

The Connecticut Behavioral Health Partnership: A Users' Perspective

A report for:

The Connecticut Behavioral Health Partnership Oversight Council

By:

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Background Information

In 2005, the Connecticut Legislature passed statutory language (PA05-280) that created the CT Behavioral Health Partnership (CT BHP): a joint venture between the CT Department of Children and Families (DCF) the State's consolidated children's agency, and the Department of Social Services (DSS) the State's Medicaid agency. The goals of the Partnership are to increase access to publicly funded behavioral health services for children and adults enrolled in HUSKY A, children enrolled in HUSKY B, and other DCF involved children with behavioral health needs, to enhance community based services in order to decrease reliance on restrictive inpatient and residential levels of care, and to maximize federal Medicaid reimbursement for behavioral health services. The legislation also required the two Departments to contract with an Administrative Services Organization (ASO) to manage this behavioral health benefit through the application of utilization management techniques, clinical management strategies, and continuous quality improvement strategies. ValueOptions, Inc. (VO) was chosen through a competitive bidding process to develop and manage the ASO.

To ensure transparency within this new structure and to guarantee provider and consumer input into the protocols and processes within the CT BHP, the legislation also mandated the formation of the CT BHP Oversight Council, a body of interested parties, appointed by the Governor and Legislative leaders. The Council is comprised of providers, consumers, and advocates of publicly funded behavioral health services and representatives from relevant State agencies. The Oversight Council meets monthly in the Legislative Office Building and currently has five sub-committees (Operations, Access and Quality Improvement, DCF Advisory, Provider Advisory , Coordination of Care) that also meet at least monthly to advise the Departments and help direct the Partnership's activities.

Over the past three years, much of the activity within the CT BHP and the Oversight Council has been fiscal and administrative in nature: developing business protocols, setting rates for services, developing service descriptions and protocols, etc. In an effort to step back from these administrative activities and assess whether the new system is actually working for children and families, the Oversight Council decided to hold a series of focus groups throughout the state to gather information from consumers and family members on a variety of topics related to access and quality of care issues. While ValueOptions has a Consumer Advisory Group that provides essential input to the operations within the CT BHP service site and the two state Departments contract

for a Member Satisfaction survey to be done on an annual basis to assess consumer response to the Partnership staff and their services, this activity was to focus on whether or not the activities of the Partnership have had an impact on the service system.

Ideas about how to best implement these focus groups were discussed in the Council meetings and it was eventually decided that the DCF Advisory Subcommittee would assume responsibility for designing and effectuating the activity.

Project Design:

Funding was sought and obtained from DCF for this project. With the level of funding made available, three focus groups were able to be convened. In order to maximize the impact of these groups, an attempt was made to locate the groups in such a way as to draw upon a wide range of CT BHP members, although it was clear from the onset that the scope of the current project would not achieve representative statewide sampling.

The DCF Advisory Sub-committee formed a workgroup to assist with the details of the focus group process. The membership of the workgroup was primarily family members who had themselves experienced receiving services under the HUSKY program. The group was charged with reviewing the design of the focus group, the topic guide, the location of the groups, the letter sent to family members asking for participation, the criteria for selection, and other details of the process. The workgroup reported progress to the Sub-committee who in turn reported to the Oversight Council, as needed. The workgroup first met in February 2008 and continued to meet throughout the process. Feedback was also solicited from the Sub-committee as a whole. Individual family members sought feedback from their various constituency groups to enhance the process and discussion as well.

The DCF Advisory Subcommittee workgroup also prioritized the need for the focus groups to be conducted in a manner consistent with state-of-the-art professional practice. Accordingly, an expert professional consultant was selected to oversee the implementation of this project. This included assisting the workgroup in revising and amending interview questions and selection criteria, conducting the focus groups, and preparing a final report for presentation to the Departments and the Oversight Council. FAVOR, the statewide family advocacy organization served as the fiduciary contractor for the project.

