Shared Participation:

Strategies to Increase the Voice of Families from Diverse Backgrounds as Partners and Advisors

Copyright Family Voices of Wisconsin 2010
ACKNOWLEDGEMENTS

Family Voices of Wisconsin is grateful to the parent and family participants for their insights and candid observations and suggestions.

A special thank you to:
- Karen Burstein - Southwest Institute for Families and Children with Special Needs
- Diana Denboba - Maternal and Child Health Bureau, DHHS
- Monica Lopez and Maggie Ramos - Alianza Latina Aplicando Soluciones
- Pat Patterson - Wisconsin FACETS
- Jenny Rodgers - The Navajo Nation
- Trish Thomas - Family Voices, Inc.
- Pam Torres and Linda Christensen - Great Lakes Inter Tribal Council

We are also grateful to Wendy Jones and other staff members from the National Center for Cultural Competence for their thorough review of this document.

This publication was supported by funding from the U.S. Health Resources and Services Administration, Maternal and Child Health Bureau, through grant number 4DOMCO4467-01-03, Wisconsin Integrated Systems for Communities Initiative.
# Table of Contents

**ACKNOWLEDGEMENTS** ............................................................................................................................................. i  

**INTRODUCTION** .......................................................................................................................................................... 1  
  - Explanation of Report  
  - Key Findings

**ENGAGING HISPANIC/LATINO PARENTS** ......................................................................................................................... 4  
  - The Listening Session  
  - Barriers to Working in Partnership with Professionals on Decision Making  
  - Recommendations for Supporting Partnerships around Decision Making  
  - Recommendations for Hispanic/Latino Parent Participation on Advisory Committees

**ENGAGING AFRICAN AMERICAN PARENTS** .......................................................................................................................... 8  
  - The Listening Session  
  - Barriers to Working in Partnership with Professionals on Decision Making  
  - Recommendations for Supporting Partnerships around Decision Making  
  - Recommendations for African American Parent Participation on Advisory Committees

**ENGAGING NATIVE AMERICAN/AMERICAN INDIAN PARENTS** ......................................................................................... 12  
  - The Technical Assistance Conference Call  
  - Barriers to Working in Partnership with Professionals on Decision Making  
  - Recommendations for Supporting Partnerships around Decision Making  
  - Recommendations for Native American Parent Participation on Advisory Committees

**COMMON THEMES ACROSS GROUPS FOR RECRUITING AND SUPPORTING PARENTS NEW TO ADVISORY ROLES** ................................................................................................................................. 15

**REFERENCES** ...................................................................................................................................................................... 16

**RESOURCES** ....................................................................................................................................................................... 17

**CHECK LIST FOR RECRUITING AND SUPPORTING PARENTS FROM DIVERSE BACKGROUNDS FOR ADVISORY ROLES** ......................................................................................................................... 18
Shared Participation

Families who have children with special health care needs have great capacity to care for their children and, through experience, are knowledgeable about the most effective and appropriate supports and services. These families have a unique perspective on the systems of supports and have firsthand knowledge of organizations’ policies, procedures and quality improvement initiatives. It is essential that providers and architects of these systems are responsive to the experiences of those directly benefiting from their services.

Families can be involved in many ways, including advisors in design, implementation, and evaluation of programs. In the current system, however, families generally, and families specifically from diverse populations, may not participate in advisory or other leadership roles. Why is this? Often, it is because support and cultural considerations are not in place when families from diverse backgrounds are sought. In addition, parents from diverse backgrounds may not be trained or may not feel comfortable being advisors to mainstream systems. Similarly, those recruiting parents from diverse backgrounds as advisors may not be aware of certain cultural values, beliefs or language barriers that prevent parents from effectively participating.

In Wisconsin, 15.3% of all children have special health care needs.\(^1\) Overall, the population of Wisconsin is growing and becoming more racially and ethnically diverse. Data from the Wisconsin Interactive Statistics on Health (WISH)\(^2\) shows that between the year 2000 and 2007:

- The Hispanic/Latino population changed from 3.6% to over 4.8% of the total population;
- The Asian population changed from 1.8% to 2.1%;
- The African American population changed from 5.9% to 6.1%, and
- The Native American/American Indian population remained at 0.9% of the Wisconsin population.

