Chapter Two

Approaches in Evaluating Local & State Level Systems of Care

Building Bridges of Support in Eastern Kentucky: Promoting Partnerships Among Families, Educators, and Mental Health Professionals

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Introduction

The Bridges Project, a Phase II Center for Mental Health Services (CMHS)-funded children's mental health initiative, is in its third year of operation. The purpose of the project is to build upon and enhance Kentucky's existing system of care in three rural Appalachian mental health regions in eastern Kentucky. This area of the state possesses characteristics that differ dramatically from the rest of the state, such as high rates of poverty, unemployment, and illiteracy. Counties in this region ranked among the lowest in the state with respect to child well being (Kentucky KIDS COUNT Consortium, 2000). Due to the rural nature of the region, lack of transportation, limited community services and resources, and a shortage of qualified human service professionals often serve as barriers to effective service delivery. Despite these barriers, the Bridges Project seeks to provide services in a way that acknowledges and builds upon the many strengths of the Appalachian culture (see Figure 1).

Figure 1
Strengths of the Appalachian Culture

- ➤ Love for homeplace
- ➤ Sense of kinship
- ➤ Self-Reliant
- ➤ Maternal Regard
- ➤ Traditionalism
- ➤ Neighborliness
- ➤ Religious tradition
- ➤ Humility and Modesty
- ➤ Feeling oriented

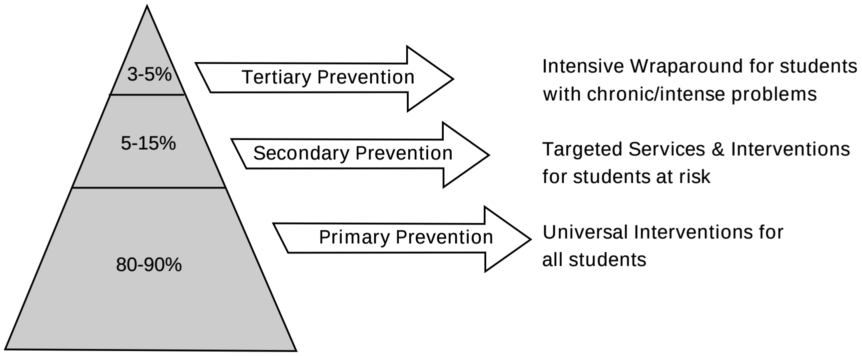
Because Kentucky has already made significant gains in building a system of care through the institution of the Kentucky IMPACT Program, the grant has enabled communities in the participating regions to expand the existing service delivery system. A 5-year evaluation of the Kentucky IMPACT Program (Illback, Nelson, & Sanders, 1998) revealed limited coordination and integration between education and other child-serving agencies in the system of care. Acknowledging schools as a critical partner in system of care efforts and the challenges and opportunities underlying their effective inclusion, the primary feature of the project centers upon integrating mental health services in schools to promote prevention, early intervention, and intensive intervention efforts. School-based Student Service Teams (SSTs), consisting of a service coordinator, family liaison, and intervention specialist, are employed by community mental health centers but located within schools. In addition, a behavior consultant is assigned to each region. In collaboration with school staff, the SST and behavior consultant facilitate the implementation of a continuum of positive behavior supports (see Figure 2; Sugai & Horner, 1999; Todd, Horner, Sugai, & Sprague, 1999). Student Service Teams and behavior consultants serve 21 schools throughout the three regions, including elementary, middle, high, and alternative settings.

This paper describes selected baseline characteristics of the children and families who received wraparound during the first year of project implementation (August 1999-September 2000), outcome data for those receiving six months of service, the nature of services received, and caregiver/youth satisfaction ratings. Implications of these preliminary findings for program development and refinement are discussed.

Method

Descriptive information was gathered for each child and family upon entry into the program. Descriptive data are available for 200 children and families who received wraparound during the first year of program implementation. While descriptive data were gathered on all children and youth receiving intensive wraparound, longitudinal and intervention-level data were collected only for those consenting to participate in the child and family outcome study. As such, outcome data are presented for a subsample of 34 children and families for whom 6-month follow-up data were available.

Figure 2
Continuum of Positive Behavioral Supports



Results

Characteristics of Participants in the Descriptive Study (N = 200)

The sample was comprised mostly of males (73.5%) with an average age of 12.7 years. The sample was 98% Caucasian, representative of the ethnic make-up of the region. Most (68%) reported annual incomes falling below the federal poverty threshold and 83% were eligible for Medicaid. While 43% lived with two caregivers at intake, 37% resided in mother-maintained homes. Strikingly, 12% were living with either a relative or friend. Almost half (46%) reported being on medication for their emotional and behavioral symptoms and 44% reported some type of chronic physical health problem. Over half (57%) had a primary DSM diagnosis of Attention Deficit or Disruptive Behavior Disorder, while 19% were diagnosed with either a mood or anxiety disorder. With respect to service use during the year prior to intake, 64% had received outpatient services and 58% had received school-based services. A far lesser number (20%) had been in a residential placement in the previous year.

Child and Family Outcomes (N = 34)

On average, caregivers reported a statistically significant decrease in problem behaviors from baseline ($M = 71.8$) to 6-month follow-up ($M = 66.7$) ($t(33) = -3.46$, $p = .002$), as measured by the Child Behavior Checklist (CBCL; Achenbach, 1991). While youth ($N = 25$), on average, reported a decrease in problem behavior over time, this decrease was not statistically significant. Functional impairment, as measured by the Child and Adolescent Functional Assessment Scale (CAFAS; Hodges, 1990), also decreased significantly from intake ($M = 105$) to 6-month follow-up ($M = 81.5$), ($t(32) = -5.52$, $p = .000$). Despite the presence of significant problem behaviors and severe functional impairment, the children and youth in the sample were reported to have average emotional and behavioral strengths at intake ($M = 105$), as measured by the Behavioral and Emotional Rating Scale (BERS; Epstein & Sharma, 1997). At 6-month follow-up, the behavioral and emotional strengths of the sample had increased significantly ($M = 112$), ($t(33) = 2.92$, $p = .006$).

Intervention-Level Assessment

For the 34 children and families for whom 6-month follow-up data were available, the most commonly reported services were traditional in nature. Almost all (97%) reported receiving individual therapy and 91% received case management services. Medication monitoring and assessment/evaluation services were commonly received services as well, with 68% and 65% of the families reporting receipt of these services, respectively. Less traditional services, such as flexible funding (35%), family support (32%), and transition services (32%) were received by a smaller number of families. At least 80% of the caregivers reported being "satisfied" or "very satisfied" with services received through the Bridges Project. Youth also reported being satisfied; however, the percentage of was lower than that of their caregivers.

Discussion

Many characteristics of this sample are consistent with previous literature describing children and youth with serious emotional disturbance (see, for example, Duchnowski, Hall, Kutash, & Friedman, 1998; Greenbaum et al., 1998; Quinn & Epstein, 1998). The finding that 12% were living with a relative/friend is not surprising when one considers the cultural characteristics of the region, i.e., a strong sense of kinship and self-reliance. It does, however, implicate that additional means of caregiver support may need to be incorporated into the system (i.e., grandparent support groups) in a culturally sensitive manner. The change over time in child and family outcomes was encouraging as was the finding that the majority of caregivers and youth were satisfied with the services received. Findings revealed that the majority of families received traditional services (e.g., individual therapy) and that fewer received less traditional services, such as flexible funding. Future program efforts are focused upon increasing the delivery of less traditional services in conjunction with those more traditional in nature.

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Child Strengths and Caregiver Strain: Is There a Relationship?

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Introduction

Community Connections for Families (CCF) is a Center for Mental Health Services (CMHS)-funded system of care grant site in its third year of operation. CCF is community-based, with five programs in different geographic locations within Allegheny County. The primary interventions are service coordination, family support, education and advocacy. One goal of these interventions is to reduce parent strain through advocacy, support and linkage with the appropriate services and supports. Another goal is to identify and utilize caregiver and child strengths. Caregivers can become better advocates for their child if their own strengths are identified and supported. Likewise, helping children and caregivers to identify and use child strengths may lead to better child outcomes (Lyons, Miller, Reyes, & Sokol, 2000). For this study, we asked if there was a relationship between parental perceived feelings of strain and a parent's ability to identify a child's strengths, and what direction that relationship might take.

Research indicates that caring for a child with a serious emotional disturbance (SED) can cause considerable strain for all family members (Messer et al., 1997; Yatchmenoff, Koren, Friesen, Gordon, & Kinney, 1998). Parents of children with emotional disorders report greater feelings of worry, depression and isolation than do parents in the general population (Friesen, 1989; Messer et al., 1997). Child and family characteristics that seem to associate with perceived feelings of burden or strain are the severity of the child's behavior (Floyd & Gallagher, 1997; Wallander et al., 1990; Yatchmenoff, Koren, Friesen, Gordon, & Kinney, 1998), social support (Trivette & Dunst, 1992), marital status (Floyd & Gallager, 1997), and formal services (Murray, 1992). While there is considerable research on the factors which predict feelings of burden and strain, as well as research on child strengths and resilience and coping (Lyons et al., 2000; Luthar & Zigler, 1991; Werner 1989), the research on the relationships between positive child characteristics and parental strain is less developed. This is a critical area for further investigation. The interactions between child and parent are not linear and unidirectional; the child's behavior and needs affect a parent and lead to certain feelings and behaviors, which in turn affect the child. Longitudinal research indicates that the psychosocial climate of the home affects the social development of children with disabilities (Nihira, Mink & Meyers, 1985). Investigating the positive child characteristics and behaviors that elicit positive responses and help parents to better cope with the special demands of a child with SED may enhance social and cognitive adjustment for the child and may also reduce feelings of strain for parents and other family members.

Method

Baseline information on 36 children enrolled in a SAMHSA-CMHS funded system of care project was used to examine the associations between parent/caregiver identification of child strengths and parent/caregiver strain. The measures used were the Behavioral and Emotional Rating Scale (BERS; Epstein & Sharma, 1998), the Child and Adolescent Needs and Strengths Measure (CANS; Lyons, Rauktis & Hladio, 2000) and the Caregiver Strain Questionnaire (CGSQ; Brannan, Heflinger & Bickman, 1998).

The BERS is a 52 item scale that measures a parent or caregiver's perception of the children's emotional and behavioral strengths in five areas: interpersonal strengths, family involvement, intrapersonal strengths, school functioning and affective strengths. Interpersonal skills measures a child's ability to regulate his/her behavior and emotions in social situations. The family involvement dimension measures the child's participation and relationship with siblings, parents and other family members. The child's perception of his/her competence and accomplishments is measured in the intrapersonal dimension, and school functioning focuses on a child's competence in school. The child's ability to express feelings and accept affection is measured in the affective strengths dimension. Higher scores indicate greater strengths. The information for the BERS was collected by a trained interviewer as part of an in-person interview with the caregiver/parent.

The CANS is a 44 item rating scale with 4 anchored levels for each item. The CANS includes assessments of child and caregiver needs as well as child strengths. The child strengths subscale assesses the degree of strengths in 11 domains: family, interpersonal, relationship permanence, service experience, educational, vocational, coping/savoring, creativity, spiritual/religious, community life and resiliency. Higher scores indicate a lower degree of strength in that domain.

The CANS is part of a strengths-based assessment and service planning process and is administered by service coordinators and family support specialists who have been trained in the administration and scoring.

The CGSQ is a 21 item scale that measures parents' feelings of burden or strain. There are three subscales: objective strain, subjective externalized strain, subjective internalized strain and the full scale. Objective strain refers to the caregiver's perception that observable, negative events (missing work, financial hardship, loss of personal time, disruption of personal relationships and social activities) result from caring for the child. Subjective externalized strain refers to negative feelings that are directed at the child such as embarrassment, resentment and anger. Internalized strain captures self-directed feelings such as worry, sadness, depression and guilt. Higher scores indicate greater strain. The information for the CGSQ is collected by a trained interviewer as part of an in-person interview with the caregiver/parent.

Results

Child Demographics

The average age of the children (*N* = 36) was eleven. There were more males (81%) than females. A little over half were African American (51%) and 43% were Caucasian.

Diagnostically, the most frequent primary Axis I diagnoses were those within the attention deficient and disruptive behavior categories. The second group of most frequently occurring diagnoses were disturbance of mood (single and recurrent unipolar depression, bipolar disorder). Parent/Caregivers described the most common behavior problems with their children to be physical aggression, hyperactivity, poor peer interaction and attention difficulties. On the CANS, caregivers also described strengths of the child: the most frequently mentioned were creativity, good interpersonal skills and strong family relationships. On the BERS, the lowest area of strength was school functioning, and the highest were intrapersonal and affective strengths (Table 1).

