

LESSONS LEARNED

Consumer Involvement in Step Ahead & First Steps

By Sue Christensen and Ann Rosen · 1994

INTRODUCTION

Throughout the country, inclusion of consumers is becoming an important aspect in all levels of program planning and decision making. In fact, federal, state, and local funding sources are increasingly mandating consumer involvement. Yet, as acceptance of this concept grows, it is clear that the *reality* of consumer involvement is only in its infancy. Few organizations or collaboratives successfully involve consumers. Even the basic questions—*What* is consumer involvement? *Why* is it needed? *Who* are consumers? *How* do you get them involved?—have multiple and conflicting answers.

In Indiana, the state has consistently stressed the importance of consumer involvement in Step Ahead and First Steps. As our service delivery systems move to become more family-centered, both research and experience stress that the integration of families into the actual planning and decision making process is imperative. But bringing consumers into the process in meaningful or lasting ways is an ongoing challenge. The ultimate purpose of the Consumer Involvement Project is to help increase consumer involvement in Step Ahead and First Steps statewide by identifying barriers and researching and developing a variety of effective strategies for involving consumers.

The initial phase of the project was carried out in St. Joseph County, where we established a group of fifteen consumers from diverse backgrounds. Each consumer selected a Step Ahead or First Steps committee to join. Consumers also met monthly as a group to share their experiences and identify what they needed to become more effective. Our role with consumers was to provide unbiased information and support, to validate the importance of their input, and to actively listen to their observations and experiences.

In addition to direct consumer participation, we conducted alternate methods of consumer input through surveys and a focus group. We also searched the literature and talked with people from around the country who have a working knowledge of consumer involvement strategies and initiatives.

This report addresses the basic questions of consumer involvement--what, why, who, and how; the barriers that consumers experience; and some strategies to help bring consumers into the process. We draw on our findings from research, from Step Ahead and First Steps council members and committee chairs, from the results of our surveys and focus group, and most importantly, from the consumers who participated in our project. In fact, this project really belongs to these consumers who taught us so much about the meaning of and the challenges to consumer involvement.

I. THE BASIC QUESTIONS

LESSONS LEARNED . . .

~ Consumer involvement incorporates the consumer perspective into the process of planning and decision making.

~ When consumers are meaningfully involved, everyone wins.

~ A person who is in need of, is currently using, or previously has used a particular service or resource can bring valuable information to the planning process.

~ Consumers get involved when they believe they can make a difference.

~ Consumers get involved if they have formed meaningful relationships.

~ Consumers get involved when they become “engaged”—when the issues they are dealing with have meaning for them.

WHAT IS CONSUMER INVOLVEMENT?

Consumer involvement incorporates the consumer perspective into the process of planning and decision making.

We have found a helpful working definition of consumer involvement from Creighton (1981): “a process, or processes by which interested and affected individuals are consulted and included in the decision making of an agency, planning group or collaborative entity” (p. 3). What that process looks like may vary greatly, but ultimately a key result of consumer involvement is that consumers’ views and experiences are directly included in the planning and decision making processes. “One measure of an effective public involvement program,” says Creighton, “is whether you can identify specific ways in which the final decision is responsive to public comment. If nothing has changed as a result of the program, it has probably met the letter of the law but not the spirit of public involvement” (p. 4).

Consumer involvement falls under the broader umbrella of citizen involvement, which has its roots in the democratic political process. Both encourage individuals to take an active role in the shaping and development of policies, procedures, and programs that impact society. Lappé and Du Bois (1994) use the term “living democracy” to describe a way of life “that meets the deep human need to know that our voices count [and] to shape the decisions that most affect our well-being” (p. 3). They see a new wave of activity among citizens eager to participate and effect change in all segments of society.

Howell, Olsen and Olsen (1987) identify three major themes which provide a theoretical framework for citizen involvement. Throughout our project, we saw evidence of these themes at work.

Democratic theory stems from Jean Jacques Rousseau, John Locke, and other eighteenth century political philosophers, who believed that “all citizens have the right to influence political decisions that affect them” (p. 5). For this to happen effectively, individuals need to have ongoing opportunities to acquire the information and develop the skills necessary to participate in collective decision making. Howell, et al. suggest that this can happen at the community level through greater democratization of decision making and participation in community-based systems, including families, schools, churches, voluntary associations, and work places.

Consumer participation thus requires the constant acquisition of information and the development of specific skills. Strengthening consumer participation in *all* community systems can lead to increased involvement in more broad-based groups such as Step Ahead and First Steps.

Social mobilization theory focuses on the power of participation as a springboard to further action. “As people join and participate in local organizations and activities, they tend to become more aware of and informed about public issues, they develop skills in discussion and decision making, and they seek greater influence on decisions that affect them” (p. 5). In other words, as people become mobilized, they are more likely to pay attention and participate in public affairs. Research suggests that this process not only effectively draws citizens into the political arena, but that it can be applied to people of all ages and socioeconomic levels regardless of previous experience with political affairs. Perhaps the following quote from a consumer involved in our project best describes this theory at work.

“There was a Medicare hearing that I went down to in Indianapolis and I never would have gone if I had not been involved in the consumer involvement group first. I also wrote letters to my representative, and I had never done that. I wouldn’t have done it if I didn’t know there were other people around me, behind me, other people doing it, other people who were saying, ‘do it,’ ‘yes, what you have to say is worthwhile,’ and ‘yes, you should stand up, and people do need you to speak up for them too.’ That was another thing. I didn’t feel like I was just talking for myself, and that’s important. You know, when you have personal opinions, you think maybe you’re the only one who feels this way, and you find out you’re not. You find out you’re also representing even a small group and speaking for them.”

Social exchange theory suggests that people usually participate in social activities to acquire benefits. Since there is also a cost to their participation (such as resources, time, and sacrifice of other activities), individuals will seek to minimize costs and maximize benefits. Thus, when looking at consumer involvement, it is essential to pay attention to those factors which draw from or add to a consumer’s “participation bank.” Once individuals perceive the rewards as sufficient for participation, they then need to feel confident that those rewards will be realized. Therefore, trust in individuals or organizations to actually follow through is an important issue in social exchange theory.

“To avoid a breakdown in confidence, officials must stress that the results of surveys, committee meetings, and other activities of the involvement program will be used to guide the planning process and develop policy proposals-*and they must carry out their promises*” (p. 9, italics added).

Creighton (1981) reinforces this theory with his summary of studies on nonparticipants. One of the reasons that people do not get involved is that they “don’t believe the impact of the decision upon them justifies participation” (p. 43).

WHY IS CONSUMER INVOLVEMENT NEEDED?

When consumers are meaningfully involved, everyone wins.

There are several compelling reasons for consumer involvement which offer benefits to the organization or group as well as to the consumer.

Looking at consumer involvement from the broader perspective of citizen involvement is again helpful. Howell et al. (1987) suggest that “if involvement programs are adequately designed and conducted, they can make valuable contributions to solving societal problems and developing stronger communities, as well as prevent costly litigation and public cynicism” (p. 1). They cite four frequently mentioned benefits of citizen involvement:

- 1) *Participatory democracy*. The opportunity for citizens to have increased access to decision makers and the possibility of providing input into decisions contributes significantly to the ‘democratization’ of political processes.
- 2) *Comprehensive communication*. Well-conducted citizen involvement programs can increase the understanding of issues and promote greater communication among all participants. Citizens can help technical experts understand local attitudes and values. They also can help decision makers identify sensitive issues and concerns in the community.
- 3) *Effective decision making*. Citizens bring new perspectives to the table. Their involvement can ensure that positions on an issue are balanced and that all of the relevant options and alternatives are explored.
- 4) *Political legitimacy*. When citizens are involved directly in decision making that affects them, it provides legitimacy and credibility for the planning and implementation process. It also helps to ensure accountability.

Creighton (1981) offers three similar goals for public involvement:

- 1) *Credibility*. When the process is open and inclusive, the decision making becomes more credible to groups with highly divergent viewpoints.

2) *Identifying public concerns and values.* Involvement provides a vehicle to help professionals understand the problems, issues, and possible solutions from new perspectives.

3) *Developing a consensus.* The greater the diversity of participation, the harder it becomes for a single philosophy to guide action. Thus, the group must find consensus on an issue-by-issue basis.

As a result of increased communication and broadened perspectives, programs are more effective in meeting the actual needs of consumers. Decision making is strengthened when it draws upon the experience of people who are directly affected and when it emerges from an interplay of diverse experiences and viewpoints. Heightened credibility translates into greater acceptance and participation of those being served.

We no longer believe that experts or parents can fix today's problems alone. "Why?" ask Lappé and Du Bois (1994). "Because they touch us all; our problems are interrelated. Second, they're complex; they involve our attitudes, our daily behavior, even such intangibles as hope itself. This means that whether they relate to environmental degradation, poverty, racism, crime, drugs, or failing schools, those problems elude hierarchical and expert-driven strategies" (p. 16).

Many consumers seem to be aware of this unique contribution they bring.

"It would smoothen all the processes so much if [consumers] were allowed to speak back and to share their experience, how it worked, how it didn't work-it would make such a difference at every level."