In total, 12% of Wisconsin’s population is identified as being from African American, Hispanic/Latino, Southeast Asian, or Native American/American Indian background. In our increasingly diverse state, viewpoints from all communities must be included so that systems of supports and services are most responsive to the needs of all children and families.

**Definitions:**
In this report we use the term “family member” and “parent” interchangeably to mean the primary provider of care for a child with special health care needs. This could include a grandparent or other close relative.

We use the term “diverse populations” to include individuals from under represented racial and ethnic groups in Wisconsin. In this report, we focus on members of the Hispanic, African American and Native American/American Indian populations.
Explanation of Report

One of the goals of Family Voices of Wisconsin is to ensure that the voices of all families of children and youth with special health care needs and/or disabilities are heard in decision making for their own children and in advisory roles. Family Voices of Wisconsin, with the support of the Wisconsin Title V Maternal and Child Health Program, undertook this project to better understand what families from diverse backgrounds identified as barriers to being partners in decision making and advisors to committees and councils around the state.

This report will document Family Voices’ conversations with parents of children and youth with special health care needs and/or disabilities from diverse cultural groups (Hispanic/Latino, African American and Native American/American Indian) and will:

1. Describe their concerns and perceived barriers to participation,
2. Share parental recommendations for how to improve their capacity to be effective decision makers for their own children and,
3. Identify parental suggestions for improvement of organizational recruitment and support for participation on advisory committees and in other leadership roles.

Family Voices of Wisconsin held two listening sessions and several technical assistance conference calls. While the comments reflected in this report are from individual listening session and conference call participants, they are consistent with the literature on supporting parents as partners in decision making and in advisory roles.

Key Findings

In order to enhance the capacity of parents from diverse backgrounds to be effective partners and advisors, organizations should focus on continuously improving their own level of cultural and linguistic competence. Becoming more familiar with the values, beliefs and practices of the cultural groups they serve will positively impact the care and services that children and families receive. Both written and oral communication should be in clear, understandable language without use of jargon. In addition, ensuring that trained interpreters are available and having trained bilingual speaking staff will greatly improve parents’ ability to be effective advocates and partners in decision making for their child.

Families from all groups talked about the importance of offering participation opportunities at a variety of levels. The following ideas were given:

- Agencies could provide opportunities to mentor and guide parents to be leaders and not just expect them to jump in to activities at a leadership level.
• Agencies might want to begin engaging parents as advisors by offering them short term opportunities to review written materials or participate in a focus group to gather opinions.

• Agencies should build on parents’ comfort levels and confidence, and then they can begin to engage their participation and commitment in more ongoing activities.

Additionally, of critical importance to increasing the effectiveness of recruitment and support of parents from diverse backgrounds is working with community liaisons. A community liaison is defined as a trusted individual who has knowledge of the community’s strengths, preferences and needs. Community liaisons can act as relationship brokers, providing information and linkages between individuals, families and communities and the organizations and systems that seek to provide services and supports. Family members agreed that the involvement of community liaisons would be key in improving their comfort level.

A community liaison is a trusted individual who has knowledge of a community’s strengths, preferences and needs.

These suggestions, and others, along with ideas for effective parental training and support, will be explored in this report. In addition, a Check List for Successfully Recruiting and Supporting Parents from Diverse Backgrounds for Advisory Roles is attached at the end of this document. We encourage your organization to share this document with others.
The Listening Session

A listening session was convened in Milwaukee with a group of Hispanic/Latino families who had children with special health care needs. The purpose of the session was to engage in dialogue and obtain suggestions for professionals as they work to greater involve families in decision making and advisory activities. Family Voices staff engaged two trusted and respected members of the Milwaukee Hispanic/Latino community as community liaisons to:

- recruit participants to this listening session
- select a convenient location and arrange for food and drinks, and
- provide interpreter services to the group.

Nine parents participated in this session. The diagnoses of their children included learning disabilities, cerebral palsy, blindness, Down Syndrome, autism, seizure disorders and multiple disabilities. The ages of their children ranged from six years old to 26 years old. Their experiences with advocacy for their children and serving as advisors to professionals and systems varied greatly and did not necessarily correlate to the ages of their children. These included: member of a focus group for a new hospital; member of an early intervention parent committee; member of a Down Syndrome clinic committee; and a school-based advisory committee. The parent who participated on the school-based committee noted that a bilingual coordinator was key to making her feel welcome and included in the committee.

