Quality of Care for Children with ADHD in New York State Participating In Medicaid Managed Care: A Qualitative Assessment

Report Developed for the New York State Department of Health, Office of Managed Care

Christopher Botsko
Jodi Anthony
Laura Sternesky

November 2006
# Table of Contents

I. Introduction ................................................................................................................................. 1  
II. Evidence-based Guidelines for Diagnosing and Treating ADHD ............................................. 1  
III. Methodology ............................................................................................................................. 5  
   A. Focus Groups with Parents of Children with ADHD ............................................................ 5  
   B. Interviews with Providers ....................................................................................................... 7  
   C. Interviews with MCOs ........................................................................................................... 9  
   D. Training and Monitoring of Interviewers ............................................................................. 11  
   E. Analysis of Interview Data ................................................................................................... 11  
IV. Findings .................................................................................................................................. 11  
   A. The Diagnosis of Children with ADHD .............................................................................. 12  
      1. Parent Perspective ............................................................................................................. 12  
      2. Provider Perspective ......................................................................................................... 15  
      3. Health Plan Perspective .................................................................................................... 16  
      4. Discussion ......................................................................................................................... 19  
   B. Treatment and Monitoring of Children with ADHD ........................................................... 20  
      1. Provider Perspective ......................................................................................................... 20  
         a. Treatment ...................................................................................................................... 21  
         b. Monitoring .................................................................................................................... 26  
         c. PCP and Specialist Recommendations .......................................................................... 27  
      2. Plan Perspective ................................................................................................................ 28  
         a. Treatment ...................................................................................................................... 28  
         b. Monitoring of Care ....................................................................................................... 29  
         c. Recommendations from Plan Interviews ...................................................................... 30  
      3. Parent Perspective ............................................................................................................. 31  
      4. Discussion ......................................................................................................................... 43  
V. Recommendations .................................................................................................................... 46  

Appendix A   Buffalo Focus Group Screening Form  
Appendix B   Focus Group Moderator's Guide  
Appendix C   Provider Interview Protocols  
Appendix D   Health Plan Interview Protocols
I. Introduction

The New York State Department of Health (NYSDOH) is sponsoring a study to assess the quality of care provided to children ages 6–12 who are diagnosed with Attention Deficit/Hyperactivity Disorder (ADHD), are enrolled in Medicaid managed care, and have no comorbid psychiatric diagnosis. The study is comprised of two components:

- A medical record review conducted by the Island Peer Review Organization (IPRO), the State external quality review organization
- A qualitative barrier assessment conducted by Health Systems Research, Inc. (HSR).

This report describes the findings from the qualitative barrier assessment. This assessment was designed to obtain input from parents, health care providers, and managed care organizations (MCOs) on the content of care being provided for ADHD, the existence of barriers to quality care, and to generate recommendations for improving care. Three data collection activities were undertaken for this study:

- Interviews with providers, including pediatricians, family practitioners, and mental health specialists
- Focus groups with parents
- Interviews with representatives of New York State Medicaid managed care plans and behavioral health vendors who work with those plans.

Though the content varied, each of these study activities included questions about the diagnosis, treatment, and management of care for children with ADHD. This report reviews best practices in care for children with ADHD and describes the methodology used for the barrier assessment, the findings from each of the three key-informant groups, and recommendations for developing initiatives designed to improve the quality of care for children with ADHD.

II. Evidence-based Guidelines for Diagnosing and Treating ADHD

ADHD is the most commonly diagnosed behavioral disorder of childhood.\(^1\) Children with ADHD can experience multiple negative consequences including school failure, depression, and physical injury. Studies have shown that certain types of treatment are effective in improving outcomes for children with ADHD. The research on effective care has been translated into guidelines for diagnosing and treating children. This section of the report describes one set of guidelines and some of the key evidence that supports them. The information gleaned from these guidelines was used to develop the study instruments. The study findings will report on the extent to which ADHD care received, provided, or covered by the respondents meets the guidelines and what barriers exist to meeting those guidelines better.

---

ADHD Barrier Assessment

The American Academy of Pediatrics (AAP) published clinical practice guidelines for the diagnosis of ADHD in primary care settings in 2000. This was followed the next year by guidelines for treatment. While other guidelines that have been published, including Practice Parameters from the American Academy of Child and Adolescent Psychiatry (ACAP), the AAP guidelines are the most relevant for this study because the vast majority of children with ADHD and no comorbid condition receive at least part of their care from their primary care provider (PCP), and any quality improvement initiatives undertaken by the NYSDOH are going to focus on diagnosis, treatment, and referral practices of PCPs.

AAP Diagnosis and Evaluation Guidelines. The AAP guidelines recommended that PCPs:

- Initiate evaluations for ADHD among school-aged children who present with behavioral or school problems
- Use Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV), criteria to make a diagnosis of ADHD
- Gather detailed information from both parents and teachers regarding the DSM-IV criteria
- Assess coexisting mental health and learning problems
- Order other diagnostic tests only as indicated on the basis of history or physical findings.

The DSM-IV criteria for ADHD consist of the following:

- A persistent pattern (i.e., present for at least 6 months) of inattention and/or hyperactivity-impulsivity that is more frequent and severe than typically observed in individuals at a comparable level of development.
- Symptoms were present before age 7.
- Impairment from symptoms is present in two or more settings (e.g., home and school).
- There must be clear evidence of clinically significant impairment in social, academic, or occupational functioning.
- Symptoms are not explained by the presence of another mental disorder.

The AAP recommends the use of DSM-IV-based ADHD-specific rating scales for both parents and teachers in the evaluation of children who may have ADHD. Among the scales that meet these criteria are the Conners Revised Parent and Teacher Rating Scales, Barkley’s School Situations Questionnaire, and the Vanderbilt scales. The AAP makes the Vanderbilt scales available on its Web site, and they are included in the Toolkit for Clinicians produced by the National Initiative for Children’s Healthcare Quality (NICHQ) in collaboration with the AAP. The AAP does not recommend the use of scales that assess a variety of behavioral conditions, because studies show

5 AAP. (2000).
ADHD Barrier Assessment

that they do not differentiate children with ADHD adequately from samples of normal, age-matched community controls. Regardless of whether a scale is used, the AAP indicates that the assessment of ADHD requires evidence directly obtained from a child’s classroom teacher or other school professional. While scales that assess a variety of conditions are not recommended, the AAP does say that evaluation of the child with ADHD should include assessment for coexisting conditions, specifically conduct disorder and oppositional defiant disorder, depression and other mood disorders, anxiety, and learning disabilities.8

Treatment and Monitoring. The AAP recommendations for treatment and monitoring include the following:

- Primary clinicians should establish a management program that recognizes ADHD as a chronic condition. This recommendation cites evidence from studies of chronic conditions that indicate better adherence to treatment and higher levels of satisfaction if a comprehensive treatment plan is developed with specific goals, followup activities, and monitoring.
- The clinician should recommend stimulant medication and/or behavioral therapy as appropriate to improve target outcomes in children with ADHD.
- The clinician should provide periodically a systematic followup for the child with ADHD. Monitoring should be directed to target outcomes and adverse effects and should be done by obtaining information from parents, teachers, and the child. The guidelines suggest that once a child is stable, an office visit every 3–6 months is needed to assess side effects and monitor the success of treatment. The guidelines also indicate that followup should be conducted at medication refill, and at this time, families can be asked about the child’s functioning in school and the child’s interpersonal relationships.
- If the child has not responded to two or three medications given at maximum dose, if the child has experienced intolerable side effects, if treatment has not brought the child’s behavior under control, or if there appears to be a coexisting condition that is interfering with treatment, the child should be referred to a mental health specialist.9
- Among the treatment tools included in the AAP’s resource toolkit for treatment and monitoring are sample management plans and a daily report card that can be used as part of a behavioral treatment plan for rewarding a child for meeting target outcomes at home and at school. The cards also can be reviewed by the physician during visits as a way of monitoring the treatment plan.10

Though the two main types of treatment that are recommended for children with ADHD – medication management and behavioral therapy – have been a key part of the treatment repertoire for ADHD for a number of years, the endorsement of their use has been solidified as a result of the Multimodal Treatment Study of Children with ADHD (MTA).

The MTA was a study sponsored by the National Institute of Mental Health (NIMH) to examine a number of different treatment strategies for ADHD that had previously received some empirical support. The MTA assigned children between the ages of 7 and 9 to one of the following groups:

8 AAP. (2000).
10 AAP and NICHQ. (2002).
Medication Management Alone. This treatment consisted of medication titration followed by monthly half-hour visits. During each visit, the provider spoke with the parent and met with the child and tried to determine any concerns the family had about the medication or side effects. The provider counseled parents about any problems that they brought up and provided the parents with educational materials on various subjects as requested. Providers were encouraged to adjust medication when signs of problems presented themselves. Monthly feedback was obtained from the child’s teacher.

Behavioral Modification Only. The families in this group met up to 35 times with a behavioral therapist, mostly in group sessions. These therapists also made repeated visits to schools to consult with children’s teachers and to supervise a special aide assigned to each child in the group. In addition, children attended a special 8-week summer treatment program where they worked on academic, social, and sports skills and where intensive behavioral therapy was delivered to assist children in improving their behavior.

Combined Treatment. This group received both types of the above treatments.

Routine Community Care. This group saw the doctor in their community chosen by their parents. About two-thirds of this group received medication during their treatment phase.11

The groups each received the assigned treatment for 14 months. The findings at the end of treatment period indicated the following:

- All four groups improved over time, but there were significant differences among groups in the rate of improvement.
- For ADHD symptoms, the medication-alone and combined-treatment groups improved significantly more than the behavioral modification and community care groups.
- In a number of other areas, combined treatment had significantly better results than the behavioral modification and routine community care groups, while medication alone did not. These areas included parent ratings of aggressive and oppositional symptoms, internalizing symptoms, teacher-rated social skills, parent-child relations, and reading achievement. Direct comparisons between medication alone and combined treatment did not show significant advantages for individual outcome measures but did show a modest significant advantage for composite indices that summed advantages across domains.
- Combined treatment also had some modest benefits in terms of non-ADHD symptoms, positive functioning, and higher levels of parent satisfaction with treatment. The latter may be especially important in terms of maintaining compliance with treatment recommendations.
- Children in the combined group were able to be treated with significantly lower doses of medication.12

---


III. Methodology

As noted earlier this study consisted of three data collection activities. This section of the report describes the methodology used in each of the three main study activities, beginning with parent focus groups followed by interviews with health care providers and then interviews with representatives from Medicaid MCOs and behavioral health vendors.

A. Focus Groups with Parents of Children with ADHD

The focus groups were designed to obtain input from parents or guardians of children with ADHD about their experiences obtaining and receiving care for their children. In addition, the groups provided an opportunity for parents to provide recommendations for improving care. HSR conducted three focus groups for this study:

- An English-language focus group in Buffalo, NY
- An English-language focus group in New York City (NYC)
- A Spanish-language focus group in NYC.

NYC was chosen because it represents such a large portion of the State population and ADHD cases. There was also a desire to obtain input from parents outside of the city, since it was expected that their experiences were likely to differ. Buffalo was chosen because it had a diverse population and was expected to be a good location for recruiting focus group participants.

For recruitment purposes, IPRO provided HSR with the names and contact information of children who were eligible for the medical record review. Medicaid managed care health plan members were included in this group if they:

- Were between the ages of 6 and 12 years
- Filled an ADHD-related prescription and/or had at least two outpatient visits with a diagnosis of ADHD between January 1, 2004, and December 31, 2004
- Met the enrollment criteria – continuously enrolled from 4 months prior to the date of the initial ADHD clinical event through 6 months following the event, still enrolled in the same plan
- Had a negative ADHD-related medication history
- Had no comorbid psychiatric conditions
- Were not on Supplemental Security Income.

The HSR staff initially recruited participants by telephoning and screening respondents from the list to confirm that their child was being treated for ADHD and that they were still enrolled in the same managed care plan. All eligible participants were offered $130 for their time and transportation and child care expenses. The screening form for Buffalo is included in Appendix A. This strategy resulted in the recruitment of most of the Buffalo participants. However, the strategy proved to be ineffective and inefficient in NYC, because about half of the telephone numbers were disconnected and people frequently did not answer their telephones or return calls when messages were left. An alternative strategy was developed that involved sending a letter in both English and Spanish addressed to the parent of children in the sampling list, informing them that they might be eligible to
ADHD Barrier Assessment

participate in a study related to their child’s health care and mentioning the incentive payment. They were asked to call a toll-free number to learn if they were eligible. This proved to be a much more effective strategy and generated most of the participants for the NYC groups. Once participants were screened and confirmed for the group, they were sent a confirmation letter with information about the group and directions to the focus group facility.

Focus groups were conducted in August 2006 with a total of 12 participants in Buffalo, 11 participants in the English-language group in NYC, and 5 Spanish-language participants in NYC. In the Buffalo group, all the participants who were recruited and screened attended the focus group, all but three confirmed participants attended the English-language group in NYC, but only half of the confirmed Spanish-language participants attended the Spanish-language group. The vast majority of focus group participants were mothers though there was one father in the Buffalo group and one in the Spanish-language group. Seven of the 12 participants in the Buffalo group lived in the City of Buffalo; the rest lived in the suburbs. All English-language participants in NYC were from the Bronx and Brooklyn, while three of the five Spanish-language participants lived in Manhattan, with the other two in the Bronx. Additional information about the characteristics of the focus group participants is shown in Table 4 below.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Race/Ethnicity of Participants</strong></td>
<td></td>
</tr>
<tr>
<td>African-American</td>
<td>25</td>
</tr>
<tr>
<td>Hispanic/Latino/a</td>
<td>39</td>
</tr>
<tr>
<td>White</td>
<td>29</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
</tr>
<tr>
<td><strong>Reported Household Income</strong></td>
<td></td>
</tr>
<tr>
<td>Under $10,000</td>
<td>25</td>
</tr>
<tr>
<td>$10,001–$19,999</td>
<td>32</td>
</tr>
<tr>
<td>$20,000–$29,999</td>
<td>29</td>
</tr>
<tr>
<td>$30,000–$34,999</td>
<td>7</td>
</tr>
<tr>
<td>Over $45,000</td>
<td>7</td>
</tr>
<tr>
<td><strong>Education Attainment</strong></td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>11</td>
</tr>
<tr>
<td>High School Graduate</td>
<td>21</td>
</tr>
<tr>
<td>G.E.D.</td>
<td>29</td>
</tr>
<tr>
<td>Some College</td>
<td>21</td>
</tr>
<tr>
<td>Associate’s Degree</td>
<td>7</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>11</td>
</tr>
<tr>
<td><strong>Child’s Medication Status</strong></td>
<td></td>
</tr>
<tr>
<td>Child Currently on Medication</td>
<td>68</td>
</tr>
<tr>
<td>Child Not Currently on Medication but Previously on Medication</td>
<td>21</td>
</tr>
<tr>
<td>Child Never on Medication</td>
<td>11</td>
</tr>
</tbody>
</table>

The HSR staff moderated the groups at focus group facilities in the Buffalo area and Manhattan. The focus group moderator introduced the topic and provided a set of ground rules for the group.
The Moderator’s Guide included questions on a wide range of topics covering the following subjects:

- Initial diagnosis and treatment for ADHD
- Ongoing care
- Knowledge of ADHD care
- Recommendations for improving care.

A copy of the moderator’s guide is included in Appendix B. For the Spanish-language group the guide was translated into Spanish by a professional translator and the group was moderated by an HSR staff person who is fluent in Spanish.

The groups were taped and professionally transcribed. The Spanish-language group was translated and transcribed in English. Each transcript was reviewed by an HSR analyst and the HSR project manager. Quotes from the transcripts appear throughout the findings section of this report. These quotes are used because they are the most effective means for conveying the experiences of families and the challenges they face as they seek care for their children. All quotes appear in italics, while text added to clarify responses appears in brackets.

B. Interviews with Providers

As part of the study design, HSR planned to conduct interviews with 15 providers. The purpose of these interviews was to find out from providers how they diagnosed children with ADHD, the types of care they provided, how health plan policies affect how they treat children, and their recommendations for improving care. Because the majority of children with ADHD receive care from their PCP, the initial goal was to conduct interviews with 12 PCPs (i.e., pediatricians and family physicians) and three specialists. NYSDOH provided HSR with a list of possible study participants. The criteria for inclusion on the list were:

- The provider made a diagnosis of ADHD for a child aged 6–12 enrolled in a Medicaid managed care plan at some point from October 2003 through June 2006.
- The provider was a family practitioner; a pediatrician (possibly a pediatric specialist such as a developmental or pediatric neurologist), a child psychiatrist, a neurologist, or a psychologist.
- The provider had seen at least 23 individual Medicaid managed care participants for ADHD-related issues.

The goal was to speak with providers who had extensive experience treating the Medicaid managed care population for ADHD. The criteria resulted in a list of 100 providers. The specialty type and location of the providers is shown Table 1 below. Within Western New York, more of the providers come from the Rochester area than any other location. There are 18 providers from Rochester and an additional 2 who are located in the same county as Rochester. This compares to two providers in Buffalo along with two others in Erie County, where Buffalo is located. The high representation of Rochester area providers reflects the fact that upstate providers are far more likely to prescribe
stimulants\textsuperscript{13} and thus were probably more likely to meet the criteria for inclusion in the sampling frame.

<table>
<thead>
<tr>
<th>Specialty Type</th>
<th>Number/Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatrician</td>
<td>67</td>
</tr>
<tr>
<td>Family Practitioner</td>
<td>7</td>
</tr>
<tr>
<td>Pediatric Neurologist</td>
<td>11</td>
</tr>
<tr>
<td>Neurologist</td>
<td>4</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>7</td>
</tr>
<tr>
<td>Psychologist</td>
<td>2</td>
</tr>
<tr>
<td>Child Psychiatrist</td>
<td>1</td>
</tr>
<tr>
<td>Developmental Pediatrician</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Location</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>NYC</td>
<td>21</td>
</tr>
<tr>
<td>Western New York (including Buffalo and Rochester)</td>
<td>41</td>
</tr>
<tr>
<td>Rest of the State</td>
<td>38</td>
</tr>
</tbody>
</table>

The NYSDOH sent a letter to all the providers on the list from the Chair of the NYSDOH Pediatric Advisory Group and the Medical Director at the Office of Managed Care, informing them about the study and that they might be asked to participate. Providers were offered a $150 stipend to thank them for their contribution to the study. HSR developed a script for recruiting providers in collaboration with NYSDOH and IPRO. The original plan was to recruit most of the providers from NYC and Buffalo so that most of them would come from the same areas as the focus group participants. HSR initially contacted providers by telephone to recruit them for the study. Interviewers ran into great difficulties getting past office gatekeepers and thus were often unable to speak directly with providers which limited the success of recruiting efforts. In order to ensure that the provider perspective was included in the study, a decision was made to send a letter direct from HSR to all providers in the sampling list asking them to call a toll free number if they were interested in participating. At the same time, IPRO contacted a number of health plans to ask their cooperation in recruiting providers. One of the health plans in the Rochester area agreed to contact providers on the sample list directly and ask them to participate. These strategies resulted in a dramatic improvement in the recruiting effort. It is important to note that as a result, the providers were a self-selected group and may be more likely than a randomly sampled group of practitioners to practice quality care for children with ADHD.

