

HCRTTP

# Promising Approaches

for Behavioral Health Services to Children and Adolescents and Their Families in Managed Care Systems

## 6: Family Involvement in Managed Care Systems

Ginny M. Wood

A Series of the  
**HCRTTP** Health Care Reform  
Tracking Project



Tracking Behavioral Health Services to Children and Adolescents and Their Families in Publicly-Financed Managed Care Systems

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for Behavioral Health Services to Children and Adolescents  
and Their Families in Managed Care Systems

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and Their Families in Managed Care Systems

## 6: Family Involvement in Managed Care Systems

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**A Series of the**

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# Promising Approaches

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### Introduction

#### Health Care Reform Tracking Project

Since 1995, the **Health Care Reform Tracking Project (HCRTTP)** has been tracking publicly financed managed care initiatives and their impact on children with mental health and substance abuse (collectively referred to as behavioral health) problems and their families. The HCRTTP is co-funded by the National Institute on Disability and Rehabilitation Research in the U.S. Department of Education and the Substance Abuse and Mental Health Services Administration in the U.S. Department of Health and Human Services. Supplemental funding has been provided by the Administration for Children and Families of the U.S. Department of Health and Human Services, the David and Lucile Packard Foundation, and the Center for Health Care Strategies, Inc. to incorporate special analyses related to children involved in the child welfare system. The HCRTTP is conducted jointly by the Research and Training Center for Children's Mental Health at the University of South Florida, the Human Service Collaborative of Washington, D.C., and the National Technical Assistance Center for Children's Mental Health at the Georgetown University Center for Child and Human Development. The mixed method design of the Tracking Project has involved periodic surveys of all states, in-depth impact analyses involving site visits to a selected sample of states, and the identification and dissemination of promising approaches and features of managed care systems.<sup>1</sup>

Throughout these activities, the Tracking Project has explored and compared the differential effects of carve out designs, defined as arrangements in which behavioral health services are financed and administered separately from physical health services, and integrated designs, defined as arrangements in which the financing and administration of physical and behavioral health care are integrated (even if behavioral health services are subcontracted).

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<sup>1</sup> All reports of the Healthcare Reform Tracking Project (HCRTTP) are available from the Research and Training Center for Children's Mental Health, Louis de la Parte Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Boulevard, Tampa, FL., (813) 974-6271. See page 33.



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## Methodology for Study of Promising Approaches

The strategies and approaches that are described in the **Promising Approaches Series** were identified by key state and local informants who responded to the HCRTTP's state surveys and who were interviewed during site visits to states for the HCRTTP's impact analyses. Once promising approaches and features of managed care systems were identified through these methods, members of the HCRTTP team, including researchers, family members, and practitioners, engaged in a number of additional methods to gather more detailed information about identified strategies within particular topical areas. Site visits were conducted in some cases, during which targeted interviews were held with key stakeholders, such as system purchasers and managers, managed care organization representatives, providers, family members, and representatives of other child-serving agencies. In other cases, telephone interviews were held with key state and local officials and family members to learn about promising strategies. Supporting documentation was gathered and reviewed to supplement the data gathered through the site visits and telephone interviews.

For each general topical area studied, a paper is prepared to explain the challenges and to describe promising approaches or features of managed care systems that are considered by key informants to improve service delivery for youth with behavioral health treatment needs and their families. These papers comprise the *Promising Approaches Series*.

The series intentionally avoids using the term, "model approaches." The strategies, approaches, and features of managed care systems described in the series are perceived by a diverse cross-section of key stakeholders to support effective service delivery for children with behavioral health disorders and their families; however, the HCRTTP has not formally evaluated these approaches. In addition, none of these approaches or strategies is without problems and challenges, and each requires adaptation in new settings to take into account individual state and local circumstances. Additionally, a given state or locality described in the series may be implementing an effective strategy or approach in one part of its managed care system and yet be struggling with other aspects of the system.

It is important to note that the series does not describe the universe of promising approaches that are underway in states and localities related to each of the aspects of managed care systems that was studied. Rather, it provides a snapshot of promising approaches that have been identified through the HCRTTP to date. New, innovative approaches are continually surfacing as the public sector continues to experiment with managed care.

Each approach or strategy that is described in the series is instructive in its own right. At the same time, there are commonalities across these strategies and approaches that can help to inform the organization of effective service delivery systems within a managed care environment for this population. An attempt is made in each paper to identify these commonalities, thus offering guidance to family run organizations, states and communities attempting to refine their managed care systems to better meet the needs of children and youth with serious behavioral health disorders and their families.

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# Overview

## Promising Approaches 6: Family Involvement in Managed Care Systems

This paper focuses on promising approaches and strategies related to family involvement in managed care systems in three states. These promising approaches include both statewide approaches focused on a total population (New Jersey Partnership for Children), (Massachusetts Behavioral Health Partnership) and a local site (Delaware County, PA) focused on a specific geographic area (**Table 1**).

<b>Table 1</b>	
<b>Promising Approaches to Family Involvement in Managed Care Systems</b>	
<b>Statewide Approaches</b>	<b>Local Approaches</b>
New Jersey Partnership for Children	Delaware County, PA
Massachusetts Behavioral Health Partnership	

The paper addresses five areas of family involvement within managed care systems: (1) Requirements for Family Involvement; (2) Family Involvement at the System Management Level; (3) Family Involvement at the Service Delivery Level; (4) Practice of Relinquishing Custody to Obtain Services; and, (4) Program and Staff Roles for Families and Youth. The following section summarizes the issues and challenges on these five areas related to family involvement in public sector behavioral health managed care that have been identified through the Health Care Reform Tracking Project (HCRTP).

Following the review of the issues and challenges surrounding family involvement in managed care systems, this paper describes promising approaches and features in these five areas. The final section summarizes the commonalities across these promising approaches and strategies described by key stakeholders. The paper concludes with a list of resource contacts for the promising approaches and a list of national organizations addressing these issues.

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# I. Family Involvement in Managed Care Systems

## Issues and Challenges

System of care values and principles<sup>2</sup> have achieved wide acceptance in the children's mental health arena, but the value of family involvement is not always internalized and operationalized among front line staff or among partner agencies and systems. Respecting families as experts on their children, enlisting them as partners in the care of their children, supporting them in their caregiver role, and involving them as partners in decision making at all levels of the system are goals that have not been fully achieved in managed care systems. Handling resistance to family involvement and encouraging staff and partner agencies to understand and adopt this value requires diligence and determination.

Since its inception, the Tracking Project has studied how managed care systems have involved families in the planning, design, operation and evaluation of service delivery systems. Early findings revealed a mixed picture with respect to the impact of managed care systems on family involvement at both the system level in planning and oversight activities and at the service delivery level in planning and delivering services for their own children. Data from the 1997 Impact Analysis Study and the 1997–98 State Survey indicated that the most common approach was to involve families as members of various state advisory structures to the managed care systems.

In the 1999 Impact Analysis, the Tracking Project intensified its focus on family involvement issues by expanding its team of investigators to include four family consultants active with the national organization, Federation of Families for Children's Mental Health. Each family member had extensive experience at the community level in planning and service delivery for her own child, as well as, involvement at the national and state levels influencing policy related to public service delivery systems. Family consultants participated in each of the site visits conducted and, in addition to contributing to the analysis of findings for the full 1999 Impact Analysis report, prepared a special report "Family Reflections," which documented the perceptions of families on public sector managed care.

## Requirements for Family Involvement

In the participatory culture that systems of care create, requirements for family involvement are essential because children with behavioral health disorders often are involved with multiple systems. Through collaboration with numerous system level planning and oversight activities, family members can influence the cross-system behavioral health service delivery system.

Respondents reported in the 1999 Impact Analyses that only three of the nine managed care systems in the 1999 sample incorporated requirements for family involvement at the system level. This represented an improvement from the 1997 sample in which only one of the 10 states in that sample reported requirements for system level family involvement.

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<sup>2</sup> Stroul, B., & Friedman, R. (1986). *A system of care for children and youth with severe emotional disturbances* (Rev. ed.) Washington, DC: Georgetown University Child Development Center, National Technical Assistance Center for Children's Mental Health.

Overall, stakeholders in both the 1997 and the 1999 samples reported that managed care systems offered few supports to family members to facilitate their involvement in system level planning and oversight activities.

The 2000 and 2003 All State Surveys added items to further investigate family involvement by assessing whether or not managed care systems incorporated a range of strategies for involving families at both the system and service delivery levels.