Barriers to Working in Partnership with Professionals on Decision Making

Participants were asked about their experiences with health care, community services and supports and other professionals as they made decisions about health care and services for their children.

Language Barriers: Language barriers were by far the greatest frustration and constraint to parents effectively participating as advocates for their children. Language barriers are presented below as attitudinal barriers and logistical barriers.

Attitudinal Barriers:

- Parents observed that professionals often spoke to the interpreter rather than to the parent. This was particularly prevalent in doctor and therapy appointments.

- Interpreters voiced their opinions along with facts that were translated.

- Participants stated that they thought professionals could, at times, be patronizing. Because English is not their primary language, families felt that professionals “talked down” to them or questioned their intellect. They also noticed other stereotypical behaviors, including having staff speak too loudly, as though increasing the volume of language would increase understanding of the language.
Logistical Barriers:

- Scheduling interpreters to be present at appointments was not always well coordinated. Families reported waiting a long time for an interpreter and sometimes had to reschedule the appointment altogether because interpreter services were not available or were too late for the appointment.

- Parents reported seeking care for their child at a hospital Emergency Room (ER) rather than at a clinic because, in their experience, interpreter services were more reliably available at the ER.

- Parents noted that even if their primary care provider is bilingual and culturally competent, other providers (including specialists, therapists and medical equipment providers) may not be. Families are then dependent upon the effectiveness and availability of interpreter services.

Parents reported seeking care at a hospital Emergency Room (ER) rather than at a clinic because, in their experience, interpreter services were more reliably available at the ER.

Misunderstanding of Cultural Values: Participants stated that the provider’s lack of understanding of their values and/or beliefs led to difficulties in being partners in decision making for their child.

The following examples were given:

- At appointments, parents wanted extended family members to be present for the discussion and/or decision making, but exam rooms were too small to accommodate other family members and larger consultation rooms were not available. Health care systems were not used to including more than the immediate family.

- Parents reported that they had difficulty collaborating with professionals on making a decision regarding their child because a prevalent cultural value of the Hispanic/Latino community is to respect professionals and not question their authority. There was consensus that this is an area where training around cultural expectations could occur for both families and professionals.
Recommendations for Supporting Partnerships around Decision Making

When asked what professionals and their organizations could do to improve parents’ capacity to partner in decision making, the following recommendations were given:

1. Develop a publication for professionals working in partnership with Hispanic/Latino families on cultural considerations for providing services and supports to children and families.

2. Families overwhelmingly preferred bilingual providers in favor of interpreters. They felt that bilingual providers would offer more authentic communication.

3. If bilingual staff is not available, then the family must be able to receive the services of a trained interpreter in a timely manner.

4. It was suggested that some sort of automatic “alert” system be implemented when scheduling an appointment to advise staff that interpreter services will be needed.

5. Attention to bilingual communication must also be present in written communication.

6. There should be more understanding among and training for professionals around the Hispanic/Latino cultural value that authority should not be questioned. This is especially relevant in asking for second opinions for their child’s health care and appealing denials for services.
Shared Participation

Recommendations for Hispanic/Latino Parent Participation on Advisory Committees

Parents were asked what professionals, agencies or community providers could do to make parents feel comfortable providing advice, including being a member of an advisory committee. They had the following recommendations:

1. Develop a publication for professionals and parents on families in advisory roles, including cultural considerations and systems expectations for families.

2. Make a personal phone call inviting a parent to participate.

3. Write a bilingual invitation letter with clear expectations. The letter should avoid jargon, be in straightforward language, and state what is expected of the parent should they decide to participate and how they will be supported to participate.

4. Be specific about the nature of the task for the advisory committee and how this particular individual can contribute to the work of the group.

5. Build on people’s experiences. Provide opportunities for parents to engage in advisory capacities with a short term commitment. The parents who had participated in advisory committees affirmed that a positive advisory experience will encourage them to take on more commitments.

6. Make sure that the organization values the thoughts and ideas of the individual and is not seeking “token” participation as a representative of their ethnic/cultural group.

7. Be mindful that diversity awareness among committee members might be an important part of the advisory group’s work, particularly if there are cultural considerations that are relevant.

