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**ACTION FOR PEOPLE WITH DISABILITY INC**

**Submission to the Discussion Paper**

***Review of the National Disability Advocacy Program***

**June, 2016**

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## **Introduction**

Action For People With Disability Inc (*Action*) was initiated by families of people with disability in 1978, as the first regional advocacy agency in NSW. *Action's* philosophy and aims at that time were considered visionary and totally focused on the rights and needs of each and every person with disability. *Action's* Constitution and policies have since been used by other advocacy agencies and some have used these to gain new funding.

Over the past 38 years, *Action* has been recognised for staying true to its original vision and aims and for the provision of a continual and high level of effective individual advocacy and support for people with disability and support to their families in the northern metropolitan region of Sydney. *Action* is governed by people with disability and family members of people with disability. *Action's* staff are people with disability and/or family members of people with disability.

*Action* appreciates the Commonwealth Government's commitment to maintain a strong and effective program of independent advocacy for all people with disability into the future, and welcomes an opportunity to present comments on the national program.

*Action* receives no NDAP funding and is fully NSW State funded.

*Action* supports monitoring of, and accountability for allocated funding by all advocacy agencies by both qualitative and quantitative measures.

This submission has been prepared following extensive consultation with people with disability and families of people with disability in *Action's* region and with *Action's* members.

## **The paper**

We are addressing this paper through our knowledge and experience of a regional advocacy agency for people with disability of all ages, in providing advocacy and/or support to hundreds of people each year.

People with disability and their families have welcomed the opportunity of input into this review that they expect will ensure their access to timely and effective provision of individual advocacy as a vital support.

*Action* is appreciative that the decision-making role regarding the funding of regional advocacy organisations will now be removed from NSW State Government Departments.

## RESPONSE TO KEY ISSUES

- 1.1 There is a documented and recognised growing need for individual advocacy for people with disability due to a higher level of expectation of younger people with disability and their families and a greater community awareness of people's rights. This growing need will be further increased by the transfer and implementation of the National Disability Insurance Scheme (NDIS). *Action* has already been providing individual advocacy for a large number of people and systemic advocacy in the NDIA and NDIS contact processes and the imposition of changes by the NDIA, prior to the rollout on 1<sup>st</sup> July, 2016.

*Action's* experience is that the provision of individual advocacy cannot be separated from regional systemic advocacy that informs State systemic advocacy, and skills support for people with the capacity to self-advocate and for families to act as Advocates for their family member. The provision of advocacy should be person-centred to address each individual situation and not based on the model of advocacy.

People with disability benefit from provision of individual advocacy that informs systemic advocacy, with the individual advocacy immediately addressing the rights and needs of the individual person and the systemic advocacy, over a longer timeframe, addressing the needs of a large group of people.

*Action's* experience is that if you are providing effective individual advocacy it is possible to provide self-advocacy skills support for some people with disability who learn from the individual advocacy provided by an Advocate. People who have the capacity to learn these skills have a growth in confidence after *Action* provides advocacy and resolves their original concern, complaint or situation. Most often, the people who readily learn these skills are people with physical disability support needs, with fewer people with intellectual disability support needs taking up this option.

In order to address some of the ever growing unmet need for advocacy, *Action* offers support to people with disability to self-advocate and also to families of people with intellectual disability to act as advocate for their family member where people feel confident to do so. It is our experience that the majority of people who do request or accept this support are people with physical disability or families of people with intellectual disability who have a level of knowledge and understanding of the implementation of disability legislation and policies. A person who is empowering families to act as advocates must have the skills and experience to determine that the family is capable of, and committed to, what actions need to be taken in the best interests of the person with disability.

This support is not cost-free to the organisation and often requires more resources than would have been used if formal Advocates on staff had undertaken the advocacy. All advocacy situations have different aspects including the person's individual needs or life situation, people in decision-making or authoritative roles in their lives (you are dealing with their individual views, perceptions and understandings), specific policies and procedures etc.

People have to be 'skilled up' for the individual situation they are addressing and for negotiating with relevant people and agencies, which usually requires debriefing following the actions they have taken and then further support in devising other actions to achieve the outcome required.

The majority of situations *Action* supports are of a highly critical nature and people with disability and their families state that even with the provision of training, they do not feel confident in their capacity to self-advocate or act as an advocate. Families have also stated their concern that at a critical time in the life of their family member and a stressful

time in theirs, yet another expectation is being placed upon them to resolve very difficult situations and so they prefer provision of formal advocacy.

*Action's* provision of advocacy and support is aided by *Action's* depth of knowledge of the region in which we operate and network, and of state based agencies for specific referrals, if required. This assists not only in our provision of individual advocacy but also the supports for other advocacy, as detailed above.

