JFA Purple Orange and SA Office of the Health and Community Services Complaints Commissioner (HCSCC) joint Submission

To the Department of Social Services Review on the National Disability Advocacy Program (NDAP)

June 2016

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About the Submitters

The office of the South Australian Health and Community Services Complaints Commissioner (HCSCC) is an independent statutory office established by the *Health and Community Services Complaints Act 2004* (the Act).

HCSCC assists people – service users, carers and service providers – this includes government, private and non-government health and community services.

The role of HCSCC is to:

- receive, assess and resolve complaints about health and community services in South Australia
- encourage and assist health and community service users to resolve complaints directly with service providers
- improve the safety and quality of health and community services in South Australia through the assessment, conciliation, investigation and resolution of complaints

JFA Purple Orange is the social policy arm of the Julia Farr Association Inc. We are a non-government, social profit organisation that conducts research and engages in dialogue with people with lived experience of disability to develop policy and practice. Our work is anchored on the principles of Personhood and Citizenship.

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Contents

1. Introduction

Thank you for the opportunity to make a submission to the National Disability Advocacy Program (NDAP) Review 2016. The fundamental importance of advocacy for supporting and improving the lives of people living with disability cannot be underestimated. This review, following the previous one (2015), of the National Disability Advocacy Framework is, again, timely and necessary as the National Disability Insurance Scheme evolves during its trial phase towards full operation.

We are supportive of the Government's maintenance of independent advocacy. We are also pleased to note the proposed NDAP initiatives, mentioned in the Discussion Paper, are intended to increase and expand the reach of funded advocacy services for people living with disability. Advocacy that aims to improve the conditions of the lives of people living with disability is no less important now, in the time of transition to the NDIS, than at any other time.

We note the Easy English version of this submission is asking different questions of submitters. We have collected responses to the Easy English version and have appended summaries of comments to this submission (see Appendix). Where possible, we have captured the sense of the issues and concerns of people responding to the questions in the Easy English version and added them to our commentary here.

Our submission outlines our position on the issues set out in the specific questions provided by the Department of Social Services in the 2016 Review Discussion Paper.

2. Responses to Specific Questions in the NDAP review

2.1. Models of advocacy (Questions 1.1 to 1.3 inclusive)

The context for the review seems to reside in the notion that advocacy should be focused on '*the human rights of the person with disability and their individual needs and not on what model of advocacy is available in their local area.*'[1]

The move to an integrated model of advocacy is admirable, if the goal of 'integrated' is to make it as easy as possible for a person to get the advocacy support they seek. This might translate to a "one-stop shop approach", where specialised knowledge and supports e.g. legal, systemic, individual advocacy and supports for self-advocacy, are readily available in a single setting, while being accessible in a greater number of locations than at present (similar models of advocacy, as far as we understand, have been adopted by the American Civil Liberties Union[2] and local government in the United Kingdom).[3]

However, one of the risks of integration, if not done well, is a loss of quality and choice associated with the diversity of advocacy methodologies. A one-stop shop can easily become a one-size-fits-all. HCSCC and JFA Purple Orange are concerned about the political attraction of a one stop shop solution that can be presented as a total solution for advocacy. Any integrated arrangement must make it possible for the advocacy-seeker to choose the advocacy pathway – for example demographic-specific, or self-advocacy, or family advocacy, or citizen advocacy – that's right for them.

Advocacy is about supporting a person's voice to be heard; and an integrated advocacy framework needs to uphold the uniqueness of each person's voice and choice, and not assume homogeneity. It must ensure individual customized information and resources to participants. We base our content in the remainder of this submission on this assumption about integrated advocacy.

