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Bill Worrell

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INTRODUCTION

This handbook was written mainly for people who are currently advisors to self-advocacy groups, such as People First, or similar self-advocate committees, such as the Consumer Advisory Committee of C.A.C.L. If you're thinking of *becoming* an advisory, we also had you in mind when writing this handbook. Finally, we would hope that friends and supports of self-advocacy who are looking at ways to support self-advocacy will find this handbook useful.

For those readers who are advisors, we hope that you will read the People First Leadership Training Manual, also produced by the National People First Project, and that you view the films "We Can D It: The Story of People First" and "Speaking for Ourselves" (available on video).

Other recommended readings have been produced by People First of Washington: “Officers Handbook”, “What a Successful Meeting”, and “Introduction to People First”. These are much more detailed, nuts-and-bolts-type of manuals that explain how People First is organized, and are useful for self-advocates and advisors.

When writing this handbook we struggled a lot with words.

Words carry a lot of significance to the self-advocacy movement. A lifetime of being labeled has made labels a major issue. Being surrounded by professionals and bureaucracies who puzzle you with needlessly complex and convoluted explanations make words and wording major issues.

As the writer of this book, I also have some likes and dislikes about words— let me explain a few of them.

Consumer is a word I dislike; it objectifies a person even more than previous terms that were more in vogue in the past “client, trainee”. It tries to change a social work relationship into an economic marketplace relationship. A person uses services; I don’t see how you can consume a service. You can’t “use it up.” It puts the emphasis on quantity, not quality. And finally, to be a consumer, you need money. As a consumer, you have some power - you can pick and choose how, what, and where you want to buy. This is far from reality for most people with disabilities, who are generally force-fed services.

Consumer has also become a nice way of saying “handicapped person”. It doesn’t make sense to talk about “a consumer” in general. Every one of us is a “consumer” of products from one particular industry or another – a supermarket, an electronics firms, a service.

In this book, we have tried to identify people in a

context. If we are talking about the effect of a disability, we will talk about “a person with a mental handicap”, or “a person with a disability”. If we are talking about a person’s role in an organization, we talk about “members” or “leaders”. In the context of a service, we prefer to talk about “service users”. Finally, if we talk about what happens to people when they are labeled “mentally retarded” we talk often about “people who have been labeled” or “labeled people”.

Quite often this book speaks of “People First” when it really means self-advocacy groups where the advisor is a non-voting participant and the members are all labeled people. We also often use the term “Association” for any service agency. In Canada, many “Association for the Mentally Retarded”, “Associations for Community Living”, etc., etc., run services or are indirectly involved in running them.

And finally, the reader will notice that we change from “him” to “her” throughout the book. This is to avoid any sexist stereotyping.

We hope this book will provide a general framework to help advisor understand their role and how they can support this vitally important movement in our society.

THE LIFE OF BEING LABELLED

We, as advisors, are probably involved in this movement because

- (1) We see that people labeled “mentally retarded” don’t have many opportunities in their lives, and
- (2) People First is a way to help people to learn to support each other, to speak out for their rights and to broaden their opportunities.

To understand our role as advisors, it’s important to understand the importance of self-advocacy to the members of the group. This means thinking seriously about the quality of the lives of labeled persons and how self-advocacy can improve that quality.

The dominant attitude propagated in our society towards people with mental handicaps is rejection.

Handicapping conditions are seen as negative, and people with disabilities as burdens on society. People who are labeled mentally handicapped are grouped together, hidden away from society, and often forgotten, either in massive institutions, or, on a smaller scale, in segregated programs.

People labeled with intellectual disabilities are cast into roles that reflect these negative values. Either a labeled person is seen as some sort of sub-human organism (“vegetable” is still a term that is used thoughtlessly in the media), or as an “eternal child” (and therefore a receiver of pity/charity). The underlying assumption is a denial that a person with a mental handicap deserves basic human rights. For example, in Canada sexual and physical abuse of labeled individuals (in institutions, in families and elsewhere) is widespread. This abuse has many forms: involuntary sterilization, behavior control through drug abuse, the use of cattle prods to control behavior.

Many rationalizations are used to justify this violation of personal and private integrity. We have all heard things like: “They don’t understand anyway”; “They don’t know any better”; or even “They can’t feel any pain”. Violence against handicapped people even includes death. It is not uncommon for people to be left to die of neglect in hospitals, institutions, nursing homes, or rooming houses.

This rejection by society affects all aspects of the life of a person labelled “mentally retarded”. Most labelled people live in constant *poverty* with no hope for improvement. Those who work in sheltered workshops are often paid as little as \$0.25 to \$1.00 an hour (sometimes nothing) to supplement their meager pensions.

In turn they may be asked to pay back this small sum to cover costs. Including these individuals, the unemployment rate for people labelled retarded is over 90 percent.

Once a person has been labelled, they are strongly *controlled* by pervasive network of government bureaucrats, doctors, parents, professionals and paid staff – the “service providers”. Many of the “rules and regulations” of this control are arbitrary and fly in the face of normally-accepted standards of basic human rights. For instance, many provinces issue “wage permits” to allow employers to pay less than minimum wage to an employee with a disability. This control of labelled people starts early in life and continues into adulthood. Most individuals become passive receivers of the services offered by society, and learn quickly to accept what is dished out to them. The few who try to buck the system are often labelled “behavior problems”, which leads to even more control by the system. Society generally *vastly underestimates* their potential as human beings.

Many of these attitudes come from a lack of information or just plain wrong information. Most of the wrong information comes from the very services that are supposed to be providing support. For instance, many self-advocates who are now living in the community will tell stories of how doctors, psychologists, psychiatrists, institutional and hospital staff and parents had predicted their total dependence and inability to cope. Just one of many flagrant examples of this is a very capable, hard-working self-advocate who was a participant in a recent Supreme Court case on forced sterilization. When she was an infant, her family doctor predicted she would ever be able to walk or talk. Not only can she walk, she gives public speeches, has been interviewed numerous times,

has worked full-time for the last ten years, and leads a very productive life.

The segregated education /employment/ residential system that dominates the lives labelled people institutionalizes and reinforces these low expectations. Even the more “progressive” segregated services do not fulfill people’s needs precisely because they are segregated and are therefore boring ghettos which offer “no future. The system expects little of these “clients.” As a result labelled people internalize this negative self-image.

Just as each individual sees himself/herself as worthless, so he or she tends to see the other people in the workshop/group home as worthless. Because people have such a negative *self-image*, the personal relationships that they value are those with so-called “normal” people. These “normal” people are often the paid professionals and staff in individuals’ lives; sometimes these “normal” people are friends of parents (i.e., the older generation). In other words, many labelled individuals do not have real friends who can offer the support that is so important for personal growth. The isolation of individuals is usually acute. There is often very little love in people’s lives.

People often do not have well-developed communication skills. Part of this is because once they are labelled “retarded”, very little effort is spent on teaching them reading or writing skills. But one of the fundamental reasons why labelled people communicate poorly is that nobody has ever expected them to do otherwise. Most of us have learned to explain what we think and feel because of the challenges in our lives that force us to express ourselves – for instance applying for a new job, getting along in personal relationships, trying to get something done by explaining your point of view

to a government bureaucrat.

Suppose you were labelled with an intellectual disability. You would be expected to be a passive, dependent person. You would not be called upon very often to explain what *you* want. Your life would often be dictated by others. Your opinion wouldn’t be valued. You’d learn to be non-*communicative*.

HANDICAPPISM

Our society values money, intelligence, aggressiveness, efficiency and rationality, beauty, youth and strength. Hierarchies of power are based on these values. People who are able to use these hierarchies rise to the top.

The opposite values to these (i.e., poverty, stupidity, laziness, backwardness, overly-emotional, ugliness, oldness, and weakness) are often seen as going together. In other words, if you are attributed with one of these traits, you should have them all. This is the basis of discrimination. For persons with disabilities, this is handicappism.

For example, in the media, which molds public opinion, successful (i.e., rich) movie and TV actors spend immense amounts of money and time on face-lifts, nose jobs, fitness programs and generally trying to look young. The vast majorities of TV programs are either “action” programs, or depict a middle-class way of life that would require a hefty income to support. Poorer people (e.g., Archie Bunker) are often portrayed as stupid, backward, ugly and old.

People labeled handicapped, particularly those labeled mentally handicapped, cannot, or are perceived as being unable to fit into these desirable roles. Therefore, a labeled person often gets her particular weaknesses attributed to her *because* she

has a handicap not because she is a person with good and bad points like everyone else.

A good example is the issue of the right of people with mental handicaps to be parents. It is widely believed that people with mental handicaps would make bad parents, that their children would grow up “retarded”, either through lack of stimulation or because of a genetic tendency (scientifically unfounded) for people with mental handicaps to have children with mental handicaps. This belief has led to massive use of forced sterilization of persons labeled with intellectual disabilities.

On the other hand, as many self-advocates have pointed out, many so-called “normal” people can be abusive, neglectful or uncaring parents. Society has never suggested that *they* should be sterilized.

Labelled people often find that as soon as they make a mistake, they are “jumped on”, with comments such as “you see, I told you he shouldn’t do that, he’s handicapped”. Or, “we gave you a chance and you failed, now listen to us for a chance”. In other words, labeled people have to be twice as good at anything they do in order to prove themselves. For instance, on the job, a person with a handicap may take twice as long to get to work in the morning as a “non-handicapped” person, but if she is ever late, she runs the risk of severe criticism or punishment that often is far worse than that reserved for a “regular” employee.

This requirement to be “twice as good” in order to be treated equally is not unusual. It happens to other people in our society (for example, black people, native people, women) who are trying to fight the prejudice society has towards them. Therefore, handicappism has the same effects as racism, sexism, and prejudice in general. It pervades the whole system of policy-making. For example, the Federal Government in 1987 approved

\$183 billion for the production of nuclear submarines. Almost simultaneously, the Ontario Government announced the expenditure of a few million on the multi-year plan to get people out of institutions and into the community.

Persons labeled mentally handicapped are among the most powerless members of our society. Their oppression is extreme. Their major handicap is the straight-jacket of isolation imposed on them by society. The result is a lack of life experiences and self-confidence.

For instance, while many advisors may have had the opportunity to choose between one job or another in their lives, a person living in a group home often doesn’t have any choice. It’s either the workshop or nothing. That same person probably doesn’t even have a choice about where to live, whom to live with, when to eat supper, or when to go to bed. Another example is the act of joining a group. Many advisors may already have had the experience of being an active member of a group, starting back in school, or later in a trade union, professional organization, or community group. People First is often the first chance for a labeled person to join a group where he or she has the power to make decisions.

Self-advocacy, then, is about the empowering the powerless. It is people who have no control over their lives daring to take a step to gain more control. It is people who have never had the chance to plan for the future, or even dream about it, daring to work towards a future that they want.

