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### Abstract

This booklet describes the importance of self advocacy. It provides examples from within N.S.W., lists considerations essential to a self advocacy group, and identifies positive outcomes as a result of the self advocacy movement. **Keyword: Advocacy**

SELF ADVOCACY NSW LTD

Past, Present & Future

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## INTRODUCTION:

As for Self Advocacy NSW Ltd, this is how we began:

At the meeting of the Western Region Rights Committee (WRRC) in November 1985, the Committee decided to apply for a Demonstration Grant from the Commonwealth Government to show that people with intellectual disabilities can speak up for their own rights, needs, and wants. This decision came out of a question put to the meeting some months before.

The question was whether or not the WRRC ought to split into two, because geographically, the committee was equally divided between the Northern and Western Suburbs of Sydney. This raised an additional question of whether we ought to keep that name. The Committee decided not to split and instead sent Jeff, David and Dale to meet with Mr B. Bolton of the Department of Community Services to discuss the possibility of funding through that Department. Within a week the Submission was sent in and the Committee waited for news. The funding was approved and SA NSW Ltd was born. The Committee's first step was to open an office. The office was officially opened on 8 June, 1986 by Ms Judy Ellis, the Director of the Office of Disability.

The 'newly formed' Self Advocacy NSW Ltd was in fact the same people, but with a very different role. Our new role is to train people with intellectual disabilities to speak up for their own rights, needs and wants. The aim behind this is to establish more Self Advocacy groups throughout the State of New South Wales. The groups so far set up by SA NSW Ltd will be discussed later on, along with comments about the 1987 State Self Advocacy Conference - a first - and essential factors involved in setting up a Self Advocacy group, (the Non-Negotiables)?

The reference to "Jeff, David and Dale" refers to Jeff Strike, David Gant and Dale Mattock.

## SELF ADVOCACY Why is it Important??

We believe that Self Advocacy is important because -

1. being involved in Self Advocacy demonstrates to all concerned that people with intellectual disabilities can do things for themselves;
2. Self Advocacy encourages people with intellectual disabilities to recognise that people with intellectual disabilities have the same rights as everyone else;

3. Self Advocacy encourages people with intellectual disabilities to take their rights seriously;
4. Self Advocacy allows people with intellectual disabilities to identify their own limitations;
5. Self Advocacy encourages the community to recognise the abilities of and reconsider their own attitudes towards people with intellectual disabilities.

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#### TRAINING - Who Does It & How??

Staff of Self Advocacy NSW Limited and members of the Board of Directors are involved in training people to speak out for themselves. Each person who takes on a training role firstly is taken through a course on Public Speaking and What Self Advocacy Means (which is run by the Office) so that each person has a definite understanding of the idea behind Self Advocacy.

Trainers will then go out to talk to groups of people with intellectual disabilities (of no less than 5) about how Self Advocacy NSW Ltd (SA NSW Ltd) was set up. This discussion was aimed at showing people that it is possible to do some thing for yourself if you put your mind to it. After this we will show a video or two which will also demonstrate people doing things for themselves and how important this is. As these videos are mostly American, the approach taken in them is very much from a Rights base. We will talk about our rights as they exist in Australia. So far we have found that the most powerful question to ask is: "What rights do you have??"

#### RESOURCES:

During this project it has come to our notice that SA NSW limited is unique in that it operates from a teaching base. Because of this uniqueness, there are very few appropriate teaching resources available for our use. The videos we currently use was originally designed to inform people who would be Advisors to a group about Self Advocacy - so we often see difficulties where people are phased by the video. However, we get around this problem by using the video to remind the trainer of issues to discuss later. Another Demonstration Project, (the National Self Advocacy Kit Project), was funded to devise alternative and more culturally appropriate resources.

#### SELF ADVOCACY IN NSW - Where is it??

There are a number of groups in New South Wales which were set up and are being supported by SA NSW Ltd., these are:

Self Add (Hunter); Patterson House Management Committee; Self Add (North Coast); and Speak Out (Albury-Wodonga).

HUNTER: The election for the Hunter group is just around the corner, so reports are currently being written by the Office-bearers during the Working Night Meetings. The organisation of the Hunter group is such that the members will meet in general session every second fortnight and will be involved in the Working Night meetings in the intervening fortnights. We feel that the concept of the Working Night is a good way to involve all the members in action from the previous general meeting.

The biggest problem facing this group is one of money. There are currently two members with the time to devote to public engagements, which helps to bring in some funds additional to membership fees, levied annually.

LISMORE: The North Coast group is currently engaged in organising a regional conference on Self Advocacy in Valla Park for some time in October, 1987. We plan to follow up this group during this conference. Each member of the Conference Committee will receive a Record of Study from the TAFE College to show that they have been involved in a Conference Organiser's Course. Since February 1987, the group has met about 5 times and now has about 15 members coming from such areas as Nambucca Heads, Grafton, Coffs Harbour, Lismore and Tweed Heads. Taree is not yet involved. North Coast is looking up!

#### PATTERSON HOUSE MANAGEMENT COMMITTEE:

The Patterson House Management Committee is one which is quite flexible. This is because Patterson House itself is a transitional house. Members therefore change rather frequently - approximately every 6 months or so. We hope that during the six-month exposure to Self Advocacy each member become more aware of his or her ability to run his or her own house after leaving Patterson House for somewhere else.

We will soon re-visit Patterson House to talk with the members of the Committee about their role. We have unfortunately had to defer the date for this meeting to a more mutually convenient one.

#### ALBURY-WODONGA:

This group was in fact up and running by March of 1987, before we visited it. The Chairman of this group was a participant at the State Self Advocacy Conference. During this gathering, he asked us many questions about how we set up our office.

At the Public Meeting, held in Albury's SS&A Club, a total of 22 people were interested to be involved on the Committee. The

group decided to begin with a BANG! During our visit, the Boarder Morning Mail and AMV 4 interviewed us about Self Advocacy. We feel that the effect of this publicity may have been quite positive on the group because initially it appeared difficult to interest people in attending this meeting. However, seeing the roll-up at the meeting was a pleasant surprise.

Since that time, reports have come in that the group has decided to be involved more socially than in a structured way. Such a step is not necessarily bad because it allows the members to get to know each other better. One of the support people whom we met during our visit, pointed to the fact that people in Albury are extremely isolated, both geographically and socially. For this reason we feel that the group is meeting one of its greatest needs by working this way. It is our opinion that Albury-Wodonga will develop past this informal stage over time to a progressively more formal one; i.e. a Committee discussing business perhaps on a monthly basis.

#### NEW GROUPS & OUR PLANS:

Dubbo -

The possibility of setting up a Self Advocacy group in Dubbo originated from a Challenge Foundation Conference held in Gilgandra in early 1987. There have so far been four people apply to become members of SA NSW Ltd through this. We have been discussing the idea with one of the four people and negotiations are progressing. We look forward to the involvement of Westhaven (the local workshop) in these discussions.

MUDGEE -

This also came about because of the invitation to talk in Gilgandra. We met with the Co-ordinator of "Peacefields" during this conference and were invited to visit the complex which he and seven other people ran. These seven people all have disabilities of one kind or another. The idea of starting a Self Advocacy group in Mudgee and surrounding district has suffered several set-backs. The two greatest of these are that the complex has since been closed due to its funding having been withdrawn and the geographical and social isolation of this region.

We feel that more footwork needs to be done in order to successfully attempt establishment of a Self Advocacy group in this area and the Co-ordinator of "Peacefields" has offered to assist us in this matter.

BROKEN HILL -

SA NSW Ltd was invited to spend two days in Broken Hill - one, talking with people who have intellectual disabilities and then on the second day, talking with staff and caregivers. This invitation was contingent however, on the successful application for the necessary funds through the Department of Health's Richmond Unit.

The arrangements were being made for us by people whom we had also encountered in Gilgandra. Unfortunately, the funding was not approved, but the non-approval of this funding was not the death-knell. The death-knell came when the staff person who was responsible for this idea resigned. Since she left, the commitment appeared to vanish with her, although there were some supportive staff still there in more junior positions.

WOLLONGONG -

We approached this idea during a YACS Staff Development lecture at which an SA NSW Ltd staff member was present. One of the House Managers present knew the Co-ordinator of the Intellectually Disabled Persons' Trust (IDPT) in Wollongong. On her return there it appears that she (the House Manager) approached the Co-ordinator of the IDPT and put us in touch with each other. There has been an invitation for a representative of SA NSW Ltd. to address a meeting in Cram House about Self Advocacy in August. The invitation to speak with people who have intellectual disabilities in Wollongong remains open.

CHATSWOOD -

There was a video being made by the Intellectual Disability Rights Service about Workers' Rights. A representative from SA NSW Ltd was asked to visit and talk about the role of a Workers' Committee. From this screening of the video and the talk after it, the Workers' Committee was restarted. It had ceased operation before because its chairman had left.

THE STATE SELF ADVOCACY CONFERENCE:

The Board decided to run a State Self Advocacy Conference in December of 1986, however this had to be deferred to March of 1987 in order to allow for ourselves and prospective registrants sufficient time to budget for the conference expenses. All told, 34 people registered for this conference from many and varied parts of the State. Unfortunately, there were no representatives from the Orana & Far West Region or the ACT. Registrants came from:



Central, North, South and Western Metropolitan Sydney; the Hunter; the North Coast; the Illawarra and the Riverina.

Jeff and Dennis were organised to set up everything during the day before we all arrived and much of the organisation had already been done through the Office; it simply remained to carry out the arrangements.

On our arrival at the Conference, Jeff and Dennis took all the registrants through the rain to the Conference Hall and gave Carl the job of reading out some previously arranged House-keeping rules.

Each day was chaired by a different chairperson: Saturday by Dennis and Sunday by Brendan. Despite the fact that the Agenda was radically altered on Sunday, it was a very good day because people were given the chance to say what they felt, who may have otherwise not said what they did.

Saturday was a good day although a good many people were of the opinion that they did not get enough of a chance to say what they wanted to because each speech was limited in time and the proceedings for Saturday ran over time. Due to having run over time, questions and answers were severely restricted.

During Saturday, a number of Self Advocacy videos were shown and a speech delivered about them. There was unfortunately insufficient time to field questions from the floor about the videos, although we had planned this to take place. Perhaps our agendas were too full?? A number of people had suggested that the conference should have gone over three days instead of two, but perhaps if we shortened our agendas, we may be able to carry out all that need be done in the two days, thereby not increasing the registration costs for people attending and having more opportunity to exchange opinions.

#### THE ESSENTIALS:

- Throughout this project, the following considerations are thought to be essential to a Self Advocacy group:
- The Committee must be able to meet freely and as often as it requires, without threat;
- The group should attempt to meet in places where other types of groups meet, which are accessible;
- Choose advisors with whom members of the group feel comfortable and between whom there is a bond of trust;

- Start slowly and rotate the positions of officers between the members to strengthen the group and develop leadership;
- Be certain to involve all the full members in the decision-making process of the group;
- Advisors are involved in a Self Advocacy group to support the full members in their decisions. One of the most challenging aspects of the advisor's role is to allow the members to make mistakes - this way the members will learn. If an advisor protects the members from making mistakes, how can the members learn?
- Ensure that the number of full members exceeds the number of advisors, so that the decisions of the members will be of their own choosing.

INCORPORATION:

SA NSW Ltd became a company limited by guarantee on April 3, 1987. The basis of this application was so that the Department of Community Services & Health (as it is now known) will be able to fund under the Disability Services Act, 1986, subject to a positive evaluation of this project later on in 1987.

GROUPS WITH WHICH SA NSW LTD IS ASSOCIATED:

The Disability Advisory Councils of Australia and New South Wales -  
David Gant has been involved with these two Ministerially appointed committees for a number of years, but due to work pressures has recently had to resign from the Disability Advisory Council of NSW. There are no plans to withdraw from the Disability Advisory Council of Australia.

The Intellectual Disability Rights Service -  
Jeff Strike and Carol Pein are both differently involved with this service. Jeff is a member of the Hypothetical Panel and Carol is a member of the Legal Rights Committee.

NSW Council for Intellectual Disability -  
Both Jeff and David are involved with CID as members of the Board of Directors. David has been a Vice-Chairperson of the Council for the past two years so far.

Citizen Advocacy NSW -  
Both Jeff and David are also involved in the CA State Council. Jeff is a Delegate from an operating programme

and David was elected into one of the five non-delegate positions.

WesCAp -

Jeff has been involved on the Management Committee for WesCAp (an operating CA programme) for two years so far, firstly as the Assistant Secretary and then as the Honorary Secretary.

CA Northside -

Brendan is connected with people at CA Northside where he and a friend put NITRO (a newsletter) together with support from the CA Northside staff.

Interestingly, after he left the workshop, Brendan and his friend placed on the back of the second edition of NITRO a pictorial statement of their dislike for the word "handicapped" in the sign displayed outside the workshop. The reconvened Workers' Committee took this as an affront to their workshop and complained to the authors. The dispute has since been resolved by the two authors and the CID Advocacy Officer at the time. We had been approached to determine in this matter by one of the parties involved. Resolution of this problem took place before such intervention was necessary.

Disabled Peoples' International (NSW Inc.) -

Carl Craber, (our treasurer), and Jeff are both involved with DPI in differing ways. Jeff is a member of the Policy and Planning Committee; Carl and Carol are representatives of people with intellectual disabilities on the DPI State Council.

Tuesday Night Club & Others -

Kevin Greenup, another of our members, is connected with many community-based recreational organisations in the western and eastern metropolitan suburbs of Sydney. The two with which he is most busily involved are the Tuesday NightClub and Junction House.

As for members involved in SA NSW Ltd, there are 13 members on the Board of Directors in SA NSW Ltd. Subcommittees established under the Board include the Publicity Committee and Policy Committee on which a number of members are involved and report regularly to the Board in general session.

#### GENERAL COMMENTS:

Due to this widespread involvement and support for the idea of Self Advocacy, there are many calls on this office and other members of SA NSW Ltd to take part in setting up other groups in New South Wales.

As well as the calls on the Office to support existing groups, there has been interest shown by a workshop to set up a Workers' Committee within that Workshop and on top of this still, calls have come from Colleges of Advanced Education, the Departments of Youth and Community Services and Technical and Further Education and groups such as the Cumberland College of Health Sciences, Macquarie University, Stockton and Mount Druitt Hospitals and the NSW Institute of Technology for student and staff development lectures.

We have been to two conferences so far, one in Gilgandra which has interested potentially another 8 people to become members of SA NSW Ltd; and the State Self Advocacy Conference, which was held in Valla Park one month later. There was also a trip made by David and Jeff to Melbourne in February of 1987 to evaluate Reinforce. Before this trip, Colin Hiscoe and Judith Buchanan visited the SA NSW office for a peer external evaluation of this project. Contact has also been made with the Office staff of SAID - the Self Advocacy office in Adelaide.

#### OUTCOMES WE HAVE IDENTIFIED:

During the life of this project so far, it has become apparent to us that as people become involved in Self Advocacy, confidence is built up by recognising the innate ability of people to do things for themselves. This has been seen in a number of people amongst the membership of each existing group. Two of our members who live very much in the western metropolitan 'fringe' have expressed a wish to be involved in a Self Advocacy group more local to their area. This is yet another call on our time and resources.

We believe that an important part of our role is to speak to current and prospective service workers (e.g. nurses and YACS District Officers) and other people whose employment brings them into contact with people who have intellectual disabilities about the meaning of Self Advocacy.

These are just as important as setting up new groups because, we have been informed, giving lectures of this type results in the following. They cause -

- people to rethink their own attitudes towards what people with intellectual disabilities can and can't do;
- people who may have previously seen people with intellectual disabilities as eternal children to realise that people who have intellectual disabilities are not ETERNAL CHILDREN and that we take our rights seriously;

- people to think about rights and recognise that people who have intellectual disabilities have the same rights as everyone else.

As for what Self Advocacy does to benefit people with intellectual disabilities, as said before, it builds confidence, but further, it teaches new skills to people involved in the Self Advocacy group.

Because people learn new skills, each person is in a better position to enforce his or her own rights. Coupled with this, the attitude change which can be caused by the lectures we give, creates more general understanding between all parties concerned. This we feel is a major outcome of Self Advocacy.

#### STATISTICAL DATA

Table 1 : Enquiries

Information	83
Media Activities	15
Appointments	28
Speaking Engagements	11
Meetings	30
Training Programmes/Requests	21
Library	00
Valla Park	29
Money Matters	15
Legal Matters	02
Others	27
TOTAL:	261

Table 2  
Calls by Mbnt\*s

	Number of
January	05
February	25
March	66
April	33
May	68
junz	64
	261

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