A total of 16 interviews were completed with providers. Table 2 displays the specialty type and location of the providers. In general, interviews by specialty type reflect the distribution of specialties in the sampling list. However, none of the psychiatrists or psychologists in the sampling list offered to participate, and attempts to contact them by telephone were unsuccessful. The completed interviews included two more specialists than the target of conducting about 80 percent with PCPs. It was initially thought that the two pediatricians who specialized in ADHD care were PCPs, but it

began apparent during the interviews that they were acting as specialists for ADHD cases. While
the percentage of providers interviewed from NYC is very close to the total in the sampling list,
Western New York is slightly overrepresented. In addition, only one of the Western New York
interviews is with a provider from the Buffalo area. Three providers (19 percent of total
respondents) were located in Rochester, and many of the others were in areas adjacent to Rochester.
This reflects the large number of Rochester area providers in the sampling list as well as the results
of the recruitment assistance provided by the health plan contacted by IPRO.

<table>
<thead>
<tr>
<th>Specialty Type and Location of Providers for the Completed Provider Interviews (N = 16)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialty Type</td>
</tr>
<tr>
<td>Primary Care Pediatrician</td>
</tr>
<tr>
<td>Family Practitioner</td>
</tr>
<tr>
<td>Pediatricians Specializing in ADHD Care</td>
</tr>
<tr>
<td>Pediatrician/Specialist (Neurologist/Developmental Pediatrics)</td>
</tr>
<tr>
<td>Neurologist/Pediatric Neurologist</td>
</tr>
<tr>
<td>Location</td>
</tr>
<tr>
<td>NYC</td>
</tr>
<tr>
<td>Western New York (including Buffalo and Rochester)</td>
</tr>
<tr>
<td>Rest of the State</td>
</tr>
</tbody>
</table>

NOTE: The two pediatricians in this category are not board-certified specialists but saw children with ADHD on a referral basis and acted as a specialist for the cases.

Interviews were conducted using two protocols, one for PCPs and one for specialists. These
protocols covered similar topics including:

- Identification of children with ADHD
- Referral practices
- Use of guidelines or protocols for identification and treatment
- Input obtained from families and schools during identification and treatment
- How health plan policies shape identification and treatment
- Types of treatment provided
- Management and monitoring of care
- Recommendations for improving care.

The interview protocols for providers are included in Appendix C.

C. Interviews with Managed Care Organizations

Prior to the start of barrier assessment activities, the NYSDOH sent a letter to all Medicaid MCOs,
informing them about this study and indicating that they would be asked to provide records for the
medical record review and might be contacted for an interview. The purpose of these interviews was

Health Systems Research, Inc.  Page 9
to obtain information about health plan policy and practices with regard to ADHD and to obtain
information about existing or planned quality improvement initiatives in this area.

In consultation with NYSDOH and IPRO, HSR selected 13 health plans and two behavioral health
vendors for interviews. Providers were selected with the goal of including a mix of plans that
covered NYC and other parts of the State, with a special focus on Buffalo, because that was the
location of one of the focus groups. Plans that served more children with ADHD, as determined by
the case record review criteria, were given a priority over plans that served fewer children. HSR sent
an e-mail to the Medical Directors of the selected plans, informing them that they had been selected
for an interview and asking them who in their organization would be the most appropriate
respondent. Among the plans and vendors initially selected, only one vendor was unable to
complete an interview.

Interviews were conducted with representatives from 12 MCOs and three behavioral health vendors
from July through October 2006. One of the MCOs initially contacted referred the interviewer to
their behavioral health vendor as the most appropriate respondent. Three of the MCOs interviewed
utilize behavioral health vendors, and interviews were completed with two of the three vendors that
served these plans. One additional plan indicated that they had a vendor, but it was an affiliated
company and therefore not interviewed.

The MCOs that were interviewed have the following characteristics:

- Seven of the plans are prepaid health services plans that serve Medicaid clients and other
  publicly funded health care program clients only.
- Five plans have both Medicaid and commercial lines of business.
- Eight of the plans enroll Medicaid managed care members in NYC. Three of these plans
  exclusively serve Medicaid managed care clients in the City, while the rest also cover other
  parts of the State.
- Four of the plans enroll Medicaid managed care members in Buffalo, including one plan that
  also serves NYC.
- One plan enrolls Medicaid managed care members only in parts of the State other than NYC
  or Buffalo.
- The three behavioral health vendors each provide services to at least two Medicaid managed
  care plans in New York State and also serve plans in other States.

Interviews were conducted using two protocols, one for managed care plans and one for behavioral
health vendors. These protocols covered similar topics including:

- Whether plans or vendors recommend or require the use of particular protocols or
guidelines for ADHD diagnosis and treatment
- Whether any disease management programs or case management services are provided for
children with ADHD
- Whether there have been any problems locating providers to care for children with ADHD
- Whether there is a utilization review process for ADHD cases
- How care for children with ADHD is monitored
- Whether any quality improvement initiatives have been developed that focus on improving
  the quality of care for children with ADHD
ADHD Barrier Assessment

- Awareness of the new ADHD Health Plan Employer Data and Information Set (HEDIS) measures and how they have affected plan policies
- Recommendations for improving quality of care for children with ADHD.

The interview protocols for MCOs and behavioral health vendors are included in Appendix D.

D. Training and Monitoring of Interviewers

A team of six interviewers conducted all the interviews for the study. The interviewers participated in a half day of training for the project. The training included an overview of the study, the purpose and objectives of the interviews, and a question-by-question review of the interview instruments. Following each interview, the study Project Director reviewed the interviewer notes and used this review to identify topics that warranted more in-depth probing in subsequent interviews.

E. Analysis of Interview Data

Interviewers either entered their information directly into a notes form while conducting the interview or entered their notes following the interviews. A few interviews were taped and interviewers used the tapes as a tool for reviewing their notes, however most interviewers found the taping process to be somewhat cumbersome and felt that asking to tape the interview might interfere with the willingness of the respondent to provide candid responses. Therefore, a decision was made to make taping an optional choice for interviewers. Notes from the interviews were entered into AnSWR, a qualitative data analysis software program developed by the Centers for Disease Control and Prevention (CDC). This facilitated analysis of the data as all the answers to individual questions could be easily reviewed.

IV. Findings

This section of the report details the findings from the study. The findings are organized into two main sections: the diagnosis of children with ADHD and the treatment and monitoring of care. Each section includes four topic areas:

- Parent perspective
- Provider perspective
- Health plan/behavioral health vendor perspective
- Discussion summarizing the key findings and discussing any discrepancies between the various perspectives.

The order of the first three topics varies by section based on which informant plays a lead role in initiating the process.
A. The Diagnosis of Children with ADHD

This section describes the findings from the focus groups and key-informant interviews regarding the diagnosis of children with ADHD. The section begins with the parent perspective because parents are most aware of the child’s history before diagnosis and are responsible for initiating the process that results in the diagnosis of ADHD.

1. Parent Perspective

Parents report similar experiences in terms of when they first began to notice problems with their child’s behavior. Many parents indicated their child exhibited symptoms of ADHD from a young age, from as young as 1 year old to approximately 4 years old. Parents described a range of symptoms, most often noting that their child was not able to sit still or concentrate, was “all over the place,” and was otherwise a “problem child.”

“My son was always very active, getting into everything right off the get-go, as soon as he could start crawling…. It wasn’t a problem though until he started school. Then he didn’t want to sit down and focus. He never wanted to be read to like his brothers did. He got into everything and broke everything. Buffalo

Now he is very active. Very extreme. He has no perception of self-safety. If he was in here, he would run into things, bang into stuff. He doesn’t notice he’s at the top of the stairs and stop to walk down. He is just off. I’ve caught him going down the escalator, and I’m grabbing him because he’s sailing through the air. It was a lot of work. Buffalo

Others described more severe symptoms, such as hitting, throwing things, and other more aggressive behavior:

[When] he was about 8 years old, when he was in school, he threw a chair at a teacher and stabbed a student and was sent to the psych ward. That’s when he was diagnosed with ADHD. He was at the aggressive level of ADHD. NYC English

Some parents also noted that they know that their child is intelligent and has a high IQ but is unable to perform well in school:

I took it on myself to take her to a testing center, just to see. I knew she was very, very bright. I took her to a testing center; they said that she was on an above-average, like a fifth-grade, level in second grade. So I figured nothing was wrong there. I took her to a public school, put her in there. They couldn’t handle her. NYC English

Most parents also indicated that they did not seek treatment actively until the child entered school, when their child’s behaviors became more apparent and more problematic as a result of the transition into a formal classroom setting. One parent described how the problems with her child, that started at age 18 months, finally culminated in an ADHD diagnosis when the child entered school:
He was just all over. He couldn’t sit still. We couldn’t feed him. We couldn’t put him to sleep. He couldn’t stay still for a few minutes. It was really bad. The doctor told us, “He is young; let’s see.” I always asked about it, but until he was in kindergarten and playing around, the teachers had a very tough time with him. We didn’t consider medication until he really had to sit when he was 6 and the teacher was always throwing him out of the class. They couldn’t have him there. That’s when he started [medication]. NYC English

Several parents in the NYC group described being in “denial” about the severity of their child’s behavioral problems for some time after the problems initially appeared. This denial and delay in the start of treatment was often mentioned in tandem with parental resistance to medication, which is discussed below.

Parents described teachers’ reports of their children’s disruptive and/or inattentive behavior as a primary motivating factor in seeking diagnosis and treatment; several indicated that the child’s school gave them a choice among seeking treatment, taking their child out of school, and having them put into special education classes. The latter consequence was considered particularly grave in NYC, where parents had a very negative perception of the school systems’ special education programs:

This year, I have to decide: either I give him medication and he will stay like in the regular class, or you go to special ed classes. And I believe I don’t want him to go there. NYC English

Well, I shouldn’t say “try”; they actually imposed it. If my son was to go to school, he had to be on the meds. Buffalo

However, while teachers’ reports of disruptive behavior were often one of the reasons parents sought treatment, parents report varying levels of knowledge among school personnel with regard to ADHD and varying availability of resources for diagnosis and treatment. One parent stated that “no one actually said ADHD” and so she took it upon herself to seek out resources and learn more before approaching a health care provider to pursue ADHD testing. Another parent described her difficulties in getting her daughter properly diagnosed:

As far as testing, I wasn’t able to get anyone to diagnose my daughter with anything. They just considered her a problem child. I actually had to go online myself and go to a teacher Web site and download a questionnaire for the teachers as well as for the parents and anyone that has any kind of interaction with her. I had to download that myself, print it out, and I had to give it to her two teachers and ask them to fill out the form and just little circles, yes or no. It took them 2 months to get that back to me. It was just yes or no questions…very simple things…and it took them 2 months to get it back to me. NYC English

In the words of another parent:

They was talking about taking him out of the class and putting him in special ed. But the school my son went to, nobody helped me. I went out on my own. One day, I found help for him in 1 day on my own. NYC English
Other parents had more positive experiences with their child’s school. One parent noted that her child’s school provided them with referrals to providers specializing in ADHD. Another parent noted that her son’s school has a mental health clinic, which she described as a “humongous help.”

The first point of contact in the health care system regarding diagnosis is generally the child’s pediatrician, but sometimes it is a psychologist or psychiatrist. A few parents mentioned calling their health insurance plan or asking their pediatrician for a referral to a specialist while going directly to a specialist was far more common in NYC. Several parents felt that their general practitioners and pediatricians were not informed enough to care for their child’s condition and thus referred them to a specialist.

A few parents described problems with delays in diagnosis and misdiagnosis. Misdiagnoses included learning disabilities and mental retardation. Additionally, several parents stated that ADHD is secondary and/or comorbid to other conditions their child has, such as lead poisoning, learning disabilities, central auditory processing disorder, and chronic health conditions related to prematurity. However, some of these comorbidities may have been assigned within the school system and so may not appear on the child’s medical record. Learning disabilities in particular are frequently assessed by the school system, and information about them is not always conveyed to the child’s health care providers.

About half the parents who participated in the focus groups stated that the primary method of ADHD diagnosis was the use of questionnaires filled out by them, their child’s teacher, and others close to their child. A few remembered being asked to keep a journal of their child’s behaviors. One parent stated that her child’s school-based therapist observed her child in the school setting. Only one parent cited the use of specific criteria – the Physician’s Desk Reference criteria for ADHD diagnosis. A number of parents admitted to having trouble recalling exactly what they were asked to do during the diagnostic phase.

Most parents indicated that either they or their child’s physician spoke to the school and/or had teachers fill out questionnaires. About half noted good communication with the various health care providers and teachers involved in their child’s care, but a few stated that there is poor coordination between different health care providers and between providers and the school. One parent reported carrying her child’s file with her to make sure that all those involved in her child’s care had the same information. Parents felt that it is important and often necessary for them to act as primary advocate for their child’s care.

Parents felt that information given to them by their child’s health care provider during the diagnosis process was helpful although several mentioned that they could use more information and took it upon themselves to research ADHD online. As previously mentioned, parents often started the diagnosis process with strong feelings about whether they would be willing to accept medication as a treatment option:

*I took him to the doctor, and she diagnosed him. I never wanted to put him on medication. That was just something I never wanted to do.* Buffalo

*I was dead set against [medication]. I have friends and family members that have their children on…Ritalin. When Ritalin first started, well, Ritalin was an experimental drug, and I didn’t like*
A few parents mentioned having doctors suggest medication while the child was in preschool, and most had a very negative reaction to that idea. Given their initial reluctance, parents also described a need for information regarding what to expect when their child started medication, which is not always fulfilled. This topic is explored further in the treatment section of the report.

2. Provider Perspective

The main topics in the interviews with providers regarding diagnosis were the use of guidelines and assessment tools.

PCPs report that they are aware of and use a variety of ADHD diagnostic guidelines and criteria, including DSM-IV, AAP, and ACAP guidelines. All of the providers interviewed use some type of assessment tool given to both teachers and parents. One provider has his office’s nurse gather information directly from the school and often finds that there is no need to do an additional assessment, because one has already been done or enough information is available to complete the diagnosis. The Vanderbilt and Conners scales were the two most popularly used assessment tools, with most providers utilizing the Vanderbilt at least partly, because it is included in the AAP’s ADHD Resource Packet. Providers note that all these guidelines are useful to varying degrees, in particular the Vanderbilt scale, which was described as a “nice benchmark” and “short and easy to score.” Most providers reported conducting in-depth interviews with parents as part of the diagnostic process. However, it is clear from the details which they provided that the thoroughness of the interview varies. Several providers mentioned using some of their own forms to supplement the diagnostic process, including forms used to obtain a medical and psychosocial history from parents and elicit feedback from teachers. Providers also emphasized that they use criteria or guidelines as supportive material in diagnosing children rather than as strict decisionmaking protocols to which they must adhere rigidly.

Providers cited several issues with available guidelines, including a lack of criteria and guidelines for children with comorbidities (almost half of their patients). One provider said her clinic has adopted the Achenbach Scale because the providers feel that it does a much better job than Vanderbilt or Conners at identifying comorbidities. However, some of the providers did feel comfortable with the ability of the Vanderbilt and Conners scales to identify signs of comorbidity and to help them determine whether they needed to make a referral to a specialist. Providers also noted that the guidelines did not come with practical information about how to integrate them into their practice routines. This critique was made even of the AAP’s ADHD Resource Packet, which is specifically designed as a toolkit that clinicians can use to implement the AAP guidelines.14

PCPs report rarely referring children to specialists for a diagnosis unless comorbidities are involved. Providers note that it often takes weeks or months to obtain specialist/referral appointments. However, access to specialists is not considered a major problem in NYC, and providers interviewed there indicate that specialists are more likely to treat children with ADHD. Specialists, for their part, note that all children have to go through their PCP before seeing them. Referrals to specialists come from PCPs, other patients, and schools, with the schools most often taking the lead in advising parents to have their child assessed.

3. Health Plan Perspective

ADHD care has not been a major focus of Medicaid MCOs. This, however, seems to be changing as a result of the new ADHD HEDIS measures and increased focus on quality from Medicaid. The main reason that ADHD has not been considered a priority is that it has not been viewed as costly or problematic and thus has not been the focus of quality improvement efforts. A number of health plans representatives interviewed said that they have not analyzed care or costs related to ADHD, so their approach to managing care for it is based on assumptions. This section of the report describes current plan practices and discusses some of the areas where plans are considering putting more focus.

Guidelines. Six of the 12 managed care plans interviewed have no guidelines for assessing children with ADHD. Two of the plans without guidelines are in the process of adopting them, and one other plan is discussing the development of a disease management program for children with ADHD. Among the plans that do have guidelines, one plan does not have its own guidelines, but its behavioral vendor does. Because the plan serves NYC, where specialists are more likely to treat children with ADHD, these guidelines cover most of the children treated for ADHD. One plan just created guidelines in 2006. One plan endorsed the AAP guidelines and another endorsed the ACAP guidelines. Two plans have their own guidelines, with one set based on the AAP guidelines and the other comprised of a mix of other organizations’ guidelines. Two of the three behavioral health vendors have guidelines, and the one that does not indicated that they do provide information about the DSM-IV criteria and tools to determine care for children with ADHD.

One of the plans currently in the process of adopting guidelines has made the identification and effective treatment of children with ADHD a priority. As part of this process, the plan has convened an Advisory Committee to address what policies and procedures to implement; this includes reviewing existing diagnostic criteria and determining whether AAP or other guidelines would be most effective. The plan recognizes that pediatricians are primarily responsible for diagnosing ADHD and believes that they are underdiagnosing this condition. It hopes that the development of guidelines will address this problem. In addition to engaging pediatricians, the plan hopes to increase the involvement of parents. It has developed fact sheets that include information and treatment options for ADHD and would like to display them in pediatric waiting rooms. The intent is that parents will read this material and subsequently initiate a conversation with their pediatrician if they are concerned that their child's behavior meets diagnostic criteria. These forms are straightforward and based on AAP guidelines.
One representative from a plan without guidelines noted that an informational booklet given to the plan’s PCPs includes information on all behavioral health disorders, including ADHD, and covers diagnostic criteria and suggestions regarding when to treat or refer to a specialist. Providers are given information on these suggested diagnostic guidelines through mailings from the health plan (which are not necessarily ADHD specific), as well as the health plan Web site. Other plans note that guidelines are made available to providers upon request.

It is important to note that guidelines are largely treated as recommendations and are not used to monitor care. One plan representative noted that if an ADHD case is reviewed, it will be examined to determine whether guidelines have been followed, but the representative also noted that reviews of ADHD cases without comorbidities are rare. Mainly, a review will occur if a child is hospitalized, which generally does not apply to these cases.

One behavioral health vendor is attempting to provide information about ADHD care, including diagnosis to PCPs through the use of a hotline staffed by behavioral health specialists. They have gotten few or no calls on the subject.

Providing Information to Parents. Only one health plan and one behavioral health vendor report sending information about ADHD to families with a child diagnosed with ADHD. The health plan sends parents educational materials and resources about parenting and is designing a Web site to make resources available to parents. A representative for this plan felt that parents should be given more information on the management of ADHD that reinforces the importance of medication adherence but also places a greater emphasis on parenting strategies that support treatment. The behavioral health vendor indicated that information sent to parents of children with ADHD who are seeing behavioral specialists includes questions to ask the doctor, safety tips for children with ADHD, resources, and a NIMH booklet. All this information was made “brief and to the point” in order to encourage parents to use it. One additional plan highlighted ADHD as the health topic of the month on its Web site in October 2006. There are links to information for both members and providers. One behavioral health vendor has abandoned an effort to send information about ADHD to parents who are already seeing a behavioral health specialist. The vendor determined that there was poor buy-in and interest from parents in the information they were providing. It is not clear whether this resulted from the quality or content of the information or other factors. One possibility is that parents who have been referred to a specialist already have been given a considerable amount of information about the condition.