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[1] Department of Social Services (DSS), 2016. Review of the National Disability Advocacy Program. DSS, Canberra, ACT. **Web**. [p4].
[2] *For example, see*: *American Civil Liberties Union Foundation of Massachusetts* website. *Mission Statement.* [*Undated*]. **Web**. (19 May 2016).
[3] *For example, see*: *Social Care Institute for Excellence* website. *Care Act 2014. Suffolk County Council. Total Voice Suffolk example of commissioning independent advocacy*. [*Updated*: March 2015]. **Web**. (19 May 2016).

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?'

And

Question 1.2 'What are the drawbacks?'

RESPONSE:

We recognise that funding can only be allocated on the basis of budgetary resources available in any period of time. In a period of static or falling government revenue, difficult decisions at the Departmental level are undoubtedly necessary. However, if the focus for the NDAP is the human rights and individual needs of people living with disability, funding allocations should be made with that focus while, nonetheless, acknowledging that specialist advocacy skills and knowledge may be geographically fragmented.

The way in which advocacy is delivered really depends on the person's circumstances. If advocacy agencies are funded to provide individual advocacy (rather than being tied to a particular type of advocacy model, i.e. family, self-advocacy, citizen, independent etc.) then it would provide far more flexibility to be able to deliver the type of advocacy support required. The question is whether specialised advocacy would be diluted as a result.

However, 'models of advocacy', as conceptual categories, are not necessarily a matter of concern for people living with disability. Regardless of models, the work of advocacy is, by its very nature, person-centred. The following perspectives are drawn from the lived experiences of people living with disability in our network. People requiring advocacy concern themselves with such matters as quality of advocacy and the capacity of advocates. Competence, friendliness, approachability and the capacity of advocates to remain committed are of concern to people living with disability. The capacity to remain committed to a person's cause is necessary, even when matters become complex or "too hard". If commitment to a person's cause is not able to be maintained then appropriate ways should be found to explain why advocacy cannot be continued, or better yet, find an advocate who *can* help. In the latter case a model of integrated advocacy might assist, particularly if it operates as a hub to match people with advocacy resources.

HCSCC and JFAPO wish to emphasize the importance that there needs to be capacity for the advocacy arrangements to deliver customised support to the person, including being available to be alongside a person throughout a complaints process.

The personal capacities and attributes of advocates and advocacy organisations will remain key markers of effectiveness of the NDAP, alongside the range of choice about the 'models' used.

Question 1.3 '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:

The issue seems to be not one of actual equitable access to services but one of geography i.e. people are not denied access to advocacy *per se*, rather they cannot access the advocacy they seek because of where they live and how their community is serviced.

This is not a new problem. Public health services have grappled with such coverage issues over many years[4] as have social services.[5] Despite the long-standing nature of issues of access and equitable spread of resources.[6,7], NDAP should be available more widely.

To assist methodological diversity and fair coverage, we suggest considering the following:

1) Resolve a standard 'one-stop' pathway that assists people living in rural areas to identify and connect to the advocacy methodology that suits them
2) Using a co-design process, clarify the process standards for each distinct advocacy methodology, as benchmarks for potential advocacy suppliers in difficult-to-reach geographic areas (as well as provide a framework to build effectiveness, engender communities-of-practice, and strengthen accountabilities). This should include capacity for co-production involving local people with lived experience
3) As part of the above process, examine which elements can be administered in rural and remote areas via tele-advocacy using accessible technology.

These may reveal a need for more funding than is currently allocated. Increased funding can be a difficult pitch given the relentless focus on deficits in some western political economies;[8] but we would argue good advocacy services are worth the investment.

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[4] *For example, see*: Edwards, S., Birks, M., Chapman, Y. and Yates, K., 2016. Miscarriage in Australia: The geographical inequity of healthcare services. *Australasian Emergency Nursing Journal*. **In Press**: *n.pages*. **Online**.

[5] *For example, see*: Taylor. A., 2016. Not Just Ageing: Policy and Service Delivery Implications from Changing Population Compositions in the Northern Territory of Australia. *In:* Wilson, T., Charles-Edwards, E. and Bell, M. (Eds). *Demography for Planning and Policy: Australian Case Studies*. Springer International, Cham, Switzerland: 91-107.