Table 1
Standard Score Means for the BERS
***N* = 36**

BERS	*Mean (10)*	*SD (3)*
Interpersonal Strengths	11	2.93
Family Involvement	11	2.86
Intrapersonal Strengths	12	2.58
School Functioning	10	3.73
Affective Strength	12	3.09
Strength Quotient	109	16.42

Note: BERS = Behavioral and Emotional Rating Scale

Caregiver Respondent Demographics

The majority of the caregivers (*N* = 36) were single biological mothers with custody of their child. Seventy-four percent of the caregivers reported household incomes under $20,000 and most of the children were receiving medical assistance. Caregivers also identified their own strengths on the CANS. The most frequently mentioned strengths were a desire to be involved with his/her child's care, good physical health, and feeling capable of managing family life. In terms of feelings of strain, 69% worry "very much" about their child's future; 43% worry "very much" about the family's future; and 42% feel "very much" guilt about their child's emotional or behavioral problem.

Table 2 presents the correlations between the BERS and the CGSQ subscales and full or global scale. The BERS subscales were negatively correlated with all of the CGSQ subscales: higher levels of child strengths (higher scores on the BERS) associated with lower levels of caregiver strain (lower scores on the CGSQ). All of the correlations were significant except for the correlations between the school functioning subscale and the strain subscale: educational strengths did not appear to associate with feelings of strain for caregivers in this group.

Table 2
Correlations Among the BERS and the CGSQ
***N* = 36**

	Interpersonal Strengths	*Family Involvement*	*Intrapersonal Strengths*	*School Functioning*	*Affective Strengths*
Objective Strain	-.56**	-.56**	-.46**	-.23	-.50**
Subjective Externalized Strain	-.53**	-.63**	-.53**	-.27	-.60**
Subjective Internalized Strain	-.40*	-.49**	-.35*	-.28	-.39*
Full Scale (21 items)	-.55**	-.60**	-.48**	-.27	-.53**

Note: BERS = Behavioral and Emotional Rating Scale; CGSQ = Caregiver Strain Questionnaire.
*$p \le .05$; **$p \le .01$

Discussion

These preliminary findings suggest the potential of identifying and building on child and adolescent strengths when working with the child and family. A strengths-based orientation views the child and family members as individuals with unique talents, skills and life events as well as specific unmet needs (Olson, Whitbeck, & Robinson, 1991). Challenged children and stressed parents have strengths, competencies and resources that can be leveraged when working with the family (Epstein, 1999).

When a parent or caregiver perceives their child to have strengths and competencies, then they may also experience fewer feelings of depression, embarrassment, fatigue, anxiety, and less of a sense of personal and family disruption. Another benefit for the child may be that a parent or caregiver who feels less strain—through the identification and nurturance of the child's competencies in social and intrapersonal areas—is better able to support and encourage the child. This does not reduce the importance of identifying and addressing the needs of the child and the parent. Rather, an integrated clinical approach that treats and reduces symptoms and behaviors of the serious emotional disturbance while building on the child's resources and skills may offer the greatest potential benefit for the child and the caregiver (Lyons et al., 2000).

There are several limitations to this study. First, the sample is small and consists of primarily urban, single-parent families. Additionally, the causal direction cannot be determined and the influence of other variables such as child functioning, social support and service utilization were not investigated as possible moderating or mediating variables. Further longitudinal research that looks at the multivariate influences, particularly the roles that perception and personality play, is needed in order to determine the direction and the nature of relationships between needs, strengths and strain. Other interesting variables to include in a multivariate analysis would be the length of time (time since first diagnosis) and the degree of experience.

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System Of Care and Delinquent Behavior: A Report from NC FACES

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Introduction

Around 60% of individuals in the criminal justice system have a diagnosable mental disorder (Bureau of Justice Statistics, 1995). More than three-fourths of youths in detention facilities in the state of Virginia were found to have a diagnosable mental disorder (OJJDP Work Session, 1995). Of youths served by juvenile justice and mental health agencies in Sonoma County, 20% were arrested over the three-year study period (Rosenblatt, Rosenblatt, & Biggs, 2000). Because the likelihood that a child with mental illness will end up in jail, in prison, in detention centers, and in other correctional facilities is quite high, there is an urgent need for programs that deal effectively with the prevention and reduction of behaviors that lead to criminal activities.

Background

North Carolina Families and Communities Equals Success (NC FACES) was funded by the Center for Mental Health Services (CMHS) in 1997 to implement a system of care for children with serious emotional disorders and their families in four sites: Blue Ridge, Cleveland, Guilford, and Sandhills. The grant includes an evaluation component in which children and their caregivers are interviewed at six month intervals to track child outcomes such as school performance, level of functioning, clinical symptomatology, substance use, and delinquent behaviors.

Purpose

We were guided by two research questions in this study: Do children who exhibit delinquent behaviors differ from those who do not, and is participation in NC FACES associated with changes in delinquent behaviors?

Methodology

Data were drawn from survey instruments used in the CMHS national evaluation. As part of the delinquency questionnaire, children 11 years and older were asked how often in the past six months they had performed behaviors such as "knowingly bought, sold, or held stolen goods." The responses were "none," "one time," and "two or more times." Delinquent behavior was measured as a dichotomous variable indicating engagement in any of the behaviors specified in the instrument. Excluded were traffic moving violations and rowdy behavior that we did not consider to be as serious as the other offenses itemized in the questionnaire. The delinquency questionnaire also provided information on other juvenile justice indicators such as arrests and detention. In addition, caregivers were interviewed on problem behaviors using the Child Behavior Checklist (CBCL; Achenbach, 1991). County statistics on juvenile complaints were further obtained from the North Carolina Office of Juvenile Justice and Delinquency Prevention.

Although the target population of NC FACES ranges from 5-18 years old, our study was restricted to children 11 years and older since the delinquency questionnaire was administered only to older children. Our baseline sample consisted of 175 children while our follow-up sample had 59 children who provided complete information on delinquency variables at initial and one-year interviews. Of those children and families who consented to participate in the evaluation, there were 85 for whom one-year interviews were due in March 2001, yielding a completion rate of 69%. Those who had missing interviews at one year did not significantly differ from those who were in the follow-up sample on age, gender, ethnic origin, and delinquency behavior at baseline. Externalizing problem behavior was the only variable where a significant difference was evident. But because those with higher externalizing problem behavior scores remained in the study at one year, this difference was not as serious a concern as it would have been had those with more problematic behaviors dropped out of the study and the program.

Results and Discussion

Forty-five percent of children in NC FACES reported performing delinquent behaviors in the six months that preceded their baseline interviews. Compared to the group that did not report delinquent behaviors, these children tended to be older and to have higher mean T-scores on externalizing problem behaviors as measured by the CBCL. Significant differences were also observed on DSM-IV diagnoses (American Psychiatric Association, 1994). The proportion of substance-related disorders (alcohol and cannabis) in the group with delinquent behaviors was almost three times the proportion found in the group with no delinquent behavior. Children with a diagnosis of Attention Deficit-Hyperactivity Disorder (ADHD) tended to be in the non-delinquent group (Table 1).

Table 1
Comparison between Groups Reporting Delinquent Behaviors and No Delinquent Behaviors on Selected Variables

Variables	*Delinquent Behaviors*	*No Delinquent Behaviors*	*All*
Mean Age	13.6	12.0***	12.7
Mean T-score (Externalizing)	72.7	69.8^{+}	71.3
% Male	70.9	69.8	70.3
% Caucasian	54.4	46.4	50.0
% Substance related Disorder	11.1	4.3^{+}	7.3
% Depressive Disorder	18.1	18.3	18.2
% Adjustment Disorder	13.9	11.8	12.7
% ADHD	30.6	58.1***	46.1
% Conduct Disorder	11.1	10.8	10.9
% ODD	34.7	32.3	33.3

$^{+}$ $p < .10$
*** $p < .001$

Results based on the longitudinal study demonstrate the effectiveness of a system of care as an intervention strategy in the reduction of delinquent behaviors. Overall, the percentage of children who reported delinquent behaviors decreased from 51% at baseline to 42% at one year (Figure 1). The number of arrests declined by half (Figure 2). Caregiver reports confirmed behavioral improvements. Mean T-scores on externalizing problem behavior decreased significantly from 74.4 at baseline to 67.8 at one year (t = 4.663, df = 45, p = .000) (Figure 3).

Participation in a system of care did not totally eliminate delinquent behaviors. Close to a quarter (24.1%) of children who did not report delinquent behaviors at baseline did so at one year. This percentage, however, is half that of the percentage reported at baseline (50.8%), suggesting that participation in a system of care may contribute to the prevention of delinquent behavior.

Figure 1
Changes in the Percentage of Children Reporting Delinquent Behavior between Enrollment and One Year
(N = 59)

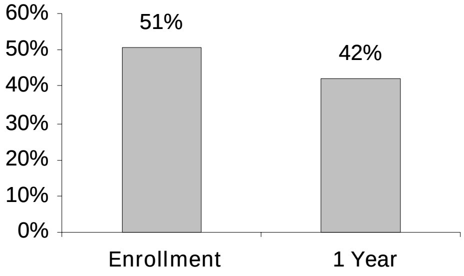


Figure 2
Decrease in the Percentage of Children Arrested between Enrollment and One Year
(N = 59)

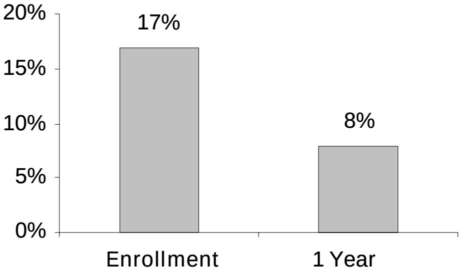
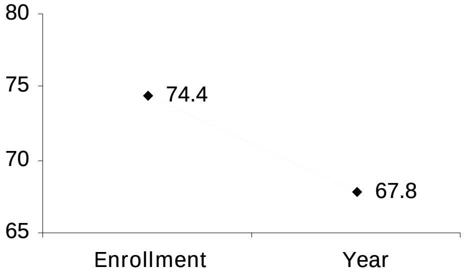


Figure 3
Changes in Mean T-Score for Externalizing Problem Behavior between Enrollment and One Year***



*** $p < .001$

Table 2
Disciplined Juvenile Complaints in North Carolina between 1997 and 2000

	% Change
Overall	-.02
Non-FACES sites	.13
FACES sites	-.10

State data obtained from the Office of Juvenile Justice and Delinquency Prevention show a decline in juvenile justice indicators for sites covered by NC FACES (Table 2). Overall, serious juvenile complaints decreased by 971 between 1997 (the first year of implementation for NC FACES) and 2000 for all 100 counties in North Carolina. While decreases were seen in half of non-FACES counties, decreases occurred in three-quarters of FACES sites. The percentage of change for the whole state was -.02. On average, disciplined complaints increased by 13% in non-FACES sites. In FACES sites, complaints decreased by 10%.

In comparing children with and without delinquent behavior, we found substance-related disorders to be associated with delinquency. More aggressive approaches with alcohol and drug dependency may be needed for the children that we serve in our programs. Likewise, the higher T-scores on externalizing problem behaviors among youth with delinquency problems call for the use of therapeutic interventions that have been shown to have some efficacy in dealing with antisocial and aggressive behavior such as multi-systemic therapy, as suggested by Rosenblatt, Rosenblatt and Biggs (2000).

Although we cannot identify the component in a system of care that contributed to reductions in delinquency behavior, efforts made by the grantee sites, and particularly their family organizations, to build on the child's strengths through the use of flex funds and informal community resources for mentoring and extracurricular activities may have played an important role. System of care demonstration sites used part of their grant money to fund nontraditional services that raised self-esteem and kept the child busy after school. These included membership in the YMCA for swimming, basketball and other activities, Tae-kwondo lessons, and tutoring in subjects where the child was having some difficulty.

The reductions in juvenile complaints that were found in FACES counties as compared to non-FACES counties indicate that a system of care may have had an effect that extended beyond the confines of the grant program. Sites in NC FACES are governed by community collaboratives made up of family members, advocates, and representatives of child-serving agencies from the public and private sectors. System of care training that was regularly provided in the grant was further open to providers from all agencies. It is possible that the values and guiding principles of the system of care were diffused from the core group to the agencies that the members represented, as well as to the wider community. Some collaboratives also pursued funding from other sources, including education and juvenile justice, to sustain the program once the grant ended.

Our results are based on a small sample size and should be interpreted with caution. Moreover, our study does not identify causal determinants for the changes shown in our outcome measures. However, the interrelationship between mental disorders and incarceration is so clearly established any delay in the implementation of programs that focus on reducing delinquency among youth with serious emotional disorders has severe and possibly irrevocable consequences on the youth, the family, and society in general.

By demonstrating that participation in a system of care is associated with both the reduction and prevention of delinquent behavior, our study implies that a system of care is an effective strategy for minimizing potential involvement with the legal system.

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Symposium

How to Be Little and Still Think Big: Creating a Grass Roots, Evidence-Based System of Care

Chair
Russell Lyman
Discussant
Joan Mikula
Authors
Susan Ayers
Ron Siegel
Russell Lyman et al.