Among plans not providing information to parents, some representatives noted that the plan may not know necessarily when a child is diagnosed, and others suggested that providing this information is left to the discretion of providers. Additionally, the fear of appearing as though the health plan is “second-guessing [providers’] decisions” keeps one health plan from directly sending information to parents.

Quality Improvement Initiatives. Plans described three quality improvement initiatives that addressed the diagnosis of children with ADHD. One plan that implemented ADHD guidelines in the past year developed the guidelines by assembling a quality committee, which was composed of an internal physician committee and community physicians. The committee conducted literature reviews and research, received feedback from community physicians, and distributed them to outside organizations for professional review. The guidelines include:
ADHD Barrier Assessment

- Information related to identification and treatment for children 6–12 years old, which includes a symptom checklist and criteria
- A list of applicable billing codes
- A bibliography with physician resources
- A sample cover letter to school principal that child is in need of evaluation
- A sample physician summary of medical assessment
- Recommendations for followup by physician, parent, and school
- The prescriber’s authorization for administration of medication in a school setting
- Handouts for parents and a parental resource list (in English and Spanish).

A behavioral health vendor has developed a quality improvement initiative focused on prevention. This initiative replaced an earlier effort discussed above to send information to families with children who were already diagnosed with ADHD and were seeing a behavioral health specialist. This vendor is the same one that has developed a call-in line for PCPs. The vendor has been extremely active in trying to address ADHD because their data show that children who are initially diagnosed with ADHD often later develop comorbidities. The quality improvement effort is a primary prevention effort that identifies children who are not already diagnosed. The rationale behind this approach is to increase early identification of ADHD and to prevent comorbidities by focusing on high-risk children. Relying on research from the CDC which indicates that children with ADHD have higher accidental injury rates and higher medical costs than children without ADHD, the plan stratifies its population based on claims data. Families with children ages 6 and up who have six or more pediatric visits or who have any accidental injuries, excluding children already diagnosed with ADHD, are sent a letter with a modified Vanderbilt screening tool. The letter suggests that parents complete the screening tool and send it to the vendor. If the screen is positive, the results are sent, with the family’s permission, to the child’s pediatrician. The overall return rate of the screening tool is 9 percent, with the Medicaid population having a higher rate of return of 12 percent. The vendor reports that this is a very unusual occurrence, as the Medicaid population is generally less likely to participate in screening activities. Almost one-quarter (23 percent) of children screened have tested positive for signs of ADHD, with a considerably higher rate (38 percent) among the Medicaid managed care population. These children have been referred for further assessment.

The vendor has received some negative feedback from parents who were upset or angry that they were sent the screening tool in the first place. Some parents feel that the plan should not be making assumptions about their child’s condition or should leave the child’s health care to the parents. The plan estimates that it has received complaints from about 1 out of every 100 parents who receive the tool. This contrasts with a larger effort at screening postpartum women for depression, which resulted in no complaints.

Another plan is conducting regular case reviews that it uses to review the diagnosis and collect data for the HEDIS measures. These reviews are initiated when the first medication prescription is issued. Nurses conduct telephone case reviews with the prescribing physician’s office. The nurses check to see if a behavioral health assessment has been completed. When cases are missing claims for an assessment, it is often because a school psychologist completed the assessment and did not bill the plan.
One plan is currently developing a quality improvement initiative related to ADHD. This plan became concerned when, as a result of the medical record review conducted for this study, it found that doctors were not providing documentation of the diagnosis. The plan is taking steps to remind providers that in order for a child to meet the criteria for ADHD, the child must have impairments in at least two settings (i.e., school, social skills, home); and that input should be sought during the diagnostic process from the member, school, and parent. While the medical record review raised some concerns, the plan is uncertain whether this is the result of poor record keeping or actual deficiencies in following diagnostic criteria.

Finally, one behavioral health vendor indicated that it does have two quality improvement initiatives related to screening and diagnosis in place, but not for the New York State Medicaid Managed Care plan with which they work. The first of these initiatives encourages parents and providers to make sure that they screen siblings of children with ADHD for the condition. The second initiative encourages mothers of children with ADHD to obtain screening for depression, since there is evidence that these mothers are prone to depression.

4. Discussion

This section brings together key findings about the diagnosis of ADHD from all three of the data collection activities for this study. Disagreements among respondent types are noted. These findings will be utilized later in the report to develop recommendations.

- **The Role of Schools.** Schools are a primary motivator and initiator for ADHD diagnosis according to both parents and providers. Parents in NYC reported being in denial about the extent of their child’s behavioral problems until the child entered the school setting and they were required to take action. Some parents felt coerced by the schools into having their child treated for ADHD, and it is important for providers to understand this, as it affects how parents view the process and their attitude toward treatment. Three physicians suggested that teachers are so eager to have children medicated that they exaggerate problematic behavior on rating scales. Despite their critical role in initiating diagnosis, parents reported that schools are not always well-informed about the condition and the diagnostic resources available to parents.

- **Guidelines.** While half of the health plans do not currently have or endorse specific ADHD diagnostic guidelines, all providers interviewed indicated familiarity with some form of established guidelines or criteria and adapt them to their own practice. At least one health plan recognized a need for more information on guidelines and has developed an internal committee to adopt guidelines. Several providers mentioned issues with currently available guidelines, including a lack of guidelines for children with comorbidities, a lack of information on how to integrate the guidelines into their practice, and a lack of information on how to assess for learning disabilities during diagnosis. Providers do not look to health plans for guidelines. It is not clear how the adoption of guidelines by health plans will change how care for ADHD is provided although adoption of guidelines may help health plans determine where to focus their own quality improvement efforts.

- **Knowledge of ADHD Diagnosis Among PCPs.** Most PCPs feel comfortable with their ability to diagnose ADHD with no comorbidities or with typical comorbidities such as conduct disorder and oppositional defiant disorder. They reported being considerably less comfortable with cases characterized by more complex comorbidities. One behavioral health
vendor has opened up an information line for PCPs to call if they have questions about ADHD, but it has gotten little to no response. The vendor suggested that this is because it does not work with PCPs on a regular basis and thus has not developed a reputation as a resource for PCPs. In order to be successful, the vendor speculated that they would have to do much more outreach to PCPs.

- **Information.** While several parents expressed a need for more information on ADHD, health plans generally left the task of providing information to parents up to the discretion of the provider, and most health plans are not sure what their providers give to patients. A behavioral health vendor that attempted to provide information to parents of children with ADHD who were seeing a specialist abandoned the effort, because it found that parents were not using the information. However, part of the issue with this latter effort is that the information may have come too late in the process to be useful for parents.

- **Parental Attitudes Regarding Medication.** Most parents began the diagnostic process with a strong reluctance to medicate their child. Sometimes this resulted from observing children who have been medicated or from fears of addiction, but usually it involves more of a general discomfort about giving a child medication to treat behavioral problems.

### B. Treatment and Monitoring of Children with ADHD

This section of the report describes the findings from the interviews and focus groups with regard to the treatment and monitoring of children with ADHD. The findings from the provider interviews are discussed first because providers play the key role in determining the course of treatment.

#### 1. Provider Perspective

This section reports findings on the provider perspective on the treatment and monitoring of care for children with ADHD. The section is organized by four topics:

- **Responsibility for Care.** What type of provider is usually responsible for the care of children with ADHD?
- **Treatment.** What are the key findings regarding the treatment of children with ADHD? This section is divided into subsections including:
  - Medication
  - Counseling and Behavioral Therapy
  - The Role of Schools and Teachers in Treatment
  - The Physician’s Perception of the Role of Health Plans in Caring for Children with ADHD.
- **Monitoring.** How do providers monitor the care they provide to make sure that there are no complications and to determine whether their treatment is effective?
- **Recommendations for Improving Care.**

**Responsibility for Care.** As noted in the Methodology section of the report, 11 PCPs were interviewed for this study. This included nine pediatricians and two family practitioners. All but one of the PCPs reported that they assume responsibility for the management of the child’s ADHD if there are no comorbidities. Providers indicated that for children without a comorbidity, ADHD treatment is relatively straightforward, and they feel well-equipped to provide care. Many PCPs
continue to treat children with the most common comorbidities, mainly conduct disorder and
oppositional defiant disorder, but usually they send the child to specialists if they exhibit more
complex comorbidities or if the child does not respond well to treatment. The one PCP who does
not assume responsibility for children with ADHD regularly was the only PCP interviewed in NYC,
where there is relatively easy access to mental health clinicians. He explained, “We refer to the
behavioral clinic for evaluation and followup consultations, because they can see children for 1 hour,
while the primary care clinic appointments are 15 minutes.”

Once a child is referred to a specialist, the specialist tends to play a key role in managing ADHD.
Two specialists indicated that if a child is stabilized on medication, they try to get the PCP to
manage the child’s care. However, most commonly, the specialist assumes responsibility. This is due
to a number of factors, including the parent’s preference, the specialist’s perception that many PCPs
do not feel well-equipped to handle these cases, and the views of specialists that PCPs often do not
provide comprehensive care. It should be noted that most of the PCPs that were interviewed
indicated that they are comfortable handling ADHD; however, that may be a product of the way the
sample was selected. The PCPs who were interviewed for this study all had a good deal of
experience treating children with ADHD, and those with more knowledge of the subject were
probably more likely to volunteer for the interview. As discussed further below, the specialist’s main
critiques of PCPs treatment involved them not paying enough attention to learning disabilities and
other related conditions or comorbidities and not providing comprehensive behavioral management
treatment and family support beyond medication.

a. Treatment

Providers were asked what types of treatment they provided to children with ADHD and what
challenges they faced in providing these treatments. The main treatments provided by PCPs and
specialists were medication and counseling. Sometimes they referred children to additional
treatment, this being a more common practice among the specialists. This section describes what
providers said in terms of the types of treatment they provided.

Medication

All the providers interviewed regularly use medication to treat ADHD. However, their perception of
this as a best practice for children with ADHD differs. Many of them, especially the PCPs, are
strong advocates for the use of medication and will work hard to convince parents to put their child
on medication. A few PCPs believe that once a child with ADHD becomes stable on medication,
the problem is solved. If the child continues to have behavioral or learning issues, then there is a
comorbidity, which needs to be identified and treated. Other PCPs and all the specialists who were
interviewed disagreed with this view of treatment for ADHD. One physician reported that all
children with ADHD should receive supportive psychotherapy because of the social aspects of the
disorders and that the family should receive counseling as well. Another provider explained that,
ideally, he starts with behavioral therapy to see if that can address the problem before he prescribes
medication. Importantly, however, both these physicians stated that they are unable to follow this
practice for all their patients, given the lack of mental health clinicians in their communities.

For those patients whose parents choose medication, all providers follow a similar treatment plan
with slight variation in frequency and duration of visits. Once diagnosed, the child is given a specific
medication and dosage. The child is then seen by the physician every 1–3 weeks to monitor the
reaction to the medication. The dosage is raised or the medication is changed until the patient is
stabilized. Once stabilized, the children are monitored every 3–6 months, with 3 months being more
common due to the need to renew prescriptions.

Most physicians interviewed start the child at a relatively low dosage and slowly increase it until the
parents or teachers report that the problems are addressed. Only one provider reported starting at a
relatively high dosage. He works in an inner-city clinic where patients often miss appointments. He
believes that he has to show an immediate change in the child; otherwise, the parent will not be
motivated to continue to bring the child in for care. He summarized this practice by saying, “I do a
hard dose because I do not want to wait and then lose them.”

Providers report a number of issues related to using medication for treatment of ADHD. The most
common issue is parents’ reluctance to use it. A number of PCPs reported that parents are
influenced by misinformation and ideologically based critiques of medication. In addition, parents
reportedly fear the side effects of medication and worry that their child may become addicted. These
challenges are addressed somewhat differently among providers, and some of their strategies are
highlighted below:

- Some doctors inform parents that they always can reconsider their decision about
  medication while they continue to monitor the child's condition. One provider reported
doing this through visits on a quarterly basis, while another one indicated that this is done
during regular well-child visits. In both these cases, the provider did not try to have them
access any alternative treatment such as behavioral therapy.
- Another provider encourages parents to read the book *The Challenging Child* and talks to them
  about how to manage their child's behavior. The clients whom she serves are mainly very
low-income, inner-city residents, and she offers this only if she thinks the parent has the
education level, stability, and motivation to implement the suggested strategy. If the child
continues to have problems, she will re-educate the parents about the utility of medication.
- A few providers suggest that parents try the medication for at least a couple of weeks. One
  provider says that he explains that the medication stays in the body only for a short time, so
they can stop at any time if there is a problem. Providers say that, assuming the diagnosis is
on target, once the parents see an improvement in their child's lives, they usually want to
stay with the medication.
- Many providers emphasize to the parent that the child is not achieving her potential because
  of the condition. A few of them give AAP provided handouts about parenting a child with
ADHD and/or and refer them to ADHD-related Web sites.
- One provider offers alternatives such as contacting the school to provide extra time for
testing, smaller classes, and individual attention.
- Only one of the PCPs reports that he makes a special effort to convince parents who refuse
medication to seek out behavioral management therapy. He indicated that there is a
behavioral therapist located near his office. The specialists generally treat these children with
therapies consistent with behavioral management therapy and sometimes refer them to other
sources for parenting training.

Compliance is another challenge with medication that was identified by the providers interviewed.
Either parents forget to refill the prescription, or they believe that once the symptoms of ADHD
disappear, they can end treatment. A few providers attributed these difficulties to the hereditary
character of ADHD, which means that parents’ organizational and time management skills are not strong. Two providers noted that parents often do not renew their prescriptions for the summer. Providers had mixed views on the idea of medication holidays for summer or weekends, with a few strongly advising against it, a few others seeing it as a strategy to help minimize increasing tolerance to medication that then requires an increase in dosage, and many simply seeing it as something that some parents inevitably will do. Some providers emphasize to parents that ADHD is a chronic and often lifelong problem. Others take the perspective based on experience that some children eventually give up the medication. Many do not discuss the issue at any length. One provider said that a particularly effective strategy to ensure better compliance is for the school to dispense the medication. One physician mails the prescriptions to the homes of patients if the family is stable and if she has a long, established relationship with them, because this increases compliance.

Counseling and Behavioral Therapy

A small number of providers reported supplementing treatment with counseling, behavioral therapy, or other strategies. Counseling and behavioral therapy referrals for ADHD-diagnosed children without comorbidities are rare: one PCP estimated that he referred to a psychologist for about 5 percent of his cases. Only one PCP said that involving a therapist or psychologist is a regular component of treatment.

Generally, if the child has oppositional defiance or conduct disorder in addition to ADHD, the PCP will continue to manage his or her care. Only if the comorbidity is more extreme, for example, bipolar disorder, will he or she refer to a psychiatrist. As one provider exclaimed, “If I referred straight ADHD cases, the social workers wouldn't have enough time to do their job.”

Both the specialists and the PCPs reported that the resources simply do not exist to get children and their parents the mental health support they need. One of the contributing factors to the lack of therapy is the shortage of mental health clinicians across most of the State. Many providers cannot find timely ongoing counseling or therapy for their patients. Because of this, they often triage their patients and refer only children with psychiatric comorbidities to mental health services. One PCP did say that he worked hard to convince parents to put their child on medication, but if they declined, he referred them to a nearby behavioral treatment clinic. He was the only physician who suggested that behavioral treatment was easily accessible.

NYC was one exception to these referral practices, as noted above, where we learned from both physicians and parents that a psychiatrist, psychologist, or therapist saw children with ADHD regularly. However, even in NYC, it did not appear that many of these families were receiving behavioral therapy as delivered in the MTA. Most of the therapy described by the providers involved the child alone and did not include parents or teachers.

Most physicians provide informal counseling during the diagnostic visit and continue to do this during monitoring visits. The specialists were much more likely to discuss in-depth counseling strategies than the PCPs were. The specialists said that they routinely include topics such as environmental modifications, importance of good communication with schools, and behavioral management techniques. PCPs tended to be vaguer and mentioned things such as promoting consistency; regular bedtimes; and, for a few who thought it important, nutritional diets.
Providers described conducting brief education and counseling sessions with ADHD patients and their families. A few said that they use counseling to set realistic expectations of the medication with parents and to help parents realize that it is not a panacea. A few others also provide guidance on topics such as appropriate discipline, the importance of not criticizing the child, and how to reward them. As one provider stated, “At school, ADHD kids are always being told that they’re ‘bad,’ or they feel embarrassed all day long. I use the phrase with parents, ‘Catch the kids being good.’ It really works and amazes parents.” Most PCPs provide brochures on ADHD and Web site suggestions. The specialists, again, were much more specific about the types of educational materials and strategies they use with parents and provided specific examples such as Collaborative Problem Solving, developed by Ross Greene. The specialist who cited this method said that it provides family-led strategies to use in the home, communication techniques with teachers, and other things that parents can do to help address their child’s condition.

Only two PCPs discussed providing, or referring to, behavioral therapy. One physician tries to personalize treatment by teaching organizational and communication skills and using relaxation techniques. The other provider spoke at length regarding the benefits of parent group behavioral management therapy and the lack of the availability of these services. In his opinion, the only evidence-based practice besides medication is behavioral management training with a group of 5–10 couples or parents learning together. Ideally, these groups would be conducted once a week for 10–12 weeks. The groups are interactive and particularly focus on ADHD. The two primary interventions that he thought have proven effective are as follows:

- The COPE Program, by Charles Cunningham in Hamilton, Ontario. The government of Canada provides funding for the provider’s clinic to conduct COPE with parents free of cost.
- Incredible Years, by Carolyn Webster-Stratton. This is for slightly younger children (up to 7 or 8 years old), but the provider thinks that research is showing it to be effective.

He attributes the limited availability of these programs to health plan policies that cover only one-on-one talk therapy or play therapy rather than parent training and education. Most parents cannot pay for such services, and therefore the first line of treatment becomes medication. Other physicians are unsure whether behavioral therapy is offered in their community. Two said that there are some neighborhood-based programs that they think offer parenting education, but their knowledge of these programs is very limited. Providers outside NYC put behavioral management training in a category with other mental health services. These services are seen as limited, require a long wait before appointments, and are thus reserved for more serious cases particularly those with comorbidities or families with serious problems.

A number of the specialists agreed with the PCP who viewed group parenting classes as a gold standard for behavioral management. One specialist wishes that his hospital had parenting classes – particularly in the management of ADHD children – and that these classes should be reimbursed by the MCOs. Many of the parents are under a lot of stress, have low socioeconomic status, and do not have the skills to parent a child with ADHD necessarily. This extra support thus would be extremely helpful. He said, “In Diabetes there is a health educator; asthma, there is a health educator. But for ADHD, they still rely on one-to-one therapy. Unfortunately, the psychiatrists have too many patients and not enough therapists. We should have health educators to deal with issues of discipline, limit setting – things like that.”
Similarly, a number of providers described the importance of the availability of a nurse or social worker, or perhaps even someone from the health plan, to counsel families on managing ADHD. Two providers suggested that home visits can be a very useful strategy to help families.