[6] *For example, see*: Australian Institute of Health and Welfare (AIHW), 2009. *The geography of disability and economic disadvantage in Australian capital cities*. AIHW, Canberra, ACT. 26pp.

[7] *For example, see*: AIHW, 2008. Rural, regional and remote health: Indicators of health status and determinants of health. *Rural Health Series No. 9*. AIHW, Canberra, ACT. 144pp.

[8] *For example, see*: Stuckler, D. & Basu, S., 2013. *The Body Economic: Recessions, Budget Battles and the Politics of Life and Death*. Basic Books, New York, New York, USA. 216pp.

2.2. Improving access to advocacy supports (Questions 2.1 and 2.2 inclusive)

Question 2.1 'How do we improve access for:

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

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

- *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?'*

And:

Question 2.2 'What are the strategies or models that have worked? What are the strategies that do not work?'

RESPONSE:

The issue seems to be, from our perspective, that advocacy services may range in quality and quantity from very good to absent for the above groups. Commentary provided to us, from people living with disability within our community, reinforces the issue of difficulties many people living with disability have with accessing advocacy (see appended comments *re* Easy English version of submission).

However, the very nature of the groups and communities, their cultural and social contexts, suggests that their direct experiences of advocacy, if any, could be lost in this review process. Similarly, if members of these groups have no experience of advocacy services, what they entail, what advocacy actually *is*, as well as potential benefits, how can useful insights into the improvement of such services be obtained?

The Discussion Paper question, by its very nature, provides an implicit invitation for others to answer on behalf of these groups, and no doubt, with the best of intentions; that, of course, is advocacy in action, necessary in this case, given the characteristics of the communities considered in *Question 2.1*.

Suggestions from people living with disability (see Appendix) about access include ideas about places where Skype sessions with an advocacy service can be undertaken; these places would be community hubs like libraries or community halls. This was felt to be particularly useful for people living in regional areas where internet connectivity is fragmented. This is an idea of great merit, but issues of privacy and confidentiality do arise, not only in the physical space but in the technological aspects of internet based communication e.g. quality and consistency of connection. Issues of access or the physical presence/absence and/or design of suitable community hubs are still pressing matters for people living with disability. Other useful ideas were offered, such as an easily accessible directory of advocacy services, with appropriately structured contact details and descriptions of services provided.

These ideas reinforce the notion that, if person-centred, individualised 'fit-for-purpose' advocacy is the intention of reforms to the NDAP then, no matter how difficult it may be, the voices of direct experience are absolutely necessary for the reforms to meet their objectives. We would hope the Department has these matters in mind when it undertakes further phases of this Submission process.

We also refer you to the three bullets given in our response in the previous section. We think that the benefits of co-design and co-production are well-documented and, because of this, when extrapolated to advocacy they can be regarded as models that have worked.

2.3. Improving the advocacy evidence base and coordination on systemic issues (Questions 3.1 and 3.2, inclusive)

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

RESPONSE:

JFA Purple Orange and HCSCC support the intention and motivation for improving the NDAP evidence-base. The Discussion Paper suggests that a data collection system already exists and that improvements are currently being undertaken. However, that system, by implication, appears to have limited access; this is understandable given issues of privacy and confidentiality.

Question 3.1 requests suggestions for appropriate mechanisms that "*information on systemic issues gets to the right people and organisations …*" While the "right people and organisations" are not defined it is unclear what an evidence base is to be used for in the context of the NDAP i.e. does the evidence-base help with Department decisions e.g. for funding and/or help with improving practice, and/or provide information in trends in needs for advocacy? The usefulness of any such undertaking on the face of it is apparent, but unclear as to how 'evidence' is to be used to effect positive change for people living with disability.