Consistent with the recommendation of the expert consultant, the focus groups were conducted in facilities set up specifically for this purpose.

Staff at these facilities coordinated the scheduling of participants and collaborated with FAVOR to arrange for participant transportation when needed, and payment of stipends.

Larger Evaluation of the Inpatient Experience:

Simultaneous to the activities associated with the Parent Focus Groups, the Oversight Council sought and received funds from the General Assembly to conduct a more extensive and rigorous evaluation of the status of the current behavioral health system. \$100,000 was allocated in 2007 to support a research activity and a small group of members from the Oversight Council met to determine the parameters of the study. It was decided that by focusing intently on a cohort of children who had been admitted to inpatient facilities, researching what kinds of services they had received prior to receiving inpatient care and what services were available upon discharge, a basic understanding of the system strengths and weaknesses could be garnered. The study was to rely heavily on structured interviews of the patients and their family members, chart reviews from the inpatient stay and review/analysis of claims data to help identify and understand the services utilized before and after hospital care. A Request for Proposal was issued by DCF to contract with a research entity to further design and execute the study. As details for this study were flushed out, it became obvious that the smaller Parent Focus Group activity would be a relevant complement to the larger study. As such, the intent of the Oversight Council was to blend these two endorsed activities into one larger study with two separate components, both designed to address the experience and clinical outcomes of CT BHP members who utilized high end services.

Unfortunately, the larger research study was never executed. By the time the formal procurement process had been completed and the contractor chosen, the state was immersed in fiscal crisis and all non-essential spending was halted. The project was suspended and as a result, the Focus Group activity resumed its original status as a stand alone activity, not tied into a larger, more comprehensive probe into the children's behavioral health system.

It is understood that the information gleaned from focus group interviews with the 21 caregivers who participated in these three groups cannot be considered a representative sampling of the experience of a majority of CT BHP members, nor is this information cast in the context that might have been provided by a broader evaluation. This notwithstanding, the information obtained details the experience of these several families and provides a glimpse of the challenges that remain when a child experiences a psychiatric crisis. As such it is hoped that the findings as reflected in this document may prove instructive and guide the

development of action steps to address the concerns expressed.

Focus Group Report

Introduction

The Connecticut Behavioral Health Partnership Oversight Council commissioned J. Dineen and Associates to conduct a series of focus group discussions with parents and guardians of children on the State of Connecticut's HUSKY plan who receive behavioral health services. The three focus group discussions were held in various parts of Connecticut. Participants came from as far south as Stamford and as far north as Windsor. For a complete discussion topic guide see Appendix A.

On March 5 and March 24, 2009 focus group discussions were conducted at a Hartford Research Center (HRC) focus group facility. The first was held at HRC's Wethersfield facility and the second took place at HRC's North Haven facility. In an effort to attract participants from southwestern Connecticut a third group was held on April 30th at The Focus Room in Stamford, Connecticut. In order to protect the confidentiality of behavioral health clients, participants were invited to the discussions via letters of invitation sent by Value Options, Inc. These invitations explained the purpose of the discussions, where and when they would take place, information about the cash incentive paid to participants and the telephone number of the facility so they could call and register to participate. The invitations also offered participants transportation to the focus group discussions. Copies of the invitation letters are found in Appendix B.

The discussions focused on participants' experiences with obtaining adequate behavioral health services for children under their care, the role of Husky insurance in obtaining and maintaining these services, barriers to successful treatment, and challenges to coordinating various health care services. The same general outline was used to guide all three discussions.

Participants in the first two focus group discussions ranged in age, family size and type, ethnicity and size of their community. The vast majority of the participants were female. Group one was solely female and there was 1 male participant in the second discussion group. Participants represented a variety of roles – birth parents, adoptive parents, foster parents, grandparents and guardians.

