CONNECTICUT COMMUNITY
KIDCARE EVALUATION

REPORT #3

A Report on
Family Satisfaction

November 2005

Prepared by:
Deborah Potter, M.A.
Virginia Mulkern, Ph.D.
Jessica Hartley, B.A.

Human Services Research Institute
Cambridge, MA

CI-DI

The Child Health and Development
Institute of Connecticut, Inc.

ACKNOWLEDGEMENTS

*For additional copies, call **860.679.1519***
*or visit **www.chdi.org** or **www.state.ct.us/dcf**.*

1. INTRODUCTION

Connecticut Community KidCare is a statewide initiative launched in 2001 to reform the way children's behavioral health services are coordinated, financed and delivered to children and their families.

KidCare is based on the following principles:

- Children with behavioral health needs should receive services in their community whenever possible
- Parents and families are an integral part of the planning and decision making process
- Services need to be provided in a linguistically and culturally competent fashion

The KidCare program offers a wide range of services and supports designed to help children with behavioral challenges experience success in their home, school and community environments. Through a range of community-based services, children with complex behavioral health needs are provided with individualized treatment plans that combine clinical services with non-traditional support services. The effort includes a network of providers who, in concert with families, provide crisis intervention, home-based services, extended day treatment and care coordination services to those children whose behaviors put them at risk for hospital or residential levels of care.

The system of care model at the core of the KidCare program specifies that family members should be actively involved in all system functions including service delivery, planning, policy development, and evaluation. Information on caregivers' perceptions of the quality and effectiveness of services is an important element of a system's quality improvement program. This study surveyed the satisfaction of caregivers who had children with intensive behavioral health needs receiving care funded through Connecticut's Healthcare for UninSured Kids and Youth program (HUSKY).

The sample of children for this study was randomly selected from the Department of Social Service's database of children who were eligible to receive publicly-funded behavioral health services as of May 1, 2004. Children who had received one or more intensive mental health services were eligible for inclusion in the sample.[1] The study was limited to children who had received intensive services because it was thought that the caregivers of these children would have enough experience with the system of care to respond to the detailed questions in the survey. Of the 1,354 children in the sample, approximately one-quarter (n=297) were excluded from the sampling frame to protect confidentiality. These were children for whom DCF had an order for temporary custody, children for whom there had been a termination of parental rights, and children who were in DCF custody.

---

[1] Intensive services included the following categories: psychiatric inpatient, psychiatric inpatient sub-acute, partial hospital, home health services, skilled nursing services, home health aid, psychiatric dual diagnosis partial hospital services, psychiatric dual diagnosis intermediate treatment, substance abuse partial hospital treatment, and substance abuse intermediate treatment.

The caregivers of these children were contacted and asked to participate in a 20-minute telephone interview. Interviewers placed calls on different days of the week and times of day, and made up to 20 calls to try to recruit each caregiver. Despite the difficulty posed by incomplete or inaccurate contact information, 322 interviews were completed between November, 2004 and March, 2005.[2] Among the potential respondents who were located, the response rate was 75% (see Appendix I for more detail on the sample).

Participants were asked which types of services their child had received during the past year, how satisfied they were with these services, and which if any services they felt their child should have received during that same time. In addition, the caregivers indicated their levels of satisfaction with services overall, as assessed by a standard instrument, the Youth Services Survey for Families (YSS-F), a 21-item tool (described in Section 4.1).

This report describes:

- Characteristics of the children receiving services
- Behavioral health services that they received over the past year
- Families' satisfaction with those services
- Barriers to accessing services
- Respondents' familiarity with DCF programs and statewide advocacy organizations

While this report provides useful information about participants' perceptions of the services their children received, there are inherent limitations to any satisfaction survey. Caregivers reported about their perceptions of improvements in the children's lives, but there are no corresponding outcome measures. In addition, perceptions are reported retrospectively and errors in memory and reporting may occur. Finally, while satisfaction is a vital dimension to measure, it is no substitute for assessing the quality of services provided.

2. CHARACTERISTICS OF THE CAREGIVERS AND THE CHILDREN SURVEYED

Most of the interviews (71%) were conducted with a biological parent. Adoptive parents represented 11% of the respondents, and grandparents were another 9%. Twenty-five additional interviews were with foster parents, legal guardians, or other relatives.

More than half (60%) of the children about whom the caregivers spoke were boys and 40% were girls. The mean age of the children was 13.9 (standard deviation=3.7). The group of children was relatively diverse in its racial and ethnic background (see Table 1). A little more than half of the children (57%) were white, about one-third (35%) had at least one Hispanic or Latino parent, and almost one-fifth (19%) were Black/African-American. For most families (80%), English was the primary language spoken in the home. Spanish was the predominant language in 11% of homes and 6% were bilingual (Spanish/English).

---

[2] Total numbers in the tables and narrative portion of this report do not always add up to 322 (the number of caregivers participating in the interviews). There are several reasons for this. In same cases, more than one response was allowed. Other times, participants did not want to answer a question. In other instances, the questions did not apply to all participants and therefore only a subset responded (e.g. about their satisfaction with a particular type of service).

Table 1: Characteristics of the Children Included in the Study

Characteristic	%	N
Race/Ethnicity		
White	57%	180
Black/African-American	19%	60
American Indian/Alaskan native	2%	5
Asian/Pacific Islander	1%	4
Hispanic/Latino parent	35%	109
Language in the Home		
English is primary language	80%	259
Spanish is primary language	11%	36
Bilingual (English/Spanish)	6%	19
Child's Living Situation		
Currently living with caregivers	87%	277
Lived in a hospital during the past year	34%	107
Lived with another family during the past year	19%	61
Lived in a residential treatment facility during the past year	15%	49
Lived with parents continuously for the past year	26%	84
Lived in jail/treatment detention facility in the past year	7%	22
Other Characteristics of the Child		
Male	60%	191
Female	40%	131
Arrested or had contact with juvenile justice system in the past	30%	95
Child has developmental disabilities	15%	46
	Mean	**N**
Mean Age	13.9 (std dev=3.7)	312

At the time of the interview, 87% of the children were currently living with the caregivers (including birth parents and others) responding to the survey. The most commonly cited places outside of the home where children had lived in the previous year were in a hospital (34%), with another family other than therapeutic foster care (19%), or in a residential treatment facility (15%).