However, taking the question at face-value, there are a number of contextual issues to consider; not least the extent of access to valid sources which would provide information about systemic issues of concern or interest; "extent of access" relates to how many people in our broader community can provide information that relates to their experiences of impacts of 'systemic issues' (i.e. collecting such information would be consistent with independent, individualised, fit-for-purpose advocacy). Whether the sampling of experiences is restricted to people finding their way to advocacy services, or not, would seem to be an important consideration. Nonetheless, there are, potentially, a number of mechanisms by which evidence can be gathered, for example, mechanisms structured as "experience-collection devices".

The construction of an online forum where people living with disability, their families and supporters (as well as others with a considered interest in issues requiring advocacy) can leave information is a possibility.

If such a forum were to be considered then a co-designed system would be an essential process of construction.[9] The use of co-design (or participatory design) practice, with people living with disability participating, would, ideally, enable broader representation of the challenges and demands affecting people living with disability.

The US website www.patientslikeme.com[10] provides a good sense of what an online advocacy database could look like where the data is driven by consumers. Because of the volume of people using patientslikeme.com, the aggregate data is becoming sufficiently potent that physicians and researchers visit the site to access the information. It is easy to imagine a similar platform for advocacy, for example gathering data about people's experiences with the different advocacy methodologies, and with different advocacy providers, in different settings, and with what outcomes.

It could also pick up systemic issues. However, this would still be dependent on policy leaders reaching in to the database to harvest the systemic issues so they can update or overhaul their systems accordingly. A shared governance group, with clear lines of communication into such policy leaders, could help to push the systemic issues along. However, such a system would be constrained by access to adequate internet resources; internet access is, unsurprisingly, reduced in households with low incomes,[11] which could be a major limiting factor for the communities considered in *Question 2.1*; such facts well known to the Department.[12] Income may be an indicator of a number of social and cultural markers that affect access to internet resources e.g. age cohorts, as well as Indigenous and community identity also affect internet use.[13] On the other hand there are substantial issues that arise from disadvantage in its various guises and contexts, not least, is building sufficient trust that the information being provided to the Department is "doing something useful" for others in similar circumstances; another aligned issue is trusting that privacy, confidentiality and rights would be maintained when providing information.[14, 15]

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[9] *For example, see*: Gyi, D.E., Porter, J.M. and Case, K., 2000. Design practice and 'designing for all'. *Proceedings of the Human Factors and Ergonomics Society Annual Meeting, July, 2000*, **44**(38): 913-916.
[10] https://www.patientslikeme.com   accessed June 2016
[11] Australian Bureau of Statistics (ABS), 2014. *8146.0 – Household Use of Information Technology, Australia, 2012-13*. ABS, Canberra, ACT. *n.pages*. **Online**.
[12] *Department of Social Services* website. *Families and Children. The Household, Income and Labour Dynamics in Australia (HILDA) Survey*. [*Updated*: 5 Aug 2015]. **Web**. (17 May 2016).
[13] ABS, 2012. *2076.0 – Census of Population and Housing: Characteristics of Aboriginal and Torres Islander Australians, 2011*. ABS, Canberra, ACT. *n.pages*. **Online**.
[14] *For example, see*: Thorseth, M., 2011. Virtuality and Trust in Broadened Thinking Online. *In:* Ess, C. & Thorseth, M. (Eds). *Trust and Virtual Worlds: Contemporary Perspectives.* Peter Lang Publishing, New York, New York, USA: 162-177.

- The constraints outlined above suggest other initiatives could be necessary to build effective mechanisms (as outlined in *Question 3.1*)*.* These might include a national body that actively supports the identification of the broadest needs of all people living with disability and works towards negotiated improvements. Such a body would be active in all areas of public and community services.

- In addition there might need to be funding support for organisations that have special content knowledge to assist in the identification and resolution of systemic issues. Such organisations would include Vision Australia, Brain Injury SA, Multiple Sclerosis Society, AFDO, Physical Disability Australia, Inclusion Australia and others.

