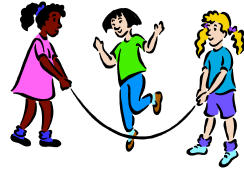


Families & Communities Together

Key Findings and Recommendations from the Evaluation of Delaware's Child Mental Health Grant Initiative



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Submitted to:

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August 2005



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Acknowledgements

The work of the evaluation team over the last 3 ½ years and this report, reflects the efforts and contributions of many individuals who participated in numerous interviews and meetings, helped with accessing management information system and record data, and reviewed drafts of many documents and reports produced throughout the evaluation.

In keeping with System of Care principles which place families at the forefront, we would like to express our utmost appreciation to the families that have taken part in the national evaluation interviews, been a part of the caregiver focus group, and shared their wisdom with us in so many ways. Special thanks go out to Isabell Banks, James and Norma Holt, Bobby Larson, Mary Ragonese, and the Delaware Federation of Families for Children's Mental Health, all who made important contributions that helped guide the work of the evaluation team. Family involvement is as critical to the success of the evaluation as it is to the success of the project.

Next we would like to thank the people on the front lines of the F.A.C.T. Project -- the Clinical Services Coordinators. Their continuing and tireless support in recruiting families for the national evaluation, collecting information about children's progress, and providing other assistance as needed reflects their commitment to the success of the project. Thank you! Your help was invaluable!

Thanks also go to the other members of the F.A.C.T. Evaluation Advisory Committee for their guidance, their work in helping provide data for the evaluation reports, and their help in shaping those reports. We also want to thank the CMH data unit for their efforts related to accessing and providing FACTS MIS data. Thanks also go out to Leslie Cooksy, former lead evaluator on the team, for her willingness to review pieces of this report after moving to a new job and for being available as a consulting resource.

Last, but certainly far from least, we would like to thank Mary Moor, F.A.C.T. Project Director, and Aileen Fink, F.A.C.T. Clinical Team Leader, for their support of and commitment to a meaningful evaluation of F.A.C.T.

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Families and Communities Together (F.A.C.T.)

FINAL EVALUATION REPORT

Delaware's Families & Communities Together (F.A.C.T.) project is a seven-year effort to establish a system of care for children with serious emotional disturbances and their families. Project activities focus on two areas: piloting a model for coordinating and providing services for these children; and facilitating the adoption of a system of care approach in the larger child-serving system. The Division of Child Mental Health Services (CMH) in the Department of Services for Children, Youth, & Their Families (DSCYF) partners with the Department of Education (DOE) to provide services to enrolled children. The F.A.C.T. project also works with other state agencies, service providers, community partners, and Delaware families. F.A.C.T. is funded by the federal Substance Abuse and Mental Health Services Administration's Center for Mental Health Services (SAMHSA/CMHS).

This is the final evaluation report and focuses on the key findings of the evaluation of F.A.C.T.'s efforts through the end of state FY2005. This report also presents recommendations for the project and for DSCYF's system of care effort based on these findings. Detailed results and a complete description of methods used during the course of the evaluation are available in the Final Technical Evaluation Report (available from the University of Delaware Evaluation Team).

Who does F.A.C.T. serve?

The F.A.C.T. project is statewide. It can serve up to 65 children at any one time. In order to be in F.A.C.T., a child must:

1. be receiving special education services locally and/or through the State Interagency Collaborative Team (ICT), *and*
2. have mental, emotional, and/or behavioral problems, *and*
3. be functioning poorly in school, home, and/or community, *and*
4. require the services of multiple child serving state agencies, *and*
5. be at risk of residential placement if intensive services are not provided.

As of May 31, 2005, 139 children had been served by the F.A.C.T. project. The first table on the next page describes these children in terms of the above criteria for enrollment. The second table compares the 139 F.A.C.T. children to the 2,164 children who had been served by CMH in FY2005. It shows that most F.A.C.T. children are boys. In addition, approximately two out of every five F.A.C.T. children are African-American. Most of the F.A.C.T. children lived with a parent(s) or other family member(s) at the time of their enrollment in the project. The evaluation had additional information about risk factors for 113 of the F.A.C.T. children. Of these children, close to one-half (46%) had a psychiatric hospitalization before enrolling in the project. During this same time period, about one-third had run away without the caregiver knowing their whereabouts (34%), and/or been physically abused (34%). In addition, about 70% came from biological families that had experienced other family mental illness issues and/or family substance abuse.

Many F.A.C.T. children come from families that have experienced family violence and family substance abuse.

Comparison of Criteria for Participation and the Population Served by F.A.C.T.

Criteria for Participation	Population Served*
Age range between 3-18	Children ranged in age from 4-18.
Age focus on children 9-14 years	60% of children were 9-14 at time of enrollment.
Involvement in special education services	100% of children were involved in special education services at time of enrollment.
At risk of placement in residential care	90% had more than one psychiatric diagnosis at the time of enrollment in F.A.C.T. 61% had at least one diagnosis that indicated mental retardation or a developmental disability at time of enrollment. 46% had a psychiatric hospitalization before enrollment in F.A.C.T.
Multiple agency involvement	In addition to involvement with special education services, 47% of children were involved with at least one other DSCYF Division at the time of enrollment with F.A.C.T. Additionally, 47% of children with an eligible diagnosis were involved with DDDS as of July, 2005.

*Status at enrollment is based on all 139 children. Status before F.A.C.T. enrollment is based on the 84 F.A.C.T. children who were receiving DCMHS services before joining the project.

