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Challenges and Opportunities in Children's Mental Health

A View from Families and Youth

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The National Center for Children in Poverty (NCCP) is the nation's leading public policy center dedicated to promoting the economic security, health, and well-being of America's low-income families and children. Founded in 1989 as a division of the Mailman School of Public Health at Columbia University, NCCP is a nonpartisan, public interest research organization.

Challenges and Opportunities in Children's Mental Health: A View from Families and Youth

by Sarah Dababnah and Janice Cooper

This report documents critical issues in children's mental health policy and service delivery from the perspective of stakeholders in the family and youth movement. The National Center for Children in Poverty (NCCP) convened the meeting that this report summarizes, Best Practices in Policy for Children's Mental Health Consultation Meeting with Stakeholders: Family and Youth Perspectives. It was designed to solicit guidance from families and youth involved in the child mental health field to support a research study entitled *Unclaimed Children Revisited*. Among the key findings of the meeting was that through a family and youth lens, many effective practices, some with supporting policy, have emerged but not been taken to scale. Another set of core findings was that family members and youth acknowledged the gains made in children's mental health but cited obstacles to improved outcomes for children and families, such as service limitations, provider attitudes and training, lack of services integration, fiscal constraints, a weak infrastructure, and a sparse array of services. The report describes participants' perspectives on the status of family and youth support and advocacy systems. It also highlights selected current innovative interventions directed or heavily influenced by parents, youth, and community advocates that strengthen family and youth influence in mental health policy and service planning and advance improved mental health outcomes for children, youth, and families.

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The ideal system would recognize that families and youth are the center of the system; ...decisions [would] be primarily based on the experiences and preferences of those being served...[and] reflect...knowledge about effective strategies, including practice-based evidence and evidence gathered through controlled studies.

Executive Summary

Overview

Children and youth with mental health problems and their families need the appropriate skills, tools, services, and supports to reach their full potential as productive, contributing citizens. Quality mental health services and supports can significantly improve their ability to attain school success, mental health, and social and emotional well-being, to maintain healthy relationships, to remain in stable living situations, and to stay out of jail and the juvenile justice system. This report, based on a meeting of youth and family members of children and youth who experience mental health problems, highlights how family-driven and youth-guided values and frameworks can improve research, policy, and practice and ultimately result in better care and healthier children and youth. Below we identify the challenges that the family members and youth reported as well as the policy, service, and research solutions that they proposed. The full report also includes examples of research, policy, and practice that involve families and youth as active partners.

The major take-home message is that a strong family-driven and youth-guided perspective in research, policy, and practice propels more effective, responsive service delivery systems. At the center of families' and youth's support for effective strategies rests their desire to see children and youth with mental health problems get better and lead productive lives. They called for an outcomes-focused delivery system that holds all stakeholders accountable, regardless of which service system the children and families are in.

Youth leaders, family, and community advocates also linked research with quality services. Today, too many children and youth with mental health problems and their families continue to encounter service delivery systems that struggle to meet their needs. Oftentimes, there are too few services, and many of those that exist rely on a deficit-based care model. Across the country, small numbers of children, youth, and their families *do* benefit from programs that focus on the individual strengths and needs. Thus, creating a policy framework that provides this kind of access to high-quality services for all children, youth, and families who need them is essential. Family members and youth recognize that they have a significant role to play in strengthening and expanding the array of quality mental health services and supports. For instance, increasingly family and youth:

- Serve as participatory researchers, system navigators for parents and youth, peer supporters, trainers, and service providers.
- Act as advocates for other parents.
- Help to address the workforce shortage, especially by increasing providers with linguistic and cultural competence.

Family members and youth also acknowledged the need for more widespread adoption of evidence-based practices and called for strategies that: (1) invest in research to determine the effectiveness of family/youth centered, and culturally and linguistically competent interventions that show promise in communities; (2) include family and youth engagement components; (3) embed strength-based and resilience principles and strategies;

and (4) emphasize functional outcomes for children and youth in the home, school, and the community.

Finally, and importantly, family members and youth also considered themselves accountable as advocates. They called for the elimination of harmful policy practices such as custody relinquishment in exchange for services. This, they noted, conflicts with societal, family, and youth values and with the basic principles of health care. Family members and youth also indicated the need to amend rules in the Supplemental Security Income (SSI) program that serve as disincentives to work. They wanted a relaxation of SSI requirements that jeopardize youth health insurance or social supports. These and other urgent policy matters often first surface from children, youth, and families affected by mental health issues. Therefore, family members and youth strongly urged states to strengthen family and youth advocacy organizations in order to better serve mental health services users.

Recommendations

To strengthen family-driven and youth-guided research, policymakers should:

- Promote collaborative partnerships with families and youth in research.
- Increase the use of positive outcomes measures.
- Ensure the dissemination of outcomes data and research through user-friendly techniques and language.

To strengthen family and youth support in the context of *all* services, policymakers, researchers, and providers should:

- Make family and youth support a funded and essential component of service delivery.
- Provide family-driven, youth-guided, and responsive services and supports in settings that are readily accessible to children, youth, and their families.
- Take family-driven and youth-guided services to scale.
- Promote mental wellness and positive social and behavioral competencies by engaging children and youth in interesting and appropriate activities.

To take family-driven and youth-guided services to scale for *high-need youth*, policymakers and practitioners should:

- Provide family-driven, youth-guided, and responsive services and supports in settings that are readily accessible to children, youth and their families.
- Require cross-system accountability for improved outcomes as a condition of funding based upon developmentally appropriate, family-driven, and youth-guided practice.
- Require greater accountability for improved outcomes for children and youth as a condition for funding residential treatment providers.
- Foster adoption of family-driven and youth-guided evidence-based practice that works in community-based setting and with diverse populations.
- Infuse family-focused, culturally and linguistically competent, and developmentally appropriate principles across all mental health services, not just those delivered within the context of systems of care.

To address harmful practices and policies, state and federal-level policymakers should:

- Eliminate the practice of custody relinquishment in exchange for mental health services for children and youth.
- Amend rules governing Supplement Security Income to remove work disincentives for youth with mental health problems.
- Implement administrative practices that strengthen the family and youth voice.
- Support organizational and leadership development for family and youth advocacy organizations.

To strengthen the policy infrastructure to better support family and youth perspectives, policymakers and advocates should:

- Increase funding and other resources to support family meetings, including transportation, meals, and on-site specialized child care.
- Expand or create opportunities for policymakers and administrators to hear directly from families and youth.

- Build in policy requirements that give families and youth roles in policymaking bodies.
- Enhance networking capacity of parents, youth, and other family members.
- Invest in family and youth advocacy organizations and services directed by youth and families.
- Expand technical assistance offered by the federal government to states and communities that do not have formal systems of care grants.
- Promote and fund the development of a public health model that embraces a universal focus on children's mental health and addresses the needs of the most troubled children and youth.

Introduction

In 1982, Jane Knitzer's seminal study—*Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services*—called attention to the desperate state of the mental health system for children and adolescents with mental health problems and their families. The study became a turning point in the mental health field and led to a series of reforms. Almost 25 years later, the National Center for Children in Poverty (NCCP) is undertaking a study to examine the status of children's mental health policies.

As a precursor to this new study, which has the working title *Unclaimed Children Revisited*, NCCP convened a meeting of family and youth stakeholders to better understand the current challenges and opportunities facing families and youth. The 16 participants came from nine states and a mix of racial and ethnic groups and geographic areas. (See Appendix A for a complete list of participants.) Below we highlight their perspectives on: (1) what it will take to create a more responsive system of services and supports, (2) how to generate a range of service choices for families and youth, and (3) the pressing research and policy challenges and opportunities. The report supplements the insights of the participants with boxes that describe examples of state and local strategies (based on their recommendations) that embed family and youth perspectives and that might be more widely replicated. Appendices provide information on participants, contact information for the resources provided, and a synthesis of the questions that family and youth participants would like answered from a national study.

To set the context, it is first important to acknowledge that family and youth stakeholders, often in partnership with others, have accomplished much to improve children's mental health services since 1982. The creation of family organizations and the empowerment of youth and families affected by mental health issues have not only resulted in increased federal and state funding for family-driven services, but also in state-level legislative and judicial actions that have changed the manner in which children's mental health services are provided. The family movement brought awareness of issues such as mental health stigma, custody relinquishment, and the role of race, ethnicity, and culture in mental health to policymakers and other stakeholders in the children's mental health field. Families and youth also refocused attention on the potential impact to children, youth, families, and society of investing in effective children's mental health services. These benefits include: decreased involvement with the juvenile justice system, fewer hospital admissions, and higher proportions of children living with their families. Increasingly, the family movement is also calling attention to the importance of early intervention and prevention strategies.

Nationally, the hub of the family movement rests in the Federation of Families for Children's Mental Health (called the Federation), a 120-chapter organization with members nationwide. The Federation has provided leadership in promoting a "family-driven, youth guided" perspective on how best to improve services and outcomes (see definitions below). Its influence comes from the thousands of families and youth across the country who speak out as service users, family members, and advocates. Figures 1 and 2 graphically depict how the concepts of family-driven and youth-guided care may be put into operation.

Family-Driven Care

Family-driven means families have a primary decision-making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory, and nation.

Youth-Guided Care

Youth-guided means young people have the right to be empowered, educated, and given a decision-making role in their care as well as the policies and procedures governing care for all youth in the community, state, and nation.*

Source: Federation of Families for Children's Mental Health: <www.ffcmh.org>; personal communication with Lorrin Gehring, 2006.

*Note: This is an abbreviated definition.

Box 1: Critical Issues in Children's Mental Health—An Overview of Family and Youth Participant Perspectives

Research Issues

- Lack of family-focused research methods
- Outcomes data difficult to access and not user-friendly
- Difficulty in understanding academic language
- Need for research to be conducted in partnership with families and youth and consistent with the principles of family-driven and youth-guided care
- Lack of research applicable to children, youth, and families from diverse racial, ethnic, cultural, and linguistic backgrounds

Service Issues

- Exclusion of families in service planning and treatment decisions—including discharge/transition planning and support in the home
- Misplaced concentration on mental illness instead of mental wellness
- Failure to use strength-based practices and resiliency models in service provision
- Over-emphasis on specific evidence-based practices rather than longer-term treatment and management strategies for the most troubled children and youth
- Limited availability of developmentally appropriate mental health services in education, child welfare, and juvenile justice systems as well as in the community
- Lack of services targeted to groups at increased risk for mental health problems and at critical points of development, such as young children transitioning to school, youth transitioning to the adult mental health system, children from communities with high crime rates, and children living in residential facilities
- Limited early intervention services and lack of systematic strategies for identifying children who show early signs of social, emotional, behavioral, or mental health problems
- Lack of a family treatment system and lack of clarity regarding the nature of intergenerational mental health issues
- Shortage of workforce training modules, especially those designed to reduce the stigma of mental health problems within communities

Advocacy Issues

- Institutionalize understanding of family-driven and youth-guided care and the importance of family and youth advocates, and develop family and youth support systems
- Eliminate policy practices that make parents relinquish custody in order to access services and provide adequate community-based services
- Develop policy assessment tools for families and youth
- Address fiscal policy gaps that fail to require grantees to partner with family and youth organizations and support the infrastructure for family, youth, and individual advocacy
- Amend the Supplemental Security Income (SSI) program to reflect changing needs of youth

Yet, despite the strides made by families in the past 25 years, significant obstacles continue to impede the full inclusion of families and youth in children's mental health care (see Box 1). The paucity of research demonstrating the importance of family and youth advocacy and support and the need for accountability in the mental health system were primary concerns of the stakeholders. Services provided by the mental health system remain insufficient and inappropriate to meet the needs of all children and adolescents with mental health needs; they especially fail young adults transitioning to the adult system and youth living in low-income or violence-plagued communities. Additionally, the lack of adequate mental health services in systems such as child welfare and juvenile justice is apparent from the dismal mental health outcomes of the children and youth involved with these systems (see Box 2).

Box 2: Mental Health Facts—Unmet Needs

- 79 percent of children with mental health problems have unmet needs.
- Children of Hispanic/Latino origin were 2.6 times less likely to have their mental health needs met than white or African-American children.

Source: Kataoka, S.; Zhang, L.; & Wells, K. (2002). Unmet need for mental health care among U.S. children: Variation by ethnicity and insurance status. *American Journal of Psychiatry, 159*(9), 1548-1555.

