

Physical Disability Council of New South Wales



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Disability Advocacy & Information Services in NSW

**Review
By DADHC**

*a response from
the Physical Disability Council of NSW*

July 2003

1. About the Physical Disability Council of NSW

PDCN is the peak body representing people with physical disability in New South Wales. We are part of a network that makes up the membership of the Physical Disability Council of Australia. At least 75% of the members of PDCN must be people with physical disability. We believe, therefore, that what we say and the representations we make to Government are based on the direct experience of people with disability. We are, we believe, an 'expert organisation'.

PDCN operates democratically as part of an effective network of disability sector organisations. We work collaboratively with agencies that share common goals. We strive to bring about significant, permanent and positive changes in the circumstances of people with disability. Our goal is to secure equal civil and human rights for people with disability.

- PDCN assists people with physical disability to represent themselves and express their own points of view to decision-makers in all sectors.
- PDCN helps to keep people with disability informed of developments of all types that might affect the lives of people with disability.
- PDCN represents the views and interests of people with disability to government and non-government decision-makers.
- PDCN works to educate members of the general public about the needs and aspirations of people with disability.

Membership of PDCN is open to individuals with physical disability living in NSW and to any person or organisation with a commitment to the rights and empowerment of people with physical disability. PDCN's Management Committee has twenty-one members, most of who are people with physical disability. Parents of children under 16 years of age are members of our committee. One third of the committee places are reserved for people with physical disability who are not resident in greater metropolitan Sydney.

The NSW Department of Ageing Disability and Home Care fund PDCN. We employ four members of staff who are based in our office in Glebe.

2. Reforming Advocacy and Information Services In NSW

PDCN believes there to be at least three core questions that must be answered if all stakeholders are to engage constructively with the reform of disability advocacy and information services in NSW. We believe that such reform is required so that everyone can better serve the interests of people with disability.

Our three fundamental questions are:

- a) What do we mean by advocacy?
- b) What is the relationship between advocacy, information and disability service provision?
- c) What should be the framework of advocacy and information service provision in NSW?

a. What do mean by advocacy?

If stakeholders in NSW are to work positively through a debate about advocacy (a debate that will sometimes be difficult) we must try to reach agreement about what we mean by “advocacy” or we need to agree that we cannot agree. Whether or not we agree on a definition, however, we have a responsibility to find ways (to the best of our abilities) to re-structure and develop an advocacy service system that serves the interests of people with disability.

We must not simply use the language of advocacy, and definitions that underpin that language, as if all current stakeholders were talking about the same things. It is clear that we do not all agree all of the time about what is or is not an appropriate definition or description of an advocacy service. The sector in NSW is going to have to tackle this unresolved question, as must the NSW Government, which will fund most of any disability advocacy service system that develops in years ahead.

It seems useful, therefore, to re-estate some principles to which PDCN subscribes. In doing so, however, we acknowledge that not every organisation currently funded under the NSW Disability Advocacy and Information Programme will feel entirely able to sign up to the following principles:

- Advocacy must be independent;
- Advocacy must be autonomous;
- Advocacy must be unambiguously on the side of the person or people with disability;
- Advocacy must focus on the fundamental human needs, rights and interests of people with disability;
- Advocacy should have a clear value base of social justice and full inclusion of people with disability as contributing/participating members of the community;
- Advocacy is about achieving justice;
- Advocacy is about achieving equity;
- Advocacy must minimise conflict of interest;
- Advocacy must remain loyal and accountable to the disadvantaged party over the long term where necessary;
- Advocacy is distinct from service delivery;
- Advocacy is not service provision or personal care support.

(Slightly revised from The National Advocacy Workshop “core principles”, June 1994. The key revision is to remove “strive to” from the first 3 bullet points.)

To the core principles above, PDCN would add the helpful comments by Robyn Banks and Rosemary Kayes, in *'Disability Advocacy: Too Much Talk and Not Enough Action'*: that the goal of advocacy should be to achieve far-reaching social change through the removal of disabling barriers and that Government should support a strong advocacy sector founded on commitments to:

- Self-determination by people with disability
- Accountability of individual advocates (and advocacy organisations)
- Systemic change rather than 'fire fighting' and/or crisis avoidance / resolution.

To which components we would add also the simple but necessary requirement that in advocacy, as in everything to do with decision-making about the lives of people with disability, there should be “nothing about us without us”. It ought not to have to be restated but it still needs to be said, unfortunately: we need to ensure that people with disability are centrally involved in the debate about disability advocacy.