Symposium Introduction

Community agencies face a daunting task in bringing scientific methods to clinical practice during an era of managed care. Three presentations in this symposium demonstrate how empirically sound outcomes projects can be created on a shoestring, addressing both the practical and technical aspects of building data systems and the political and economic aspects of supporting and making use of research to improve systems of care. The first paper discusses executive pathways to outcomes research by providing a rationale for why it makes sense for even a small human service agency to make the commitment to support research in clinical practice. This paper is followed by presentations on data from two very different programs in comparison with one another. One is an outpatient clinic in which our plans to describe families and treatment outcomes led to complexities we did not anticipate, and one is an intensive family treatment program in which we investigated the risk factors presented by different types of very challenged families. A systems perspective is then provided by a discussant from the Massachusetts Department of Mental Health, who focuses on lessons learned and directions for the future.

Executive Outcomes: Finding Data to Support Funding and Funding to Support Data

Susan Ayers

Introduction

Outcomes research must become part of the culture of clinical settings, both to ensure the viability of programs and to apply research to practice in a meaningful way. Hard data is the practitioner's strongest voice in gaining support for developing a system of care. This paper outlines an executive pathway for doing the grass roots work that made research part of the daily life of two of the mental health programs of the Guidance Center, Inc. in the urban, diverse city of Cambridge, Massachusetts. Agency vision, strategic planning, Board, staff and consumer involvement, and developing a range of key state and local relationships are essential components of the blueprint for starting from scratch. An overview of the Guidance Center's efforts to build a community based system of care will help to illustrate the complexities of developing a research paradigm across a diversified spectrum of services.

Description

The Guidance Center, Inc. is a private, non-profit agency that began meeting the community mental health needs of children and families in 1954. It was a relatively small agency (with a $2 million annual budget) until 1997 when a corporate affiliation with another local child agency allowed us to broaden our continuum of services. We offer universal home visiting for young, first time mothers and Early Intervention services; operate Cambridge Head Start Child Care; have a range of school, community and clinic based violence prevention and mental health services; and craft family support and respite services for severely developmentally challenged children. We manage almost $8 million of human service resources, employ 160 people and directly impact 3000 family members, professionals and countless others through program and case consultation. Our funding is a blend of competitively bid federal, state and local government contracts, third party revenue, foundation, business and donor dollars. Our vision is to build an integrated, multicultural, evidence based system of care that works to strengthen the children and families of our communities. Developing our Outcomes Project has been a critical means to that end.

Research became a component of the agency strategic plan in the mid 90's when we heard managed care companies touting their success with treating folks in one to four sessions with their new and improved models. We knew that these models did not apply to our core constituents of children with severe emotional disabilities and their complex families. Our challenge was to document in a quantifiable way the level of functioning of our kids and families, the kinds of risk factors they were encountering, and the variety of intensive, multi-systemic treatments they found effective. We also needed to be able to define progress in a deeper and more sensible way than the narrowly circumscribed behaviorism used by managed care companies that often place limitations on badly needed care. Information is power, and we needed it to fight back. Believing that "The best offense is a strong defense," we got to work on our Outcomes Project beginning with two mental health programs.

The process began with a vision that was driven by the agency mission. With so few resources to spare, it was essential that a research project requiring something more for everyone to do be fueled by a vision, held by the staff and Board, and be a key informant of the clinical work. In our agency, this vision focuses on moving beyond anecdotal descriptions to a more global picture of what our client population looks like, and how we can define treatment "progress" in a structured way. Therefore, we wanted to put together aggregate snapshots so that our staff, community, payers, donors and policy makers could understand who we are treating, the problems they present, and the strengths they have to work with. This vision must be shared as part of an agency consensus-building process. Everyone—from clinicians who have to complete surveys or persuade parents to do so, to support staff who must track or enter data, to Board members who must endorse the process—must feel they have a part in a valuable enterprise. They must be aware that the key to any successful business is being able to demonstrate that we offer a variety of effective products used by satisfied customers. As the process moved forward, we had to draw the staff and the Board into understanding empirical analyses of client profiles and program outcomes, so that they would continue to fuel our work. This was especially important, since beyond a very limited amount of gratefully accepted United Way support designated for outcomes, there has been no designated funding for research in our practice.

Discussion

Our vision and strategy have led us to an empirical system that is proving to have tremendous value for our programs and our stakeholders. Internally, we are now able to use functional assessments as part of the evaluation and care planning process. We are able to move beyond clinical judgment and use snapshots of risk factor clusters as we determine level of intensity and resource allocation to particular families. We are able to have a far more thorough understanding of which sectors of our population are using the most services (4% of our families use 25% of our resources). And we are now also able to investigate the outcomes of a growing number of our programs and continuously redefine what we describe as positive outcomes. For example, we know that in some of our high intensity programs a drop in a child's rate of hospitalization may be a more meaningful definition of progress than a small change in a functional assessment score.

This empirical work has dramatically altered how clinicians think about progress in treatment, and brought a new level of accountability to our services. It has also guided us as we have developed new programs. Our high intensity programs such as our Intensive Family Services and our therapeutic Family After School have arisen out of evidence-based assessment of child and family needs.

We are now also able to be accountable to our stakeholders. State funders such as the Department of Mental Health (DMH) can know whom they are serving, what they are paying for and why as they draw their monetary lines in the sand or make their case to the Legislature. The social policy implications of this work are extremely significant. The capacity for profiling service populations tends to elude most state agencies that only count “their populations, so often social policy is created with insufficient cross-agency information. Each state agency tends to focus only on their part of the elephant, whereas community providers tend to be exposed the whole animal, or at least most of it. Because we blend funding streams in order to craft wraparound services for families, hard data give us a chance to provide a “voice from the trenches” in the public policy debate. Our demographic risk factor clusters and analysis of aggregated CBCL scores are examples of windows to our client population that we can provide for legislators and social service administrators.

Finally, our Outcomes Project has put us in a strong position to positively influence the service system in our area, and to procure program funds in competitive bidding processes. Prospective funding agencies as well as foundations, the United Way and even managed care organizations learn through our proposals that we know what we are doing and can measure it. Purchasers of wraparound models of care now quite appropriately seek to buy outcomes rather than services, and our research addresses their need to quantify these outcomes. Our demographic snapshots of family protective issues for the Department of Social Services (DSS), or family mental health risk factors for DMH are examples of how our empirical work has been key in positioning us as lead DMH and DSS service managers in our area.

Conclusion

In conclusion, this has been an executive summary of how a human service agency can be little and still think big in closing the gap between research and practice. We hope that this symposium will illustrate concrete ways of how an outcomes project can be structured using the resources community agencies have, and how the data can be used to improve the quality and scope of programs, as well as strengthen voices from the trenches as they advocate for community based human services.

Many challenges remain as we’ve just begun this Outcomes journey. How do we find funding, including University partners, so we can take these initiatives to the next level? How can we encourage parents to be more involved beyond the client satisfaction survey insuring a relevant, strength-based focus? How do we take what we’ve learned and apply it agency-wide in all of our programs? Just getting this far has been one of the most stimulating and satisfying professional challenges our team has ever undertaken. We are confident that the next phases will continue to propel this “Little Engine that Could” down equally adventuresome tracks.

Closing the Gap Between Science and Practice, Starting from Scratch: The Cambridge Youth Guidance Center Outpatient Data Project

Ronald D. Siegel

Introduction

The Cambridge Youth Guidance Center is an urban, outpatient clinic serving the mental health needs of a culturally diverse, predominately economically disadvantaged population of children and families in Cambridge, Massachusetts. Despite a 40-year history of respected work in the community, little has been done in the past to systematically describe the population we treat, the services they receive, or the outcomes of these efforts.

Approximately five years ago, the leadership of our organization embarked on a project designed to collect and analyze the data necessary to make more informed management decisions about our intervention programs and strategies, as well as to (hopefully) demonstrate the value of our work to potential supporters. We headed down this road with limited money and staff to devote to the project. At the time, we did not realize just how complex and resource intensive this undertaking would be.

This presentation reviews the ups and downs of this adventure, describes our principal findings to date, and offers practical suggestions for other agencies contemplating similar projects.

Scope of the Project

Early on, it became apparent that a treatment effectiveness study, utilizing controls to ensure experimental validity, was far beyond our available resources. Nonetheless, other pertinent questions seemed amenable to quantitative investigation. We chose to focus on three goals:

- Empirically describe the population we treat using functional assessments and demographics measures,
- Correlate these variables with service intensity, duration and cost, and
- Empirically describe clinical outcomes.

Our plan of action was to first identify relevant data already being collected in the natural course of our work; then to implement the most efficient, least intrusive methods for collecting additional data that we could devise; and finally integrate these sources of data in an analysis. We will briefly describe our experience taking these steps:

Mining Existing Data

Like many agencies, we had been using a computerized billing service for several years to collect third party reimbursement. In our case, this involved a private company that utilized proprietary software to gather and organize service delivery information, and electronically bill appropriate payers. We initially hoped we could simply add additional fields to this billing system, and use its existing database for analysis. That process took over a year, and countless negotiations with the technical professionals at the billing company, to realize that this was not a viable option. The sort of proprietary software involved, while well suited to the task of billing, lacked the requisite flexibility to integrate the other data we sought to analyze. To allow the programmers at the billing company to modify the software sufficiently, we would have far exceeded our financial resources.

This false start led us to Plan B: data mining. Luckily, there are several off-the-shelf software packages designed for just this sort of situation—mining data from an older, existing, inflexible database and converting it into a format that can be used by a modern, readily programmed one. We were eventually able to use one of these utilities to regularly mine data from the billing system and import it into Microsoft Access, which could then integrate it with other data collected at the agency. This gave us a way to begin building our new database by importing basic demographic information, diagnostic data, and service records without duplicate data entry.

Collecting Relevant Demographic Data

We knew from the beginning that we would be interested in identifying the mental health risk factors affecting our clients, both to evocatively demonstrate that these children and families need help, and also to tailor our services to our particular client mix. We also wanted to see which clients were currently receiving what services. A comprehensive list of risk factors, including family disruption, abuse and neglect history, exposure to violence, and involvement with other agencies was constructed first by surveying the research literature. We then circulated a developing list to clinicians whom we asked for additional risk factors they observed in their work. This process resulted in a manageable, but remarkably comprehensive group of factors on which clinicians could report using a simple checklist. We were then able to design a data entry form in Microsoft Access with which clerical personnel could enter this information into the database.

We also sought an empirically validated measure of our clients' functioning. After some research, we settled upon the Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1991), because of its widely accepted validity, despite the measures being somewhat insensitive to short term change. It took considerable effort, and several staff trainings, to help clinicians without extensive training in research methodology to accept and begin using these instruments. Even with this effort, it was difficult to collect completed forms from many families. Nonetheless, clinicians began to find the descriptions of their clients strengths and risk factors useful for treatment planning.

Initially, the computer scoring program for these instruments could not export the data in a readily usable form, and the data had to also be passed through a data mining utility. More recently, the instruments are available in a format that imports readily into other databases, such as the Microsoft Access we are using.

Collecting Relevant Outcome Data

To better understand the course of the treatments we provide, we decided to collect a variety of data upon termination. These data include a history of collateral contacts and community supports engaged during treatment, reasons for termination, clinician rating of progress toward goals, discharge diagnosis including The Global Assessment of Functioning (GAF; American Psychiatric Association, 1994), discharge Achenbach scales, and standardized client satisfaction ratings. These materials are also collected using a paper-based system, and then entered into the Access database by clerical personnel using a simple data entry form.

Joys and Sorrows

After five years, this system is now operational, and we have collected substantial, meaningful data about the work we do. It has been a rocky road. Designing foolproof forms to gather data that do not produce erroneous or internally inconsistent information has taken considerable time and many revisions. Training clinicians to understand that all data fields must be completed has also been surprisingly difficult, and chasing down missing data on incomplete forms has been remarkably time consuming. Just keeping the flow of forms in order, given inevitable changes in personnel, has been a task. Learning enough about Microsoft Access for a computer non-professional to efficiently import and organize data for analysis, as well as create data entry screens, has involved a long and steep learning curve.

Conclusion

Despite these difficulties, the results have been exciting. We now have descriptions of who we see, which demonstrate our clients' considerable cultural and language diversity, severe histories of mental health risk factors, and serious disruptions in family functioning (see Figure 1). This information is enabling us to tailor our training and service programs to the difficulties our clients face, and to lobby effectively for funding. We can also see which of our families receive the most attention, and make informed decisions about resource allocation (see Figure 2).

We have also discovered that our families are generally quite satisfied with the services they receive, and feel that their lives have improved as a result. At this stage, we are just beginning to look at outcomes measured by changes in diagnosis and GAF, changes in Achenbach scores, and clinician rating of progress.

Quantitative description and analysis of real life treatment in a community clinic serving children and families can be done on a shoestring budget, but the project is much harder and more time consuming than one would expect. We hope that our experiences can make it easier for other agencies to embark on similar projects, and hope that we can learn from one another's efforts.

Figure 1
CYGC Individual Client's Risk Factor History
1995-2000

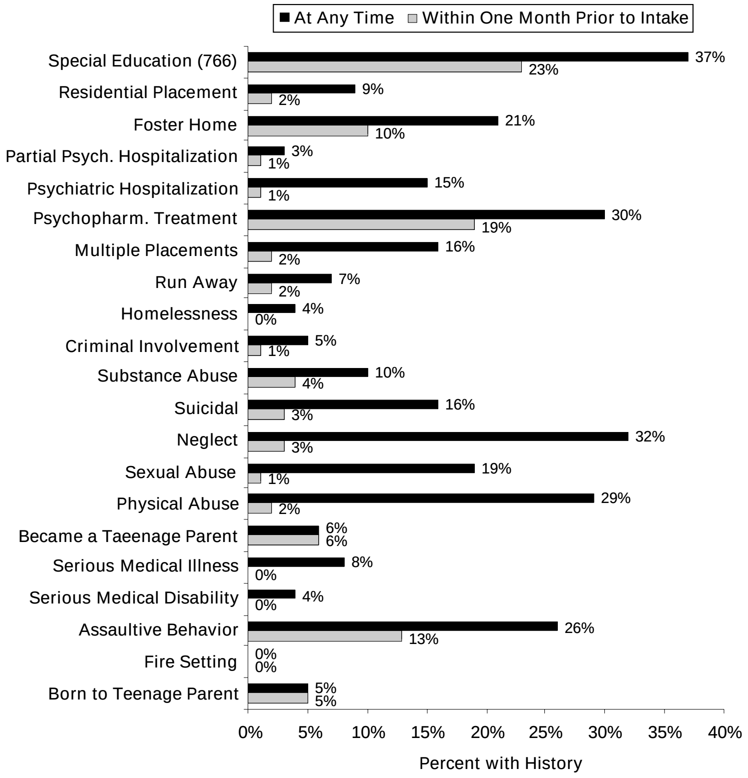
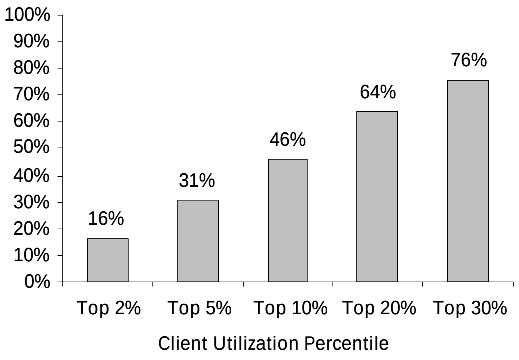


Figure 2
CYGC Service Utilization By Client
1995-2000



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Risk Factors and Treatment Outcomes In a Strategic Intensive Family Program

D. Russell Lyman & Borja Alvarez de Toledo

Introduction

The goal of this presentation of research in the Family Advocacy, Stabilization and Support Team, a program of The Guidance Center, Inc., is to provide agencies with strategies for integrating clinical research into program development beginning with your program proposal. This process includes making research part of the package of a service contract as well as part of contract performance evaluations, setting up data tracking systems, and developing user-friendly data reports. The use of research instruments in the evaluation of families (not just individuals) is presented as part of a paradigm for using empirical data in developing intervention plans. Snapshots of the data serve as a platform for program improvement and the cultivation of community support, and point to promising methods for understanding families and their needs.

Background

This is a descriptive study of child and family risk factors and treatment outcomes using a sample of 79 families treated over a 5½ year period by the Family Advocacy, Stabilization and Support Team (FASST). FASST is an intensive home based program funded by the Massachusetts Department of Mental Health (DMH), and is its most intensive community based service for children and families. It is a wraparound model designed to stabilize and support children having a serious emotional disturbance (SED) ages 4-19 years at home and in their communities. The program goal is to reduce the risk of out-of-home placement and hospitalization. Teams of FASST clinicians and family support workers are able to provide services as frequently as every day of the week, and to provide crisis intervention services seven days a week and 24 hours a day. In-home respite as well as residential placement for up to 90 days are also provided along with other goods and services purchased by the team as needed.

Method

Research measures include the Child and Adolescent Functional Assessment Scale (CAFAS; Hodges & Wong, 1996), the Global Assessment of Functioning (GAF; American Psychiatric Association, 1994), and surveys of client satisfaction. Client demographics, family structure and risk factors are collected by a survey completed by the clinician. The CAFAS and GAF are completed at intake and discharge by the clinician, with a post-treatment survey of case disposition. Our risk factor survey, developed through review of the literature, targets 43 risk factors that include child histories of hospitalization, suicide attempts, abuse or neglect, as well as family histories of domestic violence, substance abuse, incarceration or serious mental illness. Tracking of service delivery, completed daily by the clinician, provides data on the types of services utilized by different families. Qualitative analysis of the data, which is presented primarily in histograms, has led us into an exploration of the relationship between family risk factors and treatment outcomes for the child as well as to the beginnings of a framework for describing differences in service utilization across family typologies.

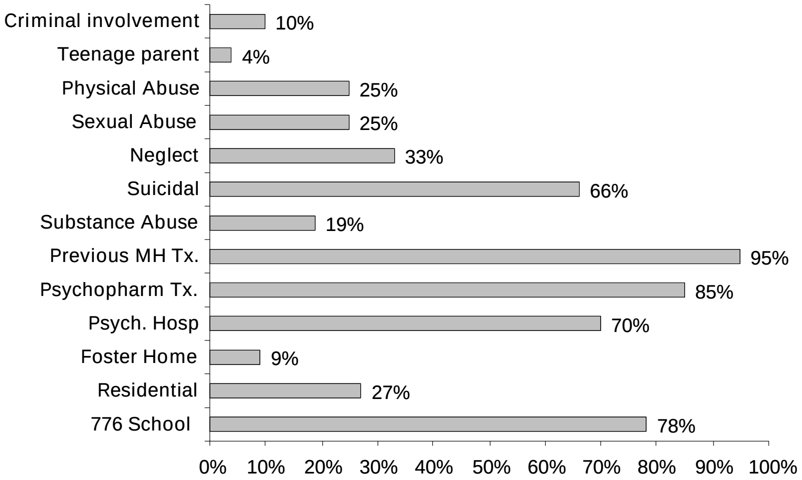
Results

Our research questions were: 1) Who are we treating? 2) What patterns of service do we find in families facing such significant difficulty? 3) What are treatment outcomes? and 4) What can we learn about how family risk factors and the child's status interact to determine outcome?

Who we are treating

Our data illustrates that only 14% of children and adolescents referred to FASST live with both biological parents. 51% live with only one biological parent, and 35% live in a blended family, with relatives, or in an adoptive or foster family. 41% present with behavior disorders. 48% are involved with DSS (for family protective issues) as well as with DMH for mental health issues. 78% have Special Education services, and 27% have been in residential treatment. 70% have experienced psychiatric hospitalizations, and 63% have presented as suicidal. Figure 1 below charts these and other risk factors.

Figure 1
Child Risk Factors
(*n* = 79)



Family risk factors were also found to be present with a high degree of frequency. Histories of major mental illness were found in 51% of the children's families, and a third of families reported major medical illness. 52% of families had histories of divorce or separation, and 41% had documented physical abuse. 57% of families showed histories of substance abuse, and domestic violence was reported in 64% of families. This type of information has been key in bringing state agencies such as the Department of Social Services and Department of Mental Health to collaborate around the multiple problems that the families of severely troubled families face.

Service delivery

Average length of stay was 4.5 months, with the most (38%) families using treatment for 7-9 months. One third were treated for 4-6 months, with nine families receiving three months or less, and three families receiving treatment for more than 15 months. One fifth of the children required residential stays of 31 days on average. Of those children who were in residential placement at intake, only one was still in placement by the fourth month. For all 79 cases, 3.2% of program service days were spent in residential placement. Analysis of wraparound service by type showed roughly equal utilization of treatment, family support (such as respite) and case management. However, we did find that families needed time to get to know us in a treatment relationships before they would use in-home family support services.

Treatment outcomes

Analysis of discharge information found modest positive change in GAF (from 49 to 56) and CAFAS (from 98 to 80). Scores within this range on both scales are descriptive of ongoing difficulty that is likely to require more than outpatient treatment. In this sense the change scores are accurate for our population but may not be as compelling as other indicators of change. For example, 85% of the children were discharged to home, with only 15% requiring a more supportive program.

Analysis of the outcome data in the context of family risk factors led us to reexamine our clinical sense that the factor most predictive of outcome is the ability of the family to provide a safe and supportive environment, rather than the degree of pathology in the child. To test this idea we used the two Family Subscales of the CAFAS to differentiate between families that were showing seriously compromised ability to provide an adequate holding environment for the child, and those who, despite facing challenges, appeared to be managing adequately. This look at the data confirmed our intuition, as described below.

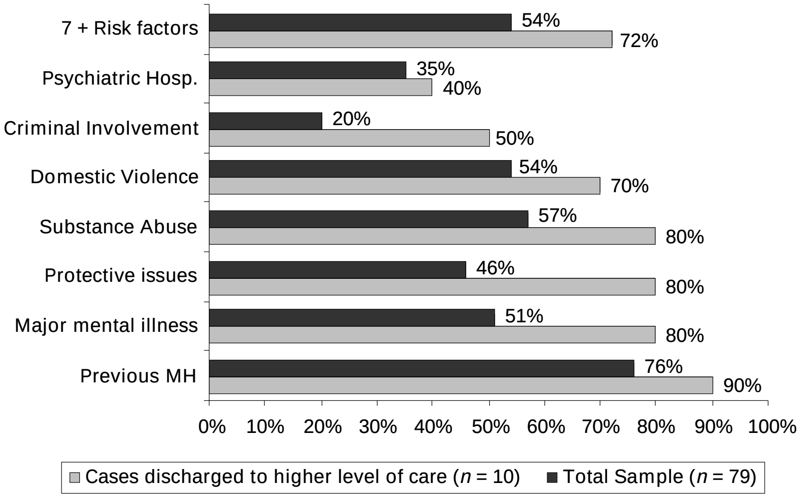
Family risk factors and treatment outcomes

Families with scores of >30 on the Family Subscales of the CAFAS (*n* = 20) were considered to be in the range of compromising challenge, and amounted to one third of the population (for Family Score <30, *n* = 59). Our risk factor data analysis confirmed the CAFAS score, showing higher percentages in every family risk factor category, including major mental illness (55%), substance abuse (65%), domestic violence (70%) and protective issues (60%). In fact, 75% of these families showed 7 or more risk factors, compared to 47% in the rest of the treatment population.

We found also that this high-end sample utilized more services, with less favorable outcomes. While other families utilized an average of 146 treatment and case management hours, these families needed an average of 194 hours. Yet nearly twice as many of these children needed to be discharged to more intensive programs (20% were discharged to a more intensive program, compared to 11% of children from less challenged families). This information suggested a closer look at those families who were unable to keep their child at home. Again, in this sample (*n* = 10) we find an even more significant loading of family risk factors, as shown in Figure 2 below.

Particularly striking in this sample of families whose children were discharged to more intensive services (generally residential placement) is the incidence of major mental illness, protective issues and substance abuse, all 80%. Not surprisingly, we find CAFAS scores that actually went up, from 124 at intake to 130 at discharge. It should be noted, in comparison to the rest of the treatment population (whose CAFAS scores went down, from 96 to 80), that these were children who were doing quite poorly at intake and even worse at discharge.

Figure 2
Comparison of Family Risk Factors
for Cases Discharged to a Higher Level of Care
(*n* = 79)



Conclusion

Our analysis of the data strongly suggests that careful examination of family risk factors can both inform treatment planning and the way we think about systems of care for seriously disturbed children and their families. Together our symposium presentations demonstrate that the analysis of empirical data can be one of our strongest tools for promoting service system change, influencing public policy and assuring program strength in a managed care world.

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Symposium Discussion

Joan Mikula

The Massachusetts Department of Mental Health (DMH) used The Guidance Center as the site to field test the use of residential funds for intensive family services in the community. The Center's ability to maintain children and adolescents in the community led to a revamping of the procurement of residential services across the state in which residential resources can now be used to support children at home and in community. The Guidance Center's qualitative data analysis has led to a statewide review and re-thinking of how the DMH supports specialized service needs which have not been considered in its funding base, most notably parents with mental illness and children and parents with substance abuse as a dominant issue. The Center's ability to isolate the variables that have led to success vs. non-success in its programs has resulted in discussion of referral patterns and protocols by the DMH. This project has clearly demonstrated that clinical research by agencies that are implementing services such as this is key to closing the gap between research and practice, and has real potential for influencing how state agencies shape systems of care.

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Symposium

An Examination of the Dawn Project System of Care: Evaluation, Preliminary Findings, and Cost Comparisons

Chair
Jeffrey A. Anderson

Authors
Jeffrey A. Anderson
Knute Rotto et al.
Geoffrey Warner et al.

Symposium Introduction

Systems of care represent a fundamental departure from traditional service provision by espousing genuine family-centered, culturally competent philosophies and by blending the funding streams of multiple services systems and payers. Although the system of care concept has gained in popularity during the past decade, these are heterogeneous approaches that require more thorough descriptions in the literature to better understand what works, for whom, and in what context. This symposium includes three papers that collectively provide an overview of the Dawn Project, a four-year-old system of care located in Marion County, Indiana.

The first paper describes the demographic characteristics of the young people who have participated in the Dawn Project. Additionally, the local evaluation of the Dawn Project and changes in CAFAS scores from enrollment to six months are presented. The second paper describes and compares services and costs of care across the three public systems that fund the Dawn Project. The final paper compares the costs of Dawn Project participation to costs incurred by the surrounding County for children who were at-risk for residential treatment. For the one-year period examined, the cost of County-managed care for this at-risk population was $5,987 per child per month, compared to the Dawn Project cost of $4,130 per child per month. Reduced length of stay in restrictive placements appears to account for some of the difference.

The Dawn Project: How it Works, Who it Serves, and How it’s Evaluated

Jeffrey A. Anderson, Harold E. Kooreman, Wanda K. Mohr, Eric R. Wright & Lisa A. Russell

Introduction

The Dawn Project, administered through a contract with Indiana Behavioral Health Choices, a private, non-profit care management organization, is responsible for creating and providing a coordinated, community-based system of services for children and youth with serious emotional and behavioral needs and their families in Marion County, Indiana. Dawn adheres to the system of care principles articulated by Stroul and Friedman (1986), within a care management structure, maintaining a $4,130.00 per month capitated rate for each participant. The project is financed by three funding partners: Indiana Division of Mental Health, Indiana Division of Special Education, Marion County Office of Family and Children / Marion Superior Court Juvenile Division. For more thorough descriptions of the Dawn Project see Anderson (2000), and Russell, Rotto, and Matthews (1999).

Evaluation

To evaluate the Dawn Project, an interdisciplinary team of researchers (including educators, sociologists, economists, psychiatric nurses, and others), family members, providers, and system level administrators are developing and implementing a comprehensive evaluation plan, called the Dawn Project Evaluation Study, which has been organized into six general areas:

Area I: Profile and Outcomes of Dawn Project Participants. The goal of this area is to examine the clinical profile of the youth and families being served by Dawn, and to determine how profiles may change over time.

Area II: Patterns of Service Use. The purpose of this area is to explore the configuration and patterns of services usage by Dawn participants and examine the operating costs of Dawn.

Area III: Dynamics of Service Coordination Teams. The goals are to document the structure of the teams and how structures change over the course of a young person's involvement in the program; describe and measure the interpersonal dynamics of each team; and develop measures of team dynamics that can be used to underpin the analyses of patterns of service use and individual child outcomes.

Area IV: Effectiveness. Defining and understanding effectiveness is challenging. Nevertheless, the evaluation team believes that this evaluation area will be informed by and evolve out of the other five areas as the initial evaluations are implemented.

Area V: Families Reaching for Rainbows Advocacy Organization. The aim of this study area is to bring an understanding of the relationship between organizational involvement of families in support group activities and their progress through the Dawn Project.

Area VI: System Level Functioning. The purpose of this evaluation component is to gain greater understanding of how well the Dawn Project adheres to the guiding principles established for systems of care for youth and their families, including family centeredness, service coordination, cultural competence, individualization, and community based treatment.

Who Participates in the Dawn Project

As of February 15, 2001, 384 youth have received Dawn Project services: Marion County Office of Family and Children (MCOFC) referred 195 youth; the Division of Special Education (DSE) referred 53 youth; Juvenile Court/Probation (JCP) referred 128 youth; and a state-operated facility (SOF) referred 8 youth. The majority of young people referred are African-American or Biracial males (N = 142, 37.0%), followed by Caucasian males (N = 111, 29.0%), American or Biracial females (N = 81, 21.0%), and Caucasian females (N = 50, 13.0%). Gender and ethnic makeup varies somewhat based on a youth's referral source. Youth referred to the Dawn Project from the DSE are more likely to be Caucasian males (N = 30), while JCP typically refers young people who are either Caucasian or minority group males (N = 97). Young people from MCOFC generally are from a minority ethnic group (N = 128). Youth from the SOF are split nearly equally between males (N = 4) and females (N = 4) and between Caucasian (N = 3) and minority background (N = 5). The average age at enrollment for Dawn participants, regardless of referral source, is approximately 13 years.

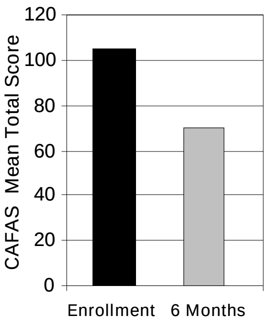
Young people in the Dawn Project have a variety of challenges at enrollment, including: criminal delinquency (e.g., conduct problems, involvement with law enforcement; 79.6%), physical abuse, sexual abuse, and neglect (72.7%), family problems (64.3%), school-related problems (62.1%), mental health-related concerns (51.1%), and alcohol and drug abuse (21.9%). Comparisons demonstrate that young people from MCOFC report more abuse than other groups. Youth from DSE are characterized by having more school-related problems and youth referred to the Dawn Project from JCP display higher rates of criminal delinquency. Youth from SOF report the high rates of family problems, high rates of school problems, abuse, and criminal delinquency.

Levels of Clinical Functioning

One fundamental purpose of the Dawn Project is to improve clinical outcomes for the young people who participate in the Project. Dawn administers the Child and Adolescent Functional Assessment Scale (CAFAS; Hodges, 1994) to rate impairment in young people in areas such as emotional, behavioral, psychiatric or psychological problems, and substance use. Using the CAFAS, Dawn's service coordinators describe and rate each youth in their caseload across various domains of functioning; these ratings are completed at enrollment and at six month intervals thereafter until disenrollment. Higher scores indicate greater impairment.

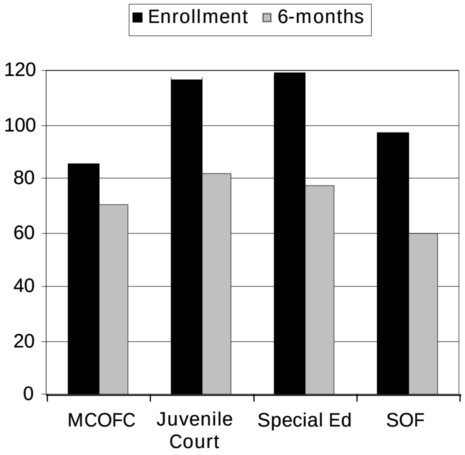
These findings are based on a sample of the 146 Dawn enrollees for which CAFAS scores were available at both enrollment and six months. The mean age of the sample was 13 years, almost 70% of the group were male, and almost 70% were either African-American or biracial. Initially, adolescents who had CAFAS data available at enrollment and six months were compared to those who did not have data available at these two points in time. No significant differences were found between the two groups on characteristics such as age, ethnicity, gender, and source of referral.

Figure 1
CAFAS Total Scores:
At Enrollment and 6 Months



At enrollment, the mean total CAFAS score was 102.00 for the 146 Dawn youth. The mean CAFAS score for the group decreased to 75.00 at six months. This is a clinically significant reduction (i.e., 20 or more points) in impairment and is statistically significant using a paired *t*-test ($t(145) = 6.11$, $p<.001$) (see Figure 1). CAFAS total scores indicate that nearly two-thirds (63.00%) of the sample were rated as having a clinically significant improvement in overall functioning over the first six months of enrollment. The remainder of the sample was divided almost evenly between those with CAFAS scores that stayed the same (21.20%) and those with scores that worsened (15.8%).

Figure 2
CAFAS Scores by Referral Source
Enrollment and 6-months



The young people in Dawn varied somewhat in their initial level of impairment as indicated by CAFAS scores. Specifically, youth referred from JCP and DSE tended to have marked levels of impairment at enrollment in Dawn (*M* = 117.00, JCP; 110.00, DSE), whereas children from the Marion County Office of Family and Children (MCOFC) and from state-operated facilities (SOF) tended to have moderate levels of impairment (*M* = 88.00, MCOFC; *M* = 95.00). Reductions in impairment were observed across children from all referral sources. Moreover, clinically significant reductions in impairment were observed at six months for adolescents referred from all sources: Juvenile Court/Probation (*M* = 94), Special Education (*M* = 84), MCOFC (*M* = 68), and SOF (*M* = 60) (see Figure 2).

Conclusion

The Dawn Project evolved out of a collective belief at the community level that services "as usual" were costly and not leading to improved clinical outcomes for young people with serious emotional and behavioral challenges and their families. Dawn was created to integrate and coordinate services across the various systems that work with young people with multi-system needs and their families, including education, mental health, probation, and child welfare, and additionally, to empower families as equal partners in service provision. Dawn has completed its third year of operations and recently received a federal CMHS grant to expand service provision to include youth in state hospitals and correctional facilities and youth who are at risk for developing more serious types of emotional and behavioral problems. Additionally, an extensive evaluation local plan is being implemented to explore profiles and outcomes of participants, patterns and costs of service usage, service coordination team functioning, overall program effectiveness, the development and functioning of a family advocacy group, and systems level changes related to the implementation of a system of care.

Preliminary analyses of available CAFAS data suggest that the overall clinical functioning of the youth and adolescents who participate in the Dawn Project improves between enrollment and six months. However, although the sample apparently is representative of the larger group, it was small. It is important that future investigations examine other types of outcome data, in addition to CAFAS scores, and include larger percentages of the young people who are progressing through Dawn to better understand whether improvements in functioning are sustained over time, related to individual or family characteristics, or attributable to specific patterns of service usage.

In sum, additional research will be needed to better understand when and why Dawn is effective, to what degree, for whom, and under what conditions. Clearly defined evaluations and outcome studies are critical to impacting policymaking related to services for children with multiple and complex needs and their families. Such research also can provide valuable information for system of care leaders who are working to both sustain and improve service coordination in multi-system collaborations.

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Cost and Service Data from an Integrated System of Care

Knute I. Rotto & Janet McKelvey

Introduction

A three-year old system of care in Indiana with a care management methodology has served over 304 youth with serious emotional disturbances who were referred from child welfare, special education, and juvenile probation. The youth are at risk of or already in residential treatment, reaching the highest level of care by each of the three public systems. This system of care braids all of the system money together into a pot for the child and family teams to purchase services and resources from a broad community support network. This summary looks at the cost and utilization data for 304 child and family teams who have purchased services and resources to support community based care. Comparing the services and costs of care of youth referred by three public systems groups shows similarities and differences (see Table 1).

Table 1
Top Five Services by Referral Source

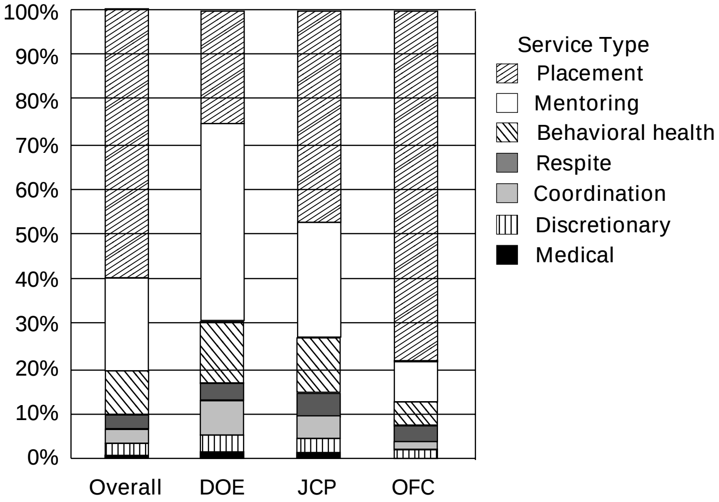
Special Education	*Probation*	*Child Welfare*
1. Educational mentor	1. Residential treatment	1. Residential treatment
2. Residential treatment	2. Educational mentor	2. Treatment foster care
3. Clinical mentor	3. Clinical mentor	3. Group home
4. Family therapy	4. Treatment foster care	4. Crisis
5. Community supervision	5. Community supervision	5. Foster care

Method

One question of interest is how youth vary by referral source, both demographically and in terms of service and cost utilization. The answer to this question not only informs the existing system of care, but also contributes to the literature about service delivery and cost utilization of youth with serious emotional disturbances. Each youth is assigned a service coordinator who, with the family, develops a child and family team that meets monthly. Additionally, each team has a standard case rate to purchase all of the services and resources necessary for the child and family. All of the services provided to the families are coded. Each of the three populations was examined, with the demographic information, CAFAS scores, and risk factors at intake. Common eligibility elements for each of the youth participating were that they had to be at risk of or already placed in residential treatment, had either a DSM-IV or a Special Education label, and were involved with two or more referral systems.

There are over 60 service codes used by service coordinators to authorize services and record the service provided to the family. The utilization data that was examined is the actual services provided to each youth and family. For this study, we have put the codes into seven categories: medical services, discretionary funds, coordination, respite, behavioral health, mentoring, and placement (see Figure 1). Examples include behavioral health, which encompasses individual, family and group therapy; mentoring, which includes six levels of mentoring, tutoring and supervision; placement, which involves foster care, group home, residential treatment centers and acute hospitals; and respite, which includes planned and crisis respite.

Figure 1
Percentage of Service Costs by Referral Source



Results

Child Welfare

Service and cost utilization. Of that $15.1 million spent in three years, $8.1 million was spent on youth referred through the Office of Family and Children (OFC). Using the service cost broad categories, the breakdown shows that more than three-quarters (77%) of the costs for the child welfare youth are placement costs. Approximately 8% was spent on mentoring, 7% on behavioral health, 3% on coordination, 3% on discretionary funds, 2% on respite, and 0.1% on medical services.

Service costs: Development over three years. A comparison of service costs across Dawn's first three years of operation shows that overall service costs for Dawn's child welfare population increased from $1 million in the first year to $3.4 million in Year 2, then in Year 3 decreased to $3.3 million. However, when the yearly increase in the number of child welfare referred children is factored in, the per-child cost was approximately $25,000 in Year 1, $37,000 in Year 2, and $28,000 in Year 3.

The spike in the Year 2 costs can perhaps be explained by the relative use of services. In Year 1, 74.6% of service costs for the children was used for placements. In Year 2, placements accounted for 79.3% of costs, and in Year 3, 75.6% of costs. In contrast, the percentage spent on mentoring dipped from 10.5% in Year 1 to 6.7% in Year 2, and then bounced up to 8.1% in Year 3. Percentage spent on discretionary funds also dipped in Year 2. Respite spending has increased all three years.

Juvenile Probation

Service and cost utilization. Approximately $4.4 million was spent on youth referred through the Office of Juvenile Court Probation. Almost half (48%) of costs for juvenile justice youth were placement costs. Approximately 19% was spent on mentoring, 12% on behavioral health, 11% on coordination, 5% on respite, 4% on discretionary funds, and 0.3% on medical services.

Service costs: Development over three years. A comparison of service costs across Dawn's first three years of operation shows that overall service costs for Dawn's juvenile justice population increased from approximately $0.6 million in the first year to $1.7 million in the second year, then up to $2 million in Year 3. When the yearly increase in the number of juvenile justice referred youth is factored in, the per-child cost was approximately $11,000 in Year 1, rose to $23,000 in Year 2, and further increased to $28,000 in Year 3.

Across the three years, shifts in the proportion of service costs spent on placement, mentoring, behavioral health, and coordination are evident. Proportion of spending on placement costs increased from 43% in Year 1 to 51% by Year 3. Proportion of costs spent on mentoring also trended upward, starting at 17% in Year and increasing to 21% by Year 3. In contrast, proportion of service costs spent on coordination trended downward (from 19% in Year 1 to 7% in Year 3), as did proportions of cost spent on behavioral health (from 16% in Year 1 to 11% in Year 3). Also of note, proportion of costs spent on respite increased from 2% in Year 1 to 6.0% in Year 2 and then slightly decreased to 5% in Year 3.

Special Education

Service and cost utilization. $2.1 million was spent on youth referred through the Division of Special Education. Forty percent of costs for youth referred through special education were mentoring costs. About one quarter (24%) of these children's service costs was placement costs. Approximately 14% was spent on coordination, 12% on behavioral health, 5% on discretionary funds, 5% on respite, and 0.4% on medical services.

Service costs: Development over three years. A comparison of service costs across Dawn's first three years of operation shows that overall service costs for Dawn's special education population increased from approximately a third of a million in the first year to half a million in the second year, then up to $1.3 million in Year 3. However, when the yearly increase in the number of special education referred children is factored in, the per-child cost was approximately $24,000 in Year 1, dipped to $17,000 in Year 2, and rose to $27,000 in Year 3.

Across the three years, drastic shifts in the proportion of service costs spent on mentoring, placement, coordination, and behavioral health are evident. For instance, in Year 1, only 21% of service costs for children in special education was used for mentoring. This proportion rose to 25% in Year 2 and then to 51% in Year 3. Although actual dollar amounts did not change much, the proportion of costs spent on placement dropped from 54% in Year 1 to 31% in Year 2, and then 14% in Year 3. Proportion spent on coordination rose from 20% in Year 1 to 23% in Year 2 and then dropped to 9% in Year 3. Proportion spent on behavioral health rose from 3% in Year 1 to 16% by Year 3, and proportion spent on respite also trended upward from 0.1% in Year 1 to 6% in Year 3.

Conclusion

In following the system of care principles and values, the Dawn Project has operationalized the delivery of individualized services using a standard case rate, child and family teams, and a broad community resource network. The service and cost data collected have been invaluable toward giving instant feedback to service coordinators, adjusting management and supervision expectations, and providing feedback to community leaders about the service mix and cost factors related to managing a system of care. The presentation of cost data is one of the first attempts to look at detailed cost and service data from a developed system of care. Examining the similarities and differences based on services utilized across public system youth receiving the same core elements should enrich Dawn's service delivery as well as inform practice and policy about developing systems of care.

Comparing System of Care Costs to County Costs for Services as Usual

Geoffrey Warner, David A. Ziska, Jeffrey A. Anderson & Eric R. Wright

Introduction

From its inception, a central premise of the Dawn Project has been that it could, by using service coordination teams and a managed care model, reduce the cost of providing care to at-risk youth. This brief report examines the question of whether the Dawn Project is an expensive alternative to in-house treatment by the Marion County Office of Family and Children (MCOFC). That is, is the cost incurred by the county in placing a child in the Dawn Project greater than, less than, or equal to, the cost incurred by the county when the MCOFC oversees a child's treatment?

Data and Methods

The cost analysis was performed by Dawn Project staff and reviewed by the independent Dawn Project Evaluation Study team. The cost data used were output from the accounting system of the MCOFC. The output file included payment information used to cut checks to reimburse the service providers. The data consisted of 12 files, each representing one month of data starting May 1998 and ending April 1999. The results of this analysis are presented in the table below. The data contained over 17,000 records for 2,173 children. Not all of these children were at-risk for residential treatment and therefore were not eligible for participation in Dawn. Because the Dawn Project targets youth who are currently in or at risk for residential placement (the highest cost treatment), this report focuses only on those youth who were in residential treatment at some time during the 12-month study period. This group of young people represents the Dawn-eligible population in Marion County.

Results

Table 1 presents a summary of the service charges paid by the MCOFC for the 276 youth who were placed in residential treatment centers at any time during the study period. The residential and total charges were computed separately; column I presents the charges for residential treatment services only and column II presents the charges for all services billed to the MCOFC. Overall, the records indicate that these young people received 512 separate service "events" representing a total of 56,690 days of service. The total charges paid by the MCOFC for these young people is estimated to be $11,212,701, or approximately $6,017 per child per month for services rendered during the 12 month study period. When the analysis is restricted to residential treatment charges (column I), the average monthly cost per youth increases to $7,151. While the costs of treating individual youth varies depending on the array of services, our analytic focus on this sub-population of young people who have had some residential services represents the population of young people most similar to those targeted by the Dawn Project.

Table 1
Summary of County Costs

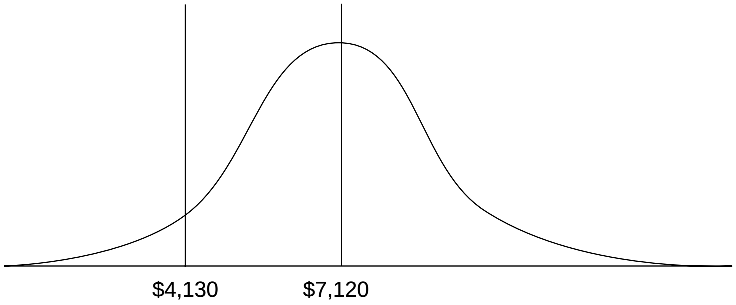
	I. Residential Treatment Charges	*II. Total Treatment Charges for All Youth Who Received Some Residential Treatment*
Number of Days in Treatment	42,089	56,690
Number of Events	349	512
Mean Days per Event	121	113
Total Cost	$9,894,210	$11,212,701
Mean Cost (per child per month)	$7,151	$6,017
Standard Deviation of Mean Cost	$1,927	$1,067

Conclusions

The Dawn Project, at a cost of $4,130 per child per month is less costly to Marion County than standard treatment at a cost of $6,017 per child per month, as estimated by provider billings. The standard deviation of the mean cost helps us determine whether this cost difference is relatively large or relatively small, because the larger this absolute difference in terms of number of standard deviations, the larger it is in a relative sense. The standard deviation of the mean cost also allows us to compute the likelihood that the County experiences a mean cost above or below the contracted payment to Dawn. The likelihood that the County experiences a mean cost for standard treatment that is greater than the payment to Dawn is computed to be 95.9%. That number should be interpreted as meaning that out of the 12 mean costs the County will experience during one year, 11 are expected to be greater than $4,130 and one is expected to be less than $4,130. Dawn not only costs the County less than standard treatment programs, it costs the County *consistently* less.

While we cannot state definitively why the cost differential exists, anecdotal evidence suggests some possible explanations. First, the Dawn Project reduces the need for/dependence on residential treatment. For the MCOFC, the average residential treatment stay averages 121 days; for Dawn clients it averages 113 days. In addition, the administrative mechanisms put in place by the Dawn Project have reduced significantly double and duplicate billings for services rendered. Regardless, these preliminary data suggest quite clearly that the Dawn Project is a less expensive alternative than the traditional array of services for this population of young people.

Figure 1
Dawn Cap Compared to Distribution of OFC Mean Monthly Costs.



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Symposium

A System of Care Comes of Age: The Rhode Island Experience

Chair
Susan Bowler

Authors
Jacob Kraemer Tebes et al.
Cathy Ciano
Anne Lebrun-Cournoyer et al.
Susan Bowler

Symposium Introduction

For the past ten years Rhode Island has been involved in the evaluation and continued development of a system of care for children with severe emotional and behavioral disorders. The symposium had four presentations: 1) an overview highlighting 24-month outcome, service system and cost outcomes; 2) the family perspective of the system of care; 3) an overview of a system of care to transition youth out of the juvenile detention facility; and, 4) an overview of state-level policy changes that have taken place and the role that evaluation and federal funding has had in helping to build a comprehensive system of care in Rhode Island.

An Evaluation of the Rhode Island Community-Based Behavioral Health System of Care for Children and their Families

Jacob Kraemer Tebes & Joy S. Kaufman

Introduction

For more than a decade, Rhode Island has provided services to children with serious emotional and behavioral disorders and their families within a statewide network of eight local systems of care. A system of care for children's mental health services is a local network of providers, families, advocates, and community organizations that work together to develop coordinated services for children and youth with serious challenging behaviors. Systems of care for children and families emphasize: 1) integrated services across providers; 2) services that are child-centered and strength-based; 3) family-focused service planning; 4) culturally competent services; 5) services that are flexible, least restrictive, and close to home; 6) the integration of natural community supports into the provision of services; and 7) community ownership through the active involvement of key community stakeholders, such as family members, providers, funders, and community representatives.

In 1990, Rhode Island implemented the Child and Adolescent Service System Program, or CASSP, with a grant from the National Institute of Mental Health. The CASSP grant established eight local systems of care, known as Local Coordinating Councils or LCCs, that are part of a comprehensive statewide system of services for children and youth with emotional and behavioral disorders. LCCs meet at least monthly and are responsible for assessing the service needs of families, identifying system barriers that impede effective service delivery, reaching out to families and local community organizations, advocating for system changes, and managing a multi-agency case review process through community planning teams.

In 1994, the CASSP structure was expanded through an additional federal service development grant to the Rhode Island Department of Children, Youth, and Families from the Center for Mental Health Services (CMHS). This second grant ensured that the CASSP philosophy and orientation to service delivery was sustained statewide. In that same year, Rhode Island was successful in obtaining another major new grant from CMHS that enabled the state to markedly enhance existing services within each of the LCCs. Known as Project REACH Rhode Island, this initiative consisted of a 5-year, $15.8 million grant from the Family Services Branch of CMHS. The overall goal of Project REACH was to develop and implement non-residential and community-based integrated services statewide.

The five specific project goals of REACH were to: 1) augment existing services; 2) develop new services when indicated; 3) monitor and evaluate the system of care; 4) assure diverse participation; and, 5) strengthen the existing interagency framework. This report evaluates the impact of the CMHS and REACH initiatives on the children's mental health system of care.

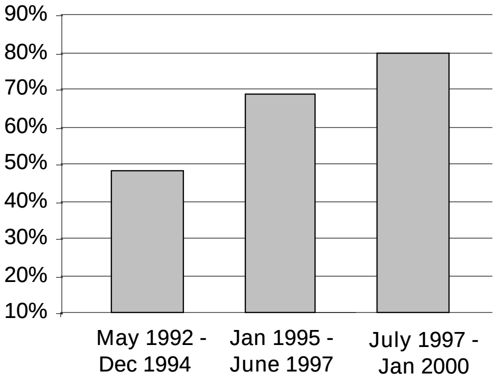
The evaluation of CMHS and REACH consisted of three components: 1) a system of care evaluation for all children and families referred to the community planning teams in each of the eight LCCs from May 1992 to January 2000; 2) an outcome evaluation of a subset of that group of families who agreed to participate in extensive interviews upon entry into the system of care, and 6-, 12-, 24-, and 36-months later; and, 3) a cost-outcome evaluation of the first 223 children and families enrolled in REACH services. A description of the methods used in both evaluation components is provided below.

System of Care Evaluation

Each family who entered the Rhode Island system of care through the community planning teams participated in the evaluation. Upon referral to the CMHS-funded program, parents were asked to complete basic descriptive information about themselves and their children as part of an evaluation of the multi-agency review and planning process. A total of 2,211 families participated in community planning team meetings and received initial reviews upon enrollment in the system of care. For each child, case review data were collected at the initial case review meeting through the use of the Resource and Outcome Data Form. This form, developed based on an earlier statewide CASSP initiative, includes sections about child demographic characteristics, such as the child's age, gender, living situation, race/ethnicity, and primary language, as well as the child's DSM-IV diagnosis. In addition, the form includes the names of case review participants involved in developing the service plan, agency and funding sources participating in development of the plan, barriers to the implementation of services, a listing of all services recommended at the initial case review meeting and those received three months later, and various assessments of risks reduced or prevented three months after the initial plan was implemented.

Figure 1 summarizes data for services received as a percentage of those recommended for the period prior to the system-wide enhancement of services (May 1992-December 1994), during the early years of system enhancement (January 1995-June 1997), and at the end of the system enhancement initiative (July 1997-January 2000). The data indicated that access to services increased significantly from early to middle to late years of the Project REACH initiative. Comparable analyses of barriers to services further indicated that barriers were dramatically reduced in a corresponding manner. Finally, as was determined by the community planning teams at each LCC, three risks—financial strains to the family, the child's placement out of the home and community, and parental separation or divorce—were reduced for the majority of children and families based on assessments made three months after entry into the system of care.

Figure 1
Proportion of Services Recommended that were Received (*N* = 2207)



Outcome Evaluation

Beginning in October 1995, each family who entered the system of care was asked to participate in an outcome evaluation. Ninety-two percent of the families approached agreed to participate, and enrollment in the outcome study was completed in January 1997. Initially, 50 families from each LCC were recruited for the outcome study for a projected total of 400 families across the state. However, since some LCCs enrolled families at a faster rate than anticipated, the enrollment period was extended statewide until each LCC reached 50 families. This brought the total to 501 participants.

Families who enrolled in the outcome study completed measures with a trained evaluation interviewer in their homes upon entry into the system of care (i.e., at baseline), and 6-, 12-, 24-, and 36-months later. Both the parent or caregiver and the child (if older than 11 years) were interviewed. Interviews lasted approximately 1 hour and 15 minutes per family member for which families received a stipend of $20 for their time. Baseline interviews were completed with 501 families; 6-month interviews with 448 families; 438 families completed the 12-month interview; 391 families the 24-month interview; and 220 families completed the 36-month interview[1]. Aspects of the procedures and measures for the outcome study were adapted as part of the national evaluation of this CMHS-funded initiative that was developed by Macro International. In addition to demographic and background information about the child and family, interviews consisted of the Child Behavior Checklist (CBCL; Achenback & Edelbrook, 1983), the Child and Adolescent Functional Assessment Scale (CAFAS; Hodges & Wong, 1996), and the Family Satisfaction Questionnaire (FSQ; Rouse, MacCabe, & Toprac, 1994). As is show in Table 1, there was a significant reduction in problem behaviors as measured on the CBCL; a significant improvement in overall functioning as measured on the CAFAS; and a significant improvement in school performance and a significant reduction in police contacts from baseline to 24-month follow-up. In addition, there was a significant increase in school attendance from baseline to 12-month follow-up (t = -4.64 (386), p = .000) and a reduction in the number of out-of-home placements from baseline to 24-month follow-up (t = -3.88 (381), p = .000). Finally, parents and caregivers were asked to rate how satisfied they were with their child's progress after receiving services, the quality of services their child received, and the extent to which they had choice and input into the services provided. In making their ratings, parents were asked to consider the previous six months when answering each question. Results stayed fairly consistent overtime with about two-thirds of parents or caregivers indicating that they were satisfied or very satisfied with progress, service quality, and degree of choice in service provision.

Table 1
Mean Score on Child and Youth Outcomes Over Time

	Baseline	*6-month*	*12-month*	*24-month*	*t*	*p value*
CBCL[1] (n = 363)	68.03	64.83	63.22	62.6	9.30	.000
CAFAS[2] (n = 323)	99.06	90.63	92.29	87.31	2.39	.001
School Attendance (n = 323)	4.23	4.45	4.62	4.48	-1.57	.117
School Performance (n = 271)	2.87	3.08	3.24	3.15	-3.11	.002
Police Contacts (n = 370)	1.24	1.01	0.80	0.47	3.55	.000

[1] Child Behavior Checklist
[2] Child and Adolescent Functional Assessment Scale

Cost-Outcome Evaluation

A total of 223 families who received Project REACH Rhode Island services during its first year of operation and who completed detailed outcome interviews at the beginning and end of that initial year were included in the study. Families were included from each of the eight service catchment areas organized through Local Coordinating Councils funded, in part, by the Division of Children, Youth, and Families (DCYF).

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[1] *It should be noted that the 36-month wave of interviews was not completed for 214 families because project funding ended prior to their 36-month scheduled interview.*

Cost estimates were based on unit costs obtained from agencies receiving DCYF funding to provide services to REACH children and youth. Estimates were based on utilization data for the following services: 1) mental health services, including inpatient hospitalization, residential services, day treatment services, and outpatient services; 2) child welfare services, including foster care; and, 3) special education services. Since Project REACH provides services to children and youth with mental health needs, considerable detail is provided about mental health costs. Unit costs associated with services were calculated based on state-of-the-art costing methods, and then aggregated for each child to provide a mean average cost per child as well as a mean average cost per service. These costs were then examined in relation to specific groups of children and youth and specific outcomes. Table 2 depicts the overall costs by service type for the 223 youth and families and the percentage of total state costs. As is shown, outpatient services represented the greatest overall percentage of state costs (42.2%), followed by special education costs (35.6%), psychiatric hospitalization (9.6%), residential services (6.6%), child welfare services (3.4%), and day treatment (2.5%). Additional analyses revealed that 20% of children accounted for 50% of the overall state costs of services and that costs allocations corresponded to a philosophy of providing services in the least restrictive setting as appropriate. That is, children who made clinical, functional, or educational gains over the course of the year generally incurred community-based services costs while those who exhibited clinical, functional, or educational losses received services in more restrictive settings, such as the hospital, residential settings, or in day treatment.

Table 2
Overall Costs for Major Types of Service
and their Percentage of the Total State Cost

	Cost for Service	*Percentage of Total Cost*
Psychiatric Hospitalization	309,584	9.6
Residential Services	212,823	6.6
Day Treatment	81,172	2.5
Outpatient Services	1,352,528	42.2
Child Welfare Services	108,176	3.4
Special Education Services	1,142,117	35.6
Total Costs	3,206,400	100.0

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Family Involvement in the Rhode Island System of Care: A Family Member's Perspective

Cathy Ciano

Introduction

I am the parent of five children, two of whom have struggled with significant mental health challenges and serious substance abuse issues over the past ten years. Through my journey as a parent seeking the appropriate supports and services for my sons, I have had an incredibly long, arduous, frustrating, and painfully emotional experience. My first taste of what it was like to reach out for help through our states' child and family serving agency was one that left me feeling very confused, isolated, and without hope. At this point in time the Child and Adolescent Service System Program (CASSP) was not an option; the process that would allow for interagency collaboration, coordination of services, and family centered practice simply did not exist.

Unfortunately, without an opportunity to become involved in the decision making processes involving the welfare and well being of my child and family, my son was continually put in situations that only perpetuated his illness. One of many very important lessons I have learned through having a family member suffer with mental illness is the devastating impact it can have on the entire family. My experience, the second time around, was with my son's continual involvement with the state juvenile justice system. By the time CASSP became a reality, my son had already been incarcerated six times and had spent a period of four years on and off, in and out of residential treatment facilities (both in and out of state), shelters, and group homes.

Although I was not familiar with the concept of family involvement, and especially after what I had learned from my experiences with my other son, I did not want anyone to make a decision about my child's welfare (including the judge) without my knowledge. At this point I was still in a constant state of trying to keep a handle on what was happening and why. It was at this point in time that I was pointed in the direction of CASSP. I am sad to say that after everything my son had been through, he had pretty much given up on the prospect of any program or service, and felt that he needed to move forward with his life without any support.

Rhode Island System of Care Initiatives

Rhode Island Parent Support Network (PSN)

I am presently the Executive Director of Parent Support Network (PSN) of Rhode Island, which is our state's support and advocacy organization for parents of children who are at risk for or struggle with emotional, behavioral or mental health challenges. I believe it is important to give a brief history of my experiences as a parent faced with perpetual crisis in order to point out what I have learned about the value of family involvement within a system of care. In 1994 the CASSP program was renamed the Children's Mental Health Services (CMHS) initiative, sponsored by SAMHSA/CMHS. There has certainly been a significant progression in terms of family involvement over the last several years. Families who are involved with the CMHS initiative are given the opportunity to identify and prioritize their needs, be involved in all aspects of developing their family service plans and, in the best of situations, learn the skills they need to become their families' most effective advocate.

As the CMHS initiative continues to grow and develop, one of the many challenges we are faced with as a system is to be sure that everyone involved remains aware of the values and principles that define what system of care is all about. A process that allows for ongoing training to support relationship building, understanding true wraparound and cultural sensitivity, is critical to the continued development of family involvement.

Fortunately, Rhode Island has made several significant accomplishments in terms of how families are involved which has allowed for the family voice and perspective to remain strong and influential.

Family Service Coordinators (FSCs) have been hired to work both with CMHS and Project Hope (discussed below). A Family Service Coordinator is a parent or caregiver of youth who have been identified as having a serious emotional disturbance. This peer-to-peer support model has been very effective in building trusting relationships with the families being served.

Initially, Rhode Island had eight half-time Family Service Coordinators, and through the continued growth of both CMHS and Project Hope we now have over twenty-five full-time Family Service Coordinators. The role of the Family Service Coordinator is to work with a family by providing support, education, and advocacy within the system of care. This model allows for the opportunity for the FSCs to meet the family in a setting that is most comfortable for them, to conduct a strengths based assessment and to provide ongoing support throughout the community planning team process.

Children's Mental Health Advisory Committee

Another area where the family voice is strong is within our Children's Mental Health Advisory Committee. This committee is the advisory body to the state Children's Behavioral Health System, and its membership is comprised of 51% parent representation. During the coarse of the last year and a half, PSN, in collaboration with several other advocacy groups, community members, and other entities involved in serving children and families, have developed the Coalition of Family Support and Involvement. Their mission is to ensure that all public policies, practices and services are family centered. A more recent development where family members have been asked to participate was on two state level screening committees. One was to hire the new special needs director for the Department of Education, and the other was to hire the Assistant Director of Children's Behavioral Health for the Department of Children Youth and Families.

The fact that the family perspective was included in these screening committees demonstrates the increased level of awareness that is happening in terms of the value of the family voice. In the area of training and technical assistance, Rhode Island has made some great strides regarding the models that are being used. For example, the Rhode Island Council of Community Mental Health Centers in collaboration with the State Department of Education, and the Department of Children Youth and Families, have been providing the Service Coordination Training, which is a workshop series designed especially for parents and providers representing mental health, education, and other child-serving agencies. Consultant trainers in parent-professional partnerships facilitate four full days of interactive educational workshops.

University of Rhode Island Partnership

Another pioneering effort supported by family members is the University of Rhode Island Partnership. Family members are involved in developing and teaching curriculum at both in-service and pre-service levels. The curriculum is based on the Early Intervention Program (for children from birth to 3 years). The role of the family members in this partnership is to instill family centered principles and practices within the curriculum, which is presented in a parent-professional partnership to participants who will be providing supports and service to families.

The CEDARR Initiative

The Comprehensive, Evaluation, Diagnosis, Assessment, Referral and Re-evaluation (CEDARR) initiative is another example of where family involvement has been introduced, and will continue to be strong. This initiative is designed to assist families to better understand their children's healthcare needs, what options are available, and how and where supports and services can be accessed. Family members have been involved in the development of the certification standards for the family centers; they have also formed an advisory body that will be responsible to oversee the quality assurance piece as well as the evaluation process.

There is presently a group of family members who are in the process of developing a curriculum, as requested by the Department of Health, that would provide an opportunity for all who will be involved in a CEDARR Family Center. This training will focus on understanding family support, cultural competence, skills for working together with families, and identifying and coordinating resources. CEDARR's vision statement captures what the initiative hopes to accomplish: "All Rhode Island children and their families will have an evolving, family centered, strength based system of care, dedicated to excellence, so they can reach their full potential and thrive in their own communities."

Project Hope

Rhode Island is in the beginning of the third year of a statewide initiative known as Project Hope. This program has been built upon the CMHS infrastructure in terms of a process that allows for the members of a community to come together with a family to help in the coordination of services and supports. Project Hope is specific to the adjudicated population at our states' juvenile correctional facility. Parent Support Network works extensively with the families who are involved with Project Hope. We are also very involved in the communities in which these families live and have been working hard to identify and build upon the informal supports that are most likely to be where families feel most comfortable and supported.

Something that we have learned through our involvement with the families connected to this project is that in order to be an effective support system, we must allow ourselves a substantial amount of time with each family. Building trust is critical and we have learned through our involvement at the Rhode Island Training School that sometimes it can takes months for a family to begin to feel safe enough to engage in even the most informal conversation. I think that we are now faced with our biggest challenge in terms of the whole family involvement piece.

Discussion

Cultural differences play a huge role when it comes to engaging families. We need to be constantly aware of the language we speak when attempting to gain the trust and interest of both the parents and the youth at the training school. The biggest issue around our language barriers tends to be more about what our culture views mental health to mean. There are many cultures that have absolutely no acceptance or understanding of what we may refer to as mental health issues. If we are not consistently conscious of our own terminology we run the risk of turning families away as opposed to bringing them in. Another very important aspect of building family involvement is being sensitive enough to know how to reach out to families and meet them where they are. Again, the more time we allow ourselves to get acquainted with the culture of a family, we will begin to become more familiar with their values and belief systems.

Clearly Rhode Island has made great strides with family involvement, but I feel it is important to point out that this is an evolutionary process and there continues to be a great deal of work to be done. I feel it is safe to say that family involvement is here to stay. However, we must continue to make it a priority as we continue to build our system of care, and understand that it is truly the key in building family responsive service delivery.

Project Hope: A System of Care for Youth Transitioning out of Juvenile Detention

Anne Lebrun-Cournoyer & Joy S. Kaufman

Introduction

Project Hope is a statewide initiative for Rhode Island youth ages 12-22 with serious emotional disturbances who are transitioning out of the Rhode Island Training School for Youth (RITS) back into their own communities. A primary goal of Project Hope is to develop a single, culturally competent, community-based system of care for incarcerated youth to prevent re-offending and re-incarceration. Project Hope is funded through a SAMHSA/CMHS system of care grant and state match monies.

Background

The high prevalence of mental health problems in adjudicated youth is well documented. A recent survey conducted at the Rhode Island Training School indicated that youth incarcerated at the state's juvenile correctional facility mirrored those in other parts of the nation. Results of this survey found that approximately 90% of the incarcerated population had either a diagnosed, or diagnosable mental health problem. In addition to exhibiting high rates of emotional and behavioral disorders, these youth reported a history of both individual and family substance abuse, with the former occurring in 88% of the study population. Further, a majority of the study participants came from economically disadvantaged areas of the state where substance abuse, domestic violence, and gang activity were common. Lastly, a majority of the population, up to 70% of the incarcerated juveniles at the RITS, were minority youth.

While the mental health needs of this population are addressed during their period of incarceration, service delivery post-discharge has met with limited success. Most of these youth, and their families, have little or no trust in the traditional social service system, which in the past had either been inaccessible to them or had not met their needs. With this in mind, and in an effort to assist youth to transition back to their communities successfully, it was determined by the state of Rhode Island that a more non-traditional approach to service delivery was essential. State leadership, in collaboration with youth and families involved in the juvenile justice system, concluded that service provision based on the Child and Adolescent Service System Program (CASSP) principles of care was needed.

CASSP principles recognize the importance of developing community-based, family centered, child focused, and culturally competent individualized wrap around services which build of the strengths of the individual youth and families. This idea was consistent with the thinking of juvenile justice policy makers nationally who, over the last decade, have been searching for new ways to avoid restrictive placement and meet the needs of offending youth in their communities in a coordinated and holistic manner.

Project Hope

Project Hope is a service delivery model that addresses the multiple needs of adjudicated youth with serious emotional disturbance through a flexible community-based service system that incorporates key elements from documented best practices in both children's mental health and juvenile justice systems. Project Hope, funded in part by the Comprehensive Community Mental Health for Children and their Families Program of the Center for Mental Health Services (CMHS), represents a partnership between the state's Children's Behavioral Health and Juvenile Corrections systems, building upon the interagency and clinical infrastructure developed in each of the state's eight mental health catchment areas.

Community-based services available to participating youth and families include but are not limited to: intensive case management; mental health counseling in a variety of modes; crisis intervention; therapeutic recreational activities; respite; mentoring; job and life skills training; educational advocacy, programming and tutoring; after school programming; and discretionary funds for more non-traditional assistance as requested/identified by the family. Youth transitioning out of the RITS, and their families, access services on a voluntary basis at the local level, through a Family Service Coordinator (FSC). The FSC is an individual employed by either a community center or the community mental health center (depending on catchment area) who has been a primary caretaker for, or who has a close relationship with, a youth previously incarcerated at the RITS. The FSC has extensive knowledge of and experience in negotiating the social service delivery systems in the area.

The FSC, with the youth and family, conducts a strengths based family assessment, identifies areas in which the family would like assistance, and identifies resources and options that the family feels would be useful and beneficial toward achieving the goal of preventing re-incarceration of the youth. The FSC then pulls together a meeting of the family support system as well as key members of the community provider agencies to effectuate an initial service delivery plan that meets the family's identified needs by building on their strengths and providing assistance as targeted by the family. Implementation of the plan rests with the case manager and others identified at the meeting with follow up meetings to adjust and fine tune the plan, set as desired by the family. Participants in follow up meetings will vary as issues arise and as the family support system builds.

Demographic characteristics of youth served by Project Hope

What follows are demographic and descriptive characteristics of the first 100 youth and families being served by the system of care. This information was collected as part of the case review meeting and includes some of the data elements required by Macro International as part of the CMHS initiative. The youth served by Project Hope were primarily male (90%), and the majority (75%) were age 16 or older. Fifty-four percent were Caucasian, 35% African American, 8% Biracial, 3% Asian/Pacific Islanders, and 1% Native American. In addition, 28% of the youth were of Hispanic or Latino origin. About one-half (53%) of the families lived below the federal poverty level and nearly all (96%) of the families met the eligibility requirements (300% of federal poverty level) for state facilitated Medicaid.

Youth were tested at entry with the Children's Global Assessment Scale (CGAS; Shaffer et al., 1993), and 81% of the youth were rated as having a clear and significant interference in functioning (*M* = 55.71). In addition the clear majority (95.4%) were identified as having a disruptive behavior disorder, 24% a substance abuse disorder, 7% an anxiety disorder, and 6% a mood disorder (see Table 1).

Table 1
Psychiatric Characteristics of Youth Served by Project Hope (*N* = 100)

Axis 1 Disorders	*Percentage*
Anxiety Disorders	6.7
Disruptive Behavior Disorders	95.4
Adjustment Disorders	0.8
Mood Disorders	5.9
Substance Abuse Disorders	24.4
Axis II Disorders	
Pervasive Developmental Disorders	3.7
Personality Disorders	7.0

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Children's Mental Health Services in Rhode Island: A Policymakers Perspective

Susan Bowler

Introduction

The Rhode Island Department of Children, Youth, and Families (DCYF) is one of three state agencies in the country that combines the management of children's mental health, child welfare, and juvenile justice services. Rhode Island law states that DCYF is "the principal agency in the state to mobilize the human, physical, and financial resources to plan, develop, and evaluate a comprehensive and integrated statewide program of services designed to ensure the opportunity for children to reach their full potential" (RIGL, 45-72.1). The values inherent in a system of care approach to children's mental health services, as well as a commitment to evaluation of services, have guided development of the Rhode Island system since 1980 when the DCYF was formed and its mission defined. Several national grant programs, including the NIMH (CASSP) State Level System Development Grant and the CMHS/SAMHSA Comprehensive Community Mental Health Services for Children and their Families Initiative, have provided both financial and programmatic assistance to DCYF in implementing this mandate for children's behavioral health. This paper will highlight the history of the system of care and the role that evaluation has played in shaping it.

The Comprehensive Evaluation

In 1990, a NIMH CASSP State System Development Grant enabled the DCYF to enhance its community-based capacity by implementing a statewide planning effort with a significant evaluation function. Evaluation and needs assessment of the state system at that time uncovered a wide consensus on the need to develop community structures that could support integrated and comprehensive planning for child and family service, as well as make families partners in service and system planning. The availability of evaluation data has provided the State of Rhode Island with information that is vital to further the process of systems development. From the initial CASSP findings to the recent site-specific process, outcome and systems level data, state administrators have used this information to inform local and state level funding decisions and policy.

Results

The comprehensive evaluation that began in the Spring of 1992 gave the Department of Children, Youth and Families (DCYF) data that were instrumental in enhancing systems growth and development. For the first time the state was clearly able to identify the populations that were being served and those that were not. This information enabled the state to target resources to enhance the cultural competency of service providers to increase access to services for the state's diverse population. In addition, the state was able to identify the barriers to receipt of services and to focus resources on helping families and the service delivery system work towards removing them. The state was also able to identify the services that although needed by children and families were not available and to target resources toward developing these services. For the first time information was also available to the state on the level of collaboration between different components of the system of care. Finally, DCYF was able to see where the system was working well to enable the state to continue to develop and nurture these components.

The information obtained in the initial two years of the evaluation influenced policy decisions in terms of resource allocation, the development of new programs, and the state mental health plan. The goals and objectives of the state's Children's Mental Health Plan focus on systems assessment, planning, and implementing a community based system of care.

The Local Coordinating Council

Encouraged by this evaluation, the Department redoubled its commitment to developing the system of care statewide. In 1994, the Department sought and was awarded two additional CMHS/ SAMHSA grants to continue system enhancement along the lines suggested by the evaluation. These grants allowed for significant expansion and refinement of the existing Local Coordinating Council (LCC) infrastructure including funds for wraparound, therapeutic recreation, and respite services to be provided to families through a strength-based, family-driven, multi-agency review process.

As the system of care continued to develop it became quite clear that the needs of incarcerated youth with a severe emotional or behavioral disorders who were transitioning back to their home communities were not being adequately served. During the mid-90s a pilot project that began to include these youth in the CASSP process and to bring them home with a full array of wrap-around services was initiated. The results of the pilot revealed that CASSP was an effective means to help stabilize these young people in the community and to reduce recidivism to the juvenile justice system. The pilot also revealed that the current system of care did not have the full array of services necessary to effectively keep these young people in the community. The state applied for and was successful in obtaining a second CMHS/SAMHSA grant to develop a system of care for youth transitioning out of the juvenile detention facility.

Along with enhancing the infrastructure and services offered by the system of care, federal dollars have supported the development of a family and community-based, culturally-competent structure for policy development. Within each catchment area, the LCCs, a collaboration of mental health, education, child welfare, juvenile justice agencies, public and private, join with parents and caregivers to build a panel of resources and service providers tailored to the particular needs and strengths of the area. At the state level, the Children's Mental Health Advisory Committee (CMHAC) meets monthly to review issues of concern, to exchange information, and to make recommendations to the Department. Co-chaired by a parent and a professional, the CMHAC is made up of parent and professional representatives of the eight local systems of care, as well as management level representatives of the DCYF and other state departments.

Funding

Funding for the system of care presently involves a wide range of state and federal sources which come through several state departments, including the DCYF, and the state Departments of Education and Health. DCYF has planned for the future of the system of care through both legislative action and through expanded use of Medicaid/EPSDT funds. Legislation has been passed that continues funding for the system of care after the initial CMHS grant ended in January of 2000. In addition, Medicaid has approved reimbursement for the Family Service Coordinators in their role of system navigators and case managers. Finally, training and technical assistance to LCCs has allowed for expanded utilization of EPSDT as a way to fund services for children and families.

Conclusion

In these efforts, both process and outcomes have been critical: the comprehensive children's mental health services grants from NIMH and CMHS have given policy makers, providers and family members an opportunity to work together for more than a decade on behalf of children and families. This process has resulted in a community-based, family-driven, culturally competent system of care that includes families as partners, has an integrated evaluation plan, and legislative and policy changes that will help the system to continue to grow and develop well into the new millennium.

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