8. Ensure that a trained interpreter is available during meetings if a member needs interpretation to fully participate.
The Listening Session

A listening session was held in Milwaukee to engage in dialogue with African American parents and grandparents. The purpose of this session was to elicit recommendations for professionals as they work with African American family members in decision making and advisory activities. During this session, Family Voices engaged the facilitation services of a well known and respected leader, as a community liaison, to assist with this process. The community liaison helped Family Voices recruit participants, identify a time that would be most convenient (a Saturday morning), secure the location and arrange for lunch and refreshments. The credibility that this community liaison gave to Family Voices was invaluable in having a very honest and open conversation.

Eight family members participated in the listening session. Ages of children, grandchildren and siblings ranged from two years old to 26 years old. Participants had children/grandchildren/siblings with a variety of disabilities, including autism, deaf/blind, learning disabilities, cerebral palsy, asthma, emotional and behavioral disabilities and muscular dystrophy.

This group was very engaged and offered many facts and considerations when agencies are looking to engage African American family members in advisory roles. Group members were extremely forthright with their opinions and were able to identify many barriers to participation along with suggestions to address these challenges.

Barriers to Working in Partnership with Professionals on Decision Making

Parents and family members identified many barriers to participation. These included:

**Socioeconomic Factors:** Poverty is the single greatest barrier that African American families identified to their involvement in greater advocacy for their family member or participation on advisory committees.

Parents spoke passionately with respect to the urgency of their primary needs (food, clothing, housing, and transportation) coming first, with education and health care needs following. A family member asked a rhetorical question, “How can I possibly plan to attend a meeting when I don’t know where my family is sleeping tonight?”

Families identified a disconnect or lack of awareness of their economic realities associated with what professionals recommended for their children and what families could actually provide. A common example was the difficulty families had providing special food for their children on a very limited food budget.
Cultural Awareness/Respect of Professionals: The perception of racial prejudice was identified as another barrier they encountered in accessing services through a variety of systems. The following examples were given:

- Family members reported they perceived that their intelligence was not valued by professionals and they experienced professionals who were threatened by knowledgeable African American parents.

- Parents talked about over identification of children for some services, including special education, and inappropriate overuse of some treatments, including antibiotics and behavior medications.

- Families reported getting the sense that some professionals perceived that “if you are a black person, you are like all other black people.” Participants thought some professionals see skin color first and foremost and make stereotypical judgments.

- Families felt blamed for their child’s disability. They perceived that some causes of a disability (e.g. Fetal Alcohol Syndrome, cocaine use) were looked at first and more often in African American families than in families from other racial and ethnic groups when identifying a cause for their child’s disability.

- Families felt many times that their knowledge about their child was not validated or considered when professionals made recommendations about services.

Language/Communication Barriers: Families mentioned that inadequate communication was a concern. The following examples were discussed:

- Information that was given to them was not always given in understandable language.

- After a long wait to see provider, they often felt rushed by the provider and weren’t able to ask all of their questions.

Cultural Beliefs and Values of Families: Families indicated that their own distrust and misunderstanding of “systems” is another barrier.

- Families reported that there is misinformation about what public supports can provide for children and youth with special health care needs. Families are fearful that supports they get from one system might negatively impact supports they receive from other systems.

- Seeking mental health services is often difficult for families, as they perceive a stigma attached to needing such services. Therefore, families reported that parents and children who would benefit from psychological counseling often do not seek it.
• Families talked about African American parents unwilling to share information with one another. The attitude of “My child didn’t get services, why should yours?” exists.

• Families felt that they are under informed about services available to their children because it is a cultural custom to rely on word of mouth and this can be inconsistent.

• When accessing support from public systems, families often are fearful. There is a feeling that “I can take care of my kids. I don’t need you to come into my house to tell me how to take care of my kids.”

A parent stated, “I can take care of my kids. I don’t need you to come into my house to tell me how to take care of my kids.”

Recommendations for Supporting Partnerships around Decision Making

When asked what professionals and their organizations could do to improve parents’ capacity to be better partners in decision making, the following recommendations were given:

1. Cultural Competence Development and Training for Professionals: Families identified a need for professional training and a better understanding among professionals, especially regarding the following issues:

   • Take a family-centered approach and look past a person’s color and/or ethnicity to work with them as an individual.

   • Eradicate stereotypes that all African Americans have the same lifestyles.

   • Show respect for African American parents. Parents are parents, regardless of ethnic makeup, and parents know their children best.