Empowerment is a process. Power is not given to people nor is it earned. It happens as a result of a constructive, meaningful activity that leads people to be more knowledgeable, skillful, informed and aware than they were before.

Self-advocacy is also part of a large movement in our society that challenges the way society works. It involves a fundamental change in the way that people think and see themselves. The positive cultural values that labelled people bring to the movement overlap with similar values that other oppressed people hold.

Self-advocacy can play a vital historic role to promote these values and challenge some of the fundamental ways society functions.

The day that labeled people are truly empowered will be the day when the world will be transformed.

WHAT IS SELF-ADVOCACY?

In the last chapter we said that empowerment is a process. Self-advocacy is an important part of that process. To learn self-advocacy, people get together with their peers to discuss common problems and find ways to help each other. Through these activities, people can learn a variety of skills and co-operative problem-solving techniques. People develop self-confidence, broaden their point of view, acquire information and new ideas. Their presence and participation in the decisions that affect their lives and the lives of others is increased. One way to conceptualize gaining power is a ladder towards empowerment.

CITIZEN CONTROL	}	Degrees of Citizen Participation and Power
DELEGATED POWER		
PARTNERSHIP	}	Degrees of "Tokenism"
PLACATION		
CONSULTATION	}	Non-participation
INFORMING		
THERAPY		
MANIPULATION		

The eight (8) rungs on a *Ladder of Citizen Participation* From: *A Ladder of Citizen Participation*, by Sherry R. Arnstein, *AIP Journal*, July, 1979, Pages 216-224

Manipulation and Therapy - These two rungs describe levels of non-participation. Their real objective is not to enable people to participate in planning or conducting programs. Their real objective is for "power-holders" to "educate" or "cure" participants.

Informing and consultation - On these two rungs, people may indeed hear and be heard - but, people lack the power to ensure their view will be heeded by the "powerful" - there is no "muscle".

Placation - This rung is simply a higher level of "tokenism" because the "power holders" still have the right to decide.

Partnership, Delegated Power, Citizen Control = Real Participation

In Chapter One, we saw how handicapped people are powerless. Now we can look at how self-advocacy can help labelled people take steps to overcome their oppression.

1) **PUBLIC EDUCATION:**

Many people in society do not have a clear idea of what mentally handicapped people need. As we said earlier, a lot of myths prevail about labelled people, many coming from the human service system. Since prejudice is based on ignorance, the general public is led to have the wrong attitude. Many people in society have no vested interest in putting down people, they just don't know any better. On the other hand, self-advocates, by speaking out in public or by showing through their presence in the community that they want to and are capable of living in the community, can change many people's attitude.

As well, too often, people with disabilities have been hidden from public view. No wonder prejudice thrives! On the other hand, public reaction to positive media interviews is generally favourable. Interview have been used very effectively by self-advocates for example, the Eve sterilization case, and many other issues.

2) **PRESSURING FOR CHANGE:**

Self-advocates who are involved in associations have a hard row to hoe. They have to address well-anchored, well-articulated prejudice. They are confronting the egos of people who are usually convince their attitudes are good and right. It may be frustrating, but these self-advocates play an extremely important role - they are trying to change the very system that is the cause of much prejudice in society. Dealing with government can be equally difficult, but both are extremely important to effect real change.

3) OVERCOMING POVERTY AND DEPENDENCE:

It is extremely difficult to get a real job when you have been labelled with an intellectual disability. However, by advocating better vocational training programs, and by talking to government-funded agencies, employers and unions, self-advocates can create a more favourable climate for employment in the community.

Also, by being active members of a People First group or an Association, people can learn marketable skills and perhaps make some contacts that will open up job opportunities and break down the walls of isolation. Although People First may not actually be able to help a self-advocate find a job it can provide some support.

4) PROVIDING MEANING AND IDENTITY:

Self-advocates can gain the incentive to learn many new skills because they are involved in an activity that has meaning in their lives. Supported by new achievements, self-advocates can break down some of the other barriers in their lives. As Pat Worth, a People First leader often says, “Now that People First is here, I have a reason to get up every morning”. Anyone who has met Pat would agree that he is living proof of the incredible progress that one person can make in feeling positive about oneself and learning to be communicative, open and supportive of others, through involvement in a group such as People First.

* * *

Self-advocacy is all about empowering the powerless. The advisor should always be asking the question, “Am I assisting people in a process which will empower them or re-enforce powerlessness? Am I enabling or disabling people”?

When given a chance, people often speak out when wanting respect and a place in the community. When they say this they aren’t speaking about a program like a sheltered workshop or a group home. They are speaking about being citizens and living with the same rights and choices as other members of the community.

Self-advocates who speak out rise important basic issues: freedom, fulfillment, self-determination. Nobody can speak more eloquently on these issues than the people directly concerned. Nobody knows the issues better than those who live the consequences of the problem. There will be no real solutions to these problems until those who bear the brunt have a real say in how the problems are solved. *Nobody* can do this for them. The most well-meaning, helpful, sensitive, committed advocate will never be able to do the job as effectively as a well-prepared, well-trained self-advocate.

How can society be convinced that people with disabilities don’t want charity and dependency if someone else is always speaking for them? How will self-advocates really become more independent if advisors, friends and supporters are constantly running in and taking over?

* * *

Self-advocacy deserves our unqualified support. This is not always easy, especially when self-advocates criticize the human service system, social attitudes, and the way “normal people” treat them. For instance, the vast majority of People First members support the principle that the only person who should make a decision about giving birth to a child, contraception or sterilization is the person him or herself. In the parent movement, opinion is divided.

Many parents feel that if their son or daughter has a mental handicap, the parent should make the decisions on these matters. But in the long run parents, professionals, human service workers and advocates who want real change in people’s lives have everything to gain by supporting outspoken, honest and forthright self-advocacy.

3

TWO WAYS TO DO SELF-ADVOCACY

Today we are seeing a growing tendency toward labelled people demanding increased participation in “Associations for the Mentally Retarded”, “Associations for Community Living”, and other agencies. We are also seeing the growth of an independent self-advocacy movement.

This handbook is written mainly for advisors to the self-advocacy movement. The kind of support advisors to the self-advocacy movement must give is different from the kind of support provided to those self-advocates who participate in Association committees. But it is worth looking briefly at some of the issues involved in these two kinds of self-advocacy.

1. PARTICIPATION BY SERVICE USERS IN ASSOCIATIONS AND AGENCIES

There are some service users who have decided that the only way they are going to improve or transform the service they are getting is to get to the source of power.

This is often perceived, with reason, to be the board of the local association. Some self-advocates have made it a major ambition to “get on the Board of the Association”, even if it may take a while. This participation in agencies and service-provider organizations is important to safeguard the rights of service users.

Services are a major part of people’s lives to varying degrees. For some people it is one hundred percent of their lives. For others it is less. Allowing them to have a strong voice concerning services they receive is a key way to give them power in their lives.

Through their participation in associations, service users can learn a lot about how the service system works, what are some of the attitudes that the system is based on, and how decisions are made about services and the people who use them. In addition, simply by participating in meetings, participants can learn a lot about how to organize the meeting, making reports, rules of order and so on. These are valuable skills that the person can then use in other parts of his or her life.

People who have been labelled are often very alone in their personal lives. Being involved in an association can allow some people to make new friends and build relationships with people who are valued members of society. At the same time, the other people in the association can enrich their lives through knowing and working with some of the users of their service.

2. PEOPLE FIRST: AN INDEPENDENT SELF-ADVOCACY ORGANIZATION

The significance of a self-advocacy organization is that it is formed, led and built by and for people labelled “developmentally disabled”. A member of a self-advocacy organization has a much greater chance of influencing the ideas and actions of the group than he would ever dream of having inside a local Association. People First is a self-advocacy movement whose purpose is to empower the members. There are three vital aspects to this movement: self-help, self-advocacy, and group advocacy.

People First, as an independent organization, has internal dynamics that can empower people through *self-help*. A group can help members make new friends, learn new skills, learn about the community and build self-esteem. This is achieved through collective discussion and decision-making in the group. These are precious skills that members value.

Aside from learning new skills, People First is also a place to share common experiences and to look for emotional and practical support. Members begin to understand.

This is very important. The first step in developing your self-confidence is to realize that you’re okay (you’re not crazy). Anger that their frustrations and problems are shared by others. They see that they are not alone about your life is understandable and normal. Your “emotional problems” are often not caused by you, but by society.

The next step in this process is to turn this anger or frustrations into constructive action advocacy, either through developing *self-advocacy* skills, or *group advocacy*.

Individual self-advocacy usually develops in several steps over a period of time. First, a problem is raised in the group. For example, John is having a problem with the hostile attitude of a staff person in the local workshop. Next, the group discusses the problem, and decides how to help John. There can be several possible solutions. For instance:

- Helping John figure out how to speak out at the workshop and stand up to the staff person when something happens. This could be done through role-playing.
- Having John, the president, and the advisor meet with the workshop manager to discuss the problem.

This whole process of discussion and decision is an essential part of self-advocacy. Through experience and practice, the members learn communication and decision-making skills that the advisor may take for granted.

Group advocacy can also take several forms. To continue with the previous example, the group could possibly decide to organize a meeting with the workshop staff, or the Board of Directors, to explain what they want in vocational programs.

PARTICIPATION IN ASSOCIATIONS & PEOPLE FIRST – THE DIFFERENCE IS IMPORTANT

There are an increasing number of associations who encourage participation by service users. This is good news for the users. Labelled persons have already played major role in one particular action by C.A.C.L. that had a major impact on many people’s lives – the favourable Supreme Court decision on the “Eve Case”. This decision states that no person can be sterilized unless that person expressly stated that she wants to be sterilized. If it hadn’t been for the insistence of the labelled persons present inside the association, there was a good chance the case would not have gone as far as the Supreme Court.

SELF-ADVOCATES IN ASSOCIATIONS:

Supporting user participation in associations is a test of association policy. There is still a long way to go. There are several pitfalls.

One danger is that of tokenism. Probably the best example of this would be an Association which has one “handicapped person” on the board but which offers no support system for that person. It doesn’t take long for that person to realize that if she doesn’t understand what’s going on no one is going to help her. This leaves her with two choices. Either she can decide to keep ongoing to board meetings because she wants to be there, or she can stop going. In the final analysis, as long as service users are a minority in agency structures, they will be relatively powerless.

What people need is a real commitment to participation by service users. This commitment must include a support system, complete with the necessary financial backing as well as a complete re-thinking about how the organization should work. For instance, how about staff and volunteer assistance for those who want to participate in the structures of Associations?

