A Study of the Quality of Children’s Mental Health Services within Florida’s Mental Health Managed Care Plans

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Executive Summary

This study provides an in-depth look at children with, or at risk of, severe emotional disturbance (SED) and their families who were enrolled in the Medicaid Prepaid Mental Health Program (PMHP) or in a Health Maintenance Organization (HMO) in the Pensacola area (AHCA Area 1). Using case study methodology, the children’s and families’ experiences were assessed in relation to the quality of mental health services provided and the quality of services by financing condition (i.e., PMHP or HMO). A small portion of the case studies included children who are not receiving Medicaid-funded behavioral health services, so that the causes of the low penetration rates in AHCA Area 1 could be explored.

How does quality of care differ by financing condition?

The majority of caregivers in both plans found it easy to contact their providers. The caregivers emphasized that being seen on time was of high importance, and they appreciated the availability of home-based services. Satisfaction with the coordination of services in both plans was also rated as very high. Cultural competency was not stressed by caregivers or providers, but this may be due in part to the lack of ethnic diversity in the Pensacola area. Lakeview Center, Inc., was complimented several times on their outreach efforts to caregivers and their needs, and other HMO providers mentioned the importance of a holistic approach to the child’s treatment that included other family members.

The majority of children were prescribed at least one, if not multiple, medications as part of their mental health services. One hundred percent of PMHP and 75% of HMO service users reported improvements in their child’s behavior that were attributed to medication. However, 44% of HMO and 71% of PMHP service users wished their child could receive more psychosocial interventions in addition to the medication. Those caregivers who most disliked medications tended to feel threatened regarding their parenting ability (e.g., “the school needs him on meds, but I can handle him”) or were concerned about the negative stigma attached to medicating children (e.g., fear of creating a lifelong need or addiction). A small number of cases involved negative side effects and complete dissatisfaction with medication.

Both plans maintained fairly individualized treatment plans, and caregivers reported provider adherence to their child’s treatment plan. More PMHP caregivers than HMO caregivers reported being invited to treatment planning meetings, but the vast majority of caregivers from both plans believed their feedback was respected and incorporated into treatment plan updates, and most caregivers were satisfied with their involvement in treatment planning.
Caregivers’ reports of child functioning as a result of receiving services was extremely positive for both financing conditions. Examples of improvement included decreased attention seeking, fewer school suspensions, and improvement in grades. Caregivers from both plans reported that services for their child had helped reduce their own stress levels, and had increased their ability to make use of informal supports (e.g., if their child is behaving appropriately, it is easier for relatives to provide respite care).

Providers in both plans employed evidence-based practices. The most commonly cited guidelines were those of the American Academy of Child and Adolescent Psychiatry (AACAP). While both managed care organizations stressed the importance of keeping up-to-date on best practices, individual HMO providers were more likely to do this through subscriptions to journals or designing community trainings or giving presentations, while PMHP providers put more emphasis on specific group training efforts.

**What are the reasons for low penetration rates in Area 1?**

While there were no significant differences in the number of barriers to accessing services between financing plans, there were variations in the types of barriers reported. Transportation was a problem for one-third of caregivers. Additional barriers encountered by PMHP caregivers included miscommunications with providers (e.g., provider missed two scheduled appointments with caregiver), a provider letting their Medicaid license expire, and lack of adequate staff to focus on adolescents. Additional barriers encountered by HMO caregivers included a lack of awareness of available services, medication side effects, being told their child does not meet the criteria for services, trouble getting through on the phone, and long wait times at provider offices. Barriers identified by providers focused on the need for more child psychiatrists (PMHP) and concerns regarding Medicaid reform (HMO).

Of the PMHP and HMO service users and non-users, over half received informal emotional, social, and/or financial help. However, non-users did not access other behavioral health services, and did not have a stronger informal support system than service users. Service use and subsequent improvement in child functioning facilitated increased use of informal supports.

**What is quality of care, and how should it be measured?**

Providers spent the majority of their interview time discussing the issues related to quality of care, such as continuity of care, empathy, ease of referral, keeping a child safe, maintaining a team approach, service coordination, and clinical knowledge. Indicators they ranked the highest included reduction or stabilization of symptoms, timely and comprehensive evaluations, and improvement in overall child stability and functioning. Caregivers placed the most importance on satisfaction with treatment plan, improvement in child functioning, and meeting the children's needs. Indicators viewed as least important by caregivers and providers were cultural competency, minimization of out-of-pocket expenses, and reduced social/economic burden to family. In general, the quality indicators that caregivers and providers ranked as most important fit into four domains: access, appropriateness, consumer engagement and outcomes.
Policy Recommendations

The following recommendations are offered as suggestions for improvements to the behavioral health service system in AHCA Area 1:

Where appropriate, providers should start children on both medication management and therapy when a child comes into services, rather than beginning medication and waiting to see if the child needs anything else.

Providers and AHCA should consider positive media campaigns and increased educational outreach to the community regarding the approved usage of medication in child populations, with the goal of reducing stigma and helping caregivers become more comfortable with receiving this type of help for their children.

Greater funding and recruitment should be deployed to increase the number of available child and adolescent psychiatrists.

Supports (e.g., emotional, financial, educational) should continue to be offered to caregivers, since their stability greatly impacts the child’s.

Flexible funding should be available to improve client compliance with treatment and presence at appointments. For example, bus passes could be offered to decrease the transportation barrier, if there is public transportation in the local area.

Medicaid policy or procedures should not be changed without first conducting focus groups with both providers and caregivers, to better understand the potential impact on service delivery and access to services.

Introduction

This study provides an in-depth look at a sample of children with, or at risk of, severe emotional disturbance (SED) and their families enrolled in the Medicaid Prepaid Mental Health Program (PMHP) or in a Health Maintenance Organizations (HMO). Using case study methodology, children’s and families’ experiences were assessed in relation to the quality of mental health services provided, as well as how quality of services varies by financing condition. A small portion of the case studies included children who are not receiving Medicaid-funded behavioral health services, so that the causes of the low penetration rates in AHCA Area 1 could be explored. This sub-study complements the other components of the PMHP evaluation and contributes to the overall understanding of how managed care structures impact children and families.

Defining Serious Emotional Disturbance

According to a Surgeon General’s report, children and adolescents with SED account for approximately 5 to 9 percent of youth ages 9 to 17 (U.S. Department of Health and Human Services [DHHS], 1999). Estimates vary, however, depending on the definition used to identify such children (Narrow et al., 1998). The category of serious emotional disturbance is an umbrella term used to classify children with various emotional, mental, or behavioral disorders that limited their functioning. However, different entities use different definitions to classify children as SED. School systems use the definition set forth by the Individuals with Disabilities Education Act (1997) to determine a child’s eligibility for
special education services. This definition includes problems related to learning or maintaining interpersonal relationships, inappropriate behavior under normal circumstances, pervasive unhappy or depressed mood, or a tendency toward developing physical symptoms or fears associated with personal or school problems. Another definition used to identify children with SED was developed by The Center for Mental Health Services. This definition requires a diagnosable mental, behavioral, or emotional disorder of sufficient duration that it meets the criteria specified in the Diagnostic and Statistical Manual of Mental Disorders (DSM) and results in functional impairment (Substance Abuse and Mental Health Services Administration, 2004). In order to serve emotionally disturbed children under the public-funded children’s mental health system, the Florida Department of Children and Families (2004) requires the diagnosis of a specific psychotic, mood, personality disorder or another allowable DSM category, or a school system’s classification of a student as SED. According to Reddy (2001), utilization of differing definitions by various referral agencies influences the types of children referred and may contribute to the under-identification of children with SED.

**Needs of Children with SED and Their Families**

A recent report published by the Urban Institute concluded “While Medicaid and SCHIP appear to improve access to care for children with mental health problems, most children with mental health problems nationwide, from all income and insurance groups, still do not use mental health services” (Howell, 2004, p. 6). Kataoka, Zhang, and Wells (2002) found that nearly 80 percent of children needing mental health services in the United States did not receive them, suggesting that an estimated 7.5 million children have unmet mental health needs. This finding supports earlier research reports that “only one SED child in four had recently received mental health care” (Costello, Messer, Bird, Cohen, & Reinherz, 1998). The presence of a serious emotional disturbance can result in varying degrees of functional impairments in children. Approximately 9%-13% of 9-17 year olds with SED have “substantial functional impairment” and 5%-9% have “extreme functional impairment” (Friedman, Katz-Leavy, Manderscheid, & Sondheimer, 1998, p. 110). An estimated 7.9% of children in Florida have been diagnosed with SED and approximately 118,449 of those children are in need of mental health services (Florida Department of Health, 2004). While differences in the definitions of SED exist, there is greater consensus that “a comprehensive array of mental health and other services is needed to meet their needs” (Stroul & Friedman, 1986). Challenges to providing appropriate and effective care to children with SED and their families have been categorized into child/family-focused barriers, informational/skill-based barriers, and organizational/regulatory barriers (Reddy, 2001).

A variety of specific needs were revealed in a recent study of 134 cases of children with serious emotional disturbance either at risk of out-of-home placement or already so placed (Kernan, Griswold, & Wagner, 2003). After-school programs, mentoring services, and respite care were among the highest reported needs (in approximately one-third to one-half of the cases). Integrated
treatment and case management services (including transitional and intensive case management) were reported to be needed in 13% to 46% of the cases. Respondents also indicated a need for family-centered services such as parent training and education, support groups, and recreational activities. Another study reported an average number of 17.5 service needs for children with severe emotional disturbance and their families (Marcenko, Keller, & Delaney, 2001). Most-needed services included recreational activities, counseling and support services, and educational supports for the identified children and parent training, support groups, counseling, and employment programs for caregivers.

Identified system gaps included lack of child care for the family during service provision, frequent changes in providers, respite care needs, and lack of available funds to cover personal costs of services. Among the system barriers listed were time constraints hindering family attendance at case conferences, lack of effective service coordination, and conflicting goals of different providers (Kernan, et al., 2003). Other researchers have found challenges related to access of child mental health services, including extended waits for appointments with providers; a shortage of child psychiatrists; lack of individualized, intensive, and crisis services; limited service options; failure of providers to identify and assess children in a timely manner; lack of interagency cooperation and collaboration; and the absence of mental health plan information provided to parents (Koyanagi & Semansky, 2002, 2003). Similar findings were reported in a study conducted with providers and parents of children with emotional disorders (Quinn, Epstein, Cumblad, & Holderness, 1996).

Practice Guidelines

Numerous practice guidelines have been developed to address the variation in clinical practices and quality of care for the treatment of mental health disorders (Azocar, Cuffel, Goldman, & McCulloch, 2001). Professional organizations such as the American Psychiatric Association (APA), the American Academy of Child and Adolescent Psychiatry (AACAP), the American Academy of Pediatrics (AAP), and the Agency for Health Care Policy and Research (AHCPR) and managed care organizations including ValueOptions, United Behavioral Health, and Horizon Behavioral Services have all published treatment guidelines on various mental health disorders for professional providers’ use. However, research has shown a low level of adherence to these treatment guidelines (Boothroyd, Stiles, Dhont, & Beiler, 2003). Gomez, Taub, and Armstrong (2000) found that although treatment protocols had been widely adopted by managed care organizations and community mental health centers, primarily to ensure service quality and consistency, these protocols were rarely used by clinicians to guide the provision of clinical services. There is variation in professional opinions in the usefulness of treatment guidelines as well. A supporting perspective is that guidelines provide a framework for collaboration between providers and consumers. An opposing view suggests that guidelines cannot substitute for professional training and offer little practical guidance (Smith, 2002). Others clinicians have reported that they should not be told how to practice (Azocar, et al., 2001).
Variability in Definitions of Quality and Quality Measures

While the importance of the quality of care provided to children and families is widely recognized, the definition of quality care varies according to individual needs and experiences. Discrepancies between views of providers and families are not uncommon. While providers seek to provide reasonable and appropriate care under the economic constraints of mental health plans, parents generally want the best and most appropriate services for their child. In a study of quality indicators for primary-care mental health services, Shield and colleagues (2003) found there was variation in the total number of indicators rated as valid by different groups. For example, from a list of quality indicators, caregivers and patients rated more indicators valid (91% and 85% respectively) than did general practitioners and psychiatrists (41% and 49% respectively). A consensus was reached among respondents; however, on 26% of the indicators, that related to equity of access to care, provision of information to patients and caregivers, confidentiality, comprehensive assessments, patient involvement in treatment planning, medication, patient-staff relations, follow-up services, referral processes, and provision of a comprehensive range of services.

A study exploring consumer and provider perspectives on service quality in community mental health care identified three major themes related to the consumer/provider relationship: bonding with providers, provider competence and knowledge, and cultural/religious competence of providers (Mason, et al., 2004).

Donabedian’s (1980) framework for assessing quality of care focuses on the structural characteristics of the healthcare organization, the processes of care and interaction between the consumer and the healthcare system, and treatment outcomes. Specific domains to consider when conceptualizing quality of care include access to services, assessment, treatment outcomes, continuity and coordination of services, and the nature of the population being served (Hermann, Leff, & Lagodmos, 2002). Quality measures have been developed (often in conjunction with guidelines) by organizations representing various stakeholder perspectives, including government agencies (state and county departments of mental health and the Substance Abuse and Mental Health Services Administration), mental health organizations (the American Psychiatric Association), managed care organizations (American Managed Behavioral Healthcare Association), and consumer groups such as the National Alliance for the Mentally Ill (Hermann, et al., 2002).

Florida’s Managed Care Organizations

Florida’s Agency for Health Care Administration (AHCA) first implemented the Medicaid Prepaid Mental Health Plan (PMHP) in Area 6 in 1996. The PMHP was a result of a 1915(b) waiver from the Federal Health Care Financing Administration (HCFA). In 2001, the PMHP demonstration was expanded, with the introduction of Access Behavioral Health (ABH), to Area 1, which includes four counties (Escambia, Santa Rosa, Okaloosa, and Walton) in the Florida panhandle. In 2002, the HealthEase HMO was established in the same area. Therefore, children in AHCA Area 1 who are Medicaid-eligible either receive services through the PMHP (ABH) or HMO (HealthEase).
A previous PMHP evaluation indicated that there may be a disconnection between service providers and recipients of services. For example, families did not understand which managed care plan they were enrolled in, or what mental health services were available to them (Armstrong, Kershaw, Gomez, & Reyes, 1998). There is the potential for families to receive the services that providers know will be authorized, rather than the services best matched to the child and family's needs. However, during the initial years of Florida's PMHP implementation, this was not found to be the case. Community Mental Health Centers (CMHCs) reported they continue to provide services regardless of authorization (Armstrong et al., 1998).

Based on stakeholder concern generated from the presentation of the 2003–2004 PMHP children's study, the current study continues to focus on AHCA Area 1 children. Areas of concern emerging for the analysis of last year's study data (Armstrong et al., 2004) include low penetration (e.g., 39% of children enrolled in the HMO received mental health services, compared to 64% enrolled in the PMHP), low trust of providers (specific to caregivers of children with SED), concern regarding medications (e.g., caregivers had trouble getting medications and having providers prescribe medications they did not want), and declining CGAS (Children's Global Assessment Scale) scores, which may indicate a decline in children's functioning.

