Family Empowerment Satisfaction Team
2008 Report
Behavioral Health Rehabilitation Services
Educating Parent/Caregivers in Wraparound for a Child Diagnosed with ADHD
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2008 FEST BHRS Report
Educating Parent/Caregivers in Wraparound for a Child Diagnosed with ADHD

TABLE of CONTENTS

Introduction/Project Overview p 2
Objective p 3
Procedures p 3
Results p 4 - 7
Discussion p 8
Conclusion p 9
References p 10
2008 FEST BHRS Report
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The Family Empowerment Satisfaction Team (FEST) Montgomery County is an independent, non-profit advocacy program of the Family and Youth Division of the Mental Health Association of Southeastern Pennsylvania. FEST asks Montgomery County families and youth who are receiving or recently received behavioral health services about their experiences - what worked and what can be improved.

FEST develops questionnaires and questions for interviews and focus groups with stakeholder involvement. These tools are used to survey and obtain family and youth feedback about accessibility, appropriateness and effectiveness as well as their satisfaction with county behavioral health services. After analyzing the data collected, FEST reports the findings to Montgomery County Behavioral Health and other stakeholders – providers, families and youth - to support the county’s continuous quality improvement efforts. The goal is to help make behavioral health services more family and youth driven.

Behavioral Health Rehabilitation Services (BHRS), commonly known as wraparound, are used in Montgomery County as a treatment for children and adolescents diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). Montgomery County Behavioral Health and Magellan are currently conducting a study, Effectiveness of BHRS for Children and Adolescents Diagnosed with ADHD, to identify how closely individual providers adhere to guidelines established for the treatment of ADHD and examining the outcomes of wraparound provided to Montgomery County youth. The 2008 FEST BHRS project was conducted at the request of the county and Magellan and will be used in Magellan’s study to provide an independent source for collecting and analyzing quantitative and qualitative data, and the findings contained in the report will be incorporated into Magellan’s study.

Wraparound is a community-based behavioral health service provided to children and adolescents with severe emotional or behavioral problems, including ADHD, that interfere with family life, school or both. Wraparound is considered a "medically necessary" behavioral health service that is Medicaid funded. The services are family and child-centered, based on individual needs, use one-on-one intervention to help modify behaviors, increase sense of responsibility, and teach problem-solving skills. A team, which includes the parents or caregivers, creates a Behavior Treatment Plan in which goals and objectives are identified to meet these needs. The Therapeutic Support Staff (TSS) works directly with the child to modify behaviors, while Mobile therapy (MT) provides psychotherapy to improve family dynamics and assist the family in implementing the treatment plan. Wraparound builds on the strengths of the child and family to meet the treatment plan goals.1

In Montgomery County, Magellan Behavioral Health contracts with providers of wraparound services and has established guidelines for providers to follow to improve the treatment outcomes for Montgomery County youth diagnosed with ADHD. Medication and psychosocial treatment options may be used individually or in combination. Wraparound incorporates psychoeducational interventions and psychotherapeutic treatments, as indicated, for a child or adolescent with an ADHD diagnosis.

Parent/caregiver education is an important component of wraparound services. Under the direction of the county and Magellan, the Family Empowerment Satisfaction Team (FEST) conducted a survey to obtain parent/caregiver input on their perception of the education they received from the wraparound provider. In designing the tool for this survey, FEST followed Magellan’s Clinical Practice Guidelines for the Treatment of Patients with Attention-Deficit Disorder2 to determine the information that should be included in parent/caregiver education. Although this project was clinically based, FEST used the same approach it uses in its satisfaction studies. FEST incorporates a peer-to-peer approach, uses quantitative and qualitative methods and employs Appreciative Inquiry3 strategies. Appreciative Inquiry is a well-established approach to organizational change that identifies and builds upon what is working well 4.
The county will present BHRS providers with a copy of FEST’s overall report. No data collected on individual providers has been used in the aggregate report in order to insure the confidentiality of parent/caregivers and providers. In the presenting the qualitative data derived from open-ended questions, all identifying information has been removed to protect confidentiality. Providers who had seven or more respondents to the survey will also receive a report compiled by FEST with individual data collected on that provider.

**Objective**

The objective of FEST’s survey was to obtain parent/caregiver input as a means of gaining information on the education they received from individual providers as part of wraparound services for their child with an ADHD diagnosis. The analysis of this data, in combination with the other parts of the study conducted by Magellan and Montgomery County Behavioral Health, will provide a measurement of the effectiveness of wraparound services for children and adolescents with a diagnosis of ADHD based on individual provider’s adherence to Magellan’s *Best Practice Guidelines* for parent/caregiver education.