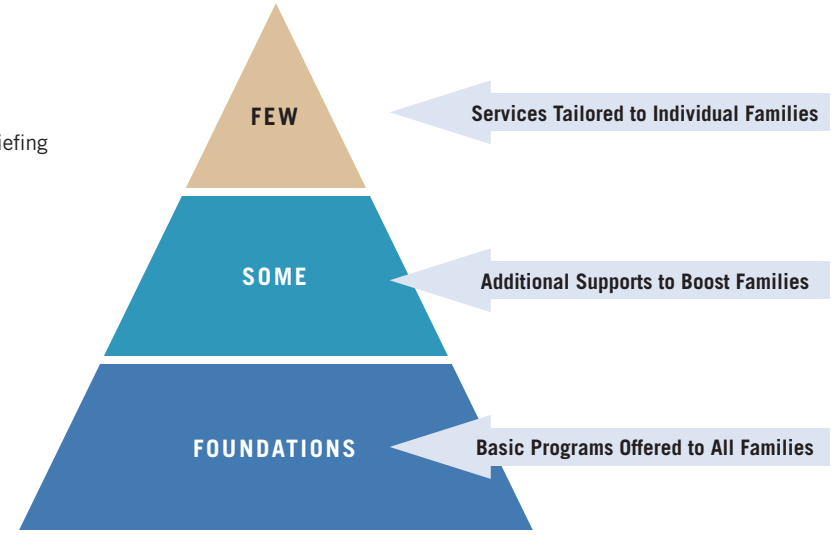
Figure 1: Three Levels of Family-Driven Care

Examples

- Behavior Management Training
- Peer Mentor
- Home Aide
- Personalized Support
- Individual Incident Reporting and Debriefing

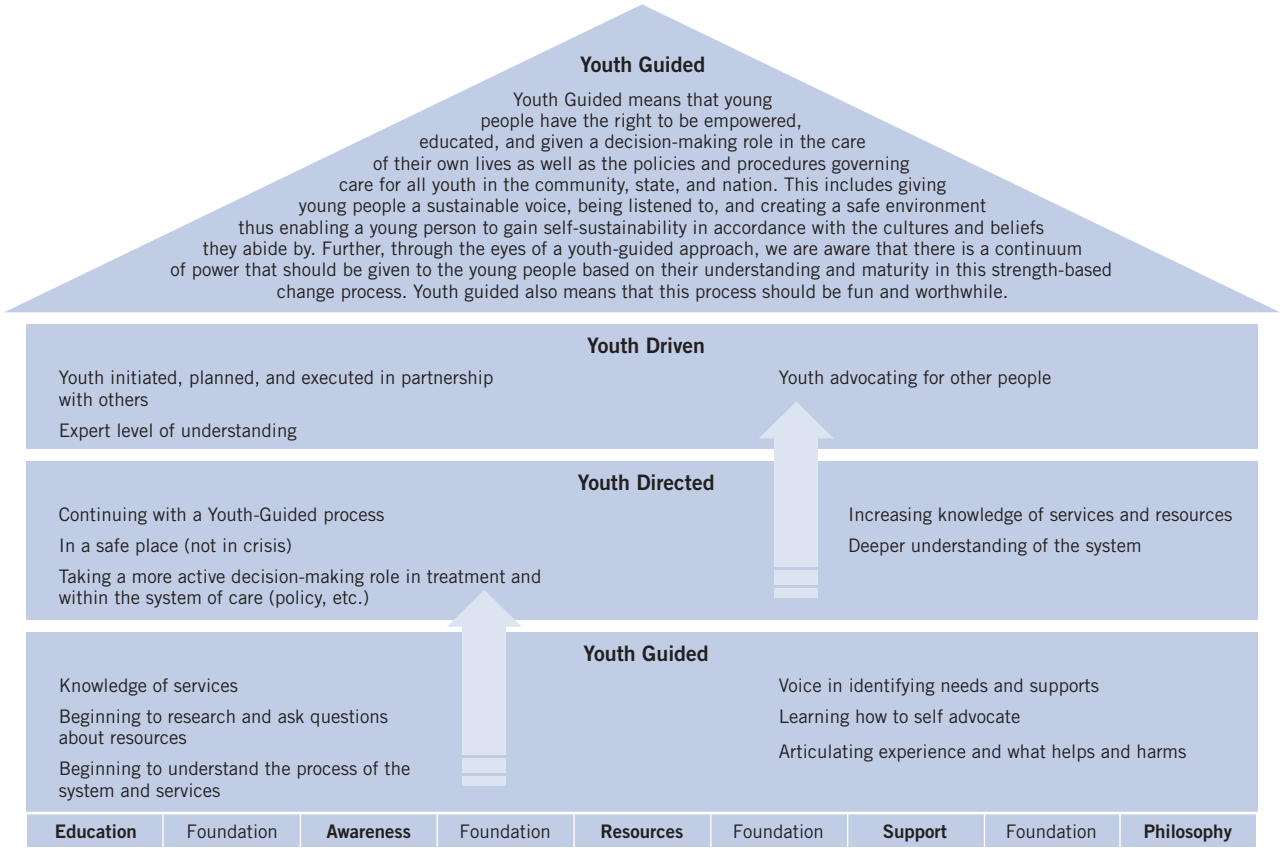
- Child Care
- Transportation
- Parent Education
- Cultural Adaptations
- Translation and Interpreters
- Participate in Institutional Planning and Evaluation

- Welcoming Environment
- Routine Communication Orientation
- Social Activities
- Participate in Individual Planning and Decision Making



Source: Osher, T. (2006). Shifting Gears to Family-Driven Care, Presentation at: "Widening the Lens: Focus on Community Connections." Colorado Springs, CO: The Colorado Child & Adolescent Mental Health Coalition's 18th Annual Conference, April 9-11, 2006.

Figure 2: Building a Youth-Guided House



Source: Youth Motivating Others Through Voices of Experience (Youth M.O.V.E.). (2005). *The house.* [Draft copy.]. Washington, DC: Youth M.O.V.E.

It's about the language that researchers use: The environment may be at-risk or dysfunctional, but the people are whole people.

A meeting participant.

Research Challenges and Opportunities from a Family/Youth Perspective

Recognizing the importance of research findings in shaping policy decisions, the meeting participants focused on two major research-related challenges: (1) expanding the research knowledge about the impact of family-driven, youth-guided services and supports; and (2) building support for more routine family/researcher partnerships in designing and carrying out studies. Family and youth stakeholders at the meeting expressed concern over a lack of focus on families in research. Participants particularly questioned whether researchers studying evidence-based practices are partnering with communities and family organizations. This is essential to ensuring that research findings are applicable to families from diverse racial, ethnic, cultural, and linguistic backgrounds. Participants also expressed concern that even when researchers were working with families and youth, the researchers might still be imposing their own agendas on communities; the participants called for families and youth to be involved in critical design and management issues in research.

Stakeholders emphasized the need for academic and research institutions to routinely, not as the exception, conduct and support family-driven and youth-guided studies. They also stressed that family members and youth ought to be trained to partner with researchers and to conduct research. Additionally, research findings must be presented in plain language in order to engage and promote understanding among not only academics, but also families and policymakers. One participant recommended and others concurred on the need for public access to outcomes data in order to create accountability for systems in all areas, but particularly in juvenile justice. Right now, these data are often difficult to access. Further, while recognizing the methodological challenges, participants agreed that the focus should be on positive outcome measurements, such as the number of children and youth diverted from incarceration and residential treatment due to their receipt of supportive services.

The participants also reported encouraging examples of approaches to research collaborations that include families and youth in the design and implementation of research projects as well as participants. For example, the research partnerships described in Boxes 3 and 4 illustrate variations on strategies that promote more collaborative research, one engaging families and community leaders actively in all aspects of research on a preventive intervention, and the other having family members and youth as equal partners on a research team. Other recent efforts include research on how to best engage families,[1] on family partnerships in schools that improve school climate and lead to positive academic outcomes,[2] and how to improve school-based mental health services implementation using a family empowerment model (such as in New York State and Utah where a National Institute of Mental Health study of the adaptation of the Parent Empowerment Program model for schools is underway) (see Box 5).

Research Recommendations from a Family/Youth Perspective

To strengthen family-driven and youth-guided research, policymakers and researchers should:

- Promote collaborative partnerships with families and youth in research.
- Increase the use of positive outcome measures.
- Ensure dissemination of outcomes data and research through user-friendly techniques and language.

Box 3: Strategy—Develop Collaborative Partnerships with Families in Research

Chicago HIV Prevention and Adolescent Mental Health Project Collaborative Board
Chicago, Illinois

and

Collaborative HIV Prevention and Adolescent Mental Health Project
New York, New York

Year Started: 1993

Goal: To promote family communication on information, values, and beliefs and to achieve the highest level of family and community partnership in intervention research.

Overview of Program: The Chicago HIV Prevention and Adolescent Mental Health Project (CHAMP) Collaborative Board was conceived as a partnership between researchers at the University of Illinois and the community members where the research was conducted. A second project, the Collaborative HIV Prevention and Adolescent Mental Health Project, followed and included parents, school staff, community members, and university representatives from New York University in New York City. On the collaborative boards of both projects, community members represented the racial/ethnic diversity of the communities involved and formed vital components of the advisory boards. These boards shaped the design of the research, provided direction to the study, implemented the study, and took part in the analysis and dissemination of results. They also helped to initiate other studies.

History: The University of Illinois at Chicago received a grant from the National Institute of Mental Health to conduct research in two low-income communities in Chicago in 1995. The study team developed a model to include an advisory board that consisted of community members, school officials, parents, and representatives of the university. The board is half composed of university representatives and half of community representatives. The study tested a manualized multifamily group intervention. In 1995, Mount Sinai School of Medicine at New York University entered into a similar partnerships with communities in New York City, including East Harlem and the Bronx. In both cities, the boards developed subcommittees ranging from Implementation and Finance to Research, Grant Writing, Curriculum, and Leadership.

Positive Outcomes: The results of the study included enhanced family decision-making, improved parental monitoring, increased knowledge of information about HIV and a greater level of ease communicating about HIV and other sensitive topics. The study design, marketing, and implementation reflected the experiences of community members. Parents on the boards brought special influence to the study design because of their involvement as study participants and facilitators. Joint trainings of university and community facilitators were conducted.

Capacity: Target population for the studies was 9 to 11-year-old children and their families. Over 350 families participated in the Chicago study, and the initial number of board members ranged from 15-25.

Sources: Baptiste, D. R.; Paikoff, R. L.; McKay, M. M.; Madison-Boyd, S.; Coleman, D.; & Bell, C. (2005). Collaboration with an urban community to develop an HIV and AIDS prevention program for black youth and their families. *Behavior Modification, 29*(2), 370-416; McKay, M. M.; Hibbert, R.; Lawrence, R.; Miranda, A.; Paikoff, R.; Bell, C.; et al. (forthcoming). *Creating mechanisms for meaningful collaboration between members of urban communities and university-based HIV prevention researchers*. New York, NY: New York University Press.

Contact: For further information contact: Mary McKay Ph.D., Mt. Sinai School of Medicine, Department of Psychiatry, One Gustave L. Levy Place, New York, NY 10029.

Box 4: Strategy—Use Family-Driven Principles to Guide Research

The Family-Driven Research Study
Federation of Families for Children's Mental Health
Georgia Parent Support Network
ORC MACRO International
Atlanta, Georgia and Rockville, Maryland

Year Started: 1999

Goal: To apply principles of family-driven care to research and evaluation through a partnership between family members and researchers in the design and implementation of a research study.

Overview of Program: The Federation of Families for Children's Mental Health (FFCM), and one of its chapters, The Georgia Parent Support Network (GPSN) in partnership with ORC-MACRO are engaged in a multiyear research study of family engagement in systems of care. The study team includes five family/youth member researchers and two researchers from ORC-MACRO. All of the family member researchers have extensive experience with the child mental health system and two family member researchers have direct family member related experience with system of care grant sites. The family members of the team are African American, Native/American Indian and white. The team surveyed children's mental health stakeholders, including family members, advocates, service providers, and administrators, to surface major themes for the research. Five themes emerged, including: family and youth empowerment and involvement, accountability, provision of the full service array, culture, and services that were strengths-based. Based upon these themes, three research questions were developed that included:

- How are families engaged in systems of care?
- What supports or inhibits family engagement in systems of care?
- Is there a relationship between family engagement and child and family outcomes?

The research strategies adopted include mailed surveys, follow-up telephone interviews, focus groups, and data extraction from ORC-MACRO's longitudinal evaluation. Three communities in Indiana, Mississippi, and Minnesota are participating in the study.

History: In 1999, ORC-MACRO entered into a contract with The Federation of Families for Children's Mental Health (FFCM), and one of its chapters, The Georgia Parent Support Network (GPSN) to conduct a special study as part of its longitudinal evaluation of the Comprehensive Community Mental Health Services for Children and their Families Program, also known as the System of Care Program. The contract is supported by the Child, Adolescent, and Family Branch of the Center for Mental Health Services of the federal Substance Abuse and Mental Health Services Administration (SAMHSA) in contract with ORC-MACRO as the national evaluators of the System of Care Program. The family-driven study is due to be completed by the middle of 2006.

Positive Outcomes: Preliminary process outcomes include joint decision-making between family member and ORC-MACRO researchers throughout the study; the ability to apply research practices in concert with principles of family empowerment and engagement; consistent participation by a majority of the family-member researchers over the course of the study; and enhanced research and family engagement skills for team members. The team recently produced a report on lessons learned and recommendations on how to implement family-driven research.