Many of the children in this study had needs which either could be or were being addressed by other child-serving systems as well as DCF. Some of these children (15%) had developmental disabilities in addition to mental health problems. Although only 7% had lived in a jail or treatment detention facility during the previous year, many more (30%) had been arrested or had contact with the juvenile justice system during that time.

3. SERVICES RECEIVED

Each caregiver was asked a series of questions to ascertain what mental health and allied services his or her child had received in the past 12 months. Caregivers were asked about the child's use of, and experience with, 14 types of services, grouped into five broad categories:

- Outpatient
- Crisis

- Residential
- Wraparound
- Ancillary services

Table 2 reports the number and percent of children receiving any service in these five broad categories, as well as the 14 types of services. The most commonly reported services were those that children typically receive as students either from, or as a requirement of, participating in a school system (e.g. annual check-ups or school-based interventions). Many outpatient mental health services, including counseling and evaluations, were frequently used, as were inpatient care and emergency care (either through hospitals or a crisis service).

Several findings regarding services received were notable. First, many children received an array of intensive services. Of the 14 types of services mentioned in the survey, caregivers reported that their child received an average of 5.8 service types during the past year. Second, these data show that slightly more than half of the children received some type of wraparound service. One-third received extended day services and smaller proportions received mentoring, respite, or in-home services (the latter from a visiting behaviorist or nurse[3]). Wraparound services are an important component of the system of care philosophy and it is encouraging that these children with intensive behavioral health needs are receiving this component of care.

Table 2: Services Received

Type of Service	N	%*
Outpatient Services	**278**	**86%**
Doctor or nurse prescribed/reviewed mental health medications	226	71%
Outpatient counseling	222	69%
Mental health evaluation or test	180	58%
Substance abuse services	24	8%
Residential Services	**159**	**50%**
Inpatient care	152	48%
Residential care	62	19%
Crisis Services	**149**	**46%**
Visit to hospital emergency department for mental health	133	41%
Crisis services (including 31 in EMPS)	98	30%
Wraparound Services	**170**	**53%**
Extended day services	105	33%
In-home services (i.e. visiting behaviorist/nurse)	79	25%
Mentoring	53	17%
Respite Care	27	8%
Ancillary Services	**300**	**96%**
Seen by a doctor/nurse for physical health problem or check up	274	86%
Educational interventions (e.g. special education or school-based counseling)	226	71%

* Note: In some cases, the caregiver did not know if the child had received the service, resulting in missing data for some variables.

---

[3] Respondents were not asked specifically about their experiences with intensive in-home service such as IICAPS, MST, MDFT, FST, or FFT.

4. SATISFACTION WITH SERVICES

Caregivers were asked to assess their satisfaction with the behavioral health services the child had received. Two types of measures were used. First, caregivers were asked to indicate how satisfied they were, in *general*, with the mental health services their child had received. While this is an important overall indicator of how well the service delivery system is operating, it provides relatively little guidance about what specific policy and programmatic changes might be necessary within particular service modalities. Therefore a second series of measures were included that asked the caregivers to assess how satisfied they were with *specific* services their child received.

4.1 Global Satisfaction

Caregivers provided a general assessment of their child's mental health care through the Youth Services Survey for Families. The YSS-F has 21 items that are divided into five domains identified through factor analysis. The domains include:

- Satisfaction with services
- Caregivers participation in treatment
- Access to services
- Cultural sensitivity of staff
- Perceived outcomes of service

The full list of items is included in Appendix III. The scoring for each domain takes the mean response of the items included in that domain and then dichotomizes that result into "disagree" or "agree."[4]

Table 3: Caregivers' Perceptions of Services Received

Domain	Mean (standard deviation)	Disagree (%; N) (average score ≤3.5)	Agree (%; N) (average score >3.5)
Satisfied with services	3.92 (1.08)	30% (90)	70% (207)
Participated in treatment	4.24 (0.88)	16% (49)	84% (264)
Good access to services	4.29 (0.84)	19% (59)	81% (256)
Culturally-sensitive staff	4.50 (0.61)	5% (16)	95% (294)
Outcomes	3.73 (1.12)	32% (98)	68% (207)

1= strongly disagree; 2=disagree; 3=neutral; 4=agree; 5=strongly agree

---

[4] The YSS-F is scored in the following manner: 1) all ratings of "not applicable" are included as missing values; 2) all cases with more than one-third of the items missing in the domain are excluded from that subscale; 3) the mean score of the items for each respondent is calculated for each domain; and 4) the percent of scores greater than 3.5 are coded as "agree," and the percent less than or equal to 3.5 are coded as "disagree."

As Table 3 suggests, the majority of caregivers reported satisfaction in each of these domains with satisfaction levels ranging from 68% to 95% across domains. These data, as well as other analyses presented in this report, support an overarching conclusion that most caregivers are satisfied with the types and quality of mental health services their children have received. Caregivers responded most favorably about the following:

- Participation in treatment
- Access to services
- Cultural sensitivity of staff

Scores in these three domains were relatively high, with the mean score approximately equivalent to "satisfied." The issues of parental participation in treatment planning and decisions as well as the cultural sensitivity of services have been at the forefront of the system of care philosophy. It is notable that 84% of caregivers expressed satisfaction with their level of participation and 95% were satisfied with provider sensitivity to their cultural and religious beliefs. Given that 35% of the children in the sample were of Hispanic/Latino origin and 22% were non-white, the high level of satisfaction with the cultural sensitivity of services is an important achievement. Analyses confirmed that levels of satisfaction among the caregivers of these children were high and that there were no statistically significant differences by the children's race/ethnicity.