Another pitfall in user participation is the tendency to screen people. Many strong advocates can be rather irascible characters, and difficult to deal with. Some don’t follow Robert’s Rules of Order very well. They may speak when it is not their turn and say things that are “off the wall”. They might have a hard time fitting into tightly-run Board meetings. But many times they have profound things to say. One test of an Association’s commitment to user participation is its choice of spokesperson. Another test of commitment to user participation is the presence of service users in monitoring and evaluation roles. This is a controversial issue because

many service providers see absolutely no role for service users on their monitoring committees. Clearly, people who use services have a lot at stake with regard to the quality of the service, yet they are usually denied the opportunity to monitor that quality.

It makes a lot of sense that labelled people should have their say inside an organization that claims to represent their interests. There are, however, severe limitations to service user participation in the management of a local Association. The most obvious problem is that they will almost always be a minority and therefore will be out-voted. Their presence is dependent on the benevolence of the majority and their ability to participate is constantly at risk. To varying degrees, the selection process is mostly, if not completely controlled by the agency. No matter how well a self-advocate may do his job, he will always have to deal in a reactive way to somebody else’s agenda and issues. It is essential to be aware of these issues if you decide to play a supporting role to a service user/self-advocate.

PEOPLE FIRST

People first can be a powerful tool for empowering labelled people. Members can learn valuable skills. Here are three examples, as explained by an advisor:

“My experience has shown that People First is a stimulating educational environment for members. When I met George, his counselor told me he couldn’t write, couldn’t count very well, and was easily disoriented. No matter how hard he had tried, he just did not seem to make progress. Today, 18 months later, George writes (even types) me 4-page letters, reports on his meetings, and has taken two plane trips alone to Toronto. Needless to say, he is an outspoken People First advocate”.

“Sue was a quiet, passive person, who appeared never to have her own opinion and never spoke up. Jim was somebody who supposedly had lots of problems counting and couldn’t do his own banking. Today, two years later, Sue is one of the more active People First presidents who initiates many new areas of work for the group and is teaching other members new skills. Jim is the treasurer of the same group – he learned a system for giving. Change at a recent dance for one hundred people”.

“This is real progress. Members learn skills though doing activities that have meaning in their lives. Learning these skills has been hard, and not without its setbacks and limitations. But the results are often far greater than some ‘professionals’ would ever have dreamed of”.

People First also teaches valuable advocacy skills. There are also numerous examples of self-advocacy and group advocacy across Canada. Here are some examples:

- * Speaking to the media about a particular issue or about the goals of People First. This has happened in several provinces and in many local municipalities.
- * Writing a letter to the government about a policy or a law.
- * Inviting the local M.P. to a meeting to tell him the group’s ideas about government policy.
- * Hiring a lawyer or going to the Human Rights Commission concerning a discrimination case.
- * Participating in a coalition of groups who are organizing around a specific issue.

These are just a few examples based on actions that several, even many groups across Canada have already taken.

Self-advocacy can be a powerful tool to transform people’s lives.

People First, as a strong organization, can potentially empower labelled persons in many ways. Constantly trying to change associations from within is a long, arduous struggle with many pitfalls. The basic difference between the two kinds of self-advocacy is: who has the power? We as advisors, have an important role to play in understanding the differences and discussing these differences with self-advocates.

All too often, People First is used as a substitute for developing user participation in associations. For instance, it is not uncommon for an association to set up a People First group as a committee of the board. This kind of situation often creates a lot of confusion and does a great disservice to self-advocates. Some of the problems that arise are:

- 1) It’s never clear who is in charge, the “People First Committee” or the Association.
- 2) People First may want to deal with issues that do not correspond to the priorities of the Associations. For example, People First may want to change the name of the Association, whereas this might not be an important issue for the Association.

It is extremely important that advisors understand the different ways that self-advocates can play their roles, so that they can assist self-advocates to achieve the structure they deserve.

SOME OTHER CONFUSIONS ABOUT PEOPLE FIRST:

It's important to be clear about how such a movement empowers the members. One of the main reasons that People First groups are sometimes not clear on their goals is that an important source of information (the advisor) is confused.

As we mentioned earlier, it still often happens that People First groups have been set up by local associations to serve mainly as social clubs, assertiveness training programs, or therapy sessions. Not only are these groups totally dependent on Associations but their activities have very little to do with self-advocacy. Groups like these don't make the statement, "We are People First". The message they send is, "We're special people who need segregated social events and therapy run by an agency". There's very little in these kinds of activities that enable people to be independent or to speak out as a group.

The focus is often on the "special problems" of the individual. Activities are focused on individual weaknesses and are aimed at individual solutions. By putting the onus of change solely on the individuals, another message that gets out is "the system is okay, we just need some help getting by". The group is not focused on taking initiatives to change the system around it; the members remain passive.

When a group functions mainly as a social event, and when it avoids controversy, the real concerns that needs of the members are repressed. This reinforces the idea that what people with disabilities need is "a chance to get out of the house", instead of real change in their lives.

People First as an independent organization has internal dynamics that can empower people. While self-help is a powerful part of the movement, People First is not a solely

a "self-help organization" as is, for instance, A.A. (Alcoholics Anonymous). People First is not "a self-help program". People First is an evolving, ongoing movement. (See leadership training manual for statements of purpose).

Its strengths are the members' commitment, their desire for justice, their pride in their independence, their understanding of how they feel about life, their common purpose and collective action. An added bonus is that many members have lots of time available to give to People First.

There are many strengths in People First. It is our job as advisors to use these strengths to help the members build a strong movement that they can be proud of.

STRENGTHENING PEOPLE FIRST – THE CHALLENGE OF BEING A GOOD ADVISOR

In the first four chapters of this manual, we looked at how self-advocacy in general can better the lives of self-advocates. For the balance of this handbook, we will be looking specifically at People first as an independent moment and the role of advisors in strengthening People First.

Several factors threaten the internal strengths of People First: A few are:

- 1) When an organization has no goals and no clear-cut activities other than meetings, it won't last long. The internal dynamics (i.e., the excitement of learning new skills) cannot be the only reason for meeting. A common complaint of ex-members of People First is that the meetings are boring.

- 2) Local groups are isolated.
- 3) Local groups can be disorganized. They may have good ideas but they don't know how to carry them out.
- 4) Outside forces and other organizations can weaken People First if they do not interact on an equal basis.
- 5) People First does not have money, highly- educated leadership, or a long history of collective experience.

The key to overcoming these and other weaknesses is the advisor. The advisor is a bridge between the community and the group members who are isolated from the community. The advisor can also play a major role in helping the members see themselves as part of a larger movement, and understand the power of an organization.

The first step to understanding the advisor's role is to understand the members. Extreme oppression profoundly affects the way that a human being can function in society. A good advisor should constantly be trying to understand the world from the member's point of view, and help the members to overcome the barriers created by their life experiences, while building on their strengths. This can only be done through building a strong relationship of trust between the advisor and the members. This trust happens when the advisor identifies with the members. It is a struggle to identify with the members, to look at the world through their eyes, to stand by the members when they are criticized, to believe in the members. This struggle is ongoing and essential.

Persons who have been labelled with an intellectual disability have never before been organized to advocate for themselves. Helping them to accomplish this is no

mean feat. To understand why this is difficult, it is important to make a distinction between the effect of a person's mental handicap on his ability to understand, and the effect of the oppression that he has experienced as a result of being labelled. A mental handicap is a permanent condition that can only be changed slightly. But the effects of oppression can be transformed from very negative to very positive.

For example, A People First member of a local group may not be able to read. Why not? This could be because she has a learning disability and despite all efforts to teach her, she can't seem to master the skill. Or, it could be because she grew up in an abusive, oppressive institution where she was kept on various drugs and where no effort was made to teach her. If the second case is true, then there is potential for her to learn to read, especially if by doing so she will be doing something that is important to her. Patrick Worth, President of People First of Ontario, learned to read when he was 16 years old, after he left the special school system.

The purpose of this example is simply to show the need to analyse people's skills, not to say that a person who can't read is bad. Whether a member can read or not, it is clear that each member has an equal right to participate fully in People First. All too often, people who support self-advocacy only work with self-advocates who have the skills valued most by society (i.e. reading, speaking). There are many challenges when working with people who have suffered extreme oppression.

THE CHALLENGES

The first step to overcoming the effects of oppression is to understand the oppression. The second step is to understand the effects. Only after this step can we look at solutions. Chapter One discussed oppression. This chapter attests to follow steps two and three.

1) THE MEMBERS ARE VULNERABLE:

People who have been underestimated, overprotected isolated or abused tend to be *afraid of change*- it's better to stick with the status quo that you know, than to venture out into the unknown and certain death. A few people who really try to break out of the system often pay the price with high stress levels and get labelled "behavior problems". When a person is afraid of changes he often deals with the fact that he is unhappy by saying that he is happy. It's a survival instinct. This explains the following event.

"When I went to visit the workers at town X to talk about People First the workshop manager insisted on meeting with me first. She spent a lot of time showing me the programs the workshop offered and said that things were going very well. She said things like, "the clients here are really happy" and "we make sure that we have good relations with our clients." That evening, when I talked to the workers about People first, it was just me and them, no staff around. I talked about the goals of People First and community living. At first, there wasn't much discussion. After I broke the ice a little and they started to understand that I had no connection with the local association and that I was there to help them, one guy got up and said, "Well, I think we don't get paid enough." Then another got up and said, "The staff don't treat us

right." Before I knew it, we were talking about health and safety conditions, counselors in group homes, how to get a union in the workshop, and even how to organize a strike. After the meeting, a couple of participants came up to me and told me that they had never in their lives spoken about what was said that evening. (Unidentified speaker, Advisor's Training Session, People First of Ontario Conference).

Another common misconception in society is the so-called "apathy" or a particular poor or dispossessed group. A good organizer that has worked closely with the people she is helping to organize will soon realize that underneath the "apathy" is fear. People who are afraid to lose what little they have, learn to cope by "staying out of trouble." It's hard to break a lifelong pattern of inaction or passivity.

The advisor, as a person, plays a vital role in overcoming fear. It's very important to constantly show through actions and words that the advisor believes in the membership and will back them up if the going gets tough.

One of the reasons that members feel so vulnerable is that they have no privacy. There are frequent discussions between the family, staff, and professionals who are involved in the lives of service users. While many advisors can rest assured that their "skeletons in the closet" will probably stay there, the smallest details of many service users lives are usually public knowledge and easily accessible.

That's why it's important that members understand that advisors will never violate confidentiality. It is a common occurrence that a group will hold confidential meetings. The advisor has to bend over backward to reassure members that he will respect that rule.

2) THE MEMBERS HAVE SEVERELY LIMITED LIVES:

Members often don't even see the options available to them when making a decision. An advisor often has a much more varied set of experiences to learn from when making decisions. Sometimes the advisor has to judge when to intervene, when a bad decision is being made because of lack of information. Here's an example:

One group was trying to find out who could explain the pension system. From their limited experience, the group members could only think of the executive director of the association. On the other hand, the advisor made several suggestions about possible sources of information: Lawyers, advocates, civil servants and politicians.

