

ADVANCING PARENT-PROFESSIONAL LEADERSHIP:

EFFECTIVE STRATEGIES FOR BUILDING THE CAPACITY OF PARENT ADVISORY COUNCILS IN SPECIAL EDUCATION

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Suggested audience for this brief: Parent leaders and advocates in special education

INTRODUCTION

The Individuals with Disabilities Education Act, last amended in 2004 (IDEA 2004), encourages parents and educators to work collaboratively, emphasizing that as a team they are uniquely suited to make decisions that help improve the educational experiences and outcomes of children with disabilities. The Advancing Parent-Professional Leadership in Education (APPLE) Project was funded to develop the leadership skills of parents individually and within their communities. The project took place in Massachusetts, where school districts are required to have a special education parent advisory council (SEPAC).

As part of the overall evaluation of the APPLE project, we asked 39 parents who participated in the leadership training about ways to create a better SEPAC and improve its capacity to effectively collaborate with educators. The 39 parents represented 21 SEPACs in Massachusetts. This brief presents effective strategies and recommendations to support parent leaders and advocates in special education, whether they are part of a SEPAC or another similar group.

THE APPLE PROJECT

- *School districts were recruited for a three-day parent leadership training.*
- *Participants formed teams, each made of up to five parents of children with disabilities and one school administrator.*
- *Training focus on diversity, reciprocal outreach, facilitation and communication methods and leadership.*
- *Teams have daily team planning time with facilitation.*
- *For more information, visit www.fcsn.org*

SPECIAL EDUCATION PARENT ADVISORY COUNCILS (SEPACs)

- *Are required by Massachusetts State Law to exist in every school district*
- *Advise school districts on their special education programs.*
- *Participate in planning, development and evaluation of district SPED programs.*
- *Regularly meet with school officials.*
- *Range in functionality and activity level.*

BACKGROUND

Research shows that parents of children with disabilities are actively involved in their children's education both at home and at school. In the 2000 National Longitudinal Transition Study 2 (Newman, 2005a), 82 percent of the 11,000 responding parents of children with disabilities ages 13 to 17 reported involvement in their children's education at home, 93 percent reported involvement in school-based activities (e.g., attending school-wide meetings and volunteering in the classroom), and 88 percent were involved in developing their child's Individualized Education Plans (IEP), a plan providing for special education (SPED) services. Research also linked parent involvement to improved educational outcomes of students with disabilities, particularly school engagement, academic performance, social adjustment and independence (Newman, 2005b).

Early evaluation findings from the APPLE project indicated that the 21 SEPACs from which we interviewed APPLE participants differed widely in their functions: some SEPACs saw themselves primarily as entities that provide information and resources and as advocates on behalf of all parents and their children with special needs in the school district, while other SEPACs regarded themselves more as a parent support group. The 21 SEPACs also differed in their levels of activity, ranging from highly active to sporadically or infrequently active. APPLE participants reported that some of the barriers to running a SEPAC and building its capacity are lack of a formal SEPAC structure, mission and vision; lack of funding, time and resources to support SEPAC efforts; small membership base and lack of diversity among members; conflict and mistrust between school districts and SEPACs; and school bureaucracy and "politics."



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EFFECTIVE STRATEGIES FOR BUILDING SEPAC CAPACITY

Based on the interviews with APPLE parents, we identified a list of effective strategies that SEPACs and other parent groups can use to improve their organizational capacity to more effectively collaborate with educators.

RECRUIT PARENTS WHO HAVE LEADERSHIP SKILL OR POTENTIAL

1 Recruiting parents who have leadership skill or potential as SEPAC leaders was one strategy that emerged in the parent interviews. Parents characterized a leader as someone who was available and approachable and was able to listen and understand. “A good leader is someone who has great listening skills, someone who can think outside the box, someone who doesn't quit answering a question,” said one parent. Knowledge about the topic at hand (e.g., SPED laws), confidence when speaking in front of people, ability to raise issues and encourage open discussion and ability not to take things personally were other leadership qualities parents highlighted. SEPAC leaders also have to be visionaries and strategists and diplomats when dealing with different groups of people, personalities and (school) politics. One goal of the APPLE Project was to help parents recognize their own leadership qualities and their expectations of others as leaders.