Comparison of F.A.C.T. Children and CMH Children

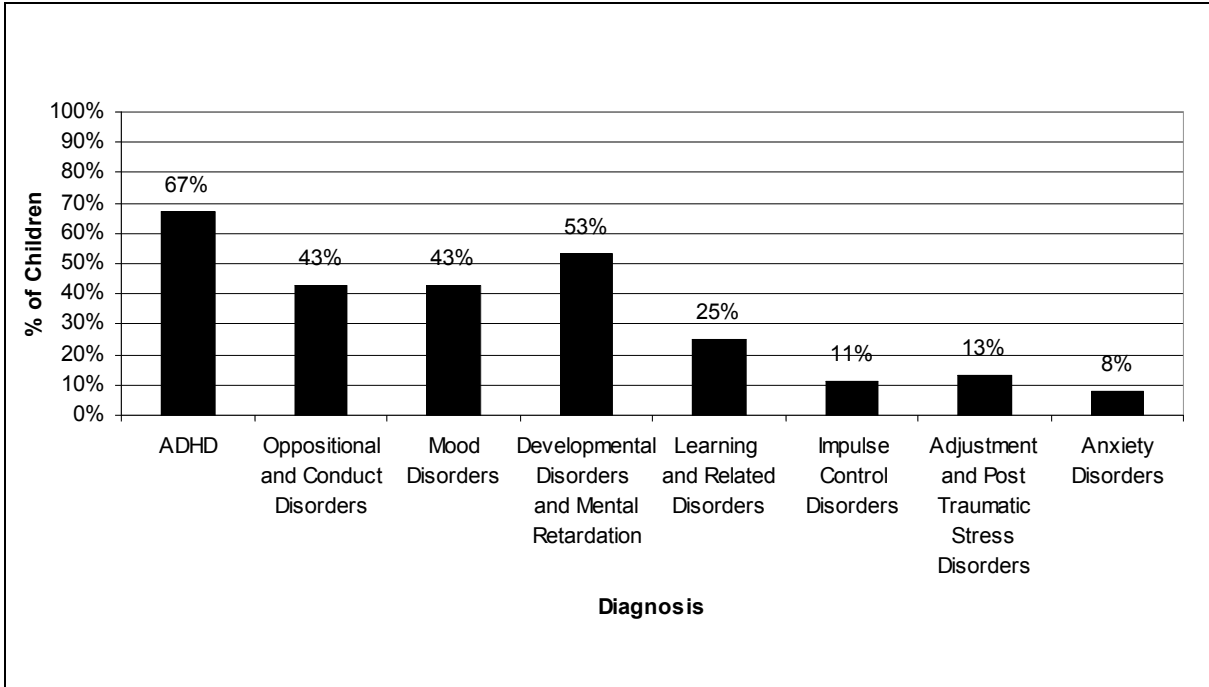
	F.A.C.T.	CMH*
<i>Sample size</i>	139	2,217
<i>Gender</i>		
Male	86%	62%
Female	14%	38%
<i>Average Age</i>	12.3 years**	11 years
<i>Race/Ethnicity</i>		
Black or African American	45%	37%
Hispanic	4%	7%
White	51%	61%
<i>Custody Status at Intake</i>		
Parents	67%	n/a
Relative	17%	n/a
State custody	16%	8%

*Based on FY2005 CMH data (age is that as of first case opening)

**Age is that as of enrollment in F.A.C.T.

The following figure shows that ADHD, oppositional/conduct disorders, and mood disorders were the most common diagnoses F.A.C.T. children had at the time they entered the project. In addition, more than half (53%) of the children had a diagnosis related to mental retardation or a possible developmental disability.

Psychiatric Diagnoses of F.A.C.T. Children at Enrollment



How long do F.A.C.T. children stay in the project?

For the 75 cases that had been discharged from F.A.C.T. as of May 31, 2005, nearly 70% had been discharged in less than 2 years. So far, the shortest stay in the project was less than 4 months. The longest stay before being discharged was almost 4 1/2 years.

On average, children are in the F.A.C.T. project for about 1 3/4 years before they are discharged.

For the 69 cases that were still active on May 31, 2005, the average length of stay was just under 1 year. So far, the longest stay without being discharged was more than 4 years and 5 months.

How do children do in F.A.C.T.?

This section describes several different elements of children's functioning. One of the major tools for looking at how children are doing is called the Child and Adolescent Functional Assessment Scale (CAFAS). The CAFAS measures how children are doing in different areas of their lives. It is completed by each child's Clinical Services Coordinator at six month intervals and near the time that the child is discharged from the program. Other ways of looking at how children are doing that are discussed in this section are: children's involvement with the juvenile justice system, their outcomes at

the point of discharge from F.A.C.T., caregiver assessments of children’s problems and strengths, school performance, and changes in the kinds of mental health services the children use.

Child and Adolescent Functional Assessment Scale

There were 67 children who had CAFAS questionnaires completed at the time they were enrolled and approximately 12 months later. After being in F.A.C.T. for a year, just over half (55%) of these 67 children were doing better and about one-quarter (24%) were doing worse. There were 41 children who had CAFAS questionnaires completed at the time they were enrolled and approximately 18 months later. After being in F.A.C.T. for a year and a half, 48% of this group was doing better and 27% was doing worse. Finally, 47 children had completed CAFAS questionnaires from the time they enrolled and from the time they were discharged. When they were discharged, just over half (55%) of these children were doing better and about one-quarter (26%) were doing worse. (See the table for more detail on the CAFAS results.) For all three groups, the most seriously impaired children showed the most improvement.

Summary of Child and Adolescent Functional Assessment Scale Analyses

Type of Change	Comparison		
	Baseline-12 Months (N = 67 children)	Baseline-18 Months (N = 41 children)	Baseline-Discharge (N = 47 children)
<i>Change in overall functioning:</i>			
% doing better	55%	48%	55%
% with no change	21%	25%	19%
% doing worse	24%	27%	26%
% ‘Marked’ or ‘Severe’ doing better	76% (29 of 38 children)	65% (15 of 23 children)	72% (18 of 25 children)
<i>Change in the number of problem areas rated “severe”</i>			
Fewer areas rated severe	51%	51%	51%
Same number of areas rated severe	22%	15%	17%
More areas rated severe	27%	34%	32%
Of those w/ 3 or more severe ratings initially, % with fewer	92% (23 of 25 children)	75% (12 of 15 children)	76% (11 of 14 children)
<i>Areas showing the most improvement</i>	<ul style="list-style-type: none"> – Getting along with others – Behaving at home – Behaving in the community – Expressing/Managing moods or emotions 	<ul style="list-style-type: none"> – Getting along with others – Behaving at home – Behaving in the community – Expressing/managing moods or emotions 	<ul style="list-style-type: none"> – Getting along with others – Behaving at home – Behaving in the community – Expressing/managing moods or emotions

Legal Involvement

Of the 17 children who had legal charges both before and during their enrollment in F.A.C.T., 10 had fewer incidents after enrolling in the project.

Data on legal involvement were available for 125 children. The evaluation looked at the number of incidents of legal involvement before a child was enrolled in F.A.C.T. and during the child’s time in F.A.C.T. An “incident” means that the child was involved in an illegal activity that resulted in at least one legal charge that was prosecuted or plea-bargained, and resulted in a sentence. The table below shows that 31 children (25%) had at least one incident before enrolling in F.A.C.T. Of these 31 children, 14 (45%) had no legal involvement after enrollment. Seventeen out of 125 children (14%) had legal charges both before and during F.A.C.T. enrollment. Of these 17, 7 (41%) had less serious incidents after enrollment and 10 (59%) had fewer incidents. Out of the 94 children who had no legal involvement *before* F.A.C.T., 9 (10%) had legal charges *after* enrolling in the project.

Overview of Legal Involvement Before and During Enrollment in F.A.C.T.

	Before Enrollment	During Enrollment
Number and percent of children with at least one legal incident (N=125)	31 (25%)	26 (21%)
<i>For those children with legal involvement:</i>		
Total # of incidents	97	66
Average # of incidents/child with legal involvement	3.1	2.5
Number and percent of children with at least one charge with a severity rating in the top half of the rating scale	15 (48%)	11 (42%)

The evaluation also explored how children who had been involved with the juvenile justice system compared to the other F.A.C.T. children. Children who had legal involvement at any time (either before or after F.A.C.T. enrollment) were more likely to be older when they entered F.A.C.T. They also had higher rates of some risk factors (running away from home, substance abuse, suicide attempts, and experiencing physical abuse) than for children without legal involvement. Children with legal involvement were also 2 ½ times more likely to be doing worse on the CAFAS at 12 months and six times more likely to be doing worse at the time of discharge. Finally, children with legal involvement were one-third less likely to have had a positive outcome at the time of discharge from the project.