Based on the other choices presented by the advisor, the members decided to ask a legal aid lawyer to their meeting as a guest speaker. In this case, the advisor strengthened the ties of the group to community organizations and lessened the group's dependence on the local association.

With less dependence comes independence and decision-making. People First can be one of the rare opportunities a person with a mental handicap has to make decisions about his or her own life and to take responsibility for those decisions.

In this case, the advisor would have been wrong not to intervene. Nobody asked him to, but the situation demanded it. The group was empowered because of the more sensible solution. One of the goals is that the members will, on their own, start basing similar decisions on a broader range of information. This is an example of *learning by doing*.

3) THE EXPECTATION OF LOSING:

Many persons labelled "mentally retarded" have often been told that they are wrong. When life has been a series of defeats and putdowns, it becomes hard to imagine radical changes.

There are several effects of this situation:

- a) Having low expectations of oneself.
- b) Having no hope for any fundamental change in one's environment.

For example, a group that is discussing wages in the workshops, a clearly massive problem of impoverishment, may come up with surprisingly minor solutions. "Well, maybe if we could get our cheques each week instead of every two weeks," "I think we should get at least, say, a dollar more a month."

As one advisor explained it:

"Some members think so little of themselves they have no idea of what rights are. Whatever happens in their lives is what happens. Period.

During one of our discussions, there was one woman in our group who realized for the first time in her life that she was being sexually assaulted by her stepfather. She hardly seemed to realize it was wrong, let alone that she could do something about it."

The members often have such a poor self-image that they feel negatively about themselves and the other members. Not only are their own opinions undervalued, but sometimes they will put down other members' opinions as "stupid" and "dumb". This makes it very hard to encourage communication between members and group solidarity. How many advisors have sat through painfully long silences when a crucial decision has to be made. Often the silence has little to do with intellectual impairment and

everything to do with a negative self-image.

To help people gain self-confidence the advisor has to help the group plan activities that have a positive impact for changing people's lives. The only way to show people how they can change their lives is to actually involve them in doing it. For instance, if a People First group succeeds in helping a member to advocate for change in her living situation, the other members will learn and take courage. Learning by doing is a powerful teacher.

Personally, the advisor should constantly show the members that contrary to society, he has high expectations of the membership. "So what if society says you can't make a decision. I think you can". An advisor who doesn't believe that each member possesses hidden gifts just waiting to be uncovered will never get very far. An advisor has to believe in the members.

The members often need lots of support in "blowing their own horns." Even when a group succeeds in an endeavor, it often happens that the members downplay the success or aren't even aware of it. How many People First members know and understand that only because of them Associations for the Mentally Retarded became Associations for Community Living? How many members know about the "Eve" decision on forced sterilization and the fact that it was a group of self-advocates who assured that victory of profound importance. The self-advocacy movement has a short but glorious history. It's something to be proud of. Very few people in society will acknowledge the accomplishments of disabled person (unless they are super human – e.g. Rick Hansen). The advisor can play a role in helping the members to "blow their own

horns" about their own accomplishments. Knowing your accomplishments as an individual, as a group, and as a movement can be an empowering experience.

4) OVERCOMING REPRESSION LEADS TO ANGER:

It is often surprising how seemingly docile people can suddenly become full of anger when they begin to realize that they have suffered in justice and that they have rights. This is one of the basic reasons that many service agencies have resisted self-advocacy.

Other people in our society have had channels to express anger and to effect change. Through experience, many of us learn how to deal with problems more or less constructively. Oppressed people are taught that their anger is wrong or has no basis. They are probably not grateful enough for everything that has been done for them.

When there is a forum to express this anger, it can be a very liberating experience. This is positive. It's a step towards fuller self-expression. It can lead to positive action to change. Often this anger can be raw anger, lashing out at everything. Too many advisors try to control the anger or even to dent it ("Don't be so negative.>").

One group in New Brunswick was totally outraged when a local restaurant wouldn't serve them when the whole group decided to go out together for dinner. They had a meeting and decided to go as a group to see the owner to demand their rights. It was a clear-cut decision and everyone agreed.

The advisor arrived late to the meeting, and when he heard of the decision, immediately tried to change it. He was worried; this was a small community and this

kind of action could cause quite a commotion. It could even get out of hand! He intervened and used his authority to convince the membership to send him to the restaurant to smooth things out.

In the end, he convinced the owner. But what happened in the group? Their first attempt to advocate as a group was nipped in the bud. The power of the advisor over the members was reinforced. The members learned nothing about how to advocate for themselves, not even by making some mistakes. Since then the group has taken to organizing mainly social events on their own. Maybe this event could have been part of the group.

Anger has to work itself out. Sometimes anger is targeted at people who have relatively little power in society: staff at workshops, parents, friends, and even advisors. While these people may be part of the cause of their anger, the main cause is perhaps farther away and less clear to them - e.g. the management of an institution or government funding policies.

5) **POVERTY:**

Oppressed people are poor. In addition, People First members often have little control over their eager spending money. This can cause some very real problems for organizing. Getting to a meeting can be complicated if it isn't paid for by the local association. Finding a private place to meet could be difficult to do if rental for a meeting room is \$20.00 a night.

Sometimes solutions to these problems are right in front of us, but we can't see them. Transportation could be solved by volunteer drivers. Meeting places can be donated – the Legion, a member's living room,

a church basement. These are all arrangements that members can make.

Groups can organize fundraising events, and build up a modest bank account. Too often the advisor recommends trying to build up a big fund for the group. The danger is that the group does nothing but fundraise, and gets lost in the process. Many other poor people have organized themselves in the past with little or no money. We can learn from them.

People who have no control over their money can have problems handling the money of their group. It's usually wise for the group to approve all expenditures, at least for long enough to understand how it works. Not having much money themselves, most self-advocates have a great respect for the importance of saving.

While many members are poor they often have lots of time. Advisors are often too busy to notice this! A good way to save money is to do things the slower way (handwrite the minutes instead of typing, walk to the meeting instead of taking a taxi).

THE ADVISOR IS A PRODUCT OF ENVIRONMENT:

It is a challenge to overcome the effects of oppression on the members. The advisor also has to face the challenge of changing the way most members of our society have been trained to act. We have been socialized to play a role of passivity and compliance with the status quo. We are products of an education system that has taught us not to question. We are uncomfortable with the unknown. It is difficult to understand oppression because we are part of the oppressive system. Our challenge is to break out of this mold, at the risk of being ridiculed, scorned, laughed at, isolated, or patronized.

The fundamental challenge to the advisor is that the members are powerless, and do not understand how to gain power. The role of the advisor is to empower.

6

EMPOWERMENT – A PROCESS AND A RELATIONSHIP

While not all advisors would agree, it is a basic premise of this handbook that advisors have enormous power in the self-advocacy movement. Advisors have greater skills, experience, and knowledge, are much more highly valued members of the community, have richer lives, and are often much more financially secure than the members. Members often look up to and respect the advisor, if only for the reason that the advisor is one of the few people who treat the members with respect and dignity. It would be dishonest to deny the power of the advisor.

The advisor can have a major influence on how a group develops for example, often when a group changes advisors, the style of the group changes. This is understandable, but not always good. For instance, People First groups involved mainly in leisure activities often

have advisors who are involved with recreational services in a local agency. It is also very true that People First groups that avoid controversy often have advisors who work for the local association or who are involved in a service that is provided for the members. In groups such as these, there are rules of operation such as: “Don’t bring your problems to a People First meeting.” I translate that into: “Don’t rock the boat by raising real problems in your life that the members of the group might identify with.

We may have a revolt on our hands!” This is also known as “inappropriate behavior” or sometimes “going off topic.”

Advisors have power. The job of the advisor is to teach his or her skills to the members so they can gain power. The issue about the power of the advisor is not: “Do advisors have a lot of power in People First?” but rather “How do they use that power in People First?” but rather, “How do they use that power to empower the members?”

Even the very best of advisors are tempted to use power unfairly over members, especially under stress. Understanding the advisor’s power and it’s misuse is an important step towards overcoming the dilemma of support vs. control.

CONFLICT OF INTEREST

One of the most challenging parts of being an advisor is when there is a conflict of interest. Conflict of interest is when the group’s needs go directly against the advisors needs. The group and the advisor have conflicting interests.

This can be a problem when the advisor is paid by the agency that serves the members. If a group wants to criticize the way the workshop is run, the

advisor may have trouble supporting the group while being a staff person at the workshop. This is the most obvious kind of conflict of interest. But sometimes, conflict of interest can be more subtle.

Advisors are often professionals, with education and social status. Members are not and never will be. Professionals are trained to see members as clients, which can be very hard to overcome in their role as advisors. Professionals are also trained to deal with people one-on-one, with measurable and predictable results. This approach doesn’t work with a group that is growing and evolving as it goes along. Professionals have a tendency to want to have things neat, orderly, and systematized. The members are perhaps not ready for a highly structured group, especially in the early stages.

Often, advisors are seeking ways to change the service system or society’s attitudes through their involvement in People First. They may have good motives, but the way that they want to do that, based on their experience in other organizations, may not be the way that People First wants to or should advocate. It has happened too often that the advisor has tried to drag a People First group into a fight between factions in an association.

Advisors may have strong opinions about what People First should be doing. If they force these ideas on members, when members are interested in other issues that can become a conflict of interest. It all depends on how the advisor does the job of advising.

Advisors have not lived the kinds of lives that the members have. That is why advisors should always ask themselves before they give advice, “Is this what I want, or what the group needs.”

Advisors who deny their power or the possibility of conflict of interest are probably manipulating the group

and its members, to avoid controversy and debate. This form of manipulation by advisors is a major problem in the movement.

Ironically, many doubters of People First don't see this situation as manipulation. Rather, the advisor is usually accused of manipulation when members of People First start gaining enough self-confidence to speak out about what they want in their lives and suggesting some changes. Often the accusers are the very people who feel attacked by the issues that the self-advocates are raising.

Labelled people don't speak out when they don't have self-confidence. When they do, it is often the advisor who is accused of manipulating. This is not only frustrating for the advisor but a put-down of the self-advocate who speaks out.

Now that we've looked at all the aspects of conflict of interest, it is probably fair to say that most advisors today are in a conflict of interest position. This is a reality. It would be disastrous for the movement if all such advisors resigned the minute a conflict of interest situation arose.

If you find yourself in this situation, it would probably be wise to figure out a back-up plan, which could include: finding a good replacement and resigning (it could take several months); working with a back-up advisor who can fill in when you're not able; or after discussing the problem with the group, not participate in discussions where you are in a conflict of interest. The first essential step for the advisor is to be sensitive to the issue of power, and to understand that the advisor's fundamental role is to empower the members.