The third focus group was held on April 30, 2009 in Stamford, CT. Like participants in the first two groups, these individuals represented a variety of age groups, family size and types, ethnicities and community sizes. This group included two male and four female participants. In

total, the three groups contained 3 men and 18 women. All of the participants were parents or guardians of children who have received both in-patient and out-patient behavioral health services. All of the families had hospital emergency room experience.

A few notes of caution when considering the study's findings and recommendations. Most importantly, in order to comply with HIPAA regulations, discussion participants for this study were self-selected. While all families who had received services within the three months prior to recruiting were invited to participate, the burden to call in and register for the discussion was placed on the respondent. This burden can impact respondent selection in three ways: First, the most disenfranchised clients are unlikely to call to register for the groups because they believe their input makes no difference; second, despite our best efforts with Spanish speaking clients we were unsuccessful in our attempts to obtain feedback from Spanish speaking families; third, because self-selected participants are likely to share a certain profile and have a particular experience or opinion they would like to discuss, they are also more likely to represent similar behavioral health needs and those needs may not be representative of the behavioral health needs of all families.

The lively discussions produced a number of interesting findings.

Discussion Findings

Access to care

- **For many behavioral health clients, crisis is the gateway to care**

All of the focus group discussions began by asking participants to describe the process of getting their child/children mental health services. This seemingly straightforward question produced a lengthy, detailed explanation from each participant. While the stories were as varied as the participants, they all had one thing in common – crisis. Every participant, in each of the three groups, told a story of escalating behaviors, of being scared of or about what was happening with their child and being frustrated because they were unable to get adequate help until there was a critical, dangerous situation.

When asked to describe the process of obtaining services, one participant said ‘. . . a crisis leads to hospitalization which “catapults” you into the behavioral health system.’ These families all expressed frustration in not receiving adequate services until their child tried to hurt themselves or someone else. “In my experience, when your kid is first sick they don’t offer you any help . . . and then your kid really starts falling apart and you tell them it is an emergency then they (DCF) put you on waiting lists.”

- **Participants describe the process of obtaining services outside of a crisis as slow and often ineffective**

In many cases attempts for help with behavioral health issues or concerns started with school. Participants reported mixed experiences working through their school system or with “child guidance.” Even participants who began the process of obtaining services through their child’s school system complained of the process taking “painfully long” and in every case the child became critical before adequate services could be put in place.

Some discussants said they tried to get their child hospitalized or placed in an in-patient facility prior to someone getting hurt. These participants said the child was put on waiting list and they were told to call daily and check on progress of the list. While frustrated with the process, every focus group participant views it as the product of an overloaded behavioral health system.

- **Very few participants believe their children receive behavioral healthcare for a sufficient period of time**

Every participant told a story of their child being discharged/dismissed from either inpatient or outpatient services prior to being stable. In most cases participants said their insurance was responsible for premature dismissal/discharge. As one parent pointed out, “one problem is the insurance. Once you get names of people who can help you, you have to find someone who takes your insurance and like 90% of them don’t. Then you find someone who takes your insurance and you get 5 sessions – 5 , half hour sessions. How can you figure someone out in 5 half hours. I’ve been doing this the kid’s whole life and I’m still figuring out how my kids work.” A participant in the first discussion noted, “my child knows exactly what to say to a therapist . . . and can keep it together for the 15 minute or half hour appointment . . then we get home and he’s off the wall.”

One consistently identified issue is the lag between hospitalization resulting from an admission via emergency room and securing a bed in an inpatient facility. Participants each complained about being asked to take home a child they felt was still a danger to themselves and/or others in their home. One woman claimed the response to telling an attending physician that she was afraid to take her child (who was awaiting an inpatient placement) home was “your insurance only covers six days.” Two participants said they threatened to give up custody if forced to take a child home. A participant in the second discussion said she refused to take a child home because he was physically abusing his siblings and she was charged with abandonment. In her words, “. . . I didn’t abandon him but I knew I couldn’t take him back into the house where he was hurting the other children.”