Outcomes at Discharge from F.A.C.T.

Of the 73 children that had been discharged from F.A.C.T. by late May, 2005, 56% were judged to have had successful outcomes (i.e., almost all treatment goals were reached). Another 23% had been placed in bed-based settings expected to last longer than three months and were considered to be unsuccessful outcomes. Almost all of this group of children entered a juvenile justice or special education placement. Most of the remaining children were discharged because the family moved out of state or the child turned 18 years old. Of this last group of children, most had made progress on at least some treatment goals by the time of discharge.

Local Data on Problems and Strengths

In the fall of 2004, the project adopted two questionnaires to gather caregiver perspectives about children's problems and strengths. The Behavioral and Emotional Rating Scale (BERS) measures children's strengths in five different life areas. The Ohio Mental Health Scales (Ohio Scales) measures how children are doing regarding a variety of problems and life skills. Both questionnaires are done every three months through an interview by the Clinical Service Coordinators. BERS and Ohio Scales were completed twice for 46 children.

For more than one-third of the 46 children, problem behaviors, as measured by the Ohio Scales, showed at least some level of improvement at follow-up. About two-thirds of these children had improved to a level where they were considered to have only minor problems during the 30-day period before the caregiver completed the questionnaire.

According to the BERS questionnaire data, children were more likely to show no change in functioning or strength scores at Time 2 than to show either noticeable improvement or noticeable worsening. The proportion of children who showed improvement (27% on average) was about equal to the proportion who showed worsening (24% on average), except on the Interpersonal and School Functioning scales, where almost twice the proportion of children improved as got worse (50% and 30% improved on the respective scales). The fact that children were more likely to show no change is not unexpected. It usually takes a longer time for strengths and functioning to improve.

Educational Data Findings

A variety of data sources were examined to try to understand how children were doing at school. Various problems and issues related to these sources limited the examination, unfortunately, to very few areas. In addition, none of the sources provided data on the complete set of FACT children, so the information provided below is not generalizable to all children in the F.A.C.T. project. (See the technical report for more information about the limitations of these findings.) The limited information on attendance indicates that very few children appear to skip school or classes and that most of the children studied attend school regularly. More than half of children studied were getting passing grades, but about one-quarter were experiencing significant problems in this area. The data also indicate that most of the children studied were working below grade level on math and reading. A majority of caregivers responding to the BERS questionnaire reported that their child experiences problems on things like completing tasks on time, doing homework, and studying for tests. Over time, however, the BERS data showed some gains in the extent to which the children were paying attention in class.

Changes in the Kinds of Services Used

F.A.C.T. tries to keep children out of bed-based services, like psychiatric hospitals and residential treatment centers, and provide community-based services, so that children can live with their families. The evaluation looked first at the number of children who were in bed-based services when they were enrolled in F.A.C.T. There were 20 children in bed-based services at the time of their enrollment in F.A.C.T. Nineteen of these 20 children moved to less intense services within 6 months of enrolling in the project, and 1 was discharged. Almost all of the 20 children stayed out of bed-based mental health services during the remainder of their time in the project.

The evaluation then looked at the 116 children who had been enrolled in F.A.C.T. for at least six months to find out how much of their time had been spent in bed-based services in the year before

enrolling in F.A.C.T. Of these 116 children, more than half (53%) had not had any bed-based services in the year before enrolling in F.A.C.T. The percentage of children who had not had any bed-based services after enrolling in F.A.C.T. was 47%, so there was very little change. Of the children who had bed-based services in the year before enrolling in F.A.C.T., almost two-thirds spent less than 25% of their service time in a bed-based service before F.A.C.T. and half spent less than 25% of their service time in a bed-based service during F.A.C.T.

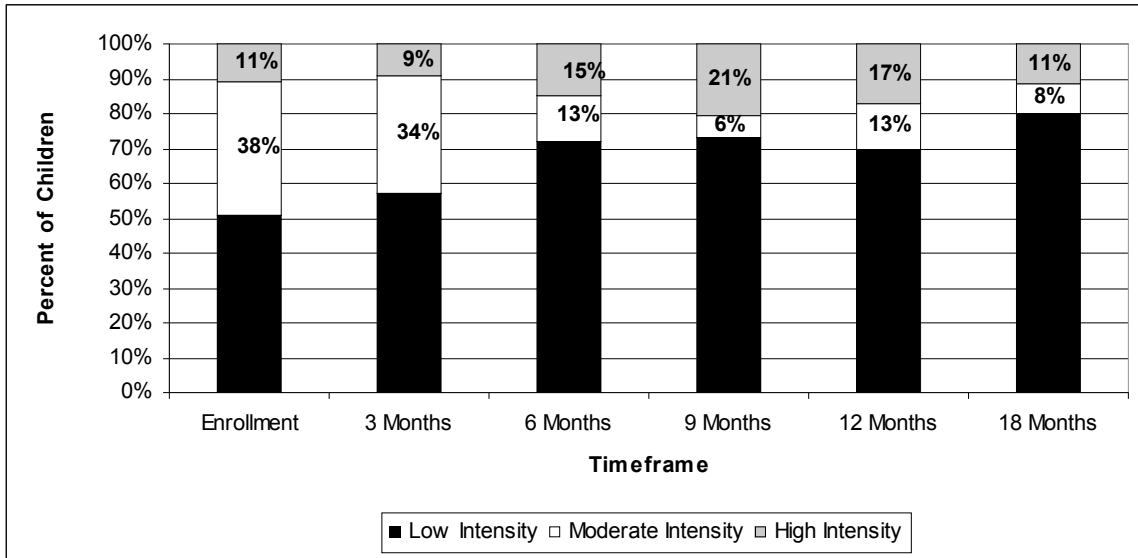
F.A.C.T. wants children to spend more time in community-based services, as described above. In addition, F.A.C.T. hopes to move children from more intense services to less intense services. The evaluation looked at three groups of children to see how the intensity of children’s mental health services was changing over time. Specifically, the evaluation looked at:

- the 116 children who had been enrolled in F.A.C.T. for at least 6 months,
- the 85 children who had been enrolled in F.A.C.T. for at least 12 months, and
- the 53 children who had been enrolled at least 18 months.

