Department of Social Services

31st July 2015

Dear Sir/Madam

Citizen Advocacy South Australia Incorporated has initiated over three hundred relationships of support for people with intellectual disability in South Australia since inception in 1986, using the Citizen Advocacy Principles and Practices as per the Citizen Advocacy model. About a third of the current relationships supported by the program are over ten years old with a few being more than twenty years in existence.

Over that time we have been grateful for the support of the Department in its various incarnations through the Demonstration Project funding and later through the National Disability Advocacy Program.

We are deeply concerned for the ongoing support of advocacy, which is independent and free of conflict of interest, for people with disability. Citizen Advocacy South Australia Incorporated supports the views expressed in the 2011 Productivity Commission Enquiry Report into Disability Care and Support which recommended that advocacy be provided and funded outside the NDIS.

The submission attached is provided in good faith that decisions made about the future of advocacy for people with disability will give greatest consideration to the people themselves who are most vulnerable in our society.

Yours sincerely,



Heather Buck

Chairperson

Citizen Advocacy South Australia Inc.

**National Disability Advocacy Framework Feedback**

July 2015

Citizen Advocacy South Australia Incorporated respectfully submits the following for your consideration.

1. ***Do you believe the current Framework encompasses your vision of advocacy in the NDIS environment? If not, what changes are required?***

Advocacy in all its forms is about speaking or acting on behalf of a person whom for whatever reason is unable to speak or act in defence of their own needs. Hence to function with legitimacy advocacy must be independent, that is free of conflict of interest, and/or perceived conflict of interest, focussed on the needs of the most vulnerable and responsive to the full variety of life issues that may appear, not just issues arising from disability services.

Advocacy programs and agencies must therefore ensure that they focus on the needs and best interests of the people they serve, with minimal conflict of interest. This is a primary reason that advocacy for people who are vulnerable due to disability should not be funded under the National Disability Insurance Scheme (NDIS) which funds service provision.

The current Framework states that the Government will ensure that advocacy will be free of conflict of interest *(see 15b “Governments will ensure that disability advocacy is free from conflict of interest and independent from broader service system that provides support to people with disability.”)* but then conflicts this in *15f by “Improving coordination and communication between the disability advocacy, mainstream sector and governments to develop the overall capacity of the sector, including promoting linkages between individual and systemic advocacy.”* Advocacy must be able to operate in all aspects of a person’s life, respond to injustices in services as well as the structures that put those services in place such as the NDIS.

The National Disability Advocacy Program (NDAP) of the Department of Social Services (DSS) would be better placed funded under the Attorney General’s Department or another such department which removes it from disability services funding.

The current National Disability Advocacy Framework (NDAF) does not clarify the relationship between the NDIS and the NDAP. The move away from National Disability Advocacy Standards is an indicator that advocacy is perceived as disability service provision. This is a grossly mistaken assumption.

Advocacy is not the same as service provision i.e. accommodation, employment support, personal assistance, therapies, respite, home help or equipment. Advocacy in any form cannot guarantee outcomes desired by the person with disability nor should it be a purchased service as it is the right of all people to be safe, have their needs met and be free of abuse and discrimination. People who are vulnerable due to disability are by definition in need of protection and defence sometimes because they may choose against what is in their best interest. Whole of life issues such as friendship, decision making, social development, likewise are not the realm of service provision but natural freely given independent relationships.

Citizen Advocacy has a broader perspective on advocacy for people who are vulnerable. Citizen Advocates are concerned with the whole person through relational advocacy which is strongly supported by the community. This means that a broad range of issues and needs can be addressed beyond the scope of the NDIS, while increasing the likelihood of people with disability being truly included in their communities, have support in their decision making, develop new skills, have safeguards in place to prevent harm, abuse and preventable crises throughout the dynamic changes of life.

***2. Are the principles of the Framework appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS? If not, what changes are required?***

The *‘disability environment’* is only changing in so far as people are experiencing the ebb and flow of their lives but their disabilities generally do not change. It is not the *‘disability environment’* that is changing it is the way that disability services are funded and delivered that is changing.