**Research Questions**

A case study methodology was used in conjunction with a case-specific administrative data analysis to answer the following three sets of research questions:

**Research Question 1:** How effective are the PMHP and HMO service systems in responding to the needs of children with SED (or at risk for SED) and their families, and delivering high quality behavioral health services?

- Is quality associated with financing condition?
- Are providers following treatment guidelines? What are the treatment guidelines they follow?

**Research Question 2:** What are the reasons for low penetration rates in AHCA Area 1?

- Are there children who are not receiving Medicaid-funded behavioral services who are obtaining relevant services from other sources and if so, what sources?
- For children and families with unmet behavioral health needs, what are the barriers to accessing and receiving Medicaid-funded behavioral health services?

**Research Question 3:** How do professional organizations, providers, and families define quality of care?

- What are the similarities and differences between the three perspectives?
- How can these three perspectives be combined to inform the development of quality indicators for future studies?
Methods

The first two sets of research questions were answered by five domains of investigation that have been adapted from Armstrong et al. (1998) and are based on professional consensus of effective practice in children’s mental health (Stroul & Friedman, 1986, 1988). The following table (Table 1) outlines the domains of investigation, indicators, and sources of data. Narrative summaries from the 28 case studies were analyzed for each domain of investigation and will be presented within the research question framework.

Table 1
Domains of Investigation, Indicators, and Source

<table>
<thead>
<tr>
<th>Domains of Investigation</th>
<th>Indicators</th>
<th>Source</th>
</tr>
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<tbody>
<tr>
<td>Effectiveness of the system</td>
<td>Services are easily accessible and conveniently located</td>
<td>In-depth interviews</td>
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<tr>
<td></td>
<td>Cultural competency</td>
<td>Case record review</td>
</tr>
<tr>
<td></td>
<td>Comprehensiveness</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Service coordination</td>
<td></td>
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<tr>
<td></td>
<td>Families are supported</td>
<td></td>
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<tr>
<td></td>
<td>Services offered in least restrictive manner</td>
<td></td>
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<tr>
<td></td>
<td>Treatment plan goals are being met</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Treatment planning</td>
<td>Treatment plan reflects practice guidelines (therapy &amp; medication)</td>
<td>Document review</td>
</tr>
<tr>
<td></td>
<td>Treatment plan is individualized and appropriate to child and family needs</td>
<td>Case record review</td>
</tr>
<tr>
<td></td>
<td>Family involvement in design of treatment plan</td>
<td>In-depth interviews</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of life</td>
<td>Family stability and functioning</td>
<td>In-depth interviews</td>
</tr>
<tr>
<td></td>
<td>Child’s functioning</td>
<td>Case record review</td>
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<tr>
<td></td>
<td>Needed supports are in place</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Experiences with the system</td>
<td>Parent perceptions related to:</td>
<td>In-depth interviews</td>
</tr>
<tr>
<td></td>
<td>Level of met and unmet needs</td>
<td>Case record review</td>
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<td></td>
<td>Level of improvement for child and family</td>
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<td></td>
<td>Child and family engagement in treatment planning</td>
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<tr>
<td>Experiences outside the system</td>
<td>Presence and perceived success of informal supports</td>
<td>In-depth interviews</td>
</tr>
<tr>
<td></td>
<td>Involvement in other systems (e.g., school, juvenile justice)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Amount paid out of pocket for non-Medicaid funded behavioral health services</td>
<td></td>
</tr>
</tbody>
</table>
The definition of quality of care is shaped by individual needs and experiences. Providers seek to provide reasonable and appropriate care under economic constraints, while parents want the best, most appropriate services for their child and unlike the providers, are not concerned about making a profit at the end of the year. Although guidelines from professional organizations were used in this study to inform protocol development, the third research question protocol was aimed at discovering how respondents define quality and what they consider to be appropriate measures.

**Study Population**

The 28 families that participated in this study were selected from among the 272 children who were part of the Area 1 children’s analysis conducted in FY 2003–2004 (Armstrong et al., 2004), the results of which were partially responsible for generating AHCA’s concern regarding the quality of care received by the children in Area 1. In the FY 2003–2004 study, children were identified as having mental health problems (i.e., they were receiving SSI because of an emotional/behavioral problem, or scored 28 or above on the Pediatric Symptom Checklist). The sampling strategy for the current study consisted of dividing these children into four pairs of groups, based on whether they were enrolled in ABH (PMHP) or HealthEase (HMO), whether they had received (users) or did not receive (non-users) Medicaid-funded mental health services (all were children enrolled in either a PHMP or HMO Medicaid plan), and whether they were identified as having or being at risk of SED. Children were eligible to participate in the current study if they were enrolled in Medicaid as of June 30, 2004, receiving SSI or TANF, and remained in the same health care plan.

Letters were mailed to caregivers inviting them to participate in the study, followed by personal contact by the research team. After receiving permission from caregivers, collaterals (service providers, teachers, and informal support persons) involved in the child’s care were also invited to participate in interviews. A total of 80 interviews and quality indicator surveys were completed. Table 2 shows that the total number of cases (as determined by caregiver consent) included 15 children enrolled in HealthEase (HMO) and 13 children in ABH (PMHP). Twenty of these children were using Medicaid-funded mental health services and eight were not. Seventeen of the children were identified as being at risk of SED in the FY2003–2004 study, while the remaining eleven were identified as being SED. Caregivers of children not using Medicaid-funded mental health services were included in an effort to better understand any barriers to obtaining services. Analysis specific to the 28 cases also included an examination of the receipt of services from other sources (Department of Juvenile Justice (DJJ), school–based mental health services, or as a result of a Baker Act), and any change in the child’s needs since the most recent SSI evaluation (a child’s behavior may have improved sufficiently that intensive services were no longer necessary, but the family may have continued to receive SSI because a re-evaluation had not been conducted). The aim of these types of questions was to uncover reasons for the low penetration rates revealed in the FY 2003-2004 child focus study.
Children receiving services from behavioral health overlay services (BHOS) and the statewide inpatient psychiatric program (SIPP) were excluded from the study population. Although these children are still eligible for Medicaid benefits, they are disenrolled from both managed care plans (HMO and PMHP), and so cannot help to determine what effect the two financing conditions have on quality of care. Case studies were limited to children living in Escambia and Santa Rosa Counties during FY 2002–2003, when the mail survey data was collected as part of that year’s child focus study.

The children included in the current study had previously been identified as having SED or as being at risk of SED as part of the inclusion criteria used previously in the fiscal year (FY) 2003–2004 Area 1 children’s study (Armstrong et al., 2004). Children were classified as having SED if they received Medicaid targeted case management services or were reported by a caregiver as receiving SSI due to an emotional/behavioral problem. Children were classified as being at risk of SED if they scored 28 or above on the Pediatric Symptom Checklist.

**Use of Administrative Data**

Administrative data for the 28 youth included in the study population were examined in an effort to better understand their service usage histories, and to determine what service data was missing from administrative datasets, and how to capture it. Databases examined to learn as much as possible regarding these 28 children included IDS, Medicaid health and mental health FFS, Baker Act, Medicaid pharmacy administrative data and Medicaid HMO/PMHP encounter data. Data analysis for Baker Act and Medicaid HMO/PMHP encounter data was conducted using currently available data from FY 2002–2003 and 2003–2004. Analysis on data from all other databases was performed using currently available data from FY 2002–2003.

**Primary Data Collection Methods**

Primary data collection was conducted through the completion of 28 case studies of individual children in AHCA Area 1. The case study method is a research design most often used to answer questions of “how” and “why” (Yin, 1989). Yin (1989) defines a case study as “an empirical inquiry that investigates a contemporary phenomenon within its real life context; when the boundaries between the phenomenon and context are not clearly evident; and in which
multiple sources of evidence are used.” The case study method assumes that each child and family served is a microcosm for service system performance. This research design, therefore, allows integration of issues of quality of care with the quality of life of individual children and families. The case study method also allows for the triangulation of data sources to increase data reliability and validity (Merriam, 1988). This study included document review (of treatment/practice guidelines), file review, and in-depth interviews. Adults interviewed for each case study included primary caregivers, service providers, therapists, teachers and other key adults in each child’s life (e.g., informal supports).

In order to include pertinent measures of quality, individual protocols were adapted from the System of Care Practice Review protocol (Hernandez & Gomez, 2003), the Medicaid Waiver Evaluation Case Study Protocol (Armstrong et al., 1998), and the Case File Review Protocol (Berson, Roggenbaum, & Vargo, 2001) and were specific to the caregivers (whether users or non-users of Medicaid-funded mental health services), service providers, teachers, informal supports, and file/document review. These protocols were used throughout the case study design and in conjunction with the administrative data analysis. Caregivers and service providers were also asked to rate a list of quality of care indicators that was adapted from those published by the American Psychiatric Association (2002) and from indicators used by Shield et al. (2003). Interviews that were not specific to individual children were also conducted with providers. These interviews focused on evidence-based practices and the measurement of quality of care.

Service providers were asked how the child’s treatment plan was developed and to what extent the goals had been met. In addition, caregivers were asked if they had seen the treatment plan, if they thought anything was missing from the treatment plan, and whether or not they thought their child’s treatment plan goals were being met. Caregivers were also asked about any additional services beyond those funded through Medicaid (school-based services) their child received, how these services were funded, and to what extent they paid for these services out of pocket.

A literature review was conducted on the quality of mental health services for children with SED, and a stakeholders meeting was convened with FMHI project staff and HMO/PMHP administrators and providers in Area 1 to gather input on measures of quality. Stakeholders were asked to rate a list of quality of care indicators and were then engaged in a discussion regarding measurement of those indicators.

Data Analysis

Data analysis of administrative data relied on currently available data from FYs 2002–2003 and 2003–2004. Content analysis was used to select common themes and trends in the data, and to condense the qualitative data into a list of variables to be examined for correlations. The research team began with text from interviews (qualitative data), made formal hypotheses as to the nature of the text’s content, performed systematic coding and analysis, and then interpreted the results in conjunction with quantitative data, thus allowing for the triangulation of data sources. Narrative summaries from the 28 case studies were analyzed for each domain of investigation and are presented within the research question framework (see Appendix A for the coding scheme).
In addition to the qualitative analysis of data obtained from in-depth interviews, a quantitative analysis was performed in order to aggregate the interview data into a manageable and reportable form. Many protocol questions used scaled answer choices (e.g., yes, no, don’t know, not applicable) to facilitate quantification. Additionally, the quality of care indicator component included in the caregiver and service provider protocols was answered using a 5-point Likert-scale, with answers ranging from not at all important to very important.

Results

Administrative Data

Ages for the 28 children included in this study ranged from 8 to 17 years, with similar mean ages for children enrolled in each finance plan (HMO mean 11.93 years; PMHP mean 11.69 years). Approximately two-thirds of the children were male, with similar distributions for each finance condition (HMO: 33% female, 67% male; PMHP: 31% female, 69% male). Table 3 presents the classification of ethnicity, and shows the majority of children included in the study were African-American.

<table>
<thead>
<tr>
<th>Race</th>
<th>HMO (n=15)</th>
<th>PMHP (n=13)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>African-American</td>
<td>9</td>
<td>60%</td>
</tr>
<tr>
<td>White</td>
<td>2</td>
<td>13%</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>27%</td>
</tr>
<tr>
<td>Total</td>
<td>15</td>
<td>100%</td>
</tr>
</tbody>
</table>

Analysis of the Medicaid encounter data revealed that in the sample of 28 children, 47% of children enrolled in the HMO and 54% of children enrolled in the PMHP had received a mental health service in FY2003–2004. It should be noted that the Medicaid encounter data may not represent the full scope of mental health services received by this population.

Table 4 presents the penetration of mental health service categories by the children in the study sample, based on Medicaid claim data during FY 2002–2003. There were no Baker Act examinations for any of the children in this study during FY 2002–2003 or FY 2003–2004.
Table 4
Number of Children Receiving Services by Plan Type

<table>
<thead>
<tr>
<th>Service Type</th>
<th>HMO (n = 15)</th>
<th>PMHP (n = 13)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Residential (IDS)</td>
<td>1</td>
<td>7%</td>
</tr>
<tr>
<td>STGC</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>MH/SA Hospital based</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Physician Services</td>
<td>6</td>
<td>40%</td>
</tr>
<tr>
<td>Treatment Planning, Testing and Evaluation</td>
<td>6</td>
<td>40%</td>
</tr>
<tr>
<td>CMH: Treatment</td>
<td>1</td>
<td>7%</td>
</tr>
<tr>
<td>BHOS</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Day Treatment Services</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Targeted Case Management</td>
<td>1</td>
<td>7%</td>
</tr>
<tr>
<td>Therapeutic Foster Care</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Other Mental Health*</td>
<td>1</td>
<td>7%</td>
</tr>
<tr>
<td>Physical Health</td>
<td>10</td>
<td>67%</td>
</tr>
<tr>
<td>Mental Health &amp; Physical Health</td>
<td>1</td>
<td>7%</td>
</tr>
</tbody>
</table>

*Other Mental Health Services includes Lab/Pathology, Speech/Language Therapy, and Occupational Therapy with Mental Health Diagnoses.

FY 2002–2003 Medicaid data also revealed the following distribution of mental health diagnoses for these children: schizophrenia/psychosis (n = 1), mood/affective disorder (n = 6), adjustment disorders (n = 2), disruptive behavior disorders (n = 3), attention deficit disorders (n = 8), neurotic disorders (n = 1), and developmental delays and autism (n = 4). This is a duplicated count; i.e., children may have been diagnosed with more than one disorder.

Very few statistically significant differences were found in the analysis of the quantitative data collected, due partially to the small sample size. Therefore, two additional analysis techniques were employed in an effort to synthesize and lend meaning to the data. Odds ratio estimates were calculated on individual variables and are mentioned in the report when significant. However, one should use caution when interpreting these statistics due to the small sample size. In addition, questions from the Primary Caregiver Protocol were grouped into applicable domains and mean scores were calculated for each domain. These data are presented in the section discussing Research Question 3 (see Table 13).

Research Question 1: How Effective Are the PMHP and HMO Service Systems in Responding to the Needs of Children with SED (or at risk for SED) and Their Families and Delivering High Quality Behavioral Health Services?
Caregiver Perspective

Access to Services

When asked about the ease of contacting providers, caregiver answers ranged from “difficult” to “very easy” with the majority reporting ease in contacting providers (Figure 1).

![Figure 1](image)

Caregivers generally reported that the children were seen often enough by providers. The majority of children and families reportedly received services in providers’ offices with appointment times and places generally being convenient as well. However, the data revealed that transportation to obtain services was a problem for approximately one-third of HMO and PMHP caregivers.

Overall, HMO service users stressed that the most important thing to them regarding access to services was that they were seen on time. One caregiver explained, “If I call them and something is not right on his card or whatever, they do the paperwork right then instead of me having to wait… and if his appointment is at 9:30, we will be seen at 9:30.” HMO caregivers also stated that they feel like they always have a number they can call, and they appreciated that they could call after hours and leave a message with the on-call nurse.

