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## Listening to the Voices of Marginalized Families

Kimberly A. Greder

*Iowa State University*, [kgreder@iastate.edu](mailto:kgreder@iastate.edu)

Mary Jane Brotherson

*Iowa State University*, [mjbrothe@iastate.edu](mailto:mjbrothe@iastate.edu)

Steven Garasky

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# Listening to the Voices of Marginalized Families

## **Abstract**

Marginalized families with minimal access to power are, more often than not, left out of the political process. In addition, their community support system may or may not have provided the kind of mentored leadership that serves to support an informed citizenry.

## **Disciplines**

Community-Based Learning | Family, Life Course, and Society | Family Medicine | Gender, Race, Sexuality, and Ethnicity in Communication

## **Comments**

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# Listening to the Voices of Marginalized Families

Kimberly Greder  
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Marginalized families with minimal access to power are, more often than not, left out of the political process. In addition, their community support system may or may not have provided the kind of mentored leadership that serves to support an informed citizenry.

If policies and programs are developed with the intent of supporting families, then it is essential that all families are a part of the decision-making process. They need to know what the policy or program will entail and how it will be carried out. It will serve society well to involve families as partners, as an equal voice, in the development of the policies and programs that directly influence their lives. Too often, policies and programs are developed for, but not with, families. And when the needs of families are not met effectively, the result is frustration on the part of policymakers, program administrators, front line workers, and the families themselves. This chapter makes the case that:

- Society is well served when “hard to reach” families are involved as partners in the development of policies and experiences that directly influence their lives.
- Key roles for leaders/facilitators include educating and empowering individuals and families to become “voices for an issue.”
- Participation requires a seat at the table, reliable information based on sound research and ongoing support.
- Family policies that are responsive to the voices of families must: (a) establish the family as the focus of policy; (b) support and respect family knowledge and decision-making; and (c) enhance the capacity of families.

**H**ow can society develop policies that help marginalized families (e.g., the poor, minorities, non-English speaking immigrants, the uneducated, the homeless, the disabled, and those dealing with mental illness and substance abuse) not only survive, but thrive and work toward a higher quality of life? One recommendation is to involve families in the decision-making process of programs and policies that affect them. However, marginalized families have the least access to power, are frequently left out of the process of defining problems and developing solutions, and often are labeled “the hard to reach” (McLeroy, Bibeau, Steckler, & Glanz, 1988).

Involving marginalized families in the policy process is not easy, but it is essential. These individuals sometimes are difficult to reach because their personal problems are so severe that they have little time, energy, or resources for participating in larger community programs. The “hard to reach” are not politically organized and they are disconnected from community political processes and power structures (McLeroy et al., 1988).

Some would argue that a key role of family professionals is to advocate for families whose voices are traditionally not heard in policy matters. However, it is proposed that a more effective role for professionals is to educate and empower all citizens—especially families who are marginalized—to speak for themselves. Specific strategies and identification of responsibilities are needed.

Are families viewed as being able to make valuable contributions to the discussion? Or is their participation in the discussion simply tolerated? A 3-pronged approach to responsibility will allow for the involvement of families as valued members in the policy arena. The responsibilities include:

1. *Family Responsibility*—Families themselves getting involved in policy.
2. *Professional Responsibility*—Professionals committing time and energy to become involved with families and paving the way for their voices to be heard.
3. *Partnership Responsibility*—Professionals and families working together to build trusting partnerships that lead to incorporating family voices in policymaking.

Professionals are accountable for the above mentioned responsibilities. Accountability refers to taking responsibility and holding oneself and others responsible for carrying out the actions. In the now familiar question “If not me, who?” professionals are asked to take a leadership role in holding professions accountable for “hearing” the voices of families.

## Strategies for Involving Marginalized Families

Marginalized families are families who face special challenges and whose voices are typically not heard in the policymaking process. They are families who have a child with a disability, families who are immigrants to the U.S. and those who do not speak English as their first language, and families who experience poverty.

Four strategies are proposed to involve marginalized families in shaping policy. Every strategy will not be appropriate for every family, and families may be receptive to engaging in specific strategies at different points in time. A goal of this chapter is that readers will learn the strengths and weaknesses of each strategy and why some strategies may work for some families and not for others. Five families agreed to share their perspectives on the strategies. Two of the families are immigrants from Mexico (Hector and Maria) and three of the families experienced poverty (Jackie, Donna, and Angie) as well as other special challenges, including an adult and a child who both have a disability (Donna). For a brief bio of each family, see Appendix A.

In order to support family involvement in policy, it is important to recognize and support the variety of interests, time, and levels of energy of each family member. Strategies of involvement are on a continuum from indirect to direct, with recognition that every family chooses when and what they have to offer. Therefore, choice and self-determination for families is key to involving families in policy. In addition, it is acknowledged that families may not be aware of the range of possibilities for involvement, and it may be helpful to share multiple options for families to consider, as well as to be open to additional ideas families may have for involvement.

Four strategies for family involvement in shaping policy include: (a) support groups, (b) parents as teachers and trainers, (c) accountability councils, and (d) partners in policymaking.

### **Support Groups**

#### **Beyond Welfare**

Families who experience special challenges may find it helpful to connect with others who face similar challenges; this allows them to share experiences, solve problems, and identify coping strategies. One example of a support group-based program is *Beyond Welfare*, which includes a support group, involvement of community members as family partners, and the nurturance of advocacy skills.

