Chapter Eight

**Family Driven
Services and
Supports**

Supporting Parent-Professional Collaboration through Strength-Based Assessment

Paul A. LeBuffe
Valerie B. Shapiro

Introduction

Since the publication of the Child and Adolescent Service System Program (CASSP) principles two decades ago (Stroul & Friedman, 1986), parent-professional collaboration has been a core value of the children's mental health system. Despite general agreement that behavioral health services for children should be "family-focused," this remains an elusive goal. For instance, active parent participation in school Individualized Education Plan (IEP) meetings is still not the norm. Turnbull, Turbiville and Turnbull (2000) summarize the research in this area by asserting that, "the IEP experience is a passive experience for most parents" (p. 637).

Two factors, one attitudinal and one technical, contribute to the continuing lack of parent-professional collaboration. The attitudinal barrier is the continued reliance on deficit or pathology-oriented assessments. The second barrier is the lack of technically sound, yet consumer-friendly, tools and techniques for encouraging, structuring, and supporting true collaboration.

Early intervention and behavioral health treatment programs continue to rely predominantly on deficit-oriented tools in assessing children and planning interventions. The two dominant behavior rating scales for use with children, the Achenbach System of Empirically Based Assessment (ASEBA; Achenbach & Rescorla, various dates) and the Behavioral Assessment System for Children (BASC-2; Reynolds & Kamphaus, 2004) both emphasize problematic behaviors. Even strength-based instruments such as the Behavioral and Emotional Rating Scale (BERS-2; Epstein, 2004) and the Devereux Early Childhood Assessment (DECA; LeBuffe & Naglieri, 1999) include deficit-oriented scales.

Although research is scarce, the use of problem-oriented assessments presents clear impediments to effective collaboration. Parents of children with problematic behavior often report that parent-teacher conferences are approached apprehensively. Parents know that they are going to be confronted with evidence of their child's misbehavior and its negative effects on the other children, the teacher, and the program. Naturally, parents often react defensively to this information either by withdrawing or by challenging the findings. Both reactions limit the likelihood of true partnership in support of the child and family.

Even when practitioners have embraced a strengths perspective, they may lack empirically sound approaches for eliciting the parent's perspective, engaging in dialogue around their child's strengths and needs, and developing a joint plan to support the development of the child. A desire to collaborate is necessary but not sufficient; practitioners need research-based tools to structure and support collaboration.

The remainder of this paper explores the DECA, a strength-based assessment for children ages two through five, and more specifically, the DECA rater-comparison techniques. Research on the utility of the DECA in promoting and sustaining parent-professional and cross-system collaboration were presented in the remaining two papers in this symposium (Thomlinson, D'Angelo & Maples, 2007; Rosas, Chaiken & Case, 2007). Knowledge of the DECA and its application in supporting collaboration will benefit practitioners in early childhood including teachers, mental health consultants and program administrators as well as parents and children.

Key Features of the DECA

The DECA is a nationally normed (n = 2,000) behavior rating scale that assesses within-child protective factors related to resilience in preschool children. The DECA provides four strength-based scales: Initiative, Self-Control, Attachment, and Total Protective Factors, as well as a 10-item behavioral concern screener. Developed to support the healthy social and emotional development of at-risk

preschool children, the DECA is now used in over 2,000 Head Start programs, early intervention programs and county and statewide systems of care.

The DECA was specifically designed to support parent-professional collaboration. Tools and techniques were developed in four areas to promote partnerships: data collection procedures, data analytic techniques, data presentation tools, and joint home-school strategy planning resources. Together these four areas provide opportunities for parent involvement and family-focused service delivery from assessment through outcome evaluation. Each of these techniques will be briefly described below.

Data Collection Procedures

The DECA best practice model recommends that parents and teachers complete a DECA on the child at the same time. In contrast to some other behavior rating scales, the DECA presents the same set of items to both parents and teachers. This allows for direct comparisons of the findings from the two raters, which facilitates discussion. In addition, DECA training and supplemental resources provide guidelines on how to invite parents to participate in the assessment process.

Data Analytic Techniques

A key element of the DECA is the comparison of the ratings provided by the two raters. The goal is to identify areas in which the two raters have the same perception of the child's strengths and needs, and areas in which their perceptions differ. There is no presumption that one rater's view of the child is more accurate or reliable than the other.

To ensure that DECA users do not over-interpret small differences in ratings, the DECA manual provides a series of tables that present the minimal T-score differences between raters required to achieve statistical significance. These minimal differences are calculated using the standard error of the difference and provide guidance on which differences represent a true difference in the perception of the child's behavior, and which merely reflect chance variation. Unlike some behavior rating scales which provide an overall index of agreement, the DECA allows the raters to compare ratings on each scale, thereby identifying specific areas of agreement or variance of perception.