There was more variation, however, in the remaining two domains: global satisfaction with services and perceived outcomes of the services. While the majority of caregivers also provided favorable ratings in these domains, a sizable minority (nearly one-third) expressed general dissatisfaction with the services that their child had received. Similarly, nearly one-third of respondents believed that the services had not been helpful.

Additional analyses were conducted to identify whether the types of services the child received or characteristics of the child or caregiver were associated with variations in responses in these two domains. Variables in these analyses included the following:

- Whether the child had received a service within each of the five service domains (outpatient, inpatient, crisis, wraparound, or ancillary services)
- Demographic characteristics of the child (race/ethnicity, gender, age, and language -- English-speaking vs. other)
- The relationship of the caregiver to the child (biological parent, adoptive, or other relationship)
- The child's living arrangements over the previous year (continuously with parents, currently with parents, lived out of the home)
- Cross-system involvement with other child-serving agencies (e.g. identified as having a developmental disability, lived in jail/detention or corrections in past year, arrested in past year)
- Termination of services (in the past or currently)
- Whether or not the caregiver was aware of the KidCare Program, the Community Collaborative, EMPS, and the statewide advocacy groups

4.1.1 Global Satisfaction with Services by Type of Service Received

The first set of analyses examined possible relationships between the types of services the child had received and the level of global satisfaction and satisfaction with outcomes. These analyses suggested that levels of satisfaction in these two domains were generally not statistically correlated with the type of service received. The only exception to this pattern was related to the use of crisis services. Caregivers' levels of satisfaction with service outcomes were inversely related to the children having received crisis services. That is, caregivers of children who had received crisis services were less likely to be satisfied with the outcomes of their children's care than caregivers of children not receiving such services (r=-.15, , p< .01,n=302).   This is not a strong relationship, but may suggest a realistic appraisal by caregivers that the need for crisis services means that services are at some point not successful in keeping the child stable in the community.

4.1.2 Global Satisfaction with Services by Characteristics of the Children and Caregivers

Further analyses explored the relationship between satisfaction in these two dimensions and characteristics of the children and caregivers (see Table 4).

Demographic characteristics of the child and caregiver bore little relationship to satisfaction in either domain, with two exceptions. Caregivers who reported that their child was white were less satisfied with services in general than were caregivers whose child was of another racial/ethnic group. Caregivers who were adoptive parents were less likely to be satisfied with services and with outcomes than were other caregivers.

Caregivers whose child had lived in a criminal justice setting or a shelter, or were homeless or runaways during some portion of the past year, were less satisfied with service outcomes than were caregivers of children who had not experienced these events.

Satisfaction also correlated with current difficulty in obtaining services. While almost three-quarters of those not currently having trouble securing services were satisfied, only 42% of those who were currently having trouble obtaining services expressed general satisfaction with services and with outcomes.

Table 4: Percent of Caregivers Satisfied with Services and with Outcomes by Service Delivery History and Background Characteristics

	% Satisfied With Services	% Satisfied With Outcomes	Significance*
Service History			
Currently having trouble obtaining services Yes (n=33) No (n=272)	 42% 73%	 42% 71%	*Satisfaction:* X^2=11.2, df=1, p=.001 *Outcomes:* X^2=9.7, df=1 p$\leq$.005
Background Characteristics			
Caregiver is adoptive parent Yes (n=33) No (n=271)	 49% 72%	 50% 70%	*Satisfaction:* X^2=4.4, df=1, p$\leq$.05 *Outcomes:* X^2=6.6, df=1, p=.01
Child's race White (n=168) Not white (n=130)	 64% 76%	 NS 	*Satisfaction:* X^2=4.3, df=1, p$\leq$.05
Living Situation			
Child lived in criminal justice or marginal setting at some point Yes (n=31) No (n=274)	 NS 	 48% 70%	Outcomes: X^2 =5.0, df=1, p<.05
System-Level Knowledge			
Range of knowledge about System of Care Components	r=.127	r=.119	*Satisfaction:* p< .05 *Outcomes:* p<.05

* All results presented with the continuity correction for 2x2 tables.

Finally, the analysis examined whether knowledge of the system of care was associated with satisfaction. Caregivers were asked whether or not they had heard about eight entities in the system of care: the KidCare Program; Community Collaboratives; Emergency Mobile Psychiatric Services (EMPS); Family Advocacy Organization for Children (FAVOR); African Caribbean American Parents of Children with Disabilities (AFCAMP)); Families United; National Alliance for the Mentally Ill (NAMI); and Padres Abriendo Puertos (PAP). A score was created, summing the total numbers of components recognized, which ranged from 0 to 8. Caregivers who were aware of more of the components of the system of care tended to report higher levels of satisfaction with services generally and with outcomes, than caregivers who were aware of fewer components.

4.2 Service-Specific Levels of Satisfaction

Caregivers were also asked to rate their satisfaction with particular services that their child had received over the past year along five separate dimensions, using a five-point scale for each dimension. These dimensions assessed the extent to which the caregiver agreed or disagreed that:

- The service was helpful
- The location was convenient
- The staff treated them and their child respectfully
- The staff understood and respected their culture, religion, and values
- They themselves participated in or were involved in the child's care

As with their global assessment of the care received, the majority of caregivers expressed satisfaction when asked about particular services. As Table 5 demonstrates, caregivers consistently tended to report that they were satisfied with the services their child received across these five dimensions.[5]   They were satisfied with the helpfulness and convenience of the services, as well as with the respect and cultural competence exhibited by the service providers. In addition, most caregivers reported participating in their child's care across service types.