*Beyond Welfare* seeks to empower families by building relationships across class and race lines (Miller, 1998). A central tenet of the program is that families in poverty need not only sufficient income, but also important relationships and meaning in their lives in order to become self-sufficient. To help develop those relationships, family partners are identified and matched with families. Typically, family partners do not experience poverty themselves, but are interested in developing relationships with people in poverty to help them become self-sufficient. Family partners listen to families, connect families to community resources, provide specific resources such as transportation, childcare, help with learning to drive or how to budget, and they solve problems together.

Family partnerships are based on common interests, but they focus on the safety, stability, self-sufficiency, and well-being of the participant family. The relationships that are fostered in this activity provide the beginning of an effective social support network—something many *Beyond Welfare* participants have never had. This aspect of the program helps to reduce isolation, erode stigma, and replace feelings of victimization while simultaneously helping participants learn new ways of coping with daily problems and setbacks. At the same time, family partners learn firsthand the strengths and challenges of people on welfare and the working poor. *Beyond Welfare* seeks to instill a sense of advocacy in families and their partners, and to build a constituency for systemic change (Miller, 1998).

Families and partners meet weekly for a meal, peer support, and advocacy activity. Meals and childcare are provided at no cost. This weekly meeting serves as a catalyst for community building. Through trusting relationships with one another, a circle of support is created to help participants identify issues they are facing and strategies for overcoming challenges. A typical agenda includes an update on what is new and positive with each person for the week, small-group work to focus on solving problems and pursuing goals, announcements of new community resources, and networking. *Beyond Welfare* includes a job coach, family therapist, and two program directors who attend each meeting to help individuals with next steps. The program is governed by a local Board of Directors comprised of a majority of members who have been or who currently are marginalized by poverty.

The program builds a constituency around the notions of caring for families, changing attitudes, practicing human service, and developing policies. Specific ways *Beyond Welfare* has helped families and partners advocate for family needs include:

1. Developing a statewide coalition of welfare recipients and working poor to advocate for childcare

2. Building a partnership with the Department of Human Services administrators and state legislators
3. Creating a vision for a new welfare system and sharing that vision with local, state, and federal officials

### **Church-based and other support groups**

Support groups represent an indirect way to involve families in shaping policy; they were appealing to the families who were interviewed for this book. The largest and most common support group that Hispanic families were involved in was the one that formed among families who attended the Catholic church in the community. Hispanic families felt comfortable going to the church and indicated that faith was the same here as it was in Mexico. The church served as a major voice for Hispanic families in the community.

Hispanic families often cited support from other Hispanic families in their communities. When parents had a concern in their neighborhood (e.g., vandalism, school policies) they would gather to discuss the problem and then decide how to address it.

*Yeah, they come in, some of the neighbors give advice to other neighbors because they are working the night shift and they don't know (about the vandalism). I mean they knock on doors and they call the police and they get together to make a complaint to the police. (Maria)*

Hispanic families new to the community sought the advice of other Hispanic families who had lived in the community for a longer period of time to find out the best way to address their concerns.

*Ask the person who has lived here longer. They know more about the community and ask them how they do it (address problems in the community). (Hector)*

When asked about participating in a support group similar to *Beyond Welfare*, the Hispanic families interviewed felt it could be beneficial if the group was primarily Hispanic and if there were interpreters. They believed that it would be difficult to participate in a group if English was the spoken language.

The three families interviewed who were experiencing poverty were receptive to participating in a support group similar to *Beyond Welfare*. Two families already had participated in a similar type of support group and found it beneficial. They thought it sounded like an effective way to get support and to help others.

*That is similar to what I am doing right now in my rehabilitation program . . . its people with similar problems and circumstances . . . I know they work. Just seeing someone that used to be on welfare and is doing good, that gives a little inspiration and hope that it's a goal that can be achieved . . . to talk to someone and knowing that I'm not going through these sort of problems alone and there are others and learn how they deal and cope with it . . . I see that support group and I see it being something good and positive. (Jackie)*

*It always helps to have an outside opinion on your problem and how you present it and what is going on rather than just your opinion and how you feel about it—that is what support groups are for. (Donna)*

To enable their participation in a support group, families experiencing poverty shared that childcare and meals would be helpful.

*It always helps to have childcare . . . it (support group) sounds like something that is also a stress reliever and could be a little enjoyable . . . Having a meal . . . being able to get away from the direct problem and be able to talk about it and hear about how other people have accomplished it. To sit down and gather together and be able to eat together—it sounds like a very good support group. (Jackie)*

Some families stated that due to the many commitments they already had, there was a limited amount of time available for participating in a support group. They wanted to share their experiences, learn from others, and support each other; however, some did not believe they were ready to be actively involved in advocacy or influencing policy.

*Maybe in the future I could see myself doing that (speaking with elected officials and others who enact policy). You know, it's kind of unique because people who are on welfare and get involved in programs like this to where they are able to talk to legislators and share their experiences. It's kind of like their way to give back to the community what the community has given to them . . . being able to go and be a representative, to speak out to help make a difference . . . being an example and showing other people it works and that you can get out of that slump. You don't have to stay in that slump and it shows them the ways they can go about it with the support groups. (Jackie)*

Families shared that support groups may not be for everybody.

*Some people may be so ashamed of their situations that they do not want to make them public. They would need a lot of encouragement to participate. (Angie)*

One parent shared that she actively advocated for her needs, as well as those of others, in addition to participating in the support group.