At enrollment, more than 50% of the children in each of the 3 groups were not receiving any high intensity or moderate intensity services. At each point in time, children were classified by the most intensive mental health service they were receiving.¹ In other words, if a child was receiving some low intensity services and some moderate intensity services, he or she would be classified into the “moderate intensity” service group. The results were similar for all three groups. (To give a picture of the kind of changes over time, the following figure shows the 18 month time group, with 53 children.) At enrollment, more than 50% of the children in each of the three time groups were not receiving any high intensity or moderate intensity services. Over time, the percentage of children in the low-intensity service group increased in each of the time groups. The 6 month and 12 month groups made increases of about the same size as the increase from 51% to 77% shown for the 18 month time group. The percentage of children receiving high intensity services stayed approximately 16% in the 6 month time group and decreased slightly from 15% to 12% in the 12 month time group. The percentage receiving high intensity services remained stable at 11% in the 18 month time group.

¹ Low intensity services included: case management only, outpatient services with or without wraparound aide services, wraparound aide services only, intensive outpatient therapy, partial day hospital, and partial day treatment. Moderate intensity services included: crisis intervention, day hospital, day treatment, treatment group home, and individualized residential treatment. High intensity (bed-based) services included: residential treatment center, inpatient hospitalization, crisis bed, and ICT residential placement.

Children's Most Intense Service Use from the Time of Enrollment to 18 Months (N=53)



How Much Does it Cost to Serve Children?

One potential effect of trying to increase the use of community-based services is that the amount of money spent on bed-based services should decrease. By decreasing expenses for bed-based services, more money can be used for community-based services. Increasing the use of community-based services may or may not also decrease the total amount of money spent on services.

Information about the costs of mental health and special education services for the state fiscal years 2002 through 2004 was examined. This information indicates that F.A.C.T. has increased the proportion of mental health service dollars spent on community-based services. In FY 2004, though, a slightly higher percentage of money was spent on bed-based mental health services. The increase appeared to be due to the introduction of an alternative (and less expensive) type of bed-based service and the enrollment of some children who needed bed-based services.

Nearly all children in each fiscal year had total mental health service and special education costs that were below the estimated average monthly ICT Residential placement cost of \$13,333. About 75% of children in those years had average monthly mental health service costs that were below the monthly Medicaid Bundled Rate of \$4,239. The cost data appear to support the notion that the system of care approach to providing mental health services to children, as represented by the F.A.C.T. Project, is a financially viable way of serving children with serious and complicated emotional and behavioral problems who are at risk of medium to long term deep-end service use.

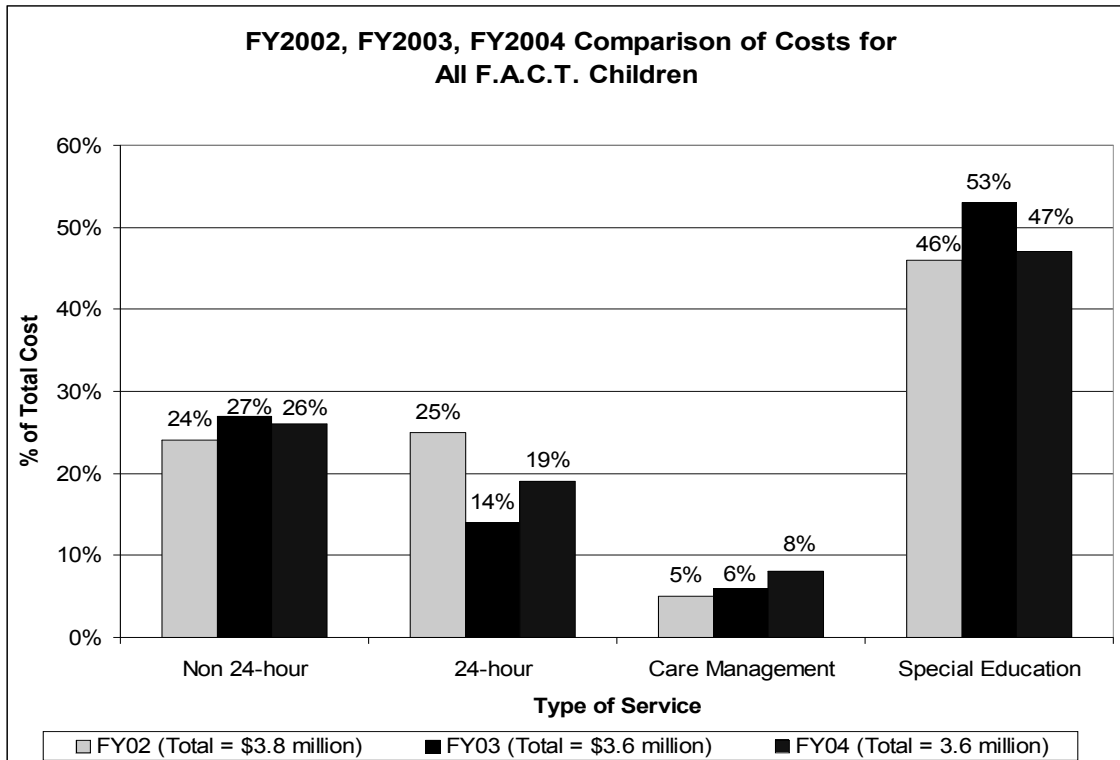
The average total mental health services cost per successful discharge outcome² (\$53,910) also indicates that success is not achieved at prohibitively high cost. The average monthly costs for most

² Discharge outcomes are based on clinical judgment and grouped into three categories: successful outcome (i.e., treatment goals were sufficiently reached), unsuccessful outcomes (i.e. went into a residential setting expected to last at least three months, or the child left, was withdrawn from or dropped out of school, or was making poor progress), or premature (i.e. the family left the project or the child turned 18 years old).

children who have had successful outcomes fall within the Medicaid Bundled Rate. Also, children the project has not been able to successfully serve are not appreciably more expensive, with respect to mental health service costs, than those with successful outcomes. Based on average total mental health costs, unsuccessful cases are less expensive than successful cases. However, looking at average monthly costs, which take into account the length of time a child was enrolled in F.A.C.T., unsuccessful cases are 17% more expensive to serve. There are substantial differences, however, in the proportion of dollars spent on community-based services, with the rate for successful outcomes far higher.

Total and Average Monthly Costs For Children Enrolled in the F.A.C.T. Project, FY 2002-2004.

	FY 2002	FY 2003	FY 2004
Total Mental Health and Special Education Costs	\$3.77 million	\$3.57 million	\$3.56 million
Average Monthly Total Cost Per Child - Mental Health and Special Education	\$6,424	\$5,537	\$5,226
Average Monthly Cost Per Child – Mental Health only	\$3,672	\$2,903	\$3,132
Number of Children included	52	60	67



F.A.C.T. Average Total Mental Health Service Costs per Outcome

	Community-Based Services	Bed-Based Services	Total Mental Health Services
Successful Outcome (N=32)	\$36,433 (67.6%)	\$17,478 (32.4%)	\$53,911
Other than Successful Outcome (N=25)	\$24,227 (45.4%)	\$29,112 (54.6%)	\$53,339
Unsuccessful Outcome (N=15)	\$19,884 (38.8%)	\$31,309 (61.2%)	\$51,193
Premature Discharge (N=10)	\$30,742 (54.4%)	\$25,815 (45.6%)	\$56,557

F.A.C.T. Average Monthly Mental Health Service Costs per Outcome

	Community-Based Services	Bed-Based Services	Total Mental Health Services
Successful Outcome (N=32)	\$1,575 (62.3%)	\$954 (37.7%)	\$2,529
Other than Successful Outcome (N=25)	\$1,401 (47.2%)	\$1,566 (52.8%)	\$2,967
Unsuccessful Outcome (N=15)	\$1,181 (39.9%)	\$1,776 (60.1%)	\$2,957
Premature Discharge (N=10)	\$1,739 (58.2%)	\$1,251 (41.8%)	\$2,990

How satisfied are family members and service providers with F.A.C.T.?

A survey of family members and service providers who are members of F.A.C.T.'s service planning teams was conducted in the summer of 2004 and the spring of 2005.³ In F.A.C.T., these planning teams are called Individualized Child Service Teams (ICST). A total of 114 people responded to the surveys (out of 297 who surveys were mailed to).

Family members were positive about many aspects of F.A.C.T.

The survey asked about how families are treated in the service planning meetings. It also asked about how individualized the services were and how much community services were used. Overall the people who answered the survey were very positive about the ICST meetings and the service planning process used in F.A.C.T. Most people felt that families were treated with respect and that they were treated as partners in the planning process. Only two primary issues were identified. The first, the existence and availability of a crisis plan, was reported as an issue in 2004, but showed improvement in the 2005 survey. The second issue was related to locating treatment and support resources in local communities that were considered to be sensitive and responsive to families' cultures and including these in the service plans. There was some

³ The survey was adapted from the Measuring the Integrity of Systems of Care (MISC) scale, originally designed by Flam, Furlong & Wood in 1998. The items were rated on a 5 point scale, where 1 = never and 5 = always.

dissatisfaction in this area, but locating these resources has been a real challenge for the project, so this finding is not unexpected. Overall, the F.A.C.T. ICST meetings and the service planning process are conducted in ways that are consistent with system of care principles and that both families and other ICST meeting participants generally feel positively about. Note, however, that this conclusion is based on survey data from less than 50% of the ICST members who were surveyed.

Is a New System of Care Being Developed?

F.A.C.T. has a goal beyond helping the individual children in the project. F.A.C.T. is also supposed to help Delaware develop a system of care for all children with mental health problems. F.A.C.T. is trying to develop this system in many ways. The major ways are:

- Involving families in all aspects of the mental health system,
- Providing services in the children's local communities in the least restrictive environment possible, as long as the specific services the child needs are available in the local community,
- Providing services that are strengths-based, family-focused and culturally sensitive,
- Expanding the service array to address gaps in the system,
- Increasing awareness about system of care principles through public awareness and social marketing activities, and
- Exploring ways to sustain the system of care after the federal support ends.

Family Involvement

F.A.C.T. has continued its strong commitment to family involvement.

Extensive family involvement in all aspects of a system of care is one of the key principles underlying the system of care approach. Reviews by external site visit teams indicate that the F.A.C.T. Project has had a good record of family involvement in project governance, service planning, attendance at system of care conferences, and program evaluation. Through much of the grant period, however, the project lacked an effective family support organization. F.A.C.T. has maintained its commitment to family involvement and addressed the key area of concern. Specific highlights of family involvement are:

- The Delaware Federation of Families for Children's Mental Health (FOF), with the guidance and support of Children and Families First, has become formally established in late 2004 as a family support and advocacy organization.
- FOF has hired parent partners to serve as resources for F.A.C.T. families, coordinated various trainings, facilitated two state-wide family-professional partnership conferences, and participated in activities intended to create awareness about children's mental health issues.
- Families have continued to expand their presence in the larger system of care through membership in various advisory councils related to children's mental health issues, and DSCYF's system of care roll-out effort.

Continued family involvement will face two key challenges when federal funding for F.A.C.T. ends in 2006. First, the system of care will need to explore alternative sources for supporting family involvement in governance and advisory meetings. National standards call for fair financial supports for family members that need to miss work to attend these types of meetings, including stipends,

travel assistance, and child care supports. Consideration also will need to be given to making meetings as accessible to families as possible. Examples include holding meetings at times that are convenient for families and using technology, such as conference calling, to make it easier for families to participate in meetings. The other challenge pertains to longer term support for FOF. As the result of a cooperative grant between DCMHS and the University of Delaware, FOF appears to have at least some level of consistent funding for the next two years. FOF will need to expand its board to better connect with potential funding sources and explore additional sources of funding and revenue.

Array of Community-Based, Family-Focused, and Culturally Competent Services

Having an array of services requires both the presence of appropriate services and coordination between services. F.A.C.T. and DCMHS have made many improvements in the service array over the course of the grant. The services that have been added, expanded, or more fully implemented include:

- Intensive Outpatient Therapy (IOP) capacity has undergone several expansions to address the needs of special populations of children. Efforts continue to expand the capacity of this service in various parts of the state and in other parts of the system of care.
- Therapeutic Respite Care service became available in 2004 to F.A.C.T. caregivers. This service was developed in response to the need for caregiver support. Most participants indicated that they would benefit from having respite care, local supports, therapy, and aides available to help them deal with their own needs resulting from caring for their children with serious emotional and behavioral problems. The continuation of this service when grant funding ends may face challenges, as attempts to secure funding for respite care in other state agencies have often been unsuccessful.
- Collaborations continue with other agencies to make mental health services available to children in the child welfare and juvenile justice systems.
- F.A.C.T. has also facilitated efforts to expand the Positive Behavioral Supports program to more local schools to help address needs for behavioral intervention and management services in local schools. Through the Positive Behavior Intervention certificate program conducted by the University of Delaware, F.A.C.T. has also sought to increase the ability of mental health providers to serve the needs of children who have both mental retardation/developmental delays and behavioral or emotional issues.
- External reviews indicate there are still service needs, including increasing the number of psychiatrists serving children, increasing service availability in Kent and Sussex counties, and working to expand the availability of mental health services and resources in the schools.

Use of a Validated Clinical Model

F.A.C.T. uses a strengths-based, family-focused, and individualized clinical model. This model has consistently received positive feedback from external reviewers, families, and service providers. In 2004, Plan of Care books which accompany the CSCs to their meetings with the family were implemented to improve the planning and monitoring of services.

Collaboration

Collaboration among agencies and partners is a key value of the system of care approach and critical to the success of such efforts. The F.A.C.T. Project appears to have fostered good collaboration among its partner agencies and organizations. However, challenges still exist.

- Collaboration was perhaps strongest at the agency level and varied somewhat at the practice level. Success at this lower level has been dependent on the extent to which case managers and equivalent positions at other child serving agencies have chosen to participate, and less on agency policies.
- The missions and policies of different child serving agencies have sometimes made it difficult to develop a single plan to guide service delivery for a given family.
- While sharing information between agencies has generally been positive, it has also been a source of frustration as laws, policies, and procedures related to information privacy have been barriers at times.

Sustaining the System

Considering all of the available data from the current year and previous years, F.A.C.T. appears to be demonstrating that the system of care is a viable approach for serving children with serious and complex mental health needs and is having a positive impact on many of the children it serves and the larger system.

Efforts to expand awareness of systems of care principles and philosophy through social marketing have continued and have produced a variety of public awareness activities. Capacity for such work has been expanded through the partnership between the Mental Health Association in Delaware and Delaware State University (DSU) to create the Center for Mental Health Education and Research at DSU and increase awareness efforts in Kent and Sussex counties. The emergence of FOF and their activities related to awareness building are also an asset. The participation of representatives from F.A.C.T., DSCYF, and the FOF on advisory councils for cultural competence, social marketing, and others is another part of laying the groundwork for broader systems change.

The Bottom Line

While evidence is still needed on the effects of F.A.C.T. on children's ability to perform in school and in functioning overall, there is a lot of good news about the F.A.C.T. project. F.A.C.T. is serving children who have complex emotional and behavioral issues and so is helping those that it is intended to serve, the children with the most serious needs. The children who are in the most restrictive services before F.A.C.T. tend to move to less restrictive services after enrolling in F.A.C.T. The children who are involved in the legal system before F.A.C.T. tend to decrease either the number or seriousness of their legal charges after enrolling in F.A.C.T. In addition, family members and other ICST members are very positive about the ICST meetings. Finally, F.A.C.T. has strengthened the state's system of care in several ways, increasing family involvement, expanding service options, and developing new partnerships.

Recommendations

The following are recommendations for the larger system of care effort in Delaware. These were developed based on information collected during the evaluation of the F.A.C.T. Project, attendance at system of care conferences, and reviews of a variety of system of care materials and meeting notes. The recommendations fall into four categories: family involvement, services/programming, systems change, and evaluation. By far, most of the recommendations center around continuing to carry out or refine certain practices, policies, etc., as Delaware's system of care effort moves forward. Evaluation of system of care activities in the future is one of the most pressing needs (echoed by the findings from the spring 2005 consultation visit by Human Systems and Outcomes). The recommendations in that area reflect both the need and the activities that will be needed to address it.

It should be noted that F.A.C.T. has played a critical role in helping to lay the ground work for system changes. The projects efforts have greatly influenced the development of the larger system of care effort in ways that should lead to better services for children with serious mental health issues.

It is important to note that, for a number of the recommendations offered, collaboration will need to occur that involves a wider variety of organizations that serve or advocate for children and families than have been involved in Delaware so far. The systems of care approach ultimately is about community ownership and involvement in improving the lives of families and children.

Family Involvement Recommendations

Systems of care are intended to be family-centered and family-driven. This principle applies to all levels of the system, not just the direct service level. A meaningful family presence is important in governing systems of care, shaping the service provided, and in advocating for changes that result in better services for children and families. The following are recommendations related to family involvement in Delaware's system of care effort.

1. *Work to ensure the long-term survival of the Delaware Federation of Families for Children's Mental Health.* The founding of FOF represents an important step in developing a family-driven statewide support and advocacy movement around children's mental health issues. The short-term future of FOF looks promising. However, the long-term future of the organization is uncertain. This is a common situation for new non-profit organizations. The following are recommendations that may help address the long-term future of FOF.
 - a. *Build connections with the charitable giving community* by expanding the membership and expertise of the board. Non-profit organizations benefit over the long-run by successfully building relationships with organizations and individuals that are willing to support the organization's mission and goals.
 - b. *Continue to seek opportunities to partner* with universities and state child-serving agencies through writing grants.
 - c. *Continue to seek sources of revenue*, including fundraising events and opportunities to provide services, trainings, workshops, etc.
 - d. *Continue to connect with other non-profit and support organizations* that focus on various issues related to children's mental and emotional well-being.

2. *Continue to recruit families to governing boards and councils that are part of the larger system of care effort.* The system of care philosophy centers around families driving and guiding the service system. Extensive and successful family involvement, though, requires a substantial and fair representation of families.

Achieving this goal, however, often means that supports must be made available to make it easy for many families to be able to attend meetings, participate in conferences, etc. For some families, participation would not be possible without these types of supports. Recommendations include:

- a. *Providing a fair stipend for attendance at meetings*, particularly when the family member must miss work to do so.
- b. *Providing assistance for travel* (e.g., mileage reimbursement, bus fare) *and assistance for child care* (e.g., child care provided at meetings, financial assistance for getting a baby sitter), as needed.
- c. *Holding meetings at times* (e.g., evenings) *and locations that caregivers find reasonably convenient.* Technology such as conference calls (video or telephone) can be used to make it easier for families or other committee members to attend meetings when they might not be able to otherwise.
- d. *Orienting families and using language they can understand.* Systems of care can be confusing to understand. Families can find it easier to be a part of governance and advisory meetings if plain language is used and if there is a process for orienting/mentoring families to build knowledge.

Services/Programming Recommendations

The availability of a comprehensive array of services and community supports that offer families real choices is a key system of care principle. Good service availability means that children have a better chance of remaining in their home communities. The ability to choose from among a variety of providers allows families the opportunity to select a provider they like and who will be sensitive and respectful of their needs and values. The following are recommendations related to services and programming in Delaware's system of care effort.

1. *Keep working to expand the number and types of services available for children with serious emotional and behavioral issues.* Delaware has made good progress in this area, but more work needs to be done, including:
 - a. *Continue efforts to address the lack of service choices in Kent and Sussex counties.*
 - b. *Work to expand the availability of mental health services in the schools.* Schools are the key system children are involved with until adulthood. As a result, schools are natural places to screen children for behavioral and emotional problems and provide interventions. More effort, therefore, needs to go into equipping schools with effective tools to intervene, including expanding the availability of the Positive Behavior Supports program and finding additional ways of making mental health resources available to schools.

