

individual & systemic advocacy



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Submission

Review of the National Disability Advocacy Framework

24 July 2015

People with Disabilities (WA) Inc. (PWdWA) would like to thank the Department of Social Services for the opportunity to provide comment on the review of the National Disability Advocacy Framework.

PWdWA is the peak disability consumer organisation representing the rights, needs and equity of all Western Australians with disabilities via individual and systemic advocacy.

PWdWA is run BY and FOR people with disabilities and, as such, strives to be the voice for all people with disabilities in Western Australia.

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Recommendations

- **The funding and administration of advocacy, both independent individual advocacy and systemic advocacy, must remain independent from the National Disability Insurance Scheme.**
- **Adequate funding must be allocated to allow appropriate organisations to deliver advocacy for people with disability and budget for an increasing demand in this type of service.**
- **Individual advocacy should inform systemic advocacy and build on key issues, it is important that with the changes in how disability services will be administered, funded and managed in the future that advocacy issues that are systemic by nature are funded so that appropriate action can be taken.**
- **Funding for advocacy must be available from both federal and state governments to ensure advocacy can be delivered at all Government levels on any issue.**
- **Advocacy assistance for people with disability must be available not only to the disability sector but also across other sectors such as education, health, justice, housing, employment and consumer protection.**
- **Funding is made available for individual advocacy for people with psychosocial disability who do not fall under the NDIS.**
- **Use the National Standards for Disability Services as the single quality framework for Advocacy services so as not to overburden the sector with a variety of systems that essentially monitor and report on the same things.**
- **Include a question/s about disability in the Australian Census to ensure that future planning of services is developed on sound evidence.**
- **Include a specific principle/outcome about Safeguarding as part of the National Disability Advocacy Framework.**

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Introduction

Since 1981 PWdWA has been the peak disability consumer organisation representing the rights, needs, and equity of all Western Australians with a physical, intellectual, psychosocial, or sensory disability via individual and systemic advocacy. We provide access to information, and independent individual and systemic advocacy with a focus on those who are most vulnerable.

PWdWA is run by and for people with disability. Its mission is “Advocating for the rights and empowering the voices of people with disability in WA”.

PWdWA welcomes the opportunity to provide feedback on the review of the National Disability Advocacy Framework (NDAF) and is encouraged that it will be guided by the principles of the *United Nations Convention on the Rights of Persons with Disabilities*.

The plethora of current inquiries indicates a resounding need for advocacy. It has been highlighted in submissions to the Joint Parliamentary Standing Committee on the NDIS, the Senate Inquiry into young people with disability in residential accommodation, and the most recent Senate Inquiry into abuse and neglect of people with disability. For example the senate report Young People in Aged Care recommendation 9 states:

‘The committee recommends that the NDIS, in all NDIS trial sites, and the relevant state or territory government in all other areas:

- assign an advocate to all young people living in residential care to provide information to a young person and their families about their options. If appropriate, the advocate can act on behalf of the young person;*
- assign an advocate to all young people at risk of entering residential care to provide information to a young person and their families about their options. If appropriate, the advocate can act on behalf of the young person. The advocate should be made available as early as possible after diagnosis of an illness or disability and be assigned before any placement commences*

The following extract illustrates the increasing number of people with disability living in Australia in the future. This data although it shows a considerable increase does not show the true extent of those people who have a disability that is not counted as severe and also one of an ageing population.

In 2099, it is estimated that approximately 4 million people will have a severe/profound core activity limitation in Australia – more than triple the current number. However, the Australian population is estimated only to double over this same time period; hence, it is likely that the same amount of informal care will not be available in the future to support people with

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disabilities. ((PwC – Disability expectations: investing in a better life, a stronger Australia)

There will be a huge strain on an already overburdened system and advocacy will play a role in making service providers more efficient and effective, and contributing to their continuous improvement. Advocacy should be viewed with a long term focus and not be affected by cuts due to a downturn in the economy. There needs to be a focus on long term capacity building strategies and not just a short term fix.

Recently, PWdWA submitted its response to the Information, Linkages and Capacity Building framework (ILC). The recognition that the ILC framework is an important element of the National Disability Insurance Scheme (NDIS) is welcomed because it allows for the development, advocacy, engagement and active participation for all people with disability and not solely individuals who are eligible for Individual Funded Packages (IFD). Advocacy organisations have been the places that many people with disability know they can contact for information, and to be heard regardless of where else in the system they have been.