Table 5: Domains of Satisfaction by Type of Service

		Percent Satisfied with….				
	N receiving service*	Helpfulness	Convenience	Respect	Culturally competent	Participation in care
Physical health service	274	91%	96%	99%	97%	97%
Educational interventions	226	84%	92%	96%	96%	98%
Medication services	226	77%	89%	95%	96%	93%
Outpatient counseling	222	75%	90%	95%	96%	96%
Mental health evaluation	180	74%	88%	97%	99%	89%
Inpatient care	152	78%	69%	93%	94%	93%
Hospital ER (mental health)	133	76%	92%	93%	95%	90%
Extended day services	105	68%	88%	90%	94%	91%
Crisis services	98	80%	84%	92%	90%	93%
In-home services**	79	74%	N/A	95%	94%	99%
Residential care	62	77%	67%	90%	97%	97%
Mentoring	53	85%	98%	98%	98%	87%
Respite care	27	93%	96%	100%	100%	93%
Substance abuse services	24	64%	73%	86%	86%	68%

* Note: In a few cases there are missing data for some satisfaction variables.
**From a visiting behaviorist or nurse.

---

[5] See Appendix II for mean scores along all five dimensions assessed for each type of service.

For some services, however, there was a sizable minority who were dissatisfied along two of the dimensions, responding that the services had not been helpful and/or that the location of the services was inconvenient. Approximately one-quarter to one-fifth of the caregivers of children receiving the following services said that they were not helpful for their child:

- Substance abuse treatment (27%)
- Extended day (25%)
- In-home services, such as those from a visiting behaviorist or nurse (22%)
- Residential care services (20%)
- Emergency room visits (22%)

More than one-quarter of caregivers reported that the location of three service types was inconvenient. These services were:

- Residential care (30%)
- Inpatient care (29%)
- Substance abuse services (27%)

5. BARRIERS TO RECEIVING SERVICES

While this population of children received an intensive array of services, many caregivers and providers believed that additional care was necessary. More than half of the caregivers (54%, n=174) reported that either they or a mental health professional believed that the child should have received at least one additional service.

These unmet needs, organized by descending frequency, are displayed in Table 6 below.

Table 6: Unmet Need

Service	Number and percent of children with reported unmet needs	
	N	*%*
Mentoring	80	31%
Extended day services	51	24%
Doctor or nurse prescribed/reviewed medications	21	23%
Educational interventions	20	22%
Mental health evaluations	28	21%
Outpatient	19	19%
Seen by doctor/nurse for physical health problem or check-up	9	19%
Residential care	43	17%
Inpatient	26	16%
Respite	41	14%
In-home services (e.g. from a visiting behaviorist or nurse)	29	12%
Crisis	19	9%
Hospital ER	8	4%
Substance abuse services	10	3%

The two services that were mentioned most frequently in this context were mentoring and extended day services. These wraparound components were cited as needed by 31% and 24% of caregivers respectively. Medication evaluations were also cited relatively frequently as unmet needs (23% of caregivers) as were educational interventions (22%) and mental health evaluations (21%).

As Table 7 suggests, however, caregivers reported that professionals tended to have somewhat different views about the relative necessity of these services than they did. First, in all but one case, the caregivers said that they identified the need for additional services more frequently than did mental health professionals involved in the child's care. Second, according to the participants, there are a few instances in which the caregivers far outweigh the providers in thinking that the child should have received a specified service. In particular, although mentoring had the greatest number of reported cases of unmet need, according to the caregivers, professionals and caregivers agreed about its necessity in only one-third of the instances (27 out of 80) in which it was identified as an unmet need. Based on the caregivers' accounts, they identified the need for mentoring more often than did professionals.

Table 7: Caregivers' Report of Agreement/Disagreement between Caregivers and Mental Health Professionals about Unmet Need

	Of those not receiving the service:						
	Total cases with an unmet need	Caregiver and Mental health professional agreed		Only the caregiver identified need		Only the mental health professional identified need	
Service	*N*	*N*	*%*	*N*	*%*	*N*	*%*
Mentoring	80	27	34%	49	61%	4	5%
Extended day services	51	21	41%	20	39%	10	20%
Doctor or nurse prescribed/ reviewed medications	21	9	43%	6	29%	6	29%
Educational interventions	20	9	45%	10	50%	1	5%
Mental health evaluation	28	11	39%	15	54%	2	7%
Outpatient	19	8	42%	9	47%	2	11%
Seen by doctor/nurse for physical health problem or check-up	9	5	56%	3	33%	1	11%
Residential Care	43	18	42%	15	35%	11	26%
Inpatient	26	6	23%	12	46%	8	31%
Respite	41	18	44%	22	54%	1	2%
In-home	29	13	45%	12	41%	4	14%
Crisis	19	7	37%	8	42%	4	21%
Hospital ER	8	1	13%	5	63%	2	25%
Substance abuse services	10	4	40%	4	40%	2	20%

5.1 Barriers Encountered While the Child Was in Treatment

Caregivers were asked if they could identify a reason that a service need had not been met. Possible reasons included the following:

- Difficulty with payment or insurance coverage
- The child and/or family did not want that particular service

- The service did not exist in the area in which they lived
- There was a waiting list or the waiting list was too long to receive the service
- The service was located too far away or was too difficult to get to
- The child/family may have been "put off" by responses from staff at the program

Table 8, below, outlines the reasons why services were not received for each type of program. The most commonly cited barriers to obtaining each service are highlighted in grey. Several findings warrant particular attention.

First, the "barrier" cited most frequently for the majority of these services (9 of 14) was related to capacity. Caregivers noted that the service was either not available in their area or that the waiting lists were too long. Capacity-related issues were most prominent for mentoring, respite care, crisis services, and substance abuse services. For five of the 14 services, the reason cited most frequently was that either the child or family did not want the service – even though someone (either the caregiver or the mental health professional) had identified a need for it. This disparity suggests that a mismatch may exist between expectations of the professionals and the families.

