



Guidelines For Establishing Family Advisory Boards

Background

INCREASINGLY, FAMILIES' OF INDIVIDUALS with special health care needs and developmental disabilities roles as advisors to the organizations and agencies from whom they receive supports and services are being recognized and promoted. Advisory boards or committees of these organizations may have varying compositions, based on the type and structure of training programs. Memberships can be composed exclusively of family members or individual constituents, or the individuals and family members may serve as part of a broader community advisory committee or board reflecting and representing the diversity of its constituencies. The process of recruiting, training, and supporting all advisory board members should reflect individual needs, strengths, and preferences in order to maximize each member's ability to participate and contribute in a full and meaningful way. The following values, guidelines, recommendations for advisory board member recruitment, and logistics and practicalities were developed by the Family-Centered and Family-Directed Practice Workgroup¹ to help training programs establish family advisory boards.

Values

While not all inclusive, the following values guide the establishment and work of family advisory boards:

- Family, as defined by each culture, is the primary system of care and support for children with special health care needs or other developmental disabilities².
- Family members are the experts and ultimate decision makers for services and supports for their children and/or themselves.
- Family-centered, family-directed, and culturally and linguistically competent practices are embedded in all board activities.
- Board membership is representative of program constituents including diverse socio-economic, ethnic, cultural, and disability groups.

¹ Authors: Angela Miney, Mark Smith, Barbara Levitz, Susan Horkey, and Tawara Goode.

² Promoting Cultural Diversity and Cultural Competency- Self Assessment Checklist for Personnel Providing Services and Supports to Children with Disabilities & Special Health Care Needs, Goode, T., 2002, NCCC, GUCDC.



Guidelines

- Ensure shared ownership of the family advisory board. This will include securing: (1) “buy in” from the highest levels of leadership within the organization; and (2) the commitment of fiscal and personnel resources to support the mission and activities of the family advisory board.
- Allocate the necessary fiscal and personnel resources and structural supports for the family advisory board. This may include, but is not limited to, funds for translation/interpretation services; family stipends; reimbursement for mileage, child care, respite care, or meals; and relief from other job responsibilities.
- Designate staff or faculty representative(s) who will serve as primary liaisons to the family advisory board.
- Garner and use input from all interested parties (family members, community members, organization leadership) in developing a clear charge for the advisory board, including its specific role and authority in the program.
- Ensure group member ownership by engaging participants in making decisions about governance processes and the operating structure for the advisory board. This may include determining: (1) need for guiding principles, by-laws or other operating procedures; (2) board leadership structure (e.g., chair, co-chairs or other elected officers); (3) approaches for conducting the work (e.g., confidentiality requirement, consensus processes, Robert’s Rules of Order, decision processes, time-limited work groups, or sub-committees); and (4) meeting frequency and sites.

Recruitment

- Use a variety of approaches to recruit Advisory Board members. This may include, but is not limited to, advertising through parent-to-parent organizations, parent training and information centers, family support programs, culture-specific advocacy organizations, and neighborhood and civic organizations; displaying posters in clinics, retail establishments, places of worship, schools, and child care programs; posting announcements in newsletters, on listservs, and Web sites including those sponsored by culture-specific media; and using word of mouth, as this is a preferred way of sharing and receiving information in many communities.
- Solicit recommendations from professional colleagues, including family faculty of MCH and other training programs, and others in community-based service and advocacy settings.
- Caregivers who are unable to participate should be invited to nominate someone whom they consider to be a member of the family (e.g., someone who has been involved with providing care such as grandparents, adult siblings, or another relative). Family choices should be honored. There are strong traditions within many cultural communities of having godparents, “aunts,” and “uncles,” who are not necessarily blood relatives, but who are actively involved with the child and family.
- Provide contact information for a person who is designated to field inquiries from interested parties.
- Ensure that the composition of the advisory board is demographically representative of the populations served by the program or organization.



Logistics And Practicalities:

- Provide, for participants, convenient meeting times and locations that will best accommodate their work and family lives. State explicitly that weekends and evenings may be the most appropriate meeting times – and that program staff will need to adjust their hours to accommodate family preferences.
- Ensure interpretation services are available if needed or preferred by any members of the advisory board. Provide orientation to all advisory board members about participating in meetings when interpretation services are used.
- Send, in advance, appropriate information in accessible formats and in a timely manner.
- Attend to and address the literacy needs of board members. Avoid using written materials as the primary vehicle to share information and/or resources.
- Consider providing a stipend for participation in recognition of members' time, commitment, and expertise.
- Inform board members in advance of covered expenses and procedures for reimbursement. Consider reimbursing with cash on site at the meeting. Arrange for pre-paid parking.
- Provide childcare and transportation (especially for members who do not drive) or a reimbursement for childcare and travel expenses.
- Provide a meal or refreshments appropriate for the time during which the meeting will be conducted (e.g., dinner or afternoon refreshment). Consider and appropriately provide for dietary restrictions and preferences, such as kosher, vegetarian, and lactose intolerant.
- Identify language preferences and translate any written materials accordingly.
- Provide the means to include all members in advisory board meetings. Some parents may not be able to attend meetings, but would be available to participate via conference calls or give input via email.
- Adhere to time lines established for meetings to honor and respect parental personal and family commitments and obligations.
- Recognize that caregivers may be reluctant to criticize professional or other medical personnel with whom they interact on a continuous basis. Ensure meeting protocols are conducive to open and honest discourse. Staff and organization must guarantee there will be no repercussions; establishing trust with individuals and families who have experienced discrimination, marginalization, or bias may be challenging.
- Identify supports that will be available to help families participate effectively. Some families may have more experience with participating on advisory boards and committees. Provide individual or group orientation before the first meeting and for all new members. Consider using a coach or buddy system to assist family members who request and need this level of support.
- Identify and implement strategies to elicit and encourage participation from all family members. Some individuals may be more willing than others to speak up in group situations or share personal information. Offer alternative ways to provide input including opportunities to provide written feedback.

Resources:

Center for Children with Special Health Care Needs Involving Families as Advisors Toolkit <http://www.cshcn.org/resources/famadvisor.cfm>.

This toolkit was developed from resources and materials used with the Family Consultant Project, which is a model for sustaining meaningful involvement of family members as expert consultants. This project was founded on the assumption that involving patients and their families in the design, implementation, and evaluation of pediatric health care services, programs, and policies makes a significant difference. Patients and their families bring fresh perspectives and creative solutions to ensure quality of care. This toolkit provides resources and handouts to help involve families as advisors or consultants in your own organization.

Caldwell, J., Hauss, S., Richins, G., & Stark, B. (2006, March). Consumer advisory committees: Recommendations for meaningful participation of individuals with disabilities and families. Silver Spring, MD: Association of University Centers on Disabilities.

A Guide for Using the Cultural and Linguistic Policy Assessment Instrument (CLCPA) <http://www.clcpa.info/>

This 43-page guide provides practical, step-by-step instructions on how to conduct an organizational self-assessment process using the CLCPA. It includes a description of the instrument, a four-phase checklist for conducting cultural and linguistic competence organizational self-assessment, definitions and a resource list, a sample consent form for focus groups, and a sample focus group protocol.