THE ROAD TO EMPOWERMENT

Advisors cannot work miracles, of course. Labelled people have a long row to hoe before they attain real equality, real power in society. But the first essential step is to develop self-advocacy. Advisors play a crucial role in this process of empowerment.

Empowerment is a long process, and there is no magic formula. Sometimes advisors see empowerment as simply informing people of their rights. It doesn't work when the *process* is ignored. People become more empowered at different speeds, and in different ways.

Results are not guaranteed, but often very positive. In fact many advisors have said that the biggest reward in being an advisor is to observe and to be a part of the empowerment of people who have been written off by society. To witness the blossoming of the human spirits among people who have been numbed by years of oppression is a constant re-affirmation of the commitment of the advisor to self-advocacy.

To be a part of that process, the advisor has to build a relationship with those who have been disempowered – a relationship based on a real desire to listen to the members, respecting the members as human beings with dignity. The rest of this book will look at the process of empowerment, and what kind of relationship the advisor has with the members in this process.

ADVISORS ARE ORGANIZERS

The role of the advisor is to help the members of the group organize themselves. The advisor does not have a vote in the group. Instead, the advisor should spend his time helping the group members figure out *why* they are organized, *how* the group should function, the goals the group is working towards, *what* activities they should do, *when*, and *where* they should do them. The advisor helps the democratic process happen in the group. The advisor helps but does not lead. Generally the advisor stays in the background. The advisor should sit in the back of the room during general meetings. A good advisor is modest and only speaks briefly when asked by the group to speak. The advisor's biggest sin is taking over a group.

Here are some major ways that the advisor can help a group develop:

1) PROVIDE INFORMATION:

The group members often lack the complete information that they need in order to make an informed decision about a particular issue. But the advisor can provide that information because the advisor has been able to live in the community for a much longer time. For instance, one group was trying to figure out how to lobby for real jobs in the community.

The advisor made several suggestions about possible sources of information: community organizers, advocates, civil servants and politicians. From their limited experience, the group members could only think of the executive director of the association. But, based on the other choices presented by the advisor, the members decided to invite as a guest speaker, a community activist who had organized an employment equity coalition of women, native people, and disabled persons. Her information was exactly what the group needed. In this case, the advisor strengthened the ties of the group to community organizations and lessened the group's dependence on the local Association.

2) HELP WITH DECISION-MAKING:

People First is often the first chance for a person labelled mentally handicapped to make decisions about his or her own life and to take responsibility for those decisions. People First is almost always the first group decision-making process for members. The advisor can help with this process by making sure that each step of the decision is well-understood by the members.

It is extremely important that the advisor respect the amount of time it may take to make a good, well

thought-out decision. *The process of deciding is as important as the outcome of the decision.* All advisors have probably made at some point the mistake of getting impatient and deciding something for the membership. This reinforces the members' negative self-image and their dependence on the advisor.

3) PROVIDE STRUCTURE:

The advisor can share his knowledge of organizing meetings, keeping records, holding elections and so on. These skills are extremely important for members to master to be able to be effective self-advocates. An organized group empowers the members. A disorganized group is weak.

It is important to see structure as a tool to help the group, but not as an end in itself. Too much structure is a burden and can hinder the development of a group. A group that is just beginning may decide not to choose a president or chairperson until it has met for six months. But experience has shown that People First need leaders and therefore work with an elected Executive.

In the history of People First, advisors have made mistakes of both pushing for too much structure, as well as too little. For example, it has often happened that groups have focused their energy on understanding how to chair a meeting, how to make a motion, how to write minutes and keep a budget, without first thinking seriously about why they were meeting and what they want to accomplish. A typical example is the group that fundraises very successfully, but has no way to decide how to spend the money because there are no group goals or

priorities. The group has to understand what its goals are before the members can decide what kind of structure they need to reach their goals. The structures can develop as the goals become more advanced, the members become more experienced, and the activities become more complex. Groups that have too much structure can easily collapse.

People First of Ontario nearly collapsed in the years of 1983-1984. The reason was that members, including leaders were unclear about the basic goals of People First, let alone the immediate goals. In addition, there was hardly any meaningful structure, and little support. To rebuild the organization, there was a long process of goal-setting, and setting up appropriate structures corresponding to the real needs of the organization as it developed. People First of Ontario is today making major strides in its development as a serious advocacy organization.

4) PLANNING:

Persons labelled with an intellectual disability often have most of their lives planned by others. The advisor can play a key role in helping the group figure out its goals and objectives for a particular period of time, and in planning each activity. As in everything else, the advisor has to respect the pace of the planning process. The *process* is extremely important. The members have to learn from that process. It is extremely important for the advisor to ensure that all group members are involved in some way in the planning. Once the group has participated in the planning process, putting the plan into action is easier because everyone understands it.

As the organizer, the advisor should constantly be passing on her skills to the members. Every time the advisor does a task or helps a member with a task, she should be thinking of how that member can eventually assume responsibility within the group. For instance, for the first meeting, the advisor might (but not necessarily) call the members on the phone a few days ahead of time to remind them of the time, date and place. Or the advisor might be in charge of making coffee and bringing cookies. But these tasks should be taken over by members fairly quickly. As these tasks are taken over, the advisor will probably take on new tasks as the group continues to meet. For instance, the first time the group decides to write a letter to the local association about a concern, the advisor may play a major role in getting the letter written.

In a sense, the advisor is working himself out of a job. A few local People First groups have no advisors. They seek advice the way most people do, from experts in the community. A few others have a system of advisors "on call". These advisors come to meetings on an occasional basis and are available to give help when needed. Most group advisors attend most meetings of the group. A good advisor always tried to change her role within the group. This evolving process should be thought-out and well-planned.

Too often in People First, the advisor backs out of a group because of burn-out. It is good for the advisor to gradually back off from parts of his job as members gain more skills. It is also natural that the advisor may want to move onto other activities after a while.

But the process of “pulling back” and “pulling out” should be gradual, planned ahead of time, and with full understanding by the members. Leaving a group should never be done without finding a replacement.

LEADERSHIP DEVELOPMENT

The only way that an advisor can pull back and support the group taking over its own affairs is by focusing on developing several people as leaders, especially since it is probably impossible for the advisor to develop all the skills in each member that he would like. He should focus on developing leaders, and encouraging these leaders to learn and use the skills the advisor has. Sooner or later, the advisor finds that a lot of skills-sharing starts to happen in the group, without the advisor being present.

Within the first few months of a group, the advisor should be meeting separately with key leaders to plan meetings and activities. This is where the advisor can play a more active role. If the group decides to elect an executive committee, the advisor should meet with the executive. This allows the advisor to play more of a “back-seat” role in general meetings, and allows the members to relate directly to their own leadership without interference.

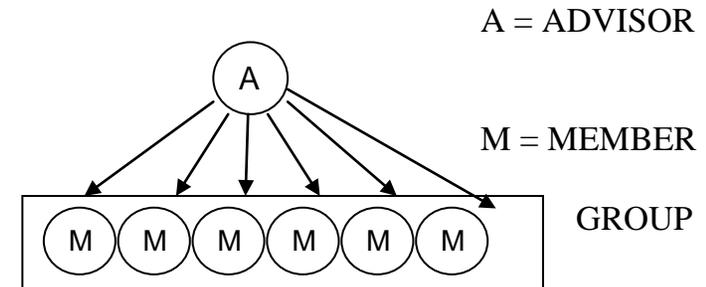
One of the biggest weaknesses in People First groups is a lack of leadership development. Some common symptoms of a group that has no leaders is when an advisor constantly makes comments like “don’t talk to me, talk to the President”, in meetings. Or, when talking to other advisors you might hear: -

“They are always calling me when there is a problem, but they never call the president or each other”.

“I have tried to back out but they won’t let me”.

“I am doing all the work”.

What do these problems tell you about how the group functions? Probably the group functions like this:



- * All lines of communication are through the advisor
- * Members take direction from the advisor
- * Members depend upon and look up to the advisor and not each other.
- * There is no model of membership control.

This model makes the statements: “*I AM THE LEADER*”

It reinforced devaluation.

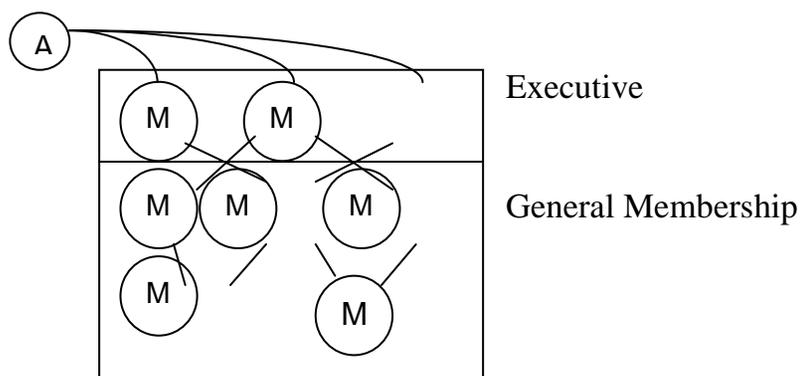
This is a model that develops because *the advisor has let it happen*. There can be one or several reasons: -

- The advisor spends time on doing the work instead of training and supporting the members.

- The advisor doesn't believe the members can run their own group.
- The advisor doesn't listen to the members and gear his advice to what the members say.
- The advisor spends her time advocating one-on-one for group members, and no time on group development etc., etc.

The only way to avoid or overcome this situation is to constantly and consciously work against the way society has trained labelled people to act. (i.e. to value the advisor "expert" and to devalue each other).

As an alternative, the advisor should promote a group dynamic that follows this model:



This model makes the statement:

“You are the leader,
We can all be leaders
We are self-advocates.”

This model promotes:

- 1) “Equality” between Advisor and Members
- 2) Devalued Persons in Valued Roles
- 3) Group Independence
- 4) Member Inter-Dependence/Interaction/
Co-operation/Solidarity.

The advisor's role is not to lead the group, but to *develop leadership within the group*. To do this, it is often best to work with a few key members who are the officially delegated or unofficial leaders. By putting energy into preparing meetings and activities with this leading group of people (through executive meetings or meeting separately with the leadership), *they* became empowered with the advisor's skills and knowledge. *They* become the experts, the ones looked up to. They became living proof that people with disabilities can become skilled leaders.

When the advisor makes judgments about potential leadership and focuses energy on those particular members he has a lot of power.

In this case, power has to be exerted wisely. The advisor can make mistakes. A common mistake is to see a potential leader as somebody who has many skills. There are at least 2 pitfalls to using level of skill as the only criteria for picking a leader:

- 1) This highly skilled person may not want to lead a group, or believe in the values or goals of self-advocacy.
- 2) People First could become a movement led by an **XXXXX** of “very capable” people, which would undermine the fundamental goals of the movement.