Second, the table demonstrates that barriers vary by type of service. Therefore, if attempts are made to reduce barriers to service delivery, different strategies will be necessary for each type of service.

Capacity issues were cited frequently as a major reason why wraparound services (mentoring, respite and extended day) were not obtained. More than 40% of caregivers who cited an unmet need for mentoring and respite care cited this reason. More than one-third who cited a need for extended day and in-home services (from a visiting behaviorist or nurse)[6] provided reasons related to inadequate capacity in their area. Capacity also was cited as a barrier to receiving crisis and substance abuse services. When access issues (such as those related to financing and eligibility) were cited, they often were associated with more expensive programs. For example, caregivers were more likely to cite difficulties with insurance for programs such as inpatient care and mental health testing/evaluation than with other services. Eligibility issues were frequently cited in explaining why residential services and educational interventions were not received.

---

[6] Again, participants were not asked about intensive in-home services such as IICAPS, MST, MDFT, FST, or FFT.

Table 8: Unmet Need and Perceived Barriers to Receiving Services*

	% (N) of caregivers reporting unmet service need	Of those who believed the service was needed and could cite a reason, the reason(s) the service was not received…				
		Payment/ insurance problems	Child was not eligible	Capacity (doesn't exist; waiting list; too far)	Child/ Family did not want it	Put off by response from staff
Mentoring	31% (80)	13% (9)	13% (9)	46% (33)	13% (9)	7% (5)
Extended day services	24% (51)	15% (7)	16% (7)	36% (17)	19% (9)	15% (7)
Doctor or nurse prescribed/reviewed medications	23% (21)	22% (4)	11% (2)	28% (5)	39% (7)	6% (1)
Educational interventions	22% (20)	21% (4)	26% (5)	26% (5)	21% (4)	21% (4)
Mental health evaluation or test	21% (28)	41% (11)	19% (5)	26% (7)	22% (6)	15% (4)
Outpatient counseling	19% (19)	22% (4)	6% (1)	22% (4)	33% (6)	11% (2)
Visit to a doctor or nurse for a physical health problem or check up	19% (9)	13% (1)	25% (2)	38% (3)	25% (2)	0
Residential care	17% (43)	19% (8)	29% (12)	29% (12)	26% (11)	12% (5)
Inpatient care	16% (26)	32% (7)	22% (5)	39% (9)	32% (7)	9% (2)
Respite care	14% (41)	19% (7)	17% (6)	44% (17)	15% (6)	8% (3)
In-home (visiting behaviorist/nurse)	12% (29)	20% (6)	17% (5)	33% (10)	17% (5)	10% (3)
Crisis services	9% (19)	17% (3)	17% (3)	44% (8)	50% (9)	17% (3)
Hospital emergency department	4% (8)	0	0	17% (1)	67% (4)	17% (1)
Substance abuse services	3% (10)	11% (1)	22% (2)	44% (4)	44% (4)	22% (2)

* Note: Percentages are calculated using the number of responses to each question. In some cases, caregivers were not sure if the item was a factor in their child not receiving services. These data are treated as missing and are not included. Shading indicates the most frequently cited reason for each service.

Additional data suggest that barriers may continue to thwart the attempts of the family and/or professionals in obtaining treatment for the child after initial treatment has been provided. First, additional barriers to ongoing treatment were encountered when existing services were terminated. More than one-third of the caregivers (38%) reported that their child had a service terminated. While services often end due to improved functioning of the child, two-thirds of the caregivers who reported a termination (64%) believed that the following types of services should have continued (see Table 9). More than one-third (37%) of the caregivers who disagreed with a service termination were concerned about the termination of counseling/therapy services. Twenty-one percent of such caregivers cited the termination of extended day services.

Table 9: Caregivers Report of Terminated Services That Should Have Continued

Service Type	%*	N
Outpatient services		**43**
Outpatient services in general	6%	4
Counseling/therapy	37%	26
Seeing a psychiatrist	6%	4
Substance abuse treatment	1%	1
Medication management	11%	8
24-hour services		**12**
Inpatient services	9%	6
Residential care	9%	6
Wraparound services		**35**
Extended day	21%	15
Mentoring	11%	8
Respite	6%	4
In-home services (e.g., from a visiting behaviorist or	9%	6
Day program	3%	2
Crisis services		**5**
ICAP program	7%	5
Ancillary services		**7**
Educational intervention	7%	5
Tutoring	1%	1
Speech therapy	1%	1

* Note: Percentage based on 70 cases identifying a particular service type.

Finally, approximately one-quarter of the caregivers (24%) reported that they were currently having trouble receiving the following services for the child (see Table 10).

Table 10: Services that Caregivers Reported Current Difficulty in Obtaining

Service Type	%	N
Outpatient services		43
Outpatient services in general	9%	5
Counseling/therapy	26%	15
Behavioral programs	3%	2
Mental health evaluation	12%	7
Neurological evaluation	1%	1
Seeing a psychiatrist	9%	5
Medication management	7%	4
Anger management	5%	3
Basic living skills	2%	1
24-hour services		9
Inpatient services	7%	4
Residential care	9%	5
Crisis services		1
Crisis services	2%	1
Wraparound services		20
Extended day	9%	5
Mentoring	12%	7
Respite	5%	3
In-home services (e.g., from a visiting behaviorist or nurse)	5%	3
Art therapy	2%	1
Day program	2%	1
Ancillary services		8
Educational intervention	2%	1
Medical care	3%	2
Dental care	3%	2
Eye care	2%	1
Housing	3%	2

In instances where caregivers identified a service that either had been terminated or that they currently were trying to obtain, that service was most frequently some type of outpatient service. Wraparound services were mentioned second most in terms of frequency. Significantly, there were no cases of crisis services having been terminated, and only one caregiver was currently attempting to obtain this service.