"I brought up a perspective that is not always brought up when you're sitting around the table. Whether it was better or worse, I don't know, but at least it was another angle, so I think that it's important that consumers increasingly get involved."

"I think it's important that consumers-regular people-go on occasion and make them [professionals] clarify what they are doing. . . . They get so used to speaking in 'committee-eese' that they forget how to communicate with the public. I think it was helpful to the group to have me there, because it makes them answer questions, even for the committee members who feel stupid asking because they're supposed to know."

"I don't think that is going to be on their priority list unless there's a parent involved who is constantly nudging saying 'What about the parents? What about the parents? What about the parents?'"

The involvement of consumers brings new information, broadens perspectives, increases accountability, and steers direction. It also has the capacity to empower participants. Lappé and Du Bois (1994) describe several categories of rewards that citizens report receiving from their increased involvement in public life.

Feeling better about themselves: More personal power, less fear. A new pride in accomplishment. Satisfaction in helping, in making a contribution, in doing their share to make the world more like it “should be.” Feeling their actions are more in tune with their values

Feeling better physically: More energy. Greater calm and serenity. An overall feeling of happiness and well-being.

Having more meaningful relationships: Caring interactions with those who share their concerns, hopes, and vision. Feelings of mutual respect among those with whom they regularly interact.

Learning: Effective interaction skills, such as how to negotiate. Greater knowledge of how the world works. Discovering the difference between what is meaningful and what is trivial. More insight into themselves. Discovering how much they have to contribute.

Satisfaction in expressing care for loved ones: Knowing that their efforts will create a better future for those they care for.

Mentoring: Satisfaction from seeing those they’ve coached grow and succeed.

Receiving recognition: Respect from others. Appreciation. Public visibility.

Feeling a sense of purpose in life, greater hope: Knowing their individual efforts are part of historic change.

Enjoying improvements in the quality of life: Better jobs, schools, neighborhoods, housing, medical care, environment (p. 30).

Our consumers, too, felt they gained benefits from their involvement, including new relationships, information, skill-building, and the ability to contribute to work towards positive change.

“I really felt like here was a view of what was ‘really going on’ and getting acquainted with some of the agencies that are involved. It was very good for me.”

“[The best thing about this project was] that I got a chance to work with people like myself who wanted to make a difference. Knowing there was somebody else out there [who felt as I did].”

WHO IS A CONSUMER?

A person who is in need of, is currently using, or previously has used a particular service or resource brings an important consumer perspective to the planning and decision making process.

It is interesting that with all the focus on consumer participation, there appears to be little consensus on just who a consumer is. Responses from a survey of Step Ahead council members show a wide range of definitions, from “any citizen” and “someone who trades something of value for something of equal or greater value” to “any county resident in need of a service provided by a Step Ahead participant,” “any person that has their life impacted on or receives services from a specific entity that provides the service,” and “anyone who lives in our county who has children.” While the state has never clearly defined a consumer in regards to Step Ahead, a current loose definition that is being used is “children and families.”

First Steps, because of its focus on the special needs child and family, has a narrower focus of consumer. Therefore, within the Interagency Executive Council (IEC), which is the oversight council for First Steps in St. Joseph County, perceptions of who is a consumer are somewhat more consistent, from “anyone who has used any part of the First Steps system,” to “parents, grandparents, foster parents and guardians of children with special needs who make use of available programs,” to “an individual who is experiencing first hand services directly.” One member also pointed to service providers as “secondary consumers” who may need “assistance, training and support to make them better able to meet the needs of the primary consumers.”

Simply put, consumers use services or resources. Another way of defining consumers comes from Gray (1989). She identifies two groups of stakeholders who need to be present in a collaborative process: those who are the *experts* and those who will be affected by the *consequences*. At times, consumers may actually fit into either or both of these categories. Emery (1989) suggests that only people who have a legitimate material interest should have input into decision making. In other words, those who may in some way be affected by the decision. On the other hand, one participant in our project stressed the importance of including consumers who are not currently using services, but who have used services in the past, because she felt there may be a reluctance among some consumers who currently receive services to “bite the hand that feeds them.” Those who are no longer dependent on services are more free to criticize or challenge the system.

Kretzmann and McKnight (1994) bring up an interesting point in their discussion about community-building. “Unfortunately, in some communities local residents have come to mistakenly believe they can build their community by an inventory of deficiencies. The common name for this deficiency inventory is a ‘needs survey.’ It is basically an effort to count up the emptiness in an individual or a neighborhood. The problem is that this information is not useful for community-building because it deals with people as potential clients and consumers. To be powerful, a community must have people who are citizens and producers” (p. 14). From this perspective, it would seem that using the label of “consumer” relegates a person to a receiving position and thus makes it difficult to also appreciate and support what that person has to give. Perhaps our consumers had a sense of this when they had the following dialogue.

“Consumer—I hate that word.”

“Why did they pick that name?”

“It’s in—PC.”

“It sounds very cold.”

Sometimes providers attempt to wear both a parent and a professional hat at the same meeting. While, technically speaking, anyone who is a parent might also be considered a consumer, wearing two hats in the same meeting doesn’t appear to work well. The difficulty is that when a person is in attendance at a meeting *because of* his or her professional position, the parent perspective gets superseded by the professional role. Consumers are especially sensitive to this distinction. Although our work in the area of consumer involvement stems directly from our experience as parents, the consumers in our project clearly labeled us as professionals:

“Ann and Sue—you put more of your professional hat on because that’s what you’re here to do, and so things that, if you were sitting here as a parent would normally pop in your head aren’t doing it.”

At times, a parent’s involvement may lead to employment or a leadership role. This is a natural and desirable outcome of consumer involvement. Once “in the system” for a period of time, however, that parent/professional is at risk of losing legitimacy *as a consumer* with other consumers.

“One of the problems when you get involved in official stuff is that you start acting like an official instead of a parent and I think it gets very complicated—parents lose the parent perspective and start wearing their professional hat.”

“ . . . [One of the other consumers] said I was more than just a parent and that it made her feel very funny, so I’ve learned from that—since then, I am very careful to say ‘parent’ because I think they need to feel like there’s more of us than of them so we can get that bond going together . . .”

HOW DO YOU GET CONSUMERS INVOLVED?

Consumers get involved when they believe they can make a difference.

Research by The Harwood Group (1991) suggests that “before they will act, citizens need to know that there is the possibility to create change from their efforts. They know that such change will not always come about; the results, in the end, may not even be positive. . . . But the potential for change must always exist. This is a pre-condition for citizen involvement in public life” (p. 45).

Implicit in this idea is the need for citizens to believe that

- they can have a say—and that they will be listened to,
- they can create and see change, which they can monitor and track,
- they have a stake in change, not individually, but sharing in the common good,
- and they can create a sense of community (pp. 45-47).

Creighton (1981) also refers to research showing that one of the reasons people do not participate is that they “don’t believe they can influence the decision” (p. 44). This echoes the tenets of social exchange theory—that people need rewards if they are to invest their time and energy in an activity, and they need to trust that these rewards have a good chance of being realized. However, trust does not always come easily.

Gates (1991) talks about the shift that has taken place in community life. “There was a time [when] citizens had fundamental trust in the large institutions of their community to ‘do the right thing.’ They assumed that government and business made decisions with the best interests of the community in mind. Clearly those days have changed” (p. 117). He cites a national Gallup poll in which respondents were asked which institutions they trusted “a great deal” or “quite a lot” to solve community problems. The respondents’ answers illustrate this lack of faith. Municipal government rated a confidence score of 23 percent, the federal government rated 18 percent, and the political parties rated 13 percent. This distrust also surfaced in our consumer group.

“We were brought up to trust people in authority. To believe what they tell you. But it’s not true. They just give you enough information to keep you under control.”

“I was very hesitant about [joining] initially . . . ‘cause I am very wary of community involvement groups that tend to be not community involvement but just talk with no purpose and nothing gets done.”

“Why are we there? What can we say that makes any difference to them? Can we really change their minds?”

Looking at involvement from the social exchange theory, the importance of trust cannot be overemphasized. “Perhaps the greatest cost occurs when citizens feel that their contribution to the planning process is meaningless. . . . when they perceive their roles as purely symbolic, as merely fulfilling a legal requirement or as undesired by [professionals] . . .” (Howell, 1987, p. 8).

Consumers get involved if they have formed meaningful relationships.

Kretzmann and McKnight (1994), writing on asset-based community development, emphasize the importance of building relationships. “If a community development process is to be asset-based and internally focused, then it will be in very important ways ‘relationship driven.’ Therefore, one of the central challenges for asset-based community developers is to constantly build and rebuild the relationships between and among local residents, local associations and local institutions” (p. 9). Lappé and Du Bois (1994) also talk about the power of relationship-building. Simply sitting and talking with citizens (consumers) helps to establish a relationship of trust. This, they say, “is where effective citizen action begins, long before any decision is made on which issues to address” (p. 58). Our experience points to the same conclusion. Having an established relationship with someone already connected with Step Ahead or First Steps seemed to be a factor in recruiting consumers as well as in their ongoing involvement. Attendance of participants in the focus group we conducted also was related to the existence of a prior relationship with the recruiter.

“Knowing [both of you] . . . helped me. Made me feel more willing to give it a shot.”

“The consumers were down to earth people. I felt at home.”

“Parents that start and then aren’t there—you say, ‘we’ll send them this and that’—that’s not as good as we can do. We need to make a personal phone call, go to their homes, call three times a week, sit down with them, check on whether they need child care, pick them up and take them with us. We have to show them we really want them.”

Consumers get involved when they become “engaged”—when the issues they are dealing with have meaning for them.

“Typically,” states Creighton (1981), “a particular public will last only as long as there is some continuing interest that the members share” (p. 37). Veteran community organizers like those at the Gammaliel Foundation stress that we should move away from a focus on *problems*, which are “broad, vague, theoretical, chronic” and begin to deal with *issues*, which are “immediate, specific, realizable, concrete, and controversial.” Problems seem overwhelming; issues create hope.

“Perhaps the most important test of whether people invest in an issue is whether they find something that they can do personally to make a difference. They look to see if they can get a ‘handle’ on the problem. If they can, they are more likely to be convinced that there is the possibility of change. If they can’t find a handle, they may not get deeply invested. In other words, people not only form opinions about the relevance of an issue, they form opinions about what can be done to solve problems. It isn’t enough to assure people that someone else is doing something about a serious problem; people want to know if they can do anything themselves” (The Harwood Group, 1993, p. vii).

Further studies by the Harwood Group (1993) emphasize the importance of “building relationships between people and the public concerns around them” (p. 43). They identified nine key factors that are constantly at work, providing what they call a “meaningful chaos” through which people become engaged to issues. These include:

Connection—People tend to enlarge, rather than narrow, their views of public concerns, making connections among ideas and topics that society tends to fragment.

Personal contact—People relate to concerns that “fit” with their personal context-not only their own self-interest, but that which is meaningful or imaginable to them in their lives.

Coherence—People want public discourse to tell the “whole story” on public concerns-with explanation, memory, and a sense of overview. They are seeking a deeper sense of understanding and meaning.

Room for ambivalence—People resist polarization on public concerns, seeking instead room for ambivalence-a gray area in the public debate in which to question, discuss, test ideas, and gain confidence about their views.

Emotion—The presence of emotion in public life is essential if people are to form and sustain relationships with public concerns.

Authenticity—Information and individuals must “ring true” to people- reflecting to people a basic sense of reality and the general belief that they are being squared with.

Sense of possibilities—People are seeking a sense of possibility-that action might occur on a public concern, and that they might play a personal role in it.

Catalysts—Everyday Americans, not just experts and elites, are key catalysts in helping people form relationships with public concerns.

Mediating institutions—Mediating institutions are key places where people come together to talk and act on public concerns (p. 4).

These factors do not happen in a linear, step-by-step process; rather, they occur over time, occur at different times, and occur in ways that actively reinforce one another. “The interplay between and among the various factors is critical . . . *that* is where the factors draw their power and relevance to citizens” (p. 43). And, they continue, if these factors are not taken into consideration, “some of the entry points and leverage points where relationships with public concerns can begin to grow” will be missed (p. 43).

II. THE BARRIERS

LESSONS LEARNED . . .

- ~ **Top-down structures present obstacles to consumer involvement.**
- ~ **Councils and committees need to clarify the basic questions about consumer involvement-what it is, why it is valuable, who consumers are, and what it takes to involve them.**
- ~ **Councils and committees need to determine their goals for consumer involvement-how, when, and why they want consumers involved.**
- ~ **The consumer's presence on a committee implies a role of expert, on equal footing with the professional.**
- ~ **The attitudes and beliefs of professionals and parents alike affect the quantity and quality of consumer participation.**
- ~ **A new understanding of power gives consumers a stronger, more authoritative voice in the planning process.**
- ~ **A welcoming meeting atmosphere sets the stage for positive consumer involvement.**
- ~ **Consumers need to know-and understand-the purpose and goals of the committee or council they are joining.**
- ~ **Consumers need communication, clarity, consistency, and contact concerning meeting times and locations.**
- ~ **Many consumers are shut out of meetings if they are held during regular working hours.**
- ~ **In order for consumers to fully participate they need information.**
- ~ **Consumer involvement is more likely to increase when people know about Step Ahead or First Steps and understand what they are about.**
- ~ **Time-for both consumers and professionals-is a factor that affects consumer involvement.**
- ~ **It is more difficult for consumers to get involved when they lack self-esteem, communication skills, and participative experience.**
- ~ **If professionals want meaningful consumer involvement, they need to be convinced that it is valuable and be committed to addressing barriers.**

STRUCTURE

The structures of Step Ahead and First Steps present obstacles that make consumer involvement more difficult.

There are major differences between the structures of Step Ahead and First Steps and those of many successful models of citizen action groups from around the country. It is important to understand these differences and to recognize that in many ways consumer involvement in these initiatives—or in any which look to “bringing in” consumers—may continue to be an uphill battle.

Most of the success stories about consumer participation are initiated and developed by individuals or groups at the grass roots level. Many involve already-functioning organizations such as churches or neighborhood groups who come together from a pre-existing power base. They are often neighborhood-based and place an emphasis on local community leadership training and development. Consumers hold the positions of power and make the decisions about what the group will do. The focus of the group’s activities grows out of direct concerns the members have about their own lives, families and neighborhoods. Successful models are built upon relationships. Each “emphasizes in its every effort a respect for diversity, tolerance, self-determination, and the right of all people to be treated with dignity” (Walker, 1987, p. 420). The ultimate goals for many of these groups are the transfer of power to communities and the transformation of individuals and neighborhoods.

The following story, from *The Quickening of America* (Lappé and DuBois) and featured in a recent Step Ahead of St. Joseph County newsletter, is an example of successful consumer involvement:

“[When] Kimi Gray . . . got her first apartment in the Kenilworth-Parkside housing project in Washington D.C. in the mid-sixties, she was on welfare, twenty-one, divorced and a mother of five. By 1980 Kenilworth-Parkside was described as ‘an open-air drug market . . . residents went without heat or hot water for months at a time . . . Rubbish was picked up so infrequently that rats infested the buildings.’

By 1982 Kimi and other tenants had created the Kenilworth-Parkside Resident Management Corporation and were responsible for managing the housing project. After four years of tenant management, rent collections increased 77 percent, crime rates reached an all-time low and the percent of tenants on welfare had shrunk from 85 percent to 5 percent. In addition, residents developed after-school programs for their children, offered courses for adults to get their high school diplomas and had an employment office. Using start-up loans from the residents’ council, they created their own businesses, eventually employing 120 residents. In 1990 the residents purchased Kenilworth.”

In contrast, the structures of Step Ahead and First Steps have already been developed with little or no consumer participation. Membership, from the state level to the county level, is primarily composed of service providers and other professionals. When consumers attempt to fit into this existing structure, they may find that the power has already been allocated, the leaders are professionals, the room for consumers is limited,

and the issues have already been defined. Leadership development and building relationships are usually not priorities and transference of power is seldom the goal. Even if consumers are welcomed, especially in their early stages of participation, they may feel more like invited “guests” with little ownership of the process.

While these factors do not preclude consumer involvement in Step Ahead or First Steps, it is important to recognize these differences and to understand the built-in barriers they create.

CLARITY

While the state has strongly emphasized the importance of consumer involvement, there has been little clarification of what that means, how it might look, or even who consumers are. For the most part, local councils and committees also lack a clear vision of or goals for consumer involvement. Without this clarity, consumer involvement remains a good-sounding idea with little or no form or focus.

Councils and committees need to clarify the basic questions about consumer involvement—what it is, why it is valuable, who consumers are, and what it takes to involve them.

While some councils and committees have had this discussion at least to some extent, others have merely acknowledged that “more consumers would be a good thing” but they have never talked through what this really means. Not only is it an important discussion to have at all levels, it is important to have it often. The answers to these questions appear to be constantly evolving as professionals and consumers experience and learn more about working together.

Councils and committees need to determine their goals for consumer involvement—how, when, and why they want consumers involved.

If a mandate by funders is the sole motivating factor in seeking consumer participation, the chances for meaningful involvement are slim. Are consumers invited for political reasons? to identify problems? to help determine more effective programs? to form policy? to evaluate progress? to measure satisfaction? to change attitudes? to become empowered? Determining why consumer involvement is wanted may suggest what kind of consumer involvement is needed.

There are other questions that need to be wrestled with at both the state and local levels-- hopefully with consumers involved in the discussions and decision making. Which consumer methods will work best for a particular situation? What is the process for consumers to join a committee? What is an appropriate balance between consumers and professionals or other community representatives? Who determines committee membership? Are there a limited number of slots for consumers? If a consumer attends a council meeting but is not a voting member, can that consumer participate in the discussion? What other avenues of consumer involvement might be appropriate?

“With us going to these groups, what is that to eventually accomplish? What is it in the end?—or will this ever end?”

A CHANGING PARADIGM

There is a major force at work in our country that is shifting the way we think about experts, responsibility, power, and how we work together. We are moving from technocracy to democracy, from expert to lay person. As we enter this new paradigm, it is not surprising that both professionals and consumers experience chaos and conflict as the old ways of doing things bump into the new. Not everyone is at the same spot along this path toward greater consumer responsibility and participation. And even when we have made a commitment to consumer involvement, our words don’t always match our actions. The old ways of working are well-practiced and easy to slip back into—for consumers as well as professionals. Often, we don’t have the knowledge or skills in place to successfully incorporate these new ideas. However, the “old ways” of operating create barriers to meaningful consumer involvement.

Roles and responsibility

The consumer’s presence on a committee implies a role of expert, on equal footing with the professional.

Lappé and Du Bois present a new model that is emerging in human services, one which challenges the old “professional as expert” model and redefines roles. The impact of this changing model has implications for both professionals and consumers, who may be at differing stages in this period of role transitioning. Consumers—as well as other committee participants—need to have a clear understanding of their roles and the roles of other participants. How are the consumer and professional roles currently defined by the consumer? by the professional?

THE NEW MODEL EMERGING IN HUMAN SERVICES

At issue	The Service Model	The Living Democracy Model
<i>Who’s in charge</i>	Professionally driven	Citizen/client driven
<i>Contribution of professional</i>	Professional provides answers	Professional is resource
<i>Process</i>	Usually diagnosing a single cause and cure	Understanding multiple causes and seeking ongoing change
<i>Procedure</i>	Bureaucratic	Informal
<i>What’s valued</i>	Credentials	Experience
<i>Communication</i>	Largely one-way	Collaborative
<i>Focus of problem solving</i>	Individual deficiency	Capacities developed through interaction
<i>Exchange</i>	Limited to fee for service	Includes mutual benefits

-The Quickening of America, Lappé and Du Bois, 1994

“I think all of us probably are struggling with going to new meetings and figuring out where we fit in—and they’re trying to figure out how we’re going to fit in. It’s really a ‘getting to know you’ kind of thing. Are we there as a watchdog? I think it’s a learning process—at every meeting we attend, they’re finding out we’re not watchdogs; we’re not there to criticize, we’re there with them. I think that’s what they’re just learning.”

Some consumers in the project commented that they needed to be careful to make sure they identified themselves as parents, rather than as being affiliated with another organization either through employment or volunteer work. Otherwise, they felt, their voices as parents became harder to hear.

Attitudes and beliefs

The attitudes and beliefs of professionals and parents alike affect the quantity and quality of consumer participation.

Both professionals and consumers seem to be struggling with what they believe about consumer involvement. Some of these beliefs can create barriers.

When asked how likely the possibility for active consumer participation on their Step Ahead committee was, the answers from committee chairs ranged from “highly likely” (1) to “likely” (2) to “somewhat likely” (2) to “not very likely” (2). While these beliefs do not necessarily correlate directly with actual consumer participation on committees, they do imply a wide range of attitudes towards involvement.

Groups say that they want consumer involvement and that they value parents’ opinions, but the experience of parents is often very different. Many have been “invited in” to these groups only to discover that their voices still are not being heard. If we believe in meaningful participation, how much listening—and changing—are we willing to do?

Consumers, too, are challenged by their beliefs. They have long been told to “leave it to the experts.” Now they hear that they are the experts. Some consumers may question if they really have expertise, while others struggle with what “legitimizes” them. Meanwhile, those who do believe they have something to offer and have had negative experiences remain skeptical of opportunities for meaningful involvement.

“Are we enough by ourselves?”

“Parents get the message from the outside world that they’re ‘just’ a parent—they tend to want to find some kind of more professional hat to describe themselves to give them validity.”

“You know, maybe I was too harsh in saying, ‘Gosh, I was waiting to be welcomed with open arms,’ and ‘Yea! A parent!’ and ‘What would you like? . . .’ What I just said about systems change is going to be hard for agency personnel and here I am with high expectations in saying that, you know, I didn’t feel welcomed. Well, gee, why didn’t I? So

if I just look at it that way and be really persistent, it's going to happen eventually . . . “

“Everything that we say is included in the minutes--things that I said are in here, so I feel like I'm an equal partner.”

The provision of stipends is often raised as a means to increase consumer involvement. The consensus of consumers in our project seemed to be that most appreciated receiving a stipend, but that it was not what held their participation. The stipend did, however, appear for some to function as a confirmation of the belief that their involvement was valued.

“[Getting the stipend] was nice; it was a motivator. Even though it was small, it gave value to that person's job--you valued us so much that you paid us to come--our opinions were worth something.”

“I would have done it whether there was a stipend or not. The stipend was appreciated because I didn't count it as my work time. . . . And I really do think a stipend makes a participant feel like they are valued. I really do. And it doesn't matter if it's a ten dollar stipend or a twenty dollar stipend--it's that you know that that person is taking time out, and probably, yes, taking extra time reading materials at home or doing something extra, and that you value that time.”

Power and authority

A new understanding of power gives consumers a stronger, more authoritative voice in the planning process.

“My perception is seeing these very strong organizations and how powerful their professional people are and how much they influence . . .”

“[I'd like to] role play--let's pretend you're in power and I'm not.”

“How can we look at people that have power and break down that barrier between us?”

“They think of parents as just young, uneducated people . . . they don't move forward as the world is moving. They're back here still trying to run the show and they don't understand they can't do that anymore . . . They feel threatened . . . because the parents have got enough power now to say we don't want to do it this way, we want to do it another way. And we mean it.”

Mathews (1994) writes about an early twentieth-century organization theorist named Mary Parker Follet who argued that “power can be either one-directional ‘power over’ or interactive ‘power with’” (p. 143). Consumer involvement draws its strength from the latter. We are currently beginning to redefine power, moving from what Lappé and Du Bois at The Center for Living Democracy suggest are the traditional perceptions of power--such as force, money, “connections,” race/privilege, law, or position (*power*

over)—to what they term “enabling” power (*power with*). When power is equated with control, it “strengthens some at the expense of others, dividing what already exists;” when power is viewed as enabling, it is “mutually expanding” and “builds on the capacities of all involved.”

According to Mathews (1994), there are many kinds of political power and it always flows in more than one direction. “Even those who have no formal power have other types of power to bring to bear on ‘the powerful.’ . . . From this perspective, the only true power is the power people create themselves” (p. 142). “True power,” argued Follet, “is rooted in our individual capacities . . . Power has to be grown, and it grows out of people’s experience, knowledge, character, and, in politics, out of their associations or ways of relating” (p. 143).

Consumers struggle with these issues of power. They seek to create their own power and often run into barriers when others operate out of “power over” systems. The following is a conversation that took place at one of the consumer meetings.

“It’s validating being a parent and knowing that you know more than the professional about what’s needed for your children. The validating is important.”

“I think it has to come from the inside though.”

“But if you go to a meeting and the professionals that are there turn you off, shut you down—which they can—then it doesn’t make any difference. If you have enough experiences like that, then you begin to feel, well, I’m just a parent, rather than I’m a parent and therefore I have some knowledge.”

“It happens with teachers; it happens with doctors.”

“It happens if you let it happen.”

“I think it can be done to you, especially if you’re beginning, just starting to access professionals. I think that, unless you’re extraordinary, you get shut down and it’s hard to know how hard to push.”

MEETING MECHANICS

The actual experience that consumers have in council or committee meetings can be a barrier if it contributes to the cost rather than benefit side of the social exchange theory.

“Costs are high when significant mental effort, embarrassment, or anxiety are present in a social exchange. During public meetings, problems and issues should be discussed in a manner that will not cause mental anxiety, personal discomfort, or continual conflict. Citizens are discouraged when agency or industry representatives present technical information in a way that is difficult to understand; frustration is compounded when official personnel do not elicit citizen questions, or when they constantly challenge

citizen interpretations of situations” (Howell, et al. 1987, p. 8).

A welcoming meeting atmosphere sets the stage for positive consumer involvement.

Early impressions can make a big difference in whether a consumer feels welcomed. It just makes sense—and almost goes without saying. Yet consider the contrast in the dialogue below, where two consumers describe their first committee meeting experience.

“I did feel welcome. People were very friendly; they made a point to welcome me. The chair made it a point to introduce herself, showed me a seat and put out my name. All those things kind of make you feel like you belong there. You walk in there and look all around and immediately its like . . . help! But I didn’t have to do that because everyone was very good about coming over and making me feel welcome. That was real important. That took care of the first barrier for me. It was a big table, lots of people, but I think that the subject matter also helped—because it was part of my life so I felt very comfortable with it. And also people were very good when they were explaining something and I didn’t understand it—and I had to do this a lot—I didn’t understand some of their terminology. I interrupted and asked them, ‘what does that mean and how does that work?’ And the thing that was good was no one rolled their eyes—they gave me the information I needed to be part of the discussion. Part of what I felt was, gosh, I’m at this meeting and I don’t know what’s going on here. You’re kind of stuck in the middle of something, and the fact that they’re willing to explain and bring me up to date was very helpful.”

“I’m the opposite of what she said. I didn’t know what was going on. I felt like I’m just going to sit here—I was way back in the corner. I thought I was on the other part of the room and everybody was right here and I didn’t know anybody and nobody made me feel welcome there. They always talk right over my head and then I’ll try to catch in on this and catch in on that and I asked a couple of questions. Everybody was talking all at once and I thought they was arguing with one another. No, I didn’t feel good. I’m totally opposite of what you said. Everything. But, you know, I still plan to go, and it will just take a little time. Usually I can go to something and it will take just a few times, but this is taking a little longer; but I’ll hang in there cause I love challenges so I’m going to go back.”

Consumers need to know—and understand—the purpose and goals of the committee or council they are joining.

Why is this committee or council in existence? What is its purpose? What are its goals? Where are they heading? How are they going to get there? Consumers need the assurance that they are there for a reason, that their contribution has meaning, and that their time is being well spent.

“The one thing that frustrated me—I had never seen the goals and objectives of the committee.”

“So, do they have a map? How do they break it down? I mean, how do you know what you’re doing is reaching the people you want to reach?”

“When I join a committee, I need someone to tell me exactly what they expect of me, what I have to do, and what they want for the outcome. That’s what I need. That’s why I felt very dysfunctional on Step Ahead, because I haven’t figured it out--and I think I’m in company with a lot of other people. But I don’t function that way. It just confuses me.”

Consumers need communication, clarity, consistency, and contact concerning meeting times and locations.

Some committees seem to exist in name only. They meet rarely or not at all. Consumers who find themselves on nonfunctional committees may quickly lose their motivation for involvement and rightfully begin to question the credibility of the organization and how much their involvement is really valued.

“[The committee I was supposed to be on] either never met or never told me about a meeting.”

Written communication or direct contact between meetings is helpful. Consumers often need to know dates well in advance so they can arrange work or child care schedules.

“I know you said like the third so and so, but it really does help a parent to have that letter in the mail to put up on the bulletin board. I’d appreciate that.”

“I left work, went to the meeting and it was cancelled; went home and the message was on the machine—it had been called in after I left for work that morning. But I also haven’t been getting any mailing whatsoever from them.”

“Apparently they had called a meeting in between the last one and hadn’t gotten ahold of everybody because they had minutes from it.”

“No mailings, no contact, no phone calls, no nothing. Last time I saw {the committee chair} was three months ago.”

“It doesn’t have to be a meeting. Even a phone call to let me know, to say look, we’re working on this, would you care to make these phone calls?”

“I went to the large meeting and heard a committee report from the committee I signed up for a long time ago, but I never was contacted about any kind of meeting—so who did this work and when?”

Clarity and consistency of meeting times and locations are also important to consumers.

“I read eight o’clock and thought, gee, eight o’clock on a Friday night is pretty late for a meeting.”

“I see the changing times and days of committee meetings as a problem cause I get terribly confused. They had second Friday at eleven in the first letter I got, and then they went to Thursday in the afternoon, and I had that other time and day stuck in my brain.”

Many consumers are shut out of meetings if they are scheduled during regular working hours.

In St. Joseph County, 63 percent of females with children under the age of six are employed. For women with children from the ages of six to 17, the number jumps to over 78 percent, or almost four out of every five mothers; close to 70 percent of homes have all parents who are present in the household working. While some of these jobs may offer the flexibility needed to attend daytime meetings, most do not.

“I got a new job, so I couldn’t attend meetings anymore.”

“I really wanted to go to that meeting, but I couldn’t get away from work.”

We asked consumers what other suggestions about consumer involvement they would give to committee chairs. Their responses:

Make sure that if you see a new person there, introduce yourself, recognize them, introduce them.

Refer to new people during the meeting.

Speak on a level everybody understands.

Check with consumers during a break to make sure they’re understanding what’s going on, to see if they have any questions.

Let them know that you want them there too, and that you value that they’ve given up their time to try to help.

If possible, get together with the new consumer either before or after the meeting to make sure they understand the goals of the committee and what’s going on.

If a consumer makes a suggestion, take it very seriously, try to act on it, don’t just say you’ll pass it along and then forget about it.

Match consumers up with a mentor who can help explain things that are going on.

Take accurate and detailed minutes.

Tape record the meetings so parents-especially those who are not strong readers- who are not able to attend a meeting can find out what happened.

Share minutes from previous meetings when a newcomer joins the committee so they can get a better handle on what’s been happening.

If most of the work gets done at the subcommittee level, help consumers get involved there.

If the consumer doesn't come again, find out why. Was it something about the committee, or is it something in their life (i.e., going back to school, change in work schedule)?

INFORMATION

In order for consumers to fully participate they need information.

Information gives people the ability to decide and to act. Creighton (1981) distinguishes between public involvement and public information. The purpose of public involvement, he says, is “both to *inform the public* and to *solicit public response* regarding the public’s needs, values, and evaluations of proposed solutions. . . . People cannot evaluate alternatives unless they have been adequately informed of those alternatives and the consequences of each” (p. 4). This need for informed participation has been recognized since the days of Thomas Jefferson, who wrote in 1820, “I know of no safe depository of the ultimate powers of the society but the people themselves. And if we think them not enlightened enough to exercise their control with wholesome discretion, the remedy is not to take it from them but to inform their discretion” (Creighton, p. 15). Boyte (1989) suggests that the emerging “information age” offers new possibilities for a wider, more active democracy. He cautions, however, that “Effective citizen action in our times is possible if--and only if--citizens develop the abilities to gain access to information of all kinds . . . and the skills to put such information to effective use.” He also emphasizes that knowledge itself is a resource “that needs to be shared, shaped, and governed by the political community of citizens” (p. 5).

Creighton (1981) defined four elements that are essential to broadened decision making:

- 1) The entire public must be informed of the consequences of a proposed action so that citizens can choose whether or not to participate.
- 2) Highly visible ways of participating must be made available so that people know how to participate if they want to.
- 3) All interested publics must be represented among participants. . . . This will require that you systematically identify the potentially affected publics to ensure that you are involving representatives of all major interests.
- 4) Equal access to information and to decision makers must be provided to all interests (p. 45).

Consumers in the project made it clear that they both needed and appreciated receiving information. They asked for:

- a brochure to pass out to other consumers, telling about Step Ahead
- a one-page description of First Steps

- past committee meeting minutes
- goals and action plans of committees
- a flow chart of the county and state Step Ahead/First Steps structures
- a glossary to clarify terms, especially acronyms, jargon
- a more thorough orientation
- a clearer overall picture of the purpose of Step Ahead and First Steps
- a list of other organizations involved
- a calendar of meeting dates, times, locations
- tape-recorded committee meetings

“They want to include parents, but do they also want to educate parents? And if they do, then they aren’t doing it.”

“They don’t have anything to read, and if they did, it would have to be, for somebody in my position, a one-page, this is our goal, this is who is involved, this is what we’re looking at now. It took me a while to figure it out, and actually I figured out more through our consumer meetings than from actually going to the other meeting.”

VISIBILITY

Consumer involvement is more likely to increase when people have heard about Step Ahead or First Steps, understand what they are about, and are aware of decisions that need to be made.

Publicity about Step Ahead and First Steps is needed on both the state and local levels. Few consumers know about Step Ahead or that they can become a part of First Steps or Step Ahead Committees. Some may be interested in participating, but simply do not have the information they need to become involved. Others may hesitate to commit their time and energy if they have never heard of the initiative. In addition, when people are not aware that decisions are being made that may affect them, they do not know that they have a reason to participate. However, warns Creighton, once they realize that they have been left out of the process, “they feel doubly betrayed . . . because of the impact, and . . . because they weren’t told about the impact before the decision was made” (p. 43).

Publicity needs to be provided in a variety of forms in order to reach deeply into the community—from billboards and bus signs to radio talk shows and visits to neighborhood council meetings. Consumers who already participate in First Steps or Step Ahead are

themselves an important vehicle to increase publicity. According to a recent Step Ahead survey, most families learn about services and programs via word-of-mouth from relatives, friends or neighbors.

“Parents need to recruit parents.”

“Being encouraged to get involved--I wouldn't have ever done it if I had not gotten called and been told there are these committees and you can be involved in them as a regular person. And so I felt like I could then and maybe I knew that (I'm not certain I knew that) but I certainly wouldn't have know when they met anyway. But it's like someone wanted me to be involved, to the extent that I could.”

It is also important to consider the message. What do consumers need to know? How do First Steps and Step Ahead connect with the issues that are relevant to consumers, such as concerns about their own families or neighborhoods?

“They've got to advertise if they want to get the community involved.”

“Nobody even knows nothing about it.”

“So the PR is very important. See, nobody knows about it. You're gonna have to reach people where they are.”

“Is there any literature in the dentists' offices? Is there anything in the schools? Is there anything anywhere that somebody would know?”

“How do you get in touch? Is there a number you can call? Can you be a donator? What kind of roles can people play? Why is it important that you participate?”

TIME

Time—for both consumers and professionals—is a factor that affects consumer involvement.

Time, certainly, is a major cost in terms of social exchange theory, and the time commitment for effective involvement may keep many consumers from participating. We found this to be the main reason among the few consumers we contacted who chose not to join the project. This lack of time is not surprising. In a recent Step Ahead survey to families, 14 percent wrote that lack of time available to spend with their families was one the biggest problems they were facing. If time is viewed as a high cost to parents, it becomes essential that they do not find the meetings they attend a waste of their time. Howell writes, “people need the assurance that their contribution to public meetings will receive a fair hearing and that time devoted to participation is well-spent” (p. 8). It also suggests that some avenues for consumer involvement need to be time-limited, such as surveys, focus groups, or specific project-oriented task forces.

The demands on consumers' time can also be a barrier to regular meeting attendance. Consumers miss meetings for many of the same reasons professionals do. Additionally, for consumers who do not work full-time outside of the home, the responsibilities of taking care of sick children or household emergencies almost always take precedence over meetings. One consumer who initially committed to the project did not continue because her husband's grandmother became ill and could not be left alone. As the only person not working full-time, this consumer felt she needed to be there for her care. Two other consumers with seriously ill parents also withdrew from the project. Consumers who did participate missed meetings for such reasons as sick children, a hospitalized foster child, waiting for a plumber, and out-of-town trips. Many consumers who do work do not have job flexibility, so when meeting times are changed or moved around, they may be unable to attend. Others cannot always get away from their jobs. Consumers may also be more likely to change jobs, which then may interfere with their ability to attend meetings.

"I wasn't able to attend the last two meetings--one I was out of town; the other I worked the night before and the meeting was early the next morning."

"I couldn't get away--didn't have an aide that day. A couple of times they changed the meeting days and times and then I couldn't go."

"I would have gone to some of the conference stuff . . . but it wasn't important enough to me to do what needed to be done—which is always a big deal when you're talking about evening or whole days . . ."

"I'm also a little scared of getting drawn in too far and sometimes if you go to something like that [a workshop] and you get too excited and then you are in over your head before you know it. [My husband] has been very nervous about my being involved even in this, because we only have so much time and there's a lot that we do."

It is important to note that lack of time on the part of professionals also contributes to involvement barriers. Council or committee chairs, who may already be stretched to their limits carrying responsibility for Step Ahead or First Steps on top of their regular full-time jobs, may have little time to focus on consumers.

CONFIDENCE

It is more difficult for consumers to get involved when they lack self-esteem, communication skills, and participative experience.

For most service providers and other professionals, attending meetings is almost always a normal part of their day-to-day routine. But meetings are *not* an every day occurrence for some consumers. They may worry about what they should wear, where they should sit, or when they should speak up. In some cases the barriers of the unknown, coupled with the effort to actually get to a meeting (transportation, child care, etc.) may be strong enough to keep consumers away, despite their good intentions, interest, and high commitment.

Consumers who do attend meetings may never have heard of Roberts' Rules of Order, which some councils and committees follow. They may feel overwhelmed by Step Ahead or First Steps jargon or complicated funding streams—which can be intimidating even to experienced professionals joining these groups. If their self-esteem is low, consumers may not trust or give validity to their own experience or feelings. They may feel uncomfortable challenging assumptions or decisions. And a negating or indifferent attitude from professionals may further interfere with a higher level of participation. Without self-confidence, meeting skills, or positive reinforcement, the “cost” of attending meetings, as related to the social exchange theory, may simply be too high.

A few parents in our group attended consumer meetings, but never made it to a Step Ahead or First Steps meeting. These parents contributed greatly to this project, enriched the consumer meetings that they attended, and brought an important perspective to the problems and goals of consumer involvement. Their voices would not only be an asset to Step Ahead and First Steps committees, they are critical to the process. We must not to lose sight of hearing from families who cannot or choose not to attend meetings, nor of addressing the factors that impede their attendance.

“I only have a high school education.”

“What do people wear to these meetings?”

“I have low self-esteem and I really need to work on that.”

“I almost didn't come to the workshop because I had a run in my nylons.”

COMMITMENT

If professionals want meaningful consumer involvement, they need to be convinced that it is valuable and be committed to addressing barriers.

Finally, consumer involvement is doable. But if consumer involvement is to become a reality, it takes above all else a belief that it is worthwhile and a commitment to make it work. Consumer involvement is not something that can be done once and checked off the list. It is an on-going process that requires time and energy for relationship-building, recruiting, training, and follow-up. Successful consumer involvement means a willingness to try new methods of outreach. It demands the sharing of information, a reallocation of resources, and a redefining of power. When consumer involvement is a priority--when it is a consideration in all aspects of planning and allowances are made for it, chances are good that it will be realized.

“I never made an active effort to reach [my committee chair]. I introduced myself and told her I was going to be on the committee and was anxious to hear what we were going to do. . . . I only have so much time, and I have to decide where to put it. . . . I can't organize the whole committee . . . because of time and that's not my job.”

III. SOME STRATEGIES

LESSONS LEARNED . . .

- ~ **The most effective strategies for consumer involvement may simply be the elimination of barriers as they are identified.**
- ~ **The results of planning and decision making can be strengthened when a variety of methods are used to gain consumer input.**
- ~ **A focus group is a method of hearing the consumers' perspectives in a time-efficient, low-risk manner.**
- ~ **A well-conducted survey helps to see the bigger picture and provides information from consumers that can be used to take action.**
- ~ **Both professionals and consumers can benefit from training to further develop skills and enhance their ability to work together.**
- ~ **Consumers gain numerous advantages when they have an opportunity to meet together and build relationships.**
- ~ **Supporting grassroots organizations in their goals and activities can be a long-term investment in consumer involvement.**

ADDRESSING BARRIERS

The most effective strategies for consumer involvement may simply be the elimination of barriers as they are identified.

The barriers discussed in this report suggest a number of strategies. Some require little more than becoming clear about why or how consumer involvement is wanted, being attentive to consumers who show an interest in participating, or listening and acting on what consumers have to say. Establishing goals for consumer involvement—and always keeping those goals in sight—will help ensure that consumers don't get left out of the picture. Other strategies may require considerable more time, effort, and resources. Increasing publicity is necessary for consumers to know about Step Ahead and First Steps. Opening up access to information also helps consumers become knowledgeable decision makers. Certainly everyone—professionals and consumers alike—would benefit from training to further develop the skills required for working together.

PROVIDING MULTIPLE AVENUES FOR INVOLVEMENT

The results of planning and decision making can be strengthened when a variety of methods are used to gain consumer input.

While the main focus of this project was to look at how to increase consumer participation in Step Ahead and First Steps council and committee meetings, it is important to recognize the value of employing other methods of participation as well. There is no such thing as a single consumer profile. Among other things, consumers differ in their areas of concern, time, knowledge, skills, and priorities. Since not all consumers will choose to attend meetings, it is essential to explore alternative strategies that offer families access to information and the ability to provide input into decision making at many different levels.

Several methods have been identified to gain access to the wisdom and experience of consumers. We will discuss two—focus groups and surveys—in greater detail. Other methods include key informant interviews, newspaper inserts, participatory television, interactive computer programs, neighborhood discussion groups, search conferences, participative design workshops, exhibits, and training sessions.

A focus group is a method of hearing the consumers' perspectives in a time-efficient, low-risk manner.

Pulling together a focus group is way to involve consumers on a time-limited basis. While focus groups are not an avenue for direct participation in decision making, they do provide useful information that can shape the direction of policies and programs. Focus groups are especially useful to get a handle on a specific problem or issue, to test a theory or proposal, to gather ideas at the beginning of program planning, or to collect preliminary information for survey development. There are several advantages to focus groups.

They are very short term and do not require a lengthy time commitment from the participant or the facilitator.

They focus on one issue, so the information that is gathered can be more in-depth.

They provide an avenue to hear consumers' concerns directly.

They can be held at a time and location convenient to consumers.

They can bring together a target audience-by income, location, age, marital status, program participation, etc.

They give a voice to more people, so may appear more legitimate.

They can take advantage of existing groups (i.e., support groups, neighborhood groups).

They provide an opportunity to access groups who are traditionally uninvolved.

They can be repeated with multiple groups for different perspectives.

They are a low-risk investment to the consumers who participate.

They eliminate issues of power.

They provide an avenue for consumers to share their ideas.

They may identify other issues that need addressing.

They give people the opportunity to be heard.

They can be a way to build networks and begin relationships among participants.

They may be the first step in a person's becoming involved in public life.

The focus group that we conducted for this project grew out of the growing interest in welfare reform in our state. The design of any welfare system that truly fosters independence and self-reliance needs to utilize the experience and insights of welfare recipients themselves. The focus group was one effective method of hearing these voices. Five current and five former recipients of AFDC were recruited by one of the consumers in our project. We joined them in a public housing community center to discuss what works well and what gets in the way of the current welfare system. A light dinner and child care were provided. The discussion touched on several issues that contribute to the ineffectiveness of the current system, including the barriers to self-sufficiency, disincentives to work, the cost of child care, transportation, the separation of families, time-limited benefits, and lack of respect. The participants felt the focus group was a worthwhile experience and believed that their input would make a difference. The full report of this information will be shared with local, state and national legislators, as well as administrators within the Indiana Division of Family and Children and other community leaders and citizens. A copy of the report will also be given to the participants of the focus group.

A well-conducted survey helps to see the bigger picture and provides information from consumers that can be used to take action.

Surveys are another time-limited avenue for consumer involvement. If used correctly, they can be a highly useful tool in soliciting consumer experiences and input. Surveys have three primary advantages: they are able to reach consumers who may not be active participants in meetings, forums, or other public gatherings; they are able to provide a better understanding of the proportions of people who think or feel a certain way (as opposed to hearing viewpoints from a handful of individuals, where it is hard to determine if they speak for a majority or few others); and, because the results are quantifiable, they present "an aura of objectivity . . . to quantitative results which can be reassuring to a decision maker . . ." (Creighton, 1981, p. 249).

It is important to note, however, that poorly designed or inadequately conducted surveys can easily be misunderstood by respondents and misinterpreted by administrators. Nonetheless, surveys can provide valuable information that can help broaden understanding of a problem, evaluate methods of operation, or determine the outcome of a program.

Some considerations to take into account when deciding on or developing a survey:

Be very clear about what you need to know, why you need to know it, and what you will do with the information once you have it.

Take the time to determine if there are other less costly or more effective avenues to obtain the information that you are seeking.

Review your survey carefully and eliminate any questions that ask for unnecessary information.

Always field test your survey before fully distributing it to check for clarity of design and actual helpfulness of responses.

Build in the capacity to pull out subgroups when analyzing survey results, i.e., by a certain location, income, age, or family type.

Consider collaborating with other agencies or groups who also may be seeking information. Can you add on questions for them? Combine surveys? Share results?

Provide an opportunity for at least one open-ended question or for comments. The information that people write in often brings up issues that you had not considered, or clarifies answers for more in-depth understanding.

Provide feedback on survey results and/or make reports accessible to participants.

Act on the survey results.

We conducted two surveys for the Consumer Involvement Project. One was a day care evaluation survey to parents that was developed with the assistance of the Step Ahead Educare Committee and an outside consultant who conducts consumer satisfaction surveys for hospitals nationwide. A local day care provider offered to pilot the survey. The questions focused on consumer satisfaction with the day-to-day operations of the center, the quality of the staff, the information that parents received, discipline, and improvements that could be made. Information from the survey results was used by the staff in program planning and the director plans to use the survey again in the future. Another survey that we conducted went to educare providers who serve subsidized clients. This survey was developed with representatives from the Step Ahead Voucher Committee and received input from the committee as a whole before being sent to St. Joseph County child care providers. The survey sought information regarding market rates, clarity of rules and forms, courtesy of the Voucher Agent staff, amount and usefulness of information received, training, and any problems with specific funding

sources. Information from this report will be shared with administrators of the various child care funding streams and with members of the Step Ahead Voucher committee.

TRAINING

Both professionals and consumers can benefit from training to further develop skills and enhance their ability to work together.

Creighton (1981) suggests that when agencies or organizations seek public involvement, it is best approached as a team effort because of the number of skills necessary. His list of needed skills includes:

Professional competence in the program area. This competence “must be visible in the individual or team conducting the program” so that credibility can be established with the public.

Communication and leadership skills. It is important to be able to listen with understanding and empathy, to share feelings and ideas in ways that minimize defensive or negative reactions, to understand group dynamics, and to develop the ability to generate commitment.

Knowledge of public involvement techniques. What are successful ways of involving the public? When are different techniques appropriate? How can they be implemented?

Public information skills. In order to reach the public, it is necessary to have a working knowledge of the media, including “how the media work, how to disseminate information through the media, and how to present information to the media in a manner that is newsworthy.”

Writing, graphics and publication skills. The sharing of information is critical to successful public involvement. Writing in everyday language and knowing how to develop effective publications will increase the potential for successful involvement (pp. 147-148).

While Creighton’s focus is on skill development of professionals, consumers, too, can benefit from increased knowledge and understanding of these and other skills. Lappé and Du Bois (1994) emphasize the importance of developing skills for one-on-one interactions, for group settings, and for self awareness. They identify ten specific skills, which they define as the “arts of democracy,” that they say are the tools required for an enhanced public life.

Active listening. Active listeners stay engaged, support the speakers’ efforts whether or not there’s agreement, search for underlying meaning, and are nonjudgmental. Active listening uncovers deeper interests, permits the discovery of mutual interests, spurs creativity, can change the speaker as well as the listener, and creates positive bonds.

Creative conflict. Constructive, honest confrontation can demonstrate that diverse stakeholders are involved, uncover interests, deepen understanding, generate more options, and build group confidence.

Mediation. When there is a skilled, neutral listener as facilitator, it helps those in conflict “hear” each other. Mediation avoids destructive conflict, makes problem solving more possible, reduces the likelihood of unproductive conflict in the future, and enhances personal dignity and mutual respect.

Negotiation. When parties can problem solve to meet some key needs of all concerned, it makes resolution more possible, maintains the dignity of all parties, makes it more likely that agreements will be upheld, and prepares the ground for future problem solving.

Political imagination. Being able to reimage the current reality to more nearly match our values and needs will spur creativity, motivate action, release and focus positive energy, and enable goal setting.

Public dialogue. It is critical that people be able to talk in public on matters that affect all of us in a manner that values differences. This public talk reveals interests, expands and deepens knowledge and generates more creative alternatives.

Public judgment. Public judgment can only be reached through talk and reflection. This dialogue and weighing can result in better solutions and in a greater willingness to accept tough trade-offs.

Celebration and appreciation. If people can integrate celebration and appreciation into all that they do, these have a great sustaining and recharging power, can build loyalty, and strengthen relationships.

Mentoring. Providing encouragement and guidance to motivate another’s learning builds self-esteem and feelings of accomplishment for all (pp. 240-283).

Walker (1987) stresses the importance of leadership development. “Leadership helps formulate a vision and rallying point for current action. The training of leaders ensures that the vision will be sustained in the future” (p. 420).

Working together requires the ability to build consensus, respect diversity, share power, explore options, set healthy group norms, plan strategically, and take action. As we move towards more consumer-driven services and to meaningful consumer participation, it becomes clear that skill-building can benefit everyone who will be involved in planning and decision making.

In addition to the monthly consumer meetings, we offered two training opportunities for consumers. Five consumers who participated in the project were able to attend a three-hour evening workshop led by an outside consultant. The focus of the workshop came from issues that had been identified by consumers, including validation of the knowledge consumers have as parents, how to feel confident speaking with professionals, how to deal with issues of power and conflict, and how to help other parents feel effective. We

also arranged for a day long workshop with Frances Moore Lappé and Paul Martin Du Bois, which was funded by Family, School and Community Partnerships for Education through the Lilly Endowment. Over forty consumers from several parent groups in the community, funders, and providers participated. This workshop looked at the broader range of citizen involvement, including topics addressing active listening, problem-solving, creative conflict, the healthy use of power and participatory planning for change. Both workshops were received positively.

“The experience was great. . . . I hope I can make a difference.”

“[The workshop was] very very useful, interesting and exciting. The connections with the other people was very beneficial.”

CONSUMER GROUP

Consumers gain numerous advantages when they have an opportunity to meet together and build relationships.

A very interesting and rewarding part of our project was the establishment of a consumer group. Consumers participating in our project met monthly to share experiences and identify what they needed to become more effective. In many ways, the group acted as a counterbalance to several of the barriers to consumer involvement. It also appears to have provided grounding in some of the basic principles of citizen participation. It served to establish and develop relationships and offered a “power base” from which to operate. Consumer discussions instilled and reinforced a hope that their involvement really could bring about actual change. While one of our focuses for this group was to identify the barriers to involvement that consumers experienced, consumers identified several other benefits that reinforced what we have learned about participation from the research.

All of the consumers enjoyed the diversity of the group; hearing other parents’ perspectives was important to them. They found the group a “safe place to ask questions” and a good source for information. For many, the discussions helped to validate their role as parents and consumers; they felt reinforced by the message that “what they had to say was worthwhile.” They felt a base of support from the group. Knowing others had similar concerns gave some the impetus to speak out. Those who struggled with getting to or feeling a part of committees received encouragement from the other consumers. Some were able to participate in the training that was offered to the group and greatly appreciated the opportunities for self-development. Others took advantage of the networking that seemed to be an ongoing component of many meetings. Consumers shared information with one another about community services and other resources available for children or families. Many also believed that the group had the potential to work together to develop strategies for making real change. These benefits can probably be best understood in the context of consumers’ own voices:

Relationships

“[The most valuable thing was] probably getting together with other consumers and knowing that they were concerned about the same things that are bothering me and were willing to put some time into doing something about it.”

“I was eager to go, see who was there, meet new people. That was really nice to find other people. And I missed it when someone didn’t come back. I wanted to get to know them better, their perspective.”

“I enjoyed the people there, even though I’m not sure there was anybody there I would have picked as a friend, but I enjoyed the diversity and it was fascinating.”

Information:

“I think it’s important for me to know what’s going on in the community at large because it will impact [my son] as the years go on . . .”

“At my first meeting here, I learned that I had a chance to fight special ed, but I didn’t know it. I knew that my child was a special ed kid, but I was so confused by the school corporation that I just felt helpless and powerless. . . . I felt like there’s nothing I can do so forget it and there’s nothing I wanna do cause if they said no it’s no. But I found out it’s not just no.”

“Now I can talk about [Step Ahead]. I’ve learned the big picture. I learned it from the parent consumer meetings, not on my own, or at all from my committee. It sunk in at our meeting.”

Validation:

“A lot of people [at the consumer meetings] said GOOD things. Getting across that being a parent is the most important job we do was very important.”

“I always felt as a parent--and especially a stay-at-home parent--that my opinion didn’t really matter. . . that nobody really wanted to listen to it. I go to meetings and feel like I should just listen and not voice anything, but then I leave the meetings with the feeling like, oh, I’m not important . . . but today, I can realize that there are people that will listen and you know, may have something they can gain from my questions or what I say.”

“It makes me feel good to come, cause I was rushed and I was like all out of sorts, but here I know I’m going someplace where kids are important. We need that, you know what I mean? to keep you going sometimes.”

“That’s why the consumer lunch meetings were important because you took time to let parents know how important they were on the committees.”

“It helps you maintain your identity as consumers.”

Support:

“I think this to me was a very stimulating thing to get me moving because these are all regular people who are just starting to get involved in things that are very confusing.”

“In this setting, I think it’s brought a lot out with people helping you feel more comfortable to go to a meeting . . . then come back here and discuss what happened, how they feel.”

“Mentoring is the key to a lot of things—can have a parent mentor another parent.”

“There might be two or three people going to a committee meeting and that would help the person who just doesn’t want to go by themselves—there’s safety in numbers.”

“In a way I guess it was like not feeling alone, like I was the only person who didn’t like the way things were going, so that made me feel more effective, because I felt like there were other people who are sincere and they were willing to do a little bit, what they could.”

Self-development:

“I guess what I need—a good thing for me would be to be more assertive, to follow up—‘Hey, I’ve still not gotten any mailings!’”

“I liked the attitude [in the consumer meetings] that if you didn’t like it, you had the power to make it different. It can be done. You can do it—it wasn’t like, ‘we will make that change for you.’”

“There wasn’t one [consumer meeting] where I left and thought, ‘well, that was a waste of my time,’ ‘cause if I didn’t get any information that would help me, I feel as though I connected with somebody . . . [and] maybe I gave them a little something to go back with that would help them.”

Training:

“[Training would be helpful] because by the time you listen a couple of times, you know what they are talking about, but you don’t really know. I know that money comes from Title XX, but if someone asked me to explain it, I really don’t know.”

“The training opportunities were really wonderful. I appreciated that.”

“That workshop the other night, that was a godsend.”

Networking:

“[The most valuable thing about this whole project was] networking with other parents.”

“I’ve made some unique community contacts. We’ll have a Girl Scout group at El Campito through a contact I met at the Youth Committee meeting. And I think we’ll do something with the North East Neighborhood Center too.”

Change agent:

“I would like to see us coming back to this group and talking more specifically about how we can influence the goals and objectives of our committees. I’d like to be able to discuss with the group how we can influence what that goal is.”

“Use this group as a brainstorming group, developing strategy and taking it back.”

“I’d like to be able to come back to this group and say, okay, this is what we want to do—what input do you have, what can you help me say to them.”

“It’s exciting ‘cause we’re in at the beginning of this. Consumer involvement is so new. You got us so motivated—that we really can make a difference. I want to see if I can make it happen.”

However, consumers had a need to insure that these meetings continued to serve a meaningful purpose and felt that it was important to more clearly define the goals of the group itself.

“The secret to this, though, is the committees. . . . To continue, I would want to put an emphasis on getting more people that really get out and go to committees.”

“Before you get more parents involved, let’s figure out what it is they’re getting involved in.”

The consumers made several suggestions for the group:

Make sure to follow up personally when someone doesn't come to a meeting.

Consider having longer meetings—it was hard to cover everything in just an hour.

Keep the notebook system—it was helpful to be able to keep everything in one place.

Mail the agenda out before the meeting so we can begin to think about the discussion topics ahead of time.

Expand our consumer base.

Provide more training to consumers, especially background on Step Ahead and First Steps and what has gone on in Indiana for services.

Get the group involved in a project that it can do.

Recruit more black parents and people from various areas.

Discuss the goals and objectives of all the committees with the whole group.

Don't let the group get so big we can't all participate in the discussions.

Consider running multiple consumer groups, perhaps in neighborhoods, with the same topics and a facilitator who brings information from group to group.

Continue the food!

The consumer group, in essence, became what The Harwood Group (1991) defines as an “alternative community.”

“At first blush, [citizens] think of [community] in traditional terms: neighbors, town centers, city council meetings. Yet, through their community involvement, it appears that some citizens have been able to create alternative communities for themselves—some new, some not so new—around such things as an ad hoc issue group seeking to preserve open space, a local school committee, a crime watch group, or the traditional neighborhood association. The group discussions suggest it is important to foster new places and organizations that help citizens create a sense of belonging in their community; this is essential to providing an arena in which people can practice politics and can exert at least some control over events around them. Part of this process is to help citizens see that they can build—or already have—places where a community exists. Only it may not be where they ordinarily look for it” (p. 48).

The “community” provided by the consumer group offered a forum for what The Harwood Group (1993) identified as much-needed discussion. “People don't learn the public's business sitting in a lecture hall, listening to a newscast or reading a report. . . .

people learn primarily through their interactions with other people.” Through dialogue, people can test their ideas, express their emotions, and sort out the realities of issues. The safety of the group provides a space “in which it is all right to be ambivalent and tentative.” This dialogue keeps people engaged and linked to political life. “Without that link, political life dies. With it, people become animated; they participate” (p. vi).

The consumer group cannot be all things to all people. However, the range of benefits available through the group appear to offer something to just about everyone. It is also important to recognize that the consumer group is not an end in itself, but a vehicle for increased and more meaningful participation in the public decision making processes of Step Ahead and First Steps. The goals for the group, then, must focus on addressing the barriers to involvement—through clarifying, networking, informing, training, building self-esteem, addressing attitudes and power issues, or increasing visibility—and on expanding access to consumers’ experiences and input.

GRASSROOTS SUPPORT

Supporting grassroots organizations in their goals and activities can be a long-term investment in consumer involvement.

It is important to look at ways to redirect resources and create new power through partnerships with people at the grassroots level. When parents find and act on their own power to make their neighborhoods, schools, churches, and support structures stronger and more responsive, they are affecting change in dynamic ways. People have the capacity to create their own solutions. When they join with others to problem-solve and put into place self-support programs, they strengthen the involvement skills that Lappé and Du Bois label the “arts of democracy”: active listening, creative conflict, negotiation, public dialogue and others.

If Step Ahead and First Steps are serious about family involvement, it cannot just be a one-way street, expecting families to come and bring their expertise and support to councils and committees. Step Ahead and First Steps must also recognize, respect, and strongly support the parent-initiated movements that are already in place as well as those which may be newly forming. We already know that relationships form a base from which trust can grow and involvement can bloom. By reaching out and making an investment in grassroots movements, we all will reap longterm benefits—Step Ahead, First Steps, consumers, *and* communities.

SUMMARY

The concept of consumer involvement is strongly rooted within the broader context of citizen participation, from which comes the basic principles of democracy: government of the people, by the people, for the people. As far back as the early days of our country, the importance of citizen involvement in decision making was recognized. This thread has continued throughout our history to the present time, where it is resurfacing as “consumer involvement.” This newer concept involves a major change in thinking. It is an extension of the idea of citizen participation in that it moves the voices of consumers into the planning and decision making process of agencies, communities and service-delivery systems.

There are many rewards when consumers are actively involved. Programs and policies are stronger and more responsive to the needs of families. The involvement of consumers brings new information, broadens perspectives, increases accountability, and steers direction. We also know that there are considerable benefits to an individual when he or she is involved in a meaningful way in the public arena. Yet even though citizen participation is at the base of our democratic principles, it is not always widely found.

Consumer involvement will not automatically happen just because it is a good idea. While there are benefits to programs, communities and individuals when consumers are involved, there are also significant barriers to their involvement. Some of the barriers identified in the consumer involvement project included working within a pre-existing structure, clarity about what consumer involvement is and why it is wanted, changing ideas about roles and power, attitudes that get in the way, negative meeting experiences, the need for information, and a lack of visibility. Surmounting these barriers requires intentionality, information, time, and—most importantly—commitment.

Though the barriers can be discouraging, we found that identification of the difficulties illuminated the strategies that could be utilized to increase the involvement of “ordinary” family members in these collaborative processes. Among the strategies we explored were addressing barriers, seeking alternative methods of involvement such as focus groups and surveys, providing training, and convening a consumer group.

Hopefully, the learnings presented here will move us further towards the meaningful involvement of Indiana families in the planning and decision making processes of Step Ahead and First Steps. If we are serious about collaboration and systems change, we *can* make it happen.

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