The DECA rater comparison technique enables parents and teachers to identify, in a methodologically sound way, areas where they agree and areas where they differ. This, in turn, facilitates a discussion about the child's behavior in the home and school settings. In these discussions, each rater can relate effective strategies for supporting the child's emerging skills, or express frustration or concern over the child's difficulties. The ultimate goal is two-fold. First, to obtain a richer, cross-informant and cross-environment understanding of the child, and second, to foster a sense of partnership based on equal contribution to the assessment of the child.

Data Presentation Tools

A key element of the DECA administration and interpretation is the Individual Child Profile. This is a graphic representation of the child's strengths and needs in the areas assessed by the DECA. On the profile, the parent's and the teacher's assessment results are presented side by side. Importantly, the parent's results are presented on the left side of the profile, conveying that their results come first. In practice, this encourages the professional to discuss the parent's perspective before presenting their own. This simple tool conveys respect for, and the primacy of, the parent's view of their child.

Joint Home-School Strategy Planning Resources

The National Association for the Education of Young Children (1987) maintains that assessment only has value if it leads to improved outcomes for children. Consequently, DECA assessment results are utilized to plan coordinated strategies to enhance the social and emotional strengths of the child in both the home and school settings. Two resources are consulted in this meeting: a strategy guide for teachers and a similar guide for parents.

In summary, in the recommended practice model, parents and teachers simultaneously complete a DECA on the child, compare their results using the rater comparison tables and the individual child profile, identify areas of common concern and jointly select complementary strategies to implement at home and school to support the child. Finally, parents and teachers meet periodically to assess the child's progress.

Conclusion

The DECA is the first standardized, published measure of within-child protective factors related to healthy social and emotional development in preschool children. One of its contributions to the field is to provide empirically sound and practical tools for eliciting, structuring and sustaining parent-professional partnerships. Since the publication of the CASSP principles in 1986, the parent-professional partnership has been a core value of childhood behavioral health systems of care. Other research will demonstrate the degree to which use of strength-based, empirically sound approaches such as the DECA actually result in increased parent-professional and cross-system collaboration; this discussion provides one instance of how well designed tools can move us closer to achieving that goal.

References

Achenbach, T. M. & Rescorla, L.A. (various dates). *The Achenbach System of Empirically Based Assessment*. Burlington, VT: Research Center for Children, Youth and Families at the University of Vermont.

Epstein, M. (2004). *The Behavioral and Emotional Rating Scale-Second Edition*. Austin, TX: Pro-Ed

LeBuffe, P. A. & Naglieri, J. A. (1999). *The Devereux Early Childhood Assessment*. Lewisville, NC: Kaplan Press.

National Association for the Education of Young Children Position Statement. (1987). *Standardized testing of young children through 8 years of age*. Washington, DC: Author.

Reynolds, C. & Kamphaus, R. (2004). *The Behavioral Assessment System for Children-Second Edition*. Minneapolis, MN: Pearson Assessments.

Rosas, S., Chaiken, L., & Case, J. (2007). Cross-setting consistent and setting specific strength behaviors in preschoolers: Influence on reported concerns. In L. Connors-Tadros (Chair), *Establishing effective partnerships in early childhood systems with families and across agencies.* Symposium conducted at the 20th Annual Research Conference–A System of Care for Children's Mental Health: Expanding the Research Base, Tampa, FL.

Stroul, B., & Friedman, R. (1986). *A system of care for children and youth with severe emotional disturbances* (Revised edition). Washington, DC: Georgetown University Child Development Center, CASSP Technical Assistance Center.

Thomlinson, P., D'Angelo, S. L., & Maples, C. (2007). Early childhood collaborative partnerships in southwest Missouri. In L. Connors-Tadros (Chair), *Establishing effective partnerships in early childhood systems with families and across agencies.* Symposium conducted at the 20th Annual Research Conference–A System of Care for Children's Mental Health: Expanding the Research Base, Tampa, FL.

Turnbull, A. P., Turbiville, V., & Turnbull, H. R. (2000). Evolution of family-professional Partnerships: Collective empowerment as the model for the early twenty-first century. In J.P. Shonkoff & S.J. Meisels (Eds.) *Handbook of early childhood intervention* (2nd Ed.). New York: Cambridge University Press.

CONTRIBUTING AUTHORS

Paul A. LeBuffe, MA
Director, Devereux Institute of Clinical Training and Research, 444 Devereux Drive
Villanova, PA 19085, 610-542-3090, fax: 610-542-3132, email: plebuffe@
devereux.org

Valerie B. Shapiro, MSS, LSW
Program Development and Implementation Specialist, Devereux Institute of Clinical
Training and Research, 444 Devereux Drive, Villanova, PA 19085, 610-542-3115,
fax: 610-542-3132, email: vshapiro@devereux.org

Discovering Parent Empowerment: Findings from Two Evaluations of Parent Advocate Trainings

Belinda H. Ramos
Geraldine Burton
Nicole McDonald
James Rodriguez
Kimberly Hoagwood
Marleen S. Radigan
Sudha Mehta
Chip McCormick
Serene Olin
Maura Crowe

Introduction

Columbia University has developed a theory-based parent intervention program for family advocates intended to strengthen advocacy and support for parents of children with mental health needs in New York State. The Parent Empowerment Program (PEP) is a manualized training program that has been piloted with a group of family support workers from New York City (G1; N = 27) and subsequently with a group of statewide parent advisors (G2; N = 60). These initiatives evaluated the impact of the training on their skills, knowledge, and sense of professional effectiveness. This presentation provided quantitative and qualitative findings from these projects and outlined the implications of training family support workers in empowerment and engagement strategies.

Method

Participants in G1 were 27 family support workers recruited from parent resource centers and family support programs in New York City. The participants were randomly selected into the training (T1; N = 15) or comparison (T2; N = 12) group. Training consisted of 40 hours of didactic teaching and skills exercises occurring in four-hour increments over 10 consecutive weeks, followed by seven monthly, in-person booster sessions. Both T1 and T2 groups completed the Vanderbilt Mental Health Self-Efficacy Questionnaire (Bickman, Earl & Klindworth, 1991), the self-assessment and general knowledge test (both based on manual content), and About You and Where You Work, a survey inquiring about demographic and work characteristics. These assessments were collected at baseline, post-training, and one year for the T1 group and at baseline and one year for T2 (demographic survey collected only once at baseline). Service Activity Reports were collected from both groups bi-monthly at three timepoints. The training group also completed evaluations for each module and the overall training (11 total). In addition, parents (N = 127) associated with the T1 and T2 groups were recruited to complete a variety of assessments, including the Center for Epidemiological Studies Depression Index (CES-D; Radolff, 1977).

Participants in G2 were 60 parent advisors trained in three regions across New York State, including Long Island Region (R1; N = 15), Central/Hudson Region (R2; N = 23), and Western Region (R3; N = 22). The three groups were trained for 40 hours over 1 week, followed by bi-weekly 90-minute consultation calls for 5 months, and an additional 12 hour in-person booster session. The Vanderbilt Mental Health Self-Efficacy Questionnaire (Bickman, Earl & Klindworth, 1991), a revised version of the Family Empowerment Scale (adapted for parent advisors; Koren, DeChillo, & Friesen, 1992), two subscales of Charles Glisson's Organizational Climate Survey (Glisson et al., 2000), and the self-assessment (based on manual content) were collected at baseline, post-training, and six months later. During the training, participants completed evaluations for each module and the overall training, as well as a knowledge retention test immediately after training and at 6 months. In addition, participants filled out bi-monthly checklists to determine their adherence to the training activities.

Results

In both studies, the overall training was rated highly (G1: M = 2.9, range 0-3; G2: M = 4.65, range 1-5). Evaluations for the individual modules were rated similarly high across all trainings (M = 3.9, range 0-4). Preliminary observation of the open-ended responses to the adherence checklist indicated that G2

participants felt that since the training they were more effective at listening, empowering parents, and in their work in general, and felt the tools gained during the training were useful.

According to the self-assessment, G1/T1 participants reported marginal improvement on the Teaching and Group Management Skill subcomponent, $t(13) = -2.14$, $p = .06$, and significant improvement on the School System Services and Options subcomponent, $t(13) = -2.29$, $p < .05$. No significant change was found on the overall score, or on the Engagement, Listening and Boundary Setting, Priority Setting Skills, Specific Disorders and Their Treatment, Mental Health System of Care subcomponents. As well, no significant change was found on the self-efficacy measure (G1 and G2) or the family empowerment measure (G2).

Our results also showed significant barriers to the family advocates work with parents. It became apparent that the participants had limited opportunity for direct parent contact on account of limited hours, competing job responsibilities, and high caseloads. On the About You and Where You Work survey, many participants reported barriers in parent participation (reported by 20%; e.g., transportation, lack of attendance), lack of resources/support (24%; e.g., high turnover rates, lack of financial support), empowerment and education (44%; e.g., training parents to advocate for themselves), systems (28%; e.g., understanding the education system), and service delivery (12%; e.g., setting priorities with parents). Additionally, G2 participants identified difficulties in working with parents with mental health needs themselves, child service delivery systems, and lack of services in rural areas. These reports were supported in our finding that 65% of caregivers ($N = 127$) in the first study showed abnormally high depressive symptoms on the CES-D ($M = 22.6$; abnormal ≥ 16). The training did not show an impact on the caregivers across timepoints.

Discussion

Results from the evaluations of the city and statewide Parent Empowerment Program trainings did not show the expected impact. Despite being highly evaluated, the training failed to show a significant impact on key outcome measures, such as self-efficacy. We are currently working on integrating what we learned from these evaluations to revise and strengthen the program. First, engagement strategies have become more structured and are now a core component of the training. Also, a framework has been formalized, combining 10 principles of parent support and principles from the theory of behavior change, which will help to ground the program as it is adapted. The framework has also aided in coming up with better ways to ensure and test for fidelity to training components. Finally, the lessons learned from these projects have allowed for a more cohesive training model including a more detailed and focused trainer's manual and role rehearsals book, as well as a supplementary guide and workbook with information and activities for parent advocates (in progress).

References

Bickman, L., Earl, E., & Klindworth, L. (1991). *The Vanderbilt Mental Health Self-Efficacy Questionnaire.* Nashville, TN: Vanderbilt University.

Glisson, C., et al. (2000). *Organizational Climate Survey.* Tennessee: The University of Tennessee Children's Mental Health Research Center.

Koren, P. E., DeChillo, N., & Friesen, B. J., (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology, 37*, 305-321.

Radolff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-401.

CONTRIBUTING AUTHORS

Belinda H. Ramos, MA
*Director of Training, Center for the Advancement of Children's Mental Health,
Columbia University/NYSPI, 1775 Broadway, Suite 715, New York, NY 10019,
646-328-4413, fax: 646-443-8190, email: ramosb@childpsych.columbia.edu*

Geraldine Burton, FDC
*Co-Project Director, Center for the Advancement of Children's Mental Health,
Columbia University/NYSPI, 1775 Broadway, Suite 715, New York, NY 10019,
646-328-4424, fax: 646/443-8190, email: burtong@childpsych.columbia.edu*

Nicole McDonald, BA
*Research Assistant, Center for the Advancement of Children's Mental Health,
Columbia University/NYSPI, 1775 Broadway, Suite 715, New York, NY 10019*

James Rodriguez, MSW, PhD
*Co-Project Director, Center for the Advancement of Children's Mental Health,
Columbia University/NYSPI, 1775 Broadway, Suite 715, New York, NY 10019,
646-328-4417, fax: 646/443-8190, email: rodriguja@childpsych.columbia.edu*

Kimberly Hoagwood, PhD
*Principal Investigator, Center for the Advancement of Children's Mental Health,
Columbia University/NYSPI, New York State Office of Mental Health, 1051
Riverside Drive, #78, New York, NY 10032, 212-543-5311, fax: 212-543-5260,
email: hoagwood@childpsych.columbia.edu*

Marleen S. Radigan, DrPH
*Associate Director, Bureau of Youth Services Evaluation Research , Center for
Information Technology and Evaluation Research, New York State Office of
Mental Health, 44 Holland Avenue, Albany, NY 12229, 518-473-9570, fax:
518-474-7361, email: coevmsr@omh.state.ny.us*

Sudha Mehta, MPH
*Center for Information Technology and Evaluation Research, New York State Office
of Mental Health, 44 Holland Avenue, Albany, NY 12229, 518-473-4316, email:
coqasam@omh.state.ny.us*

Chip McCormick, PhD
*Center for Information Technology and Evaluation Research, New York State Office
of Mental Health, 44 Holland Avenue, Albany, NY 12229, 518-474-6413, email:
istccxm@omh.state.ny.us*

Serene Olin, PhD
*Center for the Advancement of Children's Mental Health, Columbia University/
NYSPI, 1051 Riverside Drive, #78, New York, NY 10032, email: olins@childpsych.
columbia.edu*

Maura Crowe, MA
*Center for the Advancement of Children's Mental Health, Columbia University/
NYSPI, 1051 Riverside Drive, #78, New York, NY 10032, 212-543-5311, fax:
212-543-5260, email: crowem@childpsych.columbia.edu*

Implementation Challenges in Wrapping Interventions Around Families with Parental Mental Illness

Beth R. Hinden
Joan Mikula
Joanne Nicholson
Kathleen Biebel
Valerie Williams
Katherine Woolsey
Elizabeth Aaker

Introduction

The majority of adults experiencing mental illness over the course of their lifetime are parents. Yet their role and goals as parents are largely ignored by adult mental health service providers (Nicholson, Biebel, Williams & Katz-Leavy, 2004; Biebel, Nicholson, Williams & Hinden, 2004). Almost two-thirds of state child welfare agencies report dissatisfaction with the level of mental health services provided to parents of at-risk families in the child welfare system (US Government Accountability Office, 2006). More than half of families participating in the children's mental health systems of care (SOCs) program report a history of mental illness, and 39% percent of these also report a history of parent psychiatric hospitalization (Hinden, Gershenson, Williams & Nicholson, 2006). Families with histories of mental illness in SOCs evidence poorer functioning and greater caregiver strain at the time of intake, and continue to show worse outcomes over time (Hinden, et al., 2005). Clearly there is a need for new interventions to meet the needs of families living with parental mental illness, as well as for strategies to enhance the capacities of existing interventions in children's SOCs to meet the needs of parents and children more effectively.

This paper describes the development of Family Options, a family-centered, strengths-based intervention for families living with parental mental illness, and presents findings from a study of the implementation of the intervention at Employment Options, Inc. (EO, Inc.), a psychiatric rehabilitation clubhouse agency traditionally focused on individual adults with mental illnesses. Examining implementation provides an opportunity to understand factors that facilitate or impede an agency's paradigm shift from one of working with individuals to one in which families are the focus. Such examinations also can suggest strategies for the replication of the intervention, as well as recommendations for the enhancement of existing programs.

Methods

The Development of Family Options

The Family Options intervention reflects an integration of research on the experiences of families living with parental mental illness (Nicholson, Biebel, Hinden, Henry & Stier, 2001); empirically-supported models for adults with mental illness (e.g., ACT, Meuser, Bond & Drake, 2001; Strengths Model, Rapp, 1998); family-centered interventions for children with mental health and other disabilities (e.g., Burchard, Bruns & Burchard, 2002; Dunst, Trivette & Deal, 1994); and existing interventions for families in which a parent has a mental illness (Hinden, Biebel, Nicholson & Mehnert, 2005; Hinden, Biebel, Nicholson, Henry & Katz-Leavy, 2006).

These models are commonly based on an ecological rather than an individual framework for human functioning (Rapp, 1998), and emphasize identifying and building on individual and community strengths and resources, as well as promoting consumer choice, self-determination, recovery and resilience, goal planning, skill building, and empowerment (e.g., Dunst et al., 1994; Rapp, 1998; Burchard et al., 2002). While child-focused models emphasize family-centered approaches, adult-focused interventions emphasize illness management, and the improvement of functioning in important role domains. Existing programs for parents with mental illness and their children reflect all of these characteristics, along with an emphasis on parent education, skill training and support as essential compliments to case management (Hinden, Biebel et al., 2006).

Review of the literature and an iterative process involving researchers, providers, consumers, and clinical and implementation consultants led to defining eight key concepts and processes: family-centered; strengths-based; family-driven/self-determined; resilience and recovery; engagement and relationship building; empowerment, availability and access; liaison; and advocacy.

The Implementation of Family Options

Implementation is being examined through a series of focus groups and qualitative interviews with key stakeholders. Focus groups facilitated by University of Massachusetts Medical School (UMMS) researchers are being conducted with three sets of stakeholders: (a) EO, Inc. staff and members, (b) the EO, Inc. Board of Directors, and (c) the EO, Inc. management team. Their investigations are modeled upon each of three phases of implementation defined by Fixsen, et al. (2005):

- program installation (three months prior to implementation),
- initial implementation (four months into implementation), and
- full operation (one year after implementation).

Initial prompts for these focus groups addressed two constructs: relative advantage (i.e., perceptions about the advantage of a given event or situation); and innovation-values fit (i.e., how the new intervention fits with the existing structure, philosophy and way of doing business). Verbatim meeting notes were recorded, and then reviewed by the UMMS research team following each group to review themes and patterns. Themes were coded by the researchers independently following each session. Prompts were then refined to include new areas of inquiry for later groups.

Approximately 150 key informant interviews are being conducted at varying intervals throughout the 18-month implementation period with 16 key informants including the EO Inc. Executive Director and Assistant Director, two club staff members, four club members; two Board members, five Family Options staff, and the Family Options clinical consultant. The question for initial interviews was quite broad (*"What's been happening with the Family Options intervention?"*), and has been narrowed over time to focus in on emerging themes of interest. Interviews are taped and transcribed. A code-and-retrieve software program facilitates analysis of the qualitative data, focusing on themes and patterns suggested in the data and informed by the literature.

Results

Emerging Organizational Issues

Initial implementation study findings suggest that there is a great deal of support for the growth of EO, Inc. with the Family Options intervention. The implementation of Family Options seems to be consistent with the agency's strategic plan. The management team is confident in their roles and the direction the agency is taking, and Family Options fits within the philosophy of EO, Inc. However, there are concerns associated with growth. There is confusion about staff roles, worry that staff will be spread too thin, and that members who are not parents (or not currently parenting) may feel left out. People at EO, Inc. want more information about Family Options, and recommend open, clear communication with all stakeholders about the intervention.

Challenges for Staff

Issues emerged regarding staff selection, orientation, supervision, training and coaching. Family Options staff needed to be educated about the issues for families in which parents have mental illness. Staff act as advocates with collaborators in the community, and are often in the position of educating them. Family Options is a family-centered intervention requiring expertise and the facilitation of access to services and supports across adult and child sectors, while most providers have been trained and service systems organized within adult or child silos. Staff must be knowledgeable about adult and child mental health, and relevant community resources and supports for both adults and children.

Family Options is strengths-based and family-driven/self-determined. Although providers are increasingly aware of the strengths orientation, implementing this approach both conceptually and practically on a day-to-day basis can be very challenging, necessitating adequate staff training and on-going support. Finally, the ecological orientation and focus on building social and community resources define a community-based, outreach service delivery model that is emotionally and physically demanding, and can challenge staff team building.

Conclusions: Wrapping SOCs around Families Living with Parental Mental Illness

Findings from the current study indicate that organizational and workforce issues are important considerations in the development and implementation of a family-centered, strengths-based intervention for parents with mental illness and their families, within the context of an organization and service system accustomed to working with individuals rather than families. Lessons learned in implementing Family Options suggest strategies for further program development as well as the enhancement of children's SOCs, which, like EO, Inc., shares common beliefs and values with the Family Options intervention, and is well-poised to meet the challenges of working with families in which a parent has a mental illness. Specific recommendations for SOCs include:

- Educate program staff about the prevalence of parental mental illness among families participating in SOCs.
- Educate staff about the experiences of parents with mental illness and their families (e.g., parents with mental illness may be more difficult to engage as a result of the impact of prior stigmatizing experiences and possibly consequent fear of custody loss, or as a result of clinical levels of anxiety or trauma-related issues).
- Educate staff about adult psychiatric disorders and how particular symptoms may impact parenting or program engagement.
- Include parent illness management as part of the care plan, because it potentially is the lynchpin of that care plan. Include a parent's provider(s) on the team, if the parent wishes, and integrate the parent's treatment plan with the child's care plan.
- Develop and make connections with parenting and other adult resources and providers in the community. Incorporate parent/adult resources into the family's care plan.
- Help families anticipate and plan for crises, while supporting recovery and resilience in parents and children.

In sum, current conceptualizations and practices within SOCs related to interagency integration and coordination must be expanded to support integration *between* adult and child service sectors, as well as *within* these sectors. A focus on staff training and education, in combination with specific changes in practice may support improved engagement of families living with parental mental illness, as well as improved outcomes.

References

Biebel, K., Nicholson, J., Williams, V, & Hinden, B. (2004). Facilitating systems change: State mental health authorities developing programs and policies for parents with mental illness. *Administration and Policy in Mental Health, 32*, 31-48.

Burchard, J. D., Bruns, E. J., & Burchard, S. N. (2002). The wraparound approach. In B. J. Burns & K. Hoagwood (Eds.), *Community treatment for youth: Evidence-based interventions for severe emotional and behavioral disorders.* (pp. 69-90). New York: Oxford University Press.

Dunst, C. J., Trivette, C. M., & Deal, A. G. (Eds). (1994). *Supporting and strengthening families.* Cambridge, MA: Brookline Books.

Fixsen, D. L., Naoom, S. F., Blase, K. A., Friedman, R. M., & Wallace, F. (2005). *Implementation research: A synthesis of the literature.* Tampa, FL. University of South Florida, Louis de le Parte Florida Mental Health Institute, the National Implementation Research Network (FMHI Publication #231).

Hinden, B., Biebel, K., Nicholson, J., Henry, A., & Katz-Leavy, J. (2006). A survey of programs for parents with mental illness and their families: Identifying common elements to build an evidence base. *Journal of Behavioral Health Services & Research, 33*(1), 21-38.

Hinden, B., Biebel, K., Nicholson, J., & Mehnert, E. (2005). The Invisible Children's Project: Key ingredients in an intervention for parents with mental illness. *Journal of Behavioral Health Services & Research, 32*, 393-408.

Hinden, B., Gershenson, B., Williams, V., & Nicholson, J. (2006). *Families with overlapping needs*. Issue Brief. Worcester, MA: Center for Mental Health Services Research, University of Massachusetts Medical School.

Hinden, B., Nicholson, J., Williams, B., & Fernandes, B., Banks, S., & Katz-Leavy, J. (2005). *Supporting all families: Examination of families with a history of mental illness and substance abuse.* Rockville, MD: Substance Abuse Mental Health Administration, Center for Mental Health Services.

Mueser, K. T., Bond, G. R., & Drake, R. E. (2001). Community-based treatment of schizophrenia and other severe mental disorders: Treatment outcomes? *Medscape Mental Health 6*(1), 1-31.

Nicholson, J., Biebel, K., Hinden, B., Henry, A. & Stier, L. (2001) *Critical issues for parents with mental illness and their families*. Rockville, MD: Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. Retrieved: (http://mentalhealth.samhsa.gov/publications/allpubs/KEN-01-0109/default.asp).

Nicholson, J., Biebel, K., Williams, V. F., & Katz-Leavy, J. (2004). Prevalence of parenthood in adults with mental illness: Implications for state and federal policy, programs, and providers. In R. W. Manderscheid & M. J. Henderson (Eds.), *Mental health, United States, 2002.* DHHS Pub No. (SMA) 3938. (pp. 120-137). Rockville, MD: Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.

Rapp, C.A. (1998). *The Strengths Model: Case management with people suffering from severe and persistent mental illness*. New York: Oxford University Press.

U.S. Government Accountability Office. (2006). *Child welfare: Improving social service program, training, and technical assistance information would help address long-standing service-level and workforce challenges.* Washington, DC: Author.

CONTRIBUTING AUTHORS

Beth R. Hinden, PhD
Clinical Consultant and Adjunct Faculty, Department of Psychiatry, University of Massachusetts Medical School, 11 Avalon Road, West Roxbury, MA 02132, 617-877-9182, email: bhinden@rcn.com

Joan Mikula
Assistant Commmissioner for Child and Adolescent Services, Massachusetts Department of Mental Health, 25 Staniford Street, Boston, MA 02114, email: Joan.Mikula@state.ma.us

Joanne Nicholson, PhD
Professor of Psychiatry, Department of Psychiatry, Center for Mental Health Services Research, University of Massachusetts Medical School, 55 Lake Avenue North, Worcester, MA 01655, 508-856-8712, fax: 508-856-8700, email: Joanne.Nicholson@Umassmed.edu

Kathleen Biebel, PhD
Research Assistant Professor, Department of Psychiatry, Center for Mental Health Services Research, University of Massachusetts Medical School, 55 Lake Avenue North, Worcester, MA 01655, 508-856-8717, email: Kathleen.Biebel@Umassmed.edu

Valerie Williams, MA, MS
Research Instructor, Department of Psychiatry, Center for Mental Health Services Research, University of Massachusetts Medical School, 55 Lake Avenue North, Worcester, MA 01655, 508-856-8081, email: Valerie.Williams@Umassmed.edu

Katherine Woolsey, BA
Research Associate, Department of Psychiatry, Center for Mental Health Services Research, University of Massachusetts Medical School, 55 Lake Avenue North, Worcester, MA 01655, 508-856-8734, email: Katherine.Woolsey@Umassmed.edu

Elizabeth Aaker, BA
Research Associate, Department of Psychiatry, Center for Mental Health Services Research, University of Massachusetts Medical School, 55 Lake Avenue North, Worcester, MA 01655, 508-856-8745, email: Elizabeth.Aaker@Umassmed.edu

Social Supports for Youth and Families

Joan B. Kernan

Marie Morilus-Black

Introduction

Social supports for youth and families receiving mental health services are important for family success and sustainability of systems of care. We are surveying youth and families enrolled in wraparound care coordination to determine what kinds of help and social support they receive. The Social Supports Questionnaire measures include: parent/caregiver support received from people in the past six months, the different kinds of people who have helped the parent/caregiver in the past six months, youth support received from people in the past six months, and the different kinds of people who have helped the youth in the past six months. Our research question is: What kinds of help and social support do youth and families receive and from whom do they receive these supports?

Method

The design of this study is a longitudinal survey of families and youth from July, 2006 to July, 2007. Conducted in Erie County, New York, the study included parent/caregiver and youth (age 11 or older) enrolled in a Substance Abuse and Mental Health Services Administration, Center for Mental Health Services (CMHS) funded child and family longitudinal study. A questionnaire is administered during the intake interview (within 30 days of the start of wraparound) and at the six-month interview. The instrument is a Social Supports Questionnaire, adapted from Sarason and colleagues (1983), Sheffield and colleagues (2004), and the National Survey of Families and Households (Sweet, Bumpass & Call, 1988). Institutional Review Board approval was received by the University at Buffalo, Social Sciences.

The main outcome measures are the Social Supports Questionnaire items. The questionnaire has 14 items of help and support, rated from 0, *No one has*, to 3, *Family/friend does this often*. Twelve items about the kinds of people that provided support were rated 0, *yes*, 1, *no*, or "not applicable," along with a supportive rating from 1-5 for each. The youth questionnaire has slightly different wording than the parent/caregiver questionnaire, and two additional people for the "kinds of people" category. Data are collected on a paper survey with check boxes completed by the respondent. The survey is read to the youth or parent/caregiver when appropriate. Data are entered into SPSS, verified, and analyzed.

Results

For this study, 24 adult questionnaires and 18 youth questionnaires were analyzed. Subscale means for help and support received were higher for youth than for the parent/caregiver (2.2 vs. 1.6 out of a 3.0 maximum) and also for the kinds of people that help (.42 vs. .27 out of a 1.0 maximum). Higher means for youth were for the items "buy clothes for you" (2.72/3.0), "comfort you if you are upset" (2.61/3.0), "pay for a meal or something to drink" (2.61/3.0) and "show they care about you" (2.67/3.0). Low means for youth were items that "encourage you to do something difficult" (1.72/3.0). For parent/caregiver, higher item means were for "help with advice about raising children" (2.0/3.0) and "other advice, encouragement, moral or emotional support" (2.46/3.0). Low means were for "a temporary place to live if needed" (1.08/3.0).

For different kinds of people who provided help, youth reported higher means for "best friend" (.72/1.0), "sisters, brothers/stepsisters or stepbrothers" (.72/1.0). Lower means were for "people in your neighborhood" (.28/1.0). For "how supportive are these people" youth reported high means for "best friend support" (2.11/5), and "other relatives support" (2.28/5).

For kinds of people that were supportive, parent/caregivers reported higher means for "people you know from church" (.38/1), and "people you know from organizations you are involved with" (.46/1). Lower means were for "people you work with" (.13/1). For "how supportive are these people," parent/caregivers reported higher means for "people you know from organizations you are involved with" (1.5/5) and lower means for "people you go to school with" (.08/1).

Conclusion

A limitation of the study concerns the fact that questionnaires were primarily administered at the time of intake into services (22/24). Six month follow-up interviews will provide further data to analyze for changes in individual social support over time. Overall, however, social support networks are weak for both family and youth at intake to the wraparound process, including both different kinds of help and different kinds of people. Variation in scores suggests that wraparound family teams should focus on strategies that enhance the development of informal supports, to include other family members and faith-based and community organizations. Youth have different social support networks from their parents, and are more apt to include their peers and other relatives. Youth report higher mean scores overall for receiving help and support, and for the different kinds of people that provide support to them. This information is helpful to care coordinators as they develop supports for youth and families.

Analysis of 6-month follow-up data will help determine whether families and youth have increased their social support networks and have expanded the kinds of people who provide support to them. These data will be used to inform the system of care as to what interpersonal and community supports help families and youth.

References

Sarason, I. G., Levine, H. M., Basham, R. B., & Sarason, B. R. (1983). Assessing social support: The Social Support Questionnaire. *Journal of Personality and Social Psychology, 44,* 127-139.

Sheffield, J. K., Fiorenza, E., & Sofronoff, K. (2004). Adolescents' willingness to seek psychological help: Promoting and preventing factors. *Journal of Youth and Adolescence, 33,* 495-507.

Sweet, J. A., Bumpass, L. L., & Call, V. R. A. (1988). *The design and content of the National Survey of Families and Households.* Center for Demography and Ecology, University of Wisconsin.

CONTRIBUTING AUTHORS

Joan B. Kernan, BS
Research Associate, Department of Family Medicine, University at Buffalo, 462 Grider St. CC-186, Buffalo, NY 14215, 716-898-4742, fax: 716-898-3536, email: jkernan@buffalo.edu

Marie Morilus-Black, LCSW-R
Project Director, Family Voices Network of Erie County, Erie County Dept. of Mental Health, 95 Franklin St., Buffalo, NY 14202, 716-858-2697, fax: 716-858-7492, email: morilusm@erie.gov