

*Family Perspective
& Involvement*

Chapter 4

Chapter 4: Family Perspective & Involvement

Effect of Parental Impact on Mental Health Service Use Across Service Sectors

Introduction

Prior research using data from the Great Smoky Mountains Study (GSMS) indicated that perceived parental impact is one of the most important predictors of use of specialty mental health, general medical services and, to a lesser degree, school service use (Angold et al., 1998; Farmer, Burns, Angold & Costello, 1997). This study expands on prior services research using the GSMS to explore the relationship between parental impact and specific childhood diagnoses: 1) Do some child psychiatric diagnoses have a greater impact on parents than others? and 2) Is there a differential effect of parental impact on child mental health service use across service sectors controlling for child psychiatric diagnosis and functional impairment level?

Method

The dataset for this study was based on the GSMS, a representative sample of 1,421 youth (4,965 observations across 4 annual waves of data) from an 11-county, predominantly rural region in western North Carolina. Youths ages 9, 11, and 13 ($N = 4,500$) were randomly selected from all public schools in the study region. To obtain the sample of non-American Indian youth, a screening questionnaire based on the Child Behavior Checklist (CBCL: Achenbach & Edelbrock, 1983) was administered to parents. Children scoring above a predetermined cutpoint, and a 10% random sample of those scoring below, were recruited. All American Indian youth of the same age cohorts attending reservation and public schools were recruited ($n = 349$). Children and their parents were interviewed annually in person. Respondents recalled their past 3-month experiences.

Parental impact was based on parent reports of the impact of child's psychiatric disorder on family daily life from the Child and Adolescent Impact Assessment (CAIA: Messer, Angold, Costello & Burns, 1996). Child psychiatric diagnosis and child functional impairment were based on joint parent and child reports from the Child and Adolescent Psychiatric Assessment (CAPA: Angold, et al., 1995). Six common child psychiatric diagnoses were considered: 1) Conduct disorder (CD), 2) Oppositional defiant disorder (ODD), 3) Attention deficit hyperactivity disorder (ADHD), 4) Depression¹, 5) Anxiety disorders (AD)², and 6) Substance abuse/dependence (SA/SD). Diagnoses were generated using computer-

Sarah E. Teagle, Dr.PH.

Research Analyst
Mental and Behavioral Health Program
Research Triangle Institute
3040 Cornwallis Road
Research Triangle Park, NC 27709
919/541-7392 Fax: 919/541-5945
E-mail: teagle@rti.org

Adrian Angold, M.R.C. Psych

Associate Professor of Child and
Adolescent Psychiatry
Developmental Epidemiology Program
Department of Psychiatry and
Behavioral Sciences
Duke University Medical Center
Durham, NC 27710

E. Jane Costello, Ph.D.

Associate Professor of Medical
Psychology
Developmental Epidemiology Program
Department of Psychiatry and
Behavioral Sciences
Duke University Medical Center
Durham, NC 27710

¹ Depression includes major depression, dysthymia, or depression not otherwise specified.

² ADs includes separation anxiety, avoidant disorder, overanxious disorder, generalized anxiety, simple phobia, social phobia, panic disorder, and agoraphobia.

ized algorithms based on DSM-IV criteria. Functional impairment refers to difficulties that interfere with or limit a child's appropriate role functioning across 17 areas covering family life, school life, and spare time activities. Service use data were obtained from the Child and Adolescent Services Assessment (CASA; Farmer, Angold, Burns & Costello, 1994; Ascher, Farmer, Burns & Angold, 1996). Three sectors were examined: specialty mental health, general medical, and school services. Although the CASA assessed use of other sectors, the frequencies were too low to produce reliable parameter estimates. Data analysis employed a weighted Generalized Estimating Equation (GEE) approach, implemented in SAS PROC GENMOD, to produce parameter and covariance estimates corrected for the sample stratification and repeated measures design (SAS Institute, 1997).

Results

Rates of the target diagnoses across the four waves of observation were: 1) Conduct disorder, 3% of the sample; 2) AD, 2.5%; 3) ODD, 2.5%; 4) Depression, 1.7%; 5) ADHD, 1.2%; and 6) Substance abuse/dependence, 0.9%. Among the sample, 26.1% reported any functional impairment. One or more parental impacts were reported among 11.9% of the parents. An estimated 9.4% of the sample reported using school services, 4.9% specialty mental health services, and 2.9% general medical services.

Table 1 displays results of the logistic regression models run to observe the effects of child psychiatric diagnosis and functional impairment on parental impact. We found that some child diagnoses impact parents more than others, even after controlling for child's level of functional impairment. The first column of results demonstrates that having a child with any diagnosable psychiatric disorder significantly increased a parent's likelihood of reporting impact. After controlling for other diagnoses, each diagnosis remained an independent predictor of parental impact, but the magnitude of their individual effects

declined. When child functional impairment was added to the model, ADHD, depression, and ODD remained independent predictors of parental impact, but anxiety, CD, and SA/SD did not.

Next, we compared the odds of service use by sector for each diagnostic group among parents reporting impact, to parents not reporting impact (Figure 1). We observed that for each diagnosis, parental impact was associated with higher levels of specialty mental health service use, particularly if the child had an anxiety disorder, CD, or depression. Similar patterns were observed when general medical service use was considered. In the case of school service use, however, parental impact played much less of a role in whether a child in need used services.

Finally, we examined the effect of parental impact on service use, this time directly accounting for child's diagnosis and functional impairment level. We ran a series of logistic regression models, one series for each sector. Estimates from the three, final, best-fitting models are summarized below. We observed that parental impact remained an important predictor of specialty mental health ($OR = 10.01$; $CI = 6.12; 16.54$), general medical ($OR = 4.69$; $CI = 2.79; 7.88$), and school ($OR = 2.96$; $CI = 2.01; 4.37$) service use. We observed distinct patterns of

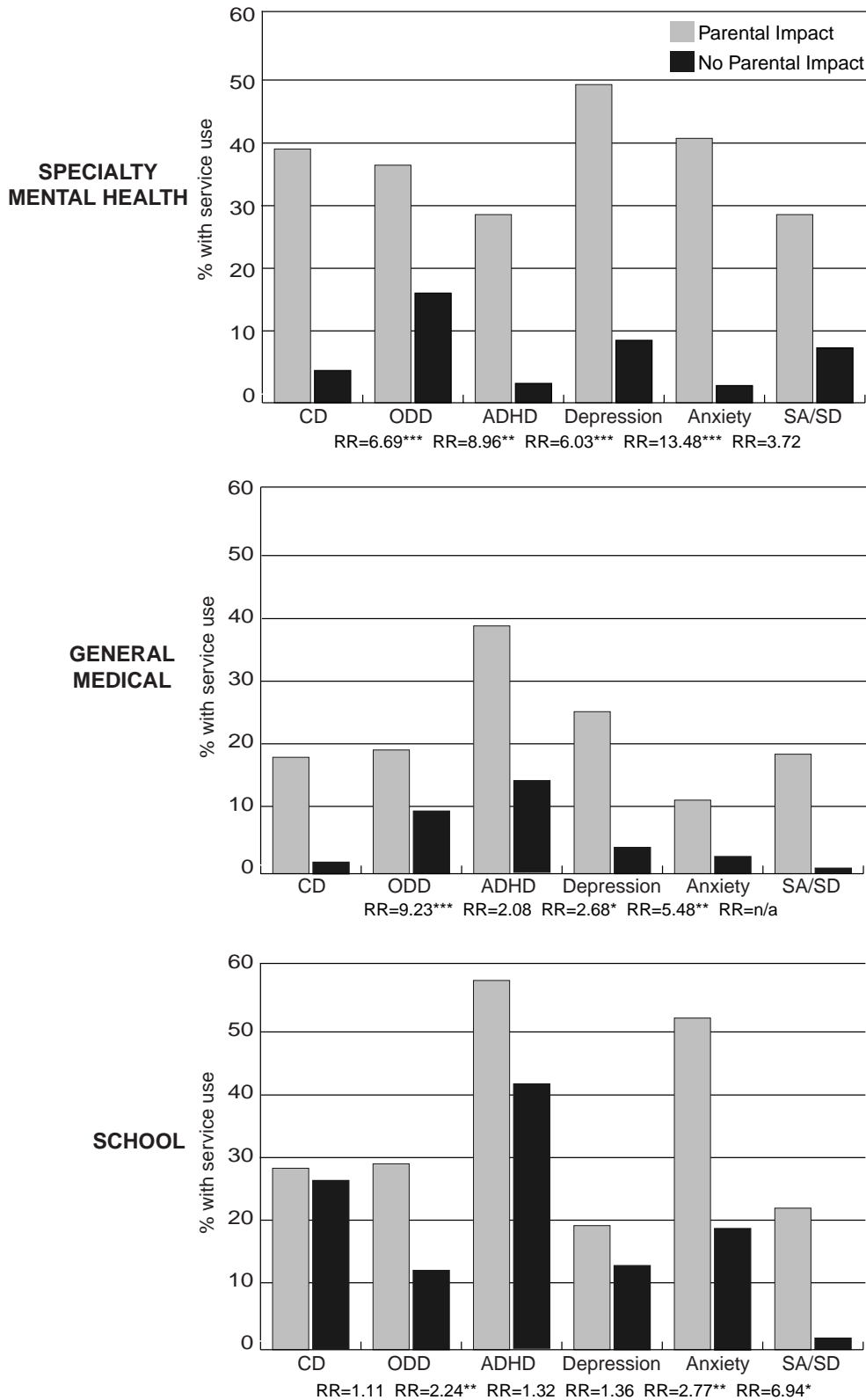
Table 1
Effects of Psychiatric Diagnosis and Functional Impairment on Parental Impact

	Pairwise OR (CI)	Controlling for Dx's OR (CI)	Controlling for Dx's & Impairment OR (CI)
CD	3.47*** (2.14; 5.64)	1.79* (1.06; 3.03)	1.10 (0.66; 1.81)
ODD	7.79*** (5.02; 12.10)	5.01*** (3.08; 8.14)	2.0** (1.17; 3.42)
ADHD	10.17*** (4.79; 21.45)	9.01*** (3.71; 21.84)	10.71*** (3.95; 29.0)
Depression	8.61*** (4.86; 15.25)	5.12*** (2.72; 9.63)	3.23*** (1.57; 6.77)
Anxiety	2.92*** (1.67; 5.13)	1.96* (1.0; 3.83)	1.26 (0.60; 2.63)
SA/SD	6.31*** (2.40; 16.57)	6.05*** (2.01; 18.21)	3.96* (1.11; 14.07)

* $p < .05$; ** $p < .01$; *** $p < .001$

Parental Impact and Service Use

Figure 1
Effects of Parental Impact on Use of Specialty Mental Health, General Medical, and School Services Among Youth With a Psychiatric Diagnosis



individual diagnoses remaining in the models across sectors. For instance, only depression remained a significant ($OR = 2.31$; $CI = 1.07$; 4.96) independent predictor of specialty mental health service use. Both depression ($OR = 3.10$; $CI = 1.18$; 8.15) and ADHD ($OR = 5.36$; $CI = 2.37$; 12.14) remained important predictors of general medical service use. In contrast, school service use appeared to be much more driven by child diagnoses. Children with ADHD ($OR = 4.69$; $CI = 1.97$; 11.17) or an anxiety disorder ($OR = 2.90$; $CI = 1.43$; 5.89), or *not* depressed ($OR = 0.37$; $CI = 0.16$; 0.82) were more likely to use school services.

Discussion

We confirmed prior analyses of the GSMS indicating that parents of children with a psychiatric diagnosis were more likely to report impact due to their child's illness. Similar to the findings in the one year analysis (Angold et al., 1998), having a child with an externalizing problem (i.e., ADHD, ODD) was more likely to cause a parent to report impact. However, we found that depression was troublesome for parents. When we analyzed the effect of parental impact on service use, we observed that parental impact determined whether a child receives mental health service use, and the magnitude of its effect differed across service sectors. We confirmed prior analyses indicating that parental impact played an important role in specialty mental health service use; and a lesser one in general medical or school service use. Use of school services appeared to be more driven by child diagnosis than use of other sectors.

Parents were indeed mediators of help-seeking for mental health services for their children. Providers need to recognize and address parental impact as part of their outreach and treatment plans. This study highlights the importance of follow-up research on parents who do not report impact yet have a youth with a diagnosable psychiatric disorder. This group may represent an important target population of youth with the greatest difficulties accessing services.

References

- Achenbach, T. M., & Edelbrock, C. (1983). *Manual for the Child Behavior Checklist and Child Behavior Profile*. Burlington: University of Vermont, Department of Psychiatry.
- Angold, A., Pendergast, M., Cox, A., Harrington, R., Simonoff, E., & Rutter, M. (1995). The Child and Adolescent Psychiatric Assessment (CAPA). *Psychological Medicine*, *25*, 739-753.
- Angold, A., Messer, S. C., Stangl, D., Farmer, E. M. Z., Costello, E. J., & Burns, B. J. (1998). Perceived parental burden and service use for child and adolescent psychiatric disorders. *American Journal of Public Health*, *88*(1):75-80.
- Ascher, B. H., Farmer, E. M. Z., Burns, B. J., & Angold, A. (1996). The Child and Adolescent Services Assessment (CASA): Description and psychometrics. *Journal of Emotional and Behavioral Disorders*, *4*(1):12-20.
- Farmer, E. M. Z., Angold, A., Burns, B. J., & Costello, E. J. (1994). Reliability of self-reported service use: Test-retest consistency of children's responses to the Child and Adolescent Services Assessment (CASA). *Journal of Child and Family Studies*, *3*, 307-325.
- Farmer, E. M. Z., Burns, B. J., Angold, A., & Costello, E. J. (1997). Impact of children's mental health problems on families: Relationships with service use. *Journal of Emotional and Behavioral Disorders*, *5*(4):230-238.
- Messer, S. C., Angold, A., Costello, E. J., & Burns, B. J. (1996). The Child and Adolescent Burden Assessment (CABA): Measuring the family impact of emotional and behavioral problems. *International Journal of Methods in Psychiatric Research*, *6*, 261-284.
- SAS Institute. (1997). *SAS/STAT Software: Changes and enhancements through release 6.12*. Cary, NC: SAS Institute.

A Qualitative Approach to Data Collection: Based on the SSI Family Impact Study

Introduction

The Supplemental Security Income (SSI) Family Impact Study seeks to understand the impact of the new regulations on families and children whose serious emotional disability (SED) had previously qualified them to receive SSI disability benefits, and for whom the continuation of this benefit is now in jeopardy or has already been lost. At the individual and family level, this is a study in coping, decision-making, and resilience in response to major changes in an important formal support system. This study is a compliment to more quantitatively designed studies through its in-depth focus on a limited sample of families, which adds a "human face" to other studies examining the impact of this legislation.

This paper focuses on: 1) research and protocol design, 2) participant recruitment and retention strategies, 3) strategies for analyzing and summarizing qualitative data, and 4) preliminary research findings.

Method

The SSI Family Impact Study utilizes one form of a case study methodology, which derives its findings from interviews with multiple sources, including the primary caregivers, and additional individuals identified as providing supports to their families. The study also utilizes a series of focus groups with parents to expand the understanding of how families have been impacted by the legislative changes. Two of the three communities represented in this study participate in the federally funded Community Mental Health Services Program for Children and Families (Kansas and New York), while two have a Medicaid managed care program for mental health services (New York and Florida).

Initial interviews were conducted between February and June, 1998. Utilizing a longitudinal design, all families were first interviewed in-depth and in-person, re-contacted every three months by telephone. A final in-person interview will be conducted during the final phase of the study in January, 2000. Families receive payment for their participation in the study. Focus groups will be conducted at two data collection points, the beginning and the end.

Parents are hired as primary researchers in the study and are involved in all phases of the study, including: 1) study design, 2) data collection, 3) data analysis, and 4) data interpretation. There are identified challenges to family/community partnership in data collection, such as pressure on family/community research assistants, trust barriers, and coordination of study without a local base of operation. Nevertheless, the benefits are also many, such as more detailed and forthcoming family responses, family voices being heard, expanded knowledge of effects of change on families, and use of

Katherine Lazear, M.A.

*Project Coordinator
813/974-6135 Fax: 813/974-7376
E-mail: lazear@fmhi.usf.edu*

Janice Worthington, M.A.

*Research Consultant
941/351-9406 Fax: 941/355-1054
E-mail: dworthing@cwix.com*

Ricardo Contreras, M.A.

*Research Associate
813/974-4598 Fax: 813/974-7563
E-mail: contrera@fmhi.usf.edu*

Elizabeth Olavarria

*Consultant
718/401-7379*

Sharon Lardieri, M.S.W.

*Research Associate
813/974-4552 Fax: 813/974-7563
E-mail: lardieri@fmhi.usf.edu*

Maridelys Detres

*Research Associate
813/9746328
E-mail: mdetre@fmhi.usf.edu*

*Department of Child and
Family Studies
Louis de la Parte Florida Mental
Health Institute
University of South Florida
13301 Bruce B. Downs Blvd.
Tampa, FL 33612*

research findings by family advocacy organizations. Figure 1 provides a summary of the data collection instruments.

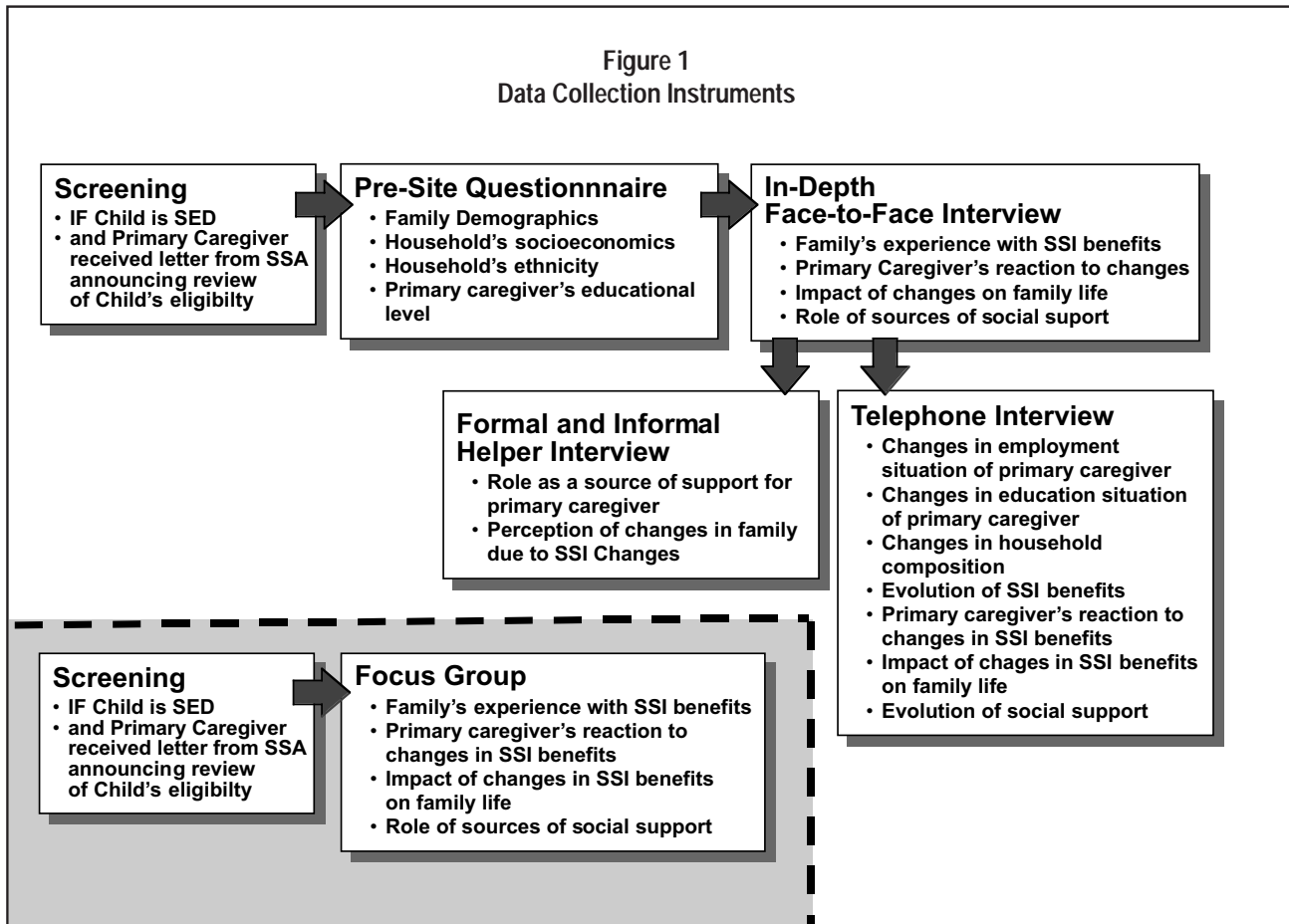
The findings from this data collection are analyzed using the NUD*IST computer software. Interviews are audio taped, transcribed and then imported into NUD*IST and categorized according to a coding list based on the study’s research questions. The research team summarizes the findings and identifies points of convergence and divergence. In addition, weekly meetings with the research team allow for the continued emergence of issues and themes.

Recruitment

Recruitment efforts for the study posed many challenges. For example, eligibility criteria was very narrow, there was no central listing of eligible population; and, population was multilingual and from three different states. Recruitment strategies

were multi-faceted and focused on enhancing retention, such as:

- Personalizing correspondence and contacts to encourage long term relationships.
- Obtaining names of collateral contacts for all recruitment participants.
- Enlisting assistance of parent groups and residents of targeted neighborhoods as recruiters.
- Using word of mouth advertising, or playing “Who do you know?”
- Using “broadcast” e-mail within host agency.
- Posting flyers in places with high traffic areas of service providers and families (i.e., legal aid offices, mental health agency waiting rooms, restrooms, social security offices, food stamp offices)
- Making presentations to service providers’ staff meetings.



Efforts were made to ensure strategies were culturally friendly by assembling a team of recruiters who were bi-lingual and had parent representation. For instance, all flyers and correspondence were in Spanish and English, and there was a programmed 1-800 telephone number with part of its outgoing message in Spanish, directing them to a Spanish-speaking recruiter.

Forty families, approximately 12-15 from each of the three sites, were selected to participate, based on 1) their receipt of a letter from the Social Security Administration (SSA) notifying them that their children's eligibility for SSI benefits was slated for

reevaluation, and 2) their report that their children were receiving SSI benefits for a serious emotional disability. Summary of the demographic information for the families appears in Tables 1 and 2.

Results and Discussion

Based on the first in-depth interviews, two preliminary areas of impact were identified: 1) loss of SSI, as reported by families, and 2) impact of the legislative process itself. First, the importance that a basic minimum income plays in the well-being of families is underscored by the impact made on areas of living, of "normalization," on family relationships, and on mental and physical health. Families report that the SSI checks were generally incorporated into the overall household budget, and had a significant impact on families' ability to afford essentials such as clothes, shoes and food for their children. Families were unable to afford school field trips and experienced a reduced ability to afford recreation for their children. The most important motivator for families' almost universal decision to appeal was financial need, their fear of losing Medicaid, and the realization that without the money they would have to seek employment, thereby seriously reducing the amount of time they spend with their child.

The second area of impact highlights the importance of an effective process of communicating and implementing legislative/ programmatic changes. Implementation impacts the ability to make informed decisions or plan for the future, as well as other related programs, services and supports. Families report that upon notification of re-determination responses ranged from a general lack of concern to an immediate and serious concern about the family's financial well-being. School was the primary source of information about the availability of SSI benefits.

Table 1
SSI Family Impact Study Collective Interview Demographics N=40

Age of Children	Mean = 12 (Range 6 to 19)
Age Began Receiving Benefits	Mean = (Range = 2 to 16)
Gender of Children	36 male, 5 female
Ethnicity	21 Caucasian, 9 Hispanic, 7 African American, 3 "Biracial" 1 Native American
Diagnosis	25 ADD/ ADHD, 7 learning disabled, 3 SED, 2 behavioral disorder, 2 seizure disorder, ODBO, PTSD, birth defect, bipolar, emotional problems, explosive disorder, dystimia, OCD, agoraphobia, cerebral palsey, emotionally handicapped intermittent explosive behavior.
Age of Primary Caregiver	Mean = 39 (Range = 21 to 61)
Gender	37 female, 3 male
Relationship to Child	33 biological mothers, 3 biological fathers, 3 maternal grand mothers, 1 relative custody
Educational Level Achieved	5 completed college, 22 AA, 5 high school and or college (or vocational training), 13 completed 12 th grade, 1 GED, 4 completed 11 th grade, 3 completed 9 th grade, 3 completed 8 th grade, 1 completed 6 th grade, 3 not reported
Number in Household	Mean = 4 (Range 2 to 7)
SSI as % of Income	K= 27%, F = 36%, NY = 54%, Mean = 41% (Range 15% to <100%)
Amount Received – SSI	K= \$387, F = \$390, NY = \$514 Mean = \$445 (Range \$128 to \$517)
Number No Longer receiving Checks	20 (K=10, F=9, NY=1)
Number Appealing	23 (K=8, F = 11, NY = 4)

With a disruption in services and supports, little has been offered in the way of formal help. Often, families report drawing upon their spiritual strength and relying on their places of worship—not just for prayer, but for concrete supports such as food, clothing, and payments for utilities.

Implications

In addition to the individual and family level of response, this study will also examine the impact of this new legislation within the context of significant changes being implemented within the state Medicaid programs in three states, Florida, Kansas, and New York. Based on how the families responded to the changes and which supports they relied on to cope with the changes in their financial circumstances, the study also assesses the impact on other systems, both formal and informal, that might be asked to assume additional responsibility for services and supports.

Table 2
Collective Focus Group Demographics *N*=13

Mean Age of Caregiver	41 (range 29 to 64)
Ethnicity of Caregiver	7 African American, 3 Hispanic, 2 Caucasian, 1 West Indies
Number Employed	6 of 13
Educational Level Achieved	4 – some college, 5 – completed high school, 1- GED, 1- Completed 10 th grade, 1 completed 6 th grade, 1 – did not respond
Gender of Child	7 males, 6 females
Relationship to Child	10 mothers, 2 grandmothers, 1 adoptive mother
Mean Age of Child	12 (range = 8 to 17)
Diagnosis	Seizures, ED/SED, learning disabled, language problems, conduct disorder, depressive disorder, speech impairment; past sexual abuse and physical injuries, behavioral disorder, mild narcolepsy, ADHD
Number No Longer Receiving Checks	7 no longer receiving, 2 denied but won appeal, 4 continue to receive
Number Appealing	11 Appealed, 2 did not appeal

* Family has 2 children participating in study

PIN-FST – Evaluating Satisfaction Through Family Interaction

Introduction

Background

In 1984, the Mental Health Association of Southeastern Pennsylvania was awarded an organizing grant from the Pew Foundation to create the Parents Involved Network (PIN). PIN is a parent-run, self-help/advocacy, information and referral resource for families whose children and adolescents have emotional or behavioral disorders. The network's goals include providing families with opportunities to share common concerns and exchange information; identify resources; and influence policy affecting children and adolescents with emotional or behavioral disorders.

In 1987, PIN established its first chapter in Delaware County, PA with an initial group of eight parents. Delaware County Office of Mental Health provided additional financial assistance for organizing purposes in 1988. During the following decade, as financial support increased, including support from Children and Youth Services, Delaware County PIN grew to include three full time advocates and established satellite offices in two Family Centers.

In January of 1997, with the advent of managed care, Delaware County PIN developed Pennsylvania's first Family Satisfaction Team (PIN-FST) to ascertain the opinion of families whose children receive services in the public behavioral health sector, specifically those children have emotional or behavioral disorders and/or substance abuse issues. The team consists of a team leader and three members, all of whom are either parents of children with emotional disorders or young adults who have been consumers in the children's mental health/drug & alcohol systems. PIN-FST receives direct feedback from families on their satisfaction with the services their children receive, as well as the process by which they access services. This summary describes a PIN-FST initiative: *The Interagency Team Meeting Survey*, and illustrates how families' opinions regarding service access have fostered systems change in Delaware County.

Method of Evaluation

When Early Periodic Screening, Diagnosis and Treatment (EPSDT) services, (also known as "wraparound") are being considered for a child, an Interagency Team Meeting must be held. Wraparound services include therapeutic staff support, mobile therapy, behavior specialist consultation and residential treatment facilities. This meeting is a requirement under the managed care pilot program in Pennsylvania. There are approximately 120 Interagency Team Meetings held each month in Delaware County. Magellan Behavior Care (MBC) is the managed care organization in Delaware County responsible for behavioral health services. As the authorizing agent of

Andrea Klein,
PIN-FST Team Leader

Della A. Beaver,
Assistant Coordinator

Christina Corp,
Coordinator

*Delaware County
Parents Involved Network
Family Satisfaction Team
20 S. 69th Street, 3rd Floor
Upper Darby, Pa 19082
610/713-2365*

services, a representative from MBC attends every Interagency Team Meeting. The Interagency Team participants represent all agencies, systems, and community supports involved in the child’s life. Parent/caregivers—and when appropriate, the children—are considered the primary participants in this process. At the conclusion of this meeting, the MBC representative provides each family with a satisfaction survey, which was developed by PIN-FST, to take home and complete. The impetus for developing a survey specific to the authorization process for access to services was that if the service access was problematic, then service delivery may be impacted, as well. This measurement instrument is used only to determine satisfaction with access to services. It is critical to ensure that this process is unencumbered.

The survey consists of eighteen items where families are asked to rate aspects of the service access process using a Likert-type scale, where A= *strongly agree*, B=*agree*, C= *unsure*, D= *disagree* or F= *strongly disagree*. There are also four open-ended questions that can be answered in more detail.

Results

Survey results were categorized into *positive* or *negative* response groups; answers in the A/B range were considered positive responses, while those in the C/D/F groups were considered negative. Written comments were also grouped into positive and negative categories. Responses were aggregated, resulting in a

percentage of positive response: items scoring at below 90% were considered to be areas of concern.

Results from the first fifty surveys returned (Phase 1) were compared with results from the second group of fifty (Phase 2). These results were then compared with the next one hundred surveys received (Phase 3). This method of comparison has enabled us to detect changes in levels of satisfaction as we progressed from one group of surveys to the next.

Questions were then assigned into one of four thematic categories according to specific areas of content. Averages were calculated for each category. Table 1 shows the percent of positive responses for each category across the three phases.

It was decided that any identified category with an aggregate score below 90% was an area of concern; categories one and three fell into this range. Therefore, individual questions listed under these categories were examined. The specific questions that lowered the score in Category I were: numbers 6 and numbers 17, and in Category III, numbers 10, 14 and 15 (see attached survey). Although Category II was above the 90% cutoff, question 13 was also highlighted as an area for improvement.

Parents’ written comments were used to identify other issues warranting attention. For example, a common opinion expressed was the desire for MBC to have one EPSDT specialist (service authorizing agent) throughout their child’s treatment of care while receiving wraparound services.

Table 1
Percent of Parents for Three Phases of Survey Results
Rating Satisfaction as “Positive” for Four Categories of Service Access

Topical Category	Survey Phases		
	Phase 1 (N=50)	Phase 2 (N=50)	Phase 3 (N=100)
Category I: Families were informed about the process	86%	86%	90%
Category II: Families felt comfortable during the meeting	96%	92%	93%
Category III: Quality of assessment and service plan	84%	88%	88%
Category IV: Accessibility of meeting	96%	94%	92%

Impact on System Change

Once a month, a meeting is held in the county offices with MBC, the Office of Behavioral Health (OBH), PIN, and the agencies that provide wrap-around service (Wraparound Workgroup). Since March 1998, the team leader of PIN-FST has attended these meetings to request input and report on the progress of the survey project. Agency providers had reviewed the survey questions and participated in initial decisions about distribution of the surveys. At each Wraparound Workgroup meeting, participants discuss survey results with PIN-FST members, focusing on those items where family satisfaction is lower than desirable. They then select one area in which to produce a positive outcome, identifying what the desired outcome should be, the steps necessary to produce the outcome, and the person who will assume responsibility for the action. The process described above is continuous since the interagency team meeting survey project is ongoing. This process has resulted in the following actions to date:

- Magellan has added a statement about freedoms of choice and the grievance and appeal process to the form given to the family. The MBC representative reads the statement aloud at the team meeting.
- Individual provider agencies have each developed ways to insure that families know they can bring an advocate or other support person with them to the team meetings.
- All provider agencies ensure that meetings are scheduled at times that are convenient for the family.
- Magellan is ensuring that the same EPSDT specialist (service authorizing agent) will follow an assigned child throughout their treatment.

Families in Delaware County report that they have been extremely pleased with the input and system changes that have evolved as a result of the PIN-FST and the Interagency Team Meeting Survey. This process was specifically created for, and by, families and young adults who have received services in the behavioral health care system. It has provided families an opportunity to both design and help implement solutions for more satisfactory delivery of services.

The Interagency Team Meeting Survey

Delaware County Parents Involved Network Family Satisfaction Team

PARENT'S OPINION ON THE INTERAGENCY TEAM MEETING PROCESS

Next to each statement, please place the letter that best matches your opinion.

A for Strongly Agree, B for Agree, C for Unsure, D for Disagree, and F for Strongly Disagree

1. I was told about the purpose of the interagency team meeting. _____
2. I understood the purpose of the interagency team meeting. _____
3. I knew who to contact if I had any questions about the meeting. _____
4. The time and location of the meeting was convenient for me. _____
5. I was informed about which agencies were represented at the meeting. _____
6. I was aware that I could have an advocate attend the meeting with me. _____
7. I felt that I could speak up at the meeting to add facts or make things clear about my child and family. _____
8. I felt that I played a meaningful part in the meeting. _____
9. My child's strengths were addressed during the team's discussion. _____
10. Our family's strengths were addressed during the team's discussion. _____
11. I was treated in a respectful manner. _____
12. I understood what was said about my child and family. _____
13. The team considered my culture and beliefs when planning for my child and family. _____
14. The services offered for my child were specific to my child's needs. _____
15. I was given choices as to who would be available to provide services. _____
16. The agencies involved were working together with the common goal of helping my child and family. _____
17. I was advised of my rights to disagree with any of the services recommended and to disagree if services were denied. _____
18. I left with a clear understanding of the services that would be provided for my child. _____

Additional Questions

Did you feel uncomfortable at any time during the meeting? YES _____ NO _____
If yes, please explain _____

Was there information that was not included and should have been included at the times of the meeting? YES _____ NO _____
If yes, please explain _____

In your opinion, what would have made this a smoother or more helpful process?

Is there anything else you would like to say about the interagency team meeting?
YES _____ NO _____
If yes, please explain _____

Date of Interagency Team Meeting _____

Thank you for your time and opinions.

The Parents Involved Network will use this information to assist Delaware County in improving the interagency team process. All personal information will be kept confidential.

Optional: Name _____
Address _____
Telephone Number _____

If you would like assistance or additional information contact Andrea Klein, Parents Involved Network, Family Satisfaction Team, at (610) 713-2491.

This document may be reprinted without permission provided credit is given to Parents Involved Network of Delaware County.

Parents as Evaluators: King County Blended Funding Project Evaluation Pilot Results

Introduction

The King County Blended Funding Project pools dollars from the mental health, child welfare, and special education systems on behalf of those children with the most complex needs in King County, Washington. Examples of expenditures are: full-time school aides, private school tuition, closing costs on a house, seed money to create a drama class, parent-to-parent support, summer camp tuition, haircuts, behavior incentives. Funds are used flexibly by child and family teams to purchase and create needed supports.

The Blended Funding Pilot Evaluation was conducted by a parent-led evaluation team consisting of parents and siblings of children involved in multiple service systems, the project director, and a research scientist. The team created a model of change, designed and implemented an evaluation protocol, and interpreted and disseminated findings.

Blended Funding Project Evaluation data were used in two ways. For individual children, feedback was provided to the child and family teams to guide the provision of care. The evaluation team has designed family-friendly formats for presenting data in ways that are easily understood by parents. Data were also aggregated across children to provide feedback to program administrators and funders to guide further development of the Project. Only aggregated results are presented in this summary.

The Blended Funding model of change formed the framework on which the Blended Funding Project Evaluation was built. According to this model of change, with the support of the child and family team and the ability to purchase needed supports:

- Parents will become empowered.
- The investment of the family and care providers on behalf of the child will increase.
- Coordination across systems will improve.
- Community connections will strengthen.
- The child's individual needs will be met.
- Children's residential and educational stability will increase.
- Child functioning will improve.
- Costs of care will decrease.

It is anticipated that these constructs will be affected sequentially, i.e., that family empowerment will be the first and that costs of care will be the last to change.

Ann Vander Stoep, Ph.D.

*Assistant Professor
Division of Child and Adolescent
Psychiatry
University of Washington
206/526-2162 Fax: 206/527-3858
E-mail: annv@u.washington.edu*

Linda Green

*Evaluation Coordinator
Federation of Families
Washington State Organization
425/277-0426 Fax: 425/277-5010
E-mail: lindagreen@home.com*

Marilynn Williams

*Director
Federation of Families
Washington State Organization
425/277-0426 Fax: 425/277-5010
E-mail: marilynn@rocketmail.com*

Robert Jones, M.S.W.

*Director
King County Blended Funding Project
Puget Sound Educational
Service District
206/439-3636 Fax: 206/439-3961
E-mail:
bjones@whitecap.psesd.uednet.edu*

Eric Trupin, Ph.D.

*Professor and Chair
Division of Child and Adolescent
Psychiatry
University of Washington
206/526-2162 Fax: 206/527-3858
E-mail: trupin@u.washington.edu*

This discussion presents results from the baseline and three-month assessments of family empowerment, service coordination, community connections, residential and educational stabilization, child functioning, and cost of care.

Method

The Blended Funding Evaluation used a pre- and post- design to examine the validity of its model of change. Trained parent interviewers met with foster, biological, or adoptive parents or other primary caretakers of Blended Funding children and conducted lengthy structured interviews at the time the child entered the program (baseline) and at 3, 6, 9, and 12-months follow-up. Interviewers call ahead and offer to bring the family pizza, ice cream, movie tickets or another small (\$10) token. Empowerment and service coordination questionnaires were administered only when family members were the interview respondents.

Measures

The Family Empowerment Scale (FES). The Family Empowerment Scale (Koren, DeChillo, Friesen, 1992) assesses the degree to which the parents have felt able to provide and find support for their child over the prior 3 months. The responses for the 11 questions on the rating scale vary from “not at all,” to “only a little,” to “some,” to “mostly,” to “very much.” Higher scores on the FES indicate more empowerment.

The Service Coordination Scale (SCS). The Service Coordination Scale (DeChillo, Koren, Schultz, 1994) assesses the family’s perception of how well service providers have worked together to coordinate services for their child over the prior 3 months. The responses for the 18 questions on this scale range from “not at all” coordinated, to “only a little,” to “some,” to “mostly,” to “very much” coordinated. Higher scores on the SCS reflect better coordination.

Child and Adolescent Functional Assessment Scale (CAFAS). Child functioning was assessed using the parent interview version of the Child and Adolescent Functional Assessment Scale (CAFAS; Hodges, 1997). The CAFAS has eight subscales and an “overall functioning” scale, which is based on the sum of the 8 subscales. The higher the CAFAS score, the more impaired the child’s functional status.

Statistical Analysis. Changes in family empowerment and service coordination scores from baseline to follow-up were evaluated using the sign test. The Wilcoxon signed ranks test was used to evaluate changes in CAFAS scores. Improvements were considered statistically significant if the two-tailed p value was $< .05$.

Costs of Care Assessment. Costs of care were assessed using the following approach. For each Blended Funding child, the three participating service systems contributed a set amount of funds each month to the Blended Funding pool to total \$6,020 (Child Welfare, \$5,000; Mental Health, \$720; Special Education, \$300). The service system representatives agreed that it was appropriate to use the pooled monthly contributions as a benchmark against which to measure whether costs were increasing or decreasing once children entered the Blended Funding Project. Once a child entered into the project, all reimbursements to professional and non-professional care-givers were made from the Blended Funding pool. For the first twenty participants, the monthly costs of care after the first month were averaged and compared to the benchmark of \$6,020.

Results & Discussion

Baseline Child Characteristics

During 1998, 13 girls and 17 boys were enrolled in the Blended Funding Project. The children ranged in age from four to 17 years, with 12-13 being the most common age at enrollment. Most were African American (40%) or Caucasian (47%). Twenty-four of the children were dependents of the state. Nearly half of the children were living in group care at the time of enrollment, with foster homes being the next most common place of residence. The majority of Blended Funding children were attending school in self-contained special education classrooms.

The most common DSM-IV intake diagnoses for the Blended Funding children were Attention Deficit Hyperactivity Disorder (ADHD) and Post-Traumatic Stress Disorder (PTSD), at 28% each. This was followed by Oppositional Defiant Disorder (ODD), at 24%. Next were depression (21%), conduct disorder (21%), and reactive attachment disorder (17%). According to parental reports, four children had been diagnosed as fetal alcohol or drug effected. Half of the children had average or above average intelligence.

Five were classified as developmentally disabled. All the children had Child Global Assessment Scale (C-GAS: Shaffer et al., 1983) scores of 40 or below, and 5 had scores of 30 or below, reflecting major impairment in several areas of functioning.

Family Empowerment

Fifteen families rated their sense of empowerment at both baseline and three-month follow-up. Significant increases in empowerment were noted across families. Twelve families reported feeling more empowered, while only two families reported a lower sense of empowerment ($p = .02$). Investigating changes in ratings for individual empowerment questions, few changes were noted in the uniformly high ratings on questions pertaining to families feeling that they make a valuable contribution to their child's well being. Few changes were noted in the uniformly low ratings on questions pertaining to families being able to ask for and get help from relatives or community members. Dramatic changes, however, were noted in families' reports of:

- getting the kinds of supports that meet the family's needs (Q3),
- their ability to choose services which they need (Q4),
- the responsiveness of the service systems to their requests for support (Q5), and
- their ability to create or find needed supports when there are no appropriate existing services (Q 11).

Table 1 displays the changes in responses to individual empowerment questions for the 15 families who completed this questionnaire at both baseline and follow-up.

Service Coordination

At baseline, the average Service Coordination rating among 18 families and across all 18 questions was a little below "some coordination." The three aspects of coordination which were rated the lowest were:

- services being inconveniently located,
- families having to fill out too many forms, and
- staff being unaware of the child's situation when the family is referred to a new provider.

Significant improvements in Service Coordination were reported at the three-month follow-up interview ($p < .01$). Seventeen out of eighteen families reported better service coordination at the time of the three month interview. The greatest improvements were reported in:

- service providers working together for their child,
- staff from different service providers giving the parent good information about their child's care, and
- staff from one provider helping the parent to get services from another provider.

Table 1
Family Empowerment Responses at Baseline and 3-month Follow-up

	Not at all	Only a little	Some	Mostly	Very Much
Q3 Baseline	17%	28%	28%	22%	6%
Q3 3-month	6%	6%	6%	44%	38%
Q4 Baseline	33%	17%	28%	17%	6%
Q4 3-month	0%	6%	19%	25%	50%
Q5 Baseline	33%	22%	22%	11%	11%
Q5 3-month	6%	6%	6%	38%	44%
Q11 Baseline	33%	22%	28%	6%	12%
Q 11 3-month	13%	6%	13%	31%	38%

Stabilization of Care

Table 2 depicts changes in the child's status from baseline to three-month follow-up. Marked changes were seen in residential and school stabilization. No child had more than one school placement during the first three months in Blended Funding, whereas five children had experienced multiple school placements in the three months prior to entering the program. Seven of the 29 children had experienced one or more residential moves in the 3 months prior to entering Blended Funding, compared to 2 of 16 children with one residential move during the 3 months post-entry. If we consider residential moves, school suspensions, school changes, arrests, and hospitalizations as disruptions in a child's developmental course, then there were a net of 12 fewer "disruptions" experienced by the cohort once they entered the Blended Funding Project, relative to baseline.

Residential placements for 29 youth between baseline and three-month follow-up are depicted in Table 3. The column on the left shows where the child was residing at the time of the baseline interview. The four rows to the right show where the child was residing at three-month follow-up. The cells in the table contain the numbers of children who started in the type of residential placement listed on the left and ended in the type of residential placement listed on the right. For example, 14 children were in residential treatment at baseline. At follow-up, five of those children were still in residential treatment; two were living with a relative; five were living in foster care; one was in detention; and one was in a psychiatric hospital.

Child Functioning

Baseline and three-month CAFAS scores were completed for 13 children. Blended Funding children were functioning significantly better within the community at three-month follow-up. None of the other changes in subscale scores, including level of functioning at home or at school, reached statistical significance. A total of 270 points would be the worst possible total functioning score. On this measure, the average baseline total score was 150, and the average three-month score was 120. This clinically significant improvement in functioning did not quite reach statistical significance (Wilcoxon Signed Ranks Test 2-tailed $p = .07$).

Costs of Care

Over the three-month period, costs increased for 6 youth, and decreased for 14 youth. For the group as a whole, costs decreased. The mean difference in monthly costs of care from benchmark to actual costs was $-1,516$ (95% $CI = -\$3,121, -\910 ; $t = 2.49$, $df = 19$, $p = .02$).

Implications

In general, these preliminary findings show that in the first three months of participation in the Blended Funding Project, significant strides were occurring in important process measures. As in other system-of-care evaluations (Bickman, 1996; Bickman, Summerfelt & Noser, 1997), the outcome that is the most challenging is to affect the child's functioning. It is too early to determine whether the Blended Funding model of change is valid, that is, whether changes occur sequentially in the specified

Table 2
Changes in Child Status from Baseline to 3-Month Follow-up

Indicator	Got better	Stayed the same	Got worse	Data missing
# residential moves	5	10 (all none)	1	0
School attendance	1	7	2	6
School performance	4	3	3	6
# school suspensions	3	7	1	5
# schools attended	5	9 (all 1)	0	2
# police referrals	1	7	1	7
# psychiatric hosp	1	15 (all none)	0	0

order. Future analyses that incorporate findings from 6 through 12 months follow-up periods will be more telling.

References

Bickman, L. (1996). A continuum of care: More is not always better. *American Psychologist, 51*: 689-701.

Bickman, L., Summerfelt, W. T., Noser, K. (1997). Comparative outcomes of emotionally disturbed children and adolescents in a system of services and usual care. *Psychiatric Services, 48*: 1543-1548.

DeChillo, N., Koren, P., Schultz, K. (1994). From paternalism to partnership: Family and professional collaboration in children's mental health. *American Journal of Orthopsychiatry, 64*: 564-576.

Hodges, K. (1990, 1994 revision). *Child and Adolescent Functional Assessment Scale*. Ypsilanti, MI: Eastern Michigan University, Department of Psychology.

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

Shaffer, D., Gould, M. S., Brasic, J., Ambrosini, P., Fisher, P., Bird, H., & Aluwahlia, S. (1983). A Children's Global Assessment Scale (C-GAS). *Archives of General Psychiatry, 40*, 1228-1231.

Table 3
Changes in Place of Residence from Baseline to 3-month Follow-up

RESIDENCE AT BASELINE	RESIDENCE AT 3-MONTH FOLLOW-UP				
	Relative home	Foster home	Residential treatment	Juvenile detention	Psychiatric hospital
Relative home	4		2		
Foster home		5	1		
Residential treatment	2	5	5	1	1
Juvenile detention		1		1	
Homeless		1			