*You need to have a personal connection to an issue and it needs to be something you are passionate about to make the extra effort to advocate for it. I've*



gone to speak at a state disabilities board and other groups about my disability and the about the House of Mercy. They (House of Mercy) have several speaking engagements lined up for me. (Donna)

## **Parents as Teachers and Trainers**

There are multiple ways that families can be involved in providing training to professionals (McBride, Sharp, Haines, & Whitehead, 1995). For example, parents facing special challenges such as divorce, drug addiction, parenting a child with a disability, teenage parenting) have served on parent panels. *Partnering with Parents: Walking the Journey Together* is a comprehensive training program for parenting educators in Iowa. Parents share their daily experiences of coping with their special challenges, focusing on what they wanted and needed from service providers to support their families. Program facilitators meet with parents before the panel session to share information about who (type of service providers) participates, the format, and sample questions. During the parent panel, parenting educators ask parents questions that will help them better understand their situations, and how program policies support or hinder family functioning. The primary goals of the parent panel are to (a) increase awareness of the values, needs, and priorities of families facing specific special challenges; (b) identify family strengths; (c) identify family coping strategies; and (d) identify ways service providers can best support families (Greder et al., 2002).

Parenting educators have stated that the parent panels are unique and beneficial. The panels provide practitioners opportunities to ask questions that they may not feel comfortable asking directly. Parenting educators also have reported that hearing from parents directly, and then debriefing as a group, helped them to better identify family strengths, understand the importance of applying family-centered principles to their work with families, more fully understand the complexity of family life, and question some of their program policies and procedures (Greder, 2004)

The disability field is providing leadership for moving from child-centered practice to family-centered practice by actively involving parents who have children with disabilities as co-instructors in college and university courses. Including family members as co-instructors is beneficial because parents are the main recipients of services and are directly affected by service providers who work with them and their children. This strategy is effective for several reasons: (a) it helps faculty become more knowledgeable and skilled in family-centered practice; (b) it helps parents reframe their situations, identify their family strengths, develop new knowledge and skills, and become self-empowered; and (c) it enhances student learning.

The responsibilities undertaken by these parents in the classroom range from serving as guest speakers to assisting with planning and instruction of some of the content. The parents are engaged throughout the entire course and they assist with evaluating student learning. For co-instruction to be successful, it is critical to identify parents who can dedicate the time, are sensitive to student needs, have effective communication skills, and are aware of their influence on learning. Many parents who have served as co-instructors have become advocates for other families in similar situations, participated in advisory and task force committees at the local, state, and federal levels, and served as speakers at conferences for professionals and parents in the early intervention field (McBride et al., 1995).

The parents believed that they could make a contribution and that they could help improve services and policies for families by sharing personal experiences and knowledge with family professionals. They felt that family professionals in general had some false information about these marginalized families, which affected how they interacted with families.

*Yes. It is good they (agency staff) know because sometimes they only think we are the way it is in the TV . . . Sometimes we don't have everything in Mexico that we have here, but we have similar things . . . it would be really interesting to share that. (Maria)*

*I think it does provide some firsthand training and experience to these agencies. You know, you can only learn so much in a book. After that . . . every individual is different . . . I think that (training) should happen . . . because these parents are giving these students some insight, you know, what it is really like . . . (Jackie)*

*That sounds very interesting to me because I am not afraid to say it like it is. (Donna)*

Barriers to participation included time (having time to participate, as well as scheduling training when they were not working), childcare, and a concern by immigrants who do not speak English well that family professionals might not be receptive to listening to their perspectives.

*Sharing our experiences and perspectives could be helpful . . . it's like moving to another world (moving to the U.S.) and we are doing a different thing . . . They gonna say we didn't tell you to come here, you came because you wanted to and you want to change it . . . Sometimes we don't get involved because we think they (agency staff) are going to make fun of us or how we live in Mexico. They think nobody wants to go there and there is no good there. But, there is good in Mexico and it is a good idea to share that (with agency staff). (Hector)*

Families experiencing poverty stated that it would be helpful to receive monetary compensation for their involvement. They regarded this possibility as an employment opportunity in which they could give back to the community and help improve services for families.

## **Accountability Councils**

Winton (2000) envisioned a day when there will be accountability councils in all early childhood education programs. Accountability councils would include parents and program staff engaging in self-study on how to improve the program and services to families. Parents would be seen as partners—and thus equals—to staff. Information and expertise would be shared through a two-way process. Parents would be financially compensated for the time, knowledge, and skills they shared while serving on the councils.

A type of accountability council that exists now is the Head Start policy council. Parents of children who participate in Head Start are elected by their parent peers to serve on the council. They meet on a regular schedule to review local Head Start policies and develop plans for best meeting the needs of children and families who participate in the program.

These councils place accountability at the grass-roots, and promote the use of local wisdom of parents and staff in shaping policies (Turnbull & Turnbull, 2000). Typically, families know their children and family situations best, and therefore will be key to improving services. By including families in active and important decision-making roles about program policies and practices, meaningful strategies for involving families will be developed (Winton & Crais, 1996).

Parents were interviewed regarding their interest and willingness to serve on accountability councils. Although all of them thought the concept was good, three of the six families believed they did not have the time or childcare situation that would allow them to serve on a council.

*We don't have the time. When coming back from the job, I picked up my kids from school, and then went home for supper and then homework. The whole evening has passed and there is not time for anything else. And, where do you leave the children?* (Hector)

*I would not make any more commitments in my life because I am running to get things done and I know if I get overwhelmed something is going to give . . . but I think it is a good idea . . . in the future it's possible.* (Donna)

For these families, non-work time was consumed by many other activities. Parents spend time with their children, helping with home-

work, participating in addiction recovery programs, family therapy sessions, and other activities. Some parents meet with their parole officer, attended community college, manage homework, and meet with human service agency staff. One family shared that language and culture could be a barrier to participation.

