

The Hon. Bronwyn Bishop, MP,
Chairperson,
House of Representatives Standing Committee on Family and Human Services,
Commonwealth Parliament,
Parliament House,
Canberra, ACT, 2600.

**URGENT SUBMISSION ON PROVIDING SUPPORT TO PEOPLE WITH DISABILITIES
THROUGH NATIONAL DISABILITY ADVOCACY PROGRAM**

Dear Ms Bishop,

I am writing to your Committee to ask for the opportunity to brief the Committee urgently on what I believe to be a disastrous and imminent plan by the Dept of Family and Community Services (FACSA) to change the present National Disability Advocacy Program (NDAP) into largely one "advocacy service" model which will impact strongly against those people with disability who most need advocacy to protect them.

It will deprive many of the protection from abuse and negligence they presently receive, it will take a high proportion of the minimal funds made available by the Commonwealth for disability advocacy (\$12m.) for administration and a help-line that those most in need are unlikely to be able to use, and many, many people will receive a poorer quality and "quantity" of advocacy, not suited to their needs. The rights of people are being trampled upon in a misguided effort to make the NDAP fit FACSA's needs for order and numbers and "case closure", rather than the needs of disabled people.

The reason for the urgency is that funding for all advocacy agencies was changed to finish on Dec 31, this year. An "Evaluation Report", due in August was not produced until early October. Comments were sought by 27th October. During this period, there were "consultation" sessions in which there was little consultation at all; advocacy agencies were *presented* with the outline of a new service model and told they must accept it. There was effectively no discussion allowed on its potential problems or outcomes, and they were also told that all advocacy agency contracts would be closed in 2007 and the advocacy work put out to tender. These sessions were told this service model is what the Dept is going to have and if agencies didn't sign the contracts by 15th Dec, they would close their doors on Jan 1.

It may be noted that the reports I received from a large number of people at these presentations around Australia vary considerably from the information on the 'consultations' given to the Senate Estimates Committee on 2nd November, 2006, regarding the degree of consultation which took place and of agencies' agreement with plans.

The whole process has been incredibly flawed and rushed. There has been NO opportunity to discuss the planned service, *which has not even been produced in written form.* There has been no chance to discuss any short or long term benefits for those who need advocacy, but more importantly, no discussion at all on likely short- and long-term detrimental and potentially life-threatening outcomes from the planned service. Nor of the likely and detrimental effects of the tendering process. As it is, because of the

uncertainty of the future, committed, caring, knowledgeable staff are being lost from disability advocacy. *Was this intended?* At least some agencies may close down, because their principles will not let them be part of further hurt to vulnerable people. *Was this intended?*

I am writing to you in the hope that you will use your Committee's influence to support the move by the Advocacy movement for people with disability, urgently to have rejected or at least to delay implementation for further examination the recent report "Evaluation of the National Disability Advocacy Programme" (attached), the consultation paper "Enhancing the National Disability Advocacy Program" (attached) and the proposed new "advocacy service." While accepting the NDAP could be improved, the whole process needs rethinking so that the outcome benefits people with disability, not further increases their powerlessness and removes for many their right to advocacy for their human rights.

The process must be stopped to allow this to happen BEFORE any changes are made, BEFORE new contracts are signed under protest. These are people's lives being played with - changes must be carefully considered first.

NB The report at its end (pp72, 73) acknowledges very quietly that "*The objectives of the program are unrealistic, are not measurable and need revision to reflect what the program can do and can realistically achieve.*" (My italics) This is nowhere else mentioned in the whole report of 73 pages. It also states the proposed centralized (NZ) system was recommended 10 years ago, but not implemented because of the costs involved. (It does not also say it was rejected by almost all the advocacy movement.)