- Obtain input from parent/caregivers of children with an ADHD diagnosis who received wraparound in the county between 2001 and 2007
- Determine the comprehensiveness of the parent/caregiver education provided by individual practitioners of wraparound services
- Use the parent/caregiver’s perspective on how closely their education followed Magellan’s *Clinical Practice Guidelines for the Treatment of Patients with Attention-Deficit Disorder*

**Procedures**

Identified a sample to survey based on instructions by Magellan. This included all parent/caregivers of Montgomery County youth with a diagnosis of ADHD who received wraparound between 2001 and 2007.

Created a questionnaire to obtain feedback from the parent/caregivers on the education they received as part of wraparound for the child with ADHD.
- Established format to address specific areas to be analyzed
- Included questions on demographics and the name of the wraparound provider
- Developed questions using a Likert Scale as a method of collecting quantitative data
- Designed questions to cover all areas of education outlined in the *Best Practice Guidelines* to be covered by the wraparound team - medication, psychosocial and psychotherapeutic treatment of ADHD
- Included four open-ended questions for more in-depth collection of qualitative data

Wrote cover letter to send to parent/caregivers when mailing the questionnaire. The letter included instructions for special circumstances: a) if more than one child in your family received wraparound services, you will receive a questionnaire for each child. Please complete a separate questionnaire for each child. b) If your child received wraparound services more than once during the years 2001 to 2007, answer the questions based on your most recent experience. c) If you were not the parent or caregiver responsible for the child at the time of services, please return this survey with any contact information that is available.

Obtained stakeholder feedback on questionnaire and letter by Magellan, parents, Delaware County FEST Team, and Montgomery County Behavioral Health

Incorporated feedback in making revisions

Questionnaire and cover letter finalized in a second meeting with Magellan and county

Received database of youth names and contact information from county and removed names with incomplete addresses

Established timetable for mailing and return date of questionnaires - 3-week turnaround from time of mailing
Mailed 961 surveys to parents/caregivers who had been identified by the county and Magellan as the subjects for this survey meeting all the following criteria: a) parent or caregiver of a Montgomery County youth who received wraparound services; b) the child had an ADHD diagnosis; c) the services took place between 2001 and 2007.

Included a brochure on FEST and the Family and Youth Division, the cover letter, and a return envelope in the mailing.

**Results**

FEST received 152 completed surveys by mail. The surveys were reviewed to ensure that the respondents met the criteria for the sample population based on answers given in survey questions 1, 2, 6 and 7. Three surveys were discarded. Therefore, data obtained from 149 respondents (N=149) was analyzed to obtain the survey results.

Basic information about the child, family, and the child’s wraparound provider – Questions 1 - 7

Are you a parent or caregiver of a child who received wraparound services in Montgomery County between the years 2001 and 2007?

(N=149) 146 respondents reported “yes”, 2 answered “no” and 1 did not respond

Was your child living with you at the time services were received?

(N=149) 148 respondents said “yes” and 1 gave no response

What is your child’s gender?

(N=149) 122 male and 27 female

Were other children living in the household at that time?

(N=149) 110 children, over 73%, lived with siblings or other children.

What age was your child at the time he or she began receiving wraparound services?

**Table 1**

<table>
<thead>
<tr>
<th>Age of Child</th>
<th># of Children</th>
<th>Percent of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>4</td>
<td>3%</td>
</tr>
<tr>
<td>4</td>
<td>15</td>
<td>11%</td>
</tr>
<tr>
<td>5</td>
<td>12</td>
<td>9%</td>
</tr>
<tr>
<td>6</td>
<td>10</td>
<td>7%</td>
</tr>
<tr>
<td>7</td>
<td>18</td>
<td>13%</td>
</tr>
<tr>
<td>8</td>
<td>11</td>
<td>8%</td>
</tr>
<tr>
<td>9</td>
<td>16</td>
<td>11%</td>
</tr>
<tr>
<td>10</td>
<td>14</td>
<td>10%</td>
</tr>
<tr>
<td>11</td>
<td>15</td>
<td>11%</td>
</tr>
<tr>
<td>12</td>
<td>7</td>
<td>5%</td>
</tr>
<tr>
<td>13</td>
<td>5</td>
<td>4%</td>
</tr>
<tr>
<td>14</td>
<td>4</td>
<td>3%</td>
</tr>
<tr>
<td>15</td>
<td>4</td>
<td>3%</td>
</tr>
<tr>
<td>16</td>
<td>3</td>
<td>2%</td>
</tr>
<tr>
<td>17</td>
<td>2</td>
<td>1%</td>
</tr>
</tbody>
</table>
What agency provided the wraparound services?