**Role of Schools and Teachers in Treatment**

The PCPs interviewed reported regularly obtaining information from teachers during the initial medication dosing. Many send out multiple assessment scales to help them determine the appropriate dosage. They primarily use the Vanderbilt tools or Conners Scale, though two providers did mention communicating through telephone calls and written notes during the titration process. Two mentioned that some children also will also have daily diaries for teacher to record behavior, but this method is clearly not used very often. It is also rare for the PCP to attend an Individualized Education Plan meeting designed to plan how a child’s disabilities will be addressed in the school setting. Most physicians do not see themselves as having a role here, and only two specialists mentioned that they see part of their role as assessing and evaluating learning difficulties that may be related to or confused with ADHD.

For the most part, communication with teachers is limited to the initial period, when medication dosages are being determined, or if something changes in the child’s behavior and their dosage needs to be reevaluated.

One of the biggest challenges in obtaining information from teachers is finding the opportunity to communicate with one another. The PCP is seeing patients when the teacher is available, or the teacher is in class when the PCP is available. Providers say that very rarely are teachers against using medication, and very often they are the ones who initially suggest to the parent that the child may have ADHD. Three PCPs, in fact, reported that at times they feel that the teacher is so eager to have the child on medication that they exaggerate the issue on the assessment forms. This is why the parent forms and views are also critically important.

Many PCPs would like teachers to receive more training on ADHD and behavioral management. They find that there is often misinformation and misunderstanding of ADHD, which sometimes results in desire for overmedicating, undermedicating, or not allowing supportive strategies such as giving the child more time to complete assignments. One provider described how the University of Buffalo currently has a grant from the Department of Education to provide behavioral management training for an entire school and then teachers complete individual daily report cards for each child on medication. These report cards are then used to assess the effect of medications on behavior.

One PCP described that her Latino patients seem to struggle more in school, yet she does not receive many referrals for ADHD for them. She believes that this may be a case of lower expectations for Latino children in the school system.

**Physician’s Perception of the Role of Health Plans in Caring for Children with ADHD**

None of the providers were aware of any guidance or tools that Medicaid managed care plans offer to assist with the diagnosis or treatment of ADHD, nor did they think such assistance was necessary. There were concerns, however, that there is not a consistent policy regarding medication across plans. PCPs found it confusing and burdensome to determine which plans allow what medications. Often, one plan allows one type of medication without preapproval while another plan requires
preapproval. The same two plans may have opposite policies about another type of medication. In addition, physicians increasingly report plans declining to cover particular types of medication. However, when probed, most physicians reported that these concerns are mainly a result of commercial plan policies, not Medicaid managed care.

There is also an issue of being paid for the time spent communicating with teachers and parents. Some providers stated that there is no provision in Medicaid managed care to pay for this communication, which often takes a lot of time. As one physician explained, “Usually the parent gives me the wrong name; I have to track the teacher down, etc.” Additionally, one doctor reported wanting to see the parent to discuss side effects and reports from school, both of which are time consuming, but seeing the child is unnecessary. However, he is not reimbursed unless the child also attends the appointment.

Two PCPs spoke passionately about the inappropriateness of plans trying to “assist” in the management of care. In one case, a patient had a seizure disorder, which the PCP entered in the child’s medical record. However, the neurologist indicated in the record that this diagnosis was questionable. The provider made this clear to the parents and made the decision to put the patient on seizure medication and watch the patient very closely. The managed care plan asked the physician whether the child was a seizure patient, and the physician said, “No.” Despite this, the plan contacted the parents and began to educate them on treating seizures. This completely confused and concerned the parents. Another PCP wants to be able to refer to a developmental pediatrician, but the child’s plan will allow referrals only to a psychiatrist or psychologist. This PCP has asked for justification regarding this decision for 2 or 3 years, but has not received an adequate response. He is under the impression that they do not trust him to make the best decisions for his patients.

PCPs who want to use counseling or behavioral therapy more often report that health plans make this difficult. Obtaining more education and counseling for parents is a struggle, and group classes, as stated above, are seen as impossible. One provider described that health plan policies will not allow him to conduct evaluations for the learning disabilities that often accompany ADHD. Instead, they require the school to conduct the evaluation, and the schools in his area are sometimes reluctant to do so. Without this evaluation, parents are not able to access the counseling and education that their child needs. Another provider explained that if he wants to bill the visit as “evaluation and management,” he is required to spend at least 50 percent of the visit providing counseling and education, which is not realistic given the other important aspects of the visit. He is also required to record the “time in,” the “time out,” the number of people who participated, and the resolution, which he considers burdensome.

b. Monitoring

As noted earlier, most providers see children on medication about every 3 months, with two saying that it is every 6 months if the child appears to be stable. Only one provider said that prescriptions are sometimes sent out without seeing the child or speaking directly to the parent. This provider said that if the child appears stable and she has worked with the family for a long time, she will mail the prescription to the family.

Providers were asked how they determine whether their treatment strategies were effective. When asked whether they conduct formal, written mutual goal setting with the parents, most providers answered, “No.” Some of them said that they develop informal goals with parents, such as “Child to
ADHD Barrier Assessment

enjoy and be successful at school” or “Child should have a happy family life.” Two did indicate that they develop target outcomes for patients that aim for improvement in their main symptoms (e.g., school difficulties, relationship difficulties). Most use informal interviewing strategies with the parent, with most of them supplementing this with the periodic use of assessment tools for parents and usually also teachers.

All of the providers interviewed reported sometimes using assessment tools in monitoring care for ADHD. About half of them use the tools on a periodic basis to assess the child’s condition with the period between administrations ranging from 3 months to a year. The other half of them use the scales only if there is a concern or evidence that there is a need to adjust medication. As with diagnosis, most of them use the Vanderbilt, with the Conners Scale being the second most popular. Providers felt that these tools are very helpful in the management of the condition, because they identify the issues the child is continuing to have (e.g., inattentiveness, aggression, a specific problem behavior). It also captures the teacher’s response to the child being in treatment. As noted above, the scales are the primary means by which most providers communicate with teachers. Providers differed in the extent to which they supplemented their use of scales with additional information. All of them held discussions with parents about the child’s progress, but it was clear that the depth of these discussions varied. A few of them collected additional information from schools, including one who used a daily report card.

Providers reported satisfaction with the assessment tools and do not see the need for additional ones for children with only ADHD. However, some expressed an interest in having tool forms that are able to assess learning problems and depression more effectively. Providers’ views differ about their responsibility for addressing learning issues with some, particularly the specialists, thinking that it is a critical component of comprehensive ADHD care and others thinking that schools either should be responsible or are better equipped to evaluate and treat these problems.

c. PCP and Specialist Recommendations

The providers who were interviewed had a number of recommendations to help improve care for children diagnosed with ADHD:

- Most recommended that steps be taken to increase access to behavioral therapy and particularly support and education to parents. This includes the need to reimburse for the use of evidence-based behavioral management practices (e.g., group parent education classes).
- One physician suggested that other plans should replicate BlueCross BlueShield of Western New York’s practice of sending doctors data regarding the medication compliance of their patients.
- Two PCPs suggested that plans should replicate what was done for asthma, including publicity and education about guidelines and preventive care. A similar campaign would educate parents, teachers, and providers alike.
- One physician suggested that there should be an open formulary for which medications can be prescribed for children with ADHD instead of being limited to only the ones a specific plan covers and which may not be the best for the child. One physician, who thought Medicaid was much better than commercial plans in this regard, recommended that
ADHD Barrier Assessment

Medicaid continue its formulary policies and not move toward the practices of the commercial plans.

2. Plan Perspective

This section reports findings on the plan perspective on the treatment and monitoring of care for children with ADHD. The section is organized into the following parts and addresses the following questions:

- **Treatment.** Do plans endorse specific guidelines for treatment? Do they send materials to families about the condition? Do they have any type of disease management program? What challenges do they see in providing treatment?

- **Monitoring of Care.** Do plans have utilization management programs for children with ADHD? How has the development of the new ADHD HEDIS measures affected them? What quality improvement initiatives have they developed or are they considering for the ADHD population?

- **Recommendations.** What recommendations did plan representatives have about improving care for children with ADHD?

a. Treatment

All of the plans with guidelines for diagnosis use the same guidelines for treatment. As noted earlier, 6 of the 12 managed care plans interviewed have no guidelines for treating children with ADHD, though two of them are in the process of adopting them. One plan interviewed described how providers would prefer to receive information and guidance from their association rather than from a plan. He also said that it is not appropriate for each plan to develop policies, because there could be conflicting information. Instead, guidelines should come from a higher or more universally authoritative source. One of the behavioral health vendors said that it has created a packet of information for PCPs and for behavioral health specialists. The packets include a list of medications that are FDA approved, the comorbid conditions for which the child should be screened, how to assess and treat these conditions, and how to choose and implement treatment plans. The vendor believes that the mental health specialists are much more likely to use the guidelines and materials than the PCPs, probably because the vendor has a closer relationship with the specialists.

Almost none of the plans send materials about the condition and treatment to families of children diagnosed with ADHD. Three plans have information on their Web site for parents regarding ADHD. One plan has developed a new initiative to be implemented in September and October 2006. The plan will identify children with ADHD through claims data and will send the parent a packet which includes a letter from the Medical Director; a brochure with frequently asked questions; and information regarding the importance of treatment, keeping appointments, and sticking to medication schedules. The package also will include an appointment planner and medication record pamphlet. The same package will be sent to primary care and mental health providers so that providers can share it with their patients. The plan also includes online courses for providers for continuing medical education credit, including ADHD courses.

Similarly, almost none of the plans have a disease-specific management program for children with ADHD. About half of the plans do have a non-disease-specific case management program to which
patients can be referred or self-refer, but this is usually for very complicated cases and often triggered by hospitalization. Only one plan reported a disease-specific management program for children with a diagnosis of ADHD, although the children must be on medication. Case reviews take place and are initiated at the first medication prescription. There is a telephone intervention center staffed by nurses who complete the case reviews and then compile this information in a practitioner profile. The nurses conducting the review look for a behavioral health assessment that confirms a diagnosis of ADHD, and they also check whether a provider obtains a minimum medication compliance of 70 percent. It is very common that the nurses who do the record reviews find that there is no claim filed for a behavioral health evaluation, because often a school psychologist completes this. The intervention center follows up with the prescribing pediatrician and school psychologist to make sure that this documentation is put into the file.

Plans are aware that there is a shortage of behavioral health providers, but most indicated that they thought that this was not a particular issue for children with a diagnosis of ADHD and no psychiatric comorbidity because they are usually treated by PCPs. One plan does have an initiative to address the shortage for children with more complex conditions. They are partnering with the School of Psychiatry at the University of Buffalo to conduct behavioral assessments for children through a fast-track referral completed within 24 hours. They then send their treatment recommendations to the pediatrician. This is reserved for the more difficult ADHD cases and children most challenging to diagnose. They also work with the Center for Children and Families at the University of Buffalo. This center offers parenting training and summer camps specifically for children with ADHD. Currently, parents have to pay for these services, but the plan is working on an arrangement to include the center on its provider list and make these services available to their members.

Most plan representatives thought that Medicaid managed care coverage was very comprehensive and compared favorably with that offered under most commercial plans. Plans indicated that commercial plans tended to have more restrictions on medication. Those that were asked specifically indicated that parents generally could receive classes, counseling, or training sessions in behavioral therapy if their child is diagnosed with ADHD. The one area where there seemed to be limitations was in the area of educational and learning disability assessments. Some plans indicated that these were not covered because they were the school’s responsibility; one plan seemed to suggest that they could be covered but that the plan preferred to defer to the school on this issue because it was the school’s area of expertise.

b. Monitoring of Care

Only two plans have a utilization review process for children with ADHD served on an outpatient basis, although neither process is exclusively for ADHD patients. For one plan, a utilization review is triggered if the child has more than 12 visits in a year. One plan conducts a regular review of medication claims, and if a prescription is not filled, it informs the doctor. This type of review is under consideration by a number of other plans as well.

All the plan and vendor respondents except two reported being aware of the ADHD HEDIS measures. The one set of respondents who were unaware included a Plan Medical Director and a representative from the plan’s behavioral health vendor. The Medical Director appeared to be unaware because the issue was considered the responsibility of the vendor, and the informant from the vendor was unaware because he was a Medical Director and HEDIS measures are the
ADHD Barrier Assessment

responsibility of the vendor’s quality improvement unit. At this point, it appears that the HEDIS measures will affect how plans approach ADHD, but it is too early to tell exactly what changes will take place. The general sense is that the development of HEDIS measures does lead plans to pay more attention to a particular condition. At this point, only one of the plans has collected and analyzed the required ADHD data, and thus most are unsure how well they are performing on the measures.

Three plans have implemented or are implementing what they see as quality improvement initiatives. The first was mentioned above as part of the disease management program. This plan analyzes whether physicians are obtaining an acceptable rate of medication adherence and whether they are completing appropriate referrals to behavioral health services. This is part of a phased-in initiative which soon will include a parental profile that examines medication adherence and access to needed behavioral health services and parenting classes. Another plan is developing an initiative that was mentioned in the diagnosis section of the report. In this initiative, whenever a prescription is written for a stimulant or Strattera, an outreach letter will be sent to the provider and to members. The provider will be reminded that they need to see the child at least three times within the first 180 days that the child receives treatment. Case record reviews also will be conducted to examine whether the appropriate visits are being conducted and properly documented.

A number of other plans indicate that they are exploring the development of quality improvement initiatives related to ADHD. One plan reported that they definitely will be implementing a quality improvement initiative related to the HEDIS measures. Another plan indicated that they had heard of another plan’s activities that they are considering adopting, which involve organizing conferences about ADHD care, telephone consultations to answer questions, and mailings geared to the pediatrician to help them better understand ADHD.

c. Recommendations from Plan Interviews

Health plans representatives interviewed recommended a number of strategies to improve the quality of care for children with a diagnosis of ADHD.

- A few plans suggested a mass media campaign to inform parents, providers, and teachers about ADHD, “There is a need to disseminate evidence-based information, especially with a somewhat controversial disorder such as ADHD.”
- A few also noted the need for a larger parental component in ADHD care to provide parents with tools to manage children with these special needs. Parents need more than medication to manage their child’s condition and need to be made aware of these other resources. Parenting classes are an important option for consideration.
- One plan reported a need to train providers to submit claims which include a full diagnosis to address the issue of underreporting. This interviewee suggested several reasons for lack of diagnoses on claims, including stigma and the incorrect perception that providers will not get paid for mental health care.
- Many plans recommended efforts to strengthen collaboration of providers, specialists, parents, and schools, though there was a great deal of uncertainty about how this could be done. One plan suggested that electronic medical records offer the best hope for coordination of care. Another suggested that Medicaid allow payment for “collateral contact,” wherein providers are paid for speaking with teachers and social workers. One plan
representative in NYC said that school-based clinics and providers are providing extensive amounts of care to the plan’s members but that the plan is unable to determine anything about the content of this care, because even if they obtain records, the school uses completely different codes. He said that in the interest of quality, it is important that the health plan is aware of the content of the care provided in the schools. As far as he knows, the schools never bill for this treatment. He would be happy to reimburse the schools for providing care to members, if he knew what they were doing.

- Creation of “ADHD evaluation centers” was suggested by one plan respondent. These centers would be centralized locations where ADHD can be properly diagnosed and treated. The length of the testing (2.5 hours) is more than any “regular provider” can do, so having a centralized location would help with more systematic, appropriate diagnosis and care. Once the children are diagnosed and a plan of care is set, they can return to their PCP.

3. Parent Perspective

This section reports findings on the perspective of the parents who participated in the study groups on the treatment of children with ADHD. The section is organized into five topic areas and addresses the following questions:

- **Access to Care.** What challenges do parents experience in accessing care for their children?
- **Medication.** How do parents view medication? What is their experience with treatment, including medication? How do they view the outcome of this treatment?
- **Behavioral Therapy, Counseling, and Other Alternatives or Supplements to Medication.** What alternatives are offered if a parent declines medication? What supplemental treatments are offered if medication is used? How do parents view these other treatments?
- **Parent Knowledge and Access to Information and Support Services.** What information are parents provided about their child’s condition? What support services have parents used? Of what support services do they need more?
- **Communication Among Providers, Schools, andParents.** What has been the experience of parent’s in terms of communication among the various individuals and organizations involved in their child’s care?

**Access to Care**

Most parents report no problems in accessing PCP care for their child. They are more likely, however, to experience long delays when trying to obtain an initial appointment with a psychiatrist or psychologist, especially if it is a provider with a good reputation for treating children with ADHD or other behavioral problems. One woman in Buffalo had to wait a year to get an appointment for her child with a clinic that specialized in ADHD care, although waiting a few months for services is more common. This is mainly an issue in Buffalo with most parents in NYC are able to access mental health care fairly easy. Often the bigger issue is locating a provider who they feel best meets their needs. Two parents in NYC experienced confusion on the need for referrals, which delayed care, but it was unclear whether this was a result of health plan policies or the parent’s confusion over how managed care works.
Only one parent in NYC appeared to be unable to access the amount of care that her child needed, but from her description, her child had severe problems that went well beyond ADHD:

There is a certain amount of visits for psychiatrists, certain amount of visits for the therapists, and a certain amount of medication. And if he runs out of his meds, or if he runs out of his visits, my only option is to take him to the psych ward, have him admitted overnight for him to get treatment.  
NYC English

A number of parents in NYC spoke about barriers to care due to Medicaid Managed Care. Unlike Buffalo, where the issue was never mentioned, the NYC English-language group got into an extended discussion about the hassles involved with managed care. One participant summed up the discussion by contrasting managed care with the old system of straight Medicaid:

With Medicaid, I didn’t have a problem, but now with these new health insurance plans that is attached with the Medicaid, now is a whole bunch of nonsense, and it makes you want to get off of it. NYC English

Some of the parents in the NYC focus group believed that the only way to get ADHD medication was through a psychiatrist. They were convinced that a pediatrician or family practice physician was not allowed to prescribe. Two parents reported difficulties when they tried to change managed care plans and enroll in one that they thought would be better for dealing with their child’s health care issues:

Respondent 1: I don’t know how to get this insurance off, and I even gave them a disenrollment form. They won’t disenroll me.  
Respondent 2: You know what you have to do? You have to go down there yourself. I had one, and it was giving me a hard time. And I called on the phone, and they wouldn’t do anything. They did the same with the forms. NYC English

Very few parents described other barriers to care beyond the waiting lists for behavioral health. One Spanish-language participant indicated that work sometimes prevents parents from following through with their child’s treatment:

Sometimes, parents are also at fault when treatment is not effective, because due to our work, we do not attend the appointments. NYC Spanish

Medication

Once the child was diagnosed with ADHD, parents found themselves making difficult choices on treatment strategies. Parents commonly reported that the physician’s first suggestion was for the child to use medication:

The first thing the pediatrician wanted to do was to give him medicine to control him. He prescribed Ritalin. As a mother who was looking for a way for her child to get better, I began giving it to him.  
NYC Spanish

Very few parents readily welcomed the use of medications, however. They had fears related to addiction, side effects, and stigma, yet they also wanted to do what was best for their children:
I never wanted to put him on medication. That was just something I never wanted to do; as a recovering addict myself, I never wanted to put him on medication. But she was like, “Okay, Mom, I need to help him.” Buffalo

I looked for a lot of information. I spoke to a lot of doctors. I have a sister who did a Ph.D. in Special Education. I used to say I wasn’t going to give it to him. As parents, we thought that if we gave him the medicine, that he was going to use drugs. NYC Spanish

While establishing medication and dosage, about half the parents reported completing forms about the child’s behavior and also asking the teachers to complete similar forms. In some cases, there was extensive use of questionnaires:

I took him to [provider name]; he specializes in children. We constantly was filling out questionnaires asking about his behavior, certain times of the day the things he would do. Even when they first tried him on the medication, the doctor sent something home for me to monitor and stuff to give to the teachers to keep filling out. Buffalo

Two parents in Buffalo who were involved with the same clinic described the use of journaling to describe behavior, and they found this to be very useful:

[Journaling] is useful because you can document what happens at the time so that when you see the person, the doctor or the psychologist, you have actual things that went on instead of trying to remember when you’re there and you get talking about one thing and forget to ask about the other things…. It just keeps you a little bit more organized. Buffalo

As noted earlier, a number of parents were unable to recall exactly what they were asked to do during the period when their child was first diagnosed and began treatment.

