XIII. Family Involvement

Previous Tracking Project findings were mixed with respect to the impact of managed care on family involvement at both the system level in planning and management activities and at the service delivery level in the planning of services for their own children. For example, both impact analyses found that, even in states with requirements for the involvement of families in planning and delivering services to their own children, implementation was variable. The 2000 and 2003 State Surveys added items to further investigate family involvement at both the system and service delivery levels.

Family Involvement Strategies

A range of strategies that potentially could be used to enhance family involvement within managed care systems at both the system and service delivery levels were presented to respondents, as shown on **Table 99.**

Table 99

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%
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%
Use of family advocates	48%	71%	6%	43%	-5%
Hiring family and/or youth in paid staff roles	27%	62%	6%	38%	11%
None	6%	0%	44%	19%	13%
Other	24%	14%	0%	8%	-16%

Consistent with 2000 results, the most frequently reported strategy, noted for nearly two-thirds of the systems in 2003 (65%), was the inclusion of a focus in service delivery on families, in addition to the child identified as in need of treatment. The second most frequently used strategy (reported in 54% of the systems) involves requirements in managed care system documents for family involvement in the planning and delivery of services for their own children. About half of the systems (49%) reportedly include coverage for and provision of family supports. Strategies used less frequently include the use of family advocates (43% of systems), requirements in RFPs and contracts for family involvement at the system level (41%), and hiring family and/or youth in paid staff roles (38%).

Marked differences between carve outs and integrated systems were found with respect to all the family involvement strategies. Between 62% and 86% of the carve outs reportedly include the various family involvement strategies, compared with only 6% of the integrated systems for three of the strategies to a high of 50% for only one strategy (focus on families in service delivery). Most noteworthy is that in 44% of the integrated systems, none of the family involvement strategies reportedly is used.

Requirements for Family Involvement

As noted above and shown on **Table 99**, 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 level compared with 13% of the integrated systems, and 67% incorporate system-level requirements compared with only 6% of the integrated systems.

Both the 2000 and 2003 State Surveys explored whether family involvement requirements are stronger, weaker, or unchanged under managed care in comparison with pre-managed care. 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 (**Table 100**). 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%). No system reported in 2003 that family involvement requirements are weaker under managed care than previously; about one-third (37%) reported no change in family requirements.

Table 100

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.

Family Involvement at the System Management Level

Previous Tracking Project activities indicated a trend over time toward greater family involvement at the system level. The 2000 and 2003 State Surveys specifically examined family involvement in managed care systems in various system-level activities.

As noted earlier, significant involvement by families in the planning, implementation, and monitoring of managed care was reported by 35% of the managed care systems, a 13% decrease from the 2000 State Survey (see **Table 16**). A significant level of family involvement in managed care planning, implementation, and refinement was found in half of the carve outs (a 14% decrease from 2000), but in only 8% of the systems with integrated designs. However, families reportedly have some involvement at the system level in more than half of all systems (56%), a 12% increase since 2000, indicating that system-level involvement has shifted in some cases from "significant" to "some".

Stakeholders in both impact analyses noted that funding a family organization to play various roles in the managed care system can be an effective vehicle for enhancing family involvement at the system level. As shown on **Table 101**, 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 101

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%

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 multi-faceted, including providing information and referral services to other families (4 states), providing 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. Some specific examples include:

- In Texas, both the National Alliance for the Mentally Ill (NAMI) and the Mental Health Association (MHA) are funded to provide consumer and family education on the NorthStar managed care system and to be actively involved in policy decisions.
- In Hawaii, the statewide family organization provides a parent partner for each community mental health center. The role of the parent partners includes consultation, support, training, and advocacy for families. The organization also coordinates a statewide youth council that provides support and advocacy.

- Maryland funds the Maryland Coalition of Families for Children's Mental Health. Roles include serving on the Administrative Services Organization (ASO) Advisory Committee and on all other governing bodies and planning councils related to the managed care system.
- In New Jersey, the managed care system supports a Family Support Organization in each of ten geographic areas to provide support and advocacy for children and families needing care, as well as to participate in policy making at local and state levels.

In addition to involvement in system management, managed care systems involve families by providing education and training and helping them to navigate the grievance and appeals process when necessary. The 2003 State Survey found that 92% of the managed care systems reportedly have strategies to help families navigate the grievance and appeals process.

Family Involvement at the Service Delivery Level

Family Involvement in Service Planning

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. Exploration of this issue across all states, however, revealed that such requirements reportedly are found in only about half of managed care systems. Consistent with 2000 results, 54% of managed care systems in 2003 reportedly have requirements in RFPs, contracts, and service delivery protocols for family involvement in service planning for their own children (see **Table 99**). Stakeholders, including families, interviewed for the impact analyses noted that, even where such requirements exist, implementation often is mixed and varies from provider to provider.

Extent of Family Focus of Services

The 2000 and 2003 State Surveys investigated the level of family focus in service delivery by assessing whether the focus of services is on the family in addition to the identified child, whether family support services are covered and provided, and whether the system pays for services for family members if only the child is covered under the managed care system.

The perception of stakeholders in all states included in the 1999 Impact Analysis was that the focus of services in the managed care systems was limited to the child identified as in need of services, rather than on the entire family. Survey findings in 2000 and 2003 reflect a different picture. As in 2000, nearly two-thirds (65%) of the managed care systems in 2003 reportedly include a focus on families in service delivery (see **Table 99**). 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. In addition, about half of the managed care systems (49%) in 2003 reported that family support services are covered in the benefit package, with carve outs far more likely than systems with integrated designs to cover family support services (67% of carve outs versus 25% of integrated systems).

Recent surveys also investigated whether managed care systems pay for services to family members if only the child is covered. As shown on **Table 102**, about half of the systems in both 2000 and 2003 reportedly 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 — 55% of carve outs reported doing so as compared with 40% of integrated systems. The issue of coverage for family members is especially important due to the relationship between Medicaid and the State Children's Health Insurance Program (SCHIP) in many states. Findings from the 2000 State Survey indicate that over half of the SCHIP programs are based on an expansion of their states' Medicaid program, and, according to SCHIP guidelines, coverage is limited to the child only, leaving a question as to how services to family members, in support of the child's treatment, will be financed.

Table 102

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 resulted in questions with respect to the impact of managed care systems on the practice of families relinquishing custody in order to obtain needed but expensive treatment for their children. Some stakeholders reported that managed care had increased the need for families to relinquish custody; other interviewees noted that this practice was a pre-existing problem that had not been exacerbated by the introduction of managed care.

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 families relinquishing custody in order to obtain 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 103**). In fact, where some impact was reported, there was more likely to be a positive impact on this practice. In 16% of the managed care systems, the practice reportedly has improved under managed care, while the practice has worsened under managed care in only 3% of the systems.

Table 103 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

Stakeholders in the impact analyses indicated that managed care had little impact on the use of family members or youth as paid staff or on the availability of family-operated programs. They indicated that both practices were rare prior to the advent of managed care, and continued to be a rarity.

The 2000 and 2003 surveys investigated the use of family advocates and other paid program and staff roles for family members, and findings are consistent for both points in time. As shown on **Table 99**, 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).