None of the participants were able to articulate how long they waited for an initial mental health appointment since many got initial services via a hospital emergency room. Many participants told stories of being in hospital emergency rooms up to 36 hours waiting for a bed. A number of patients expressed frustration at wait times for a bed in a residential facility and talked of having to call everyday for up to 2 weeks checking to see if a bed had opened. Again, most participants blamed the wait times on an overloaded system but some participants believe that hospital emergency rooms do not treat mental health crises as true emergencies, placing their children at the bottom of the triage list.

- **Catchment areas cause some frustration for participants**

A number of participants felt there were programs that fit their child's needs but are not accessible to their family because of geography. One participant noted "One of the things is . . . we would like to take advantage of some of the excellent things at his school outside of school time because they understand him and all of his diagnosis, and we can't because it isn't in our catchment area." Another participant complained of not being able to access a therapist who they had worked with during a hospitalization, and specialized in his son's diagnosis, because he was in a different catchment area. He believes that "it is ridiculous that if I'm willing to bring him there we can't go to a doctor we know works well with him." Another participant who says she lives close to the border of two catchment areas says she has to drive to a provider in her area that is further away than some of the providers in the neighboring catchment area.

- **Participants complain about lack of continuity of behavioral health care**

Only some of the participants in the third discussion were able to articulate this complaint but it runs through the stories told by the participants in all three discussions. Based on the discussions, it sounded as if every time a child's level of services changed or there was a crisis that lead to another hospitalization or inpatient placement, the cast of behavioral health service providers changed. Very few participants talked about a therapist or psychiatrist that had been with their family throughout their child's entire treatment. Most talked about a doctor at a specific facility or therapist that came with Intensive In-Home Child and Adolescent Psychiatric Services (IICAPS) or a particular Intensive Outpatient Program (IOP). Many participants described gaps in care, or an inability to obtain care from a particular doctor or therapist consistently, which left them scrambling when their child again became unstable. Parents again expressed frustration with their inability to get significant help prior to a critical situation. One parent commented ". . . in my opinion that [hospitalization] could have been prevented had there been any continuity of care."

- **Discussion participants do not distinguish between private providers and community providers. Instead, providers are categorized by their position or role in treatment**

The majority of those who participated in the focus group discussions were unsure of whether they were using private providers or community

providers for their families' behavioral health needs. Participants categorize providers by their role or type of organization they work with, they talked of psychologists, psychiatrists, social workers, therapists, hospitals, outpatient/day program, IICAPS or DCF.

Most participants said they chose providers based on who took their insurance and who worked well with their child.

- **Cultural competency is not a major issue for families participating in the discussions.**

Complaints about difficulty in finding a provider were purely logistical and not based on cultural competency issues. Finding a provider with appointments during hours their families are available is an issue for participants but this was consistently discussed in regard to working around the school/work day. Qualifications and respectful treatment varied from individual provider to individual provider even within agencies or programs.

It is important to note that all of the discussion participants spoke English comfortably. I would expect cultural competency issues to be more relevant to families whose primary language is not English and who are less assimilated to the United States. The original study design included a discussion group with behavioral health clients who primarily/only speak Spanish. The multi-phase recruiting process was unsuccessful with these families and a third group with English-speaking families was scheduled instead.

The Intake and Discharge Processes

- **Focus group participants report high levels of frustration during intake**

Due to the fact that it took a crisis for all of the discussion participants to become active in the State's behavioral health system, the conversation about service intake and discharge resembled the initial discussion on finding a provider. Generally participants complained of long wait times (up to 36 hours in the emergency room or two weeks for a residential placement), having to repeatedly tell their story to many different people and being told to take home a child who was not stable.