In comparison, it is interesting that HMO Non-users (i.e., enrollees who did not use mental health services) felt that the wait times were too long (see Research Question 2, below). This discrepancy may be explained by the fact that HealthEase (HMO) contracts with a large number of providers and thus faces a greater challenge than ABH (PMHP) in ensuring the same level of quality across all providers. For example, while HealthEase maintains a clinical director who supervises targeted case managers, it is more difficult to provide such supervision to individual physicians, who only see a child for medication management.

Lakeview Center, Inc. is the behavioral health care provider for ABH. Caregivers cited numerous examples of Lakeview’s attempts to ensure their child’s access to services. These included home visits, convenient hours such as evening appointments, offices located close to child’s school, provider’s flexibility in adding services when needed, appointment reminders, and calls to the family just to check in. For example, one caregiver stated, “It’s more convenient for me having five kids that I can do it in the evening instead of the morning.” Another
caregiver explained, “I can always call Lakeview and if they feel the problem I’m having is not being addressed by whatever services they are rendering at that particular time, they always get me in touch with the right people that can help me with that problem.” One significant barrier was reported by a caregiver whose provider changed, due to a promotion within Lakeview. The resulting miscommunications will be discussed in the barriers section of Research Question 2 findings.

**Coordination of Services**

Even though only 4 of 18 caregivers (2 HMO, 2 PMHP) reported that there was a specific person responsible for coordination to prevent the occurrence of gaps and duplication of services, there was a generally positive level of satisfaction among caregivers with coordination of services. Figure 2 presents these results.

Of the 31% of children receiving mental health services from the school system, children enrolled in the PMHP were significantly more likely to receive these services $\chi^2 (1, N = 19) = 4.55, p = .033$. The calculation of an odds ratio revealed that these children were eleven times more likely to receive mental health services from the school system than were children of HMO caregivers (OR = 11.25).

![Figure 2: Caregiver Satisfaction with Coordination of Services](image)

**Appropriateness of Services**

Caregivers generally reported feeling comfortable with their child’s primary Medicaid mental health service provider, with approximately half being very comfortable. Caregivers in both financing conditions also reported satisfaction with the relationship they had with their child’s provider and the services offered and provided. The majority of answers ranged from somewhat satisfied to very satisfied. Only one caregiver reported not being very satisfied with the relationship with the child’s provider.

In general, caregivers were pleased with the physical environments in which they received services, and 100% of caregivers thought their children were
receiving services in the most appropriate environment. HMO service users mentioned that their providers were nice to them and both groups appreciated that waiting rooms were not crowded. While this seems like a minor thing, to caregivers of ADHD children it is an enormous relief, for with less going on in the waiting rooms, their children are less prone to becoming anxious or panicky. According to caregivers, “It’s a structured environment with not too many kids. He’s not too hyper. He’s not too anxious. He goes in there and he gets seen pretty quickly.”

PMHP caregivers mentioned that they appreciated the privacy offered to them while in session and that the provider did not take phone calls while in session. One PMHP caregiver said, “Some people always have something slightly bad to say about the doctors. I have… I mean, everything they have done has been so beneficial and so helpful.” Another PMHP caregiver agreed, adding, “They have a lot of good counselors. And the counselors listen at not only your…my viewpoint, they listen also at his [child of the caregiver] viewpoint and be able to combine both of them to come out with a good outcome. Because they don’t just listen at me and what, you know, just go from there. They listen at both of us. And they use both. They listen at both people, me and him, to come out, to come up with something that’s going to be beneficial not only to myself, but also to him.”

Cultural competency was not stressed by providers during interviews. Of the five service providers interviewed, none of them reported any special needs resulting from family cultural or ethnic backgrounds and all but one stated they were able to adapt services to the family’s values, beliefs, and lifestyle. The Pensacola area is not extremely diverse and children that were included in this study were primarily African-American or Caucasian. While most caregivers (88% HMO, 100% PMHP) reported that providers were able to adapt services to fit with child and family values, beliefs, and lifestyle, there was a larger variation between responses regarding whether or not the provider considers the culture and religious preferences when working with the child and family. Seventy-eight percent of PMHP caregivers answered yes to this question, as did 43% of HMO caregivers. However, while caregivers from both plans acknowledged that they were questioned for cultural or religious issues that might impact their service delivery needs, they did not think their ethnicity or religious preferences needed to influence their child’s treatment. According to one HMO caregiver, “It’s never really been an issue—there are questionnaires you answer ahead of time, but it’s just not an issue.” Likewise, a PMHP caregiver commented, “I never really paid it much attention. I’m quite sure she does [attend to family belief system] just by meeting our needs specifically.”

In addition, those served at Lakeview appreciated the extra attention their other children received while waiting for their sibling. Children were allowed to play in a room with toys and caregivers felt appreciated when Lakeview providers inquired about the siblings’ needs as well as the caregivers’. PMHP caregivers also listed the following things they appreciated that Lakeview had done for them:

• Helped caregiver cope with daily stress.
• Called caregiver with updates of child’s treatment progress.
• Offered caregivers diagnosis-specific information and updates on new services being offered.
• Drew on other funds through Lakeview if a service that child needs is not covered through Medicaid.
• Case managers remained available to caregiver even after no longer being assigned to child’s case.
• Maintained adolescent client confidentiality from caregiver, so that child is more agreeable to sharing private issues with provider.

While case manager turnover is often cited as problematic in the industry, a PMHP caregiver explained that in her case it was not an issue. “I hate that she’s not our counselor now. But, you know, I just ran into her at the store and I still talk to her and she always tells me I’m not your counselor now, but you call me anytime.” Another PMHP caregiver shared, “That’s one thing I love dearly about my case manager. She is very concerned about my health and making sure she is there to help me to stay healthy.”

Focus on: Medication

A primary concern of the FY 2003-2004 child study was the caregivers’ issues with medication. Here, we briefly examine whether caregivers were satisfied with the type of medication their child was prescribed, and whether they would like their child to be receiving a psychosocial form of treatment instead. The overwhelming majority of children were prescribed at least one, if not multiple forms of medication (80% HMO, 67% PMHP). Ritalin and Adderol were mentioned most frequently by caregivers.

While there were a few caregivers who did not like that their children were medicated, (see below), the majority of caregivers (75% HMO, 100% PMHP) in both plans noted improvements in their child’s behavior when on medication. Comments regarding these improvements can be found in Tables 5 and 6.

Table 5
Examples of HMO Caregiver Satisfaction with Medication

<table>
<thead>
<tr>
<th>Example</th>
<th>HMO</th>
<th>PMHP</th>
</tr>
</thead>
<tbody>
<tr>
<td>“He provides his medication and keeps an update on all his activities,</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
  school activities. I bring him his report card. I let him know if he's   |
  having any problems. He makes suggestions to either change his medicine  |
  if I feel like it's not working or increase it or decrease it. And we    |
  discuss that before anything's done.”                                    |
| “If I'm not happy with anything I can change doctors or add something. I |
  like that most of all. If I feel the medication isn't working, I can     |
  change it.”                                                               |
| “Yes. I see a difference when he takes his medicine I don't have any    |
  problem out of him and next week I have an appointment to go and get     |
  another prescription because every week we have to go see the mental     |
  health doctor to update his medicine. When he is taking it I don't too   |
  much have a problem with him.”                                            |
| “It has been better. The school don't call like every day about         |
  something that he is doing.”                                             |
“The whole time he was having a problem I thought it was just nothing. And so my husband was like, let’s have him tested. And once he was tested and he started the medication, his behavior improved, his grades improved. And now that he’s older, he can recognize when he can’t concentrate.” (HMO)

“And his grades… they’re better. He takes pride in everything he does. He’s more attentive. He’s not that daredevil anymore. He thinks before he does something.” (HMO)

Table 6
Examples of PMHP Caregiver Satisfaction with Medication

“Hey yeah… You know, to see him without meds and to see him with meds is just like a Dr. Jekyll and Hyde. I mean, it’s just like a split personality. And you can tell when the real personality click in. When he, you know, compared to when he’s with medicine and without medicine. And I get a progress report every day from school, and you can tell… Oh, the teachers know when he’s not on his meds.” (PMHP)

“He’s not as angry as he was. He’s angry, he’s violent. Sometimes he gets violent, but it’s not as often as it was. The medicine does help him calm down.” (PMHP)

“He used to whine a lot and now he don’t and he was very sensitive and he is not as sensitive now.” (PMHP)

“Well, he was pretty much calmer. He was a lot calmer than he used to be.” (PMHP)

“He explained what ADHD was and tried him on medication to see if it would work and it worked.” (PMHP)

“The school wrote me a letter saying that they were going to retain him in the first grade and I let him go to summer school and that is when I put him on the medication and the summer school teachers didn’t know why they wanted to hold him back because he was up with the rest of them.” (PMHP)

However, while caregivers were pleased with this progress (see Figure 3), caregivers in both plans wished that their children could receive more psychosocial interventions in addition to the medication management (44% HMO, 71% PMHP). However, the lower desire of HMO caregivers for psychosocial intervention was not due to their having had received it, since service usage data did not show HMO participants received more psychosocial interventions. Again, it must be stressed that caregivers did not want to lose the current level of medication management, but rather, they wanted additional individual- and group-therapy for their child.

Figure 3
Caregiver Satisfaction with Effectiveness of Medication
One common theme across caregivers leery of medication was the perceived stigma attached to one’s child needing medication. Two caregivers made it clear to the research team that their children were medicated only at the request of the school. “I can deal with him, but it’s the school that needs him on meds” and “He was too hyper in class, so he wound up on medication.” Some caregivers may feel somewhat incompetent or guilty if they cannot deal with their child’s behavior through their own parenting skills. In addition, other caregivers expressed concern that their children would need medication for the rest of their lives, and that by starting this treatment they were facilitating a lifelong dependence. It appears common among caregivers to go through these emotions, especially those on Medicaid, who are often young, single parents trying to meet basic needs for their children. While providers should continue to address the stigma attached to medication and be sensitive to caregiver concerns, this dynamic is not a reflection of the success of medication in improving children’s functioning. One caregiver, who had come full circle, summarized, “I’m not too keen on putting children on medication, but if it’s going to help them improve their mental state, you just have to try it.”

In regard to the desire for more psychosocial interventions, an HMO caregiver explained, “I would prefer something for his behavior problems where he don’t have to take the medications, something like a solving plan where he could solve it in a way where medication is not involved.” Another HMO caregiver echoed this sentiment, “Maybe a counselor and someone that could… Different techniques to try when he’s realizing that he can’t concentrate or when he’s, you know, getting angry, different techniques that he could try. Because I do eventually want him to come off of the medication. If he can, I don’t want it to be, you know, long term.”

One PMHP caregiver requested therapy for her child in addition to medication management, and was told by Lakeview that Medicaid would not cover such services. Another PMHP caregiver explained, “He needs some therapy instead of seeing a nurse practitioner. It’s good to see a nurse practitioner, but it’s also good to see a therapist. He needs somebody to talk to that’s trained in that profession to see, to pull it out what’s really going on with him because sometimes he can be happy, he’ll be all right. He’ll sit around here and he’ll play or whatever, and then, all of the sudden in a snap he’ll get real angry. I can’t predict when he’s going to get violent, and he won’t talk to me.” Yet another caregiver wished for “A therapist or a mentor. Anybody that could help him express his feelings instead of holding them in and bottling them up. Anybody.” Additionally, a PMHP caregiver explained, “I think the medicine stays in the body a little longer, and I think by having other types of sessions, groups or so forth, he can benefit from that instead of medication because I know sometimes it doesn’t help. The medication is good, but [he needs] more frequent visits with the counselor and other types of outside mentors.” Anger management services were also requested by some caregivers.

A few caregivers were not happy regarding the medications their children were receiving. These cases are worth elaboration, but it should be restated that
the majority of caregivers were very happy with the progress their children were making while on medication. One PMHP caregiver acknowledged the success of a medication her young child could chew, but expressed frustration at another medication that only came in a time-release capsule. This caregiver had to divide the capsule in half, thus ruining the effect of the medication, but she did not know of another way to address her child’s difficulty swallowing large pills.

One PMHP caregiver felt that the medications were simply not doing anything for her child, and the research team encountered an HMO enrollee who had given up on services due to the effect prescribed medications had on her child. In this particular case, the caregiver had taken her child off of the medication because it made her too drowsy to function in school, too hyperactive at home, and it caused an increase in appetite. She was also concerned that the provider never interacted with her child, but rather only spoke to the caregiver. In retrospect she feels, “The doctors are too interested in just giving medication and not talking to a person. He never talked to her. They just give medicine, any kind of medicine. It doesn’t work [that way].”

**Treatment Planning**

Although caregivers were aware of a treatment plan, they did not put emphasis on the specific goals and strengths of the plan. The only treatment goals caregivers mentioned were finding the right medication dosage, anger management, and reducing disruptive behaviors at school. Caregivers provided the most feedback on being involved in updating the course of their child’s treatment (Table 7). Caregivers reported that treatment plans were updated regularly (88% HMO, 63% PMHP) and that they participated in these updates (78% HMO, 88% PMHP). Additionally, 88% and 100% of HMO and PMHP caregivers, respectively, reported that their children’s treatment plans were being followed. Additionally, a PMHP caregiver was impressed that her case manager’s supervisor had sat in on one visit to ensure that the case manager was doing all that she could for the family.

<table>
<thead>
<tr>
<th>Table 7</th>
<th>Examples of PMHP Caregiver Engagement in Treatment Plan Updates</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Whenever something happens, if they feel they have to change something along the way, I’m always invited because they have to have my input in order to get any output.”</td>
<td></td>
</tr>
<tr>
<td>“They make me feel that they need my input to make sure that they’re getting the right plan and the right idea of stuff in order to be able to treat him.”</td>
<td></td>
</tr>
<tr>
<td>“They’ll ask me what do I want to see my child do, or what do I want my child’s strengths to be, what I need for him to work on at school as well as at home, and they’ll work with him at school at that end, and I’ll work with him at home on my end. And then they’ll sit down and revise, and they’ll tell my child everything that’s going on.”</td>
<td></td>
</tr>
</tbody>
</table>

A few HMO caregivers thought their child’s treatment plan was individualized. One gave the specific example that originally her child was set up to visit a clinic that had a rotating schedule of doctors, with the result that the
child was faced with speaking to a different provider each time. This caregiver requested that her child be assigned to only one provider, and her request was met. Additionally, a caregiver who said that her son liked challenges felt that this strength was reflected in his treatment plan because, “They let him know that just because he has this particular problem, it doesn’t have to hinder him from doing anything he wants to do. He don’t have to change [his aspirations]. It just helps him better himself to do what he wants to do.” Approximately three-fourths of HMO and PMHP caregivers reported that child and family strengths were incorporated into the treatment plan. Another HMO caregiver was pleased because the provider encouraged her input on switching medications. “There was one time he was on a particular medication, Ritalin, and its side effects were too strong for him and they made him sick and he didn’t do too good. And so I went to the doctor and I researched because, you know, his suggestion was to research the disease.”