2. Parent Training: Families identified a need for their own training, especially around the ways in which systems of supports work and how to effectively advocate for their children within existing systems.
Recommendations for African American Parent Participation on Advisory Committees

Parents were asked what professionals, agencies or community providers could do to make parents feel comfortable providing advice, including being a member of an advisory committee. They had the following recommendations:

1. **Use of Community Liaisons:** Parents thought it would be very helpful to call on respected community leaders to serve as role models for families. These community leaders can also serve as cultural liaisons to give advisory committees a stamp of approval for potential participants. Families reported that the development of trust and acceptance is critical before they would be willing to enter into advisory roles.

2. **Need for Training/Support:** Acknowledge that people are afraid of the unknown. If family members have never before served in an advisory capacity, they need to enter this role slowly and gain confidence with their contributions. Mentoring by community leaders would be a very useful strategy. As one family member stated, “It is very easy to come up with 900 reasons not to be involved.”

3. **Social Networking:** Participants stated that it would be helpful to have assistance with developing relationships with other advisors with whom the parent is serving. Parents also expressed a desire to have individual conversations with the group leader to determine what accommodations are necessary for their participation.

4. **Recognition:** Family members mentioned that they would like to receive a paper certificate commemorating their participation. They said that recognition means a lot to parent participants. It is important that participants know that their opinion matters and is valued.

5. **Clear Expectations:** It was mentioned that the role of an advisory member and the organization’s expectations of the parents need to be made very clear and defined specifically.

6. **Communication:** Information needs to be presented that is understandable and free of jargon.

7. **Need for Other Supports:** Families mentioned that it is critical for them to have adequate financial supports to participate in advisory roles. These could include:
   - Having on-site childcare available.
   - If childcare is not possible, reimbursement for a sitter could be provided at the time of the meeting.
   - Reimbursement for mileage or other transportation costs would be helpful.

One family member stated, “It is very easy to come up with 900 reasons not to be involved.”
Consultation Conference Calls

Family Voices of Wisconsin was fortunate to be able to have several technical assistance conference calls with a Native American staff member at the Family Voices national office in Albuquerque, New Mexico. The staff member is quite familiar with tribes in Wisconsin and has visited several in recent years. She coordinated a call with Family Voices, a knowledgeable staff member from the Maternal and Child Health Bureau in Washington, D.C., the Director of the Southwest Institute for Families and Children with Special Needs and a representative from the Navajo Nation. It is important to note that conference call participants provided invaluable expertise and information that was consistent with what was reported by members of Wisconsin’s tribal communities in subsequent conversations. After these calls, Family Voices of Wisconsin engaged members of the Great Lakes Inter Tribal Council in several talking circles. Comments elicited from parents supported findings from our work with technical assistance consultants. We are grateful to Linda Christensen, Great Lakes Inter Tribal Council, for working with us to facilitate these talking circles.

Barriers to Working in Partnership with Professionals on Decision Making

Conference call participants stated that many non Native Americans assume that all Native Americans are the same. Each tribe is different. Each has different characteristics, different leadership structures, and different tribal cultures. Therefore, a lack of cultural understanding by professionals and providers of services and supports is a critical barrier for parents and family members from Native American backgrounds.

Recommendations for Supporting Partnerships around Decision Making

When asked what professionals and their organizations could do to enhance parent and family member’s capacity to be partners in decision making, the following recommendations were given:

1. **Cultural Literacy**: The participants stressed the importance of non Native Americans taking the time to learn the values, beliefs and nuances of a particular tribe that they will be working with. A recommended web site to get information and contact names for particular tribes is the National Congress for American Indians at [www.ncai.org](http://www.ncai.org).

2. **Community Liaisons**: Participants spoke of the importance of having professionals build relationships with trusted members of the tribe so that others in the tribe, including parents of children with special health care needs, feel comfortable building relationships as well. This is essential before connections to the community can evolve. The tribe’s Indian Council, made up of trusted and respected members of the tribe, is a good place to start.
Recommendations for Native American Parent Participation on Advisory Committees

When asked what professionals, agencies or community providers could do to make parents feel comfortable providing advice, including being a member of an advisory committee, the following recommendations were given:

1. **Find Comfortable/Familiar Locations**: A suggestion was made that advisory opportunities be coordinated with other meetings or programs in the community. Many parents are involved in their child’s education and Head Start programs are a great place to identify potential parent leaders. The Native American culture promotes a strong connection to supporting children, and Head Start programs are a natural environment in which to gather.