There is some incoherency in the principles because they refer only to disability advocacy which has been defined separately from individual and systemic advocacy. This demonstrates a poor understanding of social advocacy and the principles that underpin all forms of advocacy. This presents a difficulty throughout the whole document.

Citizen Advocacy operates with a well-defined set of principles. Where these principles match those of the framework we have no issue however in response to this question we offer the following points:

1. The framework principles limit what Advocacy is.E.g. *10b: Disability advocacy promotes the interests and well-being of people with disability and promotes their full and valued inclusion as contributing and participating members of the community.*

 Advocacy is first and foremost about responding to the abuse, ridicule, neglect and vulnerability of people with disability. True inclusion may be an outcome but not the primary role of advocacy.

1. *10c: Disability advocacy seeks to influence positive systematic changes in legislation policy and service practice and works towards promoting inclusive communities and awareness of disability issues.*

This is the role of systemic advocacy which cannot rely solely on individual advocacy programs for information on systemic disability issues. Individual advocacy programs are committed to confidentiality therefore are placed in a conflicting position if required to reveal their sources of data for systemic advocacy.

1. *10e: Disability advocacy ensures that views represented meet the individual preferences, goals and needs of people with disability*

This ignores that the majority of people with disability that experience confusion, lack of decision making experience and require support to make decisions that are in their best interests not just according to their rights or wishes.

1. *10f: Disability advocacy strengthens the capacity of people with disability to speak for themselves by actively supporting and encouraging self-advocacy.*

Self-advocacy is a model of advocacy that is limited to very few people with disability who may be taken seriously. The reality is that even ‘self-advocates’require support from a mentor, teacher, supporter who has skills in communication, to be taken seriously. This may occur as a person with disability gains skills and experience however it may be inappropriate for all disability advocacy programs to pursue this as a major goal.

1. *10i: Disability advocacy will foster effective strategic alliances to develop capacity to identify and respond to the needs of people with disability.*

It is not clear what is meant by *‘strategic alliances’.* Some forms of advocacy, for example Citizen Advocacy have as part of their model effective strategic alliances with community. However, to remain independent and free of conflict of interest advocacy agencies must be allowed to develop their own strategic alliances that are not dictated by the NDIS, NDAP, DSS or any other government policies.

***3. Are the outcomes of the Framework still relevant or should different ones be included? If so, what should be included?***

Advocacy is guided by the needs of the person which indicates some desired outcomes however advocacy cannot guarantee outcomes only the efforts towards a positive change. For example, disability advocacy organisations cannot promise economic participation or social inclusion only that the advocacy effort will be vigorous and focussed on the needs of the person with disability.

With this in mind we support the outcomes in general however there are some points to be made.

Our observations have shown that many people even with mild cognitive disability will require support to pursue their life goals and make decisions. Decision making for people with intellectual disability is a complex matter which cannot be easily addressed by a “decision facilitator” who may never have met the person before and really knows nothing about them let alone have their confidence. Therefore it is not“where necessary”but should be always readily available by advocates who genuinely know the person well.

We particularly support Outcome 12e which reflects our deep belief that to function with legitimacy advocacy must be independent, that is free of conflict of interest, and/or perceived conflict of interest to be effective.

Outcome 12f is of some concern because as with the rest of the document *‘multiple disadvantage’* as defined in the framework is not inclusive of mental illness, dual disability, and the complex life experiences of people with disability including abuse, neglect, ridicule, oppression and exploitation.

Outcome 12g is not achievable because from our experience the majority of people with intellectual disability involved in our program are not interested *in “being actively involved in all aspects of development delivery and evaluation of disability broader government policies programs and* *services.”* The majority of people with intellectual disability who we have had contact with just want what the rest of us want; a home which is stable, secure and where people can be themselves (home), something meaningful to do (work), people to share life with (family and friends) among other life giving things. How these things happen do not concern most people with intellectual disability and those who are just trying to get through each day.

**4. Are the outputs of the Framework still relevant or should different outputs be included?**

*‘Outputs’* and‘outcomes’are really the same thing. A preferable word rather than‘outputs’may be “ways” of achieving the outcomes.

