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## INTRODUCTION

Independent Advocacy SA welcomes and is supportive of a process that seeks to enhance and strengthen the National Disability Advocacy Program (NDAP) so that the program provides strong, independent social advocacy for and to people with disability across Australia.

Independent Advocacy believes it is possible for the review to further develop the program based on strong principles, a clear definition of, and framework for, social advocacy and that has coherent purpose and enhanced accountability.

The consultation paper recognizes the review findings that “*advocacy remains a valuable and much needed program*”, and outlines the areas where improvements are needed to enhance the efficiency and effectiveness of the program – objectives; funding; quality assurance; scope, priority and specialisation; geographic coverage; coordination between agencies; awareness of the program.

Independent Advocacy supports the development of an advocacy program that:

- ◆ safeguards the human and legal rights of people with disability
- ◆ is accessible
- ◆ provides good quality advocacy
- ◆ directs funded effort to those most in need of advocacy
- ◆ has clear advocacy priorities
- ◆ has consistent reporting processes
- ◆ can feed systemic advocacy efforts

as stated in the paper. However we are confused by some of the suggestions in the consultation process and address these directly below.

Further we wish to raise our objection to the time frames and the process of the consultation itself. The immediate period of short time frames to receive and respond to the consultation paper, which sits apart from the final report, is confused and overly brief, presumably because the anticipated prior timelines had not been met. It is now inappropriate to rejig funding agreements based on this ill-considered and hasty process and require agencies to sign rejigged agreements under pressure with little room for negotiation or redrafting. These processes need to be separated. There has been some relief in planning pressures now that we have an 18-month period before major changes are implemented. The immediate period of 2007 needs to be used to garner the expertise amongst advocacy agencies themselves to form a working party to develop the new framework and propose ways in which the sector as a whole comes on board to that. Competitive tendering cannot guarantee to people with disability in need of advocacy that those needs will be better served – our strongest obligation in this process. The risk is too great to losing the value that sits in the current organisations doing advocacy. This ought to be a building on strengths process. This submission supports those of the Combined Advocacy Groups of Queensland and Family Advocacy NSW in their comments about competitive tendering.

**A note about language:** Advocacy is not a service. The repeated use of this language undermines the need for advocacy to be independent of service delivery to people with disabilities and is confusing both for them and to the clarity of that separation and independence. Most generally advocates advocate **to** service providers.



In the consultation document people are referred to as “cases”. The use of this term is in conflict with the stated standard 4 – in terms of dignity and respect and standard 6 – in terms of valued status and positive language.

### **THE PROPOSED CHANGES TO THE PROGRAM:**

#### 1. Introduce measurable program goals and objectives.

Independent Advocacy SA supports the current goals and objectives of the program and the principles of advocacy, which have people with disability as the focus of the program but acknowledges the role of families. We extend this to include recognition of other allies to individuals in all our work. Supporting these relationships is vital in being of genuine assistance to people with disabilities.

#### 2. Introduce standard operating policies and procedures across all funded services as a condition of funding. These policies and procedures will focus on achieving consistent, good quality advocacy services.

Independent Advocacy is supportive of the development of a National Framework including an advocacy specific Code of Practice, which builds on current best practice in the sector and is based on the strong principles of good advocacy as established by theoreticians in the field. These have been identified in the work of Wolfensberger and examined by Cross and Zeni (1993), and Dyke, (2000). We call for a working party to be established made up of experienced leaders from the sector to do this work.

#### 3. Introduce a ‘priority table’ as a condition of funding setting out which cases advocates will give priority to, to make sure advocacy services are directed at those most in need of assistance.

At the consultation it was stated that there is intention for individual advocacy to respond to crisis this implies a preference for short term paid advocacy. There needs to be an understanding that the very vulnerable people that the program wishes to target have long-term advocacy needs and could be viewed as being in long term crisis. The invisibility of many of these people is part of their advocacy need and we assert that advocacy needs to take the lead and be pro-active in these peoples lives. The risk of crisis based advocacy is once again that the very and most vocal people are those whose needs end up being met by the Program.

