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Author: O'Brien, Sue Johnson, Kelley

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**Abstract**

AMIDA, a community based accommodation support organisation in Victoria, prepared this article as the result of its research into the effectiveness of consumer participation. In identifying the views of consumers they used methods other than written material which are a helpful guide to anyone preparing workshops for people who have disabilities. Basically consumer participation means a real exercise of power by consumers at all or some levels of an organisation. Implementing it may mean significant changes in the way an organisation operates. Research showed "that many of the problems they encountered arose more from their powerlessness and societal attitudes than from their disability.." **Keyword: Accommodation**

# IMPROVING CONSUMER PARTICIPATION

Sue O'Brien and Kelley Johnson with contributions  
from Bryan Walkinshaw (former Consumer Participation Worker)

THE ONGOING DEBATE ON HOW TO ENCOURAGE REAL AND EFFECTIVE PARTICIPATION BY SERVICE-USERS IS BROUGHT TO LIFE IN THIS ARTICLE, WHICH OUTLINES ONE ORGANISATION'S (**AMIDA**) ATTEMPTS TO INVOLVE MILDLY INTELLECTUALLY DISADVANTAGED ADULTS IN THE OPERATION OF THEIR SERVICE.

**AMIDA'S** EXPERIENCES REVEAL THAT SPECIAL EFFORTS NEED TO BE INVESTED TO CREATIVELY ENCOURAGE CONSUMER PARTICIPATION. "REAL CONSUMER PARTICIPATION MEANS THAT POWER MUST BE SHIFTED TO CONSUMERS AND MAY MEAN SIGNIFICANT CHANGES IN THE WAY AN ORGANISATION OPERATES".

THIS TYPE OF THINKING HAS LED **AMIDA** TO INSTITUTE SOME MAJOR STRUCTURAL CHANGES TO ITS ORGANISATION, MEETINGS, OFFICE AND THE WAY THE SERVICE, ITSELF, OPERATES.

THE SPECIAL EFFORTS MADE AT **AMIDA** PROVIDE US WITH A MODEL OF CONSUMER PARTICIPATION WHICH NOT ONLY BENEFITS THE CONSUMERS, BUT PROVIDES OTHER WORKERS AND ORGANISATIONS WITH MECHANISMS FOR REALISING A POLITICAL COMMITMENT TO EMPOWERING PEOPLE WHO ARE DISADVANTAGED IN SOCIETY.

## Introduction

"Consumer participation is about having real control over the decisions which affect your life." (1)

In the last issue of "Community quarterly", Chris de Meyere in the article, "Developing Consumer Participation" (2), provided a useful starting point for considering consumer participation. However, after twelve months of struggle to implement consumer participation in a community-based organisation, we feel that it does not go far enough. The problem for many people interested in consumer participation is how to implement it. Too often, as in the above mentioned article, people focus on how to 'get information from consumers' and how to educate them about consumer participation. These emphases often lead to a process of consultation in which consumers play a role, however, it is doubtful if they lead to real consumer participation.

In our experience, consumer participation means a real exercise of power by consumers at all or some levels of an organisation. Its implementation demands that the organisation examine its structures and processes to ensure

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that they are accessible to consumers and that the consumers have a 'real say'.

This is what we, as researchers, set out to do and in this article we have outlined some of the things which we learned in twelve months' work on consumer participation with AMIDA, which stands for 'Accommodation for Mildly Intellectually Disadvantaged Adults'.

AMIDA is a community-based organisation which aims to develop housing and support options for mildly intellectually disadvantaged adults in the inner urban area of Melbourne. At the time of our involvement, AMIDA was managing two community residential units and establishing an integrated rooming house; as well as providing limited outreach support for people living in the community. The management committee consisted of consumer representatives, people with intellectual disabilities (3) and other interested community members.

**"... consumer participation means ... that the organisation examine its structures and processes to ensure that they are accessible to consumers ..."**

Funding came from a number of sources, but primarily from the Office of Intellectual Disability Services.