Some leadership skills are: reading, writing, speaking, and organization. Perhaps more important abilities and assets are: commitment to the goals of the movement, believing in the members, understanding the power of and advocacy group, assertiveness, ability to work in a team,

modesty??? and life experiences. All too often, advisors ignore the second set of skills and only look at the first.

One problem that arose, especially in the early stages of People First in Canada is that in some movements leadership were people who were in many ways different than the general membership. While many of the members were often ex-inmates of institutions, poverty-stricken, abandoned or neglected by their families, isolated from the community, and lacking in many literacy skills, some leaders tended to be from a relatively better background from supportive families who kept them out of institutions and who have generally been more financially supportive, and who had better education, better social skills, etc., etc. These were the leaders nurtured by the early advisors.

Some of these leaders turned out to be strong. But several have had great difficulty leading. They had problems identifying with the members, and even would put them down as “too handicapped” or “too low-functioning”. Some leaders called themselves “advisors” to try to put themselves in a class above the “handicapped membership”. On the other hand, other potential leaders were ignored because they were less polished, or it was too difficult to deal with some of their needs.

The best approach is to try to build a team of leaders combining the skills and assets of each person. A good organizer makes mental note of how each leader can contribute to the group and knows the gifts that each member has.

Margaret may be a quiet but well-organized person. Perhaps she wouldn't be the best choice for president, but she might make an excellent vice-president. George may have problems keeping track of money and therefore might not make a very good treasurer, but he is very

enthusiastic, vocal and can type. He might make a good secretary.

The most important asset of all is commitment. Does a person really believe in this movement or not?

IS THE ADVISOR THE GROUPS ADVOCATE?

The role of any organizer is to help people organize to gain more power. A good organizer *pushes* to get things done but does not do for other people.

Once in a while, it's important for the advisor to stand up for or to help out an individual member. It's unavoidable at times. For instance, if a member needs an advocate to help her out with convincing her parents it's important that she come to a People First meeting, the advisor may well be the only local person.

It's inevitable that an advisor who is deeply committed to the self-advocacy cause will want to help each member in their life situations. The danger is becoming too involved in a one-to-one basis, as a friend and advocate, with each and every member. If the advisor has the time, that's fine. But if the vital work of group development and organizing is set aside, that's no good. It means sacrificing your main role as group facilitator for the individual advocacy. The group suffers.

Organizers in all sorts of situations find themselves developing close friendships with the people they work with. It's inevitable. It grows out of the personal commitment that an organizer might have for the cause he or she is involved in.

Persons labelled “mentally retarded” are extremely isolated and often very lonely. When somebody walks into their lives who treats them with respect and decency, it's understandable that that person is going to be very

popular. It happens quite often that an advisor to a group gets many invitations to supper, to small get-togethers and so on. It's tempting to try to become everybody's friend and advocate. Sometimes it's frustrating to have to keep a formalized distance from the members. A reasonable compromise is to develop closer relationships with one or two members, and keep the rest pretty much on an acquaintance level. You, the advisor, will not be able to transform the individual lives of 10 people, no matter how much you work. The needs are enormous and the resources are small. It's important to conserve energy for the long haul.

8

ADVISORS ARE TEACHERS

One of the biggest challenges for an advisor is to be able to listen carefully to self-advocates and to see life from their point of view. An advisor who is a bad listener is missing the first and most important step. Without listening carefully, an assisting people to express themselves clearly, an advisor very quickly falls in to the trap of speaking and doing for the self-advocate, instead of helping the self-advocate to do for herself.

The advisor who listens and is understanding and sensitive has laid the basis for trust. Self-advocates often learn through bitter experience to have limited expectations of so-called "normal" people. They don't expect much respect. Once you have shown that you respect the members as equal human beings, that you're not like the rest of society, you have built the basis for a strong working relationship with the group. The more trust there

is, the more the members will communicate to you what they *really* think and feel, not just what they think they *ought* to say. To establish this trust may take a long time, but it is essential to doing your job.

THE ADVISOR SETS THE TONE

It is extremely important to be aware that the advisor is a model to the members. What the advisor does and says are important ways for members to learn needed skills. The advisor has the knowledge, experience and skills to help the group, and is a much more valued person in society. It's natural that the members will look up to the advisor. It's also tempting to let this attention "go to your head". This is wrong. The advisor should always be humble about his contributions and emphasize that he is just taking the good ideas of the members and helping them think them through and sort them out.

Everything an advisor does, send out messages to the members. Too many "normal" people underestimate the ability of a person with a mental handicap to observe "normal" behavior and to pick up on what is a "good" way to act in a particular situation. The members of our society who have not been given a chance to speak out but who spend much of their time sitting and observing have well-developed skills of observation and pick up on the subtleties of behavior. These skills are important to understand and respect. Many advisors probably could learn a lot from the members about observation.

Dependability, honesty and enthusiasm are important quality of effective advisors. The advisor can inspire confidence in the members that there is a structure, a plan, and that the advisor is someone to be trusted. The members learn to do the same.

HOW DO WE TEACH?

When many of us think of teaching skills we think of the traditional ways our society teaches – in the classroom. Unfortunately, it has been amply shown that this system fails to teach the people who need it the most – the poor, minority groups, and persons with disabilities.

Some advisors, on the other hand, who have benefitted from this traditional system find it difficult to understand its weaknesses. When they try out these traditional methods on group members, there are problems:

Here are some symptoms of teaching problems that advisors may have: -

"I explained to them several times but they don't seem to understand".

"We have gone over the People First manual but I don't get the feeling they really understood".

"I don't want the Treasurer to go down to the bank to do the banking without me. I am afraid there will be big mistakes made".

"I was really insisting that the group get involved in this important government committee on (some issue) but all the groups want to talk about is this really minor stuff (name change, parents, problems in the workshop)".

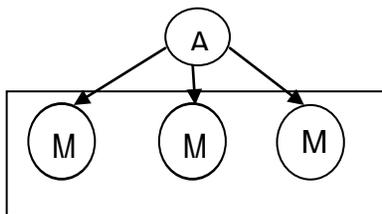
"I have explained to (a member) how to book a room, and he still didn't do it".

"We have gone over the goals of People First many times and they still don't understand".

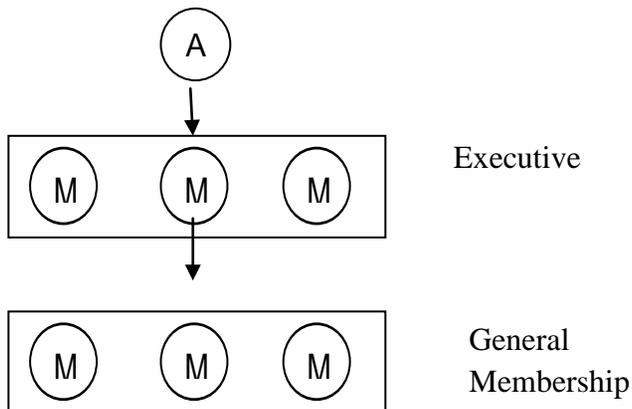
“No matter how often I talk to the Treasurer about how to keep track of the money he still makes mistakes”.

To me, these comments show that the advisor is teaching in the standard way we have always been taught thing. The “expert” (professor) is at the front of the class and possesses the knowledge. Theoretically, the expert deposits the knowledge (like a bank account) in the minds of the passive student. This is how this method of teaching looks:

THE “BANKING METHOD”



A variation on this method is the advisor “teaching” the executive, who then use the same method on the members, - the “Trickle Down” method.



There are many reasons why this method doesn’t work, especially in People First. Here are a few:

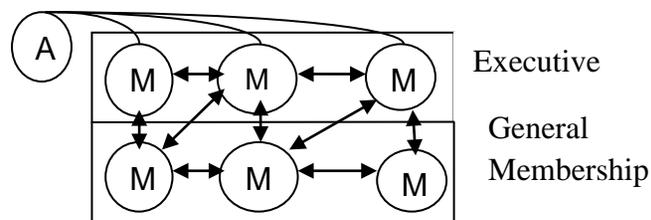
- * The advisor isn’t learning from the members. How can the advisor teaching things that are relevant to the members without learning from them *first* about their points of view?
- * Because the system is a highly centralized hierarchy, people are learning because they are told to listen, not because they feel a need to learn.
- * Because of this kind of hierarchy, the patterns of dependency and inequality between labelled and non-labelled persons is perpetuated. It also encourages leaders to act in the same authoritarian way.
- * Because the members are passive, the knowledge is separated from the action that the knowledge is needed for. In other words, how effective is it for the treasurer to learn to open up the account *before* he or she actually tries it out?
- * People First members have already tried and failed in the “regular style” type of schooling (banking). Perpetuating this pattern only recreates all the old tensions, stresses, and expectations of the system that failed them.

In People First a more effective teaching system should have the following features: -

- 1) All participants are learners and teachers. Learning is sharing ideas.

- 2) Learning starts from the concrete experience of one or several members.
- 3) Learning is directly linked to concrete actions and results; learning by doing, not by rote.
- 4) A feeling of solidarity and common cause because of (1), (2), and (3) above.
- 5) The advisor is the facilitator and organizer of ideas, instead of the all-mighty expert.

This is how that model would look:



A good way to describe this model would be:

“WE ARE ALL IN THIS TOGETHER” or

“DOING IT”

While this group learning process is going on, the ideas being shared and discussed are real and result in some kind of *change* or *action*.

An excellent time to train officers in the group process and communications is during the officer’s meetings. At such meetings, the advisor can review the following skills and more: -

- 1) How do redirect questions or statements by group members that are off topic;

- 2) How to ask everyone for an idea regarding a problem or goal;
- 3) How to facilitate group discussion;
- 4) How to speak and dress for radio, television or public presentations;
- 5) How to prepare a speech;
- 6) How to write a letter;
- 7) How to reinforce good statements, ideas, and questions from group members.

The advisor should encourage the officers to actively practice those skills with other members of the group at a meeting. The officers may want to actively train other group members once they feel they themselves possess the skills.

The advisor may with the groups consent, tape-record a meeting. The tape could be played back at the officers meeting so that the officers can hear themselves conduct the meeting. This is an excellent means of getting the officers to sit back and hear themselves lead a meeting and how to improve.

Another possibility is to video tape a group meeting. This will offer even more information when played back to the officers, providing them both audio and visual feedback.

Another advisor or a leader of another organization could also attend a group meeting and give their comments to the officers. Other people from the local community – such as a speech or communications teacher at the local university, community college or high school – could also be used for the same purpose.

The advisor should reinforce the officer for good communications. Review of weak points with suggestions of alternative ways of achieving effective communications is important. Role-playing is an excellent means of practicing in areas of needed improvement.