There are important considerations with the idea of "hubs" where, for example, integrated advocacy is practiced and personal experiences and needs are collected, curated and forwarded to the 'right people and organisations'. For example, management and quality of information will be affected by such things as, workloads for practitioners, stable and consistent reporting terminologies, reporting methods, effective prioritisation of issues, quality management and, not least, a clear understanding of the 'right people and organisations' who will receive any such reporting.

Similarly "colloquiums", composed of panels of advocacy practitioners, could be considered, being funded to meet regularly to discuss and synthesise clusters and trends of issues, or types of advocacy people living with disability are seeking. This could be characterised as an expert panel approach, but is, nonetheless, a variant of the "hub" approach; in all likelihood such an approach would need to navigate the same considerations as those outlined in the preceding paragraph.

Question 3.1 begs a number of questions not least the identities that comprise the 'right people and organisations'; it is easy to assume this collective are in a position to affect constructive change or respond adequately to any information received. However, given political distaste, in some circumstances, of public criticism of the impacts of favoured policies, or lack of political action on an emerging issue, the attention paid to some

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[15] *For example, see*: Duffy, S., 2016. *Citizenship and the Welfare State*. The Centre for Welfare Reform. Sheffield, United Kingdom. 50pp.

'systemic issues' could, at best, be selective.[16, 17] The capacity for government funding to be withdrawn adds another dimension to how evidence is collected, curated, represented and used for advocacy purposes In the NDAP.

JFA Purple Orange has made similar commentary on other matters in relation to the 2014 defunding of national peak advocacy agencies.

We think the issue can be navigated successfully, so that any such systemic advocacy hub arrangements are properly mandated and reinforce a sentiment of partnership of policy development.

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[16] Dalton, B. & Lyons, M., 2005. Representing the Disadvantaged in Australian Politics: The Role of Advocacy Organisations. *Democratic Audit of Australia Report No. 5*. The Australian National University, Canberra, ACT. 50pp.

[17] The Salvation Army, 2016. *Out of Reach: National Economic and Social Impact Survey 2016*. The Salvation Army, Redfern, New South Wales *and* Blackburn, Victoria. 61pp.

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:

In an ideal, horizontally and vertically integrated world of advocacy practice, an integrated model of advocacy would seem to be well situated to operate relatively smoothly with all these entities. However, given some of these organisations are bound by (administration of) legislation and others not, the means of working with such organisations would seem to require clarity about such matters as roles, extent of authority and focus and capacity to effect constructive change.

The obvious and simplest point-of-contact between these entities is information sharing; a product that could be generated from the evidence base proposed in Section 3 of the Discussion Paper is a Digest of systemic issues. The Department has considerable experience of commissioning and undertaking research and publishing (e.g. the *Australian Social Policy Journal*). A "Digest of Emerging or Trending Systemic Issues" could be distributed to the listed entities, which would alert them to matters of concern, or interest, from the frontline of advocacy practice in the NDAP. A Digest may be a basis for mutual working practices to be developed; the publication potentially providing an avenue where contact details, alignments of interest, capacity building and information sharing are brought together under the banner of NDAP.

The practicalities of working collaboratively can be both rewarding and challenging. However, the impacts of government policies, private/market interests and how

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social/economic issues are developing in a changing economy[18] are not going to lessen workloads for any of the organisations listed above.

The NDIS is an overdue reform, but it will not answer the challenges and demands of the lives of the majority of people living with disability who will not gain direct benefit from the Scheme.

All things considered, a useful way forward might be to establish a community-of-interest, where these various agencies meet together regularly with clear terms of reference about identifying the issues that are advancing or hindering people's prospects for good advocacy outcomes.

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[18] Parliamentary Library, 2013. *Parliamentary Library Briefing Book: Key Issues for the 44th Parliament*. Parliamentary Library, Department of Parliamentary Services, Canberra, ACT. 157pp.