CREATE A FORMAL SEPAC STRUCTURE AND IDENTITY ACROSS THE SCHOOL DISTRICT

2 Creating a formal SEPAC structure was another strategy that emerged as a first step toward providing more organized parental input on school matters affecting children with disabilities. Most SEPACs have a board or an executive committee with staff positions such as chair, co-chair, treasurer and secretary, and most hold formal elections on an annual basis to select their leaders. Four parents mentioned that their SEPACs established subcommittees or working groups that focused on particular activities. One SEPAC, for example, had a standing subcommittee charged with representing the SEPAC at school committee meetings. Another SEPAC established temporary working groups—one for organizing an annual conference and a second one for developing a SEPAC website. The other two SEPACs had committees dedicated to parent outreach and recruitment.

The majority of parents reported meeting as a SEPAC formally once a month during the school year. Officially announcing SEPAC meetings through e-mail, flyers, school newsletters and local newspapers and making meeting minutes publicly available also helped establish the SEPAC more formally. In addition to following existing state laws that guide parent involvement in special education, at least two SEPACs had established their own by-laws.

CAPITALIZE ON PARENTS STRENGTHS TO BUILD SEPAC ORGANIZATIONAL CAPACITY

3 Identifying individuals' strength and resources and putting them to use for the SEPAC was another strategy that several parents talked about. For example, one participant mentioned a SEPAC member who worked for an advocacy organization and was well versed in SPED legislation, having written and published many articles on this topic, and who also had experience in mentoring families with children with disabilities. A second parent talked about how, as a state representative, one SEPAC member kept the group up-to-date on Massachusetts state legislation and policies on special education. Capitalizing on the grant writing skills of a member helped one SEPAC obtain funding. Individual parents with human resources or business skills often helped SEPACs use their limited resources more efficiently and effectively.

In addition, participants emphasized the importance of keeping task assignments small and manageable, given that many parents have busy work and family schedules. Capitalizing on individuals' strengths was also important for parents involved in organizing the SEPAC, as one parent described: “We have a president, a vice president and a secretary ... [but] we intermingle on responsibilities, and we each jump in wherever our strengths are, and if we have a weakness, someone else will step up to the plate because they might have a strength in that area.”

COLLABORATE WITH SCHOOL AND SPECIAL EDUCATION ADMINISTRATORS AND STAFF

4 Collaborating with the school district and SPED administrators in particular was key to influencing special education programming. Establishing a relationship with administrators was not always easy and required time, effort and patience on the part of both parents and professionals. Once such a relationship had been established, however, it provided the platform for many collaborative activities. These ranged from marketing and outreach to organizing

workshops and special events. SPED administrators helped SEPACs distribute flyers and newsletters and handed out brochures to parents at IEP meetings. Three SEPAC parents reported collaborating with the SPED administrator on surveying parents on their needs.

Almost all parents reported their SPED administrator attending SEPAC meetings and providing input. SPED administrators would meet separately with SEPAC boards to provide advice on and support with specific issues. Furthermore, at least four parents said their SEPACs actively reached out to district staff and invited them to attend SEPAC meetings and provide input. Communication, both formal and informal, also played an important role in developing and maintaining SEPAC relationships with the SPED administrator.

PROVIDE INPUT ON SCHOOL POLICY AND PROGRAMS RELATING TO SPECIAL EDUCATION

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In many ways the SEPAC serves as an advocate for the SPED program, which is crucial when there is no real support for special education within a community.

About one third of the parents talked about their SEPAC's system or plan of action to provide input to the school district. Getting involved in different school committees, working groups and task forces was one mechanism of providing input. Members of three SEPACs, for example, joined task forces responsible for hiring and recruiting school and SPED administrators. Several SEPACs communicated their needs to the SPED administrator and school committee regularly. One SEPAC had a subcommittee to represent the SEPAC at school committee meetings, another had a SEPAC liaison to the school committee and yet a third had the SEPAC chair attend every meeting of the school committee. Two parents described SEPAC efforts to provide training to teachers in the form of SEPAC workshops on disability issues. One of these SEPACs also made it possible for teachers who attended these workshops to attain professional development credits. Another parent described how her SEPAC conducted research on best practices for teaching in inclusive public school settings and shared those with its school district for consideration.