- 1.2 Given *Action's* experience, we do not see any drawback to the provision of advocacy and support as detailed in 1.1, as we believe these flow from the initial contact for individual advocacy. *Action* does not provide legal support, and referrals for specialised legal advocacy are made to Intellectual Disability Rights Service located in Sydney. The only drawback is the lack of funding to employ the number of advocates that are needed to meet the continually escalating calls for advocacy and/or support.
- 1.3 *Action's* regional systemic advocacy is informed by the provision of continual and high level of individual advocacy. We are also in continual discussion and consultation with people with disability and their families. Our knowledge of how government department restructures, current and proposed legislation, policies and procedures (and ongoing changes to those) will affect the daily lives of people with disability is gained through this provision of individual advocacy. Our experience, surveys and data collection in our region have been useful to combine with that of other regional agencies on State issues of systemic advocacy and then provided to the State Peaks to inform their systemic advocacy.

Systemic advocacy through State Peaks needs to be valued as the level of specific expertise currently held by some of these bodies is of assistance to resource stretched, regional individual advocacy organisations. Systemic advocacy should be informed by the provision of individual advocacy and continual consultation with people with disability and their families.

## **RECOMMENDATIONS**

*Action* believes that access to independent, strong and effective advocacy is a vital support and safeguard for all people with disability all current resources should be continued with an increase in funding to meet the demonstrable need, including for those people with disability who do not meet the eligibility requirements of the NDIS.

Advocates must be highly skilled and with broad experience in order to ensure the outcomes wanted and needed by people with disability are achieved. This can be difficult for advocacy agencies in rural and remote areas and additional support should be provided to these agencies.

*Action* believes that this review should result in equitable access to effective advocacy for all people with disability in all regions of NSW and across Australia.

*Action* strongly believes that DSS must ensure a network of independent individual advocacy providers across each State and Territory is enabled as soon as possible. This has been a well-documented gap in service provision for people with disability living in rural and isolated regions. *Action* continually receives calls for critically needed advocacy and support from people in many areas across NSW where there is no access or no timely access to individual advocacy.

Each state and territory should have a call centre that will advise the person or family of the available advocacy to address their individual situation. The processes after dialling the call centre should be a response from a person and not a multiple process of numbers to be used to finally speak with a person. There are currently a number of funded rights based information services that could take up this vital support.

- 2.1 When *Action* was previously contacted by people with disability from Aboriginal and Torres Strait Islander backgrounds for provision of advocacy, at times we had to undertake a complex process of approach through an Elder of the community to gain consent to provide that support and sometimes this process could not be followed due to the need for privacy for a person and/or their family. Now, we would refer these people to Aboriginal Disability Network Inc located in Redfern and providing state-wide support. We can only recommend that during this review, you fully consult with this highly recommended and regarded agency which has achieved great results in reaching out to people who previously had no knowledge of advocacy or supports available.

*Action* ensures access to interpreters, with some voluntary support from *Action* members if there is an immediate critical situation until an interpreter service can be enabled, and other supports for people from culturally and linguistically diverse communities and their families. *Action* also offers referral to and advocacy agency funded to meet the needs of these people, with this offer being taken up at times. *Action* was previously contacted by a family from a Chinese cultural background for support on a specific individual advocacy situation, and when this was resolved, another group of families contacted *Action* over some months regarding the same issue for their family members. *Action* became aware that this group of families were living in adjoining suburbs and information about *Action* was being passed from family to family. *Action* was able to assist these families to meet and form the Chinese Carers Support Group.

People in rural, regional and remote locations often have a preferred regional meeting place or a trusted source of information, separate to a Government Department, from which they will accept information and invitations to forums, meetings and discussion groups. One example: *Action* was asked to facilitate some forums in country areas of NSW due to the particular expertise of one of our staff, and an example of reaching out to this group of people was through the highly regarded respite service based in Parkes. Many people attended the forum, even those families who did not access the respite service. Another forum was held in Goulburn and it was the Local Council that facilitated that forum. It is *Action's* experience that families of people with disability in remote area have to be assured that a forum or meeting will not be a waste of their time in attending and that their attendance will be of actual benefit to their family member.

In NSW, Community Visitors who have the responsibility of actually visiting each funded accommodation should have the responsibility of checking on the support available to each resident with a written response gained from each accommodation service detailing the response to specific questions. If any resident does not have the regular involvement of a family member, *Action* believes there should be a referral to the relevant regional advocacy agency to meet with that person to ascertain if there is a need for individual advocacy, particularly given the closure of Ageing, Disability and Home Care (ADHC) by 30<sup>th</sup> June, 2018. Experience has demonstrated a lack of reliance on service providers to facilitate the independent support of an Advocate for all residents with this need. This annual process will be a resource costly procedure, however, to meet the aim of improving access for people in this group, those resources need to be made available.