Advocacy agencies established under the NDAP have accomplished many changes in the lives of people with disabilities and their families:

- **Systems advocacy organisations** have worked to improve the dysfunctional services often provided (or not) for children and adults eg to gain accommodation in the community, instead of in the Dickensian institutions. Many of the improvements in services and protection of rights are the result of years of work, often involving parents and volunteers.
- **Citizen Advocacy programmes (CA)** are run by community committees, independent of services. They seek out people with disabilities who are abused, at risk, neglected or alone. Each is matched with a carefully chosen citizen advocate from the local community in a 1:1 citizen advocacy relationship; many of these last for life. The advocate protects and speaks up for his/her protégé, tries to secure him/her a safe and rewarding life and is supported by CA staff.

Citizen advocacy was developed as an answer to every parents' question "Who will care about my son or daughter when I'm gone?" *It is one form of individual advocacy, the most personalised and caring, and the most cost-effective form of advocacy. A citizen advocate may be the ONLY person in someone's life who is not paid to be there.*

Many citizen advocates around Australia have saved lives, have been available 24/365, and have changed lives for the better. They are unpaid, and represent the community taking responsibility for its own. They also concern bureaucrats and confused the report's authors; none of these seem able to deal with the fact that carefully chosen "ordinary" people can do "extraordinary" things with support but without pay, or training beyond their life experiences.

- **(Paid/direct) individual advocacy organisations** employ staff to provide advocacy for people who need assistance to right wrongs or defend a person's interests. It is generally unable to provide long-term support to individuals.
- In **self advocacy**, people with disabilities learn to speak out for themselves. This can be very risky for powerless people who may be further abused if they complain of discrimination or ill-treatment. It can be very effective speaking out for other people with disability.

Presently NDAP funds all four forms, which provide complementary services. However, due to the small amount of public funds available, there are many areas and many people needing advocacy support, generally over the long term, that do not receive it. There is clearly a need for more advocacy agencies to fill the gaps in advocacy support available. It should be noted the report acknowledges systemic and individual advocacy should be separately provided, and it is well known citizen advocacy and paid/staff advocacy should not be combined; problems arise destroying their effectiveness.

Parents seeking good services and a contributing life in the community for their disabled children often need assistance in frustrating and disturbing circumstances; a few children need protection from parents or family; people with disabilities, mild, moderate, severe and multiple, who cannot speak out for themselves and who do not have supportive families often have need of an advocate, usually over a life-time. Some organizations and services abuse, or trample on people's rights and interests.

The unmet need is, as the NDAP report states, "huge". FACSIA is seeking to extend the NDAP to meet this need. *However, the model chosen to do so will not create "better" or "more" advocacy – it will provide a much worse program than at present.*

The report itself is deeply flawed, recommendations contradict evidence given and accepted in the report, and the consultation paper (itself flawed) proposed a system which would not provide the advocacy needed. FACSIA has further extended the proposal in the consultation paper to an unwritten, presented planned model to which these agencies and staff are required to commit themselves sight unseen. *This plans simplistic solutions for very complex matters involving the lives of people – very vulnerable people – and will not meet their advocacy needs.*

The authors and FACSIA show neither knowledge of many people with disability, nor of the effect on their lives disability can have, in powerlessness, abuse, neglect, negligence, isolation and friendlessness, which sometimes result in death or further disability.

The report acknowledges the "huge unmet need" but does not explore even those available resources showing at least part of the need, it is not dealt with in the recommendations, or in the final proposal, except by planning to spread thinly the present meagre resources (\$12m.) over all of Australia in a form which will ensure good numbers of usage, but frustration, possible retaliation, despair, and less protection and action for many people. The authors were prohibited from recommending more funds be given.

The Commonwealth funds Disability Advocacy both directly, and indirectly (to a lesser extent) to the States through the CSTDA, and the pattern set by the Commonwealth is always followed a little later by the states, at least in NSW where I have most knowledge, and I believe so in other states. Of course, much of the advocacy on behalf of people with disabilities who cannot speak for themselves is directed at State services, which regularly and sometimes fatally fail to meet the needs of their clients.