However any measure which ensures that advocacy is directed at those most in need of assistance is welcome. Although Independent Advocacy SA strives to advocate for the most vulnerable people in the SA community we understand that the most vulnerable are often not found through a referral system. We actually advocate for the most vulnerable amongst those that we come to know about and that we can gain permission to enter into their lives. Some of these are amongst those most in need of advocacy, others we are only aware of. We have worked in recent years to improve our efforts in this regard and are proud to have successfully increased the proportion of people in this category. Others that we advocate for are very vulnerable in significant life areas but may have some helpful attention of other agencies or individuals. We believe that some balance of the very difficult efforts with other advocacy efforts that are more likely to have some measure of shorter-term achievement of advocacy goals with regard to addressing fundamental needs is crucial to the health of the agency. Although suitable supported accommodation is one of the most difficult things to achieve for people it would not be good for advocates to only work on such issues as it would quickly result in burnout issues.

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It is vital that in this proposed measure that the most vocal do not end up gaining the lion's share of advocacy. It is in advocacy agencies being proactive in this and not just responsive to the biggest crisis. Crisis is sometimes the time to step in but it rarely builds sustainable change and influences things towards a better long-term life improvement to direct advocacy efforts in this way. At Independent Advocacy SA we prefer to get to know a situation in some depth before determining the most strategic efforts for our advocates. There are of course times when timeliness is of the essence and we must start acting more quickly. Most particularly this applies when we only become aware of say a parent with intellectual disability shortly after their child has been removed from their care, perhaps at birth, and court, child protection and placement proceedings are imminent. There also needs to be recognition of the value of advocacy that is protective and seeks to avoid crises.

We generally do not hold waiting lists but accept some instances for investigation while seeking a pathway – perhaps outside of the agency – where advocacy can proceed if necessary. Waiting lists lead to the least vocal being given attention and often these are the most vulnerable.

4. Ask all services to meet benchmarks for service to people with particular types of disability, indigenous people with disability and those from culturally diverse backgrounds.

I believe strongly that specialisation is necessary to serve the interests of particular groups. Our, albeit not so recent, experience of advocacy for indigenous people with intellectual disability has been that there is a need to find a suitable advocacy within the indigenous community. There is other evidence that this is what they seek. This also applies to other culturally diverse groups but seemingly to a lesser extent. However it remains important that where we are advocating for a person from a culturally diverse background that we seek to make a strong connection to their community of choice in order to ensure their wellbeing into the future. We have never referred anyone on from IA on the basis of culture but instead it becomes an important part of the advocacy. However diverse cultures are underrepresented in our statistics, this is because we have a dedicated agency in SA for this work. I believe where any such group is underrepresented in advocacy efforts that new targeted efforts need to be grown to allow for that to be redressed. The expertise that is developed can be exported to other agencies or accessed by them in cooperative ways if geography restricts. Our expertise in complex advocacy scenarios involving people with intellectual disability is something we can readily share and co-strategise with other actors in the field however remote through phone link-ups and the like.

We also believe that the mechanism to ensure that the need for advocacy amongst the most vulnerable people has been served by having specialist agencies for them. Single issue and entitlement based advocacy like gaining access a particular form of treatment or membership, piece of equipment or similar is very different to advocacy that addresses long term neglect, mistreatment or isolation, with attendant maladaptions on the part of the disabled person and complex relational matters. In SA all the NDAP advocacy agencies are clear that Independent Advocacy will respond to such circumstances and they refer them to us. This has worked in SA to the best of our knowledge. We are not confident or aware that this has ever worked in a bigger and broadly focussed agency. If such more generic agencies are to be developed it is our view that they would need to be grown from an agency that already carried

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that focus and strong expertise to prevent the agency from shying back from this difficult, complex and strategically subtly nuanced work. I think the question is - Where are the examples of this working? – and then to build that into the Program. Any risk taken with this matter would be hard to justify and morally questionable. Lumping all people with disabilities together is modeling the same random congregation of them that the community has moved away from in recent decades and would be a retrograde step. The advocacy needs of a person with an intellectual disability are quite divergent from those of someone with a sensory disability or a mobility issue.