- c. *Continue expanding services for children with specialized needs.* Children with very challenging problems (e.g., fire starting) or with very specific needs (e.g., children with mental retardation/developmental delays [MR/DD] and behavioral/emotional challenges) have historically been difficult to serve in Delaware, sometimes requiring placement in out-of-state residential treatment programs far from where they live. F.A.C.T. has taken steps to address the needs of children with MR/DD issues through the Positive Behavior Intervention Certificate training program, designed to improve the ability of providers to provide effective services to these children. Service expansion through the project has included increased intensive outpatient service capacity in Sussex County, a specialized Intensive Outpatient Program for children and youth dually diagnoses with MR/DD and respite. The system of care effort does need to continue expanding service options for children with very challenging problems, as these are the children that appear to be the most difficult to serve successfully.
 - d. *Expand the availability of respite care.* This service is an important resource for families. The challenges of caring for children with serious emotional and behavioral problems can at times be so draining that caregivers may need a break but have no resource to turn to for such support. Without an opportunity to take a short break, overstressed caregivers are less able to effectively deal with challenging behavioral situations with their children. As a result, a child's behavior in these circumstances could escalate to the point that crisis services become involved. Respite care can be an important resource in keeping children out of expensive bed-based services, by providing a brief, needed break for the caregivers. This service has been introduced through the F.A.C.T. Project but needs to be expanded to the larger system of care.
 - e. *Build informal support networks.* Supports in the community, such as churches, support groups, and youth organizations, are considered to be important in helping children remain in their communities after formal and more intensive services are no longer needed. Some grant sites have staff that are dedicated to locating these resources and connecting families with them. The F.A.C.T. Project has not had a similar staffing resource available. However, the clinical services care coordinators along with the individual Interagency Child Service Teams (wraparound teams) do work to identify resources and help families connect with community supports. The issues related to establishing a family support organization has limited that avenue as a resource in developing these informal supports. As a result, this portion of the "service network" is underdeveloped. There are efforts underway, such as the Community Youth Mapping Project, to build this network and these should continue.
2. *Provide services for families.* Data from the evaluation of the F.A.C.T. Project indicate that many families served by the project were facing a variety of needs beyond those related to their children with serious emotional and behavioral problems. These issues included health problems, mental health problems among other family members, substance abuse issues, caregiver stress, etc. Since the family is central in the system of care approach and the primary support for children, it is important to address these kinds of needs. These needs argue for the inclusion of additional partners (e.g., the medical community) in the system of care effort in Delaware. The availability of parent

partners and family support groups offered through FOF that are intended as supportive family services are positive steps, but more remains to be done.

3. *Outreach to underserved populations.* Given the small number of children the F.A.C.T. Project serves at any one time, reaching out to traditionally underserved populations (e.g., Hispanics, Asians, Native Americans) has not been a practical option. There is, however, unmet need among these groups and the system of care will need to reach out to these groups. Forming partnerships with organizations that serve and are respected by these populations would be a useful strategy for reaching these groups.
4. *Explore decreasing caseload sizes to approach the national recommendation for system of care work of 1 worker per 8 children.* The nature of the case management approach used by F.A.C.T. places great demands on case managers, even with a caseload ratio of 1:15 (which is much lower than customary in Delaware). F.A.C.T. case managers have shown a great commitment to the families they serve, but the existence of risk factors related to burnout have been an observed concern. As practical, consideration should be given to reducing caseload ratios for case managers who will be serving children as part of the more intensive SOC model. Experts also caution that, because of the demands of the case management approach in systems of care, case management should be a primary responsibility and not combined with other substantial administrative tasks that require a significant portion of case managers' time. Such combinations raise the risk of burnout.

Systems Change Recommendations

A major goal of the systems of care approach is to bring about changes in the larger child and family service system that result in better services to families. Such changes often include modifications in agency policies and procedures, revision of state or local laws that govern the activities of agencies and/or the services they provide, and additions or modifications to budgets or funding policies to better support systems of care activities. The efforts of F.A.C.T. have helped bring about some important changes at the system level, but additional works needs to be done. The following are recommendations related to systems change issues in Delaware's system of care effort.

1. *Continue to build connections with other child and family serving agencies and community members to expand the reach of the system of care approach and the support for it.* Systems of care are intended to evolve over time to include a very diverse group of agency and community partners to expand the reach and potential impact of a system of care. Since children and families interact with a variety of agencies beyond those central to a system of care (typically agencies related to children's mental health, juvenile justice, child welfare, and education), it is important that SOCs evolve to include a broader array of partners. These could include the medical community, public health agencies, early child education (e.g., Head Start, Early Head Start), and community organizations that could provide informal supports to families and children (e.g., churches, local United Ways, Boys/Girls Clubs). Building partnerships with other agencies and organizations can also help build broader support, buy-in, awareness of the system of care, and a sense of community ownership, all of which can be important to the long-term survival of an SOC.

2. *Find more champions for Delaware's system of care.* Successful systems of care are often able to connect with people (e.g., community leaders, legislators, state agency/department directors) or organizations (e.g., family advocacy organizations) that can serve as advocates or opinion leaders. Such 'champions' can help systems move forward by helping to change policies and laws to help with long term success and/or bring the system of care effort into broader public awareness and garner support. Delaware's system of care effort would benefit from having additional champions within the legislature and the public.
3. *Treatment is only the beginning; plan for including screening and prevention.* An acknowledged and understandable missing link in the national system of care approach to date has been the lack of prevention efforts. National efforts have only recently begun to discuss the role of prevention in systems of care. It is important to note that the system of care approach, as implemented in most grant sites, will only treat those children and families most at need, with no activity focused on trying to reduce the number of families and children in need of services. Without eventually working to put a variety of prevention and early intervention efforts in place, the system of care in Delaware will remain in a reactive mode, focusing on trying to keep up with the increasing demand for services. By partnering with state agencies, the schools, community organizations, and universities, to develop primary prevention, screening, and early intervention programs (or tie into existing ones), Delaware's system of care effort can take steps to decrease the number of families in need of services and intervene earlier to increase the impact of services.
4. *Refine the governance structure of the system of care.* To be most effective, systems of care need effective leadership and buy-in from a broad variety of partners. In Delaware's system of care effort, leadership and governance take a variety of forms, ranging from departmental leadership, to advisory councils, to interdepartmental workgroups (including the state System of Care Committee). Delaware's SOC effort would benefit from integrating at least some of these approaches and developing a shared vision of governance and leadership among the various partners in the system of care. Ultimately, leadership of the system of care effort needs to become a collective responsibility that is independent of any one particular agency or department.
5. *Work to improve information sharing between partners.* Some frustrations were heard and experienced in the area of information sharing between system of care partners in Delaware. This issue appears most challenging at the service delivery level, particularly between the education and mental health systems. A primary cause of these issues appears to be the different federal and state policies about information sharing (e.g., HIPAA, FERPA). The result is that 'front-line' staff in various agencies often feel they cannot get information to help inform their work. There may be no easy solution to this issue, but solutions should be explored that could meet information needs while meeting state and federal laws and policies. At higher levels of the system of care, there were also suggestions that communication could be improved between agencies. Since communication is an ongoing and imperfect process, it may be worth exploring this issue periodically and making improvements as needed.
6. *Continue to explore options for funding non-traditional services (e.g., respite care).* A major issue facing system of care grant sites is finding ways to keep funding 'non-traditional' services (e.g., respite care, wraparound services) once the federal grant ends.

These services have typically not been funded by Medicaid, meaning that local systems of care must find ways to finance such services or discontinue them. Delaware will need to continue to explore ways of funding these services, including ways of pooling or blending funding or other resources from different partners.

7. *Continue to market the system of care approach to create awareness, support, and interest.* The F.A.C.T. Project, due to its limited focus, has had to balance awareness activities with its ability to meet the demand for its services. As a result, the system of care approach has not been as widely marketed in Delaware over the last six years as it might have been if its capacity to serve families was much greater. It is clear, though, from the feedback the project and the evaluation have received that families are very interested in the system of care approach, and that if the system of care approach is widely marketed, families will seek it out. A number of marketing efforts have occurred over the years of the F.A.C.T. Project and have reached various groups, including service providers, and the public to some extent. However, it would be beneficial to increase public awareness to a much greater extent. By doing so, a greater sense of community ownership and buy-in could be developed for the system of care. Partnerships with the Mental Health Association in Delaware (and MHA's partnership with Delaware State University) and the Delaware Federation of Families are in place and should be used in conjunction with existing efforts (e.g., 'May is Mental Health Month' activities) to begin an even wider marketing approach.
8. *Find a way to better harness the expertise gained through F.A.C.T. as the larger SOC is rolled out in Delaware.* F.A.C.T., its partners, and provider staff at all levels of the system of care have gained a wealth of knowledge about systems of care over the years of the grant. Systems change is difficult work, especially when attempted at a state level. The system of care effort would likely benefit greatly if the vast experiences of staff could be more effectively, more frequently, and more easily tapped to inform the larger system of care effort in Delaware. F.A.C.T. staff and others already serve in this way in addition to their primary job responsibilities. The SOC effort should continue using F.A.C.T. staff, the staff of partner organizations, and families as consultants, trainers, coaches, and/or mentors as the SOC effort moves forward over the next several years. Ideally, some staff or families serving in such roles should do so as a primary job responsibility to facilitate effective consultation, training, etc.

Evaluation Recommendations

Evaluation is an important part of systems of care. Examining how services are being delivered and planned, how they are working for the children and families being served, and what kinds of services are being used and how much they cost can provide a lot of information that can be used by the system of care. Information gained through evaluation can be used in a variety of ways, including improving services, understanding if services are helping children and families, identifying challenges the system of care needs to address, and advocating for system changes or increased funding. The following are recommendations for evaluating Delaware's system of care effort.

1. *Improve the ability of the system of care to evaluate its effectiveness and outcomes.* The move in the federal government to require social programs to measure outcomes is

likely to continue for the foreseeable future. As a result, states and organizations will probably experience increasing demands to evaluate their programs and demonstrate that they are making a difference for the people they are serving. This pressure has not yet reached the system of care effort in Delaware, but there are several steps that can be taken proactively to improve evaluation capacity.

- a. ***Build capacity.*** Because they try to change the larger service system, help families and children, and involve a variety of partners, systems of care can be challenging to evaluate. The SOC effort in Delaware should give strong consideration to hiring or training internal evaluators whose primary responsibilities would be to lead and manage evaluation efforts, particularly around the system of care effort. Also, the SOC should continue to build connections and partnerships with external evaluation resources (e.g., universities, Delaware Federation of Families, Nemours Health and Prevention Services). Such connections and partnerships could be tapped to carry out evaluation activities or to build the knowledge of internal evaluation staff.
- b. ***Adopt ways of measuring child progress and outcomes for all children served by the system of care.*** This could involve the expansion of the Ohio Scales effort in DCMHS, the adoption of a simple form for recording information about treatment progress during treatment planning meetings, revising the existing service progress rating approach (which was found to have problems), and/or requiring providers to regularly complete a standard questionnaire about each child's progress and outcomes. More information on outcomes could also be easily recorded on the form that is completed when a child leaves DCMHS services. There also needs to be a serious effort to collect similar information for children also served by other parts of the system of care (e.g., education, juvenile justice). Without such information, a full picture of children's progress and outcomes cannot be developed, making it harder to demonstrate outcomes.
- c. ***Work with ORC MACRO to explore approaches for effectively using data about service use and costs for evaluation.*** A lot of good information exists within the data management system used by DSCYF. However, until relatively recently, it was difficult to use that information effectively for evaluation purposes. Good progress has been made, but by working with MACRO (the agency that oversees the national evaluation of all grant programs like F.A.C.T.) additional methods of examining the information may be identified that would best serve the evaluation and quality improvement needs of the system of care.
- d. ***Expand the availability of cost data to better understand and demonstrate impacts of the system of care approach.*** Currently, information about the costs of serving individual children in the system of care is only readily available from DCMHS and the Department of Education. Since close to 50% of children in F.A.C.T. received services from other state agencies (as is likely to be the case in the larger system of care effort), the cost picture is incomplete without this additional information. The system of care should consider ways of increasing the amount of cost data available. The SOC effort should also consider adopting an established cost-benefit model (e.g., Yates' Cost-Benefit manual, <http://www.nida.nih.gov/IMPCOST/IMPCOSTIndex.html>) for examining costs and their relationship to outcomes and benefits.

- e. *Continue with efforts to evaluate implementation of system of care principles at the service planning level.* This includes implementing the service testing approach developed by Human Systems and Outcomes, adopting an assessment of the wraparound planning process that would be used by workers and their supervisors to improve front-line practices, and continuing to assess family satisfaction with the system of care. This recommendation could also be a way to increase involvement of family members in the system of care. Some other states have used community members as reviewers in the service testing approach. In addition, FOF could be a partner in the assessment of family satisfaction.
2. *Consider working with providers to identify evidence-based, best, and effective practices being used in Delaware.* The national movement toward identifying and using evidenced-based practices in mental health continues to gain momentum. This is potentially a double-edged sword for systems of care. On the one hand, it can result in services that have been demonstrated through research to be effective being available to more families. On the other hand, services that may be promising but do not yet have good enough evidence of effectiveness may be excluded by legislative action from being used (as has happened in the adult mental health system for one state). To try to avoid having service decisions imposed upon it, the system of care effort should strongly consider working with providers to identify, evaluate, and document best and effective practices being used in Delaware. These activities could include the assessment of practices that were considered “evidence-based” but had not yet been tested in the Delaware context. This could include surveying providers and developing collaborative grants with universities to evaluate interventions. This would allow the system of care to demonstrate the effectiveness of interventions it uses.
3. *Explore ways of securing information about educational progress on a regular basis.* In the evaluation of the F.A.C.T. Project, getting information from the schools was exceedingly difficult and, for all intents and purposes, was unsuccessful. Since many of the children most in need of the system of care approach are likely to be having some sort of problems at school, data about behavioral and academic progress is critical to effectively measuring outcomes and demonstrating effectiveness. At the same time, there are challenges presented by federal and state regulations and laws which limit the type of data schools can share. There are a variety of approaches that could be used that should produce useful information, including collecting information directly from caregivers, from educational representatives on Interagency Child Service Teams, working with existing intervention programs in the schools (e.g., Positive Behavior Supports), or developing agreements with school districts.