From its beginnings in 1981, AMIDA has operated on the philosophy that adults with intellectual disabilities have a right to participate in decisions which affect their lives. In particular, AMIDA believes that these adults have the right to participate in the planning, management and evaluation of services which they use. Consumer participation is seen as necessary for the development of relevant and appropriate services. It is also seen in a broader perspective as a developmental and politically empowering process. Today, this philosophy can be seen in practice at all levels of the organisation.

### **The Research Project**

For the past three years, funds have been obtained to employ a consumer participation worker. Twelve months ago, two of us were employed as researchers to work alongside the consumer participation worker investigating the effectiveness of consumer participation at AMIDA and the ways in which it could be improved. Our project was called 'The Consumer Participation Research Project'.

The consumers with whom we worked included the tenants of the two group houses which were managed by AMIDA, as well as a number of people with intellectual disabilities who were involved in other aspects of the organisation.

### **What is Consumer Participation?**

To begin with, we found that consumer participation, as it applied to people with intellectual disabilities, meant different things to different people. In terms of Government policy, it often meant that: "... intellectually

disadvantaged citizens have a legitimate and major role to play in planning and evaluating services". (4)

**"For many workers, consumer participation meant a focus on consultation ... but less emphasis on consumer representation on ... management committees".**

For many workers, consumer participation meant a focus on consultation with service users, but less emphasis on consumer representation on their management committees.

For consumers, it meant things like "people speaking up for themselves", "people listening to what you say" and most importantly, "having a REAL say". 'Having a real say' became the definition of consumer participation used by consumers at AMIDA. This aptly placed the emphasis on having effective involvement in the organisation rather than consumer participation as a tokenistic gesture.

For us as researchers, consumer participation at AMIDA became clearly associated with the power of consumers to have an impact on decision-making within the organisation.

Given the diversity of perceptions about what is meant by consumer participation, it was decided that the project should take a relatively broad view of it. A consumer was defined as any adult who had ever used a service for intellectually disadvantaged people, and participation was defined as any form of involvement in decision-making within a group, body or service. Our definition of a consumer did not include parents of intellectually disadvantaged persons, but rather the person who was directly using the service.

### **Identifying the Views of Consumers**

In carrying out our research, we believed that identifying consumers' needs and interests was a pre-requisite for developing avenues for greater consumer participation. Thus, this became one of the most important, yet most difficult aspect of our research. It certainly became clear within the first three months of the project that traditional research investigative methods would not work, so we modified existing methods or developed new means of obtaining people's views.

We realised that our first step was to make things relevant and understandable to consumers. We found that topics or issues for discussion needed to be concrete and related to a person's practical experience.

**"Written material ... proved to be a poor means of communication ... other methods of communication had to be developed and used ..."**

Discussions about broad concepts, theoretical frameworks, or abstract processes, for instance 'consumer participation', were not clearly understood by consumers.

Written material also proved to be a poor means of communication, even when care was taken with the wording. In discussions, language had to be simple, without jargon, clear and comprehensible. More importantly, other methods of communication had to be developed and used as well. The most effective means for finding out the views of consumers at AMIDA proved to be a workshop approach. These were designed to both provide information about the organisation and consumer participation, and to give people the opportunity to talk about how they felt about their level of participation in different parts of the organisation.

The workshops held at AMIDA took considerable time to develop. They involved the use of concrete visual aides and provided a setting which was non-threatening to participants. The most effective methods used in the workshop were:

### Photographs

Photographs proved to be one of the most successful means of obtaining responses from consumers. For the workshops, we set up photographic displays showing consumer involvement in the different parts of AMIDA, such as going to committee meetings, in-house meetings, doing things at the house and social events. Workshop participants wandered around the room to each of the displays and made comments about the activities the photographs depicted. Facilitators at each of the displays assisted this process, and encouraged comments that were positive as well as identifying 'things that needed to be improved'. The responses were plentiful (both positive and negative) and focussed on a number of aspects in each area. Comments were written up on large sheets of paper so that all participants could see them.