The NDAP and state Advocacy system therefore also help to provide to a large degree a watchdog on the services provided by Commonwealth money both directly (eg business services), and indirectly through the states. Citizen Advocacy programmes have many examples of citizen advocates standing up for their protégé's rights and interests in these services, while systemic advocacy has achieved many reforms.

Despite the report acknowledging the need for long-term advocacy, the need for other people to stand beside them and speak up for them, the vulnerability of many people with disability, particularly those most disabled; despite acknowledging the likelihood of retribution for complaints if not protected; despite acknowledging that many people with disabilities, particularly those most at risk, are only likely to confide in people they know and trust, none of this is apparent in the Recommendations. FACSIA plans to begin implementing from Jan 1, 2007 what will be in time a crisis/complaint service. The Report says (incorrectly) that disability advocacy is mostly about crises, and FACSIA plans short-term crisis intervention with "case closure".

The present advocacy agencies can indeed be improved, and many more are needed, but the planned system model will have remarkable similarities to the dysfunctional and tragic state "Child Protection Services" which in each state moves from crisis to crisis while their too few staff on the ground try to deal with massive waiting lists, prioritized (as FACSIA plans) for those most at risk, but unable even to see all of these; their staff try to patch lives and explain tragedies to the public and their chain of control. *As always, it will be the people with disabilities, particularly those most at risk, who will bear the costs of this ill-conceived report and rushed, uninformed plan.*

The Disability Advocacy movement has for many years acknowledged they are only able to meet part of the need for advocacy, and has begged for more resources. Each review has acknowledged the insufficient resources, but has not even been allowed to recommend more is needed. FACSIA plans to stretch these already vastly inadequate funds to cover all Australia and to provide high numbers of usage. It is callously ignoring what this will mean to those using (or unable to use) this service.

The NDAP was set up to help protect the rights of people with disabilities; surely changes to it should bring improvements in protection of their rights, including right to life, rights to protection and justice, and right to a decent life as a contributing member of a community. We believe the new model will make people less likely to enjoy these rights. Withdrawal of these new contracts and continuation for twelve months on the old contracts is essential to allow the new model to be thoroughly assessed.

Numbers of the highly principled staff in advocacy agencies are leaving rather than work in these circumstances, while some of the agencies are planning to close rather than compromise their principles. Certainly the call for tenders in 2007 will mean most of the skills, knowledge, networks, allies and protection in the NDAP built up over 25 years and more will be lost. The effects of the tendering process are incredible to visualize.

Instead of the skilled, thoughtful and knowledgeable systemic and individual advocacy services presently covering a wide range of need, the planned model will in two years provide a (mostly) help-line access crisis/complaint service, rendering short-term "advocacy", which the invisible people will not be able to access, and which already plans to exempt many people in need from getting advocacy help. It will fail to meet the needs of the majority of disabled people who need advocacy, most of them on a lifelong

basis, even when episodic. It will be these people who will pay the price for the ignorance of their real lives.

The effect of the planned new advocacy service will also be to lessen the meagre resources available at action level, to remove the form of advocacy most able to assist those with the greatest needs (*Citizen Advocacy*), and to deprive many people of their rights to life, shelter, a home, good care, community participation, freedom from abuse.... all we take for granted. It will take from them, (particularly those most unable to speak for themselves) the people who stand beside them, and the voices of systemic advocacy organizations.

Systemic advocacy agencies, already overworked to improve our many dysfunctional services, are being required to put 25% of effort into Individual advocacy (in which they have no expertise) and to build up to 50%. This despite the report acknowledging the need for separation of these two very different forms of advocacy.