**Focus On: Caregiver Engagement**

Although a greater number of PMHP caregivers (89%) than HMO caregivers (56%) reported that their children had treatment plans, each group reported equal involvement in treatment planning (75%) and all reported feeling comfortable at planning meetings. The data revealed a difference between financing conditions in caregivers being invited to attend treatment planning meetings (25% HMO, 67% PMHP), however. The calculation of an odds ratio estimate revealed that PMHP respondents were six times more likely to be invited to a treatment planning than HMO caregivers (OR = 6.00). This could be the result of caregivers working with primary care providers in the treatment of their children, where separate and specific treatment planning meetings may not be as formalized, but rather occur during regular doctor’s office visits. All caregivers reported that their input was respected and incorporated into treatment plans. Seventy-five percent and 88% of HMO and PMHP caregivers, respectively, said they signed a treatment plan, and the inverse ratio held for the number of caregivers receiving a copy of the plan (89% HMO, 75% PMHP).

Caregivers stated that they understood their children’s treatment plans, but a lesser number said they understood the words and terms used in the forms and documents provided to them (89% each for HMO and PMHP). One hundred percent of caregivers said that it was explained to them why the specific course of treatment was chosen for their children.

Seventy percent of HMO caregivers and 89% of PMHP caregivers reported having a role in their child’s treatment. HMO caregivers saw their main role as monitors of their child’s reaction to medications. In addition, they felt it was very important to attend sessions, listen to their child’s provider and ask questions. “I monitor his activities and behaviors because they change as he adapts to the medication,” stated an HMO caregiver. Another shared, “I constantly ask questions. I just try to make sure they stay up on their end of the bargain.” Additional activities caregivers focused on were administration of medication and making sure prescriptions were kept up to date.

PMHP caregivers gave examples of being invited to treatment planning meetings, and as signing the treatment plan. Several stressed the importance
of receiving written information on ADHD, as well as an explanation of what procedures needed to be followed in order for services to be funded through Medicaid.

One hundred percent of caregivers reported satisfaction to some degree with their involvement in planning their children’s treatment. Figure 4 illustrates the distribution of satisfaction.

![Figure 4](image)

Figure 4
Caregiver Satisfaction with Involvement in Treatment Planning

However, PMHP respondents were significantly more likely to want changes in the planning process than HMO respondents $\chi^2 (1, N = 18) = 4.00, p = .046$. Respondents cited three areas in which they wanted to see changes: counseling, medication management, and funding. Several PMHP respondents indicated that they wanted counseling, rather than or in addition to medication, for their child. Many of these respondents expressed concern about the number of different medications prescribed to their child and the readiness in which providers prescribed medication before utilizing alternative treatments such as behavior therapy. One respondent indicated that services were not available for her child due to funding constraints, and suggested that if funds were more flexible, children and families could obtain all the services they needed.

Quality of Life

Child Functioning

Another important concern generated from the FY 2003–2004 child study in Area 1 related to child functioning. While CGAS scores were used to determine this specific finding in last year’s study, qualitative data from the current study indicated that children were showing improvement in several areas.

Caregivers responded favorably to a question inquiring about how things were going for their children overall since receiving services. On a scale ranging from “poor” to “excellent,” HMO (n = 10) and PMHP (n = 9) respondents had very similar answers (Figure 5). In addition, caregivers reported that services had been helpful to their children (Figure 6).
Caregivers were asked how satisfied they were with their children’s improvement since receiving services. Two respondents (HMO) reported not being very satisfied. All other answers ranged from somewhat satisfied to very satisfied. Figure 7 shows these results.
Very few caregivers believed their child had not improved due to some aspect of services they received. For example, one discontent HMO caregiver acknowledged, “My child goes up and he goes down. I can be satisfied at one point and not satisfied at another, so it really depends on him.”

HMO caregivers cited the following ways their child had shown improvement:

- Increased interest outside of oneself,
- Increased helping behavior,
- Increased pride in academic achievement and other accomplishments,
- Fewer calls from school to report behavior problems,
- Grades have improved, and
- Increased self-awareness of lack of concentration and learning how to cope.

For example, one HMO caregiver explained, “He had Ds and Fs. And at home if you talked to him, he knew the material; it was just hard to concentrate because he would be paying attention to everything else. And now he’s A-B. So he has come a long way. And he was below level in math and reading. I think he’s on level now.”

Similarly, PMHP caregivers shared the following contributions to their child’s well-being:

- Learning to control anger,
- Leadership skills,
- Less fighting with peers,
- Less attention seeking behavior,
- Less hyperactivity,
- Less whining,
- Plays better on his own.

For example, a PMHP caregiver stated, “He’s been a lot more confident of himself. He’s not being a follower anymore.” Another shared, “He was getting into fights, suspended from school, and he’s just overall improved his whole attitude about everything.”

**Family Functioning**

Figure 8 presents the satisfaction levels with family improvement since their children began receiving services.
HMO and PMHP caregivers also reported fair-to-excellent family functioning since their children began receiving services, with services themselves rated as being “somewhat helpful” to “very helpful.”

Caregivers from both managed care plans affirmed that the services their child received helped reduce their own stress level. It cannot be ignored that families on Medicaid encounter many socioeconomic stresses, in addition to normal unfortunate events. For example, one PMHP caregiver shared, “The hurricane, the storms, just him becoming a typical teenager, it’s kind of hard being a single parent. Just being able to have enough, just having enough to get by.” Another PMHP caregiver who was caring for her grandson after his parents passed away explained, “It’s the death – all the death he’s gone through.”

HMO caregivers cited the following ways their families’ functioning had improved since their child began receiving services:

- Children were well behaved enough that others could provide respite care and interact with the children more, thus supporting the caregiver and strengthening the child’s ties to family and informal supports,
- Immediate family was able to go more places together,
- Increased parenting skills,
- Increased parents’ understanding of their child's behavior, and therefore, lessened reaction to it,
- Less sibling rivalry,
- Increased communication within family,
- Children were able to help with cooking, cleaning and/or yard work at home.

An HMO caregiver explained, “I’m less stressed. He’s more responsible, I can trust him more. Everything goes okay. Everybody’s less stressed because you don’t have that problem of constantly saying ‘don’t do this,’ ‘don’t do that,’ ‘you can’t do this.’ So, it has really helped.”
Similarly, PMHP caregivers listed the following ways that services had improved their family life:

- Caregivers learned better methods of discipline,
- Caregivers learned how to not get stressed to the point of illness,
- Lakeview helped families with special medical needs get their electrical service back after the hurricane (e.g., children were on breathing machines).

A PMHP caregiver shared, “They give me solutions to be able to deal with him without stressing myself out. I’ve used punishment, but I use it in a way that’s beneficial to me rather than picking up the belt all the time.” In addition, a PMHP caregiver expressed relief in that, “Everybody is coping with his ADHD and his mental health. Everybody knows how to treat it now. It’s not scary anymore.”

**Met and Unmet Needs**

When asked if their children needed services that were not available through Medicaid, most service users said no (78% HMO, 67% PMHP). Other than dental care, in-home counseling was the only service mentioned as being unavailable through Medicaid; however, the respondent indicated that the unavailability was because her child was already receiving counseling at school.

The majority of caregivers (78% HMO, 67% PMHP) reported that the services listed in their child’s treatment plans addressed all their child’s mental health needs. When asked whether they thought Medicaid-funded services met their children’s needs, 60% of HMO caregivers and 78% of PMHP caregivers said yes. Similarly, when asked whether services met the needs of the family, 60% HMO caregivers and 67% of PMHP caregivers said yes. Some respondents were disappointed their child’s provider never asked about family needs; while others felt that by addressing their child’s needs, the family needs were also taken care of. A few respondents also expressed concern that the medication management their child received was a short-term fix and did not address the deeper behavioral and emotional issues the family faced.

When asked if they would make changes to the services provided to their children and families, 30% of HMO respondents and 56% of PMHP respondents said yes. Respondents overwhelmingly wanted therapy or counseling services in addition to the medication their child was already receiving. Although respondents seemed to agree that they would like therapy or counseling, the type of therapy or counseling varied by respondent: including one-on-one therapy for their child, family therapy, caregiver therapy, and behavioral therapy. Family therapy and individual therapy were seen as a way for the caregiver to obtain a better understanding of their child and learn different ways to deal with the child’s behaviors.

**Out-of-Pocket Expenses**

One (HMO) of 19 service users reported having to pay for services that were previously provided at no cost and four (1 HMO, 3 PMHP) reported that
their children were not receiving services due to an inability to pay for them. All eight of the HMO/PMHP non-service users stated that they were not paying for services that were previously provided at no cost and three (1-HMO, 2-PMHP) reported that their children were not receiving services due to an inability to pay for them. There was one child (HMO, non-user) that was reportedly receiving non-Medicaid funded services, because out-of-pocket expenses had created a financial burden for the family.

**Caregivers’ Evaluations of Plan Performance**

In an effort to present a broader picture of performance by each financing condition, questions from the Primary Caregiver Protocol were grouped into applicable domains (see Appendix B) and mean scores were computed for each domain. Higher mean scores indicate more-positive responses from service users. Table 8 presents the descriptive statistics per domain of questions that assessed the experiences of caregivers. Although there were no statistically significant differences in the mean scores between financing conditions and all mean scores fell above the mid-point on each score range, the resulting data indicates that there is still room for improvement in both plans when mean scores are compared to the maximum possible score in each range.

**Table 8**

<table>
<thead>
<tr>
<th>Domain</th>
<th>No. Items</th>
<th>Possible Score Range</th>
<th>HMO</th>
<th>PMHP</th>
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<tr>
<td>Access to Services</td>
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<td>1–11</td>
<td>10</td>
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<td>Services</td>
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<td>3–17</td>
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<tr>
<td>Cultural Competence</td>
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<td>0–2</td>
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<td>.87</td>
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<td>Comprehensive Services</td>
<td>4</td>
<td>0–4</td>
<td>9</td>
<td>3.33</td>
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<td>LRE</td>
<td>2</td>
<td>0–2</td>
<td>10</td>
<td>2.00</td>
<td>.00</td>
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<tr>
<td>Individualized Treatment Plan</td>
<td>3</td>
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<td>9</td>
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<td>1.00</td>
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<td>Family Involvement in Treatment Planning</td>
<td>17</td>
<td>1–23</td>
<td>9</td>
<td>19.44</td>
<td>3.17</td>
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<td>Treatment Plan Updates</td>
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<td>0–2</td>
<td>9</td>
<td>1.56</td>
<td>.73</td>
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<td>Treatment Goals</td>
<td>1</td>
<td>0–1</td>
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<td>.65</td>
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<tr>
<td>Child Functioning</td>
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<td>8.30</td>
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<tr>
<td>Needs</td>
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<td>0–2</td>
<td>10</td>
<td>1.20</td>
<td>.92</td>
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<tr>
<td>Child/Family Improvement</td>
<td>2</td>
<td>2–10</td>
<td>10</td>
<td>8.30</td>
<td>1.89</td>
</tr>
</tbody>
</table>
Provider Perspective

Access to Services

Providers in both types of managed care plans expressed their belief in the importance of client access to services. A PMHP provider explained, “If you can’t access a service, then you can’t get served. It doesn’t matter if it’s good or bad [quality]. You’re just sort of dead in the water.” Overall, providers were satisfied with their level of accessibility, within the resources they had (see Research Question 2 findings for barriers related to lack of staff). One HMO provider boasted, “We have a very high degree of accessibility. If he misses an appointment, my staff will do everything that we can to squeeze him in as soon as he can come in. So we try to be very available, very accessible. I mean, that’s probably the major factor on our part that makes it easy for them to follow the guidelines.” PMHP providers were satisfied with timely screenings and referrals.

Providers reported an absence of gaps or duplication of services for their clients. Three providers said that the amount of interaction (frequency, length of visits) with the child and his or her family was just right (1 HMO, 2 PMHP) and two (HMO) reported having too little interaction.

Both managed care providers had much to say about the variable access to different types of medications and how they perceive it impacts caregivers and children. The HMO providers interviewed attempt to prescribe medications on the formulary list so caregivers do not have to wait for approvals through Medicaid. One HMO provider explained, “HealthEase has been really good about trying to make it easy for us to get rapid approvals for even medicines that aren’t on the formulary. You know, and that helps our accessibility is that HealthEase has decided to allow the psychiatrists to do their medication managements without having to fill out forms to get pre-authorization. So, the HMO’s accessibility to medicine has made it real easy for [caregivers] to comply with treatment.”

PMHP providers voiced concern regarding access to specific medications. According to one PMHP provider, “There are some [prescriptions] that relate specifically to ADHD and the stimulant medications that are difficult to manage. The family has to come down, pick up a written prescription, carry it to the pharmacy. It can’t be called in…. and it’s a problem when they lose it. We take a big risk writing another one.”

HMO and PMHP providers said that they had a good relationship with the school system, and that child-specific updates were transmitted between teachers and providers. However, only two of eight teachers (both PMHP) reported that they ever had the opportunity to talk with children’s mental health providers, and only one teacher said they were ever involved in treatment planning outside the school system for the child. One PMHP provider said, “We often work with school teachers. Providing input. They provide input back to us. The diagnosis itself sometimes helps them knowing that this particular student needs more structure. Sometimes they are able to go into ESE classes because of the
diagnosis.” PMHP providers mentioned an Internet database where staff could access updates on school behavior. In addition, HMO providers mentioned that they routinely sent updates on a child’s mental health treatment to that child’s primary care physician.

Both managed care plans also gave general examples of how they routinely coordinated efforts. One HMO provider explained, “I coordinate their care, I coordinate their referrals to therapists and to psychiatrists and to drug treatment if that is what they need, their primary mental health diagnosis and plug them in to the psychiatrist therapy along with their secondary primary provider.” Another HMO provider stated, “A definite indicator for me would be the ability for the various providers to stay in contact, to coordinate between providers as well as other institutions, such as the school, DJJ, and agencies.” Likewise, a PMHP provider said, “I don’t think you can have quality of care if you don’t have a team approach.” And a PMHP case manager explained, “It is the case manager’s role to keep everyone singing off of the same song sheet. So, I push for the team.” Opportunities to review cases with colleagues were also cited as beneficial aspects of service coordination.

Although providers seemed confident in their coordination efforts (100% of HMO and PMHP providers reported coordination efforts), they also indicated that they spoke to the child’s case manager on an as-needed basis (1 HMO), that they never spoke to the child’s case manager (1 HMO), that they did not remember the last instance they spoke to the child’s case manager (1 HMO), and that they talked with the child’s other providers on an as-needed basis (1 HMO) or not more frequently than every 6 months.

**Appropriateness of Services**

Although the majority of service users reported that their Medicaid plan offer them a choice of types of services (70% HMO, 67% PMHP) and a choice of providers (80% HMO, 62% PMHP), a smaller percentage did not know whether or not they had a choice of services (10% HMO, 22% PMHP) or a choice of providers (20% HMO, 12% PMHP). Regarding cultural competency, providers echoed the sentiments of caregivers that the Pensacola area was not very ethnically diverse; however, PMHP caregivers cited examples of being able to speak Spanish and HMO providers explained that despite ethnic similarities, depending on a family’s level of education and ability to understand medical terminology, they had to be able to shift the manner in which they spoke, appropriately. According to one HMO provider, “My adaptations are automatic and on an unconscious level.”