5. Focus disability advocacy services on individual and family/parent advocacy, with smaller effort directed to systemic and citizen advocacy.

We welcome a focus on individual advocacy but consider citizen advocacy to be another form of individual advocacy and indeed to be it's most pure and morally coherent form. It is our understanding that the legislative framework for the Program includes these various advocacy forms. If we consider family, parent and citizen advocacy to all be types or variation on individual advocacy the percentages are: - Individual 75%, Systemic 20% allowing the 5% to be allocated either way. Independent advocacy does not support self-advocacy as a potent advocacy form (see comments under 8. – Standard 10 Training etc.)

That this program could *“Deliver good [advocacy] to all people with disability, and the families and carers of people with disability, no matter their disability type, language or cultural background.”* This is in potential conflict with the other aspects of the stated vision, in particular to target those most in need. With limited funding it remains crucial to advocate for those who are unable to advocate for themselves. The National Disability Advocacy Program ought to provide for advocacy for people with disability and no other. It is of course important to work alongside families and/or allies of the individuals with disability but to advocate for them directly is at odds with the purpose of the program and confuses the effective prioritising of those most in need. If the needs of the person with disability are met, in most instances, the needs of the family will be met. An important principle of the program states that *“advocacy focuses on the fundamental needs and/or rights of people with disability”*. To now include families and carers as a focus for the advocacy program is a fundamental and problematic shift and is not coherent with other goals of the program. Parent advocacy is not for the person with disability and can even present a conflict with the best interests of the disabled person involved. At Independent Advocacy we have found ourselves advocating for a person with an intellectual disability where there have been one or even two parent advocates at the same ‘table’ and yet the parent or parents have been well able to direct their own effort, with an advocate simply adding weight to that. Multiple advocates is an absurdity and counterproductive to both efficiency and the outcome will serving the best interests of the person with a disability. Such situations ought to be the jurisdiction of mediation services and the like. In SA we have the Carer’s Association, a large organisation that focuses on advocacy, counselling and other support for people in these roles. Far from improving the program in the stated area of *“Coordination between NDAP advocacy.. and other bodies [doing] advocacy”* this would be a retrograde step.

That smaller effort be directed to systemic advocacy is currently the case. We would like to see this reestablished in SA in a stand alone systemic agency like Queensland Advocacy Inc.

6. Re-balance funding across States and territories to better reflect the distribution of

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the disability population.

The information provided under the heading funding in the consultation paper is simplistic and raw. It indicates that \$700 is spent per head of people advocated for per annum this makes no differentiation between types of advocacy efforts – single issue or long term. And there is no attempt to cost an advocacy effort for the target group of those in most need. The table of how funding is shared across states has no recognition of any underlying factors. There are a number of questions that come out of this variability in funding levels:

**Is it assumed that these percentages extrapolate to the broader age group?** The figures acknowledge those people aged 65 or less, however the DDA specifies no such age constraints. When this constraint is removed there is quite a different picture regarding the populations across each State and Territory.