RAISE DISABILITY AND SPECIAL EDUCATION AWARENESS AT SCHOOL AND IN THE COMMUNITY

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Several parents talked about the importance of raising awareness of disability, special education and diversity more broadly in the school and wider community. Raising awareness was a way to reduce the stigma

for children with disabilities and the isolation families can feel. One way SEPAC members raised awareness was by participating in school events, such as Parent Teacher Association (PTA) kick-off events or in local community events that celebrate multiculturalism. SEPAC members also organized their own events, such as workshops on disability awareness for parents and similar programs targeted at children of different ages.

SEPACs also partnered with community organizations: one SEPAC collaborated with the local YMCA to organize an information and resources fair targeting parents of children with disabilities. Another SEPAC collaborated with The ARC (www.thearc.org) on a puppet theater show for children to raise awareness of diversity issues, including disabilities issues. Fundraisers served to raise awareness about the SEPAC and special needs issues. Parents also reached out by distributing flyers and holding workshops on issues that are not exclusive to children with disabilities. All of these strategies can be used to raise general disability awareness and to increase and diversify SEPAC membership.

REACH OUT AND ENGAGE PARENTS, INCLUDING PARENTS FROM DIVERSE BACKGROUNDS

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Reaching parents of children with disabilities and motivating them to attend SEPAC meetings and get involved in activities was a challenge, according to almost all APPLE project participants.

SEPACs used both traditional and non-traditional approaches to “get the word out” about the SEPAC and to recruit more members, especially parents from diverse backgrounds. This included parents from different linguistic, ethnic and racial and religious and spiritual backgrounds and parents of children of different ages and with different types of disabilities and levels of abilities.

Some of the more traditional methods that SEPAC used included distributing flyers at IEP meetings, throughout the school and in communal places such as local libraries, post offices, corner stores, and churches and sharing information through the school newsletter, local newspapers, the local cable station and via the SEPAC website. Many SEPACs used e-mail and group mailing lists to announce events and share information and resources. Some SEPACs collaborated with other organizations such as the PTA to help them advertise SEPAC events. In two instances, SEPACs collaborated with school and SPED administrators and had them regularly announce SEPAC events using the school phone messaging system.

SEPACs also used non-traditional approaches for parent outreach. One SEPAC, for example, got permission to set up an information and resource table on special education and disability topics at the local library. Organizing fundraisers and participating in local community events were other avenues that SEPACs explored to reach out to parents and recruit SEPAC members. Outreach also happened more informally with SEPAC members individually connecting with parents and encouraging them to attend SEPAC meetings.

Several SEPACs tried to engage parents by accommodating their work and family scheduling needs. Participants talked about experimenting with holding SEPAC meetings and events at different times and at different locations. One SEPAC reached more families by taking events “on the road” and holding them at different schools and other venues (e.g., the public library) within the school district to reach various neighborhoods and particular ethnic groups.

A large majority of parents also talked about the challenge of increasing diversity among SEPAC members. Some SEPACs offered workshops with topics of interest to all parents, not only to those of children with disabilities, as an attempt to attract a broader, more diverse parent base. Other SEPACs tried to tailor workshops to meet the needs of specific groups of parents. One SEPAC distributed flyers in Portuguese for workshops held by the Federation for Children with Special Needs, trying to reach out specifically to Portuguese-speaking families living in their district. Providing translation support was another mechanism that one SEPAC used to better accommodate parents whose first language was not English.

SUPPORT PARENTS THROUGH INFORMATION, ADVOCACY AND RESOURCES



SEPACs supported parents of children with disabilities by providing them with information, advocacy and resources. Information sharing, workshops and invited guest speakers were standard agenda for regular SEPAC meetings. Workshop topics ranged from SPED policy and legislation and basic rights to IEP development, effective parenting and homework and organizational skills. Guest speakers included school administrators, SPED administrators, parent advocates, teachers, PTA representatives, educational lawyers, medical professionals and therapists, state representatives and local legislators.

Other SEPAC events included screenings of movies and documentaries pertaining to disability issues, hands-on demonstrations of assistive technology and how it applies to children with different abilities and needs, and annual conferences.

Two parents mentioned that their SEPACs arranged for babysitting services (for free) so parents could attend SEPAC meetings and events. Five participants reported on their SEPACs’ use of surveys to identify parents’ needs and to better tailor workshops and events to those needs. Collaboration with other SEPACs to facilitate events or to pool resources was a strategy mentioned by several parents. This was particularly important to SEPACs that had a small membership base or no or limited resources.

