadly than on a case-by-case basis. Unless there is monitoring of the types of issues addressed by all forms of advocacy, systemic issues will not be identified. Funding under the NDAP should include the capacity for monitoring of this kind, including monitoring by individual organisations but also collection and analysis of monitoring data on a national level, so that shared issues across organisations and regions can be identified and acted upon.

It is important to note that collaboration and network building requires resourcing, but that few resources are provided for this form of advocacy in the mental health sector. In particular, the collaboration between consumers, carers, service providers and professional groups is rarely encouraged or supported.

Effect of Advocacy on Public Policy

Can you describe any examples of advocacy from NDAP-funded agencies contributing to public policy? (e.g. advocacy informing government decision-making, contributing to improvements in government policies and programs.)

As noted above, the MHCA has no direct contact with advocacy agencies funded under the NDAP, and we are therefore unable to respond to this question.

Have any of the models of advocacy (i.e. individual, systemic, self, citizen, family or legal) been particularly effective in feeding into public policy? In what way(s)?

The MHCA's systemic advocacy has been effective in contributing to public policy, as it provides a body of evidence including individual, family and organisational experiences and relates this evidence to systemic issues. An example of this approach is the MHCA's landmark *Not for Service* report, published in 2005, which identified systemic issues

based on evidence collected from people with a mental illness, their families and carers, doctors, nurses, psychologists and other mental health professionals.

Another example comes from the MHCA's Carer Engagement Project, which involves running workshops across Australia and collecting information on what carers identify as their 'top issues' that need to be addressed. Although the project is still underway, the MHCA has already used evidence arising from the project to feed into public policy processes including parliamentary inquiries, and this evidence has been incorporated into reports arising from these inquiries (for example, the House of Representatives Standing Committee on Family, Community, Housing and Youth's *Who Cares? Report on the inquiry into better support for carers*). As in the *Not for Service* report, the MHCA is using individual experiences from over 1000 carers to identify systemic issues and use these as a basis for lobbying.

Meeting Present and Future Needs

Are the current models of advocacy appropriate for meeting the present and future needs of Australians with disability?

As noted above, few of the agencies currently funded under the NDAP address the advocacy needs of people with a mental illness, which differ significantly from the advocacy needs of people with physical or intellectual disability or brain injury. The MHCA would like to see greater funding of all models of advocacy for people who experience mental illness and their carers.

The MHCA considers that an additional model of advocacy that should be included in the NDAP is the model that is exemplified by the National Register, and also by the NMHCCF. In both these bodies, people with a mental illness and carers of people with a mental illness address systemic issues, but the model of advocacy that they use does not fit into the definition of 'systemic advocacy' used in this document.

Members of these bodies are volunteers (although they receive sitting fees for participation in meetings, consistent with best practice principles for consumer and carer participation), and their advocacy is based on a combination of their individual experiences and broader systemic issues. In the case of the NMHCCF, the issues addressed are identified by the consumers and carers who comprise membership of the group. This form of advocacy, which provides a consumer or carer voice to systemic issues at a national level, should form an essential part of the models of advocacy supported by the NDAP.

Are any modifications or development of the models of advocacy required to meet current and future needs?

See above.

What should a future model or models of advocacy look like?

See above.

Do you have any other comments or suggestions regarding the models of advocacy funded under the National Disability Advocacy Program?

To reiterate key points from our submission, the MHCA would like to see:

- increased funding specifically for advocacy for people with a mental illness, as the advocacy needs for this group often differ significantly from the advocacy needs of other people with disability
- recognition in the 'models of advocacy' of the involvement of consumer and carer representatives in systemic advocacy
- stronger recognition of mental illness as a disability, including the additional implications of its episodic nature.

This proforma is somewhat restrictive and in many cases the questions do not relate directly to the advocacy work of the MHCA. If you would like more information on this submission or on the MHCA's advocacy work, please contact Melanie Cantwell, Director of Policy and Projects, on (02) 6285 3100 or at melanie.cantwell@mhca.org.au.

Thank you for providing a written submission to this research project.
Please send your submission by post to:

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