Most participants said they felt involved in the process but a few felt their input was given little consideration. A parent of two children with behavioral health needs told the story of her younger son's initial hospitalization. "I told them the history of my older son, who was about

the same age when he started showing symptoms, and mentioned the mood stabilizing drug that was working well for him. It took us a lot of trial and error to find that drug and I thought this time we're not starting from zero. There is a good chance that if the drug works well for our older son it would work on his brother. My (younger) son was in the hospital for four days before they tried the drug. Why did they have to wait four days?" Other participants complained of not being listened to throughout the treatment process. "I keep saying things are not OK and the kid needs help and then we end up in the ER and the doctor calls me out in the hall to chew me out about not getting my child the help they need and sending her to therapists way out of their league . . . like this is my fault. . ."

Concerns at the end of services all centered around discharge before they felt that their child was ready or was being returned home with out the proper support.

- **Changes to the Husky program present serious challenges to families receiving behavioral health services**

Previous changes made to the HUSKY program presented a number of challenges to families whose children received behavioral health services from their primary care physician. Parents and guardians said changes to HUSKY were difficult because they resulted in needing to switch providers. "[i]t's so hard to find a provider that has appointments, at times you can be there and clicks with your kid." Some families were forced to leave providers they worked well with because some of their families' service providers accepted one type of HUSKY while others accepted a different type. "I had to pick the insurance that the most [providers] accepted. I had to drop some people that worked really well for one of the kids. I couldn't find insurance that everyone took and I can't pay for this stuff out-of-pocket."

- **Participants report little difficulty accessing medications or pharmacy services**

Obtaining pharmacy services does not present a major challenge for focus group participants. While there was much discussion about the trials and tribulations of medicating children with behavioral health needs (dealing with side-effects, finding the right drug for a particular child, and handling interactions with over-the-counter medications) most participants seemed comfortable with the amount information given and their ability to access medication. A number of participants say they depend on reference books and their local pharmacist to answer questions about their child(ren)'s behavioral health medications.

A couple of participants complained about individual providers but this did not appear to be a systemic critique. And, two participants complained about having difficulty finding a psychiatrist who took their insurance to get medications renewed after hospitalization, before outpatient services were in place.

In addition to talking about the specific aspects of the behavioral health system, discussion participants were asked to respond to a number of statements regarding their overall experiences with behavioral health services.

Transportation

- **Focus group participants complained about unreliable transportation to Intensive Outpatient Programs and long wait times when transporting between a hospital and a residential facility.**

After talking generally about the intake and discharge processes, the participants were asked to focus on specific aspects of each process. None of the participants complained of being denied transportation and it rarely came up as an issue relating to regular therapist or doctors appointments. Transportation was an issue when discussing intake at residential facilities and attending intensive outpatient programs.

Parents and guardians who depended on provided transportation to transport their child from home or school to an intensive outpatient program were among the most dissatisfied with transportation services. These complaints center on the reliability of the transportation. “It is great when it shows up but sometimes that is too early and they leave or sometimes they show up at 6:00 (pm) when she is supposed to be at the IOP at 3:00 (pm).”

A number of participants also complained about the transportation from an emergency room to an inpatient facility. In all three groups participants complained of their children waiting up to 36 hours in an emergency room for an ambulance transport. All of the participants in the discussion had experience with a child being hospitalized for a behavioral health issue. Transportation from a hospital to a residential facility or psychiatric hospital was an issue for approximately one-third of all discussion participants.

- **Transportation to appointments was an issue for families with young children**

A few of the discussion participants said they had difficulty with transportation for regular appointments. One parent told of needing to use provided transportation for regular visits because their child was extremely uncooperative when it came to going. “One of the problems is what do I do with my other kids. I called for transportation and they said I couldn’t bring my other child in the cab . . . what am I supposed to do with my other kid when I take [child] to all the appointments?” A participant in another discussion group told a similar story. “. . . When I called and explained the problem they told me to send the child alone. There is no way I’m putting my six year old in a van with some guy I don’t know. . .”