PWdWA acknowledges the ILC framework will provide one of the mechanisms by which the NDIS can influence and shape mainstream services at a systemic level; to provide better outcomes for people with disability, their families and carers. It is important to develop an ILC framework that is transferable and can work across states. Individual and systemic advocacy actually play a key role in helping get mainstream services to be inclusive and accessible for people with disability. Advocacy is all about raising the voice of the person and the issues of people with disability wherever those issues are, be it state, commonwealth or private sector.

Principles

PWdWA accepts **all nine** principles as guiding the provision of advocacy for people with disability in Australia. However in recognising the increasing importance of advocacy for reasons cited in the introduction, PWdWA considers that a number of the principles need to be strengthened to ensure that changes in the disability sector in the future will be met.

“Disability advocacy operates under relevant Commonwealth, State and Territory legislation and the principles of the United Nations Convention on the Rights of Persons with Disabilities and other relevant United Nations Rights Treaties, to protect and promote the legal and human rights of people with disability;”

PWdWA welcomes this principle. However, the recent Senate Inquiry into violence neglect and abuse in WA and the associated report ‘behind closed

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doors' provides prime examples emphasising the need for high quality individual advocacy that can represent people who are most vulnerable and at risk. Being safe and feeling safe is a basic human right. The inquiry shows that the system for protecting people with disability is 'broken'. The report illustrates many cases of illegal and inhumane practice.

John, a young man with an intellectual disability and cerebral palsy, was living in a rented unit with significant support. The family employed a qualified psychiatric nurse through an agency, with appropriate checks and police clearances. References were provided and checked. For three months, the worker was regarded as a superb support person, but after the probationary period was up, 'the wheels started falling off'. Abuse was suspected and after some weeks, a series of incidents occurred which resulted in the family terminating the workers employment. The worker tried to argue that he was unfairly dismissed, but there was significant evidence to support the family's claims. After the support worker left, another support worker alerted the family to some written material that had been left on the computer at John's unit. The support worker had been using the computer to write a rebuttal to an unfair dismissal complaint, for 'throwing a woman with an intellectual disability up against the wall and smashing her face in'. The woman had allegedly assaulted the worker. The family contacted the man's previous workplace and they substantiated that he had just lost the case and had been dismissed for abuse. - WA Disability Abuse Inquiry

PWdWA therefore recommends that this principle includes specific reference for the need to 'safeguard' individuals. Advocacy is critical to ensure this happens and the need to express this in its framework's principles is paramount.

"Disability advocacy seeks to influence positive systemic changes in legislation, policy and service practice and works towards promoting inclusive communities and awareness of disability issues;"

PWdWA strongly supports systemic advocacy. It is vital, due to the changing nature in the way systemic advocacy will be funded in the future that systemic concerns are a culmination of issues borne from individual advocacy issues or raised by individuals with disability.

In responding to government policy papers PWdWA has recently gathered the individual advocacy issues of people with employment related advocacy to inform our submission to the Employment Framework. We have also found we do a lot of individual advocacy on inclusive education issues and so we have partnered with another advocacy organisation to collate those experiences and take them to the Department of Education to work on the broader policy and practice themes.

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Some systemic issues are brought to us by individuals such as issues with accessible public transport, which will benefit all people with disability if they are addressed systemically. Other issues such as individual advocacy in relation to a person being abused or neglected are high priority and must inform government policy.

Outcomes

PWdWA supports **all seven** outcomes outlined in the discussion paper. As Advocacy moves towards a more outcome focused delivery model it is however extremely significant that the whole ethos of advocacy is not diminished that is:

Advocacy provided by all agencies for people with disability can be defined as speaking, acting or writing with minimal conflict of interest on behalf of the interests of a disadvantaged person, in order to promote, protect and defend the welfare of and justice for the person by:

- *Acting in a partisan manner (i.e. being on their side and no one else's);*
- *Being primarily concerned with their fundamental needs;*
- *Remaining loyal and accountable to them in a way which is empathic and vigorous (whilst respecting the rights of others); and*
- *Ensuring duty of care at all times.*

(PWdWA DSC tender submission)

It is important to realise that the successful outcome for advocacy is about the **process** of helping someone achieve their goal so that the individual feels empowered, heard and able to make decisions. The advocacy outcome is **not** whether the person actually achieved the goal.

PWdWA urges the review to align the outcomes and reporting of the National Disability Advocacy Framework with the National Standards for Disability Services. Contracts awarded to advocacy agencies from Department of Social Services (DSS) and in Western Australia the Disability Services Commission (DSC) are quality audited against these Standards. By ensuring the outcomes of the NDAF mirror outcomes of the quality framework of the funding bodies would ensure both consistency and reduce the administrative burden by adopting a single quality framework.