### Videos

Videos, including one produced by the self-advocacy movement and one of a skills workshop in which AMIDA participated, were extremely popular with consumers. Discussions following videos invariably produced good responses from people, particularly in relation to their own experiences. We also found that videos have great potential in outlining more difficult processes, for example, meeting procedures, rather than other methods, such as written material, cartoons and photos. At the workshop an extremely worthwhile discussion of rights and consumer participation followed a videotape produced by Reinforce (the Victorian Union of Intellectually Disadvantaged Citizens), entitled: "Don't Think I Don't Think".

### Drama

As part of the research project, consumers from AMIDA worked with the Reinforce drama group. Two plays were presented at the workshop on:

- (a) being a consumer representative;
- (b) not getting your say at a meeting.

The dramas, which were enjoyed by the audience, were a very effective way of involving consumers and communicating quite complex concepts and processes.

### Small groups

Small group discussions were used as part of the workshop. These proved to be effective when clear questions were raised for the groups to discuss and when strict time limits (about ten minutes) were adhered to.

While all of these methods were used as part of our workshops, we found that they could also be used effectively by themselves to generate discussion either with individuals or in small groups. For example, drama was used as part of the Annual General Meeting at AMIDA to start discussion about self-advocacy.

## **Strategies for Encouraging Consumer Participation**

After researching into the needs of consumers and relating these to the structures and processes used within AMIDA, a number of changes occurred within four broad areas: the way the organisational structures worked; the way meetings were run and hence decision-making within the organisation; the operation of the service and the way the office was organised. This had the effect of improving the level of consumer participation at all levels of the organisation.

**"... assistance was given to people who were exercising their right to elect people to represent them - for some, this was their first time."**

### **1. THE ORGANISATIONAL STRUCTURE**

At the time of our involvement, the community-based management structure of AMIDA included a committee responsible for policy decisions and the day-to-day running of the organisation; as well as a number of sub-committees and working parties, which looked at particular issues or aspects of the organisation, such as the 'House Resource Committee'. A minimum of half the positions on the management committee were set aside for people with disabilities. Through observing and working with this representative model, we developed several strategies for ensuring that it worked as well as possible:

#### (i) The election of representatives.

Efforts were made to ensure that consumers at AMIDA elected their representatives on the management committee, and understood the role of their representatives. The Annual General Meeting at which the elections occurred, became an event for which there was considerable preparation. For example, as mentioned previously, drama was used to demonstrate the importance of representation on the management committee; explanations of the role of representatives were given and the electoral process was described. At the meeting, assistance was given to people who were exercising their right to elect people to represent them - for some, this was their first time.

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**"Regular meetings between representatives and their constituents were established to ensure on-going communication ..."**

(ii) Accountability of consumer representatives.

Consumer representatives encountered two main difficulties in fulfilling their role at AMIDA. Firstly, there was a tendency for representatives to give their own views on an issue rather than those of their constituents. Secondly, there was the problem of conflict between representatives and their constituents due to personal problems. Regular meetings between representatives and their constituents were established to ensure on-going communication, and to provide an opportunity to resolve difficulties.

(iii) Increased numbers of representatives.

It became clear that the number of consumer representatives at any level of the organisation or at any meeting was critical in determining the impact of consumers on decision-making. As the numbers of consumers involved in AMIDA meetings or activities increased, so did their willingness to speak up and their ability to influence the organisation. This increase in consumer numbers occurred because of the changes to committee structures and processes which were being implemented at all levels.

## **II. MEETINGS**

Meetings appear to be an unfortunate fact of life for organisations like AMIDA who wish to encourage a community-based and democratic management structure. Meetings, being the forum where formal decision-making occurs, are a crucial area for effective consumer participation. We found it to be important that meetings which aim at involving consumers include issues and topics which are consumer initiated, or at least of interest to consumers. A number of techniques have been used to achieve this goal:

(i) Consumer involvement in agenda planning.