For people who have difficulty reading, there are several methods that an advisor or leader could use as teaching aids:

- Using posters, pictures and easy to understand words.
- Role-playing and skits to involve the group.
- Using humour; learning should be fun.
- Using films, videos, slide-shows.
- Going to conferences, seminars and conventions that are put on by other groups.

Finally, people learn best by doing, and often through mistakes. The Treasurer will learn budgeting by doing it. The President will learn chairing of meetings by trying it out. Too often, advisors worry about the mistakes the members might make in a new endeavour.

Advisors have at times a tricky job of balancing between letting something fall flat on its face and learning from that experience and assuring success to bolster confidence.

THINK BEFORE YOU HELP THE MEMBERS START A GROUP

If you are thinking of helping to start up a group, it would be a good idea to sit down and assess yourself and your situation. What are the circumstances for starting up the group? Who asked you here – was it the members, (or future members?), or maybe it was an agency, or another organization? Why do the members want to start the group? What are the circumstances for starting this group?

Is it clear in your mind that the members have a general idea about why they want to start a group? Generally, the potential group members will not have as clear an idea as you may have of what a self-advocacy group does. Try to introduce them to some more experienced self-advocates. If that's not possible, then you can use the *People First* film, or some written material. If you are reasonably confident that this group is something they want, then you are ready to start advising.

The most important stage of the development of a group is the beginning. How a group begins, how it functions, its basic approach and philosophy, set a lasting imprint on how the group develops. Once patterns of functioning have been established, it is extremely difficult to make changes.

If you are lucky enough to work with a group that is just starting, you can play a major role by supporting the members in their struggle to build an independent group that will support them to speak up and speak out.

In the history of People First, it has been shown that by following some basic organizing rules, you can help the members guild a group that will grow and develop for a long time.

SOME BASIC RULES

- 1) The group should *start on a clear basis*, with some clear goals, for instance:
 - * Group independence.
 - * Community living for all labeled people.
 - * Self-advocacy as a priority.
 - * Helping each other and making friends.
- 2) The member should *understand what is going on* in meetings. The meetings should happen at a pace that most people understand what is happening most of the time. The advisor in particular has to make sure that she doesn't talk in ways that confuse people.
- 3) The *members*, from the very first meeting, *should make the decisions*. Some of the members will need more support than others. Talk it through and try to help the members make responsible decisions, that they can carry through. After the decision has been made, the advisor can help the members follow-through on

their decisions. For instance, if the group decides to write a letter, make sure that it is decided *who* will write a letter, *how* it will be done, and by *when*. Then at the next meeting, make sure the group finds out whether the decision has been carried out, and if so, if there is any follow-up to act on.

- 4) *The advisor advises*, but does not do things for the members, except to do things with the members so that they can learn.
 - 5) *Don't bit off too much*. It is better to start with a small group of people who know what they want to do, than to start with a large group that is all over the map. A large group also puts a huge strain on the leaders who may be unable to manage so many people. There is no big rush to enlarge the membership. Make sure the group is ready.
 - 6) *Avoid conflict of interest*, not only for you, as the advisor, but for the group. From the very beginning, it is better for the group to think of themselves as being independent of the services who serve them. An advisor can encourage this goal by, for example, suggesting other sources of funding, or meeting outside of the workshop.
- Groups that have followed these basic rules have survived, grown, and developed. The main reasons are:
- 1) They grew at a pace where *the members* understood the process and had power.
 - 2) The members were clear from the beginning that this *was their group*, because the issue of independence was a clear goal.

Unfortunately, too many advisors think organizing a People First group is a gradual process of weaning people away from dependency on the local association or agency.

It is as if the advisor thinks that if the members talk about issues like independence, dignity, and respect, that either the group members will not understand, or they will get scared. (Or maybe the advisor is scared the group will be too independent and outspoken). Because the advisor has a lot of power in the beginning stages of a group, these basic attitudes are reflected in how the group develops.

Groups that follow these guidelines fall into a general pattern, or model.

While the *process* of building independence may be gradual, the *idea* of independence should be a major part of the group philosophy, from the beginning. When it isn't, there's a problem, and it is often an advisor problem.

This model (I like to call it "The weaning process", or "breaking it to them gently") often doesn't work well. Too many groups who have tried to follow this model have fallen apart. A typical example of this model might look like this:

People First starts as a "safe" program of the association and then gradually moves toward group independence and self-advocacy. The "People First group" starts off meeting during lunch break at the workshop. The advisor is a paid staff person who has "People First Advisor" written into her job description, and the main activity of the group is organizing the Thursday night bowling for the workshop.

The advisor may have the goal or at least claim to have the goal, of helping the group break away from the association, "when they are ready". Unfortunately, facts have shown that it rarely happens. What does that mean?

Another feature of this model in the beginning stages, is big meetings. The advisor spends lots of energy trying

To keep them big or even to expand attendance. This is especially true if the advisor is a staff person who sees People First as a program of the association. Success of a program is often measured by how many people are involved and how many activities (such as dances, bingo, etc.) you can get off the ground.

Another typical feature of this model is there is very little, if any, discussion of the basic goals of self-advocacy. The advisor often actively discourages these discussions. There is often little encouragement of structure in the group. If there is an executive the advisor puts little effort into teaching leadership skills, especially if she is already overloaded with work just trying to get all the members out to meetings and organizing all the various events. In the meantime, the members are unable to lead or play an active role in such a complex and large group, especially since the goals of the group are unclear.

A group following this model rarely evolves into an independent self-advocacy group, despite the best intentions of the leaders or advisors. There are at least two major reasons for this:

- 1) The issue of independence and self-advocacy is not a fundamental reason for the existence of the group from the beginning.
- 2) The group is too big and out of control, and therefore not run by the members, but rather only by the advisor(s).

What often happens is that the advisor either takes complete control of the group, or tries to "back out" at some point. There may be attempts to introduce the new ideas of independence, self-advocacy, group advocacy. But the patterns of dependency on the advisor,

dependency on the association (for places to meet, funding, etc.) are already so basic to the functioning of the group that the group risks falling apart if anybody tried to change those patterns

Many advisors reading this handbook will find that, while the first model for independence makes sense, they have inherited a group that looks a lot like the second model. This is a political reality everywhere across Canada. It may be hard, but there are some ways to help the members to break out of dependency.

- 1) Encourage and support discussion and debate of the self-advocacy philosophy.
- 2) Encourage people to speak out. This can be hard because often the entrenched leadership may not be used to this. The advisor may end up supporting the “misfits” or the “opposition” in a group.
- 3) Propose taking action on an issue that arises in the group. For instance, if there is a transportation problem when getting to meetings, maybe it’s time to meet the Mayor to talk about adequate public transportation.
- 4) Sometimes, the only way to transform a group is to let the old one die, or to start up a new group on a clear basis. Obviously, this can be a very painful process. Unfortunately, sometimes people’s feelings get hurt.

This chapter was about group independence and your role. Before you go on to the next chapter, it would be good for you to sit down and assess the progress of the group towards independence, and your role. Then, why not work with the group members to plan a course of action that will build strong independence and advocacy? To measure your effectiveness as an advisor, use the

yardstick of independence, of the group, and of each member.

DON'T AGONIZE, ORGANIZE

Organizing can be challenging. It's an activity that challenges some basic values in our society – individualism, and blaming the victim. Most organizers learn their skills as they go along.

John McKnight, a well-known community organizer and advocate for the cause of People First, has a list of basic rules or organizing (a list that can go on forever!). Here are some of the most important of these rules: -

1) **DON'T MEET TO TALK, MEET TO PLAN ACTION:**

Talk is cheap. Action is hard to organize, but a group that does not do anything will lose members and eventually die. This is a common problem in People First.

A variation on this problem is to talk about the goals of People First and organize activities that have nothing to do with furthering those goals. For instance, it probably doesn't make sense to organize a segregated bowling league when community living is a goal that the group is trying to promote.

2) **START WITH VICTORIES:**

When a group is starting up, it is best to take action on issues that are winnable. A good example from our history was the fight to change the name of local Association for the Mentally Retarded to Association for Community Living. This struggle spoke to a fundamental issue in the lives of the members – the effects of being labeled. Victory was possible, a name change is relatively easy to arrange, compared to, for instance, getting real jobs for people rein the community. While fighting for the name change, the members were able to educate parents, professionals and the general public about their hopes and dreams for living as full citizens in the community. Looking back on their history, People First can be proud of their accomplishments on this issue.

3) **DON'T LET YOUR ADVERSARY DEFINE REALITY:**

Many oppressed people do not look at life from their point of view but form the point of view of the oppressor. They believe the lies of the system. When dealing with the adversary, there's no point in fighting for an issue unless the group agrees on their point of view, and sticks with it.

The name change could have failed, if People first members hadn't persistently insisted that

- I. The issue was important, and
- II. That Community Living is the only acceptable name.

At several points in the struggle, well-meaning supporters had suggested the need to compromise, or that perhaps the name change wasn't very important. Thanks to their single-minded stubbornness, People First members prevailed.

4) **DON'T BE AFRAID OF POWER:**

People who are used to being powerless can get pretty scared of actually taking more power. This can mean: being afraid of anger being afraid to take action, being afraid to challenge and confront, being afraid of taking responsibility for organizing. As the group progresses, these fears will lessen. The advisor has to push and challenge the members.

5) **WHAT YOU WANT IS A PLACE AT THE TABLE, NOT TO ANNIHILATE YOUR ADVERSARY:**

The system is in place, and People First has to deal with that system. What the members want, for now, is some power over their lives. This generally means that when a decision is being made about someone's life, that person should be the major player in that decision. People First wants a place at the table.

6) **DON'T BE AFRAID TO MAKE A DEAL:**

We should never compromise on basic principles. But, at times, we have to put off our long-range goals to short-range gains. These are tactical gains towards your strategic goals. For instance, it may be impossible to change the system within the next twelve months so that workshops are closed down and there

are a wide variety of supported work programs in the community. In the short term, we could pressure for more supported work programmes, and press for better salaries in the workshops. But we should also constantly remind ourselves and the public what our ultimate goal is: working in the community.

At the same time, there are times when we can make a major breakthrough, and we can go for major changes. For instance, if government is reviewing the funding of rehabilitation and employment programmes, this would not be the time to beat around the bush. This would be the time to say that workshops are bad for people and that we want government to put their money into community-based employment programmes.

7) CELEBRATION:

Hard work and victories are important, and all too often easily forgotten. Celebration is essential to value the accomplishments of the group and of each precious member. Victory is sweet and should be honoured and applauded. Pride in accomplishments is empowering. A celebration of accomplishment is fundamentally different from the life experiences of persons labeled with intellectual disabilities.