- 2.2 Please see references to Aboriginal Disability Network and Chinese Carers Support Group above. Also, as state based strategy will not always work for these people who prefer localised support.

## RECOMMENDATIONS

Employment of person with ATSI and CALD backgrounds as advocates.

Funding to be provided for the Aboriginal Disability Network Inc and other similar agencies in other states and territories to provide training for all advocacy agencies, including cultural awareness and competence and to ensure positive liaison with local communities.

Funding to be provided to enable valuable contact by independent advocate with people living in institutions and shared accommodation who do not have regular family support.

Agencies to be supported to build links with local CALD communities, with provision of funding to have all written material translated and printed.

**3.1** It has been a frustrating experience in NSW with advocacy agencies providing inadequately framed quarterly MDS Reports and better framed, but with improvement required, Annual Reports on operations to the funding body, ADHC, with no use of that important data being made to inform Government of the use of advocacy funding and the considerable level of unmet need of provision of advocacy. *Action* believes that this data and information should be made public with discussion of these reports at regional and state and territory level, with the opportunity for people with disability and their families to comment on these reports. State and territory peak bodies should then assist in the collation of data and information from these reports to inform their systemic advocacy in their state and territory and nationally, and to inform Government of the unmet need to be addressed.

**3.2** *Action's* provision of individual advocacy ensures that we work with a range of other organisations with similar aims. Additional resources would assist regional advocacy agencies to have time to further develop these networks. State and territory networks could assist with this working with a range of other organisations, as has been achieved by the NSW Disability Advocacy Network (NDAN) that also has members who provide rights based information. This network has been operating for over 20 years and has been very effective in communicating with all relevant agencies including Government Departments and Ministers, and then providing information and assistance to members in remote regions of NSW. The barrier to the continuation of this work is a total lack of funding to continue and grow this valuable work.

## RECOMMENDATIONS

A national database with appropriately framed software should be available for all advocacy agencies to streamline the processes of identifying unmet need and also to inform systemic advocacy at state and national level.

Additional resources need to be provided through NDAP funding to enable improvements in regional agencies working with other organisations and agencies.

**4.1** *Action* believes in the absolute independence of advocacy services with no level or process of direct service provision, to remove the conflict of interest that is always present when direct services also provide advocacy. *Action's* experience over the past 38 years has demonstrated that no level or process of service provision should be undertaken by an advocacy agency.

NDAP should be aware of the round of 16 consultations undertaken by NSW Government across NSW. ADHC staff reported that it had been very clearly stated by people with disability and their families attending these forums that their advocacy was to be provided by regionally based agencies, not large state agencies with branches in each region and that no agency providing any level or type of service was to also be funded to provide

advocacy. It is *Action's* continuing experience that these requirements of people with disability and their families have not changed.

*Action* offers no recommendations on the minimising of conflict of interest for service providers who are also funded to provide advocacy, as this would be an abrogation of our responsibility to uphold the rights of people who clearly do not want this to be enabled.

- 4.2 These gaps cannot be clearly identified at this point, due to the lack of clarity from NDIA on all aspect of what are the responsibilities of NDIS, and this lack of clarity is affecting people with disability now. As gaps become evident for advocates, there needs to be a streamlined process of reporting and addressing these.

## RECDOMMENDATIONS

NDAP funding criteria be set to ensure that advocacy is provided by independent community based agencies that do not provide any level or type of service.

- 5.1 *Action* regularly refers people to Intellectual Disability Rights Service (IDRS) for cost free legal advice in all legal matters, and believes that such services should be available in every state and territory. In comparison with some solicitors available through Legal Aid, the solicitors from IDRS have a higher level of understanding and experience to support people with intellectual disability support needs. demonstrate a The only barrier to people accessing this service is that if another person with disability is involved in the situation or has previously been provided with this service, the person the advocate is referring is prevented from accessing the service.

*Action* has advocate for another such service to be funded in NSW to afford equity of access for all people with intellectual disability support needs.

- 5.2 Barriers are the lack of understanding and knowledge by local solicitors and some Legal Aid solicitors, and the lack of equity to IDRS as detailed in 5.1
- 5.3 IDRS has provided effective support for people with intellectual disability, both individually and systemically.

## RECOMMENDATIONS

Services that operate as IDRS should be funded in each state and territory.

These services should regularly consult with advocacy agencies.

There should be at least two legal services in each state and territory to afford equity of access For all people requiring this service.

Funding for these services should be at a level to ensure timely legal advice and representation.