Formal agenda planning meetings were introduced to give consumers a way of putting items on the agenda. A board was also put up in the room where the agenda meetings were held for consumers (and workers) to note issues and items that consumers raised and wanted discussed at committee meetings. Towards the end of the project, the organisation took over the responsibility of providing background information about the committee meetings by making a committee member available (on a rotating basis) to discuss the agenda items an hour before the meeting.

(ii) A fair representation of consumer interests at meetings.

Efforts, such as those mentioned above, were made to ensure that the agenda and the meetings included a fair representation of reports and issues raised by consumers. As the agendas for committee meetings were always long, and

there was strong feedback from consumers that they would prefer shorter meetings, this meant removing items or finding other ways of dealing with those items that were mainly of interest either to workers, or to only a small number of people, such as sub-committees, working parties or special meetings.

(iii) Incorporating consumer issues raised at meetings.

Often at AMIDA meetings consumers would raise issues that were not on the agenda and hence these issues tended to be lost. The strategies which were developed to ensure that these concerns were discussed included, dealing with

**"One of the most successful strategies for involving consumers at meetings was the use of small groups within the meeting."**

the issue at the time it was raised, putting the item on the agenda and/or discussing ways in which the issue could be handled.

(iv) The presentation of material.

We were aware that if consumers were to participate effectively in meetings, it was vital that they understood the issues being discussed. Considerable efforts were made at AMIDA to present reports in a way that was comprehensible. This meant:

- using simple language
- giving background
- keeping reports and issues practical
- working through from issue to proposal
- keeping reports and items short
- encouraging consumers to give reports and,
- using other forms of communication, such as videos.

(v) Small groups.

One of the most successful strategies for involving consumers at meetings was the use of small groups within the meeting. Breaking into small groups gave consumers greater opportunity to ask questions and to give their views. This

**"We looked at ways of breaking down the office bearer positions into more specific tasks ..."**

technique had added advantages of breaking the meetings, saving time and giving people a choice in what they were involved in.

This worked well when there were reports to be given or a specific task to be done by a small group, but was more difficult when there were recommendations which needed the involvement of the entire committee.

(vi) Consumers taking on more responsibilities.



We looked at ways of breaking down the office bearer positions into more specific tasks, and then allocating such tasks to a number of people. So it worked like this: the chairperson was actively involved in planning the meetings and in chairing them, that is, keeping the meeting 'on the track'. However, the other two main tasks of chairing - making sure people do not all talk at once and keeping time - was rotated amongst other people, both staff and consumers. The role of the secretary was broken down into someone to take the minutes and someone else to send them out. This was shared by the agenda planning group, which included the secretary. The co-treasurer

**"Taking on greater responsibilities meant that there was more interest and involvement by consumers ..."**

worked with the person who has previously acted in this position and thus learnt the skills involved.

Taking on greater responsibilities meant that there was more interest and involvement by consumers and also, that these roles within the organisation tended to be carried out in a way which was more relevant to consumers.

The potential problem of taking power away from a position or person (particularly a consumer) was recognised, and care was taken not to allow other people to take over the roles that consumers had.

The above strategies were successful in increasing both the numbers of consumers attending meetings and their level of participation. Once again it's important to emphasise our finding that the greater the number of consumers present, the more individual consumers appeared to be willing to speak up and the more interest was shown by consumers in the meetings.

### **III. THE OPERATION OF THE SERVICE**

The way an organisation provides services is a critical issue for consumer involvement, as service delivery has the most direct relevance and impact on consumers. In the case of AMIDA, the way that the two community residential units operated had enormous implications for consumer participation, both within the houses and throughout the rest of the organisation.

#### (i) House meetings.

House meetings (with support if required) were seen as being essential by consumers and others at AMIDA if residents at the group houses were to be involved in decision-making. It was important that these meetings were controlled by consumers (not staff) and used by them to raise issues of concern, which were later taken to management committee meetings if required.

#### (ii) Understanding the service and consumer rights.

We believed that an essential pre-requisite to being involved in a service is to understand its objectives and the way it is run. Equally important is understanding the rights (and responsibilities) as a consumer.

Strategies that we used at AMIDA to do this included:

- (a) Discussions amongst residents and a number of workers, particularly the consumer participation worker, both at an individual level and in groups.
- (b) Initial orientation evenings run for persons interested in living in the organisation's accommodation.
- (c) Speakers from local and other organisations concerned about individuals' rights.
- (d) A video was made by consumers about the operation of the houses.

(iii) Grievance procedures.

The consumer participation worker worked with consumers on developing easy to understand grievance procedures. As consumers tended to go to a range of people within the organisation with grievances, the grievance procedures had to be flexible. It was also necessary to build in options for consumers which involved going outside the organisation to self-advocacy groups and other advocacy services (5).

#### **IV. THE OFFICE**

The office of any organisation can be an area where consumers may become actively involved and hence participate in the day-to-day running of the group. From our experience, we found a number of simple strategies which may be employed to encourage consumer participation in this area:

(i) Space for consumers.

If consumers are to be actively involved in the operation of an office, there needs to be space available for their use. This may be a special room or desk or a communal area which consumers feel free to use.

(ii) A comfortable and welcoming environment.

Consumers need to feel welcome at the office or facility that they are wishing to become involved in. The tea room was the area preferred by consumers at AMIDA as it was comfortable and the place where people tended to gather to chat.

(iii) Accessibility.

Buildings also need to be accessible in terms of their location and physical structure. As most consumers are on low-income, it is particularly important that buildings are on public transport routes. For some consumers who have

physical disabilities as well as being intellectually disadvantaged, physical accessibility may also be an issue.

(iv) Easy to use equipment and simple office systems.

It was recognised at AMIDA, for example, that the filing system had to be revised because the existing system was complex and difficult to follow.

**"... we ... found that many of the problems they encountered arose more from their powerlessness and societal attitudes than from their disability per se."**

The typewriter was traded in for a more basic model that was easier to use.

(v) Encouragement.

We found it important to actively encourage consumers to take part in the office tasks. Often the office may be perceived as the workers' domain and hence there is hesitancy to take on tasks.

## **In Summary**

During the course of the consumer participation project at AMIDA we often heard the argument from groups managing services that intellectually disadvantaged people were unable to participate in making decisions which affected their lives because of their disability. While it is true that people are able to manage different levels of decision-making depending on the severity of their disability, we also found that many of the problems they encountered arose more from their powerlessness and societal attitudes than from their disability per se. If people are not given the opportunity to make decisions or to participate, then it is difficult to assess their capacity to do so.

The major finding of our research project was that any organisation committed to developing consumer participation must be prepared to look closely at its formal (and informal) structures and at the ways in which decisions are made.

Developing real consumer participation within an organisation often means that power must be shifted to consumers and this may mean important changes in the way an organisation operates.

We found that consumer participation is an ongoing process. It involves: a commitment by workers; changes to organisational structures and processes to allow greater access and increased involvement by consumers. Workers and consumers are then able to work jointly on developing further strategies and change.

While consumer participation is not without its difficulties, there are real benefits. For many workers and organisations, it will be the realising of a political commitment to empowering people who are disadvantaged in society. Consumer participation also means that valuable contributions and ideas are

not lost. At the very least, it will ensure that the basic rights of any consumer group within an organisation may be protected.

*Sue O'Brien worked as a community Housing Worker for six years, before working as a Social Researcher. Sue has been involved in social research projects in a range of areas, including disability, housing and domiciliary services.*

*Kelley Johnson has worked as an independent Researcher for four years. Kelley has a particular interest in exploring issues, such as participation and power for people who are disadvantaged by our social structures.*

Copies of the report, "Having a Real Say", can be obtained from:

AMIDA  
P.O. Box 1032  
St. Kilda South  
Victoria, 3182

Ph: (03) 534-6407

## FOOTNOTES

1. This quote was taken from comments made by a member of a Board of a community-based organisation during the 'Consumer Participation Research Project'.
2. Meyere de, Chris, "Developing Consumer Participation", Community quarterly, Number 12, 1988, Melbourne.
3. Consumer representatives were elected by the consumers, whilst people with intellectual disabilities were elected by the general membership. Primarily, the consumer representatives were consumers of AMIDA services, although this position was also open to workers.
4. Victorian Intellectually Disabled Services Act 1986, AGPS.
5. Outline of AMIDA's Grievance Procedures:

## RIGHTS

### EVERYONE HAS BASIC LEGAL AND HUMAN RIGHTS

Some of the important rights you have living in an AMIDA house or by receiving drop-in support from AMIDA workers are:

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- \* To choose an advocate (that is, someone you can trust for advice and who will help you speak up) to help represent you in any situation.
- \* To make decisions that affect your life.
- \* To have real chances to learn independent living skills.
- \* To use services in the community.
- \* To handle your own money.
- \* To be treated with respect.
- \* To privacy and enjoyment of your own personal space and things that you own.
- \* To have your friends visit.
- \* To have a say in decisions about how things are run at the house, who moves in and who the workers are.
- \* To elect representatives to the AMIDA committee whose job it is to speak up for you at the committee meetings.
- \* To have access to any information that is kept about you - your permission is needed for anyone to see this information.

## **PROBLEMS AND COMPLAINTS**

If you have a problem or complaint that concerns the house like:

- \* people not sharing house jobs
- \* people not respecting your rights
- \* complaints about workers or
- \* things that need fixing,

then here are some ways and people that might help you sort it out:

1. Talk to a friend or advocate who can help you decide on what is the best thing to do about your complaint.
2. Talk with other people in the house. Maybe one of the other tenants can help.
3. Bring it up at a house meeting - so you can all work on the problem together and decide what needs to be done.

4. Bring it up at a tenants only meeting with your committee representatives. Ask the consumer participation worker to come and help you run the meeting.

5. Talk with the house co-workers, house supervisor or the program liaison officer.

REMEMBER - IF YOU FEEL THAT PEOPLE:

- \* don't listen to you or
- \* listen but don't do anything

THEN - GO SOMEWHERE ELSE

**Co-workers**

The house co-workers are employed by AMIDA. The AMIDA committee is their boss.

1. The co-worker's job is to:

- \* help you do the things you want to do
- \* help you have more experiences to learn from as well as,
- \* help you learn things to be more independent, like cooking, using money, house-keeping, using transport, for example bus, train, tram and taxi; speaking up for yourself and using services in the community.

2. Co-workers:

- \* should let you make your own decisions
- \* should **not** make decisions for you
- \* should listen to your ideas
- \* should treat you as an adult
- \* should let you and the other tenants run the house and,
- \* should **not** run the house.

3. Co-workers and tenants or people who live in the house should:

- \* learn from each other
- \* treat each other with respect and dignity
- \* listen to each other

\* respect each other's privacy and feelings

\* be honest with each other

\* respect each other's rights.

\* If other people have the same problem, then get together because more people are stronger.

\* You have rights but sometimes you have to fight to get your rights

If you have tried all these ideas to sort out your problem and nothing has happened, then here are some other places to go for help:

Reinforce - The Victorian Union of Intellectually Disadvantaged Citizens.  
Ph: (03) 489-2003 and (03) 489-1252

Community Visitors from the Office of the Public Advocate.  
Ph: (03) 603-6777

Community Services Victoria  
Office of Intellectual Disabilities Services  
The Regional Co-ordinator  
Ph: (03) 581-222

The Director of Client Services  
Ph: (03) 616-7473

Ombudsperson  
Ph: (03) 67-7151