With many, many others with years in the advocacy field, I am deeply concerned that this plan, being rushed into execution without any consideration of its impracticality, its lack of awareness of the lives of people with disability, the risks they face of retribution if they complain, (if they can), will destroy or negate much of the good work already achieved, and it will be they who will suffer for years until departmental recognition and admission of failure. *By then, the effective and skilled advocacy agencies and their staff presently achieving a great deal against the odds will be lost.*

Ironically, the Report claims to be setting in place a system which will most help the most disabled. But the recommendations and the planned new "Advocacy service" as described in the presentations include:

- *Establishing most contact for Advocacy via a "help-line" (many people with disability will be unable to use or access this, particularly those most at risk, the abused, imprisoned, institutionalised, most disabled and many others.)*
- *Ignoring the need for different forms of Advocacy, (the Report acknowledges this), but setting up bureaucratic control and a "one-style-fits-all" service based on a crisis/complaints unit model, involving mostly one-off "advocacy." This means the majority of people needing advocacy will have to come back, and back, and back, begging for help. That is, for those who know where and how to ask – but not those most at risk whom Citizen Advocacy programmes at present go and seek out to help,*
- *Most if not all Citizen Advocacy programmes will not be there. Despite being mandated in the Disability Services Act, 1986 (Cth), they have been told they are to be replaced by the short-term crisis model. . There will be no time in the new model to seek out those most vulnerable, abused, forgotten, invisible.*
- *Setting up a widespread publicity campaign to tell all people with disabilities advocacy is available, and to contact the help-line. This may be the cruellest part of all. The Report acknowledges there is a "huge" unmet need, and not nearly enough funding for present programmes let alone to provide advocacy to all these other people. But in an unbelievable move, to control costs to the existing funds, the new service coldly and explicitly intends NOT to serve most of these people, who will be turned away in their need and expectation of help. (While those most in need still will have no way of accessing advocacy.)*

FACSIA plans to set priorities for all agencies, and those not appearing to meet these will be rejected. There simply are nowhere near enough resources to meet advocacy needs in Australia, (see p2.)

FACSIA declares it wishes to help those most at risk, but it will take resources from the ground to pay for the administration staff planned, and for the help-line. In removing the form of advocacy most able to assist those with the greatest needs (Citizen Advocacy), it will deprive many people of freedom from abuse and their chance to have a caring person in their lives who will put their interests FIRST. People with intellectual disability are among those most vulnerable to the world's neglect, cruelty, abuse and manipulation. *They and many others need someone to stand beside them, to stand up FOR them, to let their voices and needs be heard.*

THE MATTER IS EXTREMELY URGENT. If advocacy agencies are forced to sign these open-ended contracts, more staff will probably be lost forever. Many believe they cannot be part of a system which will further harm people with disability.

The whole of society is affected by how we help our citizens with disabilities; the people themselves, their families, the services, the community at large. We all need to be involved in preventing this injustice to those most vulnerable.

I hope you will be able to find time for me and others to meet the Committee before the Senate rises at the end of the year. There are a number of other organizations who would also welcome the opportunity to meet with you and would convey their concerns for the future of disability advocacy in Australia.

I believe your Committee could be in the right position to see this proposed "attention to rights of people with disabilities" is given far more thought and that the changes to NDAP will actually achieve much better outcomes for the people who so desperately need effective advocacy. Please help them!

Yours sincerely,

**Barbara Page-Hanify
(Citizen advocate since 1987)**

My background is as a professional who has used her training both in therapy and as a leader in strategic planning and development of quality services, and in recognition of the value and rights of people with disabilities. In paid work (1960-1986), and unpaid since then, I have been honoured to be a friend and advocate for people with disabilities who cannot speak for themselves. I have been involved in Citizen Advocacy since 1980. I believe I have a good appreciation of the advocacy needs of many people with disabilities, and the risks and trauma, the loneliness and isolation, the abuse and neglect that so many of them face.

There are many other people and organizations that support the facts above. Some papers are attached for your information only; permission to publish would need to be sought from the organisations. QAI, CRU and Family Advocacy have given this permission.

BPH