## Family Involvement Strategies

A range of strategies that potentially could be used to facilitate family involvement within managed care systems at both the system and service delivery levels presented to the respondents were the following:

- Requirements in Request for Proposals (RFPs) and contracts for family involvement at the system level
- Requirements in RFPs, contracts, and service delivery protocols for family involvement in planning and delivering services for their own children
- Focus in service delivery on families in addition to the identified child
- Coverage for and provision of family supports
- Use of family advocates
- Hiring family and/or youth in paid staff roles

As shown below (**Table 2**), more than half of the systems (54%) reportedly incorporate requirements for family involvement at the service delivery level and 41% of systems include requirements for family involvement at the system level. Similar to the 2000 findings, requirements at both levels are far more likely to be found in carve outs. Eighty-six percent of carve outs include requirements for family involvement at the service delivery compared with 13% of the integrated systems, and 67% of the carve outs incorporate family involvement at the system level compared with only 6% of the integrated systems.

	2000 Total	2003			Percent of Change 2000-2003
		Carve Out	Integrated	Total	
Requirements in RFPs and contracts for family involvement at the system level	55%	67%	6%	41%	-14%
Requirements in RFPs, contracts, and service delivery protocols for family involvement in planning and delivering services for their own children	52%	86%	13%	54%	+2%

To compare requirements for family involvement under managed care with previous systems, both the 2000 and 2003 State Surveys explored whether family involvement requirements were stronger, weaker, or unchanged from previous fee-for-service systems. In 2003, slightly less than two-thirds (63%) of the systems reported that family involvement requirements are stronger under managed care, a 13% decrease from 2000. Again, a substantially higher proportion of the carve outs (86%) reportedly have stronger family involvement requirements in comparison with pre-managed care than do integrated systems (29%) (**Table 3**).

	2000 Total	2003			Percent of Change 2000-2003
		Carve Out	Integrated	Total	
Family involvement requirements are stronger in the managed care system	76%	86%	29%	63%	-13%
Family involvement requirements are weaker in the managed care system	6%	0%	0%	0%	-6%
No change	18%	14%	71%	37%	19%

Despite stronger family involvement requirements under managed care in most systems, stakeholders interviewed for both impact analyses identified discrepancies between managed care policy requirements for family involvement and what actually is taking place. In addition, the perceptions of stakeholders interviewed were that the language of family involvement might be in contracts, RFPs and service delivery protocols, but very few states monitor the managed care system or earmark funds for family organizations focused on children and youth with behavioral health disorders to monitor implementation.

## **Family Involvement at the System Management Level**

For families of children with serious behavioral health disorders, the need to be recognized as partners in the planning, development and oversight of services at the system management level is a pressing one. Nationally, the federal government has encouraged attention to the importance of partnering with families in the design and implementation of behavioral health delivery systems. This emphasis was most recently incorporated in the report of the President's New Freedom Commission on Mental Health. Additionally, there is recognition that because children with behavioral health disorders often are involved in multiple systems, a cross-agency perspective is critical to the design and operation of managed care systems.

Since its inception, the Tracking Project has been looking at the issue of key stakeholder involvement in planning, developing, and refining managed care systems. Key stakeholders as defined by the Tracking Project include: families, providers, and the major state child-serving systems, including children's mental health, substance abuse, child welfare, juvenile justice, and education systems. From 1995–2000, the Tracking Project found a gradual trend toward increased stakeholder involvement, although, even with this trend, most key stakeholders lacked significant involvement.

As **Table 4** shows, between 2000 and 2003, all stakeholder groups reportedly lost ground in terms of significant involvement in managed care systems. Families reportedly had significant involvement in only about one-third of managed care systems, a decline of 13% since 2000. Carve outs are especially more active in involving families, with half reportedly involving families significantly compared to only 8% of integrated systems. However, most integrated systems and half of the carve outs do not involve families in significant ways in managed care systems, in spite of increased national attention to the importance of the family involvement. State education staff consistently has been the stakeholder least likely to be involved. Given that schools are a major provider and referral source for mental health services for children, both through regular and special education, their lack of involvement in children’s behavioral health managed care is disturbing. In spite of increased enrollment of the juvenile justice population in managed care systems, state juvenile justice staff reportedly were significantly involved in only 29 of the managed care systems. Families interviewed talked about...

**“ ...the need to have policies in support of children with behavioral health disorders so kids are treated and not punished for their mental illness.”**

(Families Interviewed)

State substance abuse staff had significant involvement reportedly at 33% of the managed care systems, a 2% decrease from the 2000 State Survey.

	1997-98 Total	2000 Total	2003									Percent of Change	
			Carve Out			Integrated			Total			1997/98-2003	2000-2003
	Significant Involvement	Significant Involvement	Not Involved	Some Involvement	Significant Involvement	Not Involved	Some Involvement	Significant Involvement	Not Involved	Some Involvement	Significant Involvement	Significant Involvement	Significant Involvement
Families	38%	48%	0%	50%	50%	25%	67%	8%	9%	56%	35%	-3%	-13%
State child mental health staff	54%	74%	0%	23%	77%	15%	46%	39%	6%	31%	63%	9%	-11%
State substance abuse staff	23%	35%	14%	48%	38%	17%	58%	25%	15%	52%	33%	10%	-2%
State juvenile justice staff	21%	23%	0%	59%	41%	46%	46%	8%	17%	54%	29%	8%	6%
State child welfare staff	37%	46%	14%	59%	27%	58%	34%	8%	29%	50%	21%	-16%	-25%
State education staff	21%	19%	36%	50%	14%	58%	25%	17%	44%	41%	15%	-6%	-4%
Providers	Not Asked	60%	5%	14%	81%	21%	65%	14%	11%	33%	56%	NA	-4%
NA=Not Applicable													

## **Family Information, Education and Training**

With all of the families interviewed for the Impact Analyses, the lack of information and education about managed care systems and how managed care systems operate was an enormous issue. Representatives from a family organization related that...

**“...because they were not at the right table when decisions were made about behavioral health managed care design options, they could not influence the state’s decision to create two managed care systems — one an acute care model, not using the system of care approach, and the other a flexible, individualized wraparound model-both of which serve children with serious disorders.”**(Representative from Family Organization)

Others interviewed talked about being active in state funded parent support groups, and, enrolled in a managed care systems and not having had opportunities presented to them to learn about managed care systems and how they operate.

The 2003 State Survey found that 61% of the managed care systems reportedly provided education and training to families about the goals and operation of the managed care systems, representing a 14% decrease from the 2000 State Survey. Findings from the Tracking Project suggest that, without consistent, ongoing information and education efforts in states, families will not be involved as full participants in all aspects of the planning, delivery and evaluation of managed behavioral health care services and supports for children and youth.

### **Funding a Family Organization for Managed Care System Roles**

The growth and development of family support and family-run organizations has been a major factor in the expansion of family involvement in planning and decision making at all levels of the system. As shown below, about half of all systems reportedly fund a family organization for various managed care roles, a finding that is consistent with previous survey results. As was true in previous survey findings, funding a family organization is much more likely in carve outs (71%) than in integrated systems (19%) (**Table 5**).

	1997-98 Total	2000 Total	2003			Percent of Change 1997/98- 2003	Percent of Change 2000-2003
			Carve Out	Integrated	Total		
Family organization is funded to play role in managed care system	45%	47%	71%	19%	49%	4%	+2%
Family organization is not funded to play role in managed care system	55%	53%	29%	81%	51%	-4%	-2%

Stakeholders in both impact analyses noted that funding a family organization to play various roles in the managed care system could be an effective vehicle for enhancing family involvement at all levels. Once a family-run organization becomes known to

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managed care organizations and service providers, family organization staff reported to the Tracking Project that often the organizations receive multiple invitations to join various state level advisory groups, to help develop assessment and clinical protocols, to recruit and train family members to be employed in various managed care system roles, etc. For example, in one state, the Tracking Project learned that the managed care organization allocated funds to a family-run organization for the purpose of developing family support services. In this state, families receiving services stated that when they need transportation to and from their provider, they would call the family organization, request transportation to attend treatment meetings and be driven by staff to and from their appointments. Added family support services were child-care at no cost to the families and a chance to talk with parents having experience raising a child with serious mental health challenges.

In 2003, survey respondents were asked to describe the various roles that family organizations carry out in managed care systems. The roles specified by states for family organizations to fulfill are diverse, including providing information and referral services to other families (4 states), identifying family members to participate on policy and workgroups (6 states), advocating with parents for mental health services for their children (6 states), providing education for families on the managed care system, and conducting family surveys and interviews.

## Family Involvement at the Service Delivery Level

### *Family Involvement in Planning Services*

Individualized services are dependent on family involvement during all phases of service delivery, including participating on the service planning/treatment team, identifying what services and supports are needed, and monitoring and evaluating the progress. A principle of systems of care is that children and parents are included in every phase of individualized services, and they are always listened to and treated with respect by professionals.

