

18 October 2019



NSW Ageing & Disability Commission  
PO Box 40 Parramatta NSW 2124  
E: [commissioner@adc.nsw.gov.au](mailto:commissioner@adc.nsw.gov.au)

### **Submission: NSW Disability Advocacy Review: Issues Paper**

The Mental Health Coordinating Council (MHCC) is the peak body representing mental health community managed organisations (CMOs) in NSW. The MHCC is also a founding member of Community Mental Health Australia (CMHA) the alliance of eight state and territory community sector mental health peak bodies. Together we represent more than 800 CMOs delivering mental health and related services nationally. Our members deliver a range of psychosocial disability support programs and services including housing, employment and social inclusion and consumer led activities. MHCC members also include organisations that provide advocacy, education, training and professional development and information services.

MHCC work in partnership with both State and Commonwealth Governments, as well as the public, community and private sectors in order to effect systemic change. We also manage and conduct collaborative research and sector development projects on behalf of the sector. The MHCC Learning and Development arm is a widely respected registered training organisation delivering nationally accredited mental health training and professional development courses to the human services sectors.

MHCC thanks the Ageing and Disability Commissioner for the opportunity to provide input into the NSW Disability Advocacy Review that sets out to better understand the purpose, functions and future needs of disability advocacy across the state.

MHCC is funded predominately by the Ministry of Health. Whilst not directly impacted by NSW Government decisions on funding arrangements for specialist advocacy services as a result of the rollout of the NDIS, MHCC offer comments to questions relevant to our experience.

### **QUESTIONS**

#### **1. Are these the right principles to apply?**

*Whilst the principles suggested are mostly apt MHCC recommend some amendments and additions to language and emphasis reflected in "Advocacy is an important element in:"*

- *Promoting the rights of people with disability*
- *Promoting autonomy, independence and safety*
- *Supporting people with disability to determine their own will and preference (rather than "what is in their best interest")*

- *Informing systemic reform and responses to the needs and aspirations of people with disability*
- *Supporting people with disability to meaningfully participate in public debate and government decision-making about matters that affect them*

*In relation to “Advocacy service providers:”*

- *Should be resourced to deliver responsive, timely, competent and effective supports and services*
- *Should be resourced in a way that supports their capacity to meet the demands of a dynamic service and system environment*
- *Should demonstrate skills and competencies to build the capacity of those they support*
- *Should demonstrate and be accountable for the outcomes and impacts of their service delivery and practice approach*

### **1.1. Are there any others?**

*It would be useful to provide a definition of ‘Advocacy’ which describes the diversity of activities advocates and advocacy bodies undertake. For example, it is important to acknowledge the work advocates do in promoting basic human rights as reflected in the UNCRPD in terms of both positive and negative rights; understanding the system and supporting people negotiate the system, access information, resources and navigate complaints mechanisms. The definition needs to describe the scope and scale of advocacy from individual support and capacity building of individuals and the workforce to providing information, access to resources and referral, as well as consulting with all stakeholders to further systemic reform.*

### **2. Are there changing patterns of need that should inform the future provision of advocacy services; for example, emerging disability related conditions, changing circumstances giving rise to new or different needs?**

*People who want to access disability advocacy services are not a homogenous group. It is vital that data informs government about the needs and goals of a diverse population, and that the unique voices of people with disability/ consumers, their carers, families and support persons are acknowledged and responded to. Advocacy services can support people to build decision-making capacity and participate in the co-design and development of services and supports.*

*Advocacy plays an important role in safeguarding and prevention and should not just be viewed as a mechanism used to manage crises by responding to complaints. The design of advocacy services can play an important role in reducing costs across the service system as well as supporting best practice approaches.*

*It is vital that an independent body such as a Public Advocate play a role in ensuring accountability, setting ethical guidelines and establishing best practice standards and the parameters for accountability. This does not in any way minimise the importance of specialist knowledge and expertise held by the different interest groups which cannot be replicated in a single model of advocacy. Community-based advocacy services with specialist expertise must continue to support individuals and represent special interests requiring systemic reform specifically affecting these groups.*

### **3. Is it important to distinguish between different advocacy focus areas (e.g. information and referral, individual advocacy, group/systemic/representative**

**advocacy) and different advocacy mechanisms (e.g., self-advocacy, campaigns, skills training and resource-development)**