2. **Build on Leadership Opportunities**: Participates stated that Head Start programs offer many opportunities for parent participation and many levels of participation, including class parent committees, site based committees, and parent policy councils. Indian Health Service clinics are another place where Native American parents can readily serve in advisory capacities. Again, these are sites that are familiar with tribal customs and culture, making it a comfortable place for parents to serve as advisors.

3. **Community Liaisons**: Participants reiterated that organizations outside of the tribe should find a friend inside the tribe who can become a partner. This person will give the organization/agency, as the outsider, credibility among members of the tribe. Credibility is essential if the organization wants to recruit parents as advisors to projects and programs. It was also recommended that the organization enlist a Native American leader to help set the agenda and help with facilitation at the committee meeting.

4. **Clear Communication**: A recommendation was made that a clear and complete agenda for each meeting will help new members of an advisory committee. Also, a participant shared that in general, Native Americans tend to be very visually oriented. Therefore, PowerPoint presentations and other visual aids help with new concepts and information. Visual aids can also assist Native Americans in explaining information to others.

5. **Non-Verbal Communication**: Professionals and advisory committee staff and members need to learn that when Native Americans nod their heads, they may only be acknowledging that someone is speaking and offering information to them. They are not, necessarily, affirming what the person is saying.
6. **Decision-Making Patterns:** It was noted that professionals and advisory committee members also need to know that Native American participants may not comment or commit to action until they have had a chance to talk over implications with their family or another member of their tribe.

7. **Cultural Considerations/Time and Logistics:** Participants stated professionals conducting advisory committee meetings need to know that the concept of “Indian time” does not necessarily correlate with Western time concepts. Some Native Americans believe that things will occur when they are supposed to, not when they are told to. This is a challenge when outsiders are used to conducting meetings with strict timelines and having specific deadlines for completing work. In addition, it was stated that when scheduling events, a tribe’s Indian calendar must be consulted for potential conflicts. Calendars differ from tribe to tribe.

8. **Social Networking/Bonding:** Participants recommended serving a meal. Good food is an important social bonding agent and shows respect for the gathering of people.

Karen Burstein, Ph.D., Director of the Southwest Institute for Families and Children with Special Needs, in follow up correspondence with Family Voices of Wisconsin, suggested the following model of organization for involvement of parent advisors. She wrote,

> “Successful projects are organized and facilitated by representative community members. These individuals are responsible for identifying new partners, ensuring engagement of key stakeholders, and continuously monitoring the cultural competence of the efforts. The community leader provides a leadership model to the community as well as provides solid leadership and direction of those working on the projects. This model not only provides reliable and valid assessment of the communities’ strengths and needs up front, but across the duration of the project, and encourages expansion of leadership opportunities within the communities and ultimately ownership of the outcomes by the respective communities.”
1. **Use Community Liaisons:** Develop relationships with community liaisons in the communities from which you want to solicit representatives. These key individuals may include leaders from faith communities, trusted service providers, tribal elders and parent leaders. By developing relationships and building trust (which takes time!), you, as an outsider to a particular community, will be regarded with valued legitimacy.

2. **Parent Mentoring/Training:** Support parent advisors by mentoring them before they are officially part of an advisory group and matching them with an existing group member who will call them before a meeting or meet afterward to answer questions. Parent leaders need to develop confidence in their contributions and need to have training and support so that they can be effective participants.

3. **Value Parent Input:** Authentically include parents as valued advisors. Ask them what they need to participate in your activity.

4. **Clear Expectations:** Make sure that the organization sets out clear expectations for parent advisors and that they understand what they will be doing.

5. **Value Time and Effort:** Reduce administrative barriers as much as possible so that parents don’t feel as though participation in an advisory capacity is a burden or that their time is wasted. Appropriate recognition and thanks are essential. An organization may also be able to demonstrate the changes that were made as a result of parent input.

6. **Need for Networking/Relationship Building:** Provide adequate break time to allow for informal networking, validation and support. It is very important for parent advisors to connect with others in a group so that their participation is affirmed.

---

**COMMON THEMES ACROSS GROUPS FOR RECRUITING AND SUPPORTING PARENTS NEW TO ADVISORY ROLES**

- **Use Community Liaisons:** Develop relationships with community liaisons in the communities from which you want to solicit representatives. These key individuals may include leaders from faith communities, trusted service providers, tribal elders and parent leaders. By developing relationships and building trust (which takes time!), you, as an outsider to a particular community, will be regarded with valued legitimacy.