Family Role in Determining Care

- **My child’s perspective is considered in making decisions about his or her own healthcare**

Participants overwhelmingly stated that they typically do not want their child’s perspective considered for multiple reasons. Many parents do not want their child’s perspective because they believe that he/she is not capable of making rational decisions regarding services. One participant responded “part of me wants my child’s perspective to be considered but I’d have to question the therapist that listens.”

Parents and guardians were also reluctant to have their child’s perspective considered because the child often didn’t want to participate in treatment. “My child’s perspective is they don’t want to be there.” Some participants did feel that their child’s input was considered when appropriate. There was not a single participant that felt their child’s perspective was ignored when they would have liked it considered.

- **I feel in charge of my child’s care**

Discussion participants initially agreed with this statement. But as the conversation progressed many expressed frustration with decisions regarding access to inpatient and outpatient services being determined by their insurance provider. A few participants characterized their feelings as if “the system” makes the real decisions about care. “You can know what your child needs, you can advocate for what your child needs but if the gatekeepers say no, you can’t get your child what she needs.”

- **I am comfortable expressing my concerns when care decisions are being made**

Discussion participants who are veterans of the behavioral health system answered yes to this overall question. Many of the participants said they became increasingly comfortable and willing to insert themselves into these conversations as they gained experience in the behavioral health system. Participants who were new to the behavioral health system were less comfortable expressing their opinion with service providers. Even the veterans expressed some trepidation about sharing their opinions. Throughout the discussions participants made comments about using caution when speaking to DCF employees out of concern that what they said might be used against them at a later time.

- **When it comes to making decisions about my child's care I am involved in the decision making process.**

Again this was a case where participants said they became increasingly involved with experience. A number of clients told of strongly inserting themselves into discussions about discharge from in-patient treatment after unsuccessful attempts to keep their child stabilized at home. "I told them I'd give up custody . . . there was no way I was taking him home . . ."

This question always brought the conversation back to the idea that the system was in charge. One participant explained, "I didn't want to open a voluntary case (with DCF) but there was no other way to get her into a residential program. You can't get a bed . . ." In the second discussion a parent commented "they told me they couldn't do any more unless something 'significant' happened. So we had to wait for him to try to kill himself . . ."

- **I feel that providers listen to me and really hear my concerns.**

Experience on this dimension really varied. The variation was not just from participant to participant but among the experiences of each participant. A parent participating in the third group noted: "My firm opinion on behavioral health and HUSKY . . . is that the care doesn't vary from institution to institution . . . but more so from person to person or provider to provider." Other participants commented that some of their service providers were wonderful and working in partnership with them while others did not seem to understand their child or family dynamics. "You have to be such a pain to these

people; you have to really be annoying. I hate that you can't ask nicely and patiently wait. In order to be heard you have to be annoying and in their face and that is the frustrating part."

- **I know who to call with a behavioral health question**

Respondents were asked to respond to this statement. Instead of talking about whether or not they knew the right person to call, participants volunteered who they call. Participants turn to a wide variety of sources when they have a behavioral health question or crisis. These sources include family, a pediatrician, someone at the child's school, a therapist, DCF, and the telephone number on the back of their insurance cards. This discussion did not produce a description of proper procedure or a clear picture of where families turn with questions or issues. Instead, participants seemed to reach out to whoever had been most helpful in the past or was available at the time.

Missed Appointments

Most of the participants in these discussions did not complain about trouble over missed appointments. When the issue was raised a few participants commented on the challenges missed appointments present. The reasons given for missed appointments were lack of cooperation from their child, child care issues and unreliable transportation.

Parents and guardians complained that it is often difficult to get a child who is not compliant with treatment to appointments on time. One parent told of missing appointments because her child runs away. This parent said that there was no follow-up and despite the fact that she called to reschedule and explain why the appointment was missed their provider dismissed them without warning.