*In school committees, the attention is for the Anglos. The Hispanics won't come. It would probably be better if there was a separate committee for Hispanic families. The meeting would need to be held when Hispanics weren't working. An interpreter would be needed. (Maria)*

Another parent shared that she felt she would have the time available to serve on an accountability council. This parent believed that her work schedule was flexible enough and she had friends who could care for her children so she could make the time commitment.

## Partners in Policymaking

In 1987, the Minnesota Governor's Council on Developmental Disabilities created *Partners in Policymaking*, a competency based leadership program for adults with developmental disabilities and parents of young children with disabilities. The program was designed to help adults and parents learn about the policymaking process, as well as develop knowledge and skills in influencing and communicating so they might become advocates at the local, state, and national levels. To date, 46 states have implemented such programs and more than 8,600 adults and parents serve on policymaking committees, commissions, and boards.

Participation in *Partners in Policymaking* involves a substantial commitment from individuals. They need to be willing to commit time (often part of a weekday and 1 day on the weekend) over the course of 1 year. Individuals apply to the program and identify a specific issue or concern that they have an interest in. Funds provided through the Developmental Disabilities Assistance and Bill of Rights Act help to pay for the costs of registration, meals, lodging, mileage, and childcare or respite care.

Through *Partners in Policymaking*, participants:

- Identify strategies to achieve inclusion and quality education
- Understand the service coordination system and services available
- Understand the principles of choice and control of resources in futures planning and the importance of proper positioning techniques for people with disabilities

- Understand that a flexible, responsive system of supports for families is the cornerstone for a true system of community supports for families
- Understand how a bill becomes a law at the state and federal levels
- Demonstrate successful techniques for advocating for services to meet the needs of unserved and underserved individuals
- Draft and deliver testimony for legislative hearings
- Learn how to meet a public official and discuss issues
- Identify strategies for beginning and sustaining grassroots level organizing
- Demonstrate proper procedures for conducting a meeting, and an understanding of parliamentary procedure and serving on boards

*Partners in Policymaking* has much to offer parents in terms of knowledge, skill-building, networking, and confidence building. However, given the large commitment of time away from home, travel, and energy that is needed to participate, it is not a fit for all parents.

*When we need something for our family or community, it is good to be involved, but, time is the issue. Perhaps if the training was for a shorter period of time and more frequent . . . we can get together a few families to have a day-care and in that case we can probably meet more often . . . parents could rotate participating.* (Hector).

*In the future, I could see myself participating in something like that . . . I can't see myself doing much of anything while I am in school except for something in (drug and alcohol) recovery.* (Jackie)

*It would interest me, but not at this time. I have my hands full, but things like that do interest me because if you want to get something done you know, you can't just talk about it to each other, you need to do something about it . . . I know that change is not going to happen by itself . . . Maybe in a year when I am a little more stable—I've been here (moved to subsidized housing from homeless shelter) for two weeks.* (Donna)

## **Professional Responsibilities: Commitments To Involving Families**

The following three strategies will help create environments in which the perspectives of families are heard:

- Incorporating the perspectives of families and including those perspectives in the training of new professionals

- Developing cultural competence within the context of self-reflection and understanding poverty as a cultural difference
- Including families in policy research and disseminating that research in meaningful ways

### ***Giving "Voice" to Families***

Who speaks for the families who do not have access to the corridors of policymaking and decision-making? Professionals have a responsibility to seek out the silenced voices of families who are affected by the policies and to make a commitment to include those family perspectives. Indeed, the inclusion of voice is a criterion by which to judge the quality of professional work (Lincoln, 1995). Lincoln wrote about the boundaries and criteria for including families in interpretive research, but many of her concepts are equally true for involving families in the policy process.

*Reciprocity.* Reciprocity is marked by a shared sense of trust and caring. As relationships are built with families, there is a responsibility to see that all parties benefit (Lincoln, 1995). Families need to be asked their preferences regarding information they want shared and whether they choose to have their names used. In a reciprocal relationship no one is left to feel violated or taken advantage of in the process. However, trust may be difficult to build when working with families for short periods of time. Maintaining anonymity may be difficult under some circumstances. These ethical issues must be examined when building reciprocity with families (Lincoln, 1995).

*Sharing of Privilege.* The sharing of privilege is also an important consideration in giving voice to families (Lincoln, 1995). Professionals accrue advantages as the successful producers of presentations, published manuscripts or other knowledgeable works that bring respect and prestige. What benefits do professionals share with families whose lives, situations and perspectives are portrayed? First, professionals need to recognize that it is a privilege to have access to families' experiences and perspectives. Second, professionals must be willing to pay families for their time and effort. For some families, compensation may include funds for childcare, transportation, or meals; for others, it may be that professionals provide opportunities for parents to be co-presenters at legislative briefings or state and national conferences, with expenses paid.

*Personnel Preparation.* One of the most important strategies to ensure that families continue to have a voice is to teach new professionals how this is done (McBride et al., 1995). It is important for students to hear the

voices of parents. This can be accomplished by including parents as instructors, asking family members to share personal stories with students, having family members present mini-units with professors or involving family members in the design and teaching of courses. Family members are uniquely qualified to provide insights, perspectives, and experiences that may not be otherwise available to students (Winton & DiVenere, 1995). Family members can illustrate what a policy means to the life of their family on a day-to-day basis.

In 2002, two Iowa State University undergraduate students shared what it meant to them to have parents included in their child development class. The class focused on the needs of at-risk children within the context of families who are at risk.