*The advocacy focus areas outlined in the paper provide a way to understand the different activities undertaken by advocacy groups. However, it needs to be recognised that different advocacy focus areas and mechanisms do not function in isolation and are characteristically interrelated. For example, there is a clear intersection across the areas that informs legislative and systemic reform. Systemic reform is not just operational, it involves practice reform informed by expertise and experience at a grass roots level which gives voice to the imperative for systemic change.*

**3.1. Should any of the above focus area categories or definitions be added to or changed?**

*Capacity building and skills training for both organisations and individuals are an important role for many advocacy bodies. These skills and capabilities are key to empowering people with disability towards self-determination and independence. It is also important to define supported decision making which has been described as the process of assisting a person to make their own decisions in order that they can identify and pursue goals, make choices about their lives and exercise control over things that are important to them.*

*What has not been identified in the diagram (p.8) are the capabilities necessary across the contexts. It would be beneficial to articulate where skilled support sits in navigating a complex terrain as an activity as well as a capability. Embedded in this, reflective practice should be emphasised as central to a best practice approach.*

**3.2. How important do you think it is that a NSW disability advocacy framework aligns with disability advocacy frameworks in other States/ Territories and nationally?**

*Whilst it may be helpful for the NSW Disability Framework to align with states and territories nationally to assist consistency of service delivery and a practice approach, the policy and service systems across states and territories are different and advocacy bodies need to be able to work within their state context, as well as nationally. A move to national consistency can sometime result in a lowering of the bar in order that all can meet it.*

*It would be beneficial to provide guidelines for advocacy with links to safeguards and develop a navigational tool to assist in terms of who and where to go to for support and information.*

**4. What other activities occur as part of effective advocacy within each advocacy mechanism?**

*MHCC stress the importance of ensuring that the role of peer advocacy is well embedded across all focus areas, and that these roles are appropriately supported and funded.*

*Likewise, in terms of supporting individuals the framework must clearly articulate advocacy for carers and support persons across all the categories of advocacy (p.10).*

**5. How could NSW best measure the outcomes of advocacy organisations?**

*It can be difficult to measure the outcomes of advocacy organisations. Advocacy, particularly systemic advocacy, may not achieve its stated aim, because of the influence of other factors (for example a lack of services or thin markets) rather than the quality and effectiveness of the advocacy per se. A reflective practice approach that looks at quality improvement, rather than using outcomes to respond punitively or to benchmark, fosters learning and cultural change. Outcome measures should be aligned and consistent with disability strategy, demonstrate a human rights perspective, and pay consideration to cultural sensitivities, safety and actively demonstrate what a responsive advocacy service looks like.*

*Consideration also needs to be paid to outcomes experienced for people with disability/ consumers and their carers as well as identifying the impact of the demand and pressures on advocacy services. The use of case studies and personal narratives where agreement as to what was to be achieved is evaluated will be useful resources of rich information. Surveys with feedback from participants or member organisations is another method.*

### **5.1. How frequently should outcomes be reported?**

*Reporting should not be onerous, many organisations currently report quarterly to their funding body.*

*Investment in the system must be established that can be used broadly, rather than everyone doing their own data collection in relation to their specific interest group. Data collected must look at individual and systems issues.*

### **5.2. How should outcomes reporting use the same indicators as the NDAP? (See: <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/national-disability-advocacy-program/national-standards-for-disability-services-indicators-of-practice-and-examples-of-evidence-for-ndap-agencies>)**

*MHCC agree that there is value in an indicator:*

- that measures service accountability*
- safeguards against undue influence*
- sets out what service users can expect*
- that data collection also tracks value for money*
- that outcome measurement informs the work of the sector*
- that it contributes to the evidence base*
- that it further informs systemic reform*
- that the workforce is skilled to undertake this work.*

### **5.3. Should advocacy reporting only cover outcomes of funded advocacy? Or should it include broader non-funded disability advocacy?**

*It should cover outcomes of funded advocacy.*

### **5.4. What assists or prevents advocacy organisations from measuring their outcomes?**

- Greater clarity needed as to the definition of outcomes*
- A recognition that factors beyond an organisation's capacity to influence can impact on outcomes*
- Resourcing*
- Better data*

**5.5. Does the Victorian report provide some helpful ideas for NSW too? If so, what should NSW concentrate on in measuring outcomes of disability advocacy?**

*The Victorian Report provides very useful ideas for measuring outcomes including:*

- *Developing clearer performance measures and targets and better ways to identify demand and measure outcomes*
- *Simplifying reporting, monitoring and quality assurance processes.*
- *Reviewing the way targets are measured.*
- *Standardising the way outcomes are measured.*
- *Improving information sharing between advocacy services and using individual advocacy reporting to inform the work of the sector and government.*

**6. What factors should help guide the design of an advocacy service system to meet the future needs of people with disability?**

*The Victorian Report points to overarching themes which are fleshed out in the report. Briefly these are:*

- *Increasing access, engagement and support for people with a disability and their families*
- *Building the capacity of the workforce*
- *Improving measurement of performance and outcomes*
- *Responding to increasing demand and gaps in service delivery*
- *Providing different models of advocacy*

*There is a considerable amount of historical information and experience that can be gathered from advocacy bodies as to what constitutes good practice and aligns with the UNCRPD.*

*Also, peak bodies operating in the disability/human services sectors promote people led quality improvement and codesign processes and are knowledgeable about best practice approaches in their area of specialisation. Characteristically, they provide credibility, collect data, develop standards, advance the workforce and provide thought leadership. They bring together practitioners and sectors to advocate collectively for issues that benefit the broader community. They influence best practice and add value.*

**6.1. What are the advantages or disadvantages of integrating funded advocacy with service support provision?**

*Integrating funding advocacy with service support can lead to conflicts of interest; isolate service users from engaging with other services, especially as services provide multiple services. Remotely located services may experience particular difficulties in this context, as they often have to fulfil multiple roles.*

*Advocacy bodies play a critical role in supporting individuals to navigate complex service systems, representing to government areas for system reform and building capacity. To do this effectively, they need to be independent of service providers. **Should funded advocacy be directed towards broader or more specific cohorts?***

*Funded advocacy needs to be able to do both, but it is important that organisations for specific groups are funded and can develop the relationships, understanding and expertise that is critical to ensuring effective advocacy.*

**6.2. What level of independence from the disability support system should advocacy organisations have in order to be eligible to be funded?**

*Advocacy services are best delivered from outside the direct service system, this allows for clarity, minimises compromise and bias. The workforce must be skilled and competent to advocate and support their clients access the services they need to meet their advocacy needs.*

**6.3. What are the advantages and disadvantages of alternative funding arrangements?**

*Expertise and insight are necessary to inform reform processes. It is important that advocacy services remain independent from funding bodies. They need to be working from a human rights perspective with clearly established principles, service standards, quality and safeguards and can negotiate conflicts of interest and other ethical issues.*

*Organisations must be able to provide frank and fearless advice to Government and other relevant bodies*

**6.4. What are factors to be considered in seeking to provide services to meet the needs of special communities like regional and remote communities, CALD, LGBTI and indigenous people with disability?**

*These cohorts are poorly represented, are often isolated and experience an absence of representation. Their voice is rarely heard, and they frequently experience difficulties regarding access outside of their communities. There needs to be widespread training available to develop cultural competence when working across marginalised groups, together with funding to support access in a diversity of ways to minimise barriers to access. Peak bodies play an important part in highlighting the shortfalls to access for particular groups, e.g., people with developmental disability, mental health conditions; coexisting physical and psychosocial disability.*

*It is important for governments to support and develop peer advocacy across different cohorts, train and fund them to work with individuals and inform systemic reform.*

**6.5. Are there technological advances that can be leveraged to help provide advocacy services to people with disability?**

*There is a growing understanding of the effectiveness of alternative ways of thinking and communicating, new models and new technologies. Leading edge modes of video conferencing, information and resource technology are all things that should be explored as alternative ways of making use of innovations that better meet today's services users.*

*The importance of systems data collection and transfer of knowledge into practice as part of evidence-based improvement is vital. Some interesting work has been developed by the NSW State Electoral Commission is worth investigating, and NSW Health InforMH, also would have some helpful input into progressing outcomes and evaluation measures.*

**7. What types of advocacy resources will be required to meet future demand?**

*Consistent access points, tools and resources to assist people navigate the system, and for services to be funded to train their workers to operate utilising best practice principles, understand duty of care v dignity of risk and understand where conflicts of interest and ethical practice intersect, and what are the likely barriers to engagement for service users.*

**7.1. What are the most significant resource deficiencies in the current disability advocacy service system?**

*Recognition that advocacy is an all of government issue across the service system is key. There needs to be a coherency of service delivery and sustainable funding, supported by a code of conduct that reflects a human rights perspective, clear complaints pathways and mechanisms.*

**7.2. Which level of government, Commonwealth or State, should be responsible for the funding or provision of the different types of resources identified?**

*The Commonwealth, states and territories all have responsibility for funding services and sector development/ training.*

*See the Victorian Government submission to Productivity Commission Review of NDIS Costs (April 2017, p.19)*

*[https://www.pc.gov.au/data/assets/pdf\\_file/0019/216064/sub0174-ndis-costs.pdf](https://www.pc.gov.au/data/assets/pdf_file/0019/216064/sub0174-ndis-costs.pdf)*

*“The role of advocacy and self-advocacy will continue to be important in building participants’ capacity to meaningfully exercise choice. Particularly during transition, some participants may need additional assistance to navigate the planning and plan implementation processes.*

*Advocacy in Victoria is currently funded through a mix of Commonwealth and State funding. A recent review of the Victorian Disability Advocacy Program highlighted opportunities to strengthen disability advocacy by increasing access, engagement and support for people with a disability and their families; building workforce capacity; improving measurement of performance and outcomes; responding to increasing demand and gaps in service delivery; and a stronger focus on systemic and self-advocacy. Victoria recommends the PC consider whether the advocacy function needs to be more explicitly recognised in the NDIA framework.”*

**7.3. What is the role of peak bodies in delivering any of the needed resources to the rest of the sector?**

*The role of Peak bodies varies enormously. Some work to highlight individual and specialist issues or represent the voice for their sector/interest group in advocating systemic reform. Some do both. Some peaks like MHCC represent service delivery organisations and play an important role in driving a reform agenda and use their expertise to develop best practice guidelines and provide the sector and its workforce resources through research and development projects, accredited training and professional development. There is no ‘one size fits all’. Peaks represent the specialist needs of their stakeholders often at both a state and national level. It would be a great mistake to think that one body alone could represent a diverse disability landscape.*

**7.4. What is the role of representative bodies in delivering any of the needed resources to the rest of the sector?**

*Representative bodies create a supportive environment for their stakeholders and take a leadership role in providing a voice for the sector through engagement with government and across agencies and sectors. They provide a clearing house for referral, information, training and sector development resources; often collect local data and provide opportunities for engagement and codesign in research and development projects. They often deliver advocacy in terms of individual support and systemic advocacy and engage with both state*

and national issues. They characteristically collaborate with government departments in projects and development of best practice approaches and outcome measurement.

**7.5. Are there specific resource requirements to enable self-advocacy supports or services to be more widely available?**

*As mentioned earlier, new technologies would be invaluable. Funding will be necessary to develop websites and interactive resources to assist people able to self-advocate. Others will need to be supported towards greater autonomy.*

**7.6. Are there capacity-building resources that advocacy services require to support their sustainability?**

*Without sustainable and sufficient funding streams, equity and access will continue to be limited. An important element in the dynamic and emerging disability service space is the need to fund widespread workforce training in supported decision-making skills and capacity building, and to fund advocacy as part of a worker's role to support individuals to become more independent and autonomous. This requires a two-tiered system that can build workforce capacity and in turn build a consumer's capacity and confidence to assert their human rights.*

**8. In what ways can the roles and responsibilities of the Australian, State and Territory Governments be better apportioned or clarified?**

*The Australian, State and Territory Governments all have a role in providing consistency, accountability and funding appropriate advocacy services so that the voices of people with disabilities are heard when governments make decisions about supports and services that affect them. Clarity as to who is funding what services is important to ensure that people are not missing out due to gaps in advocacy.*

For any further information about this submission, please contact Corinne Henderson, Principle Advisor, Policy & Legislative Reform at [corinne@mhcc.org.au](mailto:corinne@mhcc.org.au)



Carmel Tebbutt  
Chief Executive Officer, Mental Health Coordinating Council