6. FAMILIARITY WITH ADVOCACY GROUPS

There are five statewide advocacy organizations in Connecticut that focus on children's mental health services. An umbrella organization funded through DCF, the Family Advocacy Organization for Children (FAVOR), operates as a consortium through which four existing organizations work within local communities to educate and involve parents and other caregivers in mental health service delivery. The four organizations in the consortium are: the state chapters of two national organizations (National Alliance for the Mentally Ill {NAMI} and the

Federation of Families for Children's Mental Health) and two organizations with missions to serve distinct populations (Padres Abriendo Puertos {PAP} for Latino populations and African Caribbean American Parents of Children with Disabilities {AFCAMP} for African-Caribbean and other black populations).

Consistent with the system of care principles of family-focused services and responsiveness to the needs of families, DCF has invested resources in these organizations and has identified roles for them within the KidCare Program. Program goals include reaching out to parents and other caregivers to ensure that they are aware of their options, creating a platform for family involvement, and providing advocacy services for parents around specific issues. Many of the caregivers surveyed, however, were unfamiliar with DCF programming (i.e. KidCare or the Community Collaboratives) and the statewide advocacy organizations. As seen in Table 11, a relatively small proportion of the caregivers knew about KidCare (19%) or were aware that a Community Collaborative existed in their area (17%). In contrast, 54% of caregivers were familiar with the Emergency Mobile Psychiatric Services (EMPS) program operating through these entities.

Table 11: Caregiver Knowledge of System of Care and Advocacy Groups

Caregiver knows about…	%	N
DCF Programming & EMPS		
KidCare Program	19%	62
Their local Community Collaborative	17%	58
EMPS	54%	170
Advocacy Groups		
Any of the five advocacy groups	52%	163
AFCAMP	11%	35
Families United for Children's Mental Health	20%	63
FAVOR	24%	77
NAMI	27%	86
PAP	15%	49

Almost half of the caregivers in this study (49%) were not aware of any of the advocacy groups in the state working on child mental health issues. While approximately a quarter of those participating in the survey had heard of NAMI (27%) or FAVOR (24%), fewer were aware of the other advocacy groups. Only 20% recognized the state's chapter of **t**he Federation of Families for Children's Mental Health, known as Families United. Similar numbers had heard of PAP (15%) and AFCAMP (11%). When asked, more than three-quarters of those interviewed (79%) requested that they be sent materials on the advocacy groups in the state.

One of the goals of the system of care approach is to educate and involve family members in the child's care. Families are seen as vital partners in the child's well-being, and informed families participate more fully and effectively. Therefore, the lack of familiarity with the child and family-serving systems (both DCF and advocacy) may limit caregivers' ability to be effective advocates for their children.

7. SUMMARY AND RECOMMENDATIONS

The system of care model at the core of the KidCare program specifies that family members should be actively involved at all levels including service delivery, planning, policy development, and evaluation. This study surveyed the satisfaction of caregivers who had children with intensive mental health needs receiving care through Connecticut's Department of Children and Families.

Caregivers were asked to assess their satisfaction with specific services their child had received. Two types of measures were used. First, caregivers were asked to indicate how satisfied they were in *general* with the mental health services their child had received. A second series of measures asked caregivers to assess how satisfied they were with *specific* services their child received.

The report describes:

- Characteristics of the children receiving services
- Behavioral health services that they received over the past year
- Families' satisfaction with those services
- Barriers to accessing services
- Respondents' familiarity with DCF Programs and statewide advocacy organizations

Services Received

The most commonly reported services were those that children typically receive as students either from, or as a requirement of, participating in a school system (e.g. annual check-ups or school-based interventions). Many outpatient mental health services, including counseling and evaluations, were frequently used, as were inpatient care and emergency care (either through hospitals or a crisis service).

Several findings regarding services received were notable. First, many children received an array of intensive services. Of the 14 types of services mentioned in the survey, caregivers reported that their child received an average of 5.8 service types during the past year. Second, these data show that slightly more than half of the children received some type of wraparound service. One-third received extended day services and smaller proportions received mentoring, respite, or in-home services, (the latter including those from a visiting behaviorist or nurse). Wraparound services are an important component of the system of care philosophy and it is encouraging that these children with intensive behavioral health needs are receiving this component of care.

Global Satisfaction

The majority of caregivers reported satisfaction with services in each of these domains.   These data, as well as other analyses presented in the report, support an overarching conclusion that most caregivers are satisfied with the types and quality of mental health services their children

have received. Participants responded most favorably about the following:

- Participation in treatment
- Access to services
- Cultural sensitivity of staff

However, there was more variation in the remaining two domains: *global satisfaction with services* and *perceived outcomes of the services.* While the majority of caregivers also provided favorable ratings in these domains, a sizable minority (nearly one-third) expressed general dissatisfaction with the services that their child had received. Similarly, nearly one-third of respondents believed that the services had not been helpful.

These variations in levels of global satisfaction were generally not statistically correlated with the type of service received. The only exception to this pattern was related to the use of crisis services. Caregivers' levels of satisfaction with service outcomes were inversely related to the children having received crisis services. That is, caregivers of children who had received crisis services were less likely to be satisfied with the outcomes of their children's care than caregivers of children not receiving such services. This is not a strong relationship, but it may suggest a realistic appraisal by caregivers that the need for crisis services means that services are at some point not successful in keeping the child stable in the community.

Demographic characteristics of the child and caregiver bore little relationship to satisfaction in either domain; with two exceptions. Caregivers who reported that their child was white were less satisfied with services in general than were caregivers whose child was of another racial/ethnic group. Caregivers who were adoptive parents were less likely to be satisfied with services and with outcomes than were other caregivers.

Caregivers whose child had lived in a criminal justice setting or a shelter, or were homeless or runaways during some portion of the past year, were less satisfied with service outcomes than were caregivers of children who had not experienced these events.

Current difficulty in obtaining services was also correlated with satisfaction. While almost three-quarters of those not currently having trouble securing services were satisfied, only 42% of those who were currently having trouble obtaining services expressed general satisfaction with services and with outcomes.

Finally, the analysis examined whether knowledge of the system of care was associated with satisfaction. Caregivers were asked whether or not they had heard about eight entities in the system of care: the KidCare Program, Community Collaboratives, Emergency Mobile Psychiatric Services (EMPS), Family Advocacy Organization for Children (FAVOR), African Caribbean American Parents of Children with Disabilities (AFCAMP), Families United, National Alliance for the Mentally Ill (NAMI), and Padres Abriendo Puertos (PAP). A measure was created, summing the total numbers of components recognized, with scores that ranged from 0 to 8. Caregivers who had a higher score on this measure tended to report higher levels of satisfaction with services generally, and with outcomes, than caregivers who were aware of fewer components.

Service-Specific Satisfaction

As with their global assessment of the care received, the majority of caregivers expressed satisfaction when asked about particular services. For some services, however, there was a sizable minority who were dissatisfied along two of the dimensions, responding that the services had not been helpful and/or the location of the services was inconvenient.

Approximately one-quarter to one-fifth of the caregivers of children receiving the following services said that they were not helpful for their child:

- Substance abuse treatment (27%)
- Extended day (25%)
- In-home services, such as those from a visiting behaviorist or nurse (22%)
- Residential care services (20%)
- Emergency room visits (22%)

More than one-quarter of caregivers whose child had used the following services reported that the location of three service types was inconvenient. These services were:

- Residential care services (29%)
- Inpatient care (29%)
- Substance abuse treatment (27%)

Barriers to Receiving Services

While this population of children received an intensive array of services, many caregivers and providers believed that additional care was necessary. More than half of the caregivers (54%, n=174) reported that either they or a mental health professional believed that the child should have received at least one additional service. For nearly all services cited, caregivers were more likely to report an unmet need than were the mental health professionals (as reported by caregivers).

The barriers reported by caregivers varied by type of service. Issues related to financing and eligibility were encountered with the more expensive programs, such as inpatient care, residential care and mental health testing/evaluation. Eligibility issues were frequently cited in explaining why needed educational services were not received. Capacity issues were cited frequently as a major reason why wraparound services were not obtained. More than 40% of caregivers who cited an unmet need for mentoring and respite care cited this reason. More than one-third who cited a need for extended day and in-home services (such as those from a visiting behaviorist or nurse) provided reasons related to inadequate capacity in their area.

Familiarity with Advocacy Groups

Caregivers were also asked about their knowledge of the KidCare Program and the various family advocacy organizations that are operating in the state. The interview results suggest that many caregivers were unaware of the larger policy and programmatic context in which the

child's services were delivered. A relatively small proportion of the caregivers knew about the KidCare Program or were aware that a Community Collaborative existed in their area. Only half of the caregivers were aware of any statewide children's advocacy group.

RECOMMENDATIONS

The results of this survey should be encouraging to the Department of Children and Families and the Department of Social Services in Connecticut. In several important dimensions of quality, the majority of caregivers who responded on behalf of children with intensive behavioral health needs expressed satisfaction. A minority, however, were less than satisfied and their responses lead to the following recommendations:

1. Continue to increase community service capacity. Satisfaction with some dimensions of quality was lower for caregivers who were currently experiencing difficulties securing the services they felt were necessary. Additionally, more than half of the caregivers surveyed indicated that either they or a mental health professional felt that the child needed one or more service types that he or she was not receiving. This finding suggests that the capacity of the community system still remains limited and efforts by DCF to increase community service capacity and to reduce service barriers should continue.

2. Expand capacity for mentoring, extended day treatment, medication management, and mental health evaluations. At the same time certain services have been identified by caregivers as helpful, the capacity of these services remains particularly taxed. Caregivers most frequently identified a need for two types of wraparound that their children were not receiving but that they felt would be beneficial services: mentoring and extended day. Also, caregivers would have liked to have seen additional services for prescribing medications and providing mental health evaluations. While DCF is already cognizant of such needs, as resources become available to the department, these four areas might be targeted for expansion.

3. Address perceived barriers created by limitations in financing and eligibility for certain services. This report has identified particular barriers to filling unmet need. Limitations in financing and eligibility were two commonly cited barriers. While such barriers will always be perceived within the system, given that the barriers were most frequently cited in three areas (inpatient, residential, and mental health testing/evaluation), DCF might undertake a number of strategies to address concerns in these areas. While a number of strategies are possible, highlighting eligibility criteria in materials provided to family members could reduce unrealistic expectations of some family members for services. Likewise, materials that illustrate the continuum of care available to children and their families could provide families with more knowledge of alternative types of services, and alleviate some of the demand for inpatient and residential services. In addition, should resources become available to the department, expansion of eligibility criteria for these services might be considered.

4. Expand outreach and public education about KidCare services and supports. Finally, DCF has invested considerable resources and energy into developing a network of family-based advocacy organizations. The staff and family members involved in these organizations have devoted countless hours to helping families secure needed services through the system of care.

That half of the caregivers of children with intensive behavioral health needs were unaware of any these organizations and of the KidCare initiative suggests the need for greater outreach and marketing of these valuable resources. This outreach is especially important given that caregivers who were more familiar with elements of the KidCare program and the existence of the various advocacy organizations expressed higher levels of satisfaction with the helpfulness of services than did those caregivers without such knowledge.

