I. Family Involvement in Managed Care Systems

Issues and Challenges

System of care values and principles[2] 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.

[2] 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.

Table 2

Percent of Managed Care Systems Incorporating Various Types of Family Involvement Strategies

	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**).

Table 3

Comparison of Family Involvement Requirements in Managed Care Systems Versus Previous Managed Care Systems

	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.

Table 4

Percent of Reforms Involving Various Key Stakeholders in Planning, Implementation and Refinements

	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**).

Table 5

Percent of Managed Care Systems Funding Family Organization for Managed Care System Role

	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

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:

> **"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)

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**).

Table 6

Percent of Managed Care Systems Focus in Service Delivery on Families in Addition to the Identified Child

	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**).

Table 7

Percent of Managed Care Systems that Pay for Services to Family Members if Only the Child is Covered

	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**).

Table 8

Impact on Managed Care Systems on Practice of Relinquishing Custody

	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**).

Table 9

Percent of Managed Care Systems Incorporating Program and Staff Roles for Families and Youth

	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%