

Parent Leadership Development

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TITLE V/MCH BLOCK GRANT MEASURES ADDRESSED
N/A

BACKGROUND

Many federal and state laws and regulations require parent representation on panels, advisory committees, etc. The concept of the medical home is based on the active participation of parents and their effective partnerships with health providers. However, national survey data of families of Children and Youth with Special Health Care Needs (CYSHCN) indicates that less than 60% of families (including less than 50% of Latino and less than 55% of African-American families) reported that they were partners in decision-making at all levels of their child's medical needs.

The Statewide Parent Advocacy Network's (SPAN) Parent Leadership Development activities are aimed at building the capacity of families to advocate on behalf of their children, and partner with health, education, and other professionals.

PROGRAM OBJECTIVES

The overall goal of the parent leadership activities is to enhance the capacity of parents to advocate on behalf of their own and other children and families at local, state, and national levels to improve education, health, human services, and other policies affecting children, youth, and families, i.e., to strengthen the capacity of families to speak for themselves at policy and service delivery tables.

Key objectives include (a) identifying the potential leadership in every parent, particularly underserved parents, (b) providing multiple opportunities and pathways for leadership development that meet the needs of diverse families, with a particular focus on underserved, underrepresented families; (c) providing parent leadership development that is tailored to diverse needs; (d) connecting emerging leaders with established parent leaders for peer-to-peer support; (e) providing opportunities and support for parent leaders to exercise leadership skills; and (f) working with parent leaders to change policies and practices that impact children, youth and families.

TARGET POPULATION SERVED

SPAN's parent leadership activities are statewide and involve over 500 parents per year. This program targets parents of CYSHCN and their families.

PROGRAM ACTIVITIES

SPAN provides intensive leadership development, ongoing peer-to-peer support, and leadership practice opportunities for families; particularly underserved families. SPAN measures the effectiveness of parent leadership development activities through pre-post surveys of families, focus groups with participants, and documentation of the extent to which parents engage in leadership activities such as providing advocacy or parent-to-parent support to other parents, testifying at public hearings, and/or meeting with elected officials and state agency representatives. SPAN's relationship-based, "cultural reciprocity" approach seeks out, recognizes, and supports the leader in each family, providing the information and supports parents need and want.

SPAN's diverse staff members are all parent leaders who started out needing help to advocate on behalf of their own children and families, and then developed a passion to help others and change systems so that parents would not face the same challenges and barriers. All of SPAN's programs and activities are based on the input of staff, the volunteer SPAN Resource Parents (SRPs), and input from the families being served.

PROGRAM OUTCOMES/EVALUATION DATA

The SPAN evaluation process includes: evaluations of the quality, relevance, usefulness, and impact of each training and other activities; pre-post surveys for families who participate in intensive services, measuring not only quality, relevance, usefulness, and impact on their children, but also the parents' self-confidence, sense of competence, and ability/willingness to partner with professionals. SPAN also

conducts focus groups with parents and collects parent stories about longer-term outcomes.

In the last two years (2008-2009), over 1000 diverse parents have participated in parent leadership activities. SPAN has helped create, strengthen and sustain over 300 local parent support groups in urban, rural, and suburban communities and also added over 200 new SRPs including 80 Spanish speaking families. SPAN has documented the participation of over 300 diverse parent leaders in public policy advocacy activities such as testifying on proposed changes to the state special education code and funding formula; testifying before the child welfare system on their new family-centered "case practice model;" meeting with and sharing stories with the Governor's Blue Ribbon Panel on Immigrant Affairs; meeting in person with the Child Advocate and Public Advocate to report inappropriate and illegal retaliation and intimidation, particularly of immigrant families; and sharing their stories with multiple state and local agencies.

The impact of their participation is reflected in victories such as having their recommendations included in the recommendations of the Immigrant Affairs Panel (and their names were included in the acknowledgement section of the report of the panel) and decision by the state Department of Education to hold additional hearings in multiple locations at more easily accessible times and places.

PROGRAM COST

For intensive parent leadership development practices, we estimate a cost of approximately \$500/parent for a year, which includes not only our costs but also the costs that we reimburse to families such as child care, transportation, meeting refreshments, etc.

ASSETS & CHALLENGES

Assets

- Parent Leadership Development activities were written into the organization's strategic plan

Challenges

- Continuing to remain open to changes in plans that are indicated by the feedback from the families, and providing support to staff to encourage them to remain open to these necessary changes rather than being stressed by and resistant to them
- Securing the funds needed to ensure the ability of low-income families and families with greater needs to be able to participate effectively
- Supporting parent leaders as they exercised their new leadership when they faced retaliation by multiple systems

Overcoming Challenges

SPAN has addressed these challenges by:

- Remaining close to its constituency and constantly checking with them to make sure SPAN is staying on course
- Providing opportunities for staff to network with each other for support in dealing with the stress of an environment that changes often
- Being creative about securing needed funds
- Connecting parent leaders with key policy leaders such as the Child Advocate and the Public Advocate, who can help them when other systems try to retaliate against them

LESSONS LEARNED

Every parent has leadership potential; every parent can be a leader in his or her own family, community, and in systems change, if provided with the appropriate, tailored knowledge, skills, and support.

FUTURE STEPS

The Parent Leadership Development program is an ongoing project. SPAN's sustainability plan includes building parent leadership development into every aspect of its work, including the Parent Training and Information Center; Family Voices State Affiliate organization; Federation of Families for Children's Mental Health Chapter; Statewide Parent to Parent and Family to Family Health Information Center.

COLLABORATIONS

SPAN's leadership practices are conducted in collaboration with a wide variety of partners based on the target constituency, including the New Jersey (NJ) Immigration Policy Network; the Partnership for Family Success; NJ Alliance of Family Support Organizations; El Club de Padres; and various state agencies who fund this work, including the NJ Departments of Health, Children & Families (which includes the Child Behavioral Health program), and Human Services.

PEER REVIEW & REPLICATION

SPAN has presented information on its diverse parent leadership development practices at numerous national conferences, including the National Family Voices Conference, National Opening Doors Conference, the National Conference of the National Deaf-Blind Technical Assistance Center, the National Alliance for Parent Centers conference, and the National Federation of Families for Children's Mental Health Conference.

These leadership development practices have been replicated in numerous settings and with numerous populations within New Jersey. There are other parent organizations that are working to replicate this approach and are using SPAN materials as the basis for their work.



RESOURCES PROVIDED

To find out more about SPAN's work with parent leadership development, please visit:

<http://www.spanj.org/>

Key words: Parent Involvement, CYSHCN, Quality Assurance, Service Coordination & Integration, Health Inequity/Disparities, Health Promotion

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