APPENDIX I: Study Sample

In order to be eligible for the study, children had to have received services from DCF in the prior 12 months. The final sample produced 322 completed interviews with a response rate of 74.7%. Sixty-four caregivers directly refused to participate, and another 45 hung up the telephone during the brief introduction to the study and were not re-contacted. Seventy-one cases remained in circulation at the time that data collection ended. A total of 852 names were excluded from the sample including the following:

Ineligible Cases

55   Case was ineligible for the study (e.g. did not receive services in the last 12 months)

12   Family had multiple children receiving DCF services; families interviewed about one child and others were excluded

4   Duplicate names in the database

Incomplete/Inaccurate Contact Information

380   Untraceable (could not be traced through 411 and DCF did not have current contact information)

182   No contact information (address or telephone) provided

100   Contact information was for residential care or other child services placement

Did Not Conform to Field Protocol

5   Caregiver spoke a language other than English or Spanish

98   Case was retired after 20 attempts to contact caregiver

APPENDIX II: Satisfaction by Type of Service

Table 12: Satisfaction by Type of Service – Mean Score*

	The (service) care helped (child). Mean (st.dev.) n	The location of the (service) care was convenient for you. Mean (st.dev.) n	The staff treated you and (child) with respect. Mean (st.dev.) n	The staff understood & respected your culture, religion, & values. Mean (st.dev.) n	You participated or were involved in (child's) (service) care. Mean (st.dev.) n
Seen by a doctor/nurse for physical health problem or check up	4.46 (0.90) 269	4.58 (0.76) 272	4.70 (0.55) 270	4.66 (0.61) 269	4.65 (0.65) 273
Educational interventions (e.g. special ed or school-based counseling)	4.34 (1.14) 221	4.54 (0.98) 223	4.67 (0.72) 223	4.67 (0.70) 222	4.73 (0.59) 224
Doctor or nurse prescribed/reviewed mental health medications	4.01 (1.32) 215	4.35 (1.03) 221	4.63 (0.69) 222	4.61 (0.70) 222	4.56 (0.90) 224
Outpatient counseling	3.95 (1.39) 218	4.43 (1.03) 221	4.63 (0.75) 218	4.64 (0.62) 217	4.61 (0.78) 220
Mental health evaluation or test	3.96 (1.30) 171	4.33 (1.15) 175	4.64 (0.72) 174	4.72 (0.49) 173	4.42 (1.08) 177
Inpatient care	3.99 (1.3) 148	3.64 (1.6) 148	4.52 (0.85) 148	4.57 (0.80) 148	4.48 (0.97) 151
Visit to hospital emergency department for mental health	3.87 (1.48) 129	4.48 (0.95) 131	4.50 (0.93) 131	4.55 (0.75) 130	4.48 (1.02) 131
Extended day services	3.8 (1.53) 104	4.32 (1.12) 104	4.42 (1.05 103	4.60 (0.73) 103	4.44 (1.00) 104
Crisis services (including 31 in EMPS)	4.08 (1.42) 93	4.24 (1.29) 93	4.47 (0.98) 95	4.43 (0.92) 94	4.53 (0.93) 96
In-home services (e.g. visiting behaviorist/nurse)	3.88 (1.44) 77		4.56 (0.86) 79	4.56 (0.81) 79	4.72 (0.53) 79
Residential care	3.93 (1.46) 60	3.72 (1.58) 61	4.48 (1.04) 61	4.61 (0.67) 59	4.69 (0.72) 62
Mentoring	4.38 (1.09) 52	4.73 (0.49) 52	4.74 (0.56) 53	4.75 (0.48) 51	4.43 (1.07) 53
Respite care	4.48 (0.89) 27	4.63 (0.69) 27	4.81 (0.40) 27	4.78 (0.42) 27	4.63 (0.74) 27
Substance abuse services	3.59 (1.47) 22	3.68 (1.56) 22	4.36 (1.09) 22	4.32 (1.21) 22	3.82 (1.47) 22

* 1=disagree strongly; 2=disagree; 3=neutral; 4=agree; 5=strongly agree

APPENDIX III: Individual items in Scales
(Caregiver's Perceptions of Services Received)

Table 13: Caregivers' Perceptions of Services Received

Domain	Mean (standard deviation)	Disagree (%; N) (average score ≤3.5)	Agree (%; N) (average score >3.5)
Satisfied with services	**3.92 (1.08)**	**30% (90)**	**70 % (207)**
Overall, I am satisfied with the services my child received.	4.03 (1.15)		
The people helping my child stuck with us no matter what.	4.01 (1.28)		
I felt my child had someone to talk to when he/she was troubled.	4.13 (1.20)		
The services my child and/or family received were right for us.	3.98 (1.23)		
My family got the help we wanted for our child.	3.88 (1.31)		
My family got as much help as we needed for my child.	3.57 (1.50)		
Participated in treatment	**4.24 (0.88)**	**16% (49)**	**84% (264)**
I helped to choose my child's services.	4.09 (1.17)		
I helped to choose my child's treatment goals.	4.13 (1.15)		
I participated in my child's treatment	4.52 (0.79)		
Good access to services	**4.29 (0.84)**	**19% (59)**	**81% (256)**
The location was convenient for us.	4.31 (0.96)		
Services were available at times that were convenient for us.	4.27 (0.99)		
Culturally-sensitive staff	**4.50 (0.61)**	**5% (16)**	**95% (294)**
Staff treated me with respect.	4.47 (0.75)		
Staff respected my family's religious/spiritual beliefs.	4.54 (0.61)		
Staff spoke with me in a way that I understood.	4.49 (0.75)		
Staff were sensitive to my cultural/ethnic background.	4.50 (0.67)		
Outcomes	**3.73 (1.12)**	**32% (98)**	**68% (207)**
My child is better at handling daily life.	3.74 (1.36)		
My child gets along better with family members.	3.84 (1.23)		
My child gets along better with friends and other people.	3.89 (1.21)		
My child is doing better in school and/or work.	3.75 (1.36)		
My child is better able to cope when things go wrong.	3.46 (1.41)		
I am satisfied with our family life right now.	3.66 (1.33)		

* 1=disagree strongly; 2=disagree; 3=neutral; 4=agree; 5=strongly agree

**www.chdi.org
or
www.state.ct.us/dcf**