Of the total questionnaires FEST received (N=152), parents/caregivers identified only 15 out of the 27 agencies listed as the provider of wraparound. None of the respondents had used the remaining 12 agencies. Most providers identified as “Other Agency” were, in fact, on the list, so FEST entered the data from those surveys as if the agency had been marked on the list. There were five exceptions. The county and Magellan confirmed that three of those names were not providers for the county and the other two were county wraparound providers during 2001 – 2007. The data for those two agencies was used, and the three surveys with incorrect provider names were eliminated from the sample. Two surveys had more than one provider marked, and one was not sure of the provider.

At the time of services did your child have any other diagnosis besides ADHD?

(N=149) Over 72% of the children had ADHD and another diagnosis (N=108); over 15% had an ADHD diagnosis only (N=23); 12% were not sure of the diagnosis (N=4) or answered “other only” (N=14). Magellan confirmed that all children, based on their claims data, had an ADHD diagnosis when they received wraparound, even if the parent/caregiver responded otherwise.

Questions 8 – 13  Psychoeducation intervention provided to parent/caregivers

<table>
<thead>
<tr>
<th>Table 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment Plan Options (N=149)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>No Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>8) Medication options for treating my child’s ADHD were explained to me in language I could understand; how it could help, noticeable improvements, and any possible side effects.</td>
<td>26</td>
<td>70</td>
<td>20</td>
<td>12</td>
<td>12</td>
<td>9</td>
</tr>
<tr>
<td>9) After I met with the wraparound team, I understood the program and what the treatment plan goals were for my child and family</td>
<td>52</td>
<td>83</td>
<td>6</td>
<td>6</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>10) I knew that I was an important part of the treatment team.</td>
<td>75</td>
<td>62</td>
<td>8</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>11) I was given useful information about local resources for the social needs of my child and our family and where to find peer support groups.</td>
<td>32</td>
<td>47</td>
<td>28</td>
<td>29</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>12) I was given information about my legal rights to have my child’s educational needs met through the school system.</td>
<td>35</td>
<td>68</td>
<td>17</td>
<td>18</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>13) I was informed about the potential for my child to be at increased risk of suicidal behavior, and I was made aware of the warning signs.</td>
<td>18</td>
<td>42</td>
<td>32</td>
<td>32</td>
<td>20</td>
<td>5</td>
</tr>
</tbody>
</table>
Questions 14 – 17  Education related to psychotherapeutic treatments in the home

Table 3
Psychotherapeutic Treatments in home N=149

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>No Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>14) The wraparound team was aware of the challenges faced by our family.</td>
<td>59</td>
<td>70</td>
<td>14</td>
<td>4</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>39.6 %</td>
<td>47.0%</td>
<td>9.4%</td>
<td>2.7%</td>
<td>1.3%</td>
<td>0%</td>
</tr>
<tr>
<td>15) When the wraparound team came to our home, they worked with my whole family in ways to improve our interactions.</td>
<td>51</td>
<td>64</td>
<td>14</td>
<td>14</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>34.2%</td>
<td>43.0%</td>
<td>9.4%</td>
<td>9.4%</td>
<td>3.4%</td>
<td>.7%</td>
</tr>
<tr>
<td>16) I learned new parenting skills to help me be more effective and confident in handling my child’s behavior.</td>
<td>41</td>
<td>58</td>
<td>21</td>
<td>23</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>27.5%</td>
<td>38.9%</td>
<td>14.1%</td>
<td>15.4%</td>
<td>4.0%</td>
<td>0%</td>
</tr>
<tr>
<td>17) After my child’s wraparound services ended, I knew how to find and access additional services if my child ever needed them.</td>
<td>23</td>
<td>38</td>
<td>31</td>
<td>25</td>
<td>14</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>15.4%</td>
<td>25.5%</td>
<td>20.8%</td>
<td>16.8%</td>
<td>9.4%</td>
<td>12.1%</td>
</tr>
</tbody>
</table>

Was medication prescribed for your child’s ADHD?
Over 77% (N=115) of parent/caregivers reported that medication was prescribed as a treatment for their child’s ADHD.