HELP PARENTS DIFFERENTIATE BETWEEN THEIR ROLES AS PARENTS (PERSONAL) AND AS MEMBERS OF A DISTRICT-WIDE COMMITTEE (PUBLIC)



Helping all SEPAC members to separate the personal from the public, that is not letting their individual situations and emotions such as anger, frustration and despair affect their SEPAC leadership efforts, was another strategy that emerged in our interviews with parents. For example, one SEPAC leader said, “For me personally, my advocacy on behalf of my children is separate from my advocacy for the whole [SEPAC]. It doesn’t mean that they’re not intertwined, but I think it’s two different relationships.” Participants talked about how some parents tried to use SEPAC meetings as a forum to discuss personal issues rather than advocating on behalf of all children with disabilities and their families in the school district.

About a third of the participants talked about SEPAC efforts to try to reinforce this boundary by providing opportunities for emotional support for parents mostly outside of the formal SEPAC meetings. For example, one SEPAC ran a parent mentor program, and many SEPACs had monthly support groups to talk about individual concerns. SEPAC leadership often acted as go-to persons for parents with personal issues. Some SEPACs provided referrals to local support groups, like The ARC, or included contact information about local supports groups in their newsletters. In a few cases, emotional support was built into formal SEPAC meetings, where, at the end of each meeting, members would have time for open discussions.

RECOMMENDATIONS FOR PARENT LEADERS AND ADVOCATES IN SPECIAL EDUCATION

The following recommendations are derived from comments of APPLE parent leaders and the experience of Federation staff.

- ▶ **HAVE CLEAR GOALS AND OBJECTIVES FOR PARENT INVOLVEMENT.** Establishing clear goals and objectives for parent involvement is important for parent organizations so that new members understand what is expected and what they can offer, from mere attendance at meetings to taking on more active roles. This broader approach will help parent organizations to welcome, support and accommodate parents who have different needs.
- ▶ **CONNECT PARENTS TO AND HELP THEM UTILIZE EXISTING RESOURCES.** There is a wide network of parent leadership and advocacy resources both in the state (e.g., MASSPAC) and nationally (e.g., the ALLIANCE) that can help provide training, information and support to parents of children with special needs (see Additional Resources, below). Because no one parent organization can meet all the needs of a family, helping parents identify and connect with relevant resources quickly and efficiently is important. Keeping parents up-to-date on new resources is also critical.
- ▶ **PROVIDE WAYS FOR PARENTS TO IDENTIFY AND VALUE THEIR OWN LEADERSHIP STYLES.** While some parents are natural born public speakers, others are better at “behind the scenes” organizing and nurturing new members. Very often leadership experiences gained through jobs and hobbies can be effectively applied. Using the talents of many parents with different backgrounds will help a parent organization be stronger. Seeking out leadership-styles training might be worthwhile so parents can work together harmoniously and avoid conflict.
- ▶ **BE CLEAR THAT ALL PARENTS’ VOICES AND PERSPECTIVES ARE NEEDED AND VALUED.** Having one group of parents—either from one social group, or representing only one type of disability, or not representing the ethnic and racial make up of the community—will limit the ability of a parent organization to get all families involved in the conversation about special education programs. Thus, parent organizations should find out who their community is and actively reach out and engage community members in their efforts.



ADDITIONAL RESOURCES

THE FEDERATION FOR CHILDREN WITH SPECIAL NEEDS

<http://fcsn.org>

This website provides a wealth of information and resources on special needs topics; it links to parent training and workshops offered and to a searchable national family resource database.

THE INSTITUTE FOR COMMUNITY INCLUSION (ICI)

www.communityinclusion.org

This website provides information and resources on a wide array of disability inclusion topics, including education, transition and career development for youth with disabilities.

MASSACHUSETTS ASSOCIATION OF SPECIAL EDUCATION PARENT ADVISORY COUNCILS (MASSPAC)

www.masspac.org/

This website provides MASSPAC membership information and the Parent’s Desk Reference—a listing of services and professionals for families with children with disabilities.

THE PACER CENTER

www.pacer.org

This website provides information and resources on a wide array of special needs topics, with materials also available in Hmong, Somali and Spanish languages.

THE PACER CENTER’S TECHNICAL ASSISTANCE ALLIANCE FOR PARENT CENTERS (THE ALLIANCE)

www.taalliance.org

This website provides information and resources on special education topics and other issues important to parent centers serving families with children with disabilities. The website also links to a searchable national directory of parent centers.

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