*Through the stories parents shared about their lives, I have learned a great deal more than by reading a book. It put a face and emotions on the "families" we are always talking about in our class activities. It has helped me see what kind of lives parents may be living when all I otherwise would have thought about was the child. Getting to actually hear from parents helps me to better understand the purpose of being family-centered and how important it is.* (Student A)

*I have been so impacted by the personal stories of the families that I will never look at working with a child in the same way. I no longer have such a narrow perspective that focuses only on the child. That child is now a part of something larger, involving the whole family and the needs of so many other people. I hope that I will continue to grow in my understanding of the concept of supporting the whole family.* (Student B)

One parent of a child with disabilities shared the following thoughts regarding her experience co-teaching the same course:

*It is empowering. Gets me time to think about what should be happening in our community and in our own situation. I learn what is being recommended so I could try and do this for my family. It (co-teaching) was a good thing because it gave me time to sit back and think about where we were before, where we are now and how far we have come . . . The best part was the fact they wanted to know my viewpoint...they wanted me seriously involved. That was a good feeling. I felt like what a parent has to say does matter. That doesn't happen in very many situations.*

Involving students in family practica experiences can be another powerful way of teaching new professionals. In family practica or "family mentor" experiences, students are typically paired with a family for a home visit (McBride & Brotherson, 1997); Winton & DiVenere, 1995). In the student/family match, students spend time with a family in a variety of structured activities (e.g. doctor visits, using food stamps at the

grocery store, conferences with the school, problem-solving with landlords). Each student/family pair develops a plan regarding what they will do together and the family serves as a co-supervisor with the faculty member.

This process requires a relationship of trust and honesty; it also requires a commitment of time (Winton & DiVenere, 1995). Creating time and opportunities for debriefing with family members is essential. If professionals are committed to teaching with families, then new professionals will be entering the field with the skills necessary for including family voices.

## Cultural Competence

Being culturally competent is critical to making space for families' voices in policy. To be culturally competent, professionals need to be able to "stand in the shoes" of those families with whom they are working. Knowledge of different cultures, understanding of the processes of acculturation, and acknowledgment of different values in families are required. One of the challenges in the policy process is learning to think in a pluralistic fashion rather than a polarized fashion about family needs (Barrera & Kramer, 1997). Professionals must strive toward cultural competence not only for themselves, but also for their staff. (See Appendix B.)

*Self Reflection.* Turnbull and Turnbull (2001) stated that to become culturally competent an individual must first enhance self-awareness of personal values and beliefs. Often, a significant portion of a person's beliefs regarding culture and cultural diversity is based on personal experiences and emotionally laden values rather than carefully thought out arguments based on research. This may be true in particular when individuals are developing policy that affects families experiencing multiple risks and challenges. Self-reflection is a key component on the journey to cultural awareness and competence (Lynch & Hanson, 1998).

*Understanding poverty as cultural difference.* Key to effective policy development is an understanding of poverty and the cultural context it provides for families (as in the "walking in their shoes" test). Many families in poverty face multiple associated challenges such as feelings of helplessness, increased exposure to violence, homelessness, lack of adequate healthcare, hunger, exposure to substance abuse, unemployment, and single parenting. Early on, the poor learn that they are deprived and powerless. They see it (television, magazines, movies) and they hear it from their peers and parents. The contrast between the world of comfort and their own world is always in the forefront of their minds



(Chamberlin, 1999). Payne (2001) discussed the “hidden rules” among classes (i.e., poverty, middle class, and wealth). The “hidden rules” (see Appendix C) are the unspoken cues and habits of a group; they must be understood by professionals who work with families who experience poverty.

## **Including Families in Policy Research and Dissemination**

Winton and DiVenere (1995) described three categories of support for involving families: (a) emotional support, (b) instrumental support, and (c) informational support. One parent of a child with a disability who had been given a policy role on her state’s Interagency Coordinating Council said, “It is not enough to just give us a seat at the table. You’ve got to understand that we need information and support to fully participate” (Winton & DiVenere, 1995, p. 307). Parents are willing to assume these roles, if they are given support. A parent of a child with a disability stated

*One of the first speakers I ever heard talked about how hard it really is to do the research—to get people to take it seriously and to follow through on what they are suppose to do. How hard to get money for it. My husband and I both said if people gave us the opportunity we would help with research.*

*Participatory Policy Research and Analysis.* Participatory research is one methodology that can address the gap between policy researchers and the intended beneficiaries of research (Turnbull, Friesen, & Ramirez, 1998). Turnbull et al. described participatory action research, or PAR, as “a process whereby the researchers and stakeholders (those who potentially benefit from research results) collaborated in the design and conduct of all phases (e.g., specification of questions, design, data collection, data analysis, dissemination, utilization) of the research process.” (p. 178). According to them, the advantages include:

- Increased relevance of research to the concerns of family members
- Increased rigor of research
- Increased benefit to researchers in minimizing logistical problems
- Increased utilization of research by families
- Enhanced empowerment of researcher, families, and other stakeholders

Ramirez, a grassroots family advocate, described her sense of empowerment as a result of involvement in participatory research:

*In dealing with competent and caring researchers, I have confirmed as a parent and family advocate that I have much to offer. As I am increasingly involved*

*in PAR research, I realize that my experience as a parent of a child with a disability is invaluable, because it is this experience that translates into information that others, parents and professionals alike, can utilize to foster the inherent strengths of families.* (Turnbull et al., 1998, p. 180).

Other parents have found the PAR process empowering. In a study of 33 low-income women Travers (1997) found that over a period of 16 months, women involved in a process of participatory research and community organization were able to answer the questions: What are the issues my family faces? How do we develop a plan to solve the issues? What knowledge do we need? What skills do we need? What resources from other people do we need? These women participated in a series of 27 weekly group interviews at a local parent center that explored their experiences of feeding their families on a low-income budget. Through listening to others talk about similar experiences, the women learned coping strategies and ways to improve their situations.

The women visited two urban and two suburban supermarkets to collect information regarding the pricing of items they typically purchased. They found that the prices in the urban stores were consistently 5% higher than the prices in the suburban stores. The women wrote letters to the stores addressing their concerns about the inequities in price, quality, and services in the stores. Through this process the women not only developed personal skills such as the use of unit pricing, but they actively participated in identifying a concrete source of their problems. The stores, in response to the women's concerns, decreased price inequities between locations, and, in one store, created a bulk-food section. Some of the women also became involved in developing a cooperative grocery enterprise that operated out of the parent center. Thus, through the process of participatory research, the women became personally empowered, and took collective action on issues that influenced them directly.

Although there are many advantages to participatory research, there are challenges as well. Turnbull et al. (1998) identified five challenges that must be addressed:

- Increased time for planning and conducting research
- Researchers feeling criticized by parents
- Increased funding required to cover PAR costs
- Lack of family homogeneity
- Increased need to change institutional rules

*Practical dissemination.* Turnbull and Turnbull (2000) asked "What will it take for researchers . . . to be accountable for ensuring that their publicly

funded research actually benefits the intended beneficiaries?" The concern is that the family policy community of researchers does not place adequate value on dissemination and utilization of family policy research. How do professionals ensure that the results of the work get into the hands of family members and family advocates? What incentives are in place for researchers to include families in the research process and to be accountable to children, families, and taxpayers? At a minimum, policy researchers should strive to:

- Publish information learned in formats that are easily accessible and read by family members and practitioners; and
- Identify user-friendly formats to share findings with the public and decision-makers (e.g., one-page publications; fact sheets; short summaries included in newsletters).

See Appendix D for a checklist on including family voices.

## **Partnership Responsibility: Building Partnerships**

### ***Foundations of Partnerships***

Partnerships between family members and professionals are at the foundation of families having a meaningful voice in the policy process. There are a number of basic components to partnerships (Dunst & Paget, 1991): (a) mutual respect and trust, (b) honest and trustworthy communication, (c) mutually agreed upon goals and commitment, and (d) shared decision-making. In addition to these basic components, professionals must have a sound foundation in family-centered principles and recognition of logistical barriers to partnerships.

*Family-centered Principles.* Dunst et al. (1991) described family-centered principles as using family needs and desires to guide all aspects of service delivery and to aim to strengthen family capacity. In order to develop family policies that are responsive to the voices of families, professionals understand and internalize basic attitudes or principles that define family-centered policy

There are a number of ways to describe or configure family-centered principles (McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993) including the following:

- *Establishing families as the focus of policy.* Recognizing the impact of policy and policy decisions on the entire family and recognizing that families are an interactive and interconnected system in which each part affects the whole.

- *Supporting and respecting family knowledge and decision-making.* Recognizing that a family knows the most about how policy is affecting them and their lives. Family members are equal partners on the policy team and they need to be empowered to inform and make decisions on policy and develop a sense of control.
- *Developing policy designed to strengthen family functions.* Recognizing the diversity of families and family strengths and seeking to develop policy that enhances the family's capabilities and capacity. Recognizing the need to assist families in building and mobilizing their resources and competencies to meet the changing challenges.

There are entrenched system and attitudinal barriers that can thwart efforts to develop family-centered family policy. Including families as members of the partnership team for developing and evaluating family policy requires a willingness to embrace these principles and collaborative work with families in new and exciting ways.

*Logistics of Partnerships.* In addition to attitudinal barriers, there are a number of logistical barriers to be addressed if the voices of families are to be included in the policy process. Professionals need to think creatively and find ways to address the following barriers.

- *Increased time.* It takes time to arrange for family participation, to share information, and to communicate expectations. As one parent stated, *"This time issue—more than anything I think where am I going to focus my energy? Where does it need to be right now?"*
- *Childcare and transportation.* When the parent who is quoted above discussed her desire to attend a professional conference to be held locally, she stated, *"They scheduled the conference from 9 to 5 on a Tuesday. I'd really like to go, but I don't have a sitter to be with my kids for that amount of time. Maybe they could try having childcare on site with volunteers. Do they really want parents involved if they make it all day during the day without childcare?"*
- *Increased funding for parents.* Where will the money come from to support family or parent participation in the policy process? Currently the money is not included in most budgets. Again, it is time to think creatively and begin to put "voices money" into budgets.

## Conclusion

The level of involvement by citizens in the policymaking process has evolved over time. In pioneer times, decisions (policymaking) that affected the community as a whole were made in town meetings where

everyone attended, participated, and shared their thoughts. Assistance and support for neighbors in need were coordinated locally. Industrialization brought with it an era of change that included impersonalization in many facets of everyday life. Citizens increasingly had representatives who were entrusted with making decisions and protecting their interests. As urban areas grew, local groups no longer had the means to provide and coordinate support programs. These tasks were transferred to governmental bodies.

As the provision of assistance became more centralized, the feedback process changed, too. Aggregate measures of impact are used to assess and analyze programs and policies rather than getting feedback directly from the individuals served. In short, in the span of 150 years, the provision of assistance and support for families in need moved from individuals helping each other to "a system" in which families applied for help that was provided by strangers.