PWdWA has submitted a response to the proposal for a NDIS Quality and Safeguarding framework. Recommendations are proposed as follows:

- Ensure that the Developmental Domain is heavily factored into the quality and safeguarding framework as this provides real opportunity to develop and enhance natural safeguards.

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- Ensure advocacy, which plays an important role in all facets of the framework, is highly visible, resourced and accessible in the system.
- Develop mechanisms including peer support, training and self-advocacy that empower individuals, promote independence and provide options for flexibility.
- Any system development or modification is co-designed with people with disability. The system will be flawed without the design and input from people who know and live these issues on a daily basis.
- Find ways to innovate and allow a diversity of providers and ways to self-manage throughout the process and not over burden people or providers with bureaucracy which could limit choice.
- Work with mainstream safeguards including consumer affairs, police and court systems to ensure people with disabilities can use and access them, information can be shared, and that mainstream safeguards will respond appropriately.

PWdWA strongly recommends that specific reference is given to safeguarding in the principles and outcomes of the framework.

In addition to the general comments made about outcomes there are a number of specific items that need addressing:

“people with disability receive independent advocacy support that is free from conflict of interest;”

It is fundamental that advocacy is independent from the NDIS. As a member of the Disability Advocacy Network Australia (DANA), PWdWA fully supports the position statement ‘Independent Advocacy and the NDIS’ (2012) which states:

In the context of the NDIS, independent advocacy support should be available, on demand, to all people with disabilities:

- *Prior to and throughout eligibility and assessment processes*
- *when any issue or conflict arises with the NDIA or NIIS, a DSO or service provider*
- *to engage in service quality processes*
- *when an issue arises in relation to the services, supports or policies delivered by other (non NDIS or NIIS) arms of government*

The NDIS will not remove the need for independent advocacy support because:

- *No systems are perfect*
- *Systems are administered and services are provided by people who do not always act appropriately*
- *There will always be pressure on government to divert NDIS and NIIS money to other purposes*

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- *The NDIS addresses only the disability specific support needs of people with disabilities. It does not address the inequities and injustices of other sectors e.g. education, health, justice, housing, income support etc.*
- *Governments trend towards one-size-fits-all approaches and ever increasing controls over their funded programs. This, if not resisted, progressively limits the independence and autonomy of any beneficiaries.*
- *Effective advocacy requires learned knowledge and skills*

When considering this outcome of advocacy being independent and free from conflict of interest PWdWA urge DSS and the Disability reform Council not to fund independent individual advocacy support from NDIS packages, and to keep both systemic and individual advocacy separate from the NDIS. Firstly it is unknown when a person may need advocacy, so to factor that into a package is impossible. Secondly the advocacy needed may be during the planning process or a review of a persons plan or funding, so there is immediate conflict of interest.

The discussion paper talks about NDIS funding decision support, safeguarding supports and capacity building; however it is unclear what these are and who would provide this support. These items need to be detailed and clearly distinguished from independent individual advocacy. Peer support, training in assertiveness and complaints systems, mentoring, engaging options brokers or researchers may all fit in these NDIS funded supports.

“people with disability are actively involved in all aspects of the development, delivery and evaluation of disability and broader government policies, programs and services that impact them.”

PWdWA provides advocacy across all sectors. We strongly support the National Disability Insurance Agency (NDIA) to challenge other systems to fulfil their legal and best practice obligations by ensuring the enablers of the disability support system are adhered to fully. It is absolutely imperative that the key decision makers in mainstream areas such as health, housing, education and local government have an understanding of the need to include people with disabilities and an understanding of their obligations under the UNCRPD. The person with disability must be the priority and mainstream services must integrate to provide services that are person centred and provide equal access regardless of the type of disability or location of the individual.

It is important when designing a framework that people with disabilities are instrumental in its conception. Feedback is paramount and needs to be given greater credence than feedback from any other individual, service provider, government agency or business community. Co-design can be a difficult and

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challenging concept bringing together the different facets and recommendations to create a framework that priorities people with disability but one that also considers other relevant parties. People with lived experience of disability are the ones with direct expertise though and so will know what is going to work. However that expertise needs to be acknowledged as on one hand the government expects people with disability to find employment, whilst also expecting them to provide free expertise in consultations, evaluations and co-design. PWdWA recognises that this is a complex process and would welcome and encourage the opportunity to be involved.