Results of both impact analyses indicated that many managed care systems included requirements for family involvement at the service delivery level, requiring at a minimum that families be involved in treatment planning for their own children. It is important to note, however, that stakeholders interviewed for the impact analyses emphasized that, even where such requirements were in place, implementation was spotty and varied from provider to provider. For example, a representative from a statewide family organization explained it this way:

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**“ When you ask families, ‘were you involved in the development of your child’s plan?’ they respond with, ‘they asked me to sign it.’ When you ask further, ‘were you involved in its development, and were you assigned equal decision making power regarding the services and supports your family needed?’ they responded, NO!”** (MCO Administrator)

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Exploration of this issue across all states revealed that in 2000 and 2003, 54% of managed care systems reportedly have requirements in service delivery protocols for family involvement in service planning for their own children.

**Extent of Family Focus of Services**

Historically, mental health systems have been guided by the “medical model”, with the focus of services and supports on the “identified child”. In the early managed care systems studied, the Tracking Project found this to be true and that family needs typically were neither considered nor addressed. Additionally, respondents felt that for some MCOs, “family focused” was translated as the need for family therapy, rather than broader consideration of families’ strengths and needs, and the community culture in which children and families live.

Survey findings in 2000 and 2003 revealed a significantly different picture. As in 2000, nearly two-thirds (65%) reportedly include a focus on families in service delivery. Family focus is found more frequently in carve outs than in integrated systems; 76% of the carve outs compared with half of the integrated systems reportedly focus on families, in addition to focusing on the identified child. Regarding coverage for and provision of family supports, about half of the managed care systems (49%) in 2003 reported that family support services are covered in the benefit package, with carve outs (67%) more likely than systems with integrated designs (25%) (Table 6).

<b>Table 6</b>					
<b>Percent of Managed Care Systems Focus in Service Delivery on Families in Addition to the Identified Child</b>					
	2000 Total	2003			Percent of Change 2000–2003
		Carve Out	Integrated	Total	
Focus in service delivery on families in addition to the identified child	64%	76%	50%	65%	+1%
Coverage for and provision of family supports	58%	67%	25%	49%	-9%

Recent surveys also investigated whether managed care systems pay for services to family members if only the child is covered. As shown below, about half of the systems in both 2000 and 2003 pay for services to family members when only the child is covered (49% in 2003). Again, carve outs are more likely to pay for services to a family member when only the child is covered (Table 7).

<b>Table 7</b>					
<b>Percent of Managed Care Systems that Pay for Services to Family Members if Only the Child is Covered</b>					
	2000 Total	2003			Percent of Change 2000–2003
		Carve Out	Integrated	Total	
Managed care system pays for services to family member	51%	55%	40%	49%	-2%
Managed care system does not pay for services to family members	49%	45%	60%	51%	+2%

## Practice of Relinquishing Custody to Obtain Services

The impact analyses furnished somewhat conflicting results with respect to the impact of managed care reforms on the practice of families relinquishing custody in order to obtain needed, but expensive treatment. Some stakeholders reported that managed care had increased the need for families to relinquish custody; others interviewed noted that this practice was a pre-existing problem that had not been exacerbated by the introduction of managed care.

In order to clarify this issue, the 2000 and 2003 State Surveys were used to investigate this issue across all states, exploring whether managed care has improved, worsened, or had no effect on the pre-existing practice of parents relinquishing custody in order to access behavioral health services. Consistent with the 2000 findings, in over 80% of managed care systems (equally for carve outs and integrated systems) the introduction of managed care reportedly has had no impact on the practice of relinquishing custody to obtain needed but expensive services (**Table 8**).

	2000 Total	2003			Percent of Change 2000–2003
		Carve Out	Integrated	Total	
Practice of relinquishing custody is worse under managed care	4%	0%	6%	3%	-1%
Practice of relinquishing custody has improved under managed care	13%	19%	13%	16%	3%
No effect, or NA—Families do not relinquish custody to child welfare to access behavioral health services	83%	81%	81%	81%	-2%

## Program and Staff Roles for Families and Youth

Some of the states studied by the Tracking Project incorporate different approaches for the use of paid family partners within managed care systems. In one type of approach, family partners are employed by family-run organizations under contract to the state; in another approach, the state, county, or MCO directly hires a paid parent partner.

In those states that do utilize paid family partners, site visit team members asked about the possibility of conflict of interest. For example, can it be considered family involvement if family members are employed and supervised by a government agency? Is a family member co-opted or inhibited if he/she is paid and works as a family advocate in a state/county agency? Does she become a “system person?” Whose interests do family advocates then represent? Can family members only be “real” advocates if they are paid by and work for a family-run organization?

The consensus among the families interviewed was that both approaches provide different learnings, benefits, and challenges, and both provide links to resources and tools that are essential in developing an effective service delivery system. For example, the “outside advocate” employed by the family-run organization can be a player in the community’s child advocacy networks and can develop relationships to assist in children’s mental health issues at

the state and legislative levels. These “outside” advocates also can: support and train other family members at the local level to effectively participate in policy activities; provide reality-based, culturally relevant information to the state family-run organization; and, generate awareness and support for the needs of children and adolescents with serious behavioral health disorders and their families.

**“Never assume that you know how the family feels about the system — employ them inside and outside the system.”** (MCO Administrator)

An “inside” advocate employed by the MCO, the county, or the state can work with individual families whose children are receiving services and work from the inside out in collaboration with “outside” advocates in defining policy issues. In addition, parent advocates who are staff may be able to participate more readily in the MCO, state/county agency’s decision making processes as a member of task forces, committees, and in staff meetings, bringing the parent perspective. In summary, by hiring a parent advocate with experience raising a child with a behavioral health disorder, both approaches can help to reduce caregiver stress by offering support (“I’ve walked in your shoes”), to provide access to information, to how things work politically and systemically, and to educate families about managed care systems and how managed care systems work.

The 2000 and 2003 State Surveys examined the use of family advocates and the inclusion of other paid program and staff roles for family members or youth in managed care systems. As shown below, in 2003 less than half (43%) of the systems report the use of family advocates and an even smaller proportion (38%) hire family members and/or youth in paid staff roles. Both practices are far more likely to occur in carve outs (71% for family advocates, 62% for paid staff roles) than in systems with integrated designs (6% for both practices) (**Table 9**).

	2000 Total	2003			Percent of Change 2000-2003
		Carve Out	Integrated	Total	
Use of family advocates	48%	71%	6%	43%	-5%
Hiring family and/or youth in paid staff roles	27%	62%	6%	38%	+11%

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## II. Description of Promising Approaches

### Family Involvement in Managed Care Systems

As noted, promising approaches for family involvement in the context of managed care systems were identified through the Tracking Project's state surveys and impact analyses. Descriptive information on these promising features were obtained through three methods: (1) site visits to Massachusetts and Delaware County, Pennsylvania involving extensive interviews with key stakeholders, (2) telephone interviews with representatives of New Jersey's Partnership for Children Initiative, and (3) review of documents on all of the identified approaches. For each site, essential background is presented and specific strategies for involving families at all levels in planning, implementation and refining managed care systems, along with a more in-depth description of how the approach actually works.

#### • Massachusetts Behavioral Health Partnership

##### Background

The Massachusetts statewide behavioral health carve out was implemented in 1992. Operating with an 1115 Waiver, the Waiver permits the state Medicaid agency to contract with a managed care organization for mental health and substance abuse services. After many years of Medicaid managed care in Massachusetts, an important threshold has been reached in substantive family involvement in the state's managed care system. This is due to the work of the Family Advisory Council operating under a for profit behavioral health organization — the **Massachusetts Behavioral Health Partnership (MBHP)**.

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**“ MBHP established the Family Advisory Council to help give the managed care administration direction and vision.”** (MBHP administrator)

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The Family Advisory Council has mixed representation, which includes family members of adults and children as well as representatives of state mental health, mental retardation, child welfare and juvenile justice agencies. This has allowed for greater focus on family issues.

The **Department of Mental Health (DMH)** remains the state authority for mental health services with oversight responsibility but the operational responsibility is with the State Medicaid Agency. DMH is organized into six geographic areas, each of which is managed by an Area Director. Each Area is divided into Local Service Sites. Each Site provides case management and oversees an integrated system of state and vendor operated adult and child/adolescent mental health services. Most planning, budget development, program monitoring, contracting, quality improvement and citizen monitoring emanate from Site and Area offices. DMH, parents, service providers and other stakeholders crafted the following principles, which are included in all DMH child and adolescent contracts, including managed care contracts. One of the standard questions in proposal evaluation tools ask reviewers to rate the degree to which the submitted proposal conforms to these principles:

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## DMH Family Collaboration Principles

1. Parents/guardians should be viewed as the partners of professionals in the treatment of children with mental health problems.
2. Parents/guardians have the day-to-day responsibility for child-rearing and are major support for their children throughout their lives, and thus have the need for and the right to full information about their children's problems, and the range of available interventions and supports.
3. Parents/guardians and professionals bring different perspective to bear on issues, and each benefits from understanding the other's perspectives. Policies, services and supports need to be designed and evaluated with significant input from parents/guardians as well as from professionals.
4. Parents/guardians have valuable information to share with each other, and can also be sources of emotional support to each other.
5. Parents/guardians have the right and responsibility to advocate at the local, state, and national levels to secure services beneficial for children with mental health needs.

## State Level Family Organization

### *Preparing and Supporting Families for System Level Involvement*

The national momentum and leadership that system of care activities created in the early 80's spearheaded policy development in Massachusetts in the area of families as allies at the policy table. In 1989, the Department of Mental Health (DMH), the state mental health authority, funded a staff position for the **Parent Professional Advocacy League (PAL)**. The services for which DMH contracted with PAL were: (1) ensuring that the perspectives of parents are heard as they relate to policy and program issues affecting children's mental health, and, (2) promoting family collaboration in mental health practice through professional development activities." For two years, PAL's parent leader traveled the state, meeting with professionals in children's mental health and talking about the need to establish a supportive, family-centered system of care and providing family members of children with serious behavioral health disorders with mutual support and resources related to their children's conditions and information about DMH's commitment to family voices being part of policy and program decisions.

In 1992, DMH used federal block grant funds to expand family voice across the state. Parent coordinator positions were established in two of the six DMH Areas, and later expanded to all of the DMH Areas. One of the early steps taken by DMH to prepare and support families for system level involvement in planning and policymaking was resource allocation to the parent coordinators for travel to national conferences to learn what other states were doing in the development of family organizations, in the development and implementation of family support programs and in helping to shape behavioral health systems. During the following year, a total of ten family support groups were established throughout the state. A variety of training sessions were held for the parent coordinators to expand their skills and to support their work.

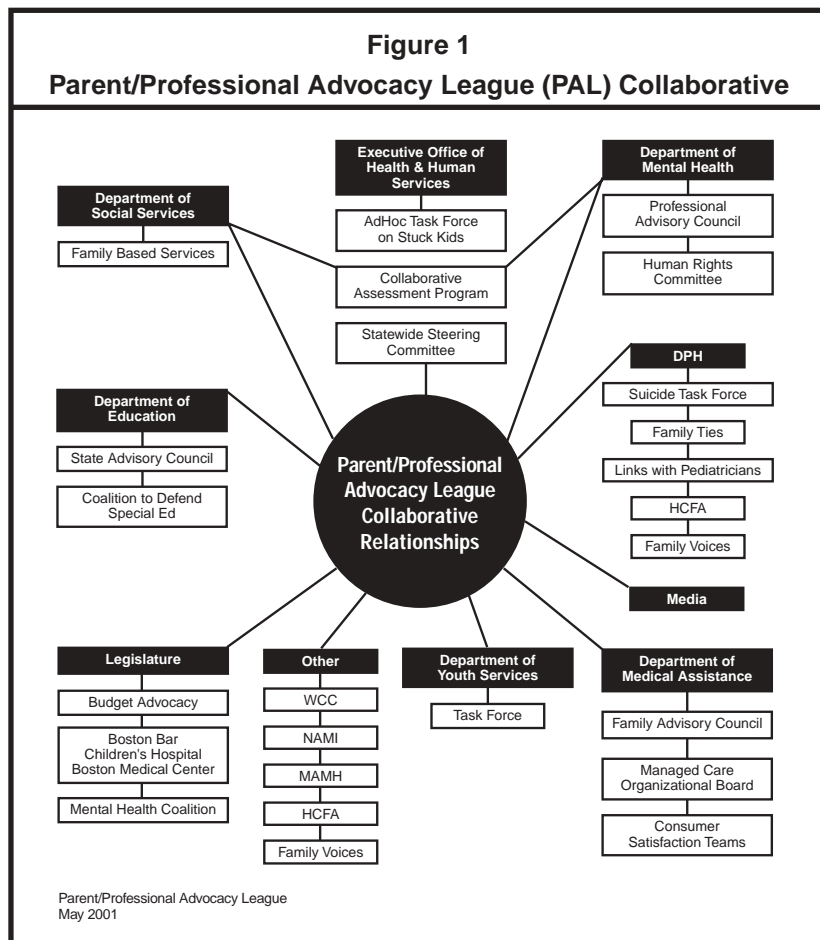
About the same time that parent coordinators were hired in the six sites, the Commissioner of DMH instructed that a DMH Core Curriculum be drawn up, and, that within a three-to five year period, every DMH state and provider employee be instructed in the components of this curriculum. A Department of Mental Health Task Force Committee was set up to develop the curriculum and the Executive Director of PAL was named as co-chair of the Committee.

Since many agencies were involved in varied training activities, a statewide needs assessment was conducted to determine which components of the Core Curriculum needed more immediate attention. Seven areas were identified as needing more precise clinical practice guidelines: the role of the consumer, the role of the family, dual diagnosis (mentally ill/chemically addicted), alternatives to restraint and seclusion, psychosocial rehabilitation, multicultural issues, and gerontology.

In 1997, the DMH Core Curriculum *Promoting Family Collaboration in the Child/Adolescent Mental Health Service System* was published. DMH asked each DMH state and provider agency to incorporate these guidelines into practice so that each DMH family could receive a reasonable and consistent standard of care in any community across Massachusetts.

PAL exists within and reflects the matrix management design of the state (Figure 1). There are seven different non-profit organizations holding parent coordinator contracts throughout the state.

While the statewide office of PAL has no direct authority over or supervisory relationships with the parent coordinators, written into the parent coordinators' contracts are the following requirements: (1) parent coordinators will communicate on a regular basis with PAL on the issues of concern to parents in the community; (2) parent coordinators will serve as a conduit through which PAL can distribute information; and (3) parent coordinators will notify PAL of public policy concerns needing citizen action.



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## ***Involving Families in Managed Care Systems***

In the early stages when state officials were developing their outline of how managed care would operate in Massachusetts, DMH created seats at the Medicaid table for PAL and the parent coordinators. As members of coalitions, networks, policy boards and planning committees in each of their areas, family members brought this broad range of experiences and expertise to the discussions of managed care systems. Their involvement led to increased understanding of and responsiveness to family issues and concerns. The Family Advisory Council has closely monitored quality of care efforts of Medicaid's statewide mental health/substance abuse managed care organization — MBHP. Through the committee's performance review activities, MBHP has been put on notice about requiring and carefully monitoring services that respond to the needs and concerns of families. PAL also played a modest part in the development of the structure and terms of the Medicaid/MBHP relationship, including its performance incentives and penalties.

In the initial planning of the managed care system with Medicaid, PAL and other stakeholders did not have the background knowledge of the system players and did a great deal of listening. However, it was reportedly a useful learning experience, and when the new contract season rolled around, family members had become experienced in mental health systems issues and design, and had made themselves part of a wide variety of advocacy efforts in legislative, legal and policy areas in partnership with other families, consumers, trade and professional groups in both mental health and health care reform.

For PAL and other family members on the Family Advisory Council developing an effective committee process has resulted in good working levels of information sharing, dialogue and substantive MBHP response to committee issues. The presence and influence of state agency committee members was key to breaking through this impasse.

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**“ This was a great process. As enlightened as I thought my thinking process was, it has changed light years. A year and a half ago, family and consumer issues — really — weren't even on my screen. Now I have internalized the perspective, what do families think? Now I am not going to move forward on a lot of things without checking with families first. I have a new healthy respect for families' experience. I make sure now that PAL is on the same professional level as sister agencies. I now consult and discuss with PAL as I do with them.”** (State Medicaid Official)

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## **Program and Staff Roles for Families**

A major focus of family members who are employed in the system is to develop culturally competent, team-centered systems of care. Although each local family network has a set of objectives based on their community's culture, one goal they share is listening to families and bringing their issues to PAL. One major concern many families report is fragmentation of service delivery. There are multiple state agencies that are in one way or another responsible for the delivery of services to children with emotional, behavioral or mental health needs. There is no single agency responsible for the delivery of behavioral health services for children and adolescents. The intricacies of the Massachusetts behavioral health system requires families to be involved with and knowledgeable about

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DMH, Department of Education, Department of Youth Services, Department of Social Services and the Division of Medical Assistance (Medicaid) policies. PAL, through its parent coordinator networks, strives to bridge the gaps between the different systems.

Massachusetts took advantage of a strong parent network in the Southeast part of the state to launch a pilot Collaborative Assessment Program (CAP). CAP is targeted to youngsters with serious emotional disorders who are on the brink of out-of-home placement but fall outside the purview of either the child welfare or mental health agencies. A jointly funded assessment and crisis stabilization service has the authority, post assessment, to assign the child and family to a specific state agency. Family input during the planning of CAP strongly recommended the inclusion of a parent position on the CAP team. As a result, when DMH, Department of Social Services and DMA (Medicaid) expanded CAP statewide, this program incorporated parents as family partners from the first day of assessment. Family partners are linked with incoming families to offer support and guidance, which can be maintained long after the assessment ends. Parents, along with DMH and DSS, participated in the hiring of the CAP project director.

The **Department of Youth Services (DYS)**, the Massachusetts juvenile justice agency, is planning to offer parent support activities to parents of youngsters in DYS custody who have mental health problems. PAL has been the motivational organizing entity and continuing advocate for expanding the role of parents employed in other child-serving agencies.

A new and promising direction for interagency focus is in the development of outcomes for children who receive services from multiple systems. DMH has convened a process with DSS, Medicaid, Massachusetts Behavioral Health Partnership (the Medicaid managed care entity), provider groups and trade associations, and families to decide on a standardized tool that will be used by all public purchasers. Family members will assume a leadership role in crafting family relevant outcomes.

## **Involving Families on Advisory and Monitoring Structures**

Within the DMH system, parents are represented on advisory boards internal and external to the Department. They are involved in assessments of the existing systems of care, and in the reconfiguration of the service array and development of new program designs. PAL helps to organize focus groups and other activities to learn the opinions of families and youth for the purpose of giving feedback to MBHP. In addition, parents are represented on all proposal review committees related to children's mental health services procurement.

PAL and Massachusetts state agencies partner with MBHP to share data, generate reports, analyze findings, and make recommendations at the monthly meetings of the Family Advisory Council. Topics such as the needs of Massachusetts's youth and policies and programs on mental health and substance abuse are addressed. PAL helps set the agenda each month, and the Director of PAL serves as co-chair. MBHP provides stipends to parents and offers trainings free of charge. MBHP routinely has PAL members review drafts of printed materials for the MCO.



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## Involving Families in Accountability

One of the many effective ways for family advocates to influence the quality and delivery of managed mental health services is to play a role in developing performance standards. MBHP invited hospital providers, auxiliary providers, consumers and family members to the table to hammer out performance standards for hospital, crisis and diversionary care.

Stakeholders, including family members, reviewed existing requirements, and, with some exceptions, agreed upon standards covering everything from components of care, aftercare planning, family involvement, continuing care, care level definitions and requirements, service linkage, staffing, assessments, treatment protocols, quality improvement, disposition planning, and performance and outcome measures.

Some specific children's hospital standards included: the availability of at least two-times-a-week inpatient family sessions; broad parental access to inpatient units; clarification of telephone access by youth; family signoff on treatment plans; staff training in family issues; closer linkages with aftercare; immediate discharge information available to families for schools and other community resources; discrete emergency protocols for children; 24-hour child psychiatrist phone availability for emergency consultation; and follow-up contacts with children and families not accepted for inpatient care.

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**“ If I sat in my office until late at night, I wouldn't have been able to come up with the range and depth of these standards. They are definitely coming from the family and consumer perspective more than other performance standards I have seen. It's not a 100 percent consumer/advocate document, and some of the outcome measures are soft background music, but enough of them are 'you must change this by this date.'”** (MBHP's Director of Network Management)

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This participatory approach to standard development demonstrates how a managed care organization can use advocates to find out how the service system is working and improve its performance, with advocates monitoring that performance. MCO staffers can also use advocates' demands internally to make change from the ground level up. Providers can turn to the demands for quality services by advocates when negotiating budgets for their services. In understanding and sparking these dynamics, PAL and its network of advocates influenced quality of care and gained a greater sense of their own effectiveness.

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## • Pennsylvania — HealthChoices Behavioral Health Services

### Background

Pennsylvania's managed care system, **HealthChoices**, was implemented in 1997 to provide managed medical, psychiatric, and substance abuse services to Medicaid recipients in a five-county area. Expanding to ten counties in 1999 and phasing in an additional ten counties in 2000, the goal of the managed care system is to “improve the accessibility, continuity, and quality of services” for the state's Medicaid population, while controlling costs. HealthChoices designed behavioral health services as a carve out.

By the time that managed care was implemented, Pennsylvania had a long history and substantial base of accomplishments in building parent/professional partnerships and community-based systems of care for children with serious behavioral health disorders and their families. The relationship between families raising children with mental health needs, **Parents Involved Network (PIN)** and **Pennsylvania's Child and Adolescent Service System Program (CASSP)** expanded when the state received a federal CASSP grant. PIN operates a statewide support, advocacy, technical assistance and information and referral resource center for families of children with emotional or behavior disorders. PIN is the Pennsylvania State Organization for the Federation of Families for Children's Mental Health. PIN's main office is in Philadelphia, and has offices in five other counties, including Delaware County.

In 1985 when the state began to implement the (CASSP) grant, it placed a CASSP coordinator in each of its counties to:

- hire child mental health specialists in its regional offices
- expand the children's mental health focus at the state level
- provide significant levels of training and technical assistance to agencies and providers on the system of care philosophy and approach, as well as on clinical best practices for children and adolescents

The introduction of managed care was seen as a strategic opportunity to strengthen the state's commitment to systems of care by incorporating the CASSP values, principles, and approaches into managed care system policy.

<b>Table 10</b> <b>CASSP Principles</b>	
<b>Child-Centered</b>	Services are planned to meet the individual needs of the child, rather than fit the child into an existing services. Services consider the child's family and community contexts, are developmentally appropriate and child-specific, and also build on the strengths of the child and family to meet the mental health, social and physical needs of the child.
<b>Family-Focused</b>	Services recognize that the family is the primary support system for the child. The family participates as a full partner in all stages of the decision making and treatment planning process, including implementation, monitoring, and evaluation. A family may include biological, adoptive, and foster parents, siblings, grandparents and other relatives, and other adults who are committed to the child. The development of mental health policy at state and local levels includes family representation.
<b>Community-Based</b>	Whenever possible, services are delivered in the child's home community, drawing on formal and informal resources to promote the child's successful participation in the community. Community resources include not only mental health professionals and provider agencies, but also social, religious, and cultural organizations and other natural community support networks.
<b>Multi-System</b>	Services are planned in collaboration with all the child-serving systems involved in the child's life. Representatives from all these systems and the family collaborate to define the goals for the child, develop a service plan, develop the necessary resources to implement the plan, provide appropriate support to the child and family, and evaluate progress.
<b>Culturally Competent</b>	Culture determines our world view and provides a general design for living and patterns for interpreting reality that are reflected in our behavior. Therefore, services that are culturally competent are provided by individuals who have the skills to recognize and respect the behavior, ideas, attitudes, values, beliefs, customs, language, rituals, ceremonies, and practices characteristic of a particular group of people.
<b>Least Restrictive/Least Intrusive</b>	Services take place in settings that are the most appropriate and natural for the child and family and are the least restrictive and intrusive available to meet the needs of the child and family.

The application of these principles was expected at all levels of an organization serving children with mental health needs and within all children's mental health functions at the state and local levels, including the behavioral health managed care carve out. The state developed a **Readiness Assessment Instrument (RAI)**, which gauged the readiness of counties for managed care and family involvement. Standards related to family involvement covered a wide array of systems-level activities, including: grievance and appeals process; quality assurance; program oversight; development of member handbooks; development of satisfaction surveys and participation on consumer satisfaction teams.

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The state held managed care-related and CASSP-related training of providers and other stakeholders at the CASSP Training Institute located at Penn State University. Trainings included CASSP values and principles; families as partners; clinical documentation; wraparound process; attention deficit disorders; treatment planning and goal setting; discharge planning; writing skills for managed care; therapeutic staff support in the schools; strengths-based assessments; use of natural supports in a managed care environment; use of outcome measures; working with youth with mental retardation; and, clinical supervision and mobile therapies. Through a partnership with the state's Medicaid agency, the Bureau of Children's Services (the agency within the Department of Public Welfare responsible for children's mental health) worked to infuse the system of care philosophy in the HealthChoices behavioral health carve out through its **Request for Proposals (RFPs)**, contracts, readiness reviews, and performance and compliance monitoring processes.

PIN organized parents across the state to ensure distinct children's services were in the RFP development. PIN family members reviewed the RFP, gave public testimony, and as a result much of PIN's comments were reflected in the final RFP document.

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## • Delaware County PA DelCare Program — Local Approach

### Involving Families in Managed Care

In Pennsylvania, each county is responsible for **HealthChoices Behavioral Health Services** and can either be the managed care entity or subcontract to a for profit or non-profit entity. In Delaware County, the Department of Human Services (Medicaid) subcontracts with Magellan Behavioral Health to perform the managed care functions. The county Office of Behavioral Health subcontracts with the **Parents Involved Network of Pennsylvania (PIN)** of the Mental Health Association of Southeastern Pennsylvania to help families educate one another (peer-to-peer training) about managed care and to ensure that families share decision-making power and responsibility in the managed care system. Additionally, funds are used for a three-day training for the BH-MCO (Magellan) and repeated annually for new staff. Other trainings include line level staff across all children's systems. Magellan also provides funding to PIN for help with transportation and child-care to facilitate family involvement at meetings and to pay family members to be involved on committees.

Delaware County was the first county to implement HealthChoices. It had a substantial base of accomplishments in building a community-based system of care for children with serious behavioral health disorders and their families. One outstanding accomplishment was the partnership developed with the Delaware County PIN organization and its members.

Before the advent of managed care in Delaware County, Delaware PIN family members learned all that they could by attending state level activities focused on managed care. The state office of PIN held extensive trainings on managed care for families across the state. In a general session at a PIN Advocacy Conference, a lawyer from the Pennsylvania Health Law Project led a discussion about family involvement in managed care. He cited where family involvement is legally mandated and provided the specific language used in the state's **Request for Proposals (RFPs)**. Following the presentation, participants developed a list of strategies and approaches for families to try in their counties. Other informational resources were: member handbooks which explained how each of the managed care programs would work in each county with telephone numbers to call for information about each county's managed care program; newsletters focused on managed care with articles on:

- What is Managed Care?
- How Does Managed Care Operate?
- What Does the Term Utilization Mean?
- What Parents Can Do to Impact the Managed Care System?

To maximize family members participation and influence in the managed care initial planning meetings, PIN leaders attended national conferences and in-state workshops, formed coalitions with other stakeholders to build capacity for children's issues, and gathered information to develop informational packets for peer-to-peer training. The variety of resources PIN offers on managed care are:

- Principles for Family Involvement in Managed Care
- Fact sheets on managed care

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- Guidelines for Family Involvement in Managed Care
  - Glossary of terms used in managed care
  - A Guide to Interagency Service Planning Team Meetings (also referred to as CASSP Team Meetings)

### ***Involving Families on Advisory Structures***

HealthChoices' performance monitoring system has indicators tied to family involvement in system planning, oversight and refinement. RFPs and contracts require that for children with serious disorders who are involved in multiple systems, BH-MCO's are required to have letters of agreement in place with county child welfare, juvenile probation and substance abuse agencies and with local school districts that address coordination of service planning and delivery. As mentioned earlier, Magellan provides funding to ensure families serve on the advisory structures.

Family members in Delaware County participate on the following committees:

- CASSP Advisory Committee
- Provider Advisory Boards
- Reinvestment planning
- Consumer and Family Advisory Group
- Mental Health/Mental Retardation Advisory Boards
- Children's Cabinet
- Children's Coalition
- Quality Assurance Committee

PIN staff routinely are included as members of program review teams that visit and evaluate all child-serving programs including visits to family-based mental health programs and residential treatment facilities. This means they look at both structures and practices at all levels to see if they are consistent with and promote the six CASSP principles.

## **Requirements for Family Involvement at the System Level**

### ***Readiness Assessment Instrument (RAI)***

When the state examined Delaware County's readiness to implement managed care, PIN family members were part of the readiness review team that examined Delaware County. The RAI addresses readiness with respect to the following areas:

- In-plan services and provider network
- Service access
- Care management and utilization management
- Coordination of care/interagency letters of agreement
- Member services
- Member complaint
- Grievance and appeal system
- Executive management
- Quality assurance
- Consumer and family satisfaction

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- MIS
  - Provider claims processing
  - Encounter data
  - Performance outcomes
  - County financial requirements
  - County solvency requirements
  - BH-MCO subcontractor financial and solvency requirements

### ***Family Involvement in Monitoring Activities***

The state Office of Mental Health and Substance Abuse Services has created a performance monitoring system, tied to a **Continuous Quality Improvement (CQI)** process. The county/BH-MCOs must submit for approval their quality management plans and their QI structure, including plans for including consumers/families in the QI process.

Delaware County's Office of Behavioral Health and Magellan developed a DelCare Quality Improvement Plan for HealthChoice. Evaluation of consumer and family perceptions and experience is a critical component of this quality improvement process.

Delaware County PIN developed the first **Family Satisfaction Team (FST)** in Pennsylvania to specifically focus on families whose children have emotional, behavioral and substance abuse issues. The Family Satisfaction Team is composed of a team leader and three team members composed of parents whose children have emotional disorders and a young adult who has received services through the children's behavioral healthcare system. The team assesses family satisfaction with service delivery and the process. The team's motto is: "Evaluating Satisfaction Through Family Interaction", and interaction is the key word, as the feedback from families is the impetus to strengthen and improve the quality of services provided to them.

The process developed by the team focuses first on surveying parents who have recently participated in interagency service planning team meetings. The domains covered by the survey include: (1) a cover letter of introduction to PIN/FST; (2) a choice survey asking families how they would like to be interviewed (phone, focus group, one on one); (3) a permission form to interview their child or adolescent; and (4) a return address stamped envelope to be sent back to PIN. Upon receipt of the survey, PIN conducts focus groups, meets one on one, or speaks over the telephone and gathers families' input on how they feel about specific services. Findings from the survey are compiled and reported on a regular basis to Magellan, the County, and providers. PIN guarantees that families' responses and comments will be treated confidentially. This type of feedback gathering has been extremely validating to families and PIN reports that the process itself leads to "satisfaction".

Another part of the FST is to determine family satisfaction with access to services. Whenever wraparound behavioral health services for children are considered under EPSDT (Early Periodic Screening, Diagnosis and Treatment) a meeting is required to access services. The interagency team participants consist of all agencies, systems, and community supports involved in the child's life. At the conclusion of the meeting, families are given a written survey asking their opinion on the interagency team meeting process by the managed care company. The surveys are returned to PIN FST, and the results are compiled into a report. The results are shared with Magellan and the County Office of Behavioral Health. Once a month, a meeting is held with Magellan, the County and the

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providers who provide wraparound services through EPSDT. The information is also reported to the Consumer and Family Advisory Committee and Quality Assurance Committee, which monitor the **DelCare Program**. As a result of this process, the following actions have taken place:

- Providers have developed methods to ensure that families can bring an advocate and/or support person to team meetings.
- Meetings are scheduled at times convenient for the family.
- Magellan has taken steps to ensure that the same care manager follows an assigned child throughout treatment.

Although many of the surveys returned to PIN FST are anonymous, families are informed of the feedback results through bi-monthly mailings to the Delaware County PIN membership.

In conclusion, the FST and the process that has been created for families in Delaware County whose children have behavioral health concerns offer not only a voice, but also protocols for solutions.



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## • **New Jersey Partnership for Children — Statewide Approach**

### **Background**

The New Jersey **Partnership for Children**, through the Department of Human Services, was implemented in January 2001. It is a behavioral health carve out, serving a statewide, total population of children and adolescents with emotional and behavioral disorders who depend on public systems of care, and their families. The population includes both Medicaid and non Medicaid-eligible children and includes children with both acute and extended service needs. The State describes the Partnership for Children initiative as: “not a child welfare, mental health, Medicaid or juvenile justice initiative, but one that crosses systems.” The initiative creates a single statewide integrated system of behavioral health care to replace the previously fragmented system in which each child-serving system (i.e., child welfare, juvenile justice, mental health and Medicaid) provided its own set of behavioral health services. The New Jersey Department of Human Services is the state purchaser, and the initiative is being rolled out by county or groups of counties over a five-year period. The goals of the Partnership for Children initiative are to: (1) increase funding for children’s behavioral health care; (2) provide a broader array of services; (3) organize and manage services; and (4) provide care that is based on core values of individualized service planning, family/professional partnership, culturally competent services and a strengths-based approach to care.

New Jersey’s Partnership for Children initiative awarded a non-risk based contract to **Value Options** to serve as a **Contracted Systems Administrator (CSA)**. Value Options is responsible for critical administrative functions that will enable the state to establish and manage a single system of entry for registering, tracking and coordinating care and service outcomes for children. The CSA will establish a single record for each child and also provide administrative support and technical assistance to the locally organized systems of care.

### **Principles and Values**

The New Jersey Partnership for Children initiative is grounded in long-standing commitment to core principles for organizing and delivering services for children and families that support the dignity and integrity of children, families, and the communities in which they live. These principles and values have driven the ongoing development of existing community-based approaches to service delivery, and continue to drive this Initiative. Those core principles include:

- **Services will be child-centered and strength-based.**

The Initiative is designed to break down barriers between child-serving systems. It addresses the whole child in all aspects of family and community life, focusing on strengths that support community living and health and social development for children and families.

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- **All services and functions will be family-focused and family-friendly.**  
The Initiative will engage families as active participants at all levels of planning, organization, and service delivery to build on family strengths and assure the family perspective throughout the entire process of system planning and implementation. All services will be designed to meet family needs for accessibility and will be respectful of family rights and responsibilities.
  - **Services will be community-based and culturally competent.**  
Child and family needs and strengths are defined culturally. To be effective, all services must address cultural diversity at the community level and deliver care consistent with community strengths and values.
  - **All services and functions will be outcomes accountable.**  
The Initiative will not simply expand services, though more services will be provided and are certainly needed. The system of care will be accountable for organizing, coordinating and delivering services that result in improved outcomes for children, families, and communities, in targeted DHS policy areas:
    - Permanency of placement and living arrangements
    - Community Safety
    - Mental Health

## **Requirements for Family Involvement at the System Level**

Families in New Jersey's Partnership for Children are fully included in all aspects of their systems of care Initiative. At the system level, family members are paid to participate on policy-setting bodies, program management committees and quality assurance activities. Family members who participate at the system level are representatives of family run organizations or are family members from the community. Family members expertise, skills and experiences are seen as essential to the expansion and growth of the Partnership for Children Initiative. The role of parents and other family members and substitute caregivers in individual service planning and development of the system of care continues to expand. To support the expansion of family involvement in service organization, management, and delivery, the Initiative is rolling out across the state one **Family Support Organization (FSO)** per county or counties.

The New Jersey Department of Human Services provides funding to FSOs at the local level and requires by contract **Care Management Organizations (CMOs)** and FSOs coordinate their efforts. The FSOs hire Family Support Partners who are parents with a child with behavioral health needs to work closely with families served by CMOs. FSOs are family run, county-based, not-for-profit organizations designed to provide the system with a perspective that is uniquely family oriented through peer mentorship, education and advocacy, information/referral and the hosting of peer support groups. The FSO acts as a guide for professionals and as direct peer support to families whose children are enrolled in local CMOs.

## **Family Involvement at the Service Delivery Level**

FSOs are responsible for serving all families of children with emotional and behavioral problems at the local level through information, advocacy, guidance, group support and volunteer opportunities. FSOs operate "warm lines" which provide over the phone

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information, referral and guidance for families in any given county who have resource questions and need for guidance and information about children's mental health and the availability of the services within the Initiative and the FSO specifically. The FSOs serve as local organizations creating support groups and information sessions to bring families together for ongoing companionship, training, problem solving, and networking. The recruitment of volunteers who are parents, caregivers or siblings of children with emotional problems, to give support and offer their unique talents to other family members, is an ongoing and important function of the FSO.

A primary responsibility of the FSO is to serve as peer support to families whose children are receiving services from the CMO. Family support partners, hired by the FSO, are individuals whose children with emotional problems have been or are involved in DHS-sponsored programs. Their experiences as caregivers to children in the State system provide a unique opportunity to offer support and guidance to CMO families based on mutual understanding and the sharing of experiences. Family support partners are present for families who request their assistance, helping to ensure that Individual Service Plans (ISPs) are supportive of family needs and true to the family's values, beliefs and concerns. Working closely with CMO care managers, family support partners serve as essential comrades to families whose children have the most complex needs. CMO families additionally avail themselves of the FSO for information sessions and skills building opportunities to help them maximize their participation and influence.

FSO staff is responsible for educating local stakeholders about the function and purpose of the FSO, the importance of family/professional partnerships and the central role of the family in providing input and direction in the care and treatment of children with serious mental health disorders. Areas of service delivery that are currently being developed include expansion of FSOs to provide services to families receiving mobil stabilization services and moderate youth case management services. Over time, and as the system matures, it is anticipated that FSOs will become the local one stop shopping location for all families/caregivers of children with emotional problems seeking peer support, educational programs or information and referral.

## **Family Involvement in the Quality Improvement Process**

Another essential role of the FSOs is the monitoring of the Initiative through the state's **Quality Assessment and Performance Improvement Program (QAPI)**. Family members serve on all the QAPI committees and provide practical ideas to the quality improvement process. QAPI reviews the entire system, but is specifically targeted to ensuring quality **Individualized Serving Planning (ISP)** at the local level for children with serious disorders. The QAPI establishes performance benchmarks and assesses quality of system performance. It is supported by an information management system at the CMO level that gathers and organizes information for ISP design and implementation, including QAPI methodology needed to track and monitor critical indicators of successful implementation of structure and process. For example, QAPI includes indicators of family involvement and satisfaction, interagency collaboration, access to community-based services, improved stability in family and other living arrangements and improved child status in key life domains.

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## III. Concluding Observations

### Common Characteristics and Challenges

- **Common Characteristics**

While the three states' approaches to family involvement in managed care systems described in this paper are unique each in its own way, they also share a number of common characteristics:

- **Values-based designs** are characteristic of these approaches, with values based on CASSP-liked principles that are relevant to children and their families. It is essential to have CASSP-like principles as a central organizing concept in managed care systems. These values place families in a leadership role in determining the course of the care their family member receives.
- **State level administrative structures.** All these approaches demonstrate state level administrative rules reflecting the will of state government to simply say “meaningful family involvement shall be”, and written policy guidelines established at the agency or organization level reflecting buy-in by agency administrators. The very administrative personnel who created the written policy guidelines are often the same individuals who serve on the board or committee with family member representatives. Family partnerships were deliberately structured at policy, management and service delivery levels.
- **Money.** True family involvement in managed care requires money. There is no integrated family involvement unless some means is found to pay those involved in such a way that allows commitment to the task on the part of family representatives. In addition to equal pay for equal work, funds were provided by these states to: pay travel expenses for family members to get to events, meetings, and activities; develop the infrastructure of family run organizations; develop new systems capacity, etc. Financial support is crucial for the survival and ongoing viability of family organizations to ensure networks of informal community resources.
- **Family run not-for-profit organizations.** The family members who governed the family organizations were key players in the development of culturally competent team centered local systems of care. Although each family organization had a set of ideas and objectives based on their collective family voices, one goal they shared was to partner with professionals working with children with serious behavioral health challenges to create a system of care that is responsive to families' needs and strengths.
- **Access is a hallmark** of all these approaches — access to information, to how things work politically and systemically, and access and participation in the dialogue of philosophies and political realities as they play out in each state's public life and policy. The approaches share a willingness to capitalize on every opportunity to include the parent voice at every relevant table and to share power.
- **Family members as quality assurance employees.** The approaches share a commitment to support and develop family members' involvement in the quality improvement processes relevant to children and data-based decision making . Family members at both the service and systems levels are able to see problems reported (data collected) and used to guide policy and service decision making.

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## • Common Challenges

- **Time and Resources.** A change in personnel at the state or county level can affect the support families have received to expand the family voice. It takes time to develop relationships and build partnerships. It takes time to bring the message of families to professionals — the new way of viewing families as well as the importance of family involvement in services and supports. It takes time to build family support networks and time is a precious commodity in families struggling to raise a child with serious behavioral health challenges.
- **Ongoing Education, Information, and Training.** Educating families in a number of critical areas is a continual challenge for these systems. Families need to have a basic understanding of managed care concepts, as well as an understanding of how the system operates, what managed care is, and what to expect. In addition, education and training is needed about the approach to care used in many of these systems for children with serious disorders (i.e., an individualized/wraparound approach, family focus, community-based services and supports, etc.). This challenge is complicated by the staff turnover that plagues many child-serving systems, especially among front-line workers. Further, families need information on what services are available, what they are entitled to, and how to access care.
- **Family Involvement Across Systems.** Although these promising approaches share a commitment to family involvement, this value is not always shared among front line staff or among partner agencies and systems. Respecting families as experts on their children, enlisting them as partners in their child's care, supporting them in their caregiver role, and involving them as partners in decision making at the system level are goals that have not been fully achieved in any of the systems. Handling resistance to family involvement and encouraging staff and partner agencies to understand and adopt this value requires attention, persistence, and funding.
- **Developing Family Leadership Skills.** Family leadership at the policy and management levels is crucial and may need to be nurtured by the organizational mentor and other state family leaders. Care needs to be taken to ensure families have the opportunity to identify those qualities, skills, and experiences they need to further their capabilities and help family members to develop them.

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## Resources

More detailed information about each of the family involvement approaches described in this paper can be obtained from the following individuals:

### Massachusetts

**Donna Welles**

Executive Director  
Parent Professional Advocacy League (PAL)  
59 Temple Place, Suite 664  
Boston, MA 02111  
Phone: (617) 542-7860  
Email: [dwelles@ppal.net](mailto:dwelles@ppal.net)  
Web: [www.ppal.net](http://www.ppal.net)

**Lee-Anne Jacobs**

Deputy Director  
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**Joan Mikula**

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Child/Adolescent Division  
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**Kathy Betts**

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Massachusetts Behavioral Health Partnership  
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### Delaware County, PA

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Delaware County Parents Involved Network  
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20 S 69th Street  
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**Heidi C. Thompson**

QI Director  
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105 Terry Drive, Suite 103  
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### New Jersey

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Phone: (609)292-4741  
Email: [Julie.caliwan@dha.state.nj.us](mailto:Julie.caliwan@dha.state.nj.us)

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## National Organizations

The following national organizations have useful information and resources in the areas of family involvement in managed care systems:

### **Federation of Families for Children's Mental Health**

1101 King Street, Suite 420  
Alexandria, Virginia 22314  
Phone: (703) 684-7710  
Email: [ffcmh@ffcmh.org](mailto:ffcmh@ffcmh.org)  
Website: <http://www/ffcmh.org>

### **Bazon Center for Mental Health Law**

1101 15th Street, NW, Suite 1212  
Washington, DC 20005  
Phone: (202) 467-5730  
Email: [webmaster@bazelon.org](mailto:webmaster@bazelon.org)  
Website: <http://www.bazelon.org/bazelon>

### **Center for Health Care Strategies**

P.O. Box 3469  
Princeton, NJ 08543-3469  
Phone: (609) 895-8101  
Email: [mail@chcs.org](mailto:mail@chcs.org)

### **Family Voices**

3411 Candelaria NE, Suite M  
Albuquerque, NM 87107  
Phone: (505) 872-4774 or (888) 835-5669  
Email: [Kidshealth@familyvoices.org](mailto:Kidshealth@familyvoices.org)

### **Families USA**

1334 G Street, NW  
Washington, DC 20005  
Phone: (202) 628-3030  
Email: [info@familiesusa.org](mailto:info@familiesusa.org)

### **National Alliance for the Mentally Ill**

Colonial Place Three  
2107 Wilson Blvd., Suite 300  
Arlington, VA 22201-3042  
Phone: (703) 524-7600  
Website: <http://www.nami.org>

### **National Mental Health Association**

2001 N. Beauregard St., 12th Floor  
Alexandria, VA 22321  
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Stroul, B.A., Pires, S.A., & Armstrong, M.I. (2003). *Health care reform tracking project: Using research to move forward: A consensus conference on publicly funded managed care for children and adolescents with behavioral health disorders and their families — September 29–30, 2003*. Tampa, FL: Research and Training Center for Children's Mental Health, Department of Child and Family Studies, Division of State and Local Support, Louis de la Parte Florida Mental Health Institute, University of South Florida. (FMHI Publication #215)

### HCRTTP Promising Approaches Series

Wood, G. M., (2004). *Health care reform tracking project (HCRTTP): Promising approaches for behavioral health services to children and adolescents and their families in managed care systems — 6: Family involvement in managed care systems*. Tampa, FL: Research and Training Center for Children's Mental Health, Department of Child and Family Studies, Division of State and Local Support, Louis de la Parte Florida Mental Health Institute, University of South Florida. (**FMHI Publication #211-6**)

Stroul, B. A., (2003). *Health care reform tracking project (HCRTTP): Promising approaches for behavioral health services to children and adolescents and their families in managed care systems — 5: Serving youth with serious and complex behavioral health needs in managed care systems*. Tampa, FL: Research and Training Center for Children's Mental Health, Department of Child and Family Studies, Division of State and Local Support, Louis de la Parte Florida Mental Health Institute, University of South Florida. (**FMHI Publication #211-5**)

Armstrong, M. I., (2003). *Health care reform tracking project (HCRTTP): Promising approaches for behavioral health services to children and adolescents and their families in managed care systems — 4: Accountability and quality assurance in managed care systems*. Tampa, FL: Research and Training Center for Children's Mental Health, Department of Child and Family Studies, Division of State and Local Support, Louis de la Parte Florida Mental Health Institute, University of South Florida. (**FMHI Publication #211-4**)

Hepburn, K. & McCarthy, J. (2003). *Health care reform tracking project (HCRTTP): Promising approaches for behavioral health services to children and adolescents and their families in managed care systems — 3: Making interagency initiatives work for the children and families in the child welfare system*. Washington, DC: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development. (**Georgetown University Publication #211-3**)



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McCarthy, J. & McCullough, C. (2003). *Health care reform tracking project (HCRTP): Promising approaches for behavioral health services to children and adolescents and their families in managed care systems — 2: A view from the child welfare system*. Washington, DC: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development. **(Georgetown University Publication #211-2)**

Pires, S.A (2002). *Health care reform tracking project (HCRTP): Promising approaches for behavioral health services to children and adolescents and their families in managed care systems — 1: Managed care design & financing*. Tampa, FL: Research and Training Center for Children's Mental Health, Department of Child and Family Studies, Division of State and Local Support, Louis de la Parte Florida Mental Health Institute, University of South Florida. **(FMHI Publication #211-1)**

## HCRTP State Surveys

Stroul, B.A., Pires, S.A, & Armstrong, M.I. (2003). *Health care reform tracking project: Tracking state managed care systems as they affect children and adolescents with behavioral health disorders and their families — 2003 State Survey*. Tampa, FL: Research and Training Center for Children's Mental Health, Department of Child and Family Studies, Division of State and Local Support, Louis de la Parte Florida Mental Health Institute, University of South Florida. **(FMHI Publication #212-4)**

Stroul, B.A., Pires, S.A, & Armstrong, M.I. (2001). *Health care reform tracking project: Tracking state health care reforms as they affect children and adolescents with behavioral health disorders and their families — 2000 State Survey*. Tampa, FL: Research and Training Center for Children's Mental Health, Department of Child and Family Studies, Division of State and Local Support, Louis de la Parte Florida Mental Health Institute, University of South Florida. **(New FMHI Publication #212-3, formerly FMHI Publication #198)**

Pires, S.A., Armstrong, M.I., & Stroul, B.A. (1999). *Health care reform tracking project: Tracking state health care reforms as they affect children and adolescents with behavioral health disorders and their families — 1997/98 State Survey*. Tampa, FL: Research and Training Center for Children's Mental Health, Department of Child and Family Studies, Division of State and Local Support, Louis de la Parte Florida Mental Health Institute, University of South Florida. **(New FMHI Publication #212-2, formerly FMHI Publication #175)**

Pires, S.A., Stroul, B.A., Roebuck, L., Friedman, R.M., & Chambers, K.L. (1996). *Health care reform tracking project: Tracking state health care reforms as they affect children and adolescents with behavioral health disorders and their families — 1995 State Survey*. Tampa, FL: Research and Training Center for Children's Mental Health, Department of Child and Family Studies, Division of State and Local Support, Louis de la Parte Florida Mental Health Institute, University of South Florida. **(New FMHI Publication #212-1, formerly FMHI Publication #212)**  
No PDF available, out of print.

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## HCRTTP Impact Analyses

Pires, S.A., Stroul, B.A., & Armstrong, M.I. (2000). *Health care reform tracking project: Tracking state health care reforms as they affect children and adolescents with behavioral health disorders and their families — 1999 Impact Analysis*. Tampa, FL: Research and Training Center for Children's Mental Health, Department of Child and Family Studies, Division of State and Local Support, Louis de la Parte Florida Mental Health Institute, University of South Florida. **(New FMHI Publication #213-2, formerly FMHI Publication #183)**

Stroul, B.A., Pires, S.A., & Armstrong, M.I. (1998). *Health care reform tracking project: Tracking state health care reforms as they affect children and adolescents with behavioral health disorders and their families — 1997 Impact Analysis*. Tampa, FL: Research and Training Center for Children's Mental Health, Department of Child and Family Studies, Division of State and Local Support, Louis de la Parte Florida Mental Health Institute, University of South Florida. **(New FMHI Publication #213-1, formerly FMHI Publication #167) No PDF available.**

## HCRTTP Issue Briefs

The following Issue Briefs are available from the National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development, 3307 M Street, NW, Washington, DC 20007, (202) 687-5000:

Pires, S. A. (2002). *Issue Brief 4. Accountability for Children with Behavioral Health Disorders in Publicly Financed Managed Care Systems*. Washington, D.C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center.

Pires, S. A. (2002). *Issue Brief 3. Financing and Risk*. Washington, D.C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center.

Stroul, B. A. (2002). *Issue Brief 2. Special Provisions for Youth with Serious and Complex Behavioral Health Needs in Managed Care Systems*. Washington, D.C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center.

Stroul, B. A. (2002). *Issue Brief 1. Service Coverage and Capacity in Managed Care Systems*. Washington, D.C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center.

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McCarthy, J. & Valentine, C. (2000). *Health care reform tracking project: Tracking state health care reforms as they affect children and adolescents with behavioral health disorders and their families — Child Welfare Impact Analysis — 1999*. Washington, D.C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center.

Schulzinger, R., McCarthy, J., Meyers, J., de la Cruz Irvine, M., & Vincent, P. (1999). *Health care reform tracking project: Tracking state health care reforms as they affect children and adolescents with behavioral health disorders and their families — Special Analysis — Child Welfare Managed Care Reform Initiatives*. Washington, D.C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center.

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 By:  
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