**Focus on: Medication**

Providers were aware of the negative stigma attached to medicating children and attempted to combat this “bad press” by providing information to caregivers and talking with them about potential advantages as well as side effects. A PMHP provider described the situation: “Very often I’ve had to spend a lot of time with families discussing the stigma of psychiatric diagnoses, psychiatric medications, and how to address that. It’s very often a barrier to treatment. People are reluctant
to start on medications. You know, don’t want to be on the Ritalin or those
types of things. There’s been plenty of bad press about ADHD and stimulant
medications that have delayed treatment for many people.”

PMHP providers reported that they send caregivers to an informational
session on ADHD before a child is evaluated. After the evaluation occurs, and
medication is recommended, an ongoing dialogue begins between caregiver,
provider, and child. For example, a PMHP provider shared, “We discuss whether
or not they want to start on medications. Whether or not the dose is appropriate.
Whether they want to increase the dose, decrease the dose, not take the
medications. We discuss methods and side effects and whether it’s going to be an
appropriate intervention for him.”

One HMO provider discussed how they continually adjust the child’s
treatment and medicine as the child grows and matures. This provider further
explained, “If he develops behavioral problems, for which he’ll need therapy or
even in-home services, those are all ready to go when they’re needed.” A PMHP
provider mentioned that at the caregiver’s request, the child goes off medication
several times each year to see if he can do without it. In both plans, providers
reportedly put more emphasis on medication as the first line of treatment
rather than psychosocial interventions. One HMO provider explained, “We do
medication management with limited psychotherapy.” Additionally, a PMHP
provider explained on one case, “Initially the treatment plan seems to mention
therapy, but the patient has seemed to do well without any additional counseling,
so I don’t think he’s missing that.” As was found with a significant portion of
caregivers, child progress is often attributed to medication.

Treatment Planning

Aspects specific to treatment planning that emerged from the provider data
included

Treatment goal development and types of goals,

Whether the goals follow treatment guidelines, and

Methods to engage family members in updates of treatment plans.

Focus On: Goals

Managed care providers from both plans included evidence-based practice in
their development of a treatment plan. An HMO provider explained, “The goals
are based on stated symptoms and diagnostically based. As physicians, we use a
medical model, that symptoms are due to a diagnosed mental illness. And from
the mental illness, you have certain needs and goals. In his case, he has problems
with ADHD behavior of sometimes being impulsive but just difficulty studying.
So, his goals are in line with Attention Deficit Hyperactivity Disorder, and the
main component of the treatment plan was using the medication and then
getting educational accommodations.” Another HMO provider shared a more
holistic approach, in stating that the plan should also include caregiver issues,
such as substance abuse, due to their impact on a child’s condition.
PMHP providers stressed that although treatment plan goals often run the risk of being very general, they make a concerted effort to include concrete and measurable goals for treatment. In addition, three aspects are critical to goal development: (a) what the family wants, (b) what published treatment guidelines suggest, and (c) what is the standard community practice within their managed care organization.

The most commonly mentioned treatment plan goals were:

- Age appropriate and on-task behavior (HMO),
- An adequate attention span for school (HMO),
- To be able to learn new things in school (HMO),
- Returning the child to the prior level of functioning (HMO),
- Maintaining the maximum benefit of medications with the minimal side effects (HMO),
- Fewer symptoms of ADHD (PMHP),
- Preventing disruptive and inappropriate behavior (PMHP),
- Taking medications as prescribed (PMHP),
- Avoiding psychiatric appointments (PMHP),
- Avoiding inpatient admissions (PMHP), and
- Avoiding arrests (PMHP).

Focus On: Engagement

HMO providers stressed the importance of agreement with caregivers regarding a child’s treatment. For example, one HMO provider explained, “What it is we’re treating has to be defined by the parents and the child.” Another HMO provider stated, “Number one, they have to approve of everything I do. One of the things I’ve always told children and teenagers is that I work for them. If they’re not happy with the medicine, if they’re not reaching their goals, then we’re going to do what we can to change it so that they can be happy.” In addition, a PMHP provider added, “Each time they come in to the appointment we review their medications and their plan. You know, are they taking medications? Do they need an increase? Are they going to therapy? Do they need therapy? Do they need case management? Those type of issues are updated in these appointments.”

Providers also placed importance on the role of empathy and the therapeutic alliance. “The most important thing to me about the quality of care is letting the patients know that I care about them. It is not the technique so much. Most of my kids have no father, just a single mom normally…,” stated an HMO provider. And a PMHP provider explained, “Being able to have that open communication with the client, because if you’re not getting truthful information from them, how can you really help them? So it is important to establish that rapport, that bond, so that they can feel comfortable in being as truthful and honest as they can.”

Another PMHP provider said her experience as a mother was helpful for empathizing with clients. “I have found that it has helped me tremendously, more
than I could ever say, to be able to put myself in the mom's situation, worried about her child and concerned about whether the information that she's getting is maybe correct or not or, to me, it has been a wealth that I can draw from. It gives me a certain level of respectability with the clients and I can say I know a little bit of the struggle that you're going through. The sense of responsibility you feel.”

**Evidence-Based Practice**

Numerous practice guidelines have been developed to address the variation in clinical practice and quality of care for the treatment of mental health disorders (Azocar, et al., 2001). Professional organizations such as the American Psychiatric Association (APA) and the Agency for Health Care Policy and Research (AHCPR) and managed care organizations including ValueOptions and United Behavioral Health have published treatment guidelines on various mental health disorders for professional providers’ use. However, research has shown a low level of adherence to these treatment guidelines (Boothroyd et al., 2003). There is variation in professional opinions on the usefulness of treatment guidelines as well. A supporting perspective is that guidelines provide a framework for collaboration between providers and consumers, and the opposing view suggests that guidelines cannot substitute for professional training and offer little practical guidance (Smith, 2002).

While caregivers were not asked questions regarding evidence-based practice, a strong theme that emerged from provider data was that both types of managed care organizations encourage training in and application of treatment guidelines and best practices in children's mental health. Of the 20 individual providers interviewed, 71% from the HMO and 100% from the PMHP indicated that they had received training related to evidence-based treatment. The majority (80% HMO, 86% PMHP) said that this training focused on treatment for specific conditions and diagnoses.

**Focus On: Training**

There are different ways to learn about evidence-based practices. While both types of managed care organizations stressed the importance of keeping up to date on best practices, HMO providers were more likely to do this on an individual basis, via subscriptions to journals, designing community trainings or giving presentations. PMHP providers put more emphasis on specific group training efforts. While neither should be deemed more correct, both approaches were taken seriously by providers. Specifically, HMO provider physicians must maintain 25 continuing medical education credits per year (but often aim for 50 to meet the American Medical Association's Physician Award status) and PMHP providers must participate in 60 hours of training per year. Providers interviewed included physicians, psychiatrists/psychologists, and case managers. A breakdown of the degrees they held follows: BA/BS: HMO (0)/PMHP (3); MA/MS: HMO (3)/PMHP (2); MD/PhD: HMO (10)/PMHP (1).

Different types of train-the-trainer models were apparent in each managed care organization. Within HealthEase, many physicians are at the point in their
career where they could host a lecture series or design a training video on their own area of expertise, such as domestic violence. Lakeview prides itself on a method they refer to as Cascade Training, in which one staff person is sent to a conference and then returns to give seminars within the organization, so that maximum benefit can be made of the original training expense. Both methods reach out to each of the respective provider communities.

Examples of reported trainings that were hosted or attended include:

<table>
<thead>
<tr>
<th>Pediatric pharmacology (HMO)</th>
<th>Domestic violence (HMO &amp; PMHP)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morning reports (HMO)</td>
<td>Medical Lecture series (HMO)</td>
</tr>
<tr>
<td>ADHD, Autism, and Depression (HMO)</td>
<td>Bipolar disorder (PMHP)</td>
</tr>
<tr>
<td>Substance abuse (PMHP)</td>
<td>Addressing mental health needs of caregivers (PMHP)</td>
</tr>
<tr>
<td>Infant mental health (PMHP)</td>
<td>Sexual abuse treatment (PMHP)</td>
</tr>
<tr>
<td>Eating disorders (PMHP)</td>
<td>Comparisons on effectiveness of ADHD medications (PMHP)</td>
</tr>
</tbody>
</table>

**Focus On: Use of Best Practices**

Lakeview reportedly employs a journal system where providers and case managers must document the date of each training they attend, what it was regarding, and how they applied it to their work. HMO providers cited that they kept evidence-based practice manuals in their office.

Examples of treatment guidelines providers used include:

- Practice parameters on ADHD by the American Academy of Child and Adolescent, Psychiatry (HMO & PMHP),
- Establishing structure and supervision for ADHD children (PMHP),
- FALGO (Florida Algorithm Project) lists specific algorithms for bipolar disorder, depression, and schizophrenia.

**Quality of Life**

**Child Functioning**

All five providers reported that the treatment plans were being followed, and three of three providers said that progress had been made on treatment plan goals. Providers reported fair-to-excellent progress was being made by children on meeting their treatment goals since the provider began working with them (Figure 9).
Family Functioning

Providers also reported on how well they believed the primary caregiver was able to deal with the child’s problems (see Figure 10).

Summary of Research Question 1: How Effective Are the PMHP and HMO Service Systems in Responding to the Needs of Children with SED (or at risk for SED) and Their Families and Delivering High Quality Behavioral Health Services?

The majority of caregivers in both plans found it easy to contact their providers. Caregivers emphasized that being seen on time was of high importance and they appreciated the availability of home-based services. Satisfaction with the coordination of services in both plans was also rated as very high. Cultural competency was not stressed by caregivers or providers, but this may be due in part to the lack of ethnic diversity in the Pensacola area. Lakeview was complimented several times on their outreach efforts to caregivers and their needs, and HMO providers mentioned the importance of a holistic approach to the child’s treatment that included other family members.
The majority of children were prescribed at least one medication as part of their mental health services. One hundred percent of PMHP and 75% of HMO service users reported improvements in their child’s behavior that were attributed to medication. Forty-four percent of HMO and 71% of PMHP service users wished their child could receive more psychosocial interventions in addition to the medication management, which finding was not attributable to HMO participants receiving more psychosocial interventions. Those caregivers who most disliked medications tended to feel threatened regarding their parenting ability (e.g., “The school needs him on meds, but I can handle him”) or were concerned about the negative stigma attached to medicating children (e.g., fear of creating a lifelong need or addiction). A small number of cases reported negative side effects and complete dissatisfaction with medication.

Both plans maintained fairly individualized treatment plans, and caregivers reported provider adherence to their child’s treatment plan. More PMHP caregivers than HMO caregivers reported being invited to treatment planning meetings, but the vast majority of caregivers from both plans felt that their feedback was respected and incorporated into treatment plan updates, and most caregivers reported being satisfied with their involvement in treatment planning.

Caregivers’ reports of child functioning as a result of services received were very positive for both financing conditions. Examples of improvement included decreased attention-seeking, fewer school suspensions, and improvement in grades. Caregivers from both plans reported that services for their child helped to reduce their own stress, and had increased their ability to make use of informal supports (e.g., when their child is behaving appropriately, it is easier for relatives to provide respite care).

Providers in both plans reported employing evidence-based practices. The most commonly cited guidelines were those of AACAP. While both managed care organizations stressed the importance of keeping up to date on best practices, HMO providers were more likely to do this on an individual basis via subscriptions to journals or designing community trainings or giving presentations, while PMHP providers put more emphasis on specific group training efforts.

**Research Question 2: What Are the Reasons for Low Penetration Rates in AHCA Area 1?**

**Caregiver Perspective**

**Barriers Encountered: Users and Nonusers**

The lack of convenient hours and the cost of transportation were both mentioned by PMHP beneficiaries as barriers to access. The data revealed that transportation to obtain services was a problem for approximately one-third of HMO (30%) and PMHP (33%) caregivers. While beneficiaries stated that they were invited to treatment planning meetings, some stated they could not attend due to their work schedule or an inability to take time off (e.g., jobs that do not
have benefits). As one caregiver explained about transportation of her daughter to services, “I would like her to be able to have more therapy, but they used to come to the house but they quit doing that and it is very hard for me to go all the way over there for her therapy. I don’t know what I am going to do in the summertime because right now school is taking her there and all I have to do is pick her up. They are talking about gas going up to $3.00 a gallon.”

One caregiver who had been receiving services no longer went to Lakeview due to the miscommunications that occurred when her provider was promoted within Lakeview and her child was assigned to a new provider. After the caregiver had taken her child to two appointments that the provider missed, she became very frustrated and stopped pursuing services. In her own words, “We had been sitting out there for twenty minutes before [the receptionist] even noticed us. ‘Oh, she’s not here today, something came up’ she told us. Every time we went for an appointment that new person was never there… and she didn’t call to tell us before we showed up. She gave me a new appointment, but I canceled … and just stopped going to Lakeview.”

Another PMHP caregiver discussed challenges she experienced when a provider’s Medicaid license expired. According to the caregiver, “It took me a week to get his medicine, a whole week he was out of medicine because they couldn’t fill it because Medicaid wouldn’t let them fill it because his license had expired. He can’t write prescriptions anymore. And I don’t think that’s right because he need them.” This same PMHP caregiver has also felt the impact of changes in Medicaid policy regarding medication her child takes. “At first I could get his medicine with no problem, but now I have to have the doctor’s authorization plus Medicaid’s authorization before I can get his medicine. It will be one or two days before I can, before they can approve the medicine before I can get the medicine. So it’s a lot of stuff done changed with Medicaid that I can’t do that I used to do.” Finally, a PMHP caregiver suggested that Lakeview needed more providers who specialized in working with adolescents.

HMO beneficiaries also stated that they had trouble getting to appointments on time. Additional barriers to quality care expressed by HMO beneficiaries included a lack of awareness of available services, medication side effects, being told their child does not meet the criteria for services despite problems witnessed by the caregiver, trouble getting through on the phone, and unusual wait times at provider offices. Regarding confusion at point of entry, one caregiver stated, “I need to get her in. I got the runaround over the phone about whether or not I had to pay for her to be evaluated.” Another caregiver shared her experience when she went for her child’s evaluation, “I had to wait three and a half hours to be seen, only to have someone tell me there’s nothing wrong with her … ‘some kids are slower than others’ … I can’t get help.” Similarly, another caregiver shared her frustration in trying to get help for her son. “They said nope, can’t touch him because he doesn’t have a certain kind of disability.”

Informal Supports

Both HMO and PMHP had users and non-users who made use of informal supports (60% HMO, 67% PMHP). Sixteen out of seventeen HMO and PMHP
caregivers stated that the individuals providing informal support were not being paid for their services. The majority of respondents had problems with finances and difficulties meeting their family’s basic needs, and so any type of help was normally solicited and appreciated. With the exception of families without close-by relatives or those involved in some type of interfamily conflict, most caregivers reported receiving help from family members and neighbors. Only a few respondents mentioned the role of faith-based organizations. Experiences with other systems included juvenile justice, child welfare, and the schools. Services normally were precipitated by an encounter with the juvenile justice or child welfare, while engagement in the school system was facilitated most often through Lakeview’s school-based mental health services. The Table 9 outlines types of supports families reported receiving.