One working definition of advocacy, which we endorse, is:

“Advocacy is pursuit of influencing outcomes - including public policy and resource allocation decisions within political, economic, and social systems and institutions - that directly affect people's lives.”

“Advocacy consists of organized efforts and actions based on the reality of "what is." These organized actions seek to highlight critical issues that have been ignored and submerged, to influence public attitudes, and to enact and implement laws and public policies so that visions of "what should be" in a just, decent society become a reality. Human rights - political, economic, and social - is an overreaching framework for these visions. Advocacy organizations draw their strength from and are accountable to people - their members, constituents, and/or members of affected groups.”

“Advocacy has purposeful results: to enable social justice advocates to gain access and voice in the decision making of relevant institutions; to change the power relationships between these institutions and the people affected by their decisions, thereby changing the institutions themselves; and to bring a clear improvement in people's lives.”

(Volume I: Reflections on Advocacy by David Cohen, Co-Director, Advocacy Institute, <http://www.advocacy.org/definition.htm>)

Working within the parameters set by the definitions and descriptions above, it's safe to consider the two ways in which advocacy has been addressed by the disability sector in NSW and by Government.

- Individual advocacy
- Systemic advocacy

And to these two types of advocacy work, we need to add consideration of this two-part question:

- What is a peak body and how does it relate to advocacy?

Individual advocacy

PDCN has made it clear (every time we have been asked) that we believe there is a pressing need for individual, one-to-one, problem-solving advocacy. We need more of such advocacy.

People with disability are, first and foremost, individuals. We belong to a socially disadvantaged group that experiences discrimination on a daily basis. But we live with the consequences of that discriminatory reality as individuals who are members of families and/or communities.

PDCN recognises that power is distributed unequally in society. There are imbalances between people with substantial or some power and those with less or no power. There are also imbalances in power between social institutions, organisations or social structures and people who relate to them in some way, often as actual or potential service users.

People with disability need the support of individual advocacy not because we are weak or deficient or incapable or inadequate but because power is distributed unevenly in society. There are histories, policies, customs, practices; cultural, racial or gender assumptions and class, ideological or social barriers that have been created and are maintained by the way power is arranged in modern, complex societies such as NSW.

Individuals with disability find themselves disadvantaged by the imbalances of power flowing from the broad context within which institutions and organisations in NSW operate. In such circumstances, individual advocacy services can help to equalise the inequality of distribution of power. It is to achieve a fairer balance of power that we favour more individual advocacy for people with disability.

Systemic advocacy

Individual advocacy is a necessary support mechanism for people with disability (and for people with no disability). But individual advocacy is not sufficient on its own.

Individuals live within social, cultural, economic, political and ideological systems. We act within and upon those systems and they act upon us. And, as we have noted, individuals, organisations and systems hold power to varying degrees.

It is clear to PDCN that people with disability (like many social groups in society) need systemic advocacy. Almost all of the work carried out by PDCN sits as evidence of the need to engage in systemic advocacy.

Our goal is relatively straightforward: we seek to change the way in which the social systems of NSW are organised to overcome the barriers of social exclusion and discrimination that work against the interests of people with a disability as a social group. There are systemic barriers, which constrain our lives as individual members of that group. They require a systemic response.

In short, therefore, we believe there is a need for more individual advocacy and for more systemic advocacy to work with people with disability as individuals and as members of social groups. The comments that follow, therefore, concern how advocacy services might be better organised in NSW.

Advocacy service development in NSW

There is a great deal of good work currently being done in NSW with regard to both individual and systemic advocacy. The NSW Government funds some of that work, some of it is funded by the Federal Government and a large part of it (we believe most of it) is carried out on a voluntary, unfunded basis.

Although services and service systems (not just disability related) may not, at first, welcome advocacy, we believe that effective advocacy results in benefits to individuals, to groups and to service systems themselves. Individual and systemic changes brought about with the support of advocacy create a new paradigm that works to the benefit of all. In short, advocacy is a good thing producing good results for everyone.

Not all the effort that goes into advocacy services in NSW results in the maximum benefit for stakeholders, however. There is currently some wastage and duplication of resources. The best intentions and efforts of concerned advocates and advocacy organisations are sometimes dissipated because the framework of advocacy in NSW is incomplete, patchy and struggling to cope (both with the task and with demand).

PDCN subscribes to these views:

1. We need additional funds to make possible a managed growth of advocacy services (individual and systemic) across the state.
2. We need better use of existing and growth funds to maximise benefit to service users and social groups of people with disability.
3. We need to build the competencies and skill bases of individual advocates and advocacy organisations. This may require specialisation of services, targeting of agencies that serve clearly defined areas and recognition (through funding arrangements) that not everyone can or should be all things to all people.
4. We need local and statewide services.
5. We need disability specific advocacy services for individuals and at the systemic level.
6. We need to ensure that all advocacy services become more culturally competent to meet the needs and aspirations of people from culturally and linguistically diverse backgrounds, including people of aboriginal or Torres Strait Islander backgrounds.
7. The generic service system of advocacy agencies (welfare rights, advice shops, the legal professions, etc) must become better equipped and ready to include more people with disability within their client profiles.

At this point, we need to return to the question: what is a peak body?

The term peak body is bandied around as if everyone knew and/or agreed about what was being discussed. We're not convinced, however, that everyone is talking about the same 'creature' when they use the term peak body. We need, at least, to agree on what we are talking about if the proposal that 'peaks should be funded' is to be picked up by Government.

According to one definition:

“A peak body is a body corporate formed to promote the interests of its member bodies. The formation and membership of a peak body is a common feature of organisations with allied purposes and aspirations, as is illustrated in local government, the professions, industry and the community service sectors.”

“The goal of a peak body is to achieve a collective outcome for their members. Primarily peak bodies concentrate on:

- *advocacy and lobbying;*
- *representation in relevant forums;”*

NCOSS describes itself as “the peak body for the social and community sector in NSW.” It is, according to the NCOSS strategic plan,

“ ... an independent voice on social and economic policy issues and reforms and is the major co-ordinator for non-government social and community services in NSW. ... [acting] as a channel for consultation with government and between parts of the non-government sector with common interests and diverse functions.”

We see common strands in these definitions (and others) of what constitutes a peak group. With regard to the NSW review of advocacy services we believe that the following components contribute to a useful description of a peak:

- A peak is independent of direct service provision;
- A peak is autonomous;
- A peak has member bodies (not just individuals) that share a common interest, purpose or aspirations;

- A peak seeks outcomes that benefit the members / constituents / customers / clients of the peak's member bodies;
- A peak exists in relation to a defined community or locality e.g. peak multicultural body; peak regional association; peak state-wide body;
- A peak may co-ordinate, lobby, represent, inform, consult with or on behalf of its member bodies who share the objectives of the peak.
- A peak has a demonstrable "footprint" within or across its constituency or locality of interest.

Many organisations can demonstrate one, some or most of these attributes. Only a peak exhibits all of them. Being biggest (in size, income or individual membership) does not make an organisation a peak. Size doesn't matter: what the organisation does is what counts.

What is the PDCN view of the relationship between advocacy, information and disability service provision?

It is something of a cliché that "knowledge is power". It's only true that power flows from knowledge if one knows what to do with knowledge or can use the knowledge one possesses. In that sense, therefore, it seems clear to PDCN that advocacy and information can be and often are closely related. More often than not one complements the other.

That is not to suggest that advocacy and information are the same things. They are clearly different.

Information can be provided without recourse to advocacy at all. The simple fact of receiving information can be empowering for disadvantaged people (including people with disability). Often, access to good quality information is all that is need to make it possible for an individual to assert his or herself within any of the power relationships we all enter into from time to time: applying for a service, using a service, seeking redress for an injustice, etc.

Advocacy, on the other hand, cannot exist without information. Advocacy is effective only when informed service users make choices that direct the work of an advocate (whether that is oneself, a volunteer or paid advocacy service provider).

Any and all services that purport to provide advocacy and/or information services must be unambiguously clear about the parameters within which they operate. We see a range of service options:

- If information provision is the sole concern of an agency that must be clearly articulated and inform the operating practices of the agency.
- If information AND advice are the concerns of an agency there must be a clear indication of the circumstances and point at which the agency's personnel move from informing to advising.
- If advocacy is the sole concern of an agency it must be made clear that informed service users direct the course advocacy takes. It may be, in some circumstances, that an informed service user rejects advice based on good quality information to pursue a course of advocacy to which the service user is, nevertheless, personally committed.
- Where an agency offers information AND advice AND advocacy services it is critically important that service users understand the differences between the three. In such circumstances we would expect to see demonstrable evidence of very high levels of staff competency.

PDCN believes that there is a direct and almost wholly irreconcilable conflict of interest between advocacy service provision and direct provision of disability services (e.g. residential or personal support services; transport or community options). We believe that organisations should concentrate on their core businesses:

- information services should provide information;
- advocacy services should provide advocacy services;
- disability services providers should provide disability services.

3. What should be the framework of advocacy and information service provision in NSW?

Based on all of the above, PDCN makes the following suggestions for constructing a framework of disability advocacy services in NSW.

Individual advocacy services:

There should be a least one cross-disability individual advocacy service in each of the eight regions created by DADHC. Each service should be managed and controlled by a cross-disability Board, the majority of whose members are people with disability living in the region served by the service. Each of the disability specific types represented by the statewide peaks (below) must be represented on Boards.

Regional services such as we describe should have:

- A viable and sustainable base with competent staff and volunteers located in the key population centre of the region;
- A broad range of skills in an adequate staff team
- Capacity to fund and/or organise outreach advocacy services in generic services outside of the key population centre
- Links to other regional advocacy services.
- Links to generic advocacy and advice services.
- Links to statewide peaks.

Systemic advocacy services

The State Government should fund a range of disability peak bodies with a statewide remit that includes systemic advocacy. We propose one each for:

- People with brain injury
- People with hearing impairment
- People with intellectual disability
- People with physical disability
- People with psychiatric disability
- People with vision impairment

additionally

- A peak body / systemic advocate body for people from culturally and linguistically diverse backgrounds.
- A peak body / systemic advocate body for people from aboriginal and Torres Strait Islander backgrounds.

It is possible that such state peaks could be funded to carry an individual advocacy caseload, particularly in circumstances where precedents may be set. Alternatively it may be that such peaks should be constructed solely on their systemic role and membership base. PDCN favours the latter.

In addition to carrying out systemic advocacy for their population groups, State peaks would be funded to commit time and resources to:

- Developing and supporting a collaborative, inter-agency 'peaks council'. We do not support the concept of a peak of peaks.
- Building the capacity of local, regional and state wide agencies in disability specialist and generic service systems to advocate on behalf of individuals with disability.

How should information services be organised?

We see a need to improve information services generally and with regard to disability specific matters. Specialist and generic information services should work together to build a network that covers all people across the whole state. It is clear, also, that State supported disability information initiatives need to relate better to developments underway in State information services generally, they should connect with Commonwealth initiatives and they should be consistent with and informed by local government practice.

We caution against an over-reliance on IT when considering the development of services that meet the information needs of people with disability. IT generally and web-based systems in particular can be powerful tools that assist people to find

information and begin to use it. But they are tools not panaceas. We note that a substantial proportion of the population does not have direct access to the Internet. This is particularly true for people on low, fixed incomes such as recipients of Disability Support Pension.

Knowledgeable, expert, trained, competent information professionals are essential to the development of information services for people with disability. IT systems are useful tools but they can never substitute for human assistance in negotiating one's way through the information maze with which many people are confronted. The human dimension to providing information to people with disability must never be lost, forgotten or under-valued.

The development of good quality information systems and networks that meet the information needs of people with disability will require the following:

- Understanding that people with disability are not reducible to their impairment type or condition. We are whole human beings with a diverse set of information needs that are just as broad as the population as a whole. Developing systems that meet the information needs of people with disability requires, therefore, action with regard to:
 - Generic information services; as well as
 - Disability specialist information services.
- All generic information providers (e.g. events, tourist, transport, consumer, weather, employment, legal, etc, etc) must ensure that their offices, their personnel and their information systems are inclusive of and accessible to the whole community, including people with disability.
- Disability specialist information services need to be developed and supported as complementary to generic services not substitutes for them.
- There should be a disability information resource with trained, expert, specialised disability information contact staff in each DADHC region. Such resources need not be separate organisations. They could be focused units

within existing generic providers or information units linked to regional individual advocacy services.

- Where disability information services covering regions currently exist these should be supported to grow into the regional base of the type we describe above.
- In addition to regionally based resources there should be a disability specialist, statewide service using web technology and a 1800 number operating as a common entry point to the following services:
 - Sign post to local services;
 - Sign post to disability specialist information;
 - Information only (not advice or advocacy) with access to currently available and emerging information databases;
 - Internet access to self-searching databases;
 - Referral to interpreting services;
 - Service capacity building.
- A non-government, not for profit organisation acting on behalf of the NSW Government, should operate the statewide information service we describe above. The provider should be managed by a Board of people with disability drawn from the stakeholder interests represented by statewide peaks and partners from Government and non-government information experts.

PDCN Submission ends

Wednesday, 16th July 2003.