I feel that the combination of wraparound services and medication was of greater benefit to my child than medication alone.
Over 83% of N=115 felt the combination of treatments was better than medication alone.
Strongly Agree 43.5% (50)  Agree 40.0% (46)  Undecided 15.7% (8)  Strongly Disagree 0.9% (1)

Questions 20 -22  Education on psychotherapeutic treatments related to school

Table 4
Psychotherapeutic Treatments related to school issues N=149

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>No Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>20) The wraparound team supported me in working with my child’s school to ensure that he or she was receiving appropriate educational support services</td>
<td>41</td>
<td>64</td>
<td>14</td>
<td>20</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>27.5%</td>
<td>43.0%</td>
<td>9.4%</td>
<td>13.4%</td>
<td>5.4%</td>
<td>1.3%</td>
</tr>
<tr>
<td>21) The wraparound team assisted in identifying natural supports in the school for my child.</td>
<td>31</td>
<td>55</td>
<td>25</td>
<td>23</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>20.8%</td>
<td>36.9%</td>
<td>16.8%</td>
<td>15.4%</td>
<td>7.4%</td>
<td>2.7%</td>
</tr>
<tr>
<td>22) I understood I played an important part in my child’s education.</td>
<td>63</td>
<td>53</td>
<td>7</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>55.7%</td>
<td>35.6%</td>
<td>4.7%</td>
<td>2.0%</td>
<td>0.7%</td>
<td>1.3%</td>
</tr>
</tbody>
</table>
Qualitative Results

23) How did the wraparound provider help you the most with improving your child’s behavior at home?

Most parents answered this question with something positive and often concrete. Some parents said that they were taught behavior modification techniques, including the use of charts, rewards and praise. They were taught coping skills and to recognize “triggers” that caused the child to loose control.

“Broadening my understanding of parental styles, discipline “
“Parental support and providing us with techniques/coping strategies that we hadn’t used before, one on one work helping my child learn some new coping techniques”
“Behavioral specialist gave us a lot of help”

Some thought working with the family improved the child’s behavior.

“The program helped the family work with the child as well as the child learning how to work with the family”
“Wraparound helped most when a TSS come to our home and helped/taught my son how to play/interact with his sister.”

Other parents found that having someone working with the child helped the most.

“Having someone to talk to and helping him express his feelings verbally instead of being violent”
“Controlling anger - more personal contact”
“By talking to him and having him open up about his problems”

24) What was your child’s best experience with wraparound services?

Many of the experiences involved developing a relationship, having someone give the child attention and doing things together.

“Someone to be with, help on issues”
“The friendship she is able to have”
“The fieldtrips and one on one”

Helping the child to learn ways to control their anger and behavior were cited as the child’s best experience with wraparound.

“Our MT helped our son learn sensory ways to deal with times he feels out of control”
“Learning about her feelings”
“Help with his anger”

Other children developed self-confidence, felt better about themselves, and became more social as a result of wraparound.

“A greater feeling of self-confidence which came through all the of the things they helped us to put in place”
“He is much more socially confident now and happier, more easy-going, less negativity than before”
“Finding out he was a better person than he thought he was”

25) How is your child doing now?

A few parents reported that their children were “very well” or “great”. Some simply said “Not good”, while most saw signs of improvements, although the child might still be struggling.

“He really enjoys school. He was voted good citizenship for 3rd qtr in 3rd grade, responsibility award”
“Very well, taking guitar lessons”
“Better than before but still have issues. I (mom) feel much more in control of the situation”
“He is doing better socially outside of school. Academically he struggles”
“Not there yet - but doing better”

26) Based on your experience, is there anything that you would change to make wraparound services better?

Many parents thought improvements were needed with staff retention. Some felt more attention should be paid to working with the family. Others mentioned checking up on the child more often, aftercare visits, and extending the length of time their child could receive services.
Discussion

Parent/caregiver education is an important component of wraparound. The original goal of this project was to measure individual provider’s adherence to Magellan’s guidelines for educating parent/caregivers as part of wraparound for a child diagnosed with ADHD. Based on the total responses for each provider listed on the survey, only 1 provider had a large enough sample to be considered statistically reliable. 12 providers were not represented in the completed surveys and the remaining providers had low numbers of responses. Only six agencies had over 10 responses. Without sufficient data, the performance of individual providers could not be assessed. However, the aggregate data collected in the survey is useful in looking for general trends of all providers. The parent/caregiver perspective helps illustrate areas in which the education has been successful and areas needing improvement.

