

Disability and Carers Group
Department of Social Services
disabilityadvocacy@dss.gov.au

Re: Review of the National Disability Advocacy Program

Dear Sir/Madam,

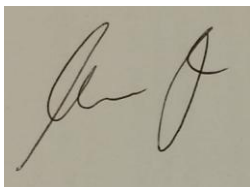
Tandem Inc. welcomes the opportunity to respond to the Review of the National Disability Advocacy Program Discussion Paper. Our submission focuses on the recognition and inclusion of family members/carers who support people with psychosocial disability (Mental Health) in advocacy in Victoria

Tandem, formerly known as the Victorian Mental Health Carers Network, was established in 1994 and is the Victorian peak body for families/carers of people with experience of a mental illness or emotional distress. Tandem is a not for profit, community based organization. Tandem promotes and advocates for family/carer involvement in treatment and recovery of people experiencing mental health difficulties, family/carer participation in planning, delivery and evaluation of mental health services and appropriate support for families/carers. Our principal areas of work are: systemic advocacy, contributing to mental health policy development, information provision, development, delivery and promotion of family inclusive training for the mental health workforce, development delivery and promotion of training for families/carers in being effective carer representatives and administration of the Victorian Carer Support Fund on behalf of area mental health services.

Tandem works collaboratively with the Mental Health Consumer peak body VMIAC as well as service providers to support service delivery improvements resulting in better health outcomes overall for people experiencing mental health difficulties and their families/carers.

Thank you for accepting our submission. For further information, please feel free to contact me at marie.piu@tandemcarers.org.au or by telephone on 03 988035501 or 0428945230.

Yours sincerely,



Marie Piu
A/ Executive Director
Tandem Inc.



tandem

representing Victorian
mental health carers

Tandem submission to the Review of the National Disability Advocacy Program

**A Submission by Tandem Inc,
Representing Victoria's mental health carers
June 2016**

About Tandem

Tandem is the Peak body for mental health carers in Victoria. We advocate for:

- Involvement in planning and care
- participation in system change
- support for families and carers

Tandem, formerly known as the Victorian Mental Health Carers Network, was established in 1994 and is the Victorian peak body for families/carers of people with experience of a mental illness or emotional distress. Tandem is a not for profit, community based organization. Tandem promotes and advocates for family/carer involvement in treatment and recovery of people experiencing mental health difficulties, family/carer participation in planning, delivery and evaluation of mental health services and appropriate support for families/carers. Our principal areas of work are: systemic advocacy, contributing to mental health policy development, information provision, development, delivery and promotion of family inclusive training for the mental health workforce, development delivery and promotion of training for families/carers in being effective carer representatives and administration of the Victorian Carer Support Fund on behalf of area mental health services.

Our mission is to ensure that the importance of the contribution, expertise, experiences and needs of families and other carers is recognised and that these needs are addressed. Families and other carers of people with mental health issues will be partners in treatment, and service delivery, planning, research and evaluation. The lived experience of families and other carers will be key drivers of policy and program formation at both the individual and systemic level.

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Background

Tandem welcomes the Department of Social Security commitment to the National Disability Advocacy Program and welcomes the opportunity to provide feedback with a view to delivering the best outcomes to those that need it most. We are hopeful that our reflections go some way towards highlighting the particular needs of Mental Health Carers for advocacy support.

Formal advocacy services such as those funded by the NDAP play a key role in pursuing and achieving these objectives. However, in many cases advocacy in the area of mental health is performed largely by family members /carers. The role of a mental health carer is an enormously complex and often difficult role. The pressures and demands of the caring role directly impact on a person’s identity and life journey. The hopes, dreams and aspirations of carers themselves often play a secondary role¹.

In the forward of **A Practical Guide for working with Carers of People with a mental illness**² launched in March 2016, Prof. Allan Fels Chair of the National Mental Health Commission notes that the 2.4 million people who care for those with a mental illness, and those who work with these carers, have been, to a large extent, the unsung heroes in mental health in this country. They will remain the bedrock of the system. This Guide recognises carers are a crucial component of any partnership approach to service delivery. It has been developed to assist staff across service settings in Australia in recognition and support of carers, to enable them to continue in their role as partners in recovery. Mental illness and its treatment is a unique journey. Illnesses are episodic in nature and the need for care changes. People will move in and out of different stages at different times³. The Guide reminds us that Carers are often ‘hidden’, or do not identify as a carer. Children who become carers face particular difficulties in being recognised and having their needs met. In culturally diverse communities, responsibility for the provision of care may involve the entire community and may provide additional challenges during the process of identifying who is a carer.

A carer may need to assist a person with disability to express their wishes or to physically access an advocacy service. In some cases, a carer may even act on behalf of a person with disability, accessing advocacy services to deal with issues they have identified that the person they care for is facing. Tandem engages with many carers who are seasoned advocates, usually without any particular training or formal recognition. For many carers, advocacy is a normal part of life. Whether or not they use the term, advocacy is often something they have been doing for years or even decades. Carers advocate because they have to in order to improve the support and inclusion of the person they care for. However, performing the role of advocate can come at a cost for carers, who have to balance advocacy with their often demanding caring role, not to mention other responsibilities such as working or raising a family. The cost is usually the carer’s own wellbeing. Many carers report that they are simply too busy or exhausted to advocate effectively.

¹ Lovelock, 2015

² <https://www.mindaustralia.org.au/resources/families-and-carers/a-practical-guide-for-working-with-carers-of-people-with-a-mental-illness.html>

³ Ibid p8

Others lack the skills and confidence required to do so. Carers need support if they are to advocate effectively for the people with psycho-social disability that they care for, help them to access formal advocacy services and empower them to self-advocate.

Acknowledging the role of carers and including them in service provision are key principles enshrined in the Statement for Australia's Carers, part of the Commonwealth Carer Recognition Act 2010⁴: The relationship between carers and the persons for whom they care should be recognised and respected. Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.

The vision for NDAP

Tandem supports the DSS vision for the NDAP in principle, however we caution against a 'consistent' approach if that means making the assumption of homogeneity. It is imperative to be mindful that people with current disabilities, ages, genders and ethnicities will need tailored advocacy service responses and may in fact, be excluded by default if the service offering is not culturally 'safe' in the case of Aboriginal community members or be delivered by advocates without an understanding of the particular disability, in this case psychosocial disability and Mental Health issues more broadly.

Models of advocacy

Tandem notes that NDAP agencies are currently funded for the model or models of advocacy they deliver. Tandem cautions that a focus on the human rights of the person with disability may result in the exclusion of family/carers. This has been a feature of the NDIS roll out where reports of family/carer exclusion have been noted where the person with a disability does not explicitly acknowledge the Carers' role and need for support.

Question:

1.1 *How do people with disability, their families and carers benefit when agencies are funded to provide only one or two models of support?*

Response

Tandem believes that advocacy services should be required to engage in both *systemic* and *individual* advocacy. Systemic advocacy agencies that do not inform themselves of issues through active involvement in advocacy at a grass roots level may lack the authority to speak on behalf of those they purport to represent. Tandem attests that as a peak body representing Mental Health Carers working in partnership with other peak bodies such as Victorian Mental Illness Awareness Council, representing those with a lived experience of mental health, form a natural system for capturing trends and identifying human rights and service access issues within the disability services sector being best placed to identify and map service demand and gaps.

Question:

1.2 *How do we value and support the various models of advocacy while ensuring equitable access to individualised, fit-for-purpose advocacy, regardless of location?*

Response

For the reasons outlined in the above response, Tandem believes that it is only fit-for-purpose individualised advocacy services that can make a positive contribution to those with a disability and their families/carers. The way this can be supported through the NDAP is by funding disability specific (mental Health in this case) complementary services that can work in partnership to provide a holistic advocacy service such as that described above by VMIAC and Tandem in each State and Territory.

⁴ <https://www.legislation.gov.au/Details/C2010A00123>

Improving access to advocacy supports

Question:

2.1 *How do we improve access for:*

- *people with disability from Aboriginal and Torres Strait Islander communities and their families?*

Response

Tandem acknowledges the Aboriginal and Torres Strait Islander people as the first people of Australia. Tandem would stress the importance of Co-design and Co-Production of advocacy services to ensure that these services are culturally appropriate and safe for community members to access. This can only be done by authentic engagement with Aboriginal controlled agencies such as VACCHO and VALS in Victoria.

- *people with disability from culturally and linguistically diverse communities and their families?*

Response

As peak body for Mental Health Carers in Victoria, which has arguably the most culturally diverse population in the country, it continues to be essential for us to advocate for services to provide community members with access to information in their language of choice and routinely have access to interpreters as required.

- *people with disability in rural, regional and remote locations? People who are very socially isolated including those with communication difficulties and those in institutional care?*

Response

Tandem believes that where it is not possible to provide face to face assistance, the use of technology to facilitate disability specific advocacy is paramount, rather than access to a generic service, for those from rural regional and remote locations. This may result in a partnership between a local generic and state-wide disability specific service to provide the best possible service.

Improving the advocacy evidence base and coordination on systemic issues

Question

3.1 *What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations?*

Response

Tandem suggests there should be a consistent data collection process across NDAP funded agencies which could be compiled by DSS as a tool to inform government and other funded agencies of service trends and to assist in the proactive identification of advocacy shortfalls. Systemically, it is important to identify that mental health does not always have a universal language or understanding. Tandem joins VMIAC in acknowledging that in some instances the language of disability is more acceptable within communities rather than mental health. Whilst we promote data collection, Tandem also recognises that systemic advocacy has a myriad of opportunity to step outside the breath of what we can facilitate. As Tandem and VMIAC share a 'no wrong door policy' both peak bodies are often made aware of barriers experienced by each other's members and are able to tap into each other's expertise.

Question

3.2 *How can we help disability advocacy organisations work with a wide range of other organisations with similar aims, such as:*

- *disabled people's organisations (DPOs)*
- *the Australian Human Rights Commission*
- *Ombudsman organisations*
- *aged care advocacy organisations*

- *state disability advocacy organisations*
- *peak bodies?*

Response

Tandem believes that the current competitive environment accentuated by the NDIS could potentially create further barriers to working in partnership as agencies see themselves as having to compete for a slice of the same pie. Despite this environment Tandem strives to work in partnership and collaborate wherever possible to ensure the best possible systemic advocacy result for its members. An authorizing environment to support such working partnerships perhaps with funding attached could be appropriate for DSS to consider as part of its funding agreements with those providing NDAP going forward.

The interface with the NDIS and addressing conflict of interest

Question

4.1 *What steps or organisational structures should be put in place to ensure conflicts of interest do not arise, or are minimised?*

Response

Tandem concurs with the position that the Victorian Office of the Public Advocate has stated in its response to DSS in the current review:

- Effective advocacy requires independence, which places the organisation outside the service system, so it can provide an effective critique and uncompromised advocacy support.
- Advocacy and service delivery need to remain separate to ensure that both services are not competing for the same resources and also to ensure that the advocacy organisation is not viewed as being part of the service system.
- Advocacy organisations should not provide service and advocacy to the same person.⁵

Question

4.2 *How do we avoid gaps between supports provided by the NDIS and advocacy funded by the NDAP?*

Response

The inclusion of Family Advocacy and Parent Advocacy in the current NDAP acknowledges the importance of supporting carers to advocate with and for people with disability. Family and parent advocacy needs to be a priority as the National Disability Insurance Scheme (NDIS) rolls out, as carers will play a key role in supporting many people with disability to prepare for and access the NDIS. Many carers will support participants with the planning process, and many will assist participants with managing and implementing their plan. Some carers will naturally take an advocacy role, but others may require the support of a friend, service provider representative or advocacy service. Information and resources need to be readily available to carers to help them advocate effectively. Adequate advocacy services also need to be on offer for carers who do not feel confident advocating for themselves.

In its recent response to the NDIS consultation on its planned I & Linkages C tier of operation, Tandem supported the Mental Health Council of Australia proposal *that maximising access to ILC⁶ interventions would be cost effective and seem likely to save costs by preventing psychosocial disabilities from emerging or worsening over the long term.* The importance of this prevention and early intervention investment is no more apparent than when we consider the vulnerability of children and young people who are often the 'hidden' mental health carers. It has been shown that providing parenting and family based interventions to parents with a mental illness is clearly linked to improved outcomes for their children noting a 40% reduction in the risk they will also develop mental health issues.⁷

⁵ Office of the Public Advocate submission to the REVIEW of NDAP, 2016

⁶ Originally designated as Tier 2 of the Scheme.

⁷ Goodyear, M et al, Standards of practice for the adult mental health workforce: Meeting the needs of families where a parent has a mental illness [http://tandemcarers.org.au/images/Goodyear%20et%20al%202015%20\(2\).pdf](http://tandemcarers.org.au/images/Goodyear%20et%20al%202015%20(2).pdf)

Under the NDIS support for carers is currently tied to consumer needs and consent. Tandem wants to reiterate that carers have their own support needs separate to the consumer and that carers are often 'hidden'. The international experience of disability support insurance reveals that carers have not received support through individual support packages. This suggests that access to mental health specific advocacy services are critical to ensure these vulnerable 'carers' are supported and empowered to avoid them becoming mental health service consumers themselves.

Of the NDAP providers in Victoria, only the Victorian Mental Illness Awareness Council explicitly provides advocacy to those with mental health issues. There is currently no specific advocacy service for mental health carers. If disability advocacy services were better resourced and more intentional about building the capacity of carers, advocacy support would be more equitable and independent. People with mental health issues (psychosocial disability) and their carers need informed, trained advocates available to sit down with them as they prepare for the NDIS, engage in the planning process and implement their plan. Carers who are not equipped to self-advocate, or who lack informal networks to assist, also need access to independent, professional advocates to attend planning sessions with them.

Although Tandem acknowledges that additional funding has been provided through the NDAP to address advocacy needs particular to the NDIS context, the current framework does not identify two areas in which advocacy will be critical as the NDIS rolls out: the availability of advocates to attend planning sessions, and access to advocacy services for people who are not eligible for NDIS packages.

Ongoing block funding for disability advocacy that extends to people with disability and their carers who do not have access to an NDIS package is also very important, as not all people with disability will be eligible for an NDIS package. While the soon to be finalised Information, Linkages and Capacity Building (Tier 2) component of the NDIS will go some way towards meeting the advocacy needs of this group, it is not a dedicated advocacy program, and will not be independent of the NDIA. Therefore, Tandem believes that the Department of Social Services needs to ensure that there are no advocacy service gaps created by the transition to the NDIS for people with psychosocial disability and their carers.

Understanding and improving access to justice

Question

5.1 *What forms of legal review and representation do people with disability need most?*

5.2 *What barriers prevent people with disability from accessing justice?*

Response

People with disabilities, in particular psychosocial disability, do not always have equitable access to legal services. In Victoria, unless you are on a community treatment order you are unlikely to be able to access subsidized legal services. If you are a Mental Health carer any legal advice sought is likely to be at your own expense and so dependent on your ability to pay.

Conclusion

Tandem supports the continuation and review of the National Disability Advocacy Program, bringing it into line with the evolving sector as it transitions to the NDIS. However, we strongly believe that due to the unique needs and knowledge required, mental health carer support and carer advocacy need to be a greater focus at this critical time.

Tandem notes that the only NDAP provider in Victoria specifically funded to support those with lived experience of mental health is VMIAC which is the equivalent Victorian peak body for Mental Health Consumers. VMIAC is funded to provide individual, group and systemic advocacy. This is welcomed by Tandem however due to the issues highlighted for Mental Health carers it believes that a benefit arising from this review would be to recognise the critical role Mental Health Carers play in the health and wellbeing of those with Mental Health issues and ensure funding is provided to those supporting them. As

previously mentioned Tandem currently works in partnership with VMIAC wherever possible to address the advocacy needs of Mental Health Consumers and Carers however does not receive funding for individual advocacy and so its role must ostensibly remain systemic. A funding model going forward that supports and rewards partnership within the framework of an authorizing environment across disability specific agencies such as VMIAC and Tandem in Mental Health, would strengthen community support and achieve much more meaningful and sustainable results.

As highlighted by Professor Allan Fels, Chair of the National Mental Health Commission in 2016, the 2.4 million people who care for those with a mental illness, and those who work with these carers, have been, to a large extent, the unsung heroes in mental health in this country. They will remain the bedrock of the system. Tandem calls on the Department of Social Security to recognise this vital role and ensure that they are supported by specialist mental health carer advocacy support as currently provided for a range of other disabilities.