Table 9
Examples of Help Provided by Informal Supports

<table>
<thead>
<tr>
<th>Emotional support</th>
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<tbody>
<tr>
<td>Mentor through Big Brothers Big Sisters Program</td>
</tr>
<tr>
<td>Support group for ADHD</td>
</tr>
<tr>
<td>Money to cover counseling not funded by Medicaid</td>
</tr>
<tr>
<td>Transportation to school and providers</td>
</tr>
<tr>
<td>Church services and youth group</td>
</tr>
<tr>
<td>Respite care</td>
</tr>
<tr>
<td>Money to cover household expenses</td>
</tr>
<tr>
<td>Organization of family events such as child birthday parties</td>
</tr>
</tbody>
</table>

Caregivers were most appreciative when friends and family would spend time with their child. For example, one caregiver explained, “My mother-in-law researches the disorder and suggests things. Like now she has him in baseball. It gets him to be more active. That helps. He takes it out on the ball.” Another caregiver explained, “It makes for less stress when there’s more than one person involved. My child doesn’t feel like, oh people don’t like me because I have a problem.” Family members who paid their child for services were also cited as being helpful by some caregivers. Not only did the “service” keep the child occupied, but it also gave the child pride in begin productive. For example, one family member paid a child a set amount for performing different yard work tasks.

Assistance with homework and discipline was also mentioned. One caregiver explained, “If I’m not able to help her with her homework or have to go to work, somebody is always here to help her with it.” Another caregiver felt fortunate that she had a family member affiliated with the Sheriff’s office who could explain to her child what would happen if he broke the law.

Those that attended church also reported it to be beneficial. “He go to church and the Preacher talk to him and… You know, they talk to all the children and see if they’re having problem, and let the children know that they’re there to help them, you know, they’re just a phone call away and stuff of that nature,” stated one caregiver. Another strategy employed by one family was for the father to take
on increased responsibility at work so that his wife could stay at home. This made
the mother feel that she could deal with her son's behavior better.

In conclusion, one caregiver summarized, “It’s not that they help with
[formal] treatment, but that they’re another source of treatment. It gives my child
different experiences and more opportunities to work through his frustration.”
When asked what would happen if these informal supports did not exist,
caregivers said they would still get by, but that it would be more difficult. “I
would try to find another resource,” stated one caregiver, “I know they’re out
there, but it’s just hard getting them.”

Provider Perspective

The barriers to service delivery most frequently mentioned by providers were
scarcity of child-specific mental health providers in AHCA Area 1, the effects of
Medicaid reform, and fear of further detrimental changes in Medicaid policy.

Focus On: Lack of Providers

Lakeview providers were in agreement. “Northwest Florida has fewer
services.” And while “Lakeview is good at getting people in” providers hoped
for “more services and more doctors.” This, unfortunately, had implications
for client’s access to services. One PMHP provider explained, “There are some
services within our agency that are harder to get access to than others. Psychiatry
being an example. We’ve been interviewing for a second psychiatrist for years and
years now, and we’ve had a couple of people come and go, and it’s been very hard
to get a staff.” Another PMHP provider echoed this sentiment. “There’s such a
high demand, especially in my field for children, some of the therapists have been
pushing their caseload above a hundred, and if they can only get in maybe once a
month it’s essentially irrational services because you don’t have a staff to meet the
need. That’s always just a constant problem. I don’t see that, unfortunately going
away.”

Lack of inpatient beds was also a problem providers chose to address in the
interviews. According to one PMHP provider, “Baptist has been overflowing
for the past few months. They’ve had to send a few kids to Panama City. Of
course, the parents don’t like to hear that because it’s a two-hour drive. It’s very
inconvenient. We don’t like to lose control but when the beds are full, and that
happens, what do you do?” Finally, one PMHP provider warned, “I don’t think
the public wants to hear that we need more Medicaid money because we need
another children’s therapist or another psychiatrist, but, the way I look at it, you
deal with it, especially with the children, you deal with issues they’ve got now, or
you’ll deal with it when they’re an adult. You’ll deal with it in the legal system.”

Focus On: Medicaid Reform

The second challenge addressed by providers is what has happened due to
Medicaid reform, and fear of future changes. Regarding the current impact on
clients, an HMO provider explained, “In their efforts to make it more efficient,
you know, it’s also made it harder, less accessible. I mean, the one thing that’s really frustrating is when kids are found temporarily ineligible for Medicaid, and then the kids are off of medication for a month or two. When kids go off their medicine things fall apart and then sometimes it leads to hospitalization. I mean, while they’re still on Medicaid, everything goes smoothly, but they’ll just be stopped suddenly. You know, with no ability, with almost no ability to prepare.”

Providers feared possible changes the Legislature could make as part of the impending Medicaid reform efforts. Another HMO provider explained, “Things kind of get lost or not done right, and so I may get the approval and I may not, but then the pharmacy won’t find out, and sometimes the parents don’t know what to do and so they just do nothing. And, you know, having these types of things takes advantage of people who really are struggling and don’t understand and don’t have a whole lot of intelligence to be able to figure everything out, and in the end, they are the ones that get hurt. You know, the most vulnerable people get hurt by all these systems that they put in place to save money because it requires more activity than they’re used to.”

Vignettes

The following six case studies illustrate how the findings from Research Questions 1 and 2 come together to create lived experiences, both successes and challenges, for families living in Area 1 who are enrolled in either the HMO or PMHP Medicaid plans. Each case study presents the most salient issues in the child’s pursuit of behavioral health services, as well as lessons that can be learned.

Case Study 1: Daniel & Consumer Education (HMO)

Daniel is twelve years old and currently in the sixth grade. He likes computers and would like to be a computer programmer some day. According to his mother, he has a great sense of humor and is very smart. The family is close; they can talk to each other and often help each other with homework, cooking, cleaning, and other household chores.

Things weren’t always as good, though. According to Daniel’s mom, “[I]t was really hard. It was the anger, he couldn’t concentrate and [it was] just stressful, because you really didn’t know what was going on or why he was like this.” Daniel has since begun taking medication for ADHD and has seen a great improvement. Daniel went from failing most of his classes to being an Honor Roll student. His mom reported that he is much more responsible and everyone is less stressed.

Research & Workshops

The family attributes this improvement to the medication, but also acknowledges that their understanding of Daniel and his ADHD diagnosis has helped a lot. Daniel’s mental health provider has encouraged Daniel’s family to research ADHD and has recommended the family attend workshops on ADHD at a local hospital. Daniel’s mom explained, “Now I really understand what he goes through. . . .you know, the workshops and the suggesting that we research the
disease. I understand more how the brain works with this type of disease and how the medicine corrects that problem.”

Daniel has also benefited from the research and workshops. Not only has he been doing better in school and getting into less trouble, his mom also reports that he is taking responsibility for his actions. “Because it’s not only me understanding the disease. . .I’ve explained to him what [disorder] he has and the purpose of his medication. And so by him recognizing when he’s not on it, by him recognizing when he’s starting not to be able to focus, it’s motivation for him to take his medication because he knows he does better.”

Conclusion

Although everyone agrees that the medication Daniel has been receiving has helped Daniel stay more focused and made it easier for him to control himself, the overwhelming number of references to understanding Daniel and his diagnosis made it obvious that the research and workshops were an important influence on the family’s ability to deal with his behavior. The decision by Daniel’s provider to utilize outside resources has proven to be a critical asset to Daniel’s overall improvement.

Case Study 2: Claire, and Poor Provider Relationships (HMO)

Claire, a twelve-year-old female is currently doing well in the seventh grade at a new private school. She enjoys reading and math and is a good artist. Claire also attends church with her cousin and is currently in the church youth group. Claire and her sister are in the custody of their maternal aunt, because her mother has been in and out of drug treatment programs for the last several years. Claire’s aunt has significant support from the rest of the family and they often spend weekends out together.

Services

Claire was receiving medication management for ADD from her primary physician and a local psychiatrist. However, Claire’s aunt reported that she was dissatisfied with the services she received and ultimately stopped going. She reported that the doctor did not ask her or Claire any questions about Claire’s behavior or how the medication was working, and instead merely prescribed whatever he felt like. According to Claire’s aunt, Claire was on five to six different medications while receiving services. Claire also experienced severe side effects, including erratic behavior, exhaustion, and appetite problems. Not only were the side effects problematic at home, but they also affected Claire’s school performance. Claire’s aunt felt like the doctor was “just giving medicine and not really talking to the person.”

Claire has not been on medication since leaving her provider, but has seen a dramatic improvement in her behavior and school functioning since beginning at a new, private school. Claire’s aunt felt that she was doing much better at the new school, because the school listened to her and understood how to deal with Claire’s behavior problems in class.
Conclusion

The challenges Claire and her aunt experienced while receiving services from her primary care provider and mental health provider highlight the importance of a good relationship and open communication between provider and client. It also shows how important it is to address each case individually and take the family’s cultural beliefs into account. The lack of communication and individualization of services caused Claire and her aunt to seek other ways to deal with Claire’s problems.

Case Study 3: Alex, and a Positive Provider Relationship (HMO)

Alex is in the 8th grade. He is very outgoing and gets along with everyone. Although his mother says he is very smart, he has performed poorly in school and recently failed the FCAT, mostly because he has trouble staying focused in class. Alex lives with his mom and two brothers. According to his mother, there is some sibling rivalry, but they usually get along very well and help each other out.

Services

Alex is currently receiving medication management for ADHD, which has caused problems in his school functioning. Although he hasn’t met any of his goals yet, Alex’s mother reports that he has slowly been improving. Alex, his mother, and his psychiatrist have been trying to find a medication that helps Alex the most.

A couple years ago, Alex changed service providers. Alex’s mom had requested “a compatible” doctor and she feels that she found this in Alex’s current psychiatrist. Alex’s mom said, “I feel like I’m treated like my child’s important. He’s the most important child in there. . .He gets direct, special attention. . .I love that doctor. . . [he] is really interested in the child’s developmental stages.”

Conclusion

Alex and his mother obviously have a good relationship with Alex’s doctor. They have continued to pursue different treatment options with him and are optimistic about Alex’s improvement. Their relationship with Alex’s doctor seems to have fostered a more positive outlook and has left communication open to discuss what treatment options are best for Alex.

Case Study 4: Anthony, and Family Support (PMHP)

Anthony is in the fourth grade where he gets mostly A’s and B’s. Anthony is a great help around the house. He is an excellent house cleaner and he has a lot of patience with the younger children. According to Anthony’s aunts he likes to read and play sports. Anthony’s parents passed away several years ago, and his grandmother is currently taking care of him. His aunts are also very active in his life, taking him on weekend outings and generally helping his grandmother care for him.
Anthony is receiving case management and medication services. His case manager meets with his grandmother at home on a weekly basis and meets with Anthony and his teachers at school on a weekly basis. According to Anthony’s grandmother, Anthony’s case manager really “knew what I was going through, but she not only talked to me, she talked to my children. . . . She talked to Anthony.” Anthony’s grandmother repeatedly expressed how important it was that the case manager included everyone, even her children (Anthony’s aunts), in the development of Anthony’s treatment plan. The resulting plan focused not only on Anthony’s needs, but things that needed to be done to keep the grandmother healthy enough to care for Anthony. Since the grandmother had had a stroke several years ago, maintaining her physical health was very important for being able to treat Anthony.

Conclusion

Family involvement and engagement is very important in any situation, but especially so in this case. Since Anthony’s grandmother is his primary caregiver, maintaining her health was an important part of treating Anthony; and if she were unable to care for him, his treatment would have been more difficult. The family’s providers adapted to this situation well, providing services in the family’s home and at Anthony’s school, and incorporating the grandmother’s needs in the treatment plan. By including everyone in the treatment planning and updates, including Anthony’s aunts, they were also able to utilize the family’s strengths and make sure everyone worked together to help both Anthony and his grandmother.

Case Study 5: Tyrone, and the Client-Provider Disconnect (PMHP)

Tyrone is very energetic and outgoing. He likes to play sports, especially basketball and football. Although Tyrone lives with his mother, his aunt and grandmother actively participate in his treatment. The two of them often transport him to and from appointments, and his aunt attended his most recent IEP meeting.

Services

Tyrone is currently in a third grade ESE class. His particular school works to provide a more structured and supportive environment for children who are struggling in regular school due to severe behavioral and emotional problems. Since beginning at this new school in January, Tyrone has done very well, and according to Tyrone’s mother, both his grades and his behavior have improved. In addition to the school services, Tyrone is also receiving daily therapy from the school counselor and medication management from a nurse practitioner. Tyrone also has a case manager who meets with him and his mother at least every two months.

Although Tyrone appears to be receiving many very supportive services, Tyrone’s mother has expressed concerns about his treatment. According to her, he
cannot swallow the pills he is prescribed. She breaks them up so that he can still take them; however, this reduces their effectiveness, and so is a matter of concern. She indicated that Tyrone has tried several different pills and hasn’t been able to swallow any of them, and none of them have had any lasting results. Tyrone’s mother also expressed that she wanted Tyrone to receive more than just school counseling. She seemed to think the school counselor only saw him as needed rather than daily, and she thought a counselor or mentor outside of the school would be more appropriate. She is also dissatisfied with Tyrone’s medication management. She seems to feel that a nurse practitioner is acceptable, but that a psychiatrist would be better able to deal with Tyrone’s problems taking pills. She said that she had expressed these concerns to his case manager several times, but that she was told Medicaid would not cover these services since Tyrone was already receiving counseling at school and medication management with a nurse practitioner.

Conclusion

Tyrone’s mother is obviously frustrated with the type and quality of services her son is receiving. She feels there are better alternatives than what Tyrone is currently receiving, but has not had much help in pursuing these treatment options. On the other hand, Tyrone’s mother also seems to be unaware of the actual services Tyrone is receiving and what services might be available to her. Better communication and more caregiver engagement might help to eliminate this disconnection between the family’s needs and the provision of services.

Case Study 6: Devon, and Alternative Treatment Options (PMHP)

Devon is in the second grade. According to his mother, he enjoys singing and playing football. In the first grade, Devon had problems concentrating in class; instead of working, he would sing and dance. Because of these problems he was retained in the first grade. In order to bring him up to grade level, Devon was enrolled in summer school.

Services

Prior to starting summer school, Devon began receiving mental health services for his behavior problems. The change was so dramatic that the summer school teachers weren’t sure why he was retained. Devon’s mother says that he no longer whines, and he is not as sensitive as before treatment. Devon’s mental health provider agrees that Devon’s behavior has greatly improved with medication, and that any other services are necessary.

Although Devon’s mother agrees that Devon’s behavior has improved, she wishes there were other services to improve his behavior. She expressed concerns about giving him medication at such a young age, indicating that, “I was always told if you put a kid on medication when they are young they grow up and they have to take their medication.”
Conclusion

This case demonstrates a disconnection between what the client wants, and what the provider is offering. Although medication seems to be working very well for Devon, it does not appear that other treatment options were pursued first. In this situation, Devon's mother might benefit—and appreciate—service alternatives to medication, such as educational workshops and behavior management.

Summary of Research Question 2: What Are the Reasons for Low Penetration Rates in AHCA Area 1?

Although there were no significant differences in the number of reported service access barriers between the types of plans, there were variations in the types of barriers reported. Transportation was a problem for one-third of caregivers. Additional barriers encountered by PMHP caregivers included miscommunication with providers (e.g., a provider missed two scheduled appointments with caregiver), a provider letting their Medicaid license expire, and lack of adequate staff to focus on adolescents. Additional barriers encountered by HMO caregivers included a lack of awareness of available services, occurrence of medication side effects, being told their child does not meet the criteria for services despite problems witnessed by the caregiver, trouble getting through on the phone, and unusual wait times at provider offices. Barriers identified by providers focused on the need for more child psychiatrists (PMHP) and concerns regarding Medicaid reform (HMO).

Over half of PMHP and HMO service users and non-users received emotional, social, or financial help from informal supports. However, non-users of mental health services did not access other behavioral health services, and did not have a stronger informal support system than service users. Mental health service use and subsequent improvement in child functioning facilitated increased use of informal supports.

Research Question 3: How Do Professional Organizations, Providers, and Families Define Quality of Care, and How Should It Be Measured?

The definition of quality of care varies according to individual needs and experiences, and discrepancies between the field providers and families are not uncommon. While providers seek to provide reasonable and appropriate care under the administrative and economic constraints of the mental health plan, parents generally want the best and most appropriate services for their child. Different components of quality care include access to services, assessment, treatment outcomes, continuity and coordination of services, and the nature of the population being served. Quality measures have been developed by organizations representing various stakeholder perspectives, including government agencies (state and county departments of mental health and the Substance Abuse and Mental Health Services Administration), mental health organizations (the American Psychiatric Association), managed care organizations (American Managed Behavioral Healthcare Association), and consumer groups such as the National Alliance for the Mentally Ill (Hermann, et al., 2002).
Caregiver Perspective

Of the 19 caregivers receiving services, 18 stated that they thought their children were receiving quality services from Medicaid providers. When caregivers were asked whether they thought their child was receiving quality mental health services, they discussed client/provider communication, trust of providers, willingness of providers to share diagnosis-specific information, and the ability of caregivers to make changes in their child’s treatment. Table 10 lists several examples of what caregivers consider important for the quality of care their children receive.

Table 10
Caregiver Examples of Quality Service Delivery

<table>
<thead>
<tr>
<th>Example</th>
<th>Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Someone who really listens and who will work for the best interest of the child, instead of their job.” (HMO)</td>
<td></td>
</tr>
<tr>
<td>“When I bring it to the doctor’s attention that my child has been acting out or exhibiting a strange behavior pattern, he will talk to him and ask him why and he waits for an answer.” (HMO)</td>
<td></td>
</tr>
<tr>
<td>“If I have a problem, I let them know and I can change, you know, change anything at anytime.” (HMO)</td>
<td></td>
</tr>
<tr>
<td>“Because they help him. They’re there for him any time he needs them. They tend to his needs as best they can.” (PMHP)</td>
<td></td>
</tr>
<tr>
<td>“They provide the medication to help my baby and they do tests and I didn’t want to believe he was ADHD until we got the test and they showed me a graph on how they determine it. They let me look at everything.” (PMHP)</td>
<td></td>
</tr>
<tr>
<td>“She keeps me informed about problems AND solutions.” (PMHP)</td>
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</tr>
</tbody>
</table>

Provider Perspective

Going beyond the rating of quality of care indicator activities, providers and other professional stakeholders suggested the following considerations for defining quality of care:

- Inclusion of the client’s geographical needs in assessment,
- Patient and family involvement in treatment planning and delivery of care with a family-focused, strengths-based approach,
- Consideration of family issues when evaluating and treating the client’s condition,
- Maintaining a team approach to include the client, family, and providers as team members, Ease of obtaining referrals,
- Communication and collaboration between and among providers and parents and between inpatient and outpatient systems to ensure effective service coordination and continuity of care,
- Adequate access to services including sufficient number of providers and frequency of services,
- Empathy,
- Keeping a child safe,
- Clinical knowledge and ongoing training of providers,
A beneficial client/provider relationship including open communication and bond between the client and provider,
Utilization of evidence-based practices,
Fidelity to the treatment plan,
Child outcomes including acceptable completion of treatment plan goals, and 
Patient and family satisfaction.

One provider defined quality of care as the focus on social and occupational functioning with the goal of restoring functionality to as close as possible to the level of functioning that existed prior to manifestation of the condition while maintaining maximum treatment benefits with minimal side effects (especially regarding medications). Examples from each interview have been integrated into the findings sections for Research Questions 1 and 2, per specific topic.

Providers and stakeholders suggested measuring quality of care via qualitative and quantitative methods, including

Obtaining patient and collateral reports;
Obtaining information from the other systems in which the child is involved;
Reviewing provider records to verify that treatment recommendations are being followed by providers and the family;
Reviewing records for evidence that communication and coordination has occurred;
Examining administrative data;
The use of standardized tests and measures (i.e. the Child Functioning Assessment Rating Scale-CFARS, and Global Assessment of Functioning-GAF);
Length of time between point of contact to screening, referral to evaluation, and referral to therapy;
Number of crisis stabilization unit intakes and readmissions; and
For children in more restrictive treatment settings, examining plans for re-entry into the community.

Similar quantitative and qualitative methods have been recommended in previous research. The Final Report of the Mental Health Statistics Improvement Program (MHSIP) Task Force on a Consumer-Oriented Mental Health Report Card presents a framework focused on the domains of access, appropriateness, and outcomes (DHHS, 1996) with related quantitative and qualitative measures to assess quality of care. The American Psychiatric Association (2002) included access, quality/process/appropriateness, satisfaction/perceptions of care, and outcomes/effectiveness as domains in their overall quality framework, while recommending similarly related quantitative and qualitative measures.

Caregivers (both mental health service users and non-users), providers (those participating in interviews related to children included in the current study and those participating in non–child-specific interviews related to quality of care and evidence-based treatment), and other professional stakeholders rated a list of 36 quality of care indicators on a 5-point Likert scale. The numeric values assigned to
answers were as follows: very important = 5, important = 4, somewhat important = 3, not very important = 2, and not at all important = 1. Tables 11 and 12 present the top- and bottom-ranking quality indicators as scored by caregivers and providers. While the overwhelming majority of indicators received mean scores above 4, an independent t-test revealed significant differences in the means of seven indicators (Table 13).

### Table 11

<table>
<thead>
<tr>
<th>Highest-Ranking Quality of Care Indicators, by Respondent Group</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregivers</strong></td>
</tr>
<tr>
<td>Indicator</td>
</tr>
<tr>
<td>Child/family satisfaction with treatment plan</td>
</tr>
<tr>
<td>Improvement in overall family stability and functioning</td>
</tr>
<tr>
<td>Child’s needs are being met</td>
</tr>
<tr>
<td>Child/family given information about child’s condition, treatment, etc.</td>
</tr>
<tr>
<td>Improved school attendance</td>
</tr>
<tr>
<td>Confidentiality of services</td>
</tr>
<tr>
<td>Improved school performance</td>
</tr>
</tbody>
</table>
The Table 13 presents the quality of care indicators where ratings between caregivers and providers were found to be statistically significant.
Table 13

Differences in Quality of Care Indicators Between Respondent Groups

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Caregivers</th>
<th></th>
<th></th>
<th>Providers/Stakeholders</th>
<th></th>
<th></th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Mean</td>
<td>SD</td>
<td>n</td>
<td>Mean</td>
<td>SD</td>
<td></td>
</tr>
<tr>
<td>Confidentiality of services</td>
<td>27</td>
<td>4.74</td>
<td>.45</td>
<td>34</td>
<td>4.38</td>
<td>.89</td>
<td>.046</td>
</tr>
<tr>
<td>Improved school attendance</td>
<td>27</td>
<td>4.74</td>
<td>.59</td>
<td>33</td>
<td>4.21</td>
<td>.54</td>
<td>.001</td>
</tr>
<tr>
<td>Improved school performance</td>
<td>27</td>
<td>4.74</td>
<td>.53</td>
<td>33</td>
<td>4.24</td>
<td>.56</td>
<td>.001</td>
</tr>
<tr>
<td>Decreased school problems</td>
<td>27</td>
<td>4.70</td>
<td>.61</td>
<td>33</td>
<td>4.30</td>
<td>.53</td>
<td>.008</td>
</tr>
<tr>
<td>Child/family satisfaction with providers</td>
<td>27</td>
<td>4.70</td>
<td>.54</td>
<td>34</td>
<td>4.29</td>
<td>.84</td>
<td>.032</td>
</tr>
<tr>
<td>Child/family satisfaction with treatment plan</td>
<td>27</td>
<td>4.78</td>
<td>.42</td>
<td>34</td>
<td>4.12</td>
<td>.88</td>
<td>.000</td>
</tr>
<tr>
<td>Provider satisfaction of mental health plan design</td>
<td>27</td>
<td>4.70</td>
<td>.54</td>
<td>34</td>
<td>4.26</td>
<td>.71</td>
<td>.010</td>
</tr>
</tbody>
</table>

Although caregivers rated items relating to academic involvement (improved school attendance/performance and decreased school problems) higher on the scale of importance for indicators of quality than did providers, it should be noted that the reduction or stabilization of a child’s symptoms scored highest among providers (Table 11). These differences in ratings do not necessarily indicate a divergence in mental health priorities between caregivers and providers. Caregiver ratings of the school performance indicators may be a reflection of the specific challenges experienced by their children. Providers, on the other hand, may view reduction in symptomatology as the starting point from which specific beneficial outcomes stem.

In addition to examining the views of the groups involved in treatment, it may also be beneficial to recognize the influence of the specific groups themselves. Shumway et al. (2003) examined views of policy makers and primary stakeholders regarding the importance of schizophrenia treatment outcomes. Although both groups placed a high value on functional outcomes, policy makers rated medication side effects as significantly less important than primary stakeholders. The authors point out that this belief of policy makers could make them less likely to allocate financial resources to the purchase of medications that are more effective, yet more expensive than conventional medications. Similarly, the current study’s findings indicate the convergence of views between caregivers’ and service providers’ ratings on some quality of care indicators (e.g., meeting a child’s needs received very high ratings by both groups and there was also agreement between groups on the lowest rated indicators, i.e., minimization of social/economic costs including out-of-pocket expenses and culturally competent
services). However, the significant differences found between ratings on school performance indicators affirms the need for providers to continue to collaborate with families on what areas of functioning are important to caregivers when providers are guiding the treatment planning process.

Another interesting finding from the quality of care indicator data was that caregivers rated improved overall family functioning (mean = 4.78, SD = .51) higher in importance as an indicator of quality than overall child functioning (mean = 4.59, SD = .64). The inverse was true for provider ratings of these two indicators (child functioning: mean = 4.79, SD = .48 and family functioning: mean = 4.58, SD = .61). Although it stands to reason that improved child functioning should also lead to improved family functioning to the extent that child disturbance affects the family dynamic (which may account for provider ratings), caregivers’ higher rating of family functioning as an indicator of quality of care serves as a reminder that the impact of serious emotional disturbance extends beyond the child himself. This in turn is the ongoing impetus for parents, providers, teachers, and other stakeholders who have potential influence on the systems of care in which the child and family are involved to engage in and foster continuing dialogue and collaboration in order to effectively provide services to meet child and family needs.

Upon analysis of survey results, stakeholder rating activities, and national standards, the following framework regarding quality indicators emerged:

**Concerns and Indicators Related to Access**

The following were priority concerns generated from caregivers, providers, and national standards:

- Timely evaluation,
- Comprehensive evaluation,
- Cultural competency (e.g., linguistic access),
- Flexible system-of-care to meet needs of all levels (e.g., full range of services), and
- Communication between systems.

**Concerns and Indicators Related to Appropriateness**

The following were priority concerns generated from caregivers, providers, and national standards:

- Appropriate referrals,
- Treatment plan is individualized,
- Treatment plan reflects professionally accepted guidelines,
- Medications are prescribed based on best available evidence and established protocol/guidelines,
- Services maximize continuity of care,
- Professionalization of staff (e.g., full range of licensed mental health professionals), and
- Training in and application of best practice guidelines.
Concerns and Indicators Related to Consumer Engagement
The following were priority concerns generated from caregivers, providers, and national standards:
Child/family given information about child’s condition/treatment/etc.,
Child/family input is considered and incorporated in treatment, and
Child/family satisfaction with treatment plan.

Concerns and Indicators Related to Outcomes
The following were priority concerns generated from caregivers, providers, and national standards:
Improvement in child’s functioning and stability at home and school,
Child exhibits a reduction or stabilization of symptoms,
Improvement in overall family stability and functioning, and
Child’s needs are being met.

Summary of Research Question 3: How Do Professional Organizations, Providers, and Families Define Quality of Care, and How Should It Be Measured?
Providers spent the majority of their interview time discussing issues of continuity of care, empathy, ease of referral, keeping a child safe, maintaining a team approach, service coordination, and clinical knowledge as they related to quality of care. Indicators they rated the highest included reduction or stabilization of symptoms, timely and comprehensive evaluations, and improvement in overall child stability and functioning. Caregivers placed the most importance on satisfaction with the treatment plan, improvement in child functioning, and child’s needs being met. Indicators viewed as least important by caregivers and providers were cultural competency, minimization of out-of-pocket expenses, and reduced social/economic burden to family. Overall, the quality indicators caregivers and providers ranked as most important fit into four domains: access, appropriateness, consumer engagement and outcomes, which also reflect the domains included in the consumer-oriented mental health report card developed by the Mental Health Statistics Improvement Program Task Force (DHHS, 1996).

Summary and Discussion
Overall, caregivers were positive about their child’s experiences in the system. The majority of caregivers in both plans expressed satisfaction with the coordination of services, including their ability to get in touch with providers and the development of an individualized treatment plan. Although cultural competency was not stressed by either caregivers or providers—most likely due to the lack of ethnic diversity in the Pensacola area—caregivers appreciated the availability of home-based services and Lakeview was complimented several times on their outreach efforts to caregivers. In addition, HMO providers mentioned the importance of a holistic approach to treatment that includes addressing the needs of other family members.
Both HMO and PMHP providers maintained fairly individualized treatment plans and caregivers reported provider adherence to their child’s treatment plan. More PMHP caregivers than HMO caregivers reported being invited to treatment planning meetings, but the majority of caregivers from both plans felt that their feedback was respected and incorporated into treatment plan updates, and most caregivers were satisfied with their involvement in treatment planning.

The majority of children were prescribed at least one medication, and sometimes multiple medications, as part of their mental health services. Although 75% of HMO and 100% of PMHP service users reported improvements in their child’s behavior that were attributed to medication, 44% of HMO and 71% of PMHP service users wished their child could receive more psychosocial interventions as well as medication management. However, medication management also caused some caregivers to feel threatened regarding their parenting ability (e.g., “The school needs him on meds, but I can handle him.”) or were concerned about the negative stigma attached to medicating children (e.g., fear of creating a lifelong need or addiction). A few caregivers also expressed concern over the number of different medications their child received, which sometimes resulted in little if any improvement, and in some cases negative side effects were reported. These concerns, as expressed by both HMO and PMHP service users, should be taken into consideration. Rather than only relying on medication management, providers should include therapy in treatment whenever possible. Positive media campaigns or increased educational outreach to the community may also help reduce the stigma associated with medication therapy, and help caregivers become more comfortable with it.