2.4. The interface with the NDIS and addressing conflicts of interest (Questions 4.1 to 4.3 inclusive)

Question 4.1 'What steps or organizational structures should be put in place to ensure conflicts of interest do not arise, or are minimized?'

RESPONSE:

The Productivity Commission, in its major report on how care and support of people living with disability should be managed in Australia, had this to say:

> '[a]*dvocacy plays an important role in the disability system. Systemic advocacy pushes for broad policy and social change, while individual advocacy promotes the interests of particular individuals by acting on their behalf to resolve specific issues. These functions should lie outside the NDIS, reflecting the potential conflict of interest that would arise were the NDIS to fund advocacy bodies whose role was to challenge the disability system overseen by the NDIS.*'[19]

The means of addressing conflicts of interest was separation in relation to the Local Area Coordinator (LAC) role:

> '[t]*o avoid any conflict of interest, they could not be employed by a provider that is also providing supports to the person. And as LACs would serve a regulatory function for the NDIS, concerns about potential conflict of interest suggest that people with disability should not hire LACs.*'[20]

The issue has been well laid out in the preamble to the Questions in Section 4 of the Discussion Paper. The directive from the Council of Australian Governments (COAG) Disability Reform Council (DRC) is clear: if registered providers wish to provide services from/to a NDIS marketplace *and* also provide independent advocacy services (funded through the NDAP) then '*they will need to demonstrate they have mechanisms in place to avoid potential conflicts of interest and duplication of funding.*'

Question 4.1 has, apparently, altered the unequivocal wording of the DRC directive i.e. from 'potential' to actual conflicts of interest; there is also a shift from *avoidance* of conflicts of interest to *minimisation* of them.

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[19] Productivity Commission, 2011. Disability Care and Support. *Productivity Commission Inquiry Report No. 54. Vol 1*. Productivity Commission, Melbourne, Victoria: 26.
[20] Productivity Commission, 2011. *Op cit*: 411.

There is a clear need to exclude service/product suppliers (market supply) from being able to offer advocacy services (market demand), because of a clear-cut conflict of interest.

However, the issue becomes more problematic if there is a conflict of interest between services that are all located in the demand side of the market, for example where advocacy agencies might also be involved in training services or brokerage services, services which might at times disappoint their customers sufficiently to trigger a need for advocacy support to make a complaint.

Again we would suggest a co-design approach to resolve which conflicts of interest are unacceptable, and which conflicts of interest can be managed via mitigation arrangements, and what such arrangements might comprise.

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

RESPONSE:

Question 4.2 is unclear in its assumptions; the services provided by the NDIS, including what the Information, Linkages and Capacity Building (ILC) component might deliver, are in the main directed to eligible NDIS participants i.e. those people living with disability who will receive an individualised support package from the Scheme. NDAP services can be accessed by potentially eligible participants of the NDIS.[21] The majority of people living with disability in Australia will not access funding from the NDIS; however, they might access information from the ILC, by which NDAP could be promoted. There will be overlaps in NDIS and NDAP, but it is unclear at this vantage point (transition phase of the NDIS) what NDIS supports and potential 'gaps' the question alludes to.

It is unclear what gaps are being envisaged (per *Question 4.2*) given the assumption that NDAP will not be a restricted service, because of the operation of the NDIS; rather NDAP would run in parallel and presumably would be complementary to the NDIS in some circumstances. However, it is not assumed that the '*reasonable and necessary supports*' provided through the NDIS will include ongoing advocacy services for an eligible participant; such a situation would appear to contravene *section 34(f)* of the *National Disability Insurance Scheme Act 2013* (Cth).

The ILC component of the Scheme might be in the minds of the authors of the Discussion Paper in asking *Question 4.2*. As mentioned previously, it would appear that the NDAP could

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[21] *National Disability Insurance Scheme* website. *National Disability Advocacy Program*. [*Undated*]. **Web**. (19 May 2016).

be promoted within the ILC framework (as a necessary service) but remain apart from the service provision aspects of the NDIS.