Once parents decided to use medication, determining the appropriate medication dosage was “trial and error.” It was reported as a very difficult time for parents, children, and siblings:

It’s hit or miss. The right medication. The right dosage. “We’ll try a little bit of this; we’ll increase it a little more. Oh, that’s not working either. Well then, let’s try this…. And so, by the time it’s getting into the child’s system, you’ve lost part of the school year. It’s nasty for the parent. It’s nasty for the teacher. It’s nasty for the siblings, because nobody knows what you’re going to get and what you can expect. Buffalo

Respondent 1: When on Ritalin, he wanted to commit suicide and even had thoughts of stabbing us. He was hearing voices in his head. We put him on Strattera, and it works fine.
Respondent 2: We had just the opposite. On Strattera, he heard voices. He tried to kill his sister with scissors. We put him on the Ritalin, and it’s different…. What I’m fearing now is liver damage. Buffalo

For some parents, this initial experience with medication was enough to make them decide not to use it anymore:
They [the school] can’t force him to take medication. I’m not with that for my son. I’m not going to let them put him on medication. He tried it, and he went berserk. Buffalo

I took him to a psychologist, and she gave him medicine. It made him drowsy. He would not eat or sleep or do anything. It made him worse. I decided on my own to take that away. He has behaved the same in school. He has not changed. I did not see any improvement with the medicine. NYC Spanish

Yet while most parents thought not using medication was ideal, for many parents there were no other viable alternatives, and most who tried it saw some positive results after their child was medicated:

We went through all the parenting courses, and nothing worked…. Once on small doses of Adderal, he did, like, a 360. It was like, "Wow, I can actually have conversation with him; he can actually sit down and read something." Buffalo

I give him the medicine so that when he gets to class, he can focus on what the teacher is doing instead of having his mind wander around. The medicine does not make him down. He plays basketball and is as active as any child. NYC Spanish

I find my son’s self-esteem is so much better since I started medication. I was so against medication, I just couldn’t think of it. But I was talked into it by doctors, and I think I’m doing the right thing, because I see this whole – the way he thinks about himself, the way he talks about himself – he’s happier. And he is able to learn better. And he is accepted by schools. NYC English

Other parents have had less successful experiences with medication, and that has made them skeptical of it:

They were both diagnosed with ADHD. Then they both were put on Strattera. That didn’t do anything at all for them. Then they were both put on Risperdal, which really didn’t do anything either. Then they are both on Adderal XR now. It doesn’t so much do anything, but the doctor now, the psychologist, now keeps trying to talk me into putting them on Ritalin, and I keep telling him, “No, I hear too many bad things about it.” Buffalo

I went back to the doctor, and I told him I was no longer going to give my child that medicine, because he sleeps all day and does not want to eat. He switched to Adderal, and the same thing happened. My son would take the medicine and vomit. I decided not to give my son any more medicine, and I looked for another type of treatment with psychologists and things like that, but not with the medicine. NYC Spanish

Some parents indicated that medication helped their child complete their school work, but they still had behavioral issues that were causing difficulties for them at school:

Respondent 1: Yeah, my 8-year-old is able to complete her school work, but she just has that counter about her, like if someone bothers her or hits her, she will lash out. Respondent 2: Mine is like that, too. NYC English
He’s been on a little bit of everything, and I watch him like a hawk. I just agreed in 2004 to put him on the Ritalin where he is manageable. I still bend over backwards…. Just got a note Friday: he kicked, bit, scratched, and injured another student. Buffalo

For others, their children did well for a while but now are facing difficulties:

So the medication helped him, but he’s 13 now, and he’s been on it since then [since first grade]. So it’s like, he is getting immune to this, or he’s moved from Adderal to – now the older he gets, the worse he gets. As [in] being suspended 15 times out of the school year. Buffalo

Many parents also reported that when faced with decisions regarding treatment, they felt ill-equipped, because they did not understand enough about ADHD, so it was difficult to know if they were doing the “best” thing:

He [the therapist] asks me what I think. If I think she should go higher. If I think she needs to go lower. If I think she needs extended release. I’m like, “I’m not the therapist. I’m not the psychiatrist here. You should be able to tell me this. I’ll tell you how she is doing, but you should be able to tell me whether or not you think she should go higher or lower.” NYC English

A few felt more comfortable with their role and were willing to make these dosage-related decisions:

The doctor can’t possibly know how your child is behaving all the time and how she or he is outgrowing this medication, because he is growing. The dosage should have to change as they grow. So I’m actually – I will tell the doctor, “You know what? I seen it at, like, 3:00. Those extended release really isn’t doing so well anymore. Because she is not doing – she used to be able to sit through her homework, and now it’s not.” So he’ll say, “Do you think we should increase the dosage?” And I say, “That’s sounds like a good idea. Let’s try a few more milligrams.” NYC English

Parents often felt that the PCP did not have adequate knowledge or information to care for their child with ADHD:

We take them to the doctors, and these doctors are not geared to ADHD. There are groups for cerebral palsy, but nothing for ADHD. [If] I could have just sat like this when [he was first diagnosed], I think it would have been so much better for me. I could say, “Listen, you can go here; they are going to talk to you about it.” I felt like a guinea pig. I felt like I was making my son be a guinea pig. Even when I put up resistance, it was like, “You have to try this.” Because no one gave me a strong support. They gave me support, but they didn’t say, “Okay, come on; we gonna walk through this; we gonna go do this,” where I felt secure in what I was doing. Buffalo

Some families were able to find specialists who were more knowledgeable about the condition and resources available for treatment, but that sometimes took a while:

Once he started going to his counselors who actually knew about ADHD, experienced and knew about kids, they actually were able to tell us what was out there, where we could go. But my general doctor – I am not going to say be cared less; they just weren’t informed; they weren’t geared on it. Buffalo
Parents received different advice on the consistency of dosage, with a number of parents reporting that either their doctor told them not to give medication on the weekends or during summer holidays, or they as parents chose not to use medication during these time periods because they were afraid of their child building an immunity to the dosage and then having to raise it or because they or their spouses were uncomfortable with the idea of giving the child medication:

They don’t want him to take the medicine on the weekend or through the summer; they want it to run its course. Buffalo

It was very hard for my husband. He cannot accept the fact that my son needs medication. I don’t give it to him every day, because he does not need it every day. When I don’t give it to him, I run the risk that the police will take [unintelligible]. Sometimes I worry so much about not giving it to him, but I want him to enjoy the world. NYC Spanish

At least one parent felt that now that her child was over the ADHD, she could begin to wean him off of medication:

So that’s why I was thinking, you know, when you said, “What do they do when they get older?” It’s like, basically, you can kind of train your kid in the process on how to respect others: “Don’t come to somebody and yell and scream at them. You know, come to them; you want to act grown; come to me like you’re grown and respect me.” So basically, you know, you can kind of wean them off. Buffalo

Most parents reported that their child was regularly monitored while on medication. Almost all of the participants reported being seen at least every 3 months, with some, especially those seeing mental health specialist, being seen more often. One respondent reported that their child’s medication was monitored every 6 months by their PCP, but the child also was seeing a psychiatrist on a monthly basis:

My kids see a psychiatrist that – basically, we have to see her every month, or you don’t get the medication. Buffalo

There were only two parents, one in Buffalo and one in NYC, who stood out because they were not being monitored regularly by their PCP and were not seeing any other providers:

He has been doing good on the medication. He doesn’t really see the doctor real regularly. Maybe once a year. But they don’t really check him often. He did fail this year at school. This is his first year. They’ve been wanting to fail him since he was in pre-K. Buffalo

Participant: I actually just called the nurse and said, “Please send me a new prescription.”
Moderator: And how often do you see the pediatrician?
Participant: I don’t see [him], only if she’s not feeling well. Not about the ADHD. NYC English
Behavioral Therapy, Counseling, and Other Alternatives or Supplements to Medication

While most parents used medication to treat their children, there were a number of them who refused to medicate their child, either because they did not think it was right or because of bad experiences with medication. One of these parents in Buffalo was a strong advocate for discipline and exercise as a solution:

*It's in controlling the kid. The problem lies in your house, your kids: you got to straighten it out. I take the kids and run them. It's like having a little doggy. You run that dog for 3 hours out of the day, and I guarantee that dog ain't coming home to chew nothing. You run that kid out, you take him out, ballgame, "I throw this, let's go jogging, let's go throw some rocks in the creeks, or let's go swimming in the park," whatever. I cut the drugs. Buffalo*

Most other parents who took this position continued to seek treatment or support from the health care systems in addressing their child’s condition. Access and information about alternatives to medication seemed to vary widely depending on the participant. For some, it was simply up to the parent to figure out what to do. They received little guidance from the physician and school:

*She really didn’t tell me anything but, “Oh, he has ADHD, and I’m going to put him on this.” And as soon as I shut down [said no to medication], it was like, “Okay, well, that’s all that I have to say to you.” Buffalo*

Other parents were given alternative choices and support:

*Being that I refused medication, she set me up with, like, routines, like during the day, like when he is home and stuff like that. I found that to be a big help. He is still hyper or whatever, but he came a long way. NYC English*

*Well, because I didn’t put her on medication right away, they gave me options, behavior charts, and schedules. NYC English*

Some parents were provided with other options, and the experience helped convince them that their child needed medication:

*I went to the parenting classes because I was just – I agreed that my kid was not going to have no medication. So I agreed. I was like, “Okay, we’ll do the parenting courses; you teach me how to restrain him; we can go through all this.” Well, we went through all that, and nothing worked. So they talked me into “Okay, well we’ll start him at a low dose.” Buffalo*

Regardless of whether they also used medication, most families in these groups had some experience with other treatments involving counselors, psychologists, or psychiatrists. Almost all of the parents in NYC – among both the Spanish- and English-speaking groups – reported that their children attended counseling regularly. Many children saw counselors or therapists both in and outside of school. While slightly fewer children in Buffalo were receiving treatments from mental health specialists or counselors, most of them were. In both places, there seemed to be great variability with the frequency and duration of these visits, with some children and parents meeting with a
counselor for an hour-long session every 1–2 weeks, while with others it was much less frequent and seemed to create cause for concern:

> When you go see the therapist, you just get, like, 20 minutes. What can a therapist do for your child in 20 minutes? You dealing with this kid 24/7, and you go to a therapist for help, and he’s only giving you 20 minutes of help. Then they want you to evaluate your child, and then they want to portray your child as something that he’s not, and that child is stuck with that image all through his life. NYC English

> She sees her therapist once every 2 months to get her prescription. We see him for 15 minutes…. He asks her how she’s doing, is she focusing, how is her classes. “Good. Here’s your prescription; go home.” NYC English

The extent of counseling varied, and only a few families and children appeared to be receiving comprehensive behavioral therapy:

> In my son’s school, like I said, they have a mental health clinic, and I’m not going to lie: they’ve done a great job with kids with ADHD, because they had a focus group for the parents where they had it at least twice a week. They did everything. They gave us books. They gave us so much information on how to deal with kids who have that, how to like, like – they had told her how to give him different routines. They gave so much information, and they showed us how to deal with these kind of kids and things like that. They also meet with us about once a week, depending on your schedule; the therapist and the counselor meet with you, and you work together. NYC English

> He has a star program his counselor started up. We started it at home. So it’s a continuation, and this is what the psychologist and his actual school counselor, we work on. Buffalo

The most common experience appeared to be that while parents were taught some behavioral techniques there was limited followup. Parents reported that children often outsmarted the technique by going to a grandparent or other relative for something if the parent did not allow it. Other times, it just stopped working:

> Well, my kids started out with that whole sticker chart, too, and it started out really well, but then after a while, they didn’t care anymore. “So what? So it’s a little snack. Who cares about a snack? That doesn’t make a difference to me.” Buffalo

The Spanish-speaking group in NYC did not agree with some of the techniques that are taught in behavioral therapy:

> Respondent 1: She [the psychiatrist] wants me to discipline him by giving him a chocolate if he does well. I tell her that he has to do good things on his own initiative and not because he is going to get something in return.

> Respondent 2: That also happens with my child’s psychologist. Now the child has the mentality that if they do something, they deserve a prize. When I come home and he says he did something good in school, he expects a prize and gets mad when I tell him he should not expect one, and that he should do things that benefit him in the future.
**ADHD Barrier Assessment**

Respondent 3: *When he gets a good grade on a math test, I celebrate it by hugging and kissing him. I celebrate it like if he were the greatest thing. When he asks for a prize, I say, “Wait a second. You just did a test; you did not create the Eighth Wonder of the World.”*

Respondent 4: *I did not even give my children anything during Christmas. If back home in my country I was not given anything, why should I give them something?” NYC Spanish*

Only one of the Spanish-speaking parents felt comfortable with the advice and care that they were receiving from mental health specialists:

*The psychologist has told me… “You have to be consistent.” She has also told me to let him unwind after he comes home from school, and then I should begin talking to him. This way feels that I support him and I am concerned about him.* NYC Spanish

**Parent Knowledge and Access to Information and Support Services**

Most parents reported that their doctor provided basic information about ADHD. Most indicated that providers explained some about what the parent should expect with medication and gave general parenting advice. However, they are looking for more support and information, both at the provider’s office and in the community:

*The Providers* should have a plan, just like you do when you go the OB-GYN for your first baby. On the first visit, you get prenatal pills; when you come back, they size the baby…. Tell me what ADHD is so I can learn. There is no programs out there, no groups you can go to; there is no information unless I brush into somebody that’s already went through this. Like with Down’s Syndrome, you are introduced into what you can do, how many places you can go, where your help is. Buffalo

*If you have a computer and Internet, you find it on the Internet just by luck. Or if you know a parent who has a child with ADHD, then you talk to that parent and they know something and you know something or they know somebody. That’s how it go. You do it like that. But we [are] on our own. We [are] in limbo.* NYC English

Parents did not view their health plans as a resource:

*New York State, they have all these little insurance companies that all they do is call, and they just give you phone numbers. You can’t get help. And the doctors aren’t going to talk to you, like even just basic information, because you have to make an appointment.* NYC English

One parent in NYC reported that she got very limited information on how to handle her child’s ADHD until she was reported to child protective services:

*The only way I managed to get help and information and parenting was because the school called ACS [the child protection agency] on me because my son had ADHD and they called ACS on me saying that I was neglecting him. That was their part. I was neglecting him medically. When I went, the social workers came and they seen I was a good parent and everybody was where they were supposed to be; that’s when I started getting the information I needed for my son.* NYC English
Parents described how changing their own behavior was important in changing their child’s behavior:

> I have to get me together, because if I’m upset and yelling at him, it just aggravates the situation with him. So I have to calm me down, put myself in time out, and then deal with him. And it works.

NYC English

Two parents brought up the issue of the importance of involving both parents in the treatment process. The first was the parent in the Spanish-language group who said her husband was opposed to medication. The second was the one in the NYC English-language group who discussed the benefits of the classes to which she was referred as the result of being referred to ACS:

> And he also started inviting my husband: “Because you have an ADHD child, you might understand; because you are the mother, and you get overwhelmed,” but the mother is nothing like the father. So then you have to try to work with the husband. It’s chaos.

NYC English

A few parents in Buffalo had access to mentoring programs, one run by Big Brothers/Big Sisters and one specifically for children with behavioral issues. In each of these groups, the child is matched up to a mentor and has the opportunity to go on group outings and parties. The latter group appears to be run using behavioral therapy techniques:

> My son has earned star status in one of them where he gets picked to do even more superior events, go on trips to Canada for camping, and things like that. Whereas if a kid has a behavior problem, the group mentor is going to take them inside and say, “You called one of your group members fat today, and we can’t be doing that. You hurt his feelings, and the consequence is going to be you can’t go to group next week.”

Buffalo

Unfortunately, the two mentor programs in Buffalo both have waiting lists. Just as importantly, it is difficult to find out about these and parenting support activities. Parents reported finding programs by luck:

> So it’s like a hit-and-miss sometimes, if you don’t know these programs are out here. Like I said, I thought he was going to be just like one of those children who you kept in the house because he couldn’t be handled outside.

Buffalo

I think it’s up to the parent to search. It’s not up to the doctors, but you would think they would do it.

Buffalo

The stress of taking care of any children, and particularly those with ADHD, is high, and parents constantly struggle with whether they are doing the right thing and whether they can handle the challenges their children are facing:

> I tell my son to behave. Every day, when I come home, there are messages from school. Sometimes I can’t help crying, I’ll start crying on the bus. He says to me, “Mommy, you know when you’ll be happy? The day I die.” I tell him I don’t want him to die.

NYC Spanish

> I have another child at home who is sick. She has a seizure disorder. So it’s hard to control this one, who is climbing the walls and knocking everything down, and control the other one and then have the
A few parents had the opportunity to participate in group parenting classes, which they found very helpful:

Groups are good. Sometimes I get depressed. I leave work (unintelligible), what will I find at home? I want to cry. We [the group] get together, and we talk about what is going on, and this motivates me, because it allows me to see that he is not doing as bad as others. NYC Spanish

They had that focus group for us parents once a week. And it was for a couple months. It was just so great to be able to sit down as mothers, talk about what’s going on. You learn a lot, and we got to vent and they gave us educational books. Every week, we had homework. We had pamphlets. It was really, really good. It was about 10 of us. And with the children, they had dinosaurs group. So while we were doing that, they were doing something else with the kid. NYC English

Other parents, who have not had such opportunities, expressed a desire to have an information group, even a parent support group, to help them manage their child’s ADHD:

It will benefit the parent and in turn benefit the child… and make the whole situation better and educate them a bit better than just giving them a pamphlet. Buffalo

If the health care organization could organize something like this, like a support group in the Boroughs, you know, a weekly thing or a monthly thing even. Somewhere, I mean, just from being here, I learned my daughter should be getting four-times-a-month therapy. She should have therapies in school. There should be someone there for her to talk to on a daily basis. I don’t have any of that. I have nowhere to turn to find out that kind of information. Because when I call the health care organization, they give me the behavioral science department, and they give me a therapist’s phone number and say, “Hey, call this guy. Call one of these guys and see who can help you out.” I end up with a therapist who really doesn’t care. NYC English

Communication Among Providers, Teachers, and Parents

Parents reported a wide variety of experiences in terms of communicating with providers and teachers and how these various providers communicated with one another:

So they basically – during the school year, they [school counselors] stay and work in the school Monday through Friday, and they see certain kids. But they don’t send me anything home. I go on the Internet, and I look up things. NYC English

Even in the same community, there were marked differences depending on which provider and school the families were involved:
The doctor was always involved with the school. He sent all the paperwork and questionnaires, and he would talk to both the school and the pediatrician. Everybody. It was like a circle of us, social workers, everybody. We had to stay in the same circle so we can all work together. Buffalo

The doctors did not get involved with the schools. I brought the paper to the school. I sent the paper back to the doctor. And then each one, each department, doesn’t talk to the primary physician. So nobody really knows what’s going on in the circle. It’s even a problem getting written reports sent to all the doctors involved. A lot of times, the papers don’t get there at all. And there is no phone communication at all. Buffalo

The psychiatrist would just give out these forms that I would take to the school and have the teacher fill them out, and then I would send them back to the doctor. And the psychiatrist doesn’t communicate with the pediatrician. Buffalo

Given that there was often this confusion or miscommunication, and given that so much of the treatment felt “experimental,” parents felt that ultimately they had to rely on their own knowledge of their children and be their child’s number one advocate:

In my experience, the parent has to be the advocate for all that communication. If you are not, the paperwork gets lost. It doesn’t get sent you. … Because so many people are juggling so much paper, so the cases who are not saying anything are going to get set to the side. But the parent that keeps calling, it’s, “Okay, this lady is driving me nuts; let’s [take care of it].” Buffalo

In NYC especially, the schools played an extensive role in treating children and addressing issues involving ADHD. The experiences varied, with some parents reporting that the school played a very positive role:

The teacher let me know that the treatment was working. She would even know when I’d forget the medicine. NYC Spanish

The school committee takes care of providing you all the information that appears on the Internet, and they mail it to your home so that you are always up to date on how to take care of your child and if a new method becomes available. I am very happy with what the school is doing regarding this. NYC Spanish

In my son’s school, they have a mental health clinic, and they’ve done a great job with kids with ADHD, because they had a focus group for the parents where they had it at least twice a week. They did everything. They gave us books. They gave us so much information on how to deal with kids [with ADHD], like how to give him different routines. They also meet with us about once a week, depending on your schedule; the therapist and the counselor meet with you and you work together. And for the kids who have ADHD, they also had a focus group, and they did it also, all kinds of things. And that helped him a lot. NYC English

Other parents had much more negative experiences:

She came to the school, and she would take my son out of class and then talk to him, and then I will go, like, in the evening and talk to her as well. That was going well, and then they stopped that. Then they told me, “Okay, well, we going to pick it up again.” Never picked it up. NYC English
They don’t want to give him this kind of treatment; they don’t want to give him intervention, because his IQ is high. And most of these teachers are not educated for kids with ADHD. They just say, “He’s a problem child; get him out my classroom.” NYC English

Parents often do not know what questions to ask and how to make the system work for them. A physician who treated two of the children who were discussed in the Buffalo group was considered highly effective because she helped parents figure out which questions to ask so that they could obtain effective treatment for their child. The physician understood the system enough that she could help parents get their children what they needed from both the health care system and the school system.

She actually knew the questions to ask me for me to ask questions to get stuff started. Because I didn’t know what to ask. I didn’t know what to say or what to even look for. She would come, and she would say, “What school is he in? What program?” Buffalo

4. Discussion

This section of the report brings together key findings about the treatment and monitoring of ADHD from all three of the data collection activities for this study. Disagreements among respondent types are noted. These findings are utilized in the next section to develop recommendations. This summary is organized into the following categories:

- The awareness and use of guidelines and treatment plans in developing and implementing treatment strategies;
- Findings related to the use of medication;
- Findings related to the use of mental health strategies;
- Findings involving the experiences of key participants in the treatment and monitoring of care for children with ADHD;
- Reported outcomes of treatment strategies and quality improvement initiatives.

Overall Awareness and Use of Guidelines. Most providers appear to be aware of guidelines and to make use of them to at least some degree. As noted above, they tend to follow them in terms of monitoring medication. Most, but not all, are aware of studies and guidelines promoting behavioral management therapy and incorporate some of the principles of this into their counseling efforts. As noted above, providers do not follow guidelines in terms of goal setting. Providers do not look to health plans for guidance on treatment. More health plans are adopting or endorsing guidelines.

Treatment Plans and Goal Setting. There appears to be very limited use of treatment plans and goal setting. Most providers do not undertake these activities. Quite a few parents report that they would like a clearer picture of what to expect from their child’s treatment and what they could do to help their child.

There are a number of findings related to the use of medication as a treatment strategy:

- Parent Resistance to Medication. Many providers are convinced that parents’ resistance to medication is the product of misinformation generated by negative media attention and
ideologically based critiques of medicating children. While this may play some indirect role, at least among the parents who attended the focus groups, their resistance to medication results from an uncertainty over what is best for their child and a fear or direct experience of negative side effects. Many physicians, especially PCPs, see side effects as easily addressable problems or something that just has to be tolerated. For parents, the side effects are much more important to how they view medication and are often very disturbing to them. While many parents indicated that doctors discussed side effects, others indicated that they did not provide enough information.

- **Monitoring of Medication.** Overall, most providers report that they monitor medication according to what is recommended in guidelines. Most providers and parents report that children on medication are seen at least every 3 months, though some providers said that once a child has achieved stability, they may see them every 6 months. There were a few exceptions, and it is possible the providers interviewed for the study are not representative of the provider community as a whole. They were partly included in the sample because they serve so many children with ADHD and it is possible such providers are more likely to follow treatment guidelines. In addition, self-reports such as these are not the most effective way to determine if providers are complying with guidelines regarding the number of recommended visits. In addition to the question of the accuracy of reporting, two of the health plans indicated that record keeping among providers is sometimes problematic. They may not be documenting all visits, the content of treatment, or the types of referrals.

- **Treatment of Children Whose Parents Decline Medication.** Many of the PCPs report offering limited alternatives to parents who decline medication. Often they provide general parenting advice or parenting materials related to creating a more structured environment. A few PCPs indicated that they do not believe that there are any effective options besides medication. Like most other parents, most of these parents are not offered behavioral therapy because of either limited supply or lack of knowledge on the part of their providers. Some of the parents who were offered alternatives saw positive results, and others decided to give medication a try after they did not see such results.

Another set of findings covers mental health approaches other than medication:

- **Access to Mental Health Care.** Overall, access to mental health care and mental health providers appears to be a problem outside NYC. In many cases, this means a wait of at least a few months to see a mental health provider. Quite a few providers outside NYC have determined that because the supply of therapists is limited, they will refer only if a child has a comorbidity or if the family is so disorganized that additional help is warranted. This limits access for families that may benefit from additional treatment. The biggest concerns about limited access to mental health care were raised by PCPs outside of NYC. Parents in the NYC focus group did not experience this problem, and the Buffalo group had mixed experiences in this regard. However, it is important to note that the experiences reported by the parents in NYC and Buffalo may differ from those in other parts of the State. NYC families have access to far more mental health providers than in other parts of the State, and they are far more likely to receive their ADHD care from these providers. While access to mental health care providers is more limited in Buffalo, it still seems to exceed what was reported by providers in other areas. In addition, Buffalo has at least one model program for ADHD care, and a few of the families in the focus groups were receiving services from this program.

15 Radigan et al. (2005.)
program. Information from providers outside of NYC and Buffalo suggests that access to multimodal treatment and behavioral therapy alone are far more limited in other areas of the State, where focus groups were not conducted.

- **Access to Behavioral Therapy.** Even in NYC, where the availability of mental health specialists is relatively high, the supply of behavioral therapy appears limited. One of the specialists interviewed in NYC treats a large number of children with ADHD and is very knowledgeable about the condition but did not think she had many options for referring families to behavioral therapy. Because it required fairly extensive parental participation, the provider needs to be located in the parent’s neighborhood. To the extent that she is able to have her patients access therapy, it is through having them work with the clinic social worker who refers the parents to community organizations that offer parenting education and other programs for families of children with behavioral problems. Most parents in both New York City and Buffalo have not attended the type of parent training programs or sessions that are part of behavioral therapy for children with ADHD.

- **Reimbursement for Behavioral Therapy.** Providers are under the impression that plans do not cover behavioral therapy, although plans indicate that they do. Many providers think that only therapy with the child is covered, but the managed care plans that were interviewed indicate that family therapy is covered under Medicaid. This difference may result from a number of factors. First, providers may be simply mistaken, or plans may be minimizing the challenges in getting referrals for this covered. Second, it may be that many commercial plans do not cover behavioral therapy and providers have generalized this to all plans. The failure of commercial plans to cover this therapy may have reduced the supply of this therapy as well. Third, plans may cover the therapy, but the reimbursement level may be too low to attract providers, and thus providers may consider reimbursement to be the primary issue.

- **The Content of Therapy Provided to Children with ADHD.** A very fuzzy picture emerges regarding the content of therapy that is being provided to children with ADHD. Part of the reason for this is that children are receiving therapy from multiple sources. In NYC especially, the school system provides a considerable amount of care, and providers and many parents are unsure what type of care is provided in this setting. Many psychiatrists and therapists do appear to be implementing some aspects of behavioral management, but it is unclear how comprehensive the treatment is. Mental health providers more commonly direct their efforts at children, though some do involve parents. Those parents who have been involved with group counseling or parenting education generally view the experience positively. However, Spanish-language parents appear more likely to disagree with the tenets of behavioral management, particularly the rewarding of children for positive behavior.

There are a number of key actors involved in the treatment of children with ADHD. The key findings regarding the role and experiences of these actors include the following:

- **Family Impact.** Parents especially, but providers also to a degree, report that having a child with ADHD has a serious impact on both them and their families.

- **Medicaid Managed Care.** Overall, Medicaid managed care policies do not appear to be presenting problems for providers. A number of providers did raise concerns about insurance policies that limited their flexibility in terms of what types of drugs to prescribe, and that reduced the availability of behavioral therapy by not allowing family therapy. However, most thought that the former problem was primarily an issue with commercial
plans, and this might be the case for the latter issue also. The MCOs that were asked directly about reimbursement policies in this area said that family therapy can be covered under Medicaid. Providers and at least one plan think that reimbursement should be provided for the time spent communicating with schools.

- **Communication and Coordination Among Providers and with Schools.** As noted earlier schools play an important role in providing care to children with ADHD, yet communication between schools and providers is often limited to the completion of assessment scales. Some providers are able to collect other information from schools to help in monitoring treatment, but this is the exception, not the rule. Most PCPs have limited involvement with assessing learning difficulties and do not appear to provide much input to the schools in this regard. Very few providers understand the resources that parents may access at school to help with treatment. Those that do are able to provide much-welcomed assistance to parents who often have difficulty navigating school system programs for children with problem behavior.

Finally, there are some key findings in relation to the outcome of treatment and monitoring and efforts to improve these:

- **Treatment Results.** The most common treatment for ADHD is medication, usually accompanied by some type of therapy in NYC and occasionally accompanied by other therapies elsewhere. Most parents who treat their children with medication see positive results, though sometimes it takes a while before they find the right medication and dosage. Some parents are so disturbed by their child’s reaction to medication that they decide to discontinue this treatment approach. Some of these parents are able to manage their child’s behavior successfully using behavioral management techniques. Many of the children who improve with medication still continue to face difficulties in terms of academic and behavioral problems at school. There were quite a few providers who were very articulate about the need to combine medication with other strategies to address the challenges faced by families of children with ADHD, but there were many others, mainly PCPs, who were quite satisfied with the outcome of medication alone and felt that their role was limited to determining the appropriate medication strategy and providing general advice to parents.

- **Quality Improvement Initiatives.** Currently, there are limited quality improvement initiatives being implemented, but there has been a growing interest in this area.

### V. Recommendations

The overall purpose of this study has been to assess the care provided to children with ADHD in New York State and to examine barriers to high-quality care. Based on this assessment, recommendations for steps to improve care are provided below.

This study was sponsored by the NYSDOH Office of Managed Care, and a priority has been given to developing recommendations relevant to that office. However, the assessment also has revealed problems that go beyond the scope of activities overseen by the Office of Managed Care. These include activities related to the education system, the availability of mental health providers, the promotion of comprehensive models of ADHD care, and the development of culturally sensitive behavioral management strategies. These recommendations are also included, with the acknowledgment that any attempt to address them will require the involvement of multiple agencies.
and organizations and that these initiatives may need to be led by organizations other than the one that sponsored this study:

- **Compliance with the HEDIS ADHD criteria should be assessed and steps should be taken to increase compliance. In addition, opportunities for improving other aspects of ADHD care should be identified and pursued.** This study has occurred at a time when there is a great deal of interest in improving ADHD care. The development of HEDIS measures for ADHD has created a tremendous opportunity to address ADHD quality of care issues. There is a great deal of interest among health plans in developing initiatives for improving ADHD care. In addition, there is growing evidence that care for children with ADHD is more costly than is often assumed, and this evidence is likely to motivate plans to take a closer look at the condition.

Helping plans to succeed in meeting goals in terms of the HEDIS measures is very important. One area that clearly will need to be addressed is ensuring that providers are effectively documenting their visits and procedures. There is evidence that this is a problem. Addressing this also will present an opportunity for reviewing assessment procedures and ensuring that information from schools and other sources are effectively integrated into a child’s medical record. The major limitation of the HEDIS measures is that they focus only on the monitoring of medication. This is an especially important area, and given recent publicity about potentially dangerous side effects and parental concern about them, it is absolutely critical that providers see children on a regular basis to monitor care. While parental and provider reports collected here suggest that most physicians are following recommendations on the schedule of visits, the medical record review being conducted by IPRO indicates that there are problems with compliance in this area. It will be very important to address this issue while also taking the opportunity created by the focus on the HEDIS measures to address other aspects of ADHD care, particularly the availability of other evidence-based treatments such as behavioral therapy.

- **Behavioral therapy needs to be offered more, either as an alternative or supplement to treatment with Medication.** As noted repeatedly, most parents are not comfortable with the idea of medicating their children, and quite a few simply will refuse to do so. Many providers find this a difficult issue, because they believe, with a considerable amount of justification, that medication is the most effective available treatment. However, parents are the ultimate decisionmakers in this regard and can undermine the effective use of medication if they do not comply with treatment requirements. Therefore, it is important for providers to be able to respond effectively with alternatives to medication. Most providers are well-aware of findings that medication is the most effective treatment, but many tend to disregard MTA findings that comprehensive behavioral modification results in improvements similar to what is seen for community treatment. Parents who are provided with behavioral therapy are also more satisfied with the treatment their child receives, and there is evidence from the followup MTA study that behavioral management therapy can have lasting effects. There is some indication from the parent focus groups that those parents who are offered alternatives

---


are more likely to accept medication if those alternatives are not effective. The parent focus groups and many of the interviews confirm again what has been found repeatedly in the literature on ADHD – that medication helps reduce symptoms – but many of these families have other issues that need to be addressed if the child with ADHD is going to achieve their potential.

Providers should be offering behavioral therapy if parents decline medication, and it should be offered more widely as a supplement to medication. As part of a quality improvement initiative, plans could be asked to document how often this is occurring and to provide incentives or encouragement to increase this effort. In order for this recommendation to become a reality, there must be efforts to ensure that there is an adequate supply of behavioral management therapy available.

- **New York State Medicaid and its managed care health plans need to clarify and inform providers regarding the types of therapy can be reimbursed.** There is a lack of clarity among providers on whether family or group therapy can be reimbursed. It is unclear from the interviews whether Medicaid has limitations in this regard, particular health plans have policies that prohibit or discourage the use of these therapies, providers are misinformed, or whether the main issue is limitations in commercial plans or that reimbursement rates are so low that they effectively prohibit the use of these therapies.

- **There is a need to explore whether the mental health therapy being offered to children with ADHD is evidence-based.** It is unclear to what extent the mental health care being provided to children with ADHD is evidence based. While providers do seem to incorporate aspects of behavioral management into their care, it is not clear how comprehensive the treatment is. Children with ADHD, especially in NYC, are receiving a substantial amount of mental health care. However, it is not clear to what extent that care is similar to the type of behavioral therapy that has been shown to be effective in the MTA and other studies. The development and monitoring of clearer criteria for what constitutes evidence-based care may help address this issue and promote the availability of behavioral therapy.

- **The Office of Managed Care and Medicaid MCOs should encourage providers to develop explicit treatment plans and to set goals for treatment.** Very few of the providers interviewed report developing explicit treatment plans that include clear goals for treatment. This is recommended in treatment guidelines and would help provide parents with more information about what they should be expecting from treatment and when a different course of treatment might be warranted.

- **There is a need to address the availability of mental health providers outside NYC.** Like almost all other States, New York faces challenges in providing mental health care for children in rural areas and smaller cities. The lack of availability of providers limits the ability of providers in these areas to implement evidence-based care and creates a shortage mentality, which makes providers reluctant to refer to care unless a child is seriously disturbed or a family is seriously disorganized. Though they are not the focus of this study the biggest impact is probably on children with comorbidities who often have to wait many months to receive treatment. There were a few families in the focus groups who had children with apparent comorbidities and it was clear that these children may face serious risks if treatment is delayed when they are in crisis. This issue is a tremendous challenge that came up repeatedly in this study.
Having health plans adopt guidelines may not be an effective approach to improving care. It is not clear that having health plans adopt guidelines will have a direct effect on how care is provided. In general, providers do not look to health plans for guidelines. Plans may want to adopt guidelines and then use them to create criteria for monitoring care or to help support an approach to quality improvement, but they should not see them as a way of directly impacting what providers do.

Providers need to provide parents with a clear understanding of possible side effects of ADHD medication. If doctors want to promote compliance with medication and help parents come to the right decision for themselves and their child about treatment strategies, they need to pay more attention to the issue of side effects and to spend time discussing what to expect and how side effects can and cannot be addressed. It may be helpful to find out more from the child about how the side effects are impacting them, since this may help to address the parents’ concerns. Parents’ concerns over side effects should be treated seriously and should not be dismissed as the result of misinformation.

Efforts should be undertaken to promote better communication between providers and schools. As noted repeatedly throughout this report, schools are providing substantial amounts of ADHD care and play a key role throughout the process of diagnosis and treatment. Yet communication between the health care system and school system are limited. The challenges in improving this situation are extensive. One provider who was interviewed works in a school-based clinic founded on the principle of promoting integration between education and health care, yet because of changes in the administration of the schools and health care center and preoccupation with the demands of their own individual sectors, there is currently almost no communication between the organizations. Efforts to improve communication are needed to ensure that ADHD care addresses the problems that often motivate parents to seek care and that have a tremendous impact on the child’s current and future well-being. In addition, it would help ensure that efforts to improve care are not duplicating what already is being done within school systems. Such an effort would require the collaboration of providers, health plans, and multiple agencies at the State and local level. One initial step both Medicaid and health plans can take is to review policies regarding the reimbursement of providers for time spent communicating with schools.

Steps should be taken to promote comprehensive care models that address the needs of children and their families using medication and/or other approaches. A few parents and providers reported participating in comprehensive models that attempted to address many of the issues cited here. These models included providers who were aware of, and could help parents navigate, the community system, including both education and health care. The Center for Children and Families at the University at Buffalo, The State University of New York is one example of such a model. The Center provides multimodal, family and school centered treatment for children with ADHD. The services include a summer treatment program that was incorporated into the MTA and Parent Training classes. The Center’s resources are also used by the City’s Children’s Hospital whose outpatient clinic was treating some of the children from the focus group with multimodal treatment. Programs of this type help address the needs of children in schools and recreational settings and help parents by providing opportunities to talk with other parents with similar experiences. Providers are often too quick to dismiss the tremendous knowledge that parents have about their child’s condition and available resources to address it. While misinformation can be a problem, the parents we spoke with are seeking the best possible care they can locate and
could benefit from a setting where they can assist each other to obtain it. In addition, this represents an opportunity to help alleviate the tremendous stress experienced by many of these families. New York State Medicaid, health plans and other agencies and organizations should explore how they can create policies that allow model approaches to reach larger portions of the population of children with ADHD.