The 1960s ushered in an era of change. "Power to the people" movements sprung up from frustration with impersonal assistance systems. Movement leaders sought change at a variety of levels with a central theme of wanting to return political power and decision-making back to the local level. Results were mixed. New programs were established, while others were changed. In general, however, additional citizen involvement in the political process was limited. These movements lost steam in the 1970s and 1980s as programs were further centralized to achieve efficiency. The dawn of the computer age saw policymakers and analysts relying more and more on computer simulations to predict the impact of policy proposals. Local level input from individuals directly affected by policies and programs again took a backseat as these simulation models relied on information provided through large, national, all-purpose surveys sponsored in part by the federal government.

The process of obtaining input for policy development and decision-making took a sharp turn in the 1990s as then President Clinton began to rely more and more heavily on his favorite communication forum, the town meeting. Through these dialogues, policy ideas were introduced for citizen review and feedback was sought for future consideration. At this time, policy analysts also began to recognize the value of obtaining input from program participants and families outside of the mainstream. Opinions of citizens were sought on a variety of subjects and policy issues. Policy historians began to question how failed policies such as the urban renewal movement of the 1960s might have been avoided had affected families been given the chance to speak.

All families regardless of situation and background can make valuable contributions to the policymaking process. Giving families in need a voice in decisions regarding which supports are made available to them and how they are provided is essential to improving existing systems. As public decision-makers continue to wrestle with providing more families assistance with fewer resources, it is vital that they seek the wisdom that can only come from those individuals who live in need on a daily basis.

Giving families a meaningful voice in the policy process requires a partnership between family members and professionals. Partnerships by definition require give and take by both parties. This chapter emphasizes how professionals can empower families to give input that can be used in informing the policy process. It is imperative that professionals give something back to the engaged families, something they use to meet their needs. Interviewees were emphatic that involvement takes time. Professionals must be willing to help families overcome barriers to involvement and compensate participants for their efforts whether this is through financial remuneration, or by providing child care, transportation or meals when meeting with them.

The demographic composition of the U.S. is changing. The mean age of U.S. residents continues to increase; minority populations are growing at rates much faster than that of Whites; non-traditional households continue to replace the traditional family unit. The populations with whom professionals work are changing as well. As a result, policies, programs, and practices put into place long ago under conditions that have changed have become obsolete and must be revisited. Now, in a time of limited resources that is likely to continue for some time, it is wise to hear from everyone, including those who have been less likely to participate in the past.

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## **Additional Resources**

Beyond Welfare

[http://www.beyondwelfare.org/core\\_features\\_bw.htm](http://www.beyondwelfare.org/core_features_bw.htm)

Minnesota Governor's Council on Developmental Disabilities

<http://www.partnersinpolicymaking.com/>



## **APPENDIX A**

### **Biosketches of Families Interviewed**

#### ***Jackie (single mother living in poverty)***

Jackie is a 36-year-old Caucasian single female parent who recently graduated from a rehabilitation program (for alcohol and drug addiction) at a homeless shelter and has moved into subsidized housing with her two young children (ages 2 and 3). Soon, her 16-year-old daughter, who has been at a drug treatment center for the past year, will move in with her. She also has two children (ages 9 and 14) who live with her ex-husband a few miles away. Her 18-year-old daughter lives in another state and has a young child. She is working on a degree at the local community college.

She feels very good about the rehabilitation program she went through and believes she is on the right track now. Fortunately, she receives childcare assistance for another 6 months to help pay for care of her youngest children as she goes to school and studies. Her family participates in the Food Stamp Program, the Family Investment Program (FIP, Iowa's version of AFDC), subsidized housing, and Child in Need of Assistance Program (CHINA). Jackie participates in two support groups weekly (one for alcohol recovery and one for drug recovery). A home visitor meets with her and her young children weekly to work on the children's speech development. A family therapist will meet with her and her teenage daughter on a weekly basis in the future to help the family transition to the teen moving home. Values that Jackie said are important to her and her family are the common bond they share and respect for each other. She does not want her children to have to go through what she went through, and hopes that they will finish school, go to college, and have a career.

#### ***Donna (single mother living in poverty)***

Donna, in her 40s, is Caucasian and is a single parent. She has a son, Chek, who is 9 years old and has ADHD (Attention Deficit/Hyperactivity Disorder). Donna has a cognitive disability that is the result of a head injury she suffered about 10 years ago. She has difficulty processing too much information at once, and is only able to focus on one task at a time. She and her son participate in Social Security Supplemental Income (SSI), Family Investment Program, subsidized housing, the Food Stamp Program, Medicaid, and Title 19. She and her son recently moved to an apartment. Donna spends much of her time focusing on recovering from methadone and alcohol addiction by participating in support groups, studying for her massage therapist license, playing with her son, participating in meetings at her son's school, and participating in family therapy sessions with her son. Donna says that it is important for her to spend time with her son and for them to enjoy their time together. She hopes that he develops good manners, has a sense of compassion and respect for other people and for nature, and is honest and fair.

### ***Angie (married mother living in poverty)***

Angie is a 28-year-old Caucasian married mother of a 5-year-old son, and she is 5 months pregnant. Her current pregnancy has been physically difficult for her. Her 11-year-old stepson lives with his biological mother in the same town and they do not see him often as the two families do not get along well. Her husband is in the military and for the last year has only been able to be home on the weekends. Due to his frequent absence, the financial stress they are experiencing, and the relationship difficulties they have experienced with his ex-wife, there is quite a bit of tension in their household. Angie tries to cope with her depression by seeking the support of friends, family, and agency staff who are supportive. She works part-time as a housecleaner at the nursing home in town. Their family participates in the Food Stamp Program, Medicaid, and the Family Investment Program. Angie said that a value that she and her family holds is being able to spend time together, communicating with each other, and working their problems out. She hopes that her children can excel at doing things they want to do and doing things "right."

### ***Hector (immigrant from Mexico)***

Hector, in his mid-30s, is a Hispanic father of three young children (6, 8, 11 years old). He has lived in the U.S. for 11 years (2 years in Idaho and 9 years in Iowa): Eight months ago his wife, Esmeralda, and children joined him. He came to the U.S. to earn money for his family. He did not realize it would take 8 years before his family would be able to join him. Hector moved to Iowa because his brother was there and said there was work that paid well. Both Hector and Esmeralda work at a local meat-packing plant. She works at night and he works during the day so that one parent is always there before and after school. Although he and his wife can understand a little English, they do not speak it very well. Spanish is spoken at home and the children are learning English at school. The population of the school that the children attend is about 50% Hispanic; many of the classes are taught in both English and Spanish. The Catholic church plays a large role in their life (i.e., faith, information and resources, translation). Values that are important to him are love of family and respect for family (especially parents). He believes his children will have more opportunities and a better education in Iowa than they would in Mexico.

### ***Maria (immigrant from Mexico)***

Maria and Chuy are Hispanic parents of two girls (3 and 11 years old). They are both in their 30s and have lived in the U.S. for about 12 years (1 year in California and 11 years in Iowa). They met when they both were working in California. They decided to move to Iowa because Maria had family in the state who reported that there were jobs that paid well. Maria recently quit the meat-packing plant to work at a hospital and Chuy works at the meat-

packing plant. They both commented that it is their perception that people think the only work that people from Mexico can do in the U.S. is migrant farm work or working in a meat-packing plant. They said that they have additional skills and could develop others if given the chance. Both Maria and Chuy can understand English fairly well, but do not feel confident in speaking English. They have sent their daughter to a school in town where English is spoken. However, they are discouraged that their daughter is not given more support at school to learn English. The school does not have a translator, and their daughter has to catch up on her assignments in the library by herself. The daughter never gets caught up because her class continues on with additional topics as she is trying to catch up on her assignments. Maria and Chuy do not participate in any school committees because only English is spoken and they do not feel the needs of the Hispanic children are taken into account. Both Maria and Chuy want their children to be healthy and to have a good education. Loving each other and their children is very important to them.

## **APPENDIX B**

### **How to Enhance Cultural Competence**

- Make time and space for self-reflection on what is being learned about cultural difference and the implications for policies. Take the “step in their shoes” test frequently.
- Learn about the cultural groups of the families. Where are they from? What languages(s) are spoken in their home? What cultural practices are important to them? Who do they see as community leaders?
- Learn and use the words and forms of greetings in the families’ language.
- Use trained interpreters to assist in understanding family information and perspectives and allow additional time for this.
- Recognize that some families may be surprised or suspicious about the extent of collaboration or about the family-professional partnerships that are proposed.
- Recognize that past experiences families have had with agency professionals may influence their readiness for collaboration.
- Examine written information to ensure that it is in the appropriate language and at the correct reading level. Recognize that some families may be able to speak their native language, but are unable to read it. Provide reading support in a respectful manner.

Adapted from Lynch and Hanson (1998).

## **APPENDIX C**

### **Hidden Rules of Poverty**

#### **(The unspoken cues and habits of a group)**

Understanding hidden rules can help professionals become culturally competent when working with families experiencing poverty.

Possessions—people

Money—to be used, spent

Personality—for entertainment. Sense of humor is valued.

Food—key question is “did you have enough?”

Clothing—valued for individual style and expression of personality

Time—present is most important. Decisions made for moment based on feelings or survival.

Education—valued and revered as abstract but not reality

Destiny—cannot do much to change chance. Believes in fate.

Language—is about survival

Family structure—tends to be matriarchal

World view—sees world in terms of local setting

Love—love and acceptance conditional, based upon whether individual is liked

Driving force—survival, relationships, entertainment

Adapted from Payne (2001).

## APPENDIX D

# Checklist for Conducting Participatory Policy Research with Families: Including Family Voices

<b>GETTING STARTED WITH FAMILIES</b>	<b>COMMENTS ON HOW FAMILIES ARE INVOLVED?</b>
<p>Recruit families for participation</p> <p>Discuss expectations and participatory roles (family voices) with families.</p> <p>Share written materials, background knowledge, and potential policy/research questions with families</p> <p>Address logistical barriers with individual family members</p> <p>Arrange for payment of family members for participation</p> <p>Set dates/timelines for meetings and data collection so families can plan</p>	
<b>IMPLEMENTATION WITH FAMILIES</b>	<b>COMMENTS ON HOW FAMILIES ARE INVOLVED?</b>
<p>Involve family members in the ways and in the amounts of time which they can commit</p> <p>Conduct interviews, policy meetings, focus groups, and observations including family voices as much as possible</p> <p>Schedule time with families to review their changing participation needs</p> <p>Schedule time with families to review and discuss data collected and summarized</p>	
<b>DISSEMINATION WITH FAMILIES</b>	<b>COMMENTS ON HOW FAMILIES ARE INVOLVED?</b>
<p>Share information with all families involved in the policy research</p> <p>Provide final data summaries to families for feedback</p> <p>Include family members in publishing or presenting the final products</p> <p>Interview family members regarding their participation to self-reflect on how to improve for the future</p>	

Adapted from Hemmeter, Doyle, Collins, and Ault (1996).