One way to contemplate possible gaps is by considering how advocacy can, among other things, help people to make plans and take decisions, and also to make complaints. The NDIS is involved in both planning and complaints. In relation to planning, and as JFAPO has set out in a separate communication to the NDIA, there is a good opportunity for exploring how the NDIS might invest in pre-planning – the planning that people do before they show up at the NDIS. If this is soundly anchored with community agencies, potentially including agencies who are involved in advocacy, this can help reduce the risk of gaps in how people get advocacy support to articulate their needs and wants.

In this way, if an NDIS participant is able to access customised advocacy support in the form of pre-planning assistance, this will help raise the chances the participant is truly active in developing a plan that meets their needs and wants.

Separately, NDIS participants may need advocacy assistance to complain about the NDIS process or the subsequent services. We think the current appeals process could benefit from being reviewed to ensure it effectively maps across to independent advocacy services so that a participant can take the advocate of their choosing into that process.

Similarly, we think that any general complaints process within the NDIS, designed to assist participants who are unhappy with supports/services received, could again benefit from being reviewed to ensure it effectively maps across to independent advocacy services.

In these ways we think the risk of gaps can be minimised.

Question 4.3 'What policies and strategies do we need to protect the rights of people with disability?'

RESPONSE:

The Question poses an interesting perspective on current policies and strategies within NDAP. The impression is given that *Question 4.3* is actually directed to people with insider knowledge i.e. those with particular knowledge of NDAP policies and strategies. However, this is undoubtedly not the case; the question is assumed to be a general enquiry.

The impression of insider-enquiry the Question creates is because of the existing body of legislation and other instruments that protect the rights of people living with disability in this country. Australia has ratified the UN Convention on the Rights of Persons with Disabilities, which has led to the development of the National Disability Strategy, National Disability Agreement and other such high level responses to the Convention. Does *Question*

4.3 implicitly not acknowledge the existence of this legislation and other relevant initiatives? That would seem to be unlikely: the Department would be in the forefront of good practice in this regard, having due regard to its duties and obligations about the rights of people living with disability.

It must be assumed that NDAP advocacy is, often about the negative impacts on people living with disability as a result of non-compliance and ignorance of how the Convention, and its requirements, should be addressed in policies, strategies, decision-making and everyday actions of the public, private and civil sectors. This body of knowledge and practice would, it is assumed, find its way into NDAP policies and strategies, regardless.

We suggest that the implementation of the National Disability Strategy is where the answers to this question properly lies.

As an example of thoughtful implementation of rights based issues, we refer to the SA Government's Attorney General's Department (AGO) work on disability in justice. Characterised by consultation and co-design, the work is generating a range of safeguards to help protect the rights of people living with disability. [22]

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[22] Government of South Australia, 2014. *Disability Justice Plan 2014-2017*. Attorney-General's Department, Government of South Australia, Adelaide, South Australia. 13pp.

2.5. Understanding and improving access to justice (Question 5.1. to 5.3 inclusive)

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

And:

Question 5.2 'What barriers prevent people from disability from accessing justice?'

And:

Question 5.3 'What models of legal advocacy are the most effective?'

RESPONSE:

We acknowledge the complexity of issues for advocates and people living with disability when interacting with the justice system.

Again we commend the South Australian Government's *Disability Justice Plan*[23] to the Department for its insights and initiatives, for addressing some of the issues raised in the Section 5 Questions and, not least, in its acknowledgment of the many and complex barriers that people living with disability face in accessing the justice system. For example, an issue highlighted by some people living with disability is appropriate education of police about perceptions and their approach to people living with neurological or intellectual disability when policing. These are matters the *Disability Justice Plan* and its integrated approach to access to justice, addresses also.[24]

Without wishing to nominate a specific model of legal advocacy we believe good legal advocacy is no different from good advocacy generally, other than it would also include detailed knowledge of legal systems. Again, authentic co-design is a way of unpacking the elements of good legal advocacy, and to a detail sufficient to commission it.