Concerns related to medication management notwithstanding, caregivers’ report of child functioning as a result of services was extremely positive for both financing conditions. Examples of improvement included decreased attention seeking, fewer school suspensions, and better grades.

Although caregivers reported improvement overall, several barriers to services were discussed. Transportation was cited as a problem for one-third of caregivers. Some caregivers noted that they were unable to obtain other needed services due to funding, and several expressed frustration about not qualifying for services even though they knew their child had problems. In order to overcome these challenges, it could be beneficial for providers to create a flexible funds account to be used for needs not normally covered by Medicaid. Possible uses for such a fund may include bus passes or additional counseling for caregivers and family members. Such non-traditional assistance may help families not currently using behavioral health services to access needed services as well.

In addition, both providers and caregivers reported barriers due to repeated changes in the Medicaid program. One caregiver mentioned difficulties obtaining medication because of changes related to Medicaid’s authorization for medication. Previously, service users only needed their psychiatrist’s prescription to obtain medications, but after recent changes, service users must obtain authorization from both their psychiatrist and Medicaid prior to filling prescriptions. This was seen as just one more hurdle for already overstressed caregivers to overcome. One
psychiatrist also mentioned that sometimes, due to Medicaid changes, service users would even become temporarily ineligible for Medicaid services. During this time, service users are unable to fill prescriptions, attend appointments, etc. In light of these barriers, it may be beneficial to hold focus groups with providers and service users before changes are made to allow for a better understanding of the potential impact such changes may have on service delivery and access to services.

Several PMHP providers also mentioned a need for more child and adolescent psychiatrists in the Pensacola area. One provider stated, “some of the therapists have been pushing their caseload above a hundred.” Providers must then prioritize who they see and how often they see them. Rather than seeing patients once every week or two as they would like, some psychiatrists were only able to see clients once a month. One psychiatrist even discussed having to prioritize patients based on the severity of symptoms; ultimately short-changing clients with less severe symptoms. Some caregivers discussed long wait times for appointments, and one caregiver stopped services because her child's provider missed several appointments. The lack of child and adolescent psychiatrists also impacts families' ability to access services. Another psychiatrist pointed out that due to the shortage of child and adolescent psychiatrists, there was a wait time of up to several months just to get an evaluation. An increase in local funding and local recruitment strategies might help to increase the number of child and adolescent psychiatrists in the area.

Providers also discussed continuity of care, empathy, ease of referral, keeping a child safe, maintaining a team approach, service coordination, and clinical knowledge as components of quality of care. Providers seemed to be especially concerned with stabilizing symptoms and reducing the amount of services needed. Providers seemed to feel that timely and comprehensive evaluations are key to overall child stability and functioning. Caregivers also placed great importance on improvement in child and family functioning, although they put more emphasis on the treatment plan being followed and child’s needs being met than did providers. Although caregivers discussed issues related to out-of-pocket expenses incurred due to treatment, such as transportation challenges, both caregivers and providers put relatively little importance on minimizing out-of-pocket expenses and reducing social/economic burden to the family.

Over half of all users reported receiving emotional, social, and/or financial support from informal sources; however, families not utilizing behavioral health services (non-users) did not have stronger informal support systems than those who did use behavioral health services (users). Caregivers from both plans reported that services for their child had helped to reduce their own stress levels and had increased their ability to make use of informal supports (e.g., if their child is behaving appropriately, it is easier for relatives to provide respite care). Several caregivers also mentioned that therapy for themselves and their family would be helpful in equipping them to deal with their children's needs and thus reducing stress. In light of this, providers should continue to offer caregivers different supports (e.g., emotional, financial, educational) and encourage the use of informal supports.
Providers in both plans employed evidence-based practices. The most commonly cited guidelines were those of the American Academy of Child and Adolescent Psychiatry. While plans in both types of managed care organizations stressed the importance of keeping up to date on best practices, HMO providers were more likely to do this on an individual basis via subscriptions to journals or designing community trainings or giving presentations, while PMHP providers put more emphasis on specific group training efforts.

Limitations

Several limitations existed throughout data collection and should be kept in mind when interpreting results. The research team experienced difficulty locating caregivers. The hurricane that severely damaged the Pensacola area during the summer of 2004 displaced many individuals and caused transportation problems. For example, one caregiver was found at an emergency shelter facility after the research team inquired with neighbors upon seeing that the family’s house was no longer inhabitable. When caregivers were found, many were still under significant amounts of stress from the hurricane.

In addition, providers for child-specific interviews were included in this study based on caregiver identification. While the research team sought to empower caregivers and let them tell us who was most central to their child’s behavioral health services, some caregivers did not know who their child’s provider was. In addition, caregivers often did not know which managed care plan they were enrolled in. This could be attributed to stress from the hurricane and/or ongoing socioeconomic stress of caregivers whose children are enrolled in Medicaid. Several of the caregivers were young single parents who shared that they had trouble meeting their child’s basic needs such as food, shelter, and transportation. Some caregivers also were dealing with significant health and mental health issues of their own.

Additionally, the research team was only able to complete a case (e.g., interview appropriate providers and conduct file review) if a caregiver consented. In several cases, the caregiver felt comfortable with their own interview (payment was given at time of interview), but declined to sign the consent for the research team to talk to other adults that were important in the life of their child.

Finally, the identification of participants from data more than one year old is not preferable, and often not feasible. While attempting to continue this study on the population that generated concerns in the FY 2003-2004 child study, the research team was met with several barriers due to changes with the passage of time (see Table 14 for breakdown of children who had to be excluded from the 269 child mail survey group). Next year’s child study will use a current list of beneficiaries and service users obtained directly from the managed care organizations, and specific to children with SED.
Table 14
Breakdown of Exclusions

<table>
<thead>
<tr>
<th></th>
<th>HMO</th>
<th>PMHP</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Original Number in Sample Still Enrolled in Medicaid During FY2002</td>
<td>112</td>
<td>157</td>
<td>269</td>
</tr>
<tr>
<td>Were Still Enrolled as of 6/30/2003</td>
<td>104</td>
<td>137</td>
<td>241</td>
</tr>
<tr>
<td>Were Still Enrolled as of 6/30/2004</td>
<td>91</td>
<td>127</td>
<td>218</td>
</tr>
<tr>
<td>Children at the same address</td>
<td>-9</td>
<td>-3</td>
<td>-12</td>
</tr>
<tr>
<td>Children turning 18 before 4/30/2005</td>
<td>-9</td>
<td>-17</td>
<td>-26</td>
</tr>
<tr>
<td>Children in foster care</td>
<td>-1</td>
<td>-6</td>
<td>-7</td>
</tr>
<tr>
<td>Children receiving other government funded services (i.e., OBRA)</td>
<td>-5</td>
<td>-9</td>
<td>-14</td>
</tr>
<tr>
<td>Children outside of Area 1</td>
<td>-1</td>
<td>0</td>
<td>-1</td>
</tr>
<tr>
<td>Switched Plans</td>
<td>-4</td>
<td>-2</td>
<td>-6</td>
</tr>
<tr>
<td>Final Sample</td>
<td>62</td>
<td>90</td>
<td>152</td>
</tr>
</tbody>
</table>

Policy Recommendations

In conclusion, the concerns regarding child functioning mentioned previously that were generated from last year’s study were not reflected in the current study. There was tremendous emphasis on the medication of children in Area 1, but caregivers were generally satisfied with treatment and response to treatment. However, they did wish for additional psychosocial interventions. Transportation was seen as the biggest barrier to service use, and children who are not receiving services did not report a significant increase in help from other sources. Service users were more likely to make use of informal supports due to the positive effect of services on their child’s behavior.

The following recommendations are offered as suggestions for improvements to the behavioral health service system in AHCA Area 1:

Where appropriate, providers should start children on both medication management and therapy when a child comes into services, rather than beginning medication and waiting to see if the child needs anything else.

Providers and AHCA should consider positive media campaigns and increased educational outreach to the community regarding the approved usage of medication in child populations, with the goal of reducing stigma and helping caregivers become more comfortable with receiving this type of help for their children.

Greater funding and recruitment should be deployed to increase the number of available child and adolescent psychiatrists.

Supports (e.g., emotional, financial, educational) should continue to be offered to caregivers, since their stability greatly impacts the child’s.

Flexible funding should be available to improve client compliance with treatment and presence at appointments. For example, bus passes could be offered to decrease the transportation barrier, if there is public transportation in the local area.
Medicaid policy or procedures should not be changed without first conducting focus groups with both providers and caregivers, to better understand the potential impact on service delivery and access to services.
References


## Appendix A: Qualitative Data Codes — PMHP Children's Quality of Care Study

### Appropriateness of Services

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess</td>
<td>Type of assessment done and how this affected services received</td>
</tr>
<tr>
<td>Serv Type</td>
<td>Issues regarding type of service received</td>
</tr>
<tr>
<td>Medication</td>
<td>Issues regarding type of medication received</td>
</tr>
<tr>
<td>CC</td>
<td>Cultural competency</td>
</tr>
<tr>
<td>Compr</td>
<td>Comprehensiveness of services</td>
</tr>
<tr>
<td>LRE</td>
<td>Services offered in least restrictive manner</td>
</tr>
</tbody>
</table>

### Access and Coordination of Services

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access</td>
<td>Services are easily accessible/convenient</td>
</tr>
<tr>
<td>Coord</td>
<td>Service coordination</td>
</tr>
<tr>
<td>Ind tx</td>
<td>Tx plan is individualized/appropriate to child/family needs</td>
</tr>
<tr>
<td>Engage</td>
<td>Family involvement in tx plan design</td>
</tr>
<tr>
<td>Updates</td>
<td>How, why and when treatment plan is updated</td>
</tr>
<tr>
<td>Goals</td>
<td>Treatment plan goals are being met</td>
</tr>
</tbody>
</table>

### Evidence Based Practice

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tx guide</td>
<td>Tx plan reflects practice guidelines</td>
</tr>
<tr>
<td>Train</td>
<td>Ongoing training</td>
</tr>
<tr>
<td>Com Prac</td>
<td>Accepted provider community practice/standards</td>
</tr>
</tbody>
</table>

### Quality of Life

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family s/f</td>
<td>Family stability/functioning</td>
</tr>
<tr>
<td>Child func</td>
<td>Child functioning</td>
</tr>
<tr>
<td>Supports</td>
<td>Needed supports in place</td>
</tr>
<tr>
<td>Needs</td>
<td>Level of met and unmet needs</td>
</tr>
<tr>
<td>Improve</td>
<td>Level of improvement for child and family</td>
</tr>
</tbody>
</table>

### Experiences outside the system

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inform sup</td>
<td>Presence and perceived success of informal supports</td>
</tr>
<tr>
<td>Other sys</td>
<td>Involvement in other systems (e.g., school, JJ)</td>
</tr>
<tr>
<td>OOP</td>
<td>Amount paid out of pocket for non-Medicaid funded services</td>
</tr>
</tbody>
</table>

### Quality Indicators

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>QOC-Define</td>
<td>How providers and caregivers define quality of care</td>
</tr>
<tr>
<td>QOC-Measure</td>
<td>How providers and caregivers would measure quality of care</td>
</tr>
<tr>
<td>QOC-Other</td>
<td>Other issues related to quality of care</td>
</tr>
</tbody>
</table>
Appendix B: Items Included in Question Domains

Access to Services
- Are services available for as long as you need them? Please explain.
- Have you experienced any problems or barriers to receiving services? If yes, please explain.
- Has any progress been made on overcoming these obstacles? Please explain.
- How easy is it for you to contact the provider?
- Is this location convenient for your child and family? Please explain.
- Are the times of appointments convenient for your child and family? Please explain.
- Is transportation to obtain services a problem? Please explain.

Service Coordination
- Is there a person(s) who is/are responsible for coordinating the services you and your family receive to prevent service gaps and duplication of services? Who is this person?
- How satisfied have you been with the coordination of services for your child and your family?

Services
- Is there anything about the treatment that is difficult to follow? Please explain.
- How comfortable do you feel with your (child’s name)’s primary Medicaid mental health service provider?
- What would you change, if anything, about the services your child and family are receiving?
- How satisfied are you with the relationships you have with the various providers?
- How satisfied are you with the services offered and provided?

Medication
- Have you noticed any improvement in your child’s emotional state or behavior at home and at school since he/she began taking these medications? Please explain.
- How satisfied are you with the effectiveness of these medications? Please explain.

Cultural Competence
- Has the service provider been able to adapt the services your child and family receive to fit with your values, beliefs, and lifestyle? Please explain.
- In your opinion, does your child’s provider take your culture/background and religious beliefs into consideration when working with your family? Please explain.
Comprehensiveness of Services

Does (child’s name)’s Medicaid plan offer you a choice of types of services for (child’s name)?

Do you have a choice of providers?

Are there services your child or family needs that are not available through Medicaid (e.g., special assessments)? Please explain.

Are you given referrals for these services?

Least Restrictive Environment (LRE)

Do you think your child is receiving services in the most appropriate environment? Please explain.

In your opinion, are the services your child receives provided in the least restrictive setting? Please explain.

Individualized Treatment Plans

At the very beginning of the interview, you shared what you like best about your child and his/her interests? Are these things included in the plan?

You also shared what you like best about your family and its strengths? Are these strengths included in the plan?

Do the services listed in the mental health treatment plan address all of (child’s name)’s mental health needs? Please explain.

Family Involvement in Treatment Planning

Does your child have a mental health treatment plan? Please explain how you were involved.

Were you involved in developing a mental health treatment plan for your (child’s name)?

If (child’s name) is old enough, did he/she participate in the treatment planning?

Were you invited to a treatment-planning meeting?

Were you given sufficient notification to attend? Please explain.

Did you feel comfortable participating in this meeting? Please explain.

Do you understand the treatment plan? Please explain.

Do you understand the meaning of words and terms used in forms or documents provided to you? Please explain.

Has it been explained to you why this specific course of treatment was chosen for your child?

Do you have a specific role in your child’s treatment? Please explain.

Did you sign the case/treatment plan?

Did you receive a copy of the case/treatment plan?

Do you think your input was respected and were your wishes included in the development of the treatment plan? Please explain.

How satisfied are you with the level of your overall involvement in planning the treatment to help (child’s name).
Is there anything you would change about the planning process for services to (child’s name)? Please explain.
Have you been asked what your preferences are for a service provider? Was your request met?

**Treatment Plan Updates**
- Is the plan updated or changed at certain times, or on a scheduled basis?
- Do you or your child participate in these updates?

**Treatment Goals**
- Is the treatment plan being followed? Please explain.

**Child Functioning**
- How are things going for you child overall since receiving services?
- To what extent have services helped your child?

**Family Functioning**
- How are things going for your family overall since your child has been receiving services?
- To what extent have services helped your family?

**Needs**
- Do the services you receive address all your child’s needs? Please explain
- Do the services you receive address all the family’s needs? Please explain.

**Child/Family Improvement**
- How satisfied are you with the level of improvement your family has shown since receiving treatment?
- How satisfied are you with the level of improvement your child has shown since receiving treatment?