Besides, a good party is lots of fun!

COMMITMENT

The basic commitment of the advisor is the commitment to empowerment. Are we committed to empowering the members?

Advisors are important, but not always needed. A few groups in Canada do not have advisors, but they are rare. Maybe in the future, there will be no need for advisors. Our goal should be that a group develops the skills and the links with the community to be able to use the many advisors in the community that we all use in our lives.

In the meantime, advisors should realize that this role demands commitment.

To build a good relationship with the membership and leadership takes an important commitment of time and energy. It is best to be aware of the commitment from the very beginning and plan your time and energy accordingly. For instance, experience had shown that an

Advisor cannot be effective if he simply attends meetings and does nothing in between. An advisor who views his job as a series of meetings is probably not in the right line of work.

The beginning stages of forming the group can often be demanding for advisors and members alike. There are points in the development of the group, especially if a new activity is taken on, when the advisor may have to plan to invest a greater than usually amount of time. It takes time and energy to build People First. Members have often said that an advisor should budget at least two year's involvement in People First in order to see real progress.

A good advisor is aware that his involvement was his choice. He made the commitment, and he should deal with problems that arise. He owes it to the members. People First is hard work. It's no easy task challenging the way a whole society treats handicapped people.

There are times when advisors find their commitment to be stretched to the limit. "Burn-out" is a problem. At those particular times, it's important to examine how we're doing our job and how to do it better. We all need to sit back and look at ourselves at certain crucial points in our work.

The following "Ten Questions" are a good way to gauge how you are doing as an advisor: -

1. Am I really listening to what self-advocates have to say or am I imposing my point of view?
2. Do I see the real human growth and potential in self-advocates or do I see "disability" and "limitations?"
3. Have I checked out my actions and feelings with the self-advocates?
4. Are any of my actions based upon a potential conflict of interest or a need to be controlling in any way?
5. Do my actions:
 - * Increase the self-respect, self-confidence, self-reliance in self-advocates and encourage them to take risks?
 - * Decrease the self-advocates' dependence on me?"
 - * Increase self-advocates' opportunities to understand and participate in the decisions that affect their lives?
 - * Teach people a process for making decisions, solving problem, and doing things on their own vs. controlling things?
 - * Decrease the chances that I will be seen as a manipulator?
 - * Increase self-advocates' opportunities to understand and participate in the decisions that affect their lives.
6. Do my actions promote respect and recognize individual growth as well as group spirit? (Lasting growth takes time).
7. Do my actions encourage and assist self-advocates in obtaining and understanding a wide variety of information and different points of view so that people can make informed decisions? Have my actions developed allies for the self-advocates point of view?

8. Do my actions recognize that anger is okay and indeed justified in many instances and encourage people to use anger for positive personal growth and societal change?
9. Is it okay for self-advocates to:
 - * Question my point of view?
 - * Work me out of a job?
 - * Tell me that they don't need me and can decide on their own?
 - * Give me negative feedback about what I am doing?
 - * Not see me as an authority figure?
10. Do I realize that advisors as well as self-advocates and self-advocacy organizations are fallible human beings prone to making mistakes and have problems just like anyone else and any other organization?

12

CONCLUSION

This handbook has probably not provided all the answers to the questions you may have about the advisor's role. What we have tried to do is to outline, based on the experiences of advisors, leaders and members, the basic guiding principles of the work of the advisor. There are other very useful resources which you can find in the appendix. These resources give more concrete, detailed information on how to organize.

This handbook has tried to communicate to its readers that the most important factor to someone being a successful advisor is that person's philosophical values. An advisor may have many skills to offer the membership such as: planning skills, book-keeping skills, public speaking skills, or/and understanding of rules of meeting procedure. But these skills are of very limited value if the advisor has the wrong attitude.

To have the right attitude, we have to try to look at life through the eyes of the person who has been labelled, understand what it means to be labelled, and why self-advocacy is so important. Self-advocacy is crucial to empower labeled people, to fight against their own oppression.

The role of the advisor is to empower the powerless – a challenging but rewarding role. This handbook has tried to look at several aspects of the advisor’s role from the point of view of the oppressed: as a teacher, as an organizer, as a supporter. By committing oneself to supporting labelled people, so that they can take action to empower themselves, we are committing ourselves to a hopeful future. The payoff for the advisor is that the hopeful future is for everyone involved...advisors and members.

Now it’s your turn to finish this conclusion. Why don’t you write your statement of commitment to the People First movement? Put it down on paper, and show it to the members to discuss. If you are an advisor, or a potential one, it could be useful for you and the members to also write up a contract that states the nature of your job, and your relation to the members. A contract is a good way to clarify your role and it gives everyone the opportunity to review periodically how the work is proceeding.

GOOD LUCK AND GOOD WORK.

SOME ADDITIONAL RESOURCES

This is not a complete list of everything ever written or produced about self-advocacy; it is a list of the major resources that National People First has found to be most useful. Some of the basic materials for organizing a local group can be obtained through National People First by requesting the “Basic Information Package.”

BOOKS:

ALINSKY, S.D. (1971). *Rules For Radicals! A Practical Primer For Realistic Radicals*. New York, Vintage Books.

Kahn, S. (1970). *How People Get Power: Organizing Oppressed Communities for Action*. New York, McGraw – Hill Book Company.

HANDBOOKS AND MANUALS:

- * *An Advisor's Guidebook for Self-Advocacy*. By J. Jeff Woodyard. From Kansas UAF, 348 Haworth, University of Kansas, Lawrence, Kansas 66045, \$4.00, 135 Pages.

An introduction to self-advocacy and the role of the advisor. Covers many aspects of self-advocacy and advisor activities such as planning, forming committees, incorporation, and using the media. Provides some exercises and examples for presenting material to members. One drawback of the Manual is that it is American, and therefore does not all apply to the Canadian context.

- * *An ANDI Workbook for Looking at Places People Live and Work*. Consumer version by William Allen and Nancy Gardner. From KUAF, 348 Haworth Hall, University of Kansas, Lawrence, KS 66045, \$4.00, 60 Pages.

Based on ANDI (A Normalization and Development Instrument) and designed to be used either with a regular ANDI team or separately. Includes specific things to look for in the programme, rights, the building, and the staff.

- * *The Housing Checklist*. By Bill Allen. From Bill Allen, 1700 Second St., Suite 2384, Napa CA 94559. No charge. (Also available, at no charge, are a few audio cassettes of Nancy Gardner's Elf-Advocacy Workbook.)

A checklist for people with disabilities of things to look at, about where people live, whether house or an institution. Basis for discussion among residents or for talking with staff members.

- * *Leadership Training Manual*, from National People First Project. This manual is aimed at leaders and potential leaders. It discusses issues such as "What is self-advocacy? How to plan for action, the role of the advisor and what is leadership?"

- * *People First Self-Advocacy Manual*. By Charles K. Curtis. From the British Columbia People First Project (1982), 156 Pages. Available through the National People First Project.

A highly detailed manual which addresses seven major areas including "Speaking Out? Why? How?" "What Are My Rights and Civil Liberties?" and "Being a Good Citizen." Each area is thoroughly broken down into its respective content parts and serves as a curriculum guide.

- * *The Poole First Handbook*. By Washington People First, P.O. Box 381, Tacoma, WA 98401, \$10.00, 103 Pages.

Describes the philosophy of People First, how to start a chapter and have successful meetings, training for officers, setting goals, handling the chapter's money, doing public relations, and his for helpers. Includes some graphics helpful for non-readers.

- * *The Self-Advocacy Workbook*. By Nancy E.S. Gardner. From Kansas UAF, 348 Haworth, University of Kansas, Lawrence, Kansas 77045, \$13.00, 262 Pages.

Large-print book written specifically for people with disabilities. Covers many aspects of the self-advocacy group such as forming and running a group, the advisor, planning, committees, and publicity. Each chapter introduces new terms, has a story, questions and answers, and a checklist. Again, does not totally apply to the Canadian context.

- * *Speaking UP and Speaking Out*, from Washington People First (see address above), 89 Pages.

A handbook on many aspects of self-advocacy, based on the First International Self-advocacy Leadership Conference held in Tacoma Washington in 1984.

- * *The Washing People First Officers Handbook*

An excellent guide for officers of local chapters about how to be an effective officer, and how to chair meetings. Many local groups across Canada have found this handbook extremely useful and practical. Recommended for leaders and advisors alike.

AUDIO-VISUAL MATERIALS:

- * *People First*. From James Stanfield Associates, P.O. Box 1983, Santa Monica, CA 904406.

Documentary movie of the second People First convention in Oregon in 1975. Present information from members on what People First is all about and what it means to them.

- * *Rights Now!* From the G. Allen Roeher Institute, Kinsmen Building, 4700 Keele St., Downsview, Ontario, Canada, M3J 1P3, \$250 Canadian plus 10% Postage.

A reading-free learning program on rights and responsibilities. Includes slide tape. "Leader's Guide (on tape), "Leader's Guide Manual," posters, and six flip chart pictures color-code with six cassette tape labels. Includes issues of job discrimination, political rights, living independently, and tasking risks.

- * *Speaking For Ourselves*, from National People First:

Pat Worth, President of People First of Ontario tells about his life and how People First has made him a better person and a strong self-advocate. This is an excellent film to show to People first groups and supporters who want to learn more about People First and features the song "Speaking for Ourselves".

- * *We Can Do It*, from National People First:

A film that truly captures the People First philosophy at work. In this film you will see members of the self-advocacy movement speak about their lives and their vision of equality and dignity. You will hear People First members discussing such issues as family relationships, sheltered workshops, forced sterilization, and the humiliation of being labelled. All express the desire to be contributing members of society and to be "people first" – individuals with rights and responsibilities. An excellent tool for community organizations and the general public.

SELF-ADVOCACY NEWSLETTERS:

- * “The National Organizer”. From the National People First Project, Kinsman Building, 4700 Keele Street, Downsview, Ontario, Canada, M3J 1P3, \$5.00 per year.
Self-advocacy newsletter includes news from local chapters, reports of meetings, and letters from People First members.
- * “People First of Washington Newsletter”. From People First of Washington, P.O. Box 381, Tacoma, WA, USA. 98401, \$3.00 per year.

ARTICLES:

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- Lambert, P. (1987) “How would you like it?” *Entourage* 2(2), 15-17.
- Park, P. (1987) “People First: A National Perspective.” *Entourage*, 2(2), 6-7.
- Yarmol, K. (1987) “Pat Worth – Self Advocate par Excellence.” *Entourage* 2(2), 26-29
- West, A. (1987) “Consumer Advisory Committee Member offers suggestions for greater involvement” *Entourage* 2(2), 8-9.
- Worrell, B. (1987) “Walking the Fine Line; The People First Advisor” *Entourage* 2(2), 30-35.