**“Disability Advocacy”**

**What is it? Is it helping or is it part of the problem?**

Jenny Harrison BBSc, Grad Dip Psych; MPAA

– 31st July 2015

I appreciate the opportunity to make a submission to the review of the “National Disability Advocacy Framework” (NDAF). I make this submission as an individual.

I believe the NDAF is deeply flawed. The NDAF reflects values and attitudes toward the experience of disability that appear to be embedded in a non- disabled, service centric, charitable perspective that has failed to adequately reflect the voice of the people it wishes to serve. In addition, I believe the NDAF uses language and expressions that further discriminates, marginalises and disempowers those it serves, albeit unwittingly. The language, expression, concepts; and views expressed are not consistent with a framework that should be attempting to address major social and human rights injustice.

Australians living with disability are significantly disadvantaged and Australia compares poorly on the international stage. The NDAF requires significant challenge and change; I fear the current review is inadequate and fear the Discussion Paper (NDAF – DP) may limit the scope required to bring about a progressive response. I fear there has been inadequate engagement with the community to have the consultation necessary, in particular consultation with the people it wishes to serve.

The current senate inquiry into the abuse of people within disability service organisations plus the media coverage of incidents of abuse, have already highlighted the inadequacy of the Disability Services Commission and the Office of the Public Advocate, particularly, in the way in which administrators have seen their role. The current evidence indicates violence, abuse, sexual abuse, neglect and exploitation toward those of us who live with disability is deeply embedded in our culture. The organisations set up to oversee and regulate the service sector have failed. It would appear advocacy services have also failed to make a difference?

I believe advocacy services have a history of being difficult to access, ad hoc, without professional standards of practice, without evidence based practice and are marked by a lack transparency or accountability. In addition, there is an inherent view embedded that the ‘voice’ of a person with a disability is inadequate and advocacy will enable this voice to be heard. The argument assumes advocacy will enhance, or provide a voice that will be listened to. The writer does not believe there is evidence of this.

There are a plethora of individuals who call themselves “Disability Advocates” and organisations who regard themselves as “Advocacy Organisations” or advocacy is a part of their role. I refer to those funded through the Department of Human Services (DHS). There needs to be greater accountability in terms of what and how advocacy is delivered. There are additional individuals and groups who establish themselves and claim to be “Disability Advocates”, “or Representative” of people with disabilities. There is a need for these groups and individuals to provide information about which they are, what their professional qualifications are, and be able to demonstrate they are representative.

Other human rights movements have been led and driven by those being oppressed. This voice is the one that counts, the impassioned voice, the voice of experience, the lived experience. In addition, there is a process which is part of the movement for social change in which those who are oppressed speak out, develop a voice, unite, develop strategies, and demand equity – having others assume that voice is not helpful, it lacks authenticity and can be driven from a different set of agenda’s. The work of Paolo Friere (1970) needs to inform our views of advocacy and a movement for change. There needs to be a greater accountability from those claiming to be representative.

It is the view of the writer that the language, expression and discourse used in:

1. The “National Disability Advocacy Framework” (NDAF)
2. The Discussion Paper (NDAF:DP) offered to guide the responses;

Reflect a dominant discourse which needs to be examined. Both documents use a discourse that has persisted across decades and dominates across those services referred to as ‘disability service providers’. I have labelled this “Disability Speak”.

“Disability Speak”

The NDAF uses language and expression that communicates a view that living with disability is ‘outside’ the mainstream of society. The language and expression reflects confusion about the model in which it aligns – social model or charity model. The language and expression constructs a way of thinking about the experience of disability and creates a discourse that dominates. The discourse ‘Disability Advocacy for People with Disabilities’ reflected in the 2 documents is not helpful and does not engage the community as a whole.

Institutionalisation offers a life outside of society marked by physical separation but also a language and set of rules assigned to this ‘special’ population of residents, the term special is used ironically. The NDAF has continued to retain an image that living with a disability implies - living in a particular environment/ sector / system / service system / be a user of disability services / who needs to be included and allowed to participate. One gathers from the document that it has been driven and written by those engaged in the issues from a non-disabled and service centric experience of ‘disability’. Consequently the NDAF continues, what the writer believes, is an out dated and paternalistic attitude toward living with disability that fails to adequately engage with a broad range of people in the community who may or may not live with disability.

The definitions provided are often inadequate and both documents fail to provide references. It would appear ideas expressed by Wolfensberger (1970) are being used. Wolfensberger provided considerable theoretical work as he responded to the lives of people living in institutions in the 1970’s. It is important to review his notions of advocacy that underpin the NDAF and ask the questions - are they relevant to us in 2015, are they working for us as a community, are they bringing about change.

Individuals generally identify with a range of characteristics or attributes – gender, age, marital status etc. as opposed to identifying with any one feature. However, the NDAF refers to people in such a way that implies there is a single defining feature of ‘disability’ that people identify with. There is one mention that other characteristics may be present and this is referred to as having ‘multiple disadvantages’. This view of the experience of disability is a good example of NDAF being driven by ablest notions.

“Examples of Disability Speak in the NDAF and the NDAF-DP”

1. The title “*Disability Advocacy*” is a construct that doesn’t make sense. What is meant is Advocacy Services.
2. Line 1, pg. 1“*Disability Ministers*” is a construct that is not used elsewhere nor does it make sense. What is meant is Ministers with relevant portfolios and/or all Ministers and/or whole of government – e.g. list Ministers and/or portfolios
3. Point 5, pg1 “*People with disability*” followed by “*their* ability” – this is referred to as “othering” – it’s a way of talking about groups that we see as distinctly separate to us, ‘they’ are different to ‘us’ – using the terms them, they and their; are forms of othering. “Othering” is disempowering it indicates that the writer sees themselves as different to the ‘other’ group. We need language that engages all of us.

E.g. Living with disability can mean facing ….one’s ability to ….

1. Point 5, pg. 1 there is a use of language that minimises the experiences of living with disability “*often face barriers and attitudes that impede their ability* to *participate* in society resulting in *poorer life outcomes”.* We need language that calls it what it is, based on a social model and free of ‘othering’.

Eg. Living with disability means experiencing discrimination that prevents equal citizenship and opportunities to participation.

1. Point 5, pg1 “*Disability Advocacy* *provides* *people with disability* the *opportunity to participate in decisions that impact their lives* to *ensure their rights* are *promoted and protected*.” This is an aspirational statement rather than a statement about what ‘*disability advocacy* is doing’. The language is about *providing opportunities to participate in decisions*– this sounds benevolent, charitable, paternalistic as opposed to the language of human rights. *To participate in decisions that impact their lives* – I demand more than participation in decisions about my life, all adults do. I think this statement is extremely disempowering. *Their rights*, othering, implying *their rights* are different to others. *Their rights are promoted and protected –‘othering’* and promoted and protected by others. Rights being promoted and protected implies a violation of rights, then this needs to be said.

Eg. The right to make decisions about one’s life is fundamental.

1. Point 6. There needs to be a reference to Human Rights and Anti-Discrimination legislation which protects all in the community. The additional legislation and strategies are a result of the discrimination embedded in our community and a system that fails to see all people as having the same rights. This needs to be stated. Point 6 then funnels advocacy down through these limited mechanisms providing a further limited view of options and processes. There is a view that special legislation and processes are provided to ‘people with disability’.
2. Point 7. *The target group of the framework are people with disability.* Again this is aspirational. Is it saying that services are going to provide for 20% of the population, and children? Does the target group refer to themselves as ‘people with disability’? Is there an assumption that all people who experience disability require advocacy? This fails to acknowledge the roles and skills people working within the community have in addition to living with disability. Lawyers, commissioners etc.
3. Point 7. *The framework is underpinned by a person centred approach whereby policies and programs are designed to respond to individual needs and aspirations.* This sounds good and reflects wording in other documents, very much the language of the community services in relation to the experience of disability, but it fails to make sense and fails to equate to the broader community. Is it presuming that everyone is a service user? Is it seeing Advocacy services being similar to recreational services or career services that may be provided? Those in charge designing what is best for individuals.
4. Point 7. *Consideration of the role of families and carers will be taken into account. However, the needs and aspirations of the person with a disability are paramount.* This fails to make a constructive point but succeeds in articulating an attitude that they are at odds. The statement fails to acknowledge the role parents and families have to play as a result of advocacy services being inadequate or lacking skills to bring about the change required. In many situations advocacy services rely solely on the interpretation or views of the parent or family member, as the advocacy services do not have the skills or will to communicate directly with the individual. I have witnessed many circumstances in which advocacy services have failed to attempt to communicate with an individual and rely only on the views of the parent or supporters. This statement fails to acknowledge the reality of advocacy practice.
5. Point 8. *The Framework recognises and acknowledges that people with disability can experience, additional disadvantage including, but not limited to gender, age, education, sexuality, geographic location, ethnicity and cultural background.*

This statement communicates a lot about views embedded in this document. The view appears to be that ‘disability’ is the primary feature associated or given to a person, in contrast to a view of a person with a whole range of defining characteristics that one may identify much more strongly than ‘disability’. It also constructs a view that other defining characteristics are additional disadvantage. The writer found this a particularly offensive way of talking about a person. It also failed to context ‘disability’ as a part of the human condition. In addition, socio economic status is probably the most important factor yet omitted.

Eg. The Framework recognises that all members of the community can experience discrimination based on gender, age, education, sexuality, geographic location, socio economic group, ethnicity and cultural background. The experience of disability brings additional disadvantage.

1. Point 9, This has not included a reference for the definitions and they do not compare favourably with other definitions of advocacy.(a) *Disability Advocacy enables people with disability to participate in the decision making processes that safeguard and advance their human rights.* Rather than providing a definition the document attempts to provide an aspirational statement which is disempowering and fails to make a coherent construct. (b) *Individual advocacy supports people with disability to exercise their rights, through either one to one support or by supporting people to advocate for themselves individually, through a third party or on a group basis.* Again this does not fare well as a definition of advocacy. (c) *Systemic advocacy seeks to introduce and influence longer term changes to ensure the rights of people with disability are attained and upheld to positively affect the quality of their lives.* Again this does not fare well as a definition.

I assume the definitions and descriptions of advocacy are based on work by Wolfensberger (1970’s). This needs to be challenged and examined.

Point 10, the Principles.

1. Point 10, ‘*the parties to this framework;* the parties need to be identified.
2. Point 10, (a) *“Disability Advocacy operates under relevant Commonwealth, State and Territory legislation”,* Needs to state what it operates under, anything relevant is nonsensical.
3. Point 10, (b) *‘Interests, wellbeing, their full and valued inclusion,* Aspirational, lovely words but what about Human Rights and Equity, their – ‘othering’. The Principal understates thereby not serving people adequately
4. Point 10, (c) Aspirational, doesn’t set any principle.
5. Point 10, (d) where is the evidence based research to back up this statement?
6. Point 10, (e) Aspirational, not a principle. Where is the evidence based research?
7. Point 10 (f) Aspirational, paternalistic, judgement embedded ‘they can’t do it’. The term ‘self-advocacy’ is also disempowering. What other person in the community has to wear a label of ‘self-advocate’ when speaking up for themselves? It is quite bizarre and a prime example of this development of a language, words and labels specifically for someone who identifies with disability.
8. Point 10 (g) Aspirational.
9. Point 10 (h) Aspirational.
10. Point 10 (i) Aspirational.
11. Point 11. An agreement by whom to what.
12. Point 11. *People with disability have access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling full community participation.* This would appear to be a central premise so really important. As stated it promotes an ideal that is expressed by those in the service sector with a reluctance to engage in language of legal rights, equal rights instead we get ‘enjoy human rights’ and ‘full community participation’. This understates the issues that one is faced with, ‘othering’ and paternalistic.
13. Point 12. (a), (b),(c),(d),(e),(f),(g). Outcomes need to be measureable, these are not – they are wordy aspirations. Measureable outcomes lead to data collection and research and evidence based practice.
14. Point 13. Outputs in support of agreed outcomes but which goes with what.
15. Isn’t this output the same as outcome (f)
16. Where is the evidence based research you speak about here??
17. Isnt this output the same as outcome (g)
18. How does it do this?
19. How does this happen?

This section fails to give us more than aspirational statements. There is nothing about the profession or work of either the advocate or the organisations that employ them. There is nothing about standards, professional practice, and accountability, measuring outputs or outcomes.

Reform and Policy Directions

1. Point 14, meaningless – what commitment is required?

Point 15, meaningless – what improvements? Service delivery and access but what about ‘the practice’.

Point 15 (b), How will Government ensure disability advocacy is free from conflict of interest and independent of broader service system. There needs to be a transparent process in place and compliance mandatory...

The discussion paper continues the use of language and expression that reflects a non-disabled, service sector, charitable model approach to advocacy, the experience of disability plus the review of the NDAF.

“Examples of Disability Speak”

Line 9, *disability environment*

Line 18, *what is disability advocacy* – another round of silly definitions in addition to the NDAF. Eg. Advocacy= finding a job?

Line 26*, Governments are working together to make it easier for people with disability to get the advocacy they need and to improve the support they receive.*

The message is that the voice of the person is not adequate.

Pg. 3 Line 1-6. It is pleasing the words used in the NDIS have moved away from ‘advocacy’ to one of support. The picture here is that the person’s voice is being supported. There needs to be an image that there is a continuum of support and that people enter at different points.

Pg. 3 Line 12 and Point 1, *NDIS environment* – what does this mean – language that creates a sense of institutionalisation for recipients of funding, as opposed to members of the community.

Point 5, *Current and future* d*isability environment –* not appropriate terms to describe the community people live in.

The writer believes there needs to be a significant ‘disruption’ to the discourse that dominates the NDAF and the Discussion Paper. There is a strong sense of allegiance to Wolfensberger 1970 and a traditional, service centric discourse that continues to dominate. A disruption to this discourse will require some supporters to step aside, or stand behind, allowing those willing and able to disrupt, to bring change. Young voices within our community are vital to this process of ‘disruption’.

**Advocacy Services in Action**

Over the 21 years of my daughter’s life I have engaged advocacy services on her behalf. I will attempt to briefly summarise the experience and my concerns.

* They communicated directly with me about the issues. Never with my daughter.
* Advocates had no legal background or qualification, yet one provided legal advice and support to follow a legal process
* The schools were not interested in what the advocates had to say
* The advocates were not always aware of the school systems that related to my daughter
* One advocate attended school meetings and having a witness there really helped me – I had someone else witnessing the discrimination.
* One wrote letters of demand to the school that were ignored
* I attempted to contact an organisation for children with disability; I tried for a year to meet with them. I did give up trying.
* I stopped trying to engage an advocate for my daughter and continue to take that role, reluctantly.

I found the process time consuming. I had to meet with the advocate, provide them with information and develop a plan. I was concerned they did not communicate with my daughter. In the end I found organisations were no more interested in hearing from the advocate or advocacy organisation, than from me. In fact, on occasion, there was a shutting down of communication and a bringing in of numbers, at meetings.

Neither I nor my daughter has been asked to give feedback about our experience of engaging an advocate or advocacy service.

Amongst my cohort of parents most of us are professional with post graduate qualifications. Generally, the experiences reported are that advocates have limited skills, often low level qualifications in their fields of study and often less experience with the organisations we are dealing with every day. The lack of skill will or time for the advocate to communicate directly with our sons or daughters has been a common experience. There are no professional qualifications for an advocate. Anyone can call themselves an advocate or a disability advocate. I believe the term ‘disability advocate’ is nonsensical and people should be asked to stop using it.

The most common experience I hear is that outcomes were no better, with an advocate. There was often less interest in hearing from them, as opposed to those of us directly involved and have the skill and will to communicate with our son or daughter.

Alternatively when I took a legal process over an issue of discrimination and had a qualified lawyer acting on my behalf we achieved a positive outcome. Although, a positive outcome over that issue the success did not lead to any system improvement for my daughter.

All the issues facing my daughter were fundamentally discriminatory. I would have valued an accessible legal service with qualified and experienced human rights lawyer.

I found a lack of “professional practice”, a lack of credible experience with the legal system, and often a lack of knowledge of the systems in which we were experiencing barriers.

“Joining advocacy groups”

I have been involved in some groups that have included advocacy as part of their purpose. I found the experiences were dissatisfying personally and saw minimal contribution to a movement for change.

* Parent group – there were many differences in what parents viewed as ‘inclusion’ or ‘human rights’, interest was driven by son or daughter’s needs, dissatisfying in terms of bringing about significant social change. Parents are protective so often the results are practices and projects that ‘protect their son or daughter’, as opposed to being progressive or significant to a movement for change. Parents are already doing a bigger job than most in providing support to their sons or daughters. In addition, they feel compelled to change the world. Having a son or daughter with a disability does not mean parents necessarily have the skills nor the vision to bring about a movement for change. In fact, they can be supporters of the status quo and users of the dominant discourse I am critical of.
* Group that advocated for inclusive education – dissatisfying in terms of outcomes leading to the belief that change needs to be coming from within the education system.
* Groups that want to provide systemic advocacy – as previously stated, any divisions of individual advocacy and systemic advocacy are reflective of an acceptance of the kind of definitions put out by Wolfensberger (1970). There needs to be better education and examination of what constitutes systemic advocacy and social action.
* I have concerns about those who have a discourse that separates ‘advocacy on an individual issue’, e.g. with an individual and ‘systemic advocacy’. I have concerns about a discourse that imagines one organisation can do ‘individual advocacy’ and another does ‘systemic advocacy’. I believe this discourse highlights a lack of understanding of advocacy and reflects a failure in the NDAF to better inform.

**Conclusion**

It is the writers hope that the review will produce a ‘disruption’ to the current dominant discourse. Engaging with younger voices in the community is essential to this process.

It is the writer’s belief that a framework for Law and Social Justice is required. This needs to come from the voices of people with the lived experience. Any national framework for advocacy needs to be firmly engaged and driven by the voices of people living with a disability. Any other system of delivering such services will only maintain a counter movement that is driven, managed and controlled by those in the dominant group, the oppressors, albeit unwittingly. This group need to stand beside and stand behind.

The writer would like to see a greater examination of the terms used in the NDAF and the NDAF-DP. A shift away from Wolfensberger’s (1970) definitions to a language consistent with other human rights movements for social change.

The writer would like to see a greater engagement with other human rights groups, within Australia and internationally reflected in a framework for Law and Social Justice, to develop practice and a culture of social action.

The writer would like to see DHS genuinely support more grassroots activism through its support of advocacy. This will require significant change in attitude from within the department.

The writer would like to see the work of Paolo Freire be used as guiding principles and a development of a framework that is driven by those whom the NDAF desires to serve.

“No pedagogy which is truly liberating can remain distant from the oppressed by treating them as unfortunates and by presenting for their emulation models from among the oppressors. The oppressed must be their own example in the struggle for their redemption (Freire, 1970, p. 54).[[7]](http://en.wikipedia.org/wiki/Paulo_Freire#cite_note-7)

Likewise, the oppressors must be willing to rethink their way of life and to examine their own role in the oppression if true liberation is to occur: "those who authentically commit themselves to the people must re-examine themselves constantly" (Freire, 1970, p. 60).

I appreciate the opportunity to submit.

Regards

Jenny Harrison