Capacity: The findings of this study will impact policies and practices in systems of care and how research is conducted in system of care sites.

Source: Bates, B. (2005). *The family-driven research study: Lessons learned by families and researchers working together.* Atlanta, GA: ORC MACRO and Federation of Families for Children's Mental Health.

Contact: For further information contact: Shannon Crossbear, Co-Director of Training and Evaluation or Trina Osher, Co-Director of Policy and Research, Federation for Children's Mental Health, 9605 Medical Center Drive, Rockville, MD 20850.

Box 5: Strategy—Support Parent Empowerment

Parent Empowerment Program
New York State Office of Mental Health
Mental Health Association of New York State and Columbia University
New York

Year Started: 2000

Goal: To facilitate the empowerment and education of parent/family advocates or workers as a way to improve access to and the delivery of improved mental health services for children and youth

Overview of Program: The *Parent Empowerment Program* (PEP) was developed collaboratively by the New York State Office of Mental Health, the Mental Health Association of New York State, and researchers at Columbia University's Center for the Advancement of Children's Mental Health and Mount Sinai School of Medicine (Mt. Sinai). It was developed based on two theoretically-based interventions for engaging and empowering families. The National Institute of Mental Health has funded two ongoing projects to test the PEP in two settings: community-based mental health organizations and schools.

History: In 2000, representatives from the Mental Health Association of New York City (MHA-NYC) (G. Stolper, Director), the NYC Parent Resource Center, Columbia University (P. Jensen), Mt. Sinai (M. McKay), and Vanderbilt University (L. Bickman) began exploratory meetings, growing out of their shared concerns about the difficulties with access to and poor quality of services for minority children and families. Given these concerns, the collaborators decided to seek the most effective means of improving MHA-NYC's children's services. This team determined that the best means for improving access and quality would be through the development of empowered and knowledgeable families. As a result, the team began a systematic review of the literature and all available evidence concerning documented and manualized parent empowerment programs. Team members also contacted other university-based researchers across the country engaged in research in the area of parent empowerment, major mental health advocacy organizations, including the Federation of Families for Children's Mental Health, the National Alliance for the Mentally Ill, the National Mental Health Association, Children and Adults with Attention-Deficit/Hyperactivity Disorder, and federally supported technical assistance and training centers, to obtain all available training materials and manuals concerning parent empowerment strategies.

The search yielded only one program that met the criteria for (1) careful manualization and explicit training procedures, (2) empirical evidence supporting the efficacy of the intervention, and (3) feasibility—a self-efficacy intervention developed by Heflinger and Bickman (1996). However, the Bickman-Heflinger intervention was tested on largely Caucasian military families, not on families of color. In addition, the study occurred within an enriched continuum of services (Fort Bragg, North Carolina), not in a service-poor urban setting. Finally, the model did not fully engage community members as collaborators in delivering the empowerment intervention. Instead, the model was largely professionally driven and delivered. Parents were recipients but not agents of change.

Using a participatory collaborative model, the team obtained broader stakeholder input on how the manual might be most effectively adapted to the needs of MHA-NYC families. As a result, a collaborative board was formed, consisting of additional consumer-stakeholders (including parents and state/city policy representatives) to oversee the adaptation and implementation of the program. Decision-making authority is vested within this board and is shared equally among all partners. Ongoing opportunities for communication were built into the process. The board determined that several content areas needed to be added to the manual to help parents know exactly what to ask for. Thus, in addition to self-efficacy exercises, role-plays, and general training on how to access MHA-NYC's mental health, primary care, and school services, the board requested that specific additional information on common service issues related to depression, conduct problems, trauma/post-traumatic stress disorder, ADHD, comorbidity, and medication management be added. The manual is conceptualized as containing a flexible set of content areas, to which additional modules can be added as needed.

Positive Outcomes: The effectiveness of PEP is currently being tested and/or evaluated in three separate projects in two types of settings: community-based mental health organizations and public schools in New York State.

Capacity: A total of approximately 130 parent/family workers and 330 families are or will be participating in two research projects and one evaluation effort.

Sources: For further information contact: Kimberly E. Hoagwood, Ph.D., Professor of Clinical Psychology in Psychiatry, Columbia University and Director of Research on Child and Adolescent Services, New York State Office of Mental Health,1051 Riverside Drive, #78, New York, NY 10031.

I think one thing we are in agreement on right now, is that we cannot necessarily say we have a children's mental health system.

Charles Curie, Administrator, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services, July 17, 2003.

We still do not have an affordable, available system where if a family needs services that they can get what they need for their child and themselves.

A meeting participant.

Service Challenges from a Family/Youth Perspective

Strengthening Family Support in the Context of Services

The concerns that the meeting participants expressed about the status of services and service delivery clustered in four areas. First, and most importantly, they called attention to the importance of strengthening supports for families and youth through service delivery and reimbursement mechanisms. They stressed the critical role that families and youth play in children's mental health treatment, and the skills and knowledge families and youth contribute. They also emphasized how important it was that service providers strive to fully engage the family and maintain a standard to encourage their routine inclusion in discussions and decisions. Participants argued, often based on hard lessons, that survival in the mental health system would be easier for youth if parents are given the support and training they need to understand their rights, youths' rights, and what services are available. Additionally, the entire service system should strive to help families and youth develop their leadership skills and foster self-advocacy.

The participants also reported that the range of approaches to strengthening family and youth support is growing. For example, one of the most important developments over the past several years is the implementation of culturally and linguistically responsive family support strategies that help families understand and navigate the systems as well as create peer support groups and self-advocacy (see Boxes 6 and 7 that describe such strategies in Tampa, Florida through Familias Latinas "Dejando Huellas" and in Minnesota through the Parent-to-Parent Program of the Minnesota Association for Children's Mental Health). Some programs also use family members as brokers to help the families, such as the Family League of Baltimore City in Baltimore, Maryland (see Box 8). In other areas, like Burlington County, New Jersey, family support and advocacy is delivered in conjunction with intensive case management and under the auspices of a care management entity (see Box 9).

Participants also reported strategies that link culturally responsive family support with receipt of particular types of services. For example, in Maricopa County, Arizona the Family Involvement Center (FIC) supports a range of child behavioral health reforms through a managing entity: ValueOptions. The FIC's Latino Support Center has increased access to family support services and facilitated the inclusion of a diverse range of family voices in policies and reform in conjunction with the Regional Behavioral Health Authority (RHBA), ValueOptions (see Box 10).

Box 6: Strategy—Address Linguistic and Cultural Barriers

Familias Latinas "Dejando Huellas"
Federation of Families for Children's Mental Health (FFCMH)
Tampa Bay Chapter
Tampa, Florida

Year Started: 2004

Goal: To promote the mental health of Spanish-speaking families and their children through advocacy, service, and support

Overview of Program: Familias Latinas "Dejando Huellas" is the only local organization created for and by Spanish-speaking community members to serve Hispanic children, youth, and their families with mental health needs. The organization focuses on highlighting the emotional, behavioral, and mental health needs of children and youth within the local Hispanic community and seeking resources and support to address those needs. Familias Latinas "Dejando Huellas" is an official chapter of the Federation of Families for Children's Mental Health and is the first in the nation* dedicated to addressing the mental health needs of Hispanic children and youth. Meetings and all official business are conducted entirely in Spanish.

History: Studies conducted in the Tampa Bay Area (1990-2000) indicated that Hispanic/Latino families were not receiving adequate mental health and other services mainly due to language and cultural barriers. The chapter had its first meeting in June 2004 when parents discussed their needs and their desire to organize a Federation chapter. Founders of the group struggled with how to reach families in the community. They concluded that by relying on parents and natural helpers with knowledge of how to successfully navigate the mental health services system they could help parents seek services for their children's well-being. The organization is an affiliate of the Hispanic Services Council (HSC), a local agency that refers families who are seeking mental health services for their children to Familias Latinas "Dejando Huellas."

A natural helper conducts home visit with families who schedule appointments with us to learn more about Familias Latinas "Dejando Huellas" and services that are available for their children. They conduct follow-up home visits and connect families with agencies and providers. Families learn to trust and have hope so they can say, YES WE CAN! Parents become motivated after attending support group meetings in the community where mental health issues are discussed. The organization provides education and orientation for parents, host conferences, presents at community events, and organizes social activities and celebrations. Parents are provided with education and orientation to becoming active and involved with their own communities.

Positive Outcomes: Familias Latinas "Dejando Huellas" includes a diverse membership representing various parts of the Tampa Bay Area. The group has increased awareness among mental health providers in Hillsborough County of the various cultural and linguistic barriers that reduce access to services for Hispanic families for whom English is a second language. The support group also anticipates expanding its membership over the next year and increasing representation of families from diverse Hillsborough County communities including Town 'N Country, Wimauma, and Plant City.

Funding: The group receives funding through a grant to develop community outreach services for school-based case management. Additional funds are being sought from local sources.

Capacity: Familias Latinas "Dejando Huellas" currently has 33 active members.

Contact: For further information contact: Luz Garay, Executive Director at (813) 974-6212, lgaray@fmhi.usf.edu or 11725 N. 17th Street, C102, Tampa, FL 33612.

* During its history, the Federation has established ties with a number of culturally specific family organizations, including an American Indian chapter Tiwahe Akil Nawikcacijipi based on the Pine Ridge Indian Reservation in South Dakota, translated in English as "Defend the Family," a Hispanic Chapter in East Little Havana in 1993, and the Parent Resource Network in Richmond. Both the Parent Resource Network and Tiwahe Akil Nawikcacijipi remain in operation. Sources: Ramona White Plume, Barbara Huff, and Mareasa Isaacs. Personal communication, 2006.

Box 7: Strategy—Develop Networks of Parent Support

Minnesota Association for Children's Mental Health Parent-to-Parent Program
Minnesota

Year Started: 2002

Goal: To build an information and support network of parents of children and youth with mental health problems from different cultural communities facing similar challenges.

Overview of Program: The Parent-to-Parent Program was created with the hope that by developing support groups and educating parents of children with mental health problems, they will learn to become advocates not only for their own children, but also for a more culturally and linguistically responsive system and to improve the mental health system overall. The program provides:

- A safe and familiar cultural environment in which parents can begin to understand their child's mental health needs.
- Knowledge and competencies to locate, access, and utilize available resources.
- Development of support networks of families of children with mental health needs.

History: The Ramsey County Children's Mental Health Collaborative funded the first Parent-to-Parent Program in 2002, which proved to be a huge success. The Parent-to-Parent Program was adapted from the National Disability Support Program of the same name. During the first year, membership in the program grew from four parents to 25 parents. In 2003, the Minnesota Association for Children's Mental Health (MACMH) began housing the program after witnessing the potential of the program to make a significant impact in culturally diverse communities in Minnesota.

Positive Outcomes: Parents enthusiastically participate in programs which are sensitive to their diverse cultures, languages, and beliefs. One parent, after being mentored by a parent in the program's philosophy, implemented a program in her community and now advocates for children's mental health at the local, state, and federal levels.

Funding: The program is funded by a variety of sources, including The Minneapolis Foundation, The Saint Paul Foundation, and The Blue Cross and Blue Shield of Minnesota Foundation.

Capacity: The Parent-to-Parent Program currently serves African-American, Somali, Latino, Hmong, and Cambodian cultural communities in Minnesota. In addition to culture-specific groups, St. Paul has a program for an open group. In total, the Parent-to-Parent Program serves approximately 140 parents.

Contact: For further information, contact Julie Ainsworth at (651) 644.7333, (800) 528-4511 (MN only), info@macmh.org or 165 Western Avenue North, St. Paul, MN 55102.

Box 8: Strategy—Develop and Enhance Family Advocacy

Baltimore Families First
The Family League of Baltimore City
Baltimore, Maryland

Year Started: 2005

Goal: To enable parents of children with developmental disabilities and mental health needs to access appropriate, culturally-sensitive services.

Overview of Program: The program employs three "Family Navigators," who themselves are family members of children with developmental disabilities or mental health needs, to provide parents of children with similar challenges with access to services and information, such as:

- Developmental Disabilities Administration resources and provider information
- Parent support groups
- Camps and recreational activities
- In-home behavioral support
- Evaluations and assessments
- Family preservation services
- Parent education
- Leadership training
- Interagency team services for children in need of services from multiple agencies
- Tutoring services
- Child care resources
- Special education advocacy, including assisting families at individualized education program (IEP) meetings
- Respite care
- Future planning services
- Financial assistance for families facing eviction or utility discontinuation
- Assistance at Juvenile Justice hearings

All of the services are provided free-of-charge to qualified families.

History: Baltimore Families First is an initiative of The Family League of Baltimore City, Inc. (FLBC), a quasi-public, nonprofit organization founded in 1991. Although it does not provide direct services, the organization is focused on encouraging family-centered, community-based, and culturally competent care and is dedicated to empowering families, engaging communities, and developing public-private partnerships.

Positive Outcomes: Despite its short tenure, Baltimore Families First has already prevented the eviction of seven families of children with auticism from their homes.