Overall, the survey responses by parent/caregivers were positive regarding the education they received. Reviewing the data presented in Table 2 reflects high percentages of agreement in several aspects of psychoeducation covering treatment options. Over 91% of parent/caregivers agreed or strongly agreed that they knew they were an important part of the treatment team. Also over 90% agreed or strongly agreed that after meeting with the wraparound team, they understood the program and the treatment plan goals. This suggests that parents felt they were included in the initial decision making process and grasped the concepts of wraparound.

Equally notable was the number of “undecided”, “disagree”, or no response about having received information to find local resources for the social needs of the child and family and groups for peer support. Qualitative data collected supports a lack of information for parent/caregivers. When asked what they would change to make wraparound better, responses included “Add info about social groups for children w/ PDD” and “Having a program that helps children learn how to socially interact with peers”.

All three areas of wraparound with data presented in Tables 2, 3 and 4, show a similar pattern. Regarding education on psychotherapeutic treatments at home, fewer than 41% (N= 61) agreed that they knew how to find and access additional services after wraparound. Again, the qualitative data supports this with statements such as “More social services identified to support ADHD child…” and “Internet resources. Help the parent find support for his/ her disabilities and the child’s.”

Parents expressed that they had good experiences with wraparound when the wraparound team actually got them services, but they seemed to feel lost in getting services when wraparound ended. The qualitative data provides examples. “NAME! He was excellent both working with my son + helping me get services” and “Helped my husband and I to learn techniques to deal with emotional outbursts and ways to prevent them from escalating out of control. Was a great resource to help us get the services my son needed from school district.”

When asked if they knew they played an important role in their child’s education, over 91% of parent/caregivers agreed or strongly agreed. Conversely, fewer than 58% agreed with the statement that the wraparound team assisted in identifying natural supports in the school for the child. The obvious similarity in the questions where fewer parent/caregivers said they agreed was the reference to resources, supports and access to services that would be critical for the long-term success of wraparound once the services end.

Even if providers give parent/caregivers a list of resources in the community, parents may need education on ways to identify resources and build a support system. When wraparound providers demonstrate how to connect with resources, it is possible that the connection can be sustained when wraparound ends, such as in this example. Responding to the question what was your child’s best experience with wraparound services, the parent/caregiver wrote, “Getting him involved in the YMCA.” If there are no support groups, education about online support groups or how to start a support group may benefit some families. Sometimes the issue may not be finding the support group, but learning about transportation to get there or where to find the childcare so they can attend.
Does educating the parent about resources and developing natural support get in-depth enough to uncover less obvious needs to connect with the resource? Does wraparound teach parent/caregivers to look for supports that may be easily overlooked – for example, a neighbor, another child at school who can act as a mentor and role model, involvement in sports teams, or any activity of interest to the child, such as Boy Scouts, church activities, art lessons, or getting involved in community service? Several parent/caregivers offered ideas to improve wraparound that may not be intended to address this issue, but could have potential for developing unexpected supports or resources in the community.

“Yes - make it larger - get more people to join this excellent program. Offer to colleges to get gifted, caring people to be a part of this …”
“Yes. It would be nice if wrap services had money to fund the tx of art therapy, play therapy like family based. “

In conclusion, Magellan’s guidelines for the treatment of a child with ADHD serve as a basis for wraparound providers to follow when educating parents/caregivers of youth receiving services. FEST conducted a survey of parents/caregivers of Montgomery County youth who were diagnosed with ADHD and received wraparound between 2001 and 2007. FEST collected data from the sample parents/caregivers using a tool designed to include questions that were strength-based and covered all areas of psychosocial treatment outlined in Magellan’s treatment guidelines: treatment options, psychotherapeutic treatment in the home, and psychotherapeutic treatment related to school. The data collected was insufficient to examine the adherence to the guidelines for the twenty-seven individual providers of wraparound used in Montgomery County. However, an analysis of the aggregate data, both quantitative and qualitative, is provided in this report. A discussion of the results focused on a pattern that emerged when reviewing the data from all three areas of parent/caregiver education.

In each cluster of questions, parent/caregivers showed high levels of agreement when asked about their understanding of the role they played in wraparound and their understanding of the process. However, agreement was consistently lower when the questions referred to the education provided on accessing resources, services and natural supports for their child and family. Overall, many parent/caregivers felt that wraparound was beneficial when staff remained consistent, were well-trained and when both parties communicated.
References

1 Wraparound or BHRS Services
http://www.dpw.state.pa.us
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2 Clinical Practice Guidelines for Patients with Attention Deficit/Hyperactivity Disorder
Magellan Health Services Clinical Practice Guidelines Task Force
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