Outputs

In general, PWdWA supports the outputs detailed in the NDAF. However PWdWA considers that there is a shortfall in funding to achieve some of these outputs. For example,

Disability advocacy that promotes community education and awareness of disability issues and rights;

Systemic advocacy that positively contributes to legislation, policy and practice that will support the agreed outcomes.

Following the various reviews of advocacy services at a national and state level there is a clear shift towards funding Individual advocacy services but a lack of clarity in funding for other types and in particular systemic despite strong evidence to support its continuation. Promoting community education, raising awareness and shaping policy and practice requires sustainable funding and whilst Individual advocacy will identify the issues there is not enough funding to support these activities. For example, we firmly advocate the need for adequate financial resource to implement the many initiatives identified in the ILC framework. It is important that capacity building and community awareness are fully costed and integral to budget planning and are not considered as voluntary arms and 'good will gestures' of the community sector, who are already stretched to the limit.. To achieve robust, relevant and effective capacity building requires sound investment into the community infrastructure through appropriate funding and support. An approach which is too slow will mean that people remain isolated with support in their homes if ILC change isn't keeping pace with the NDIS rollout.

PWdWA is also disappointed in the lack of acknowledgment for the need for advocacy in recent framework proposals such as the Safeguarding and Quality Framework and the Information Linkages and Capacity Building Framework even though there are an abundance of case studies to support

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the need for advocacy. Detailed are extracts from PWdWA's submissions on the frameworks which highlight this:

The ILC Framework is an essential element of the developmental and preventive safeguards for people with disabilities. This needs to be acknowledged as it is through capacity building and connection with mainstream that people with disabilities can safely take risks to learn and grow and experience good lives. Ensuring mainstream services like consumer affairs are working with people with disabilities and Disabled Person's Organisations brings the safeguards the rest of the community use into the disability sector and could strengthen those safeguards for the whole community e.g., understanding contracts in plain English. The ILC should also therefore be funded and implemented properly as an acknowledged part of the Quality and Safeguarding Framework. (PWdWA ILC framework submission)

Advocacy has an important role to develop a person's capacity to act with informed choice and control. PWdWA is disappointed that advocacy whether it be individual, self or systemic is very much understated in the current proposal and would strongly encourage its inclusion in a revised framework. Independent individual advocacy builds a person's capacity as the advocate is working alongside a person, helping them to understand their options and ensuring their voice can be heard. Advocacy is also a form of independent monitoring as it raises issues from an individual to a systemic level to address systemic abuse and discrimination. The ability to build capacity in terms of knowledge of rights, knowledge of complaints systems, confidence in self advocacy are all areas that will develop natural safeguards. Investing in community infrastructure whether it is through advocacy, peer support, education and training, awareness raising and improving the flow of information will all help to developing natural safeguards. (PWdWA Quality and Safeguarding submission)

PWdWA recognises the need for the following outputs:

Disability advocacy that is informed by an evidence base and is provided in an accountable and transparent manner;

Disability advocacy that is planned and delivered in a coordinated manner and supports communication between disability advocacy support, disability services, mainstream services and governments;

However, PWdWA is concerned about the lack of available data about people with disability to inform advocacy services. The lack of data around disability in the Census is concerning for PWdWA. There is a missed opportunity to collect data at a national level that would not only provide an evidence base

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for advocacy services but also inform and enable many organisations working in the disability sector to plan more effectively.

Conclusion

In conclusion, the current framework does partially identify what is needed in the current and future disability environment. However, the framework needs to be flexible to accommodate changes in terms of political stance, economic pressures, changes in demographics and service delivery. PWdWA anticipates a much greater need for advocacy as more people become better informed and knowledgeable about their rights together with more people being eligible to access services. NDIS is new and developing, evidence from trial sites already shows that the demand for advocacy services will grow as people begin to use the new system.

It is important that the principles reflect individual choice and are an enabler for people to reach their goals by informed decisions. A principle which focuses on preventing abuse, harm and neglect would strengthen the framework.

It is important that appropriate funding is attached to advocacy services to ensure the outputs can be delivered. Promoting an awareness of disability issues and advocacy that contributes to legislation require financial resources. Currently, it is not clear from Government as to how community education and systemic advocacy will be funded. More consideration also needs to be given to data collection and the distribution of this data to allow services providers to plan and deliver advocacy in a coordinated manner.

The outcomes of the NDAF are consistent with the outcomes of the National Standards for Disability Services. It is important that quality frameworks for measuring outcomes also reflect this and do not create duplication. As funding providers shift towards an outcome driven culture it is greatly significant that the outcomes for advocacy are enablers for individuals to achieve their own goals and not the actual goal itself.