**How much does an individual advocacy effort cost?** Independent Advocacy began an advocacy effort approximately 1 year ago for a 37-year-old man who has lived in a large institution for people with intellectual disability in Adelaide since he was 4 years old. He has become blind during this time, perhaps due to the repeated bashing of his head on the brick walls of his bare room. When his advocate first came to know his circumstances his activity schedule amounted to 2 \_ hours per week outside of his room apart from occasional stays in the infirmary. Due to his reputation of violence and his need for safety from other residents as well, he was locked in his room much of the time, he had no means apart from yelling to attract attention to a need of any sort including to use a toilet. In the communal toilet there is no toilet paper supplied due to the behaviours of other residents. This man had no furniture apart from a bed with a heavy canvas blanket, no linen or pillow. He is autistic and has only a few words that are readily understood. We believe he has been subject to abuse. The practices at this institution are entrenched. Although the State Government is devolving the institution he was initially not identified as being eligible to live in the community. Advocacy, working alongside a significant ally and the responsiveness of the State government has resulted in significant improvements in his life whilst working towards a guaranteed place on the list of those scheduled to move from the institution in the next 5 or 6 years. Getting to know this man and his needs in order to advocate effectively, advocating with reference to the entrenched practices within the institution, the complexities of his history and circumstances, achieving an appropriate guardianship arrangement, an improved lifestyle, (including supporting him to purchase a potable airconditioner for relief from simply shocking summer temperatures in his room) and protecting him in general have cost approximately \$10,000 in advocacy wages so far. We anticipate withdrawing from this effort when he is accommodated appropriately and supported by an organisation that uses non-aversive support practices - when he is well enough, happy enough and safe enough. This may be in 3 years or 10, the yearly figure will of course reduce over that period. **What is the cost of this man's safety and wellbeing?** We know of but have not been invited into 25 other residents' lives with similar levels of vulnerability. We also believe he would be amongst the 50 or so most vulnerable people in the State. We hope any funding formula will take them all into account.

**What would it take for the funding to be equitable?** If any individual in any State is not to be disadvantaged in achieving equity then the simple sums that come out of the table provided indicate there needs to be an increase in program funding to bring the overall program funds up to the order of \$22 million nationally. Clearly there would need to be a more sophisticated mathematical model to create the formula for funding each State in a truly equitable manner, if that is an agreed goal, which might address greater complexities like geographical and 'tyranny of distance' issues and complexities within economies of scale. While waiting lists

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and unmet need exist it would be inappropriate to reduce any existing funding arrangements as a redistribution process versus developing new efforts to address those needs. The allocation of funding should further take into account the advocacy needs of the particular population as well as the amount of State funding available or assist in the transition period to achieve greater State funding. However State funding, indeed any funding through Human Service departments of Government reduces the independence so vital to the independence of advocacy. This independence is crucial in achieving even basic protection for vulnerable people like the man described.

## **Does there need to be funding opportunities for particular circumstances or advocacy efforts?**

i) the slow devolution of a particular large institution which is now occurring in Adelaide means new lifestyle arrangements being created for large numbers of people some of whom are amongst the most vulnerable people in the State – this calls for a significant amount of individual advocacy;

ii) where the practice of a State Government Department shifts combined with new knowledge that has the potential to better address a significant and ongoing need, might call for redoubled advocacy efforts in order to take real advantage of those circumstances – such a window of opportunity may currently exist in South Australia for parents with significant intellectual disability.

The people identified as in need of advocacy within these groupings may require advocacy for some years until new practices, services or programs are firmly established and any gains have guaranteed safeguards. Population numbers as a guide for levels of advocacy funding may be too simplistic to account for any number of important considerations.

## **7. Make sure people with disability know more about their rights and responsibilities by promoting services and introducing a centralised referral service with a single Free-call telephone number.**

This seems on the face of it to be a nice idea but very simplistic really and an unjustifiable cost for any value gained. There needs to be a commitment to more resources before further promotion is undertaken otherwise you are promoting waiting lists only. The move towards standardising names of agencies is probably the most possible and useful of the suggestions here, certainly the cheapest. The people who are the stated focus of the Program either could not access a centralised referral point, and what are you going to ask them – which State do you live in? and then send them to the generic agency there! Systemic work needs to be done here to convince service providers and other natural referral points to more routinely refer vulnerable people without creating expectations of automatic eligibility.

## **8. Improve the quality assurance system, including the introduction of Key Performance Indicators and external auditing that services meet the quality Standards. Require minimum qualifications for paid advocates.**

We agree with the proposal to refine the current disability service standards and replace the existing 101 supporting standards with a smaller number of KPI's, which would be further defined through a series of sign posts and evidence guidelines. We agree that this approach will make it easier for advocacy agencies to identify what they need to do to make their advocacy the best it can be. Currently both the language and orientation of the standards are related to service provision and acts against this intention. We have confidence however that this can be a straightforward translation from the existing standards.

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**Standard 3: Decision-Making and Choice.** Maintaining the ‘service’ language and making reference to activities of every day life distances this standard from the realities of advocacy efforts. A reinterpretation of this standard as

*“Each person with a disability has the opportunity to participate as fully as possible in making decisions about the advocacy efforts pursued and actions taken on their behalf. Where their capacities limit this participation then their best interests will determine the efforts and actions taken on their behalf.”*

is an example of just such a straightforward translation. This is not a rewrite of the Standards as much as a minor but useful modification for advocacy.

In addition to the proposed **KPI 3.1** there are others needed to provide evidence of this standard being met. There are problems with the proposed **KPI 3.2** including where the person with a disability being advocated for seeks advocacy for things which are vexatious or not in their best interests. Advocates and their agencies need to have clear policies and understandings with those they advocate for and their allies that the agency’s activities cannot be hijacked towards these things. Further and most importantly there is a need for organisations to have or develop policies and procedures about how to conduct advocacy when a person’s incapacities negate their ability to participate in any useful or significant way in these decision making processes. Considering that speaking, acting and writing on behalf of vulnerable people with disabilities is their core activity it is anticipated such processes ought be very well developed. At the very least an advocate cannot do something that makes such a person more vulnerable, nor should they pursue things that are not valuable to the person or the community in which they live. It is my understanding that these are the people (those that cannot readily speak for themselves) that the National Program seeks to target most strongly! Examples of possible KPI’s are as follows:

- ◆ *The advocate supports the person with a disability to understand, to the fullest extent possible, information regarding advocacy undertaken on their behalf.*
- ◆ *The person with a disability is consulted as an integral part of the ongoing decision making processes relating to the advocacy conducted on their behalf.*
- ◆ *An advocate is able to demonstrate the process it follows to determine a decision on behalf of a person who is unable to participate in such processes and on what is the declared values basis for that process.*
- ◆ *Advocates collaborate and consult, to the fullest extent possible, with the person with the disability in order to make decisions on the actions, strategies and processes involved in advocacy actions on their behalf.*

**Standard 10: Service recipient training and support.** “The ability to self-represent and self-advocate for each person with a disability is optimised by effective and relevant training and support. Independent advocacy began as a self advocacy agency.” Independent Advocacy began as a self-advocacy agency, Self Advocacy for the Intellectually Disabled (SAID). We discovered that self-advocacy seems to make the vulnerability of people much greater because they could be on their own when they had been given “effective and relevant training and support”. The self-advocacy group tended to become member’s whole focus and they failed to achieve good relationships outside the group. Self-advocacy persistently resulted in an “Us and Them” situation and lack of trust for people without intellectual disability or outside the support group. The group’s support workers were seen as having all the answers, having too powerful a position. It also acted against participatory goals and was

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another experience of being congregated and segregated. To congregate people in this way leaves them further vulnerable to exploitation and coercion and achieves the image that people with disabilities belong together. It also does not target the most vulnerable people who are unable to take advantage of any such training. This is the least effective advocacy form and it is our experience that self-advocates are not taken seriously like other advocates.

**Standard 11: Staff recruitment, employment and training.** Agencies should seek the best available advocates to advocate on behalf of already devalued individuals, groups or classes of people. This is in order to avoid causing further harm through ill-considered action and lack of appropriate strategies. It is so crucial to the advocacy effort that each person employed as an advocate be a valued member of the community and has relevant and potent knowledge, skills and values that there should be KPI's that address this directly beyond the standard 8. These ought to address rigorous staff recruitment processes, job descriptions, appraisal processes and training and development.

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