1. Regarding 13a please note the comment above in outcome 12f (question 3 paragraph 4) about *‘multiple disadvantage’.*
2. 13b refers again only to disability advocacy rather than the full spectrum of advocacy styles. Most advocacy is provided on a referral basis which indicates that the needs are identified by someone somewhere. Is that not evidence based? Citizen Advocacy intentionally seeks out those people who are vulnerable and would not otherwise be identified as having needs.

Systemic advocacy must derive information from a broader base than individual advocacy because it must pick up issues relevant to numerous people experiencing similar issues.

1. 13c As a means to remain free of conflict of interest and effective in their work advocacy programs must select their own pathways of communication and alliances to support their work.

***5. Does the Framework identify what is needed in the current and future disability environment? If not, what changes are required?***

No, because:

It is not clear where advocacy will be placed in relation to the NDIS, therefore the independence and freedom from conflict of interest is not secured.

The framework assumes a great deal about the capacity of people with disability. It is focussed on the “higher” end of the bell curve in terms of ability with little consideration for people who have intellectual disability, communication issues and multiple complex needs.

The framework is naïve in understanding of the full range of needs among people with disability and the variety of advocacy responses that are required to address those needs. The framework, although stating that the *“need to improve outcomes for individuals with a disability experiencing multiple disadvantage underpins the Framework”,* does little to address the realities of people with intellectual disability who experience greater and more complex needs. The realities of abuse, neglect, exploitation and vulnerability of the majority of people with disability are not mentioned at all throughout the framework but rather focusses on rights and wishes. The needs of people to be protected from harm and for advocacy to address issues in their best interests are not considered.

Coherency in defining the types of advocacy that would genuinely make a difference for people would be a good starting point as would a clear definition of what social advocacy is and identify the principles underpinning all advocacy.

Recognition of the real life experiences of most people with disability (i.e. abuse, neglect, ridicule, oppression and exploitation) which advocacy protects against is another important aspect of the equation that has been overlooked or discounted in this framework would be useful.

Reintroducing the National Disability Advocacy Standards (NDAS) would useful because they better reflect the nature of social advocacy than the National Standards for Disability Services (NSDS). The NSDS yet again place advocacy together with service provision which is inappropriate.

 **6. Do you have any other comments, thoughts or ideas about the Framework?**

The following comments were made and regarded as worthwhile but did not fall easily under the questions provided. Hence these comments are offered here.

The Framework assumes that people who would benefit from advocacy either already have some idea of their wishes and skills to seek advocacy or they have someone significant in their lives to make things happen (e.g. family members). Many people have neither of these and for some people those closest to them are their abusers.

In order to have any influence advocates, paid or unpaid, should be acknowledged as significant others to the person with disability and have impact on the decision making, capacity building and safeguarding to be delivered under the NDIS. They are often the people who know the person best… sometimes even better than the person’s own family.

DEFINITIONS:

1. The definitions or descriptions, whichever they be, are confusing and inconsistent. We first need to understand the people who may benefit from advocacy. Then we must understand what advocacy is even in its broadest definition. Surely the whole framework is about disability advocacy! Advocacy is not just about supporting people to exercise their rights or to advocate for themselves. Advocacy is more than that. Advocacy is about ensuring that vulnerable people are not abused, neglected or devalued first and foremost. Their rights as equal citizens are part of the story but not the whole story.
2. The definition of Citizen Advocacy in the current framework is incorrect. A more accurate definition is that Citizen Advocacy seeks to support people with disability by matching them with suitable individuals from the community who enter together into a freely given, independent and unpaid relationship of support.

Please also see ‘National Disability Advocacy Program’- Citizen Advocacy. Film produced by DSS, 2013.

1. *‘Person-centered and self-directed approach’* are included in the definitions as though they are the same thing. They are not.

*‘Person-centered’* is a planning model which places the person in need at the centre of the planning. It is about how we work with the person, what is in their best interest, as well as what their wishes are, then we work out how to best make it happen for that individual. It takes into account the experiences of the person, significant others, circumstances, skills, personality, interests among many other attributes.

*‘Self-directed approach’* is a funding model not a planning model. Full control can only be achieved if the person has the skills to be in full control. If assistance is needed control is at risk.