Complaint and Appeals Process

- **Most participants did not know about the complaint and appeals process**

In total five knew and 16 did not know about the CT BHP complaint and appeals process. Those who are aware of the process said they remember reading about it. None of the participants had filed a complaint so they were unable to provide feedback on this issue. Participants said they had never considered filing a complaint over denied services although at least one participant said she was considering filing a complaint about inadequate services. As one woman

put it, “you get so used to being turned down, turned away and having to fight for everything that it stops occurring to you to complain about it; you have to fight and scream for everything. . .” A participant in the second group pointed out that typically they are handed this type of information in the emergency room, in the middle of the night when exhausted and completely focused on securing care for your child. “It was probably in the twelve pages of stuff I was handed at 3 a.m. There was only so much I could process and retain at that point. . . .once you get home you don’t really have the time to go back and review that stuff.”

- **Awareness of the Connecticut Behavioral Health Partnership is low among discussion participants**

Overall awareness of the Connecticut Behavioral Health Partnership is low among participants. In total seven of the twenty-one discussion participants say they have heard of CT BHP. Four of the participants familiar with CT BHP were unable to articulate the role it plays in providing services. These participants said that they had heard of the Connecticut Behavioral Health Partnership or they recognized the name from “letterhead.” One of the parents who said they were familiar with the term described CT BHP as a “service liaison” connecting families with providers. Another participant described them as a “resource that you call when you don’t know who to call or you need to find something new.”

Out of all twenty-one discussion participants, only one had gone to the CT BHP web site. This participant said she did not use the website regularly and was not able to offer any suggestions for improvement.

- **Parents who use peer support programs find them invaluable**

Only a handful of the discussion participants take advantage of peer support programs. The program users speak very highly of their experience with these programs and recommended them to other participants. As one participant noted “It keeps me from going crazy . . .”

SUMMARY AND CONCLUSION

Summary of Findings

The findings of the study lead us to conclude that knowledge and awareness of the Connecticut Behavioral Health Partnership is very low among discussion participants. Low levels of knowledge and awareness among users diminishes the effectiveness of because families cannot take advantage of services and supports with which they are unaware or unfamiliar.

Most of the discussion participants were unable to get children in their care behavioral health services without a significant mental health “crisis.” Even those who started receiving support via their school system said their child did not receive an adequate level of services prior to a mental health emergency. Participants said behavioral health services were not delivered for a sufficient period of time. Almost every participant told a story of being asked to take their child, who was unstable, home from a hospital. And, a number of participants felt there were emergency room visits and hospitalizations that could have been prevented if they had been able to get additional help prior to a crisis.

Initially discussion participants said they felt involved in their decisions regarding their child’s (or child under their care) behavioral health care. Many even agreed with the statement “I am in charge of my child’s care.” As the conversation progressed in each focus group, parents and guardians complained about having to “yell,” “scream” and “threaten” in order to have their point of view be considered. Discussants noted that level of their involvement in care decisions increased with experience in the behavioral health care system.

The discussion guide developed for the focus groups was ambitious. We had many more questions than we could effectively discuss in the allotted time. For this reason, and because it was difficult for participants to answer questions without sharing a significant amount of detail from their own experiences, the “wrap-up” questions, including asking participants what they liked best about the behavioral health care system and what the system does well, were not included in the discussion.

Overall, the study finds:

- For most discussion participants, crisis is the gateway to behavioral healthcare for their children. Participants describe the process of obtaining services outside of a crisis as “painfully” slow and often ineffective.

- Involvement with, and control of, decisions regarding their child's care increases with experience in the behavioral health care system.
- Very few participants believe their children receive behavioral healthcare for a sufficient period of time. Almost every participant told of being asked to take a child home who they believed to be unstable.
- Participants complain about lack of continuity of behavioral health care. Many point to this lack of continuity as a source of inadequate care and unnecessary hospitalizations.
- Focus group participants report high levels of frustration during intake and discharge. Frustration is with the process of securing services, with some of the care providers, and with the behavioