



**NATIONAL CENTER FOR PARENT LEADERSHIP, ADVOCACY, & COMMUNITY
EMPOWERMENT (NATIONAL PLACE)
BRIEFING PAPER ON PARENT/FAMILY SUPPORT AND
ENGAGEMENT ACROSS SYSTEMS**

“Ensuring a place at the table for every family”

There are many pressing issues that require the attention of family-led organizations around the country – education, health, mental health, early childhood, parent support. But there is one overriding issue that cuts across all these other issues – strengthening families and including their voices in the discussion and decision-making processes on issues that affect their children.

The National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE) has a vision: that all families will be effective partners in improving services to and outcomes for our nation’s children, especially those who face the greatest challenges. Our mission is to empower families and family-led organizations, and to support them as they advocate for enhanced, meaningful parent involvement and leadership in all policy decision-making that impacts services for children and families.

Sadly, despite multiple federal and state requirements to involve families in the decisions that affect their children, families are often not at the table – or even in the room – when key decisions are being made. Whether it’s education (Elementary and Secondary Education Act waivers, Individuals with Disabilities Education Act monitoring decisions); mental health (decisions to eliminate the requirement for states to spend a minimum % of their SAMHSA block grant dollars on children’s services); health (state decisions on whether or not to expand Medicaid, or to move to Medicaid managed care for children with special healthcare needs); or human services (cuts to family support for children with developmental disabilities, elimination of all funding for US DHHS Family Support 360 programs), families are the missing link. Even when families are invited to the table, meetings are too frequently held at times and locations that are not convenient to families; families are not provided with the same information as the professionals at the table; and families do not receive the training and support that professionals do as a routine part of their jobs, so family input is limited. This failure to engage families results from a mix of causes: professionals’ belief that parents have nothing to contribute; professionals’ lack of knowledge and skills to meaningfully engage families; and the low priority placed on effective family engagement demonstrated clearly by the paltry funding allotted to this purpose across agencies.

There are a few exceptions, but limited or non-existent family input into and impact on policy is the norm. This dooms our reform initiatives across agencies to almost certain failure.

National PLACE, 35 Halsey Street, Newark, NJ 07102
www.parentsatthetable.org

Background

A family is a child's first, most important, and longest-running teacher, caregiver, and child developer. Informed parents have the potential to prepare their children for a physically and emotionally healthy and productive life, or to set their children on a path that may lead to childhood mortality, disease, violence, substance abuse, or obesity.

Unfortunately, services and supports are often not organized in ways that are easy for families to access. There is no one agency that looks at or plans for the multidisciplinary needs of children and their families. Families may need to go to multiple systems, participate in multiple need assessments and eligibility determinations, and interact with multiple "helping professionals," who may not always be very helpful given insufficient knowledge, expertise, and/or high caseloads.

The barriers to accessing services often exist because families, particularly low-income and immigrant families, are seldom included as equal partners in determining the services and supports they need, identifying the barriers to access, and developing systems that are more responsive to family needs.

Parents will make good choices when they have easy access to understandable information, quality services, and supports – from parents who have direct experience navigating family-serving systems - to help them understand their rights and service options and how to exercise them. And systems are more likely to make good decisions about appropriate policies, programs, and services if they have ongoing input from diverse family membership and representatives from family-led organizations with a broad base of knowledge of family strengths and needs and how systems can better meet those needs.

Recommendations

The focus of these recommendations is the services and supports families need to be effective partners in decision-making and to access the services and supports they need to achieve that goal. The recommendations are four-fold. First, provisions in federal laws regarding parent involvement and decision-making must be preserved and strengthened. For example, the Individuals with Disabilities Education Act (IDEA) should be amended to require informed parental consent not only for the implementation of the initial Individualized Education Plan (IEP) but for each subsequent IEP. The Elementary and Secondary Education Act (ESEA) should be amended to provide parents with the opportunity to challenge school decisions about their child under Title I in administrative proceedings such as those that exist under IDEA. Federal laws about state children's mental health, juvenile justice, and child welfare systems should be amended to incorporate stronger parent involvement provisions.

Second, families need access to education and support to prepare them to be effective partners in decision-making about their individual child and family across systems. There are existing models that can be enhanced to address this need. In early intervention and education for children with disabilities, the US Department of Education funds Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs). In Title 1 of the Elementary and Secondary Education Act, there was funding for state Parent Information and Resource Centers. In health for children with special healthcare needs, there are state Family to Family Health Information Centers (F2Fs) and Family Voices State Affiliates. In mental health, there are Statewide Family Networks and Federation of Families for Children's Mental Health State Organizations and Chapters. In family support, there are Parent to Parent (P2P) programs. In early childhood, there are Head Start Policy

Councils, Policy Committees, and Parent Committees. However, these parent support resources are underfunded, particularly given the increasing diversity of the families they serve and their ever-more complicated needs. Therefore, we recommend both increased funding for existing federally-funded family education and support organizations, and implementation of funding focused on providing family information and support in other systems where such organizations do not exist (child welfare, juvenile justice) or do not exist in every state (SAMHSA-funded Statewide Family Networks). Family-led organizations whose primary focus is informing and supporting parents are critical in empowering individual families, both around their individual child and family and in systems improvement. These family-led organizations will play a key role in identifying gaps in needed services and supports for families and communicating information on these gaps to state and federal agencies.

Third, resources must be devoted to building the capacity of families to participate effectively and as truly equal partners with professionals – government agencies, service providers, and professional advocates – in systems change and improvement. There must be funded, multi-tiered opportunities for families to develop leadership knowledge and skills to more effectively represent diverse family voices in systems change across systems that serve children and their families. The funding provided to family-led organizations to inform and support families must include funds to identify, train, and support diverse family leaders in systems change activities. These family-run organizations would also provide professional development and support to government and private agencies and organizations that serve children and their families to enhance their family-centered services and supports, capacity to partner with families in systems-change and improvement efforts, and improve cultural competence.

Ensuring that these responsibilities are conducted by a family-run organization is critical to their success. An important part of effective systems is how successful they are in providing families with the tools they need to parent, from information about child development to services for families needing help. But families are more than just consumers of services, they are leaders, too. Who is best to identify family needs, assess the effectiveness of services, or impact on policy development? Giving families a voice in decisions that affect them means more than asking parents for input on what they need or including them on advisory bodies. It means making sure that they have the knowledge and skills to influence policy decisions that impact on them and their children, and ensuring that diverse family voices are represented in policy development that affects children and their families. Providing an opportunity for families to attain these skills can best be accomplished by supporting statewide family-run entities to provide leadership training and support to existing and potential family leaders.

Both national and state government agencies too often fail to recognize the expertise that family organizations bring to the policy table. To address this concern, our final recommendation is that federal agencies include representatives from national and state family-led organizations in their strategic planning, program evaluation, and policy development, and require the involvement of the relevant federally-funded family-led organization on state advisory committees established under federal mandate (for example, State Interagency Coordinating Councils and State Advisory Panels must be required to have a representative of their federally-designated parent center; State Medicaid Advisory Panels must be required to have a representative of their F2F; State Children’s Mental Health Advisory Council must be required to have a representative of their Statewide Family Network and FFCMH chapter; State Task Forces on Child Abuse and Neglect must be required to have a representative of their (to be developed) child welfare family leadership organization; etc.).