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[23] Government of South Australia, 2014. *Disability Justice Plan 2014-2017*. Attorney-General's Department, Government of South Australia, Adelaide, South Australia. 13pp.
[24] Government of South Australia, 2014. *Op cit*: 2 *et seq*.

3. Appendix

NDAP Review – discussion with people living with disability

Notes - May 2016

General comments based on the Easy English version questions:

What is the most important aspect of advocacy?

- To help with complaints
- If being excluded from community or denied a service
- If living in an institution or abusive situation
- To advocate to families who may not listen to the individual, and think they know best
- People need to be clear about the difference between advocacy and support. It is speaking, acting or writing on behalf of a person in need in their best interests.

What barriers exist to accessing advocacy?

- Embarrassment
- Whether individual feel they are worthy
- Whether individual thinks their disability is severe enough to ask for help
- Navigating the pathway to access advocacy – difficulties in finding information
- Not taking medication – unable to recognise they may need assistance with a certain situation
- Fear of retribution, particularly in accommodation services. Services users within a system can't say too much – they have to get others outside the system to speak for them
- Conflict of interest for staff to raise issues about the service they work for with an advocate on behalf of an individual
- Gatekeeping by accommodation staff – residents, particularly those living with intellectual disability may not know advocacy services exist
- Staff may direct which advocates individuals access – e.g. to an internal organisational advocate rather than an external independent one
- Children can't speak up for themselves – rely on parents having advocacy skills.

What would make accessing advocacy easier?

- Advocacy database like a phonebook with easy search capabilities - needs to be regularly updated and easy to use and well indexed

- People living with disability need to learn to work together – to have a collective voice
- If different types of advocacy groups collaborated
- Local Aboriginal elder could be conduit between individual needing advocacy and advocacy service
- Geographical gaps in advocacy coverage – use Skype to access the appropriate advocacy service as many rural people don't have internet access at homes - the local town could have Skype access points (e.g. library, church, post office) which people could book for advocacy appointments
- Capacity building of people living with disability.

What makes good advocacy/ a good advocate?

- Seeing some action – seeing something fixed
- Advocates need to know what they are talking about
- Approachable personality
- Trustworthy
- Patient
- Specialised
- Easy to talk to
- Understanding
- Building confidence so that people realize the advocate is "one of us"
- Must know disability system well – preferably living with disability
- Takes time to get to know the person – particularly if the person is non-verbal. This may take months. Get to know the people in that person's life – as they know them the best
- Advocates need to understand what a good life looks like. It shouldn't be any different for a person living with disability to be part of the community and have their rights upheld
- Someone who makes useful suggestions
- Having an advocate helps you be believed
- In a disability support service, often getting people together in social environment will result in someone offering to assist/advocate on someone else's behalf in particular situations
- Carers of people living with disability have to be involved as sometimes (e.g. for someone with a brain injury) they are the connector between the person living with disability and the community
- Advocates need to understand that it may cost them emotionally to be an advocate as it is not a comfortable role. This needs to be understood upfront so the advocate doesn't disappear when it get too hard. When this happens the individual needing

advocacy bears all the emotional costs, and may leave them in a more vulnerable position.

Other comments

Gaps between NDIS and NDAP

- Need a good communication system between government systems
- Database (mentioned earlier) advertised to all service agencies – doctors, nurses, support agencies, domestic violence agencies so they can provide referral advice.

Access to justice

- Police need more education in the way they treat people e.g. with brain injury. Need a quick method to involve a doctor with expertise if someone is detained by police. Police often make assumptions about people with brain injury - that they are drunk if they slur words or walk unsteadily. Will going to jail be beneficial, if it is just that the person has committed an offence as they hadn't taken their medication? Once in prison people may get tied up with drugs and come out worse off.