- **Parent Mentoring/Training:** Support parent advisors by mentoring them before they are officially part of an advisory group and matching them with an existing group member who will call them before a meeting or meet afterward to answer questions. Parent leaders need to develop confidence in their contributions and need to have training and support so that they can be effective participants.

- **Value Parent Input:** Authentically include parents as valued advisors. Ask them what they need to participate in your activity.

- **Clear Expectations:** Make sure that the organization sets out clear expectations for parent advisors and that they understand what they will be doing.

- **Value Time and Effort:** Reduce administrative barriers as much as possible so that parents don’t feel as though participation in an advisory capacity is a burden or that their time is wasted. Appropriate recognition and thanks are essential. An organization may also be able to demonstrate the changes that were made as a result of parent input.

- **Need for Networking/Relationship Building:** Provide adequate break time to allow for informal networking, validation and support. It is very important for parent advisors to connect with others in a group so that their participation is affirmed.
1. National Survey of Children with Special Health Care Needs, 2005/2006, State and Local Area Integrated Telephone Survey (SLAITS), Centers for Disease Control and Prevention, National Center for Health Statistics, Hyattsville, MD


Family Voices of Wisconsin would like to recommend the following publications and websites for those readers interested in learning more about cultural competence and the involvement of parents and family members from diverse and underserved backgrounds in decision making and advisory roles.

**Publications:**


Thomas, J. & Jeppson, E.S. (1994) Essential Allies, Families As Advisors, Bethesda, MD: Institute for Family-Centered Care


**Websites:**


US Department of Health and Human Services, Office of Minority Health [www.omhrc.gov](http://www.omhrc.gov)

Wisconsin Department of Health Services, [www.dhs.wisconsin.gov/health/MinorityHealth/resources/culturalcomp.htm](http://www.dhs.wisconsin.gov/health/MinorityHealth/resources/culturalcomp.htm)

National Center for Cultural Competence, [http://gucchd.georgetown.edu/](http://gucchd.georgetown.edu/)

The Institute for Family-Centered Care, [www.familycenteredcare.org](http://www.familycenteredcare.org)

National Congress for American Indians, [www.ncai.org](http://www.ncai.org)

Great Lakes Inter Tribal Council, [www.GLITC.org](http://www.GLITC.org)
CHECK LIST
FOR RECRUITING AND SUPPORTING PARENTS
FROM DIVERSE BACKGROUNDS FOR ADVISORY ROLES

Family Voices of Wisconsin has created this check list to assist organizations in their efforts to recruit and support parents for advisory roles. Asking the following questions when your organization is soliciting input from parents may increase your success rate for recruiting and supporting individuals for leadership roles.

___ 1. Has the organization considered using community liaisons? These key individuals, who may include leaders from faith communities, trusted service providers, tribal elders and community parent leaders, can help an organization develop relationships and build trust with the community and can help break down barriers to parent participation. They can help as facilitators and can assist an organization in understanding the cultural values that may impede full participation.

___ 2. Does your organization provide parent mentoring or other training opportunities? Current or potential parent advisors can benefit greatly by being “mentored” before and after they are officially part of an advisory group. Parent leaders need to develop confidence and need to have training and support so that they can be effective participants. Providing short-term advisory opportunities, like being a member of a focus group or listening session, can help a parent develop their skills and self-confidence.

___ 3. Do you show parents that your organization values their input? Authentically include parents as valued advisors. Ask them what they need to participate in your committee and be prepared to respond to these requests (e.g., childcare, transportation, stipends).

___ 4. Does the organization lay out clear expectations for advisory members? Make sure that the organization sets out clear expectations for parent advisors and that they understand what they will be asked to do.

___ 5. Are parent advisors shown that their time and effort is valued? Reduce administrative barriers so that parents don’t feel as though participation in an advisory capacity is a burden or that their time is wasted. Appropriate recognition and thanks are essential, which could include a certificate of appreciation or personal phone call thanking them for their participation.

___ 6. Is time made available for informal networking/relationship building? Provide adequate break time to allow for informal networking, validation and support. It is very important for parent advisors to connect with others in the group so that their participation is affirmed.

___ 7. What else could help? Think about the unique needs of your organization and how individuals will feel most included.