Funding: The program is supported by a federal Family Support 360 Implementation Grant through the Administration on Developmental Disabilities of Maryland and the (Maryland) Governor's Office of Children, Youth, and Families. The program's annual operating budget is $312,500.

Capacity: Between 50 to 60 families in Baltimore City with children with developmental disabilities and/or mental health needs ages birth-21 are served. The program responds to approximately 100 calls per year.

Contact: For further information, contact Robin El-Amin Family Navigator at (410) 662-5500, Ext. 267, rparentadvocate@aol.com, or 2700 North Charles Street, Baltimore, MD 21218.

Box 9: Strategy—Build Local Family Support Organizations

The Family Support Organization of Burlington County
Burlington County, New Jersey

Year Started: 2001

Goal: To provide one-on-one support, education, and advocacy for parents enrolled in intensive treatment in a care management organization as well as community outreach for other parents of children with behavioral, emotional, or mental health problems.

Overview of Program: The Family Support Organization of Burlington County supports four primary activities:

- Family Support Partners that ensure peer support and advocate for families involved with intensive mental health care management
- Community outreach efforts designed to engage families whose children do not receive intensive case management services through support groups and peer-driven events
- Youth partnerships that seek to empower youth with emotional, behavioral, or mental health needs as they join together in positive peer leadership and self-advocacy programs
- A call-in help line

History: The general movement towards the system of care philosophy led to a federal SAMHSA grant for a system of care effort in Burlington County. A family support organization emerged as a part of that effort. Soon afterwards, the state of New Jersey implemented systems of care throughout the state. Each county then had a fully funded family support organization with the mission of working extensively with parents of children enrolled in intensive treatment in care management organizations as well as outreach to the community.

Positive Outcomes: Parents involved with the strength-based, community-centered, family-driven organization have experienced encouraging results, such as:

- Improved access to services
- Increased knowledge about navigating the system
- Local, state, and national influence and leadership skills
- Decreased feelings of isolation
- Policy changes
- Shift in dynamics between professionals and parents

Funding: The Family Support Organization is primarily funded by the State of New Jersey in addition to various local grants. The annual budget is approximately $453,000.

Capacity: The Family Support Organization of Burlington County is staffed to support parents of 180 children enrolled in the care management organization. The organization works with parents until the parents believe they can self-advocate. The organization also attempts to involve as many community members as possible in their outreach efforts.

Contact: For more information, contact Deborah Kennedy, Executive Director at (609) 265-8838, Ext. 774, dkennedy@fsoburlco.org or Eayrestown Road, Lumberton, NJ, 08048.

Box 10: Strategy—Family Support and Service Coordination through Local Managed Care Organizations

Latino Parent Support Group
Arizona Family Involvement Center
Maricopa, Arizona

Year Started: 2003

Goal: To assist and support families and caregivers and to help policymakers, agencies, and providers transform systems to ensure children and youth with emotional, behavioral, or mental health disorders succeed in school, live with their families, avoid delinquency, and become productive adults.

Overview of Program: The Latino Parent Support Group is a program of the Family Involvement Center (FIC), which serves Maricopa County, the most populous county in the state of Arizona. The support group meets monthly and provides a complete dinner and on-site child care for participants. Using a mixed format of open agendas and scheduled speakers, the group offers a forum for parents to discuss their issues and gain insight from other parents' experiences. Support group meetings are conducted in Spanish. All materials are produced in Spanish and English. Through a special grant, FIC purchased an audio system that facilitates participation by speakers of English or Spanish in presentations, focus groups, and other activities by allowing real time translation into the other language.

History: The FIC evolved in 2002 out of Arizona's "300 Kids Project," a pilot project mandated following the settlement of Arizona's "Jason K" lawsuit. (See Box 21.) In October 2003, eight individuals attended a support meeting and the Latino Parent Support Group was formed. The Latino Parent Support Group became a natural feeder group for activities sponsored by the FIC. Other activities undertaken by the FIC, and consistent with state reform initiatives at the time, included assuring that parents were actively involved in the planning, training, and facilitating of the Arizona Model to providers who were in the process of hiring family members to be part of Child and Family Team wraparound services. FIC recruited family members, screened candidates, and made recommendations for hiring to providers who needed Family Support Partners. At the same time, the Regional Behavioral Health Authority (RHBA), ValueOptions, began to offer training for Arizona's new model for child behavioral health fashioned after the Jason K reforms. Meetings organized by FIC became a venue for parents and professionals to learn from each other.

Positive Outcomes: Major outcomes of the work of the Latino Parent Support Group include: increased access to family support services for families of culturally/ethnically and linguistically diverse backgrounds; expanded opportunities for input into local, regional, and state planning efforts to support families; creation and expansion of a corps of culturally, ethnically, and linguistically diverse individuals equipped to self-advocate and to advocate on behalf of others. Specific examples of these strategies include a focus group conducted in 2005 that brought to the forefront the access issues facing the Latino community; the recommendations of these "family voices" compelled providers, child-serving agencies, and the local RHBA to recognize the service disparities. As a result, these issues are now being addressed by ValueOptions and it is working directly with the providers to ensure delivery of higher-quality and more culturally and lingusitically appropriate services to the Latino community. Spanish-speaking parents recently participated in the annual Jason K planning meeting with the plaintiff's lawyers, Arizona Department of Health Services, ValueOptions, and the Comprehensive Service Providers under the managed care contract. All of the stakeholders were at the same table, and all were able to make recommendations.

Funding: Funding is provided by the Arizona Department of Health Services, Division of Behavioral Health Services, the RBHA (ValueOptions), and other sources.

Capacity: The Latino Parent Support Group has 184 active members. It employs two staff to facilitate at monthly meetings, as well as three respite child care providers for the 20 to 24 children who accompany their parents to meetings. FIC constituents include the parents and caregivers of over 15,000 children in the public behavioral health system.

Contact: For further information, contact Josie Gutierrez Bejarano at (602) 288-0155, Ext. 207, (602) 396-1753 (cell), josie@familyinvolvementcenter.org, or 1430 E. Indian School Road, Suite 110, Phoenix, AZ 85013.

We need to provide services where families are.

A meeting participant.

If we don't get treatment for [a depressed] mom, we are creating the next generation of problems for her kids. We don't have a way to connect the adult and the children's mental health systems.

A meeting participant.

Offering Developmentally Appropriate Services Where the Children, Youth, and Families Are

A theme that surfaced repeatedly during the discussions was that families and youth want services to be readily available and accessible in courts, schools, and other nonmental health settings and systems. Services should also be readily available for children living in communities with high rates of violence. Special services emphasized by the participants include quality education, especially in residential programs, classes for youth to acquire skills to live independently, transitional services for young adults aging out of the youth system, a family treatment system to better connect the adult and children's mental health systems, and early intervention programs. The meeting participants called for service providers to offer training and workforce development programs, with a special emphasis on stigma reduction. Training collaborations that involve universities and communities were recommended. Participants also called for a renewed emphasis to promote mental wellness and positive social and behavioral competencies as well as services linked to points of transition (such as young children transitioning into school or youth transitioning into the adult mental health system). They felt that too many services are still not strength-based and fail to incorporate building resiliency within communities. Parents and family members deeply want their children to have opportunities that promote skills that can be used in the real world and that capture the imagination of youth. One example of this is a project in San Francisco created by the Youth Communication Team of Pacific News Services, a multimedia organization. The project, The California Council on Youth Relations, provides a forum for youth advocacy and peer support and the opportunity to learn critical communication skills (see Box 11). Youth expressed the need for strengths-based prevention and intervention strategies that engaged them (see Box 12).

Service Recommendations from a Family/Youth Perspective

To strengthen family and youth support in the context of services, policymakers, researchers and providers should:

- Make family and youth support a funded and essential component of service delivery.
- Provide family-driven, youth-guided, and responsive services and supports in settings that are readily accessible to children, youth, and their families.
- Take family-driven and youth-guided services to scale.
- Promote mental wellness and positive social and behavioral competencies by engaging children and youth in interesting and appropriate activities.

Box 11: Strategy—Promote Youth Peer-to-Peer Advocacy, Support, and Skills Development

California Council on Youth Relations
San Francisco, California

Year Started: 2005

Goal: To provide a nonadversarial venue where young people can exchange advice, develop advocacy skills, and give input to policymakers and practitioners who make decisions that shape their daily lives and the systems that affect them—Child Welfare, Juvenile Justice, Foster Care, Mental Health, and Education.

Overview of Program: The California Council on Youth Relations (CCYR) is a new project of the Pacific News Service's Youth Communications Team. Working with youth and elders from a wide variety of community-based organizations, the project team developed a speakers' bureau of youth advisors with specific experience, knowledge, and wisdom in current systems that affect youth. The CCYR Speakers' Bureau provides access to the raw youth voice that is so often missing in discussions of youth systems, and builds constructive, productive working relationships among youth, policymakers, legislators, and service providers. Through their involvement in the CCYR, young people learn to function as advocates, activists, and advisors, affecting changes in themselves and in systems that directly impact their lives. In addition, the project's network of youth-oriented community-based organizations (CBOs) helps to create opportunities for youth to shape the CCYR agenda around their concerns, which include environmental justice, health, sexual health, homelessness, violence, emancipation, and education.

History: Pacific News Service (PSN), a 35-year-old nonprofit, began as an alternative news service for mainstream newspapers during the Vietnam War and has evolved into a multimedia organization dedicated to bringing the least-heard voices and ideas into the public forum. PNS's mission since the mid-1990s has been to create more inclusive communications through the content it produces and by developing and strengthening youth media and ethnic media outlets that reflect and serve the more disconnected segments of society. YO! Youth Outlook, the flagship youth project, integrates and incubates the work of several niche media projects: The Beat Within (incarcerated youth), Silicon Valley De-Bug (temporary workers), Sprawl (suburban voices), Roaddawgz (homeless youth), SNAG (Native Americans) and Afghan Journal. PNS also runs an ethnic media association. The Youth Communications' Team of which the CCYR is a part, uses writing, illustration, video, radio, and events to bring out unheard youth voices and promote civic engagement. In addition to the print publications above, PNS produces a weekly TV program for the local Warner Brothers affiliate; weekly radio spots for KMEL's Street Soldiers, KPFA's Flashpoints, Hard Knock Radio, and KALW's Upfront; and youth forums hosted at The Commonwealth Club. The CCYR young people who have experienced incarceration and foster care have become the experts and resources of strategic information for policymakers and practitioners.

Positive Outcomes: CCYR accomplished several major goals in its first year:

- Youth speakers' bureau of more than 50 young people with experience in the Juvenile Justice, Mental Health, and Foster Care Systems who are enthusiastic to speak publicly about their experiences and recommendations. Each month two to three new youth are recruited for the speakers' bureau.
- A 10-point plan for prevention and intervention strategies that will benefit the mental health of young people involved in county/state systems.
- Policy roundtables in Sacramento hosted by the California Research Bureau and attended by 300 people including: 20 youth speakers, 15 CBOs statewide, 4 legislators, and 50-70 policymakers.
- A DVD capturing the 10 core recommendations youth have made around mental health.
- 10 youth panels for a range of public and private organizations.
- Youth-led discussions with invited experts in the fields of education, juvenile justice, law, and policy reform. Invited guests have included Raquel Danoso, an educational policy analyst at the Latino Issues Forum; Gina Peralta, a Santa Cruz County probation officer; and Vylma Ortiz, a researcher on the disproportionate confinement of minorities.

Capacity: Youth Communication's Team serves more than 6,000 youth per year, 500 on an intensive basis.

Contact: For further information contact: Patricia Johnson at (415) 503-4170, pjohnson@newamericamedia.org, or 275 Ninth Street, San Francisco, CA 94103.

Box 12: Ten Strengths-Based Prevention and Intervention Strategies for Mental Health from California Youth Developed by the Youth Communications Team

Prevention
How can the Education, Foster Care, and Juvenile Justice Systems be improved to support young people's own efforts to maintain their mental health?

1) **Establish long-term relationships with adults.**
Maintain long-term relationships with adults who are available on a consistent basis. Knowing that an adult won't give up or go away opens the door for communication.

2) **Make meds make sense.**
Young people should be given a clear explanation of what their prescribed medication will do, including side effects and how they will feel when they stop taking it.

3) **Consider confidentiality.**
Make it clear upfront what information will be held confidential and what can not be held confidential so that the young person can make a safe decision about what to share.

4) **Seek culturally positive environments.**
Young people are often asked to heal in institutional environments. Allowing young people to design and affect their environments—from asking to meet their therapist in a donut shop to choosing pictures for the walls—will open them to positive adult relationships.

5) **Hear the youth voice.**
Young people should be considered experts on what they have experienced and what they need.

Intervention
What kinds of interventions change the mentality of young people who have experienced trauma so that they do not repeat the abuse or self-abuse they learned as coping tools?

6) **Cultivate personal interests.**
Using mental health funds and time to help a young person access music, art, sports, dance, or other activities can build self-esteem that has a life of its own beyond therapy.

7) **Fix the situation, not just the kid.**
Many young people need help finding jobs, apartments, or help with school. Adults who find practical solutions can gain the young person's trust in the healing process.

8) **Provide good information.**
Young people make great decisions when they have accurate information they trust.

9) **Avoid labels and stigma.**
Labels, like depressed, and even the words "therapy" and "mental health" carry a stigma that can turn young people off.

10) **Be a role model.**
Young people often respond positively to peers and adult mentors who have "been there" and can relate to their struggles as well as model successful life changes.

Source: YO!TV. (2006). *Bringing young people to the policy table: A year of discussions on mental health in foster care, juvenile justice, and education* [Documentary]. Sacramento and San Francisco, CA: California Research Bureau and Pacific News Service.

Delivering Evidence-Based Practices in the Context of Family and Cultural Values

Many participants raised issues concerning evidence-based practices. Evidence-based practices are clinical interventions and supports for which there is rigorous research that demonstrates their repeated effectiveness.[3] Concerns included the perception that training for evidence-based practices often indirectly incorporates concepts that lead to blaming parents; the belief that in practice, evidence-based treatments may limit the creativity and flexibility to attain the successful outcomes families and children desire; and, the impression that a disconnect exists between Medicaid reform and evidence-based practices. The participants noted one challenge was how to offer and sustain choices in providers, services, and supports that were congruent with the family's culture, especially in communities of color. Currently, there is little research to determine the impact of culturally specific, family-driven, and youth-guided interventions on the delivery of services. In particular, many successful community-based interventions and practices lack rigorous empirical evidence and need to be part of a research portfolio to determine and/or validate their effectiveness. Similarly, some practices deemed evidence-based lack family, youth, or community engagement components or other factors that may foster better adaptation in communities where initial testing was not done.

Family members and youth also reported concern that evidence-based practices have done little to facilitate implementation of policies to empower families and youth. From this perspective, they identified four important issues. First, they stated there should be equal respect for the expertise of all stakeholders, including parents, families, youth, professionals, community organizations, funding sources, and academic researchers. Too often, they do not feel this respect. Second, there is not always an honest appraisal of the limitations of evidence-based treatments. The existence of evidence to support a particular practice does not necessarily mean that a practice is appropriate in all settings for all children, youth, and families. Third, there is a general lack of recognition that evidence-based practices must be based upon and integrated with a system of care philosophy that emphasizes cultural competency, family and youth empowerment, developmentally appropriate practices, and community-based processes. As examples, they pointed to research that suggests inconsistent results when evidence-based treatments are implemented in real-world settings.[4] Lastly, they were concerned that debate on evidenced-based practices often involves use of complex language to define and address issues.

Strengthening Services and Supports for High-Need Youth

The participants also addressed the need for greater efforts to improve outcomes and the daily experiences for children and youth facing the highest levels of challenge. For example, despite the cost and recent attention to the issue, many states continue to send children and youth out of state in order to receive services, and many parents must still give up custody in order to access services. (See Box 13 for how Kansas, with support from the state's parent organization, has attempted to address custody relinquishment.) Many participants felt that the lack of progress on the issue of custody relinquishment reflects a lack of commitment to a community-based service delivery model.

A second concern was that the system of care approach was designed in order to bring together families in a unified system of care; participants noted that this vision of interagency coordination, family support, and individualized goal plans has yet to be achieved, except for a small number of children. Another area in need of improvement relates to continued problems experienced by children and youth placed in residential care. Residential care needs to be better integrated into the system of care to ensure appropriate predischarge planning and care continuity in the community. Participants also called for greater attention to better outcomes from residential care, including improved school success, reduced involvement with Juvenile Justice, better mental health functioning, and better success in permanent and stable living environments. These residential programs should better engage families and youth, and the care delivered in residential facilities

Box 13: Strategy—Decrease Custody Relinquishment

Kansas Home and Community-Based Services Waiver for Children with Serious Emotional Disturbance
Kansas

Year Started: 1998

Goal: To decrease need for out-of-home placement by increasing the range of community-based services eligible for Medicaid reimbursement.

Overview of Program: The Kansas Home and Community-Based Services Waiver (HCBS) for children with serious emotional disturbance (SED) expands the Medicaid eligibility of families whose incomes exceed standard thresholds by considering only the child's income for the waiver's purpose. Expanded Medicaid-reimbursable services include wraparound facilitation, parent support, respite care, and independent living support. With these new services as well as in-home therapy, case management, and attendant care, parents are presented with alternatives to out-of-home care and are able to keep their children at home and in their communities.

History: Kansas has a long history of embracing the wraparound process and of support from the federal government to create family-driven services. The U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) funded two system of care demonstration sites to develop community-based services. Data from these initiatives suggests that serving children with serious emotional disturbance in the community is cost-effective compared to state hospital care. An alliance between mental health providers, social services, and families (organized by Keys for Networking) influenced the state legislature to fund the waiver in 1998 and a statewide family system of care in 2000.

Positive Outcomes: An independent evaluation conducted in 2005 found that the waiver program led to improved access, quality, outcomes, and cost effectiveness. The children with SED covered under the waiver are more likely to be in permanent homes, have fewer interactions with law enforcement (99 percent had no law enforcement contact), and experience better school performance, including higher grades in school (87 percent were at or above average) and increased class attendance (85% had regular attendance) than children with SED who are not in the waiver program. In addition, 98 percent of services had documented wraparound team involvement and 96 percent of them were deemed family-centered. Annual per child cost for the waiver ranged from $4,613 in 2000 to $13,587 in 2003 compared to per child costs for hospitalizations of $24,972 in 2000 to $26,236 in 2002, and represented the lowest of any state-run care option (foster care, juvenile detention, residential care) for children with SED.

Funding: The waiver is funded primarily through Medicaid. Kansas is required to provide 39 percent of the funding. In 2002, the state began collecting parental fees from selected families with the means to contribute to a portion of the services for their children. Parental fees make up part of the state's portion of funding. The federal government provides the remaining 61 percent through its matching program. In 2002, the entire cost of the waiver was $6.5 million dollars, including a $2.5 million dollar contribution from the State of Kansas.

Capacity: In fiscal year 2004, approximately 2,000 children were served under the Kansas Home and Community-Based Waiver.

Sources: Adams, J. (2003). Testimony before the Senate Committee on Government Affairs. In Committee on Governmental Affairs, United States Senate. *Nowhere to turn: Must parents relinquish custody in order to secure mental health services for their children?* Washington, DC: U.S. Government Printing Office; Government of Kansas Homepage <www.kansas.gov>. Kansas Department of Social and Rehabilitation Services <www.srskansas.org/services/hcbs.htm>. Barfield, S. T.; Holmes, C.; Chamberlain, R.; Corrigan, S. K.; & Barket, A. (2005). *Home and community-based services: Mental health waiver for children and youth with severe emotional disturbance*. Lawrence, KS: University of Kansas School of Social Welfare, Children's Mental Health Research Group.

should more adequately address life skills development and ensure quality educational services (see Box 14).[5] An example of youth advocacy designed to improve residential treatment is described in Box 15.

A constant theme of great concern to both families and youth was the lack of supportive services for youth aging out of the mental health system. Youth leaders at the meeting expressed frustration at being trapped between two systems. The first system—the child and youth mental health system—creates policies that assert older youth are developmentally ready to enter the adult system based upon their age. However, the second system—the adult mental health system—is ill-equipped to meet older youths' needs as young adults.

Box 14: Mental Health Facts—Residential Treatment Programs

Prevalence

- There is documented decline in residential placements in some communities.[1]

Demographics

- Latino youth are less likely to enter placement than their peers.[2]
- African-American youth are more likely to be in placement than their peers.[3]
- African-American youth are more likely to be discharged into foster care than other youth and less likely to be discharged into permanent placement than other youth.[4]
- Males are more likely than females to enter residential treatment.[5]

Placement Needs

- An estimated 40 percent of the boys and nearly 30 percent of the girls in residential treatment could have been treated in the community, based upon their level of risk.[6]

Complex Needs:

- Youth in residential care are more likely to have suicidal tendencies, comorbid mental health conditions, and experience abuse and neglect.[7]

Factors Associated with Youth in Residential Placement

- Data from one state shows that the mean number of prior placements is increasing substantially.[8]
- In one state study, youth in residential treatment were seven times more likely to live away from their families and more than 15 times more likely to come from corrections than any other setting.[9]
- In one state longitudinal study, over 30 percent of youth in residential placement for the first time had experienced 11 or more prior placements with nearly 40 percent of youth entering from secure facilities.[10]

Aspects/Components of Residential Treatment

- One study documented that 43 percent of children and youth in residential treatment centers across four states received antipsychotic medication without a history of psychosis.[11]
- Family functioning was associated with positive outcomes for children in residential treatment, and the use of a family functioning assessment to determine placement was strongly associated with improved outcomes.[12]
- Residential and day treatment providers perform poorly when it comes to ensuring a smooth transition for children in their care, especially with regard to school records and standards.[13]
- More than a quarter of teachers and one-fifth of principals in residential and day treatment programs do not follow a state or local district mandated curriculum but one they have developed.[14]

Cost

- In 2002, states spent over $4.28 billion for children and youth placed in over 30,000 residential treatment facilities.15
- Nationally, per capita cost for residential treatment in 2002 average $14.7, and over 26 states spent more per capita, compared to total per capita children's mental health spending of $57.63 in 2003.[16]

Outcomes

- Youth with substance use disorders (SUD) and youth with affective disorders are more likely to experience negative outcomes.[17]
- Residential treatment for youth with mental health diagnoses was not predictive of positive outcomes.[18]
- Youth with SUD and externalizing disorders are more likely to move to more restrictive care levels.[19]
- In one state, more than 40 percent of youth discharged from residential treatment experienced negative outcomes (such as psychiatric hospital admission, detention, running away, or other residential placement).[20]

Sources: 1. Budde, S.; Mayer, S.; Zinn, A.; Lippold, M.; Avrushin, A.; Bromberg, A.; et al. (2004). *Residential care in Illinois: Trends and alternatives.* Chicago, IL: Chapin Hall Center for Children at the University of Chicago. 2. Ibid. 3. Pottick, K.; Warner, L. A.; & Yoder, K. A. (2005). Youths living away from families in the U.S. Mental Health System. *Journal of Behavioral Health Services & Research, 32*(2), 264-281. 4. See Budde, Mayer, Zinn et al., in Source 1. 5. See Pottick, Warner, & Yoder in Source 3. 6. Lyons, J. S. & McCulloch, J. R. (2006). Monitoring and managing outcomes in residential treatment: practice-based evidence in search of evidence-based practice. *American Academy of Child and Adolescent Psychiatry, 45*(2), 247-251. 7. See Pottick, Warner, & Yoder in Source 3. 8. See Budde, Mayer, Zinn et al., in Source 1. 9. See Pottick, Warner, & Yoder in Source 3. 10. See Budde, Mayer, Zinn et al., in Source 1. 11. Rawal, P. H.; Lyon, J. S.; MacIntyre, I. J. C.; & Hunter, J. C. (2004). Regional variation and clinical indicators of antipsychotic use in residential treatment: A four-state comparison. *Journal of Behavioral Health Services & Research, 31*(2), 178-188. 12. Sunseri, P. A. (2004). Family functioning and residential treatment outcomes. *Residential Treatment for Children and Youth, 22*(1), 33-54. 13. Gagnon, J. C. & McLaughlin, M. J. (2004). Curriculum, assessment, and accountability in day treatment and residential schools. *Exceptional Children, 70*(3), 263-283. 14. Ibid. 15. Center for Mental Health Services. (2002). *2002 state tables.* Table 15a. Expenditures (in Thousands of Dollars) By State According to Organization Type: 2002 IMHO. Rockville, MD: Substance Abuse and Mental Health Services Administration. 16. Center for Mental Health Services. (2005). *2002 state tables.* 15b. Expenditures Per Capita By State According to Organizational Type: 2002 IMHO. Rockville, MD: Substance Abuse and Mental Health Services Administration; Lutterman, T. (2004). Fiscal year 2003 state mental health agency revenues and expenditures: key findings [Power point presentation prepared for the National Association for State Mental Health Program Directors (NASHMPD). Alexandria, VA: NASMHPD Research Institute. Based on data from FY'2003 Revenues and Expenditures Study and 2004 State Profiles System. 17. See Budde, Mayer, Zinn et al., in Source 1. 18. Ibid. 19. Ibid. 20. Ibid.

Box 15: Strategy—Provide a Forum for Youth Voices

Community Alliance for the Ethical Treatment of Youth (CAFETY)
New York, New York

Year Started: January 2006

Goal: To create a forum for youth advocacy and support designed to develop and shape youth-guided policies and practices with a specific emphasis on the ethical treatment of youth with behavioral, emotional, and mental health problems in institutional settings.

Overview of Program: Community Alliance for the Ethical Treatment of Youth (CAFETY) developed a forum to connect youth who have attended abusive facilities. It currently focuses on unregulated and unlicensed residential treatment facilities and advocates for regulation and efficacy in treatment. It is committed to ending institutionalized child abuse and human rights violations in institutional settings. CAFETY provides youth with access to resources and tools to become better advocates in their community, to work toward ending the over-institutionalization of youth, and to increase access to community-based care.

History: Co-founders Charles King and Kathryn Whitehead, who met unexpectedly through unfortunate circumstances, chose to turn trauma into empowerment. They both attended unregulated facilities at a young age and both worked separately to advocate on behalf of youth incarcerated at the unregulated 'therapeutic' boarding schools they had attended. They soon realized that the ills they witnessed: perpetual human rights abuses, mistreatment of youth, and ineffective care at their respective schools, was not uncommon in residential care. Frequent contacts with other youth who also attended wilderness camps, therapeutic schools, and other programs and had virtually identical stories to their own, convinced them of the need for unity, transparency, and activism, as well as learning and empowerment. Thus CAFETY was formed. Through its group of core members, it joined the forces of youth who attended facilities across the United States and abroad. Each member is deeply committed to:

- Use their powerful stories to prevent further mistreatment of youth.
- Dedicate time and energy to influence policy that supports ethical practice and efficacy in the treatment of youth with behavioral, emotional, and mental health difficulties.
- Facilitate youth empowerment through education on what constitutes appropriate and ethical therapeutic intervention.

The group is acquiring nonprofit status. It plans to create a newsletter to disseminate information through written as well as visual artistic expression.

Positive Outcomes: CAFETY has successfully established its core group. It supports a virtual community for youth to share their experiences, empathize, and support one another. CAFETY has received positive feedback from youth who have found their voice in contacting Congress and contributing to efforts to change policy and law. It also established forums to educate youth by inviting experts like Dr. Charles Huffine to connect with youth and reestablish belief and trust in the mental health profession. CAFETY members regularly recruit other youth, inform the press, and network with like-minded-organizations and politicians in an effort to educate and bring attention to the mistreatment of youth at unregulated facilities.

Capacity: CAFETY has 118 members and 8 core group members from across the United States; it plans to expand its support base by forming youth chapters at various U.S. colleges.

Contact: For further information, contact Kathryn Whitehead at (917) 687-8639 or katw@nyc.rr.com; Charles King at (206) 417-5167 or jking222222@msn.com; or Bill Boyles (407) 506-8380 or bill.boyles@gmail.com.

As the focus on youth development and transitional services grows, positive service and support-linked strategies are emerging. For example, in Westchester County, the Youth Forum works to give youth facing mental health challenges the transition skills they need, building group support for the youth (see Box 16). A different approach, but with the same overarching goal of promoting knowledge, self-advocacy capacity, and skill building is reflected in the Peer-to-Peer Youth Transition Program developed by the Georgia Parent Support Network (see Box 17). This is a peer-to-peer program that employs older youth as mentors of younger youth and thus is a "two-fer," impacting both the younger and older youth in positive ways.

The participants also raised a more general set of seemingly intractable challenges that have been highlighted many times before. Treatment and other services provided to children and adolescents with mental health needs are still inadequate. Professionals, participants noted, often have negative attitudes, are not trained to meet the needs of the families, and do not represent the cultural and ethnic diversity of the communities they serve. Participants also listed an uninviting treatment environment, unequal distribution of resources, lack of accessible treatment options for children not in a formally funded system of care community, and lack of collaboration and sustainable infrastructure as major concerns with services. They also noted that respite care continues to be hard to locate (see definition below). One example where efforts to address these concerns are underway is highlighted in Box 18 where the California Mental Health Act is described. It mandates the expansion of culturally and linguistically competent approaches to service delivery and planning with the aim of eliminating racial, ethnic, and linguistic disparities in access and outcomes. It also requires county mental health authorities to engage families and youth in planning, service delivery, training, and other workforce development activities.

Respite Care

Respite care refers to temporary care of an individual in order to give family members or other caregivers a break from the daily tasks associated with caregiving, according to The Arc, a disability advocacy organization. Respite care at times involves overnight care. Research shows that respite care is associated with improved family and system outcomes. Caregivers who accessed respite care for children with mental health problems experienced increased optimism for caring for children at home and a decrease in some areas of caregiver stress. In addition, children and youth with mental health problems who accessed respite care realized more than two and a half times less out-of-home placement and a dramatic decline in average lengths of stay for those in out-of-home care. For more information on respite in general, see The Arc web site at <www.thearc.org>.

Source: Bruns, E. J. & Burchard, J. D. (2005). Impact of respite care services for families with children experiencing emotional and behavioral problems. *Children's Services 3*(1), 39-6l. Retrieved February 10, 2006, from <www.leaonline.com/doi/abs/10.1207/S15326918CS0301_3>.

Recommendations for High-Need Youth from a Service Perspective

To take family-driven and youth-guided services to scale, policymakers and practitioners should:

- Provide services and supports in settings that are readily accessible to children, youth, and families.
- Require cross-system accountability for improved outcomes as a condition for funding based upon developmentally appropriate, family-driven and youth-guided practice.
- Require greater accountability for improved outcomes for children and youth as a condition for funding residential treatment providers.
- Foster adoption of family-driven and youth-guided evidence-based practices that work in community-based settings and with diverse populations.
- Infuse family-focused, culturally competent and developmentally appropriate principles across all mental health services, not just those delivered in the context of systems of care.

Box 16: Strategy: Provide Peer-to-Peer Support Opportunities and Facilitate Youth Empowerment

Family Services of Westchester County, New York: Youth Forum
Westchester County, New York

Year Started: 1993

Goal: To create a forum for youth with mental health needs that connects peers through recreational activities and support groups, improves mental health services in Health, Justice, and Education Systems, advocates for other youth with similar issues, and educates others in order to reduce the stigma associated with mental health problems.

Overview of Program: Youth Forum is a peer-led, peer-driven support program that provides opportunities for youth between the ages of 16-24 that have experience with the Mental Health, Criminal Justice, Special Education, and/or Child Welfare Systems. The program meets twice a week for two hours and includes dinner. The youth developed "Knowledge Nights," which are support nights that help educate youth regarding various topics, including hygiene, self-care, self-esteem, sex education, anger management, slam poetry, and drama. The program is voluntary, has an open door policy, and allows members to choose what night they wish to attend. The program also includes peer support projects, such as "rap sessions," advocacy, outreach, and leadership initiatives. Additionally, Youth Forum promotes social activities such as movies, picnics, bowling, and trips to New York City. Youth Coordinators help educate school officials, mental health professionals, probation officers, and others about issues relating to mental health. Youth Coordinators also speak at conferences, participate in training panels at a local and national level regarding the stigma of mental health, attend and facilitate aging-out network meetings and support circles, and lead various subcommittees.

History: In 1993, Westchester County Department of Community Mental Health staff and parents of children with special needs began noting that there were very few services for older adolescents and young adults who had been "heavy users" of mental health, special education, juvenile justice and residential treatment services. Many of these young people had been out of the community for extended periods in residential, detention, or hospital settings and had difficulty fitting in again once they returned home. These young adults began expressing dissatisfaction with some of their experiences and requested opportunities for peer support services. As a first step in providing a group socialization experience, and to give the young people an avenue to express their dissatisfaction, Westchester County Department of Community Mental Health, working in conjunction with Family Ties, a Westchester grassroots parent support organization, invited a group of older adolescents and young adults who considered themselves veterans of the child serving systems, to present their ideas, criticisms, and suggestions for change to the Westchester Department of Community Mental Health and the Family Ties organization. The Children's Mental Health Services Director promised the group that whatever emerged would have the attention of the Commissioner of the Department. The Family Ties founder also pledged that the parents' group would give top priority to whatever emerged from these efforts.

Positive Outcomes: The program has grown tremendously since its creation. Over 104 youth participate in the program and on any given "Knowledge Night," 12 to 18 youth attend.

Funding: The program was previously funded through a federal SAMHSA grant and the Westchester Youth Bureau. Currently, Youth Forum receives $40,000 from the Youth Bureau of Westchester. Family Services of Westchester matches this amount. Youth Forum is also in the process of fundraising.

Capacity: Youth Forum currently serves over 104 youth throughout Westchester County, including the communities of White Plains, Yonkers, Mt. Vernon, New Rochelle, and Peekskill.

Contact: For more information, contact Kimberly Cuccia, Program Coordinator, at (914) 872-5287 or kcuccia@fsw.org or peer leaders at (914) 872-5280 or 1 Summit Avenue, White Plains, NY 10606.

Box 17: Strategy—Institutionalize Transitional Support for Youth

Georgia Parent Support Network: Peer-to-Peer Program
Georgia

Year Started: 2004

Goal: To hire young adults age 18 and older transitioning into the adult mental health system to be mentors to youth ages 16-17.

Overview of Program: In order to support a seamless transition to the adult mental health system, Georgia Parent Support Network developed a program for young adults ages 17-24 that includes:

- Life skills development
- Financial management
- Educational opportunities
- Employment support
- Linkages to mental health services

History: The Peer-to-Peer Program grew out of a small system-of-care pilot program that provided services to children and youth until their 18th birthday. Once they turned 18, young adults in need of mental health services were referred to the adult system with no transitional support. Consequently, many of the youth ended up in jail or homeless. The Peer-to-Peer Program expanded on the original pilot by employing the older youth to mentor younger youth. In addition to mentoring, the participants learn to create life plans as well as gain professional skills in fundraising and presentations. The Peer-to-Peer Program benefits both the young adults as well as the youth currently in the child mental health system by creating peer networks, engaging youth in educational experiences, exposing them to travel, and providing career development opportunities.

Positive Outcomes: Since the program is relatively new, there is currently no longitudinal evidence supporting its success. However, there is anecdotal evidence of young adults with significant mental health disabilities achieving impressive goals such as job placement after participation in the program.

Funding: The Peer-to-Peer Program is funded through a variety of sources, including the federal Community Mental Health Services (CMHS) Block Grant, Medicaid, and private fundraising. The portion of funding from the CMHS Block Grant is part of its adult mental health allocation. The annual budget is approximately $125,000.

Capacity: The Peer-to-Peer Program currently has four paid staff members and nine youth participants.

Contact: For further information, contact Anna McLaughlin, Chief Executive Officer, at (404) 758-4500, Anna.McLaughlin@GPSN.org, or 1381 Metropolitan Parkway, Atlanta, GA 30310.

**Box 18: Legislation that Strengthens the Family Voice and Services 1—
Mandated Family Involvement: California Mental Health Services Act (2005)**

The California Mental Health Services Act (MHSA), formerly Proposition 63, became law on January 1, 2005. The MHSA, a ground-breaking mental health financing law, imposes a 1 percent tax on any income in excess of $1 million and establishes a Mental Health Services Fund. The tax will raise an estimated $600 million per year.

The law was established with the following goals:

- Define serious mental illness among children, adults, and seniors as a condition deserving priority attention, including prevention and early intervention services, and medical and supportive care.
- Reduce the long-term adverse impact on individuals, families, and state and local budgets resulting from untreated serious mental illness.
- Expand the kinds of successful, innovative service programs for children, adults, and seniors begun in California, including culturally and linguistically competent approaches for underserved populations.
- Provide state and local funds to adequately meet the needs of all children and adults who can be identified and enrolled in programs under this measure.
- Ensure that all funds are expended in the most cost-effective manner, and services are provided in accordance with recommended best practices subject to local and state oversight for accountability to taxpayers and the public.

In fiscal years 2005-2008, 10 percent of the funds will be allocated for education and training purposes. This includes strategies to increase the number of qualified mental health providers and to integrate the perspectives of family members and mental health consumers into training and educational initiatives. Twenty percent of the funds generated will be dedicated to prevention and early intervention programs to support outreach to educate Californians regarding the early signs of mental health disorders, improve access to medical care for children with severe mental illness, reduce negative outcomes resulting from untreated mental illness, and diminish stigma and discrimination from mental health problems. Ten percent is also allocated for county-level prevention, innovation, and system of care services. Five percent of the funds are set aside for innovative programs that increase access for underserved groups, improve quality of services, and promote interagency collaboration. The remainder of the funds is reserved for city and county mental health programs for services to children and adults with serious emotional disturbance and serious mental illnesses. While there are no specifics on evaluation, the law establishes principles for an inclusive planning process, and the state mental health authority has identified specific outcomes associated with the funding.

Source: California Department of Mental Health home page: <www.dmh.cahwnet.gov/MHSA/>.

Policy Issues from a Family and Youth Perspective

The participants focused on two types of policy challenges: first, eliminating some of the policies in place that are counter to efforts to place families and youth in the center of a responsive service system and to the system of care values that have governed so much of the children's mental health reform efforts, and second, strengthening the policy and fiscal infrastructure to better support families and youth in research, services, and advocacy.

Eliminate Harmful Policy Practices

One of the most harmful policies to which participants pointed, permits, and in some cases, requires families to relinquish custody of their children in order for them to receive services. (See definition below.) This is a longstanding challenge, and although a number of states have developed legislative responses, the practice continues. In 2003, the U.S. General Accounting Office reported that at least 12,700 families relinquished custody of their children in order to receive mental health services.[6] A study on custody relinquishment policies suggests that laws and policies that prohibit this practice must be accompanied by policies that promote service expansions to be most effective.[7] One approach that some states have used is to implement the Home and Community-Based Waiver of the federal Medicaid program as described in Box 13. Efforts to enact national legislation to address this situation have not been successful.

Custody Relinquishment

Custody Relinquishment refers to the practice of "voluntarily" giving up one's child or children to the Child Welfare System in order to access mental health services for them.

A different example of a policy in need of amendment cited by the participants focuses on a particularly problematic component of the Supplemental Security Income (SSI) program (see Box 19). Some participants, especially youth, contend that the SSI program does not match their evolving needs.

Box 19: Mental Health Facts—Supplemental Security Income (SSI) Eligibility and Work Incentives

- Eligibility for SSI requires that a child or adolescent must meet income eligibility criteria and have a physical or mental condition that results in "marked and severe functional limitations" that has lasted, or is expected to last, at least 12 months, or is expected to result in death.[1]
- Over 30 percent of youth on SSI are youth with mental health impairments.[2]
- In 2005, a monthly cash payment of $579 represented the maximum federal payment for SSI for an individual with a disability.[3]
- Participants, advocates, and researchers worry that the program contains inherent disincentives to work that are exacerbated when a child turns age 18.[4]
- The law requires that at age 18, a young adult already enrolled in SSI must undergo a SSI redetermination process.[5]
- One report suggests that more than 25 percent of child SSI recipients lost their benefits upon turning 18 as a result of the redetermination process.[6]
- Complex work rules for SSI and Medicaid are a major impediment to working for young adults. In addition, both child and young adult SSI recipients risk losing their SSI and/or Medicaid benefits if their incomes become too high.[7]
- According to one national study, only 25 percent of former child SSI recipients were enrolled in Medicaid, and over 50 percent were uninsured.[8]
- Work incentives introduced in 1999 have not gained as much traction as initially expected. The National Survey of Children and Families (NCSF) revealed that only 22 percent of child SSI recipients know about these work incentives.[9]
- In FY 2005, $12.4 million was earmarked for the SSI Youth Transition Demonstration designed to enhance incentives to work.[10]

Sources: 1. U.S. Social Security Administration. (2006). *Social Security: Benefits for children with disabilities* (SSA Publication No. 05-10026) <www.ssa.gov/pubs/10026.html>. 2. Bazelon Center on Mental Health Law. (2005). *Moving on: Federal programs to assist transition-age youth with serious mental health conditions* <www.bazelon.org/publications/movingon/>. 3. U.S. Social Security Administration. (2005). Introduction. In *2005 annual report of SSI* <www.ssa.gov/OACT/SSIR/SSI05/index.html>. 4. Wittenburg, D. & Lopest, P. (2003). Policy options for assisting child SSI recipients in transition. Washington, DC: Urban Institute. Paper prepared for Ticket to Work and Work Incentives Advisory Panel <www.urban.org/UploadedPDF/410872_SSI_Kids.pdf>. 5. See Source 3. 6. See Source 2. 7. See Wittenburg & Lopest in Source 4. 8. Lopest, P. & Wittenburg, D. (2005). *Choices, challenges, and options: Child SSI recipients preparing for the transition to adult life.* Washington, DC: Urban Institute <www.urban.org/UploadedPDF/411168_ChildSSIRecipients.pdf>.

Policy Recommendations from a Family/Youth Perspective

To address harmful practices and policies, policymakers at both the state and federal level should:

- Eliminate the practice of custody relinquishment in exchange for mental health services for children and youth.
- Amend rules governing Supplement Security Income to remove work disincentives for youth with mental health problems.
- Implement administrative practices that strengthen the family and youth voice.
- Support organizational and leadership development for family and youth advocacy organizations.

Strengthen Policies that Promote a Strong Family Voice in the Broader Policy Framework

Participants recommended adoption of policies at the state and national levels that promote a recovery/resilience framework such as one that ties funding to a requirement that grantees partner with and train families and youth in order to develop a useful service system for all parties involved. They also suggested devising a user-friendly policy assessment tool to help families evaluate policies that impact children, youth, and families.

Strengthen the Policy Infrastructure for Families and Youth

Participants identified three major approaches to facilitating family and youth empowerment in children's mental health practice and policy. These encompassed: inclusion of families and youth in research and planning (described earlier), organizational development for family and youth organizations, and promotion of a system of care framework that values the inclusion of families in a culturally responsive way. Overwhelmingly, family and youth participants agreed that when families and youth are included in all aspects of research and program planning, outcomes tend to be more positive. Family and youth involvement with professional researchers and service providers encompass many roles and levels, such as state and national mentors, family advocates and trainers, and training and education for family and youth. Of all their accomplishments, participants noted that the advocacy movement seemed to be most proud of moving the mental health system to embrace youth-driven "realistic" outcomes versus outcomes based solely on cost. They noted the importance of measuring the occurrence of families staying together, reduced hospital admissions and length of stays, less involvement with Social Services or Juvenile Justice, increased education on parental and youth rights, and larger community collaboration and involvement in the movement. Others in the field also point to the inclusion of families and family organizations in the Request for Proposal process and in the data that is being collected. They also spoke eloquently of the importance of having families sit at policymaking tables.

At the same time, they note that family and youth advocacy organizations that have played a significant role in these positive gains also have to grapple with difficult issues related to their growth and development, including:

- How to balance the need for independence and federal funding
- How to sustain a strong family voice without federal financing
- How to prevent external funding sources from causing conflict among family organizations over financial support and sustainability

The participants also highlighted ways in which family organizations are strengthening their internal infrastructure to become more effective policy advocates through joint planning and by developing networks and support groups. For example, recently, two organizations, the Federation of Families for Children's Mental Health and United Advocates for Children of California (a Federation chapter in California) undertook a strategic planning process to identify ways to strengthen the family advocacy movement. Federally

funded system of care sites have achieved some success by promoting the voices of families and youth and encouraging support at the national, state, and county levels. Other advocacy organizations are building on successful efforts to expand and find funding to sustain their vision. (See Box 20.)

The participants also called attention to the role of legislation and litigation in supporting families and youth empowerment, and in reducing harmful policies. For example, in Maryland, state efforts have been targeted to reducing the reliance on out-of-home placements. There, the state legislature mandated a role for families on the coordinating council charged with overseeing restrictions on the use of out-of-home placement for children and adolescents (see Box 20). In California, the recently enacted California Mental Health Services Act (see Box 18 above) embeds principles of family support and requires family members to be part of the county-level and state planning processes, as well as the oversight board. It also addresses workforce issues and mandates a five-year plan that increases human resource capacity, establishes regional partnerships to increase workforce diversity and reduce stigma, and promotes the hiring and use of family members as part of the mental health workforce and as trainers and planners in education programs. In other states, family and agency leadership have forged coalitions promoting effective change. In New Jersey, a strong partnership between county-level family support organizations (FSO) and care management organizations has resulted in a strong network of family support and advocacy (see Box 9 above). Rhode Island and Kansas were also mentioned as having strong policy-linked strategies promoting youth and family empowerment.

In other states, litigation has been a catalyst. For example, in Arizona, the Jason K litigation was the catalyst for the kind of family support service-linked strategy highlighted in Box 21). In Alabama, RC v Hornsby radically altered the delivery of services to children, youth, and their families (see Box 22). As a result of the litigation, family member inclusion has been institutionalized in managed care through service and support roles (as described earlier, in New Jersey and Arizona).

Box 20: Legislation that Strengthens the Family Voice and Services 2—Out-of-Home Placement
Maryland House Bill 1386 (2002)

Maryland House Bill 1386 was signed by then Governor Parris Glendening on April 25, 2002. An important component of the legislation included appropriate use of out-of-home placement for children. The statute proposed to reduce unnecessary out-of-home placements by establishing and maintaining a government fund that set aside resources for services to prevent out-of-home placements. The centerpiece of the legislation emphasized family- and child-oriented services, early intervention, interagency efforts to maximize all available financial resources, and fiscal incentives to encourage more efficient uses of state funds for child and family mental health services. The legislation mandates that a parent or parent advocate be a member of the local coordinating council that also includes representatives from various governmental systems and service organizations. Parents and caregivers may receive assistance in determining their child's need for services and referral to public and private resources, as well as the local coordinating council. Baltimore Families First, a program profiled in this report, is partially funded through this legislation.

Source: Maryland General Assembly bill information page: <mlis.state.md.us/2002rs/billfile/HB1386.htm#Sponsors>.

Although not a major focus, the participants also identified ways that the federal government could be more supportive of a strengthened family and youth voice in shaping services and policies for children and families facing mental health challenges. For example, family members and youth participants voiced concern that the Substance Abuse and Mental Health Services Administration (SAMHSA), the federal agency charged with oversight for child mental health, did not always model administrative practices consistent with support for strengthening the family and youth voice. Thus they questioned the restrictions on technical assistance to funded system-of-care sites when all states could benefit from support to develop systems of care. They also pointed out that despite widespread support and encouragement of blending and braided funding at the local level, federal agencies do not routinely model or encourage this except in demonstration programs. Finally, the participants raised concerns that while SAMHSA funds multiple technical assistance centers, only a small proportion of technical assistance supports the development of family and youth support, advocacy, and organizations.

Box 21: Litigation that Spurred Reform 1—Jason K. v. Eden Settlement (Arizona, 2001)

The Jason K. v. Eden settlement in 2001 made significant changes to the provision of child behavioral health services in the state of Arizona. In the settlement, the state adopted a vision that included children, youth, and families at the center of care delivery and supports. The state concurred with: 1) a set of principles to guide the system of care; 2) outcomes-focused benchmarks for implementation and quality improvement; 3) stipulations for training; and, 4) conducting a pilot program, funding flexibility, and service expansion, including substance abuse and Medicaid benefit redesign. Highlights of the settlement include: respite care as part of the Medicaid benefit set; increases in capacity for specialty providers; a demonstration "300 Kids Project" to serve as a model for services reform; a training program using a family-centered, strengths-based approach focused on unified assessments and care planning; development of child and family teams; and implementation of the wraparound process. The 12 Jason K. principles embedded in the system of care encompass the following:

- Respect for collaboration with the child and family
- Adoption of functional outcomes
- Cross-system collaboration
- Service accessibility
- Incorporation of evidence-based practices
- Treatment in the most appropriate settings
- Timely access to services
- Strength-based, family and child tailored services
- Focus on stable child placement
- Respect to child and family cultural background
- Support for services to support independence
- Anchoring and connection to natural supports

Box 22: Litigation that Spurred Reform 2—The Case of R.C. v. Hornsby (Alabama, 1988)

R.C. v. Hornsby (Alabama) represents a milestone in Alabama case law. Stemming from a landmark lawsuit, it is touted as the first "bottom-up" reform of the Child Welfare System in the United States. The 1988 lawsuit centered on "R.C.," an 8-year old boy in state custody who was committed to a state psychiatric hospital, despite the fact that he had never been diagnosed with a psychiatric disorder. After R.C.'s father objected to the boy's care, the father was denied visitation rights. Protracted negotiations between representatives for R.C.'s father and the state led to an out-of-court settlement in 1991. The agreement compelled the state to adopt a family-centered response to meeting the mental health needs of children in the Child Welfare System. Alabama counties now emphasize the importance of family preservation while taking into account each child's individual situation and needs. State officials, plaintiffs' attorneys, and experts, county workers, and family and youth stakeholders all collaborated in developing a set of principles and values to guide a reformed strength-based system. R.C. v. Hornsby mandates the creation of a new system of home- and community-based care for children with mental health disorders in or at-risk for entering the Child Welfare System. Its ongoing implementation is supported by a multi-million dollar financial settlement and a plan detailing activities that:

- Promote stability and permanency in children's current living situations.
- Protect children from abuse and neglect.
- Maintain children's residence with or near their families when possible.
- Encourage academic achievement.
- Prepare the children to become productive and successful adults.

Source: Bazelon Center for Mental Health Law: <www.bazelon.org/issues/children/publications/rc/> or contact (202) 467-5730. A copy of the book describing the events surrounding the lawsuit can be ordered at the web site.

Promote Early Intervention

The group discussed the value of a public health framework for children's mental health. As opposed to the medical model that focuses on the individual alone, the public health model is population-based with a universal-focus and concentrates on the interplay of individuals, communities, behaviors, and social and cultural values. However, some participants cautioned that when embracing the public health model, some of the gains achieved, including special focus on the most seriously disturbed children, should be maintained. The public health model is a particularly useful framework because it allows for attention to earlier intervention through both a policy and practice lens, something that parents of children often call for when they recount their struggle to get help as soon as they knew something was wrong. One example of a legislative approach to addressing the challenge of early intervention is that of the Minnesota Association for Children's Mental Health; this parent support and advocacy organization was pivotal in the implementation of a 2003 law that requires continuing education credits related to the recognition of the early onset of children's mental health problems as a teacher certification requirement (see Box 23).

Box 23: Strategy—Link Policy to Action

Minnesota Association for Children's Mental Health: Teacher Training
Minnesota

Year Started: 2005

Goal: To train educators to understand risk factors, early warning signs, early intervention strategies, and educational implications of mental health challenges in children.

Overview of Program: The Teacher Training is a four-hour session that provides teachers with the ability to:

- Describe the continuum of mental health services
- Recognize key warning signs of mental health challenges
- Identify the impact a mental health problem has on a child's ability to learn
- Carry out the next steps for a child who exhibits key warning signs
- Follow confidentiality and privacy policies

History: In 2003, the Minnesota legislature passed a law requiring Continuing Education Credits on recognizing early-onset mental health challenges in children as a precondition for teachers' license renewal. The Minnesota Association for Children's Mental Health (MACMH), a parent advocacy and support organization, is one of the organizations that provides training to meet this requirement.

Positive Outcomes: Currently, over 2,000 teachers have been trained by MACMH to recognize key warning signs of mental health challenges and next steps to take once a problem has been identified.

Funding: Because the Minnesota legislature did not provide funding for Teacher Training, MACMH developed a fee-for-service training program. At times, MACMH is able to draw on other funding sources to defray the costs of the training program.

Capacity: MACMH conducts multiple trainings annually for the general educator population or for entire school district staff.

Contact: For further information, contact Wendy Mahoney at (651) 644-7333 or (800) 528-4511 (MN only), info@macmh.org, or 165 Western Avenue North, St. Paul, MN 55102.

Policy Infrastructure Recommendations from a Family/Youth Perspective

To strengthen the policy infrastructure to better support family and youth perspectives, policymakers and advocates should:

- Increase funding and other resources to support family meetings, including transportation, meals, and on-site specialized child care.
- Expand or create opportunities for policymakers and administrators to hear directly from families and youth.
- Build in policy requirements that give families and youth roles in policymaking bodies.
- Enhance networking capacity of parents, youth, and other family members.
- Invest in family and youth advocacy organizations and services directed by youth and families.
- Expand technical assistance offered by the federal government to states and communities that do not have formal system of care grants.
- Promote and fund the development of a public health model that embraces a universal focus on children's mental health and addresses the needs of the most troubled children and youth.

Toward the Future

Despite a rigorous discussion by family and youth stakeholders on the setbacks they experienced, a self-assessment of the advocacy movement reveals many contributions to the system of care and improved outcomes for children and youth with mental health challenges. Participants credited a strong family movement with the incorporation of a definition of empowerment and how it is used into the system of care philosophy. In addition, robust state and regional family organizations have emerged. The movement has brought attention to some difficult and intractable issues, such as stigma, custody relinquishment, spirituality, and language. Advocacy groups have also fostered recognition by funding entities, clinicians, educators, and policymakers that families and youth must participate at critical points in the prevention, care delivery, and support processes. Family organizations in states such as North Carolina, Georgia, Minnesota, and West Virginia (see Box 24) have created peer-to-peer support for families, youth, and the elderly. Other states, such as New York, California, and Florida, have created youth empowerment projects.

At the same time, there is much more to do. What the participants seek, and what most families want when they describe their vision for the ideal care and support system to ensure optimal mental health for children, youth, and families is a system of services and support founded on respect. The ideal system, they concluded, would recognize that families and youth are the center of the system; thus, any decision must be primarily based on the experiences and preferences of those being served. The ideal system would also reflect the comprehensive base of knowledge about effective strategies, including practice-based evidence and evidence gathered through controlled studies.

Participants also reiterated the importance of a culturally and linguistically competent mental health system. Members of the group said that services should not be "one size fits all;" rather, research and services should recognize that acceptability, language, and societal norms will differ by community. Additionally, they noted that it is important to realize, even within cultural communities, there are groups of individuals with little past representation and the ideal system should be up to the challenge of continuously adapting to all these needs. They also called for significant attention to the situation of historically underserved populations but also affirmed that all users of the mental health system deserve a seamless integration of general medical care, education, and other services.

Other key aspects of an ideal system include early identification and intervention and system administrators knowledgeable about the evidence on risk, resiliency, and protective factors. Increased education on the critical nature of early intervention and treatment and a better understanding of the role of risk and protective factors in preventing problems associated with lack of treatment will result in overall increased public awareness and support among policymakers, stakeholders, providers, and community organizations. There would be financial support for family-driven and youth-guided state planning entities as well as funding for strength-based services and positive outcome measurement. Above all, the participants emphasized over and over the importance of creating and sustaining an infrastructure that would embed support for families and youth in every aspect of research, services, and advocacy if we are to meet the shared family and societal goal of improving outcomes for children dealing with mental health challenges (see Box 25 for a Summary of Findings).

Box 24: Strategy—Establish and Maintain Statewide Family Organizations

Parent Support and Education
Mountain State Parent, Child, and Adolescent Network (MSP-CAN)
West Virginia

Year Started: 1993

Goal: To provide support, education, information, and referral for parents, families, and the community focusing on the emotional, behavioral, and learning needs of children and youth.

Overview of Program: MSP-CAN provides information, support, advocacy, and training to families of children diagnosed with serious emotional disturbance. In addition to fiscal consultation and organizational development services, MSP-CAN provides extensive family training services on issues such as parents as advocates, multidisciplinary team process, Individuals with Disabilities Educational Act (IDEA), positive behavioral supports, transitional services, attention deficit hyperactivity disorder (ADHD), mediation, support group development, Section 504, the individualized education plan (IEP) process, and legislative advocacy.

History: MSP-CAN began with a small group of parents of children with emotional, behavioral, or mental health challenges gathering at the Federation of Families for Children's Mental Health conference in Key Bridge, Virginia. Since then, MSP-CAN has grown into a statewide organization actively involved in public education for parents and professionals, advocacy for children with emotional problems, a support and referral system for families, and an active partner in a variety of collaborative efforts across the state of West Virginia.

Positive Outcomes: There has been a noticeable decrease in the number of children with severe emotional disturbance (SED) in out-of-home placement across the state. Additionally, school attendance has increased by 50 percent among children with SED. The numbers of discipline reports have decreased by 42 percent. The school graduation rate has increased along with a decline in the drop-out rate.

Funding: MSP-CAN's annual budget is approximately $200,000, of which the federal Community Mental Health Services Block Grant comprises 35 percent, the State of West Virginia provides 46 percent, and private funding covers the remaining 19 percent.

Capacity: MSP-CAN serves all 55 counties in West Virginia.

Contact: For further information, contact Teri Toothman, Executive Director, at (304) 233-5399, Ext. 5, or ttoothman@mpscan.org, or 1201 Garfield Street, McMechen, WV 26040.

Box 25: Summary of Findings

Overview: Family and Youth Speak

What Families and Youth Report Has Changed since Unclaimed Children, 1982

- Increased access to services
- Stronger "family voice"
- Evolving infrastructure that supports family and youth ownership of the system of care
- Enhanced systemwide focus on stigma reduction and positive outcomes
- Greater levels of respect for families as partners in an inclusive care delivery process
- More strategies and policies that serve to build trust between caregivers, youth, and providers
- Family members and youth as strong advocates for quality, accountability, and outcomes
- Expanded range of effective practices
- Development of family support practices
- Widespread dissemination and focus on evidence-based children's mental health practices

What Families and Youth Say Needs to Change

- Service delivery and supports need to be strengthened and expanded
- Research, treatment, and supports must include enhanced roles for families and youth
- Service array within the mental health system, across child-serving systems, and in different settings must be responsive to community needs and lead to positive youth outcomes
- Racial and ethnic disparities need to be addressed
- Stigma must be eliminated
- Mental health professionals and other service providers must reflect respect for the families and youth that they serve
- Custody relinquishment in exchange for services must be eliminated
- Funding policies that lack flexibility or foster dependence should be reformed
- Quality care and positive outcomes should be the prevailing standard for all services and supports, including residential treatment

What Families Want

- Research that is inclusive of families at all stages
- Increased access to outcomes data
- A family support/youth development-oriented policy assessment tool
- Policies that promote family support and youth empowerment that include funding, partnerships, and training geared towards family and youth advocacy
- A rigorous education campaign and inclusive advocacy agenda to foster greater family empowerment and support

Endnotes

1. For an overview of the research see: Hoagwood, K. E. (2005). Family-based services in children's mental health: A research review and synthesis. *Journal of Child Psychology and Psychiatry, 46*(7), pp. 690-713; and Friesen, B. J.; Pullmann, M.; Koroloff, N. M.; & Rea, T. (2004). Multiple perspectives on family outcomes in children's mental health. In M. Epstein; K. Kutash; & A. J. Duchnowski (Eds.), *Outcomes for Children and Youth with Emotional and Behavioral Disorders and their Families.* Austin, TX: PRO-ED Inc.

2. Christenson, S. L. & Havsy, L. H. (2004). Family-School-Peer Relationships: Significance for Social, Emotional and Academic Learning. In J. E. Zins; R. P. Weissberg; M. C. Wang; & H. J. Walberg (Eds.), Building Academic Success on Social and Emotional Learning: What Does the Research Say? (pp. 59-75). New York, NY: Teachers College Press.

3. A formal definition of evidence-based practices comes from Hoagwood and colleagues. "Evidence-based practice in the field of children's mental health research as been describes ad a body of scientific knowledge about service practices—for example, referral, assessment, and case management—or about the impact of clinical treatments or services on the mental health problems of children and adolescents. Hoagwood, K.; Burns, B. J.; Kiser, L.; & Ringelsen, H. S.; (2001). Evidence-based practice in child and adolescent mental health services. *Psychiatric Services, 52*(9), pp. 1179-1189.

4. McKay, M. M.; Hibbert, R.; Hoagwood, K.; Rodriguez, J.; Murray, L.; Legerski, J.; et al. (2004). Integrating evidence-based engagement interventions into "real world" child mental health settings. *Brief Treatment and Crisis Intervention, 4*(2), pp. 177-186.

5. For research on the association between family functioning and residential treatment outcomes see, Sunseri, P. A. (2004). Family Functioning and *Residential Treatment Outcomes. Residential Treatment for Children and Youth, 22*(1), 33-54.

6. U.S. General Accounting Office. (2003). *Child Welfare and Juvenile Justice: Federal agencies could play a stronger role in helping states reduce the number of children placed solely to obtain mental health services* (GAO Report No. GAO-03-397). Washington, DC: U.S. General Accounting Office.

7. Friesen, B. J.; Pullmann, M.; Koroloff, N. M.; & Rea, T. (2004). Multiple perspectives on family outcomes in children's mental health. In M. Epstein; K. Kutash; & A. J. Duchnowski (Eds.), *Outcomes for Children and Youth with Emotional and Behavioral Disorders and their Families*. Austin, TX: PRO-ED Inc.

APPENDIX A:
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APPENDIX C:
Families and Youth National Survey Questions

The National Center for Children in Poverty asked participants to develop questions that might be used in the upcoming national survey of state mental health directors for Unclaimed Children Revisited. The following represents a summary of the wide range of questions generated by the meeting participants, grouped by category:

Service Array

1) Does the state provide transitional services for individuals moving from the child to the adult care system?
2) Does the state support family and community placements over out-of-home or out-of-state residential care?
3) Is the state placing adequate resources into prevention, services, and supports for children at-risk for suicide?

Care Coordination

1) What proportion of youth in the mental health system is referred by other systems (such as educational, juvenile justice or child welfare)?
2) What proportion of youth served within the Mental Health System has also been involved with the Juvenile Justice and Child Welfare Systems?

Outcomes

1) What proportion of families in Child Welfare is reunited?
2) What proportion of youth served in your system is living independently?
3) What proportion of the youth served in your system is employed 10 years after leaving the system?
4) What is the average length of time a youth is served in the system?

Fiscal Issues

1) How many systems of care sites does the state support without federal funding?
2) How do states avoid fostering conflict among family organizations related to funding and sustainability?

Policy

1) Do you have legislation for children's mental health that is unfunded?
2) What policies are in place to prevent families from relinquishing custody?
3) Do you have policies that mandate use of evidence-informed practices?
4) What is your opinion of evidence-informed practices?
5) How widespread are their use?
6) Do you have language in all contracts that include families and youth in delivery of all services?
7) Do you enforce existing policies mandating family involvement?
8) When decisions are made at a local level, how do you ensure that practices reflect the true intent of the policy?

Advocacy

1) Do you have a family advocate and a youth advocate as part of the state decision-making team?
2) Do you support sustained activities that support the family and youth empowerment movement?
3) Are youth involved in a youth development board outside of a formally funded system of care site in your state?
4) Does the state research and collect data on the impact of family organizations?

Providers

1) What is the proportion of ethnic populations in your service area?
2) How representative is your staff of these populations?
3) What proportion of your staff receives training, including mentoring and coaching, regarding cultural competency?
4) What proportion of your workforce is comprised of family members?
5) What proportion of your workforce is comprised of youth ages 16-25?