- Behavioral therapy techniques may be resisted because of cultural beliefs about rewarding children and providers may need to consider how to address this issue so they can provide culturally appropriate treatment that is also evidence-based. The discussion in the Spanish-language group suggests that providers need to consider culture when working with families who are relatively new to this country. While the general point is not surprising, the groups did suggest that Spanish-language families may consider techniques that reward children for good behavior to be objectionable. However, it is not clear that anyone clearly explained to these families the rationale behind the treatment and that it has been shown to be effective. This illustrates a common theme in the findings: since parents are the key partners in caring for children with ADHD, any attempt to improve care must ensure that consideration is given to providing them with information and support that helps them make educated decisions about their child’s care.

- More information is needed about the quality of care for children with ADHD and psychiatric comorbidities. While this study focused on children with ADHD and no psychiatric comorbidities, issues regarding care for these children did come up repeatedly. These children make up a large proportion of the population of children with ADHD. Most of the PCPs interviewed appear to be following the AAP’s guidance by referring these cases to specialists when their coexisting condition interferes with treatment. However, little is known about the treatment outcomes for these children and research provides only limited guidance on how to handle these cases. It is clear from the small number of parents who participated in the focus group and had children who, based on parental reports, appeared to be exhibiting serious behavioral problems that go beyond ADHD that these families are under serious strain and the ongoing care of these children is likely to be costly and challenging. There is a need to know more about how these children are being treated and the best course of action for them in terms of addressing their ADHD and other problems.
Appendix A: Buffalo Focus Group Screening Form
Screening Form for Participation in New York State
Department of Health ADHD Focus Groups (Buffalo)

Hello, may I speak to the parent or guardian of (NAME OF CHILD)?

[IF THEY ARE UNAVAILABLE] When would be a good time to reach her/him?

[IF THEY ASK IF YOU WOULD LIKE TO LEAVE A MESSAGE] I will call back later thank you.

[IF THEY HAVE MOVED] Is there a phone number I can reach them at? (______________) Thank you. [HANG UP]

[ONCE THE PARENT OR GUARDIAN IS ON THE PHONE] Hello, my name is (YOUR NAME) I am calling from Health Systems Research for the New York State Department of Health. I am calling about an opportunity to participate in a study being done for the Department of Health. This is not a sales call or an attempt to sell you anything. If you qualify for the study and participate you will be paid money for your time and expenses.

In order to find out if you qualify, I need to ask you some questions. Is that okay?

1. First, the reason we are calling you is because our information indicates that you have a child, (NAME OF CHILD), who at some point in the last few years has been treated for ADHD or Attention Deficit Hyperactivity Disorder? Is this information correct?

(____) Yes [GO TO QUESTION 2]

(____) No

↓

1a. I just want to confirm that (NAME OF CHILD) has not been treated for ADHD which usually involves problems such as trouble concentrating or sitting still or having too much energy and being too excited. You are saying that [he/she] has not received such treatment?

(____) RESPONDENT CONFIRMS THAT HE/SHE HAS NOT RECEIVED SUCH TREATMENT

↓

I have no further questions, thank you very much for your time. [HANG UP]

(____) THE RESPONDENT INDICATES THEIR FIRST ANSWER WAS MISTAKEN AND THE CHILD HAS RECEIVED TREATMENT FOR ADHD [GO TO QUESTION 2]
2. Are you the person in your household that knows the most about (NAME OF CHILD)’s treatment for ADHD?

(____) YES  [GO TO QUESTION 3]

(____) NO

2a. Is that person available to talk now?

(____) YES

Can you put them on the phone? [WHEN THEY COME TO THE PHONE] I am calling for the New York State Department of Health. I am calling about an opportunity to participate in a study being done for the Department of Health. I understand from talking to (NAME OF ORIGINAL RESPONDENT) that (NAME OF CHILD) has been treated for ADHD and that you are the one in the house who is most knowledgeable about that treatment. I have a few questions to ask in order to see if you qualify for the study. If you qualify and participate you will be paid for your time and expenses. [GO TO QUESTION 3]

(____) NO [FIND OUT THE PERSON’S NAME]

When would be a good time to call in order to talk to them? (_______________) Thank you. I will call back later. [HANG UP]

[IF THEY LIVE ELSEWHERE] Is there a phone number I can reach them at? (_______________) Thank you, I will try and reach them there. [HANG UP]

3. For this study, we are bringing together a group of parents and guardians so we can find out more about your thoughts on ADHD, the health care your child has received, what you think has worked well and what you think could have been better. You will be asked to share your thoughts with a group of about 8 to 10 other parents. The group is a one-time thing and will last just over 2 hours. We won’t try to sell you anything and you will be paid $100 for your time and $30 for travel and childcare expenses. Your participation in the group is completely voluntary and you are free to leave at any time. The session that we are inviting you to attend is on August 8 at 5:45 and will be held on Eggert Road in Amherst, just off of Main Street, are you available on that day and time and would you be able to fit this into your schedule?

(____) Yes  [GO TO QUESTION 4]

(____) Not Sure

If you think you may be able to attend we can go through the rest of my questions to see if you qualify and then at the end you can decide if you will be able to make it. [GO TO QUESTION 4]

(____) No

I have no further questions thank you very much for your time. [HANG UP]
4. Is (NAME OF CHILD) still in the (NAME OF PLAN) health plan?

(____) Yes  [GO TO QUESTION 5]

(____) No or Not Sure

4a. What health plan is (he/she/NAME OF CHILD) enrolled in?

IF THEY PROVIDE A NAME THEN ENTER IT HERE AND READ WHAT APPEARS AFTER THE →

(______________________________________________________________)

IF THEY SAY DON’T KNOW ASK THEM IF THEY CAN CHECK THEIR INSURANCE CARD, IF THEY ARE UNABLE TO LOCATE IT OR UNABLE TO CHECK SAY → We will go ahead with the interview, and if you qualify we will sign you up but in the meantime we will need to check and see if your child is in one of the Health Plans that are in this study. If not we may need to call you back and let you know that you are not eligible to participate.

IF A PERSON IN THIS SITUATION IS ENROLLED, MAKE SURE IT IS BROUGHT TO THE ATTENTION OF CHRIS BOTSKO

5. [IS THE RESPONDENT COMMUNICATING EASILY IN ENGLISH WITH LITTLE OR NO DISCERNABLE ACCENT OR (IF SCREEN IS BEING DONE IN SPANISH) ARE THEY CLEARLY COMFORTABLE COMMUNICATING IN SPANISH?]

(____) YES  [GO TO INVITATION]

(____) NO OR NOT SURE

5a. What language are you most comfortable speaking?

(____) English [GO TO INVITATION]

(____) Other

5b. Would you feel comfortable speaking English with group of 8 to 10 parents discussing topics like doctor visits and health care?

(____) Yes  [GO TO INVITATION]

(____) No OR Not sure

I have no further questions thank you very much for your time. [HANG UP]
Case Identification Number:

INVITATION

Thank you for answering my questions. You are one of the people we would like to talk with for this study. As I said the study is being conducted to talk with families about their experiences getting treatment for a child with ADHD. The goal is to obtain information that can help improve treatment for children with ADHD. We will be doing this by holding group discussions with families who have children who have received such treatment. The group discussion will be a meeting of about 8 to 10 people like you and a group discussion leader. You will be asked questions about your experiences obtaining care for your child including what worked well and what did not work well. We will be taping the session so that we have a good sense of what people said. We will keep that tape and everything you say completely confidential and you will be free to leave at any time for any reason. At the end of the group you will be paid $130 to thank you and to cover the cost of transportation and child care.

As I mentioned earlier we are holding one of these discussions in the Buffalo area on August 8 at 5:45 pm at Buffalo Survey and Research which is at 1249 Eggert Road in Amherst right off of Main Street. It will last until 8:00 pm.

6. Will you be able to attend?

(____) Yes  [GO TO QUESTION 7]

(____) No

   Thank you for your time. Have a good day. [HANG UP]

(____) Not sure/CAN’T FIND OUT RIGHT AWAY/MAY NOT BE IN TOWN

   6a. Would it be okay if I called you back again to check, if we still need people in a few days?

   (____) Yes

   Thank you and either I or one of my co-workers may call you back. [HANG UP]

   (____) No

   Thank you for your time. Have a good day.

7. Great. We will be mailing you some additional information about the group. Please make sure you arrive no later than 5:45. We will begin the discussion right at 6 pm. If you get to the session after the discussion has started, we may not be able to include you. We are counting on you to participate so please call me if something comes up and you can no longer come. Again, my name is (YOUR NAME) and if your schedule changes or you have any questions you can call the following number toll free 1-866-776-5187. We will call to remind you about the group a day or two before it takes place.
Case Identification Number:

As I said we are going to be sending you some additional information about the group. In order to do that, I need to confirm the spelling of your name and an address so that I can send you this information.

First Name:
Last Name:
Street:
City/Town:
Zip Code:

CLOSING
Thank you very much for agreeing to participate we are glad you will be able to help. If you have any questions or concerns please feel free to call the toll free number. Have a good day.

IMPORTANT: REMEMBER TO ENTER THE DISPOSITION OF THIS CALL IN THE CALL DATABASE. IF THIS PERSON HAS ACCEPTED PLEASE MAKE A COPY OF THIS FORM AND GIVE IT TO CHRIS BOTSKO
Appendix B: Focus Group Moderator's Guide
New York State ADHD Quality of Care Focus Group
Moderator's Guide

I. WELCOME/BACKGROUND INFO (10 minutes)

Welcome to our group discussion. Thank you for taking the time to participate in our focus group discussion about health care for children diagnosed with ADHD. My name is __________, I am here with my colleague __________ and we work for Health Systems Research, Inc. based in Washington, DC. Our company is helping the New York State Department of Health to learn more about the experience families have with health care when one of their children is diagnosed with ADHD. We will use your ideas to provide recommendations that will help State agencies and other organizations explore how to improve treatment for children with ADHD.

Have any of you ever been in a focus group before? The purpose of focus groups is to get the honest opinions of small groups of people about a specific topic. These topics may range from what people think about a particular soft drink, soap product, or in our case, health care for children diagnosed with ADHD. In order to be an effective way of obtaining information there are a few rules that it will be helpful to follow.

I would like to review these ground rules now:

- There are no right and wrong answers. We are here to find out about your experiences. We do not do not work directly for the State of New York or for any agency or organization that provides the health care we will talk about today, so feel free to tell us your thoughts, whether they are positive or negative.

- It is ok to disagree with one another. We want to hear everyone’s point of view. However, if you disagree, please do so respectfully.

- Only one person should talk at a time. We are tape recording this session so that we do not miss anything important. If two people talk at once, we can not understand what anyone is saying. I may remind you of this during the group.

- We would like everyone to participate. You each do not have to answer every question. If, however, some of you are shy or I really want to know what you think about a particular issue, I may ask you about it.

- We have a lot that we want to talk about today. So, do not be surprised if at some point I interrupt the discussion and move to another topic. But, if there is something important you want to say, let me know and you can quickly add your thoughts in before we change subjects.

- We will be using first names only today. Everything you say is confidential. After we conduct several of these group discussions across the state, we will write a report for
the New York State Department of Health. Your name will not appear anywhere in the report. The tapes we make today will not be shared with the Department of Health. Anything you say today will not be attached to your name at any point. Nothing that you say will affect your eligibility for or the services you receive through any of the programs we talk about today. We are required by law to keep information about you and your child’s care confidential.

- Do not worry about offending us. We really want to learn from you and find out what you think about the issues we talk about tonight. Please tell us your honest opinions.

- I want to make a couple more points related to the tape recording. Please speak up. If you speak too quietly, it will be too difficult to hear you later on the tape. Also, please do not bump the table or tap your hands on the table. Anything close to the microphones sounds incredibly loud on the tape and it will drown out your voices. ________ is also taking notes in case the tapes do not come out clearly and she will be handling the tape recorders.

The group will last two hours. You will not get out any later than ________. We will not be taking a formal break, but if you need to leave for a restroom break, the bathrooms are __________.

At the end of the session, we will provide you with a payment for your time and expenses associated with coming tonight. We will also ask you to complete a short anonymous survey.

Any questions before we begin?

II. INTRODUCTION AND ICE BREAKER (10 minutes)

Let’s get started.

Start with the participant to your right. Have them respond in round robin fashion.

1. Please tell me your first name, how many children you have and their ages. Please indicate which one of them has received treatment for ADHD.

2. We want to start with a general question, thinking about all your children what concerns you the most about them?

   PROBE: What keeps you up at night?
III. MAIN FOCUS GROUP QUESTIONS

A. Initial Diagnosis and Treatment for ADHD (25 minutes)

Now I want to turn to your experience with health care for your child who received treatment for ADHD. I want you to think back to when your child was first diagnosed and treated with ADHD.

1. (ROUND-ROBIN) What first led you to become concerned about your child’s behavior and to discuss this with someone else like a doctor or other health care professional?

   PROBE: Did someone like a teacher or other family member mention something?

2. Who exactly did you discuss it with?

   PROBE: Was this a doctor, school nurse, social worker?

3. What happened when you talked to a doctor or other health care worker about this?

   PROBE: What kind of questions did they ask you?

   Were you asked to fill out a survey or questionnaire about your child’s behavior?

   Did they talk with anyone at your child’s school at all or give you something to give the school?

4. How was it decided that your child had ADHD and needed treatment? What worked well about how this was handled? What could have been better?

5. What made it hard to get care for your child? What helped? What help did you receive?

   PROBE: (NEED TO MAKE SURE YOU UNDERSTAND WHO PROVIDED HELP OR WHO PRESENTED OBSTACLES) Who exactly did this?

B. Ongoing Care for ADHD (40 minutes)

1. Once you were told your child had ADHD, what treatment did the child receive?

3. PROBE: Who was mainly responsible for your child’s care (Your regular doctor? A specialist? What kind of specialist?)

   Did your child receive medication? How long did they receive medication?
   Did your child see a specialist for any type of behavioral therapy? What kind of specialist? What was that like?
2. How often did you see a doctor or other health professional about your child’s ADHD?

3. What did you hope your child’s treatment would do? Did you and the doctor or specialist discuss and agree upon goals for your child’s treatment?

4. What did the doctor or other health professional responsible for your child’s ADHD treatment do to find out whether or not your child’s treatment was working? PROBE: Were you asked to fill out questionnaires or surveys?
   - Did they talk or send information to anyone at your child’s school?
   - Did they discuss whether your child’s treatment goals were met?

5. What information were you given about your child’s condition and treatment? What were your biggest concerns about your child’s condition and treatment? Who do you talk about your concerns with?

6. How well did your child’s doctor and other health care providers listen to your concerns about your child’s condition and treatment?

7. Were you given any information about ways to handle your child’s behavior for example suggestions for how they should be disciplined, how to manage family life? Who gave you this information? Was it helpful? What would have made the information more helpful?

8. What worked well about your child’s treatment? What could have worked better?

9. Have you ever decided not to do what a doctor or other health professional said you should do to treat your child with ADHD?

   (IF YES) Tell me about that.
   PROBE: Have you ever not filled a prescription you were given? How come?
   - Have you ever not made an appointment when your doctor said you should go see a different doctor or health professional? How come?

10. What role did your health plan play in getting your child help for ADHD? Does your health plan have any special programs for children with ADHD? Did they send you any special information?

11. Were there any ADHD services your doctor recommended that you could not get for your child because your health plan did not cover them? What services?

12. Were there services your child needed that you had to pay for? If yes, what services?

13. What role has your child’s school played in his or her treatment for ADHD? Does the child get any special help at school because of their ADHD?
C. Knowledge of ADHD Care

(15 minutes)

Now I want to ask a few questions about what you know about care and treatment for ADHD.

1. What do you know about the treatments that are available for ADHD? How did you find out about options for treating your child?

2. Do you feel you know enough about ADHD?

(IF NO) What aspect of ADHD would you like to know more about? How would you like to get this information? PROBE: For example, written materials, parent groups, etc.

D. Recommendations

(15 minutes)

I want to ask for your suggestions about how to make things better in caring for children with ADHD.

1. What do you think is most important in getting the best care for a child with ADHD?

2. What could your health plan or Medicaid do that would help make things better for you and your child in terms of addressing issues involving ADHD?

3. What could doctors and other professionals (for example mental health specialists, schools and teachers) do that would help make things better for you and your child in managing ADHD?

IV. CLOSING

(5 MINUTES)

Check for questions or follow-up from co-moderator.

Thank you very much for coming. The discussion has been very helpful and we will do our best to convey your experiences and suggestions in the report we prepare.

Is there anything I haven’t asked about that you would like to tell me related to the topics we have discussed?

Please complete the form with a few questions about you and your children…..be sure NOT to include your name on that form. Also please sign a receipt for the money you receive as a thank you.
Appendix C: Provider Interview Protocols
Interview Guide
Providers (Primary Care Providers: Family Physicians, Pediatricians)

NYS Department of Health Study
Medicaid Managed Care and ADHD Quality of Care

The New York State Department of Health is sponsoring a study to assess issues related to the quality of care provided to children with a diagnosis of ADHD enrolled in a Medicaid managed care plan. The Department of Health and IPRO, the state external quality review organization, have contracted with Health Systems Research, Inc. (HSR) to conduct the study. The results of the study will be used to strengthen the quality of care provided to these children.

Thank you for agreeing to this interview. The objectives of the interview are to learn more about how care is delivered to children with a diagnosis of ADHD and to explore your ideas about challenges and opportunities to improve the quality of care for these children. We are focusing on children ages 6 – 12 years with a diagnosis of ADHD with no psychiatric comorbidity who are insured through a Medicaid managed care plan. Your responses will be confidential and nothing you say will be linked to your name or practice. In appreciation for your contribution to the study and the time you spend on this interview you will be sent a check for $150. I would like your permission to tape record the interview so I can use the tape to supplement my hand written notes. The tapes will not be shared with the Department of Health or IPRO. Do I have your permission to tape this conversation? (IF THEY SAY NO SAY, “I UNDERSTAND” AND PROCEED TO CONDUCT THE INTERVIEW WITHOUT TAPING, IF THEY SAY YES YOU CAN INITIATE TAPING)

The interview should take no more than 1 hour. Do you have any questions before we get started?

I. Provider Information (COMPLETE AS MUCH AS POSSIBLE PRIOR TO INTERVIEW)

a) Interviewee information (MAKE SURE YOU CONFIRM SPELLING OF NAME AND ADDRESS FOR PURPOSES OF SENDING INCENTIVE PAYMENT):
   Name
   Type of Provider
   Contact:
   Address:
   Email
   Telephone

b) Geographic area served by the provider

c) Number of years in practice
II. Identification of Children with ADHD.

First, let’s talk about diagnosing children with ADHD.

a) What guidelines are you aware of for the diagnosis of children with ADHD? How useful are they in providing guidance for the diagnosis of children with ADHD?

b) What protocol do you follow to diagnose or rule out ADHD? (i.e., How do you usually go about diagnosing or ruling out ADHD?)

Ask:
- Do you use DSM - IV or other diagnostic criteria
  - Why or why not used?
- How is input from family or school used?
- Do you ever refer child and family to a specialist or other provider for evaluation and/or counseling when diagnosing or ruling out ADHD?
  - What type of specialist or other provider?
  - How long does it usually take for the child and family to obtain an appointment?

III. Treatment of Children with Diagnosis of ADHD

Now we are going to turn to the treatment of children with ADHD.

a) I am going to ask you what you typically do when a child is diagnosed with ADHD, remember we are focusing on children with ADHD with no psychiatric comorbidity. When a child is diagnosed with ADHD, do you:

NOTE TO INTERVIEWERS FIRST FIND OUT WHICH OF THE THREE BULLET POINTS BEST DESCRIBES WHAT THEY TYPICALLY DO FOR CHILDREN WITH ADHD

- Typically assume responsibility for all the child’s health care needs including management of ADHD, or [IF YES, SKIP TO b)]

- do you assume responsibility for all the child’s health care needs including management of ADHD and consult with a specialist or other provider, or

[IF YES]
  - What type of specialist or other provider?

  - What components of care require consultation/referral?
    - medication management
    - behavioral therapy
- family therapy
- other

- What is your experience in obtaining timely referrals for consultation or additional mental health services?

- Does your office facilitate the referral (e.g. by scheduling the appointment for the family)?
  (IF THE OFFICE DOES NOT FACILITATE THE REFERRAL) Is that because mental health providers do not allow your office to facilitate referrals?

- How frequently do you consult with other providers once you provide a referral? [GO TO b.]

  • do you use a specialist to manage the ADHD while you continue to meet the rest of the child’s health care needs?
    - What type of specialist?
    - How is overall care of the child coordinated?
    - How informed are you usually kept about the child’s treatment for ADHD? [GO TO b. THEN g.]

b) How do health plan policies affect your management of children diagnosed with ADHD?

  Probe for:
    - Positive and negative effects

c) If the child is diagnosed with another mental health disorder in addition to ADHD, how are the child’s needs managed?

d) What guidelines or protocols do you use for the management of children diagnosed with ADHD?

  Probe for
  • AAP Guidelines, Academy of Child and Adolescent Psychiatry Practice Parameters
  • And/or health plan-specific protocol
    PROBE: Which health plans provide protocols that you use?
  • Other?
  • Would other/additional guidelines or protocols be helpful to you?
e) Are parental and teacher rating scales used to assist in ADHD management?

**IF USED** How are they used? How frequently? How helpful are they?
**PROBE:** Do you use them before and after prescribing ADHD medication to help guide decisions about medication management (e.g., dosages or change in medication)?

**IF NOT USED** Why don’t you use them?

f) What types of treatment do you typically provide to children with a diagnosis of ADHD? [SKIP QUESTION IF THE CHILD IS REFERRED OUT FOR THESE SERVICES.]

Probe for

- Medication: [IF YES] What challenges do you face in managing medication? What would help you be more effective in this area?
- Counseling: [IF YES] What challenges do you face in providing counseling? What would help you be more effective in this area?
- Behavioral Therapy: [IF YES] What challenges do you face in providing behavioral therapy? What would help you be more effective in this area?
- Are there other treatment strategies you use?

g) What strategies do you use in working with parents and families of children diagnosed with ADHD?

Probe for:

- Do you do mutual goal setting? Do you do written treatment plans for families? What information or resources do you provide them? What advice do you give them? What discipline strategies do you recommend?
- What challenges do you experience in working with parents and families?
- What changes would improve how you work with parents and families?
**PROBE:** This could include changes in areas such as your office practices, health plan policies or practices, or state policies or regulations.
h) What strategies do you use in working with teachers and the school system in regard to children diagnosed with ADHD?

Probe for:

- How frequently do you try to obtain information about what is going on in school?
- What are the challenges you experience in working with teachers and the school system?
- What changes would improve how you work with teachers and the school systems?
  **PROBE:** This could include changes in areas such as your office practices, health plan policies or practices, school system policies or practices, or state policies or regulations.

IV. Monitoring and Evaluating Care Provided to Children with a Diagnosis of ADHD

a) How do you monitor the care provided to children with a diagnosis of ADHD?

Probe for:

- Who is involved in this process (family, teachers, mental health specialist, etc.)?
- What determines how often you see the child?
- How do you judge whether the treatment strategy you are using is working?
- What is the role of the health plan in helping you monitor the care provided?

V. Recommendations

a) What steps could be taken to improve the quality of the care provided to children with a diagnosis of ADHD? Are there steps that Medicaid Managed Care Plans could take that would make care more effective?

b) What would help you to improve the care your practice provides to children with ADHD?

**PROBE:** This could include things such as additional information about effective treatment, policy changes, information that you can provide to parents or anything else you can think of.
VI. Closing

a) Is there anything else that you would like to add?

b) May I contact you again if I need to clarify something you said during this interview?

c) Thank you very much for your time.

Date of Interview:

Interviewer:
The New York State Department of Health is sponsoring a study to assess issues related to the quality of care provided to children with a diagnosis of ADHD enrolled in a Medicaid managed care plan. The Department of Health and IPRO, the state external quality review organization, have contracted with Health Systems Research, Inc. (HSR) to conduct the study. The results of the study will be used to strengthen the quality of care provided to these children.

Thank you for agreeing to this interview. The objectives of the interview are to learn more about how care is delivered to children with a diagnosis of ADHD and to explore your ideas about challenges and opportunities to improve the quality of care for these children. We are focusing on children ages 6 – 12 years with a diagnosis of ADHD with no psychiatric comorbidity who are insured through a Medicaid managed care plan. Your responses will be confidential and nothing you say will be linked to your name or practice. In appreciation for your contribution to the study and the time you spend on this interview you will be sent a check for $150. I would like your permission to tape record the interview so I can use the tape to supplement my handwritten notes. The tapes will not be shared with the Department of Health or IPRO. Do I have your permission to tape this conversation? (IF THEY SAY NO SAY, “I UNDERSTAND” AND PROCEED TO CONDUCT THE INTERVIEW WITHOUT TAPING, IF THEY SAY YES YOU CAN INITIATE TAPING)

The interview should take no more than 1 hour. Do you have any questions before we get started?

I. Provider Information (COMPLETE AS MUCH AS POSSIBLE PRIOR TO INTERVIEW)

d) Interviewee information (MAKE SURE YOU CONFIRM SPELLING OF NAME AND ADDRESS FOR PURPOSES OF SENDING INCENTIVE PAYMENT):

Name

Type of Specialist

Contact:
   Email
   Telephone

e) Geographic area served by the provider

f) Number of years in practice
II. Identification and Referral of Children with ADHD.

c) Please describe how children with potential or actual diagnosis of ADHD reach your practice? Are they:

- Brought to you by parents

- Referred to you by:
  - Family physicians
  - Pediatricians
  - Neurologists
  - Schools
  - Health Plans
  - Other

Probe for: Which is the most common way that children with ADHD reach your practice?

d) What protocol do you follow to diagnosis or rule out ADHD? (i.e, How do you usually go about diagnosing or ruling out ADHD?)

PROBE:

- Do you use DSM-IV or other diagnostic criteria
  - Why or why not used?

- Do you use protocols from Health Plans you accept?
  PROBE: Which health plan protocols do you use?

- How is input from the family or school used in your assessment?

III. Management of Children with Diagnosis of ADHD

h) I am going to ask you what you typically do when a child is diagnosed with ADHD, remember we are focusing on children with ADHD with no psychiatric comorbidity. When a child is diagnosed with ADHD, do you:

- Refer the child back to his/her primary care provider? or
• Collaborate with the primary care provider in the management of the ADHD?

PROBE: for areas of collaboration and extent of collaboration (how often do they see the child? How often do they communicate with the PCP?):

- Medication management
- Behavioral Therapy
- Family Therapy
- Other

PROBE: Do you typically collaborate with other health professionals (e.g., other specialists) when treating a child with ADHD?

i) How do health plans policies affect your management of children diagnosed with ADHD?

PROBE:
- Positive and negative effects?
- How the policies could be improved to support provider and strengthen care delivered?

j) What guidelines are you aware of for the diagnosis and treatment of children with ADHD? How useful are they in providing guidance for the diagnosis and treatment of children with ADHD?

k) What guidelines or protocols do you use in your own practice?

PROBE:
- AAP Guidelines, Academy of Child and Adolescent Psychiatry Practice Parameters
- And/or health plan-specific protocol

PROBE: Which health plans?

- Other?

- How do you use them?
l) Are parental and teacher rating scales used to assist in ADHD management?

**IF USED** How are they used? How frequently? How helpful are they?

**PROBE:** Do you use them before and after prescribing ADHD medication to help guide decisions about medication management (e.g. dosages or change in medication)?

**IF NOT USED** Why don’t you use them?

m) What types of treatment do you typically provide to children with a diagnosis of ADHD?

- Do you prescribe medication?: [IF YES] What challenges do you face in managing medication? What would help you be more effective in this area?

- Do you utilize counseling?: [IF YES] What challenges do you face in providing counseling? What would help you be more effective in this area?

- Do you provide behavioral therapy?: [IF YES] What challenges do you face in providing behavioral therapy? What would help you be more effective in this area?

- Are there other treatment strategies you use?

n) What strategies do you use in working with parents and families of children diagnosed with ADHD?

**Probe for:**

- Do you do mutual goal setting? Do you do written treatment plans for families? What information or resources do you provide them? What advice do you give them? What discipline strategies do you recommend?

- What challenges do you experience in working with parents and families?

- What changes would improve how you work with parents and families?

**PROBE:** This could include changes in areas such as your office practices, health plan policies or practices, or state policies or regulations.
h) What strategies do you use in working with teachers and the school system in regard to children diagnosed with ADHD?

Probe for:

- How frequently do you try to obtain information about what is going on in school?
- What are the challenges you face in working with teachers and the school system?
- What changes would improve how you work with teachers and the school systems?

**PROBE:** This could include changes in areas such as your office practices, health plan policies or practices, school system policies or practices, or state policies or regulations.

IV. Monitoring and Evaluating Care Provided to Children with a Diagnosis of ADHD

b) How do you monitor the care provided to children with a diagnosis of ADHD?

**PROBE:**

- Who is involved in this process (family, teachers, mental health specialist, etc.?)
- What determines how often you see the child?
- How do you judge whether the treatment strategy you are using is working?
- What is the role of the health plan in helping you monitor the care provided?

V. Recommendations

a) What steps could be taken to improve the quality of the care provided to children with a diagnosis of ADHD? Are there steps that Medicaid Managed Care Plans could take that would make care more effective?
b) What would help you to improve the care your practice provides to children with ADHD?

PROBE: This could include things such as additional information about effective treatment, policy changes, information that you can provide to parents or anything else you can think of.

VI. Closing

d) Is there anything else that you would like to add?

e) May I contact you again if I need to clarify something you said during this interview?

f) Thank you very much for your time.

Date of Interview:

Interviewer:
Appendix D: Health Plan Interview Protocols
The NYS Department of Health is sponsoring a study to assess the quality of care provided to children with a diagnosis of ADHD enrolled in a Medicaid managed care plan. NYS has contracted with Health Systems Research, Inc. (HSR) to conduct the study. The results of the study will be used to strengthen the quality of care provided to these children.

Thank you for agreeing to this interview. The objectives of the interview are to learn more about how the health plan delivers care to children with a diagnosis of ADHD and to explore your ideas about current best practices, challenges and opportunities to improve the quality of care for these children. We are focusing on children ages 6 – 12 years with a diagnosis of ADHD with no psychiatric comorbidity who are insured through a Medicaid managed care plan. Your responses will be confidential and nothing you say will be linked to your name or plan. I would like your permission to tape record the interview so I can use the tape to supplement my hand written notes. The tapes will not be shared with the Department of Health or IPRO. Do I have your permission to tape this conversation? (IF THEY SAY NO SAY, “I UNDERSTAND” AND PROCEED TO CONDUCT THE INTERVIEW WITHOUT TAPING, IF THEY SAY YES YOU CAN INITIATE TAPING)

The interview should take no more than 1 hour. Do you have any questions before we get started?

I. Description of the Health Plan (COMPLETE AS MUCH AS POSSIBLE PRIOR TO INTERVIEW)

   g) Name of the Health Plan:

   h) Do you have a behavioral health vendor?
      (IF YES) What is their responsibility with respect to ADHD versus the plans?
      PROBE: Does the vendor do any screening, identification or outreach?

II. Identification of Children with ADHD

   e) Are guidelines or protocols recommended by the plan for the identification of children with ADHD?

      PROBE: Are there particular screening and assessment tools or activities that you recommend or require?

   f) Once a child is diagnosed are parents or providers sent any special information?

III. Management of Children with Diagnosis of ADHD
o) Do you have any disease management programs when members are identified as having ADHD and no psychiatric comorbidity? Are there requirements for regularly reviewing the cases?

p) What guidelines or protocols are used for the management of children diagnosed with ADHD? What about if the child is also diagnosed with another mental health problem, how does that change things?

PROBE: Use AAP Guidelines, Academy of Child and Adolescent Psychiatry Practice Parameters or health plan-specific protocol?

q) Do you provide case management to children with ADHD?

(IF YES) What type of case management is provided?

PROBE: Does it include home visiting? Case conferences with doctors? Is it telephonic?

What criteria are used to determine when a child needs case management?

PROBE: Do they have to have a co-morbidity or been hospitalized?

What are the credentials of the case management staff? What role do they play in managing care?

r) Has your plan experienced challenges finding providers who can manage ADHD?

PROBE: This could include mental health specialists or other providers who are needed to manage care for children with ADHD?

s) Given the complexities of ADHD (emotional/behavioral components and impact on family and school life of the child), what is your assessment of the adequacy of policies and procedures the health plan currently has in place to effectively manage the care of a child with a diagnosis of ADHD?

PROBE:
- What is working well?
- What are the challenges? (Do providers know enough about the condition? Do they practice evidence-based care? Do providers receive an adequate reimbursement?)
- How could care be improved?
- What would it take to improve it?
IV. Evaluation of Care Provided to Children with a Diagnosis of ADHD

c) Please describe your utilization review process and any procedures that are specific to the review of ADHD cases?

d) How do you monitor the care provided to children with a diagnosis of ADHD?

Probe for:

- Who is involved in this process (including, do you collect information from parents on their perception of their child’s treatment? Are there outcome measures you monitor?)

- How often does the monitoring occur?

- What happens to information obtained from monitoring?

e) Have you implemented any quality improvement initiatives focused on improving the quality of the care provided to children with a diagnosis of ADHD?

(IF YES) Tell me about this

PROBES: What outcomes have you focused on? What changes have you seen? How well do you think these have worked? What are your next steps?

(IF NO) Do you think such initiatives would be helpful? Why or why not?

f) Is your plan aware of the HEDIS ADHD measures?

(IF YES) Have these done anything to change your plan’s approach to ADHD?

g) Thinking about all those involved in ADHD care, including those at the family, community, provider, health plan, and regulatory level, are there things that you think could be done to improve the quality of care for children with ADHD?

PROBE: Are there any Medicaid policies that you think need to be changed in order to improve the quality of care for children with ADHD?

V. Closing

g) Is there anything else that you would like to add?

h) May I contact you again if I need to clarify something you said during this interview?

i) Thank you very much for your time.
The NYS Department of Health is sponsoring a study to assess the quality of care provided to children with a diagnosis of ADHD enrolled in a Medicaid managed care plan. NYS has contracted with Health Systems Research, Inc. (HSR) to conduct the study. The results of the study will be used to strengthen the quality of care provided to these children.

Thank you for agreeing to this interview. The objectives of the interview are to learn more about how the health plan delivers care to children with a diagnosis of ADHD and to explore your ideas about current best practices, challenges and opportunities to improve the quality of care for these children. We are focusing on children ages 6 – 12 years with a diagnosis of ADHD with no psychiatric comorbidity who are insured through a Medicaid managed care plan. Your responses will be confidential and nothing you say will be linked to your name or plan. I would like your permission to tape record the interview so I can use the tape to supplement my hand written notes. The tapes will not be shared with the Department of Health or IPRO. Do I have your permission to tape this conversation? (IF THEY SAY NO SAY, “I UNDERSTAND” AND PROCEED TO CONDUCT THE INTERVIEW WITHOUT TAPEING, IF THEY SAY YES YOU CAN INITIATE TAPEING)

The interview should take no more than 1 hour. Do you have any questions before we get started?

I. Description of the behavioral health vendor (COMPLETE AS MUCH AS POSSIBLE PRIOR TO INTERVIEW)

   i) Name of the Behavioral Health Vendor:

   j) Name and contact information of interviewee:
      Email
      Telephone

   k) Geographic area served by the behavioral health vendor:

   l) Number of years the vendor has served the Medicaid population:
II. Identification of Children with ADHD

g) What are the behavioral health organization’s policies and procedures for diagnosing or ruling out ADHD?

Probe for type of staff (e.g. mental health) involved in process, diagnostic criteria used (DSM IV, other); family involvement in diagnostic process.

h) Are all children diagnosed with ADHD able to receive services covered by your organization or are there additional criteria they must meet?

i) Do you have a particular protocol that is followed when a member of one of the health plans you serve receives an initial diagnosis of ADHD?

PROBE: Are parents or providers sent any special information? Are there requirements for regularly reviewing the cases?

III. Management of Children with Diagnosis of ADHD

t) Are there guidelines or protocols you recommend for the management of children diagnosed with ADHD and no comorbid psychiatric disorder? What is used if the child is also diagnosed with another mental health problem, how does that change things?

PROBE: Use AAP Guidelines, Academy of Child and Adolescent Psychiatry Practice Parameters or health plan-specific protocol?

u) What challenges do your members experience in accessing care for ADHD?

v) Has your organization experienced any challenges in finding providers who can manage ADHD?

(If YES) What factors do you think contribute to this problem?

w) Are parental and teacher rating scales used to assist in ADHD management? Do you require or recommend the use of such scales? How frequently are they supposed to be administered?
x) Given the complexities of ADHD (emotional/behavioral components and impact on family and school life of the child), what is your assessment of the adequacy of policies and procedures your behavioral health organization currently has in place to effectively manage the care of a child with a diagnosis of ADHD and no psychiatric comorbidity?

Probe for:

- What is working well?
- What are the challenges? (Do providers know enough about the condition? Do they practice evidence-based care? Do providers receive an adequate reimbursement?)
- How could care be improved?
- What would it take to improve it?

IV. Evaluation of Care Provided to Children with a Diagnosis of ADHD

h) Please describe your utilization review process and any procedures that are specific to the review of ADHD cases?

i) How do you monitor the care provided to children with a diagnosis of ADHD?

Probe for:

- Who is involved in this process (including, do you collect information from parents on their perception of their child’s treatment? Are there outcome measures you monitor?)
- With what regularity does the monitoring occur
- What happens to information obtained from monitoring?

j) Have you implemented any quality improvement initiatives focused on improving the quality of the care provided to children with a diagnosis of ADHD?

(IF YES) Tell me about this (Probes: What outcomes have you focused on? What changes have you seen? How well do you think these have worked? What are your next steps?)

(IF NO) Do you think such initiatives would be helpful? Why or why not?

k) Thinking about all those involved in ADHD care, including those at the family, community, provider, health plan, and regulatory level, are there things that you think could be done to improve the quality of care for children with ADHD?
PROBE: Are there any Medicaid policies that you think need to be changed in order to improve the quality of care for children with ADHD?

V. Closing

j) Is there anything else that you would like to add?

k) May I contact you again if I need to clarify something you said during this interview?

l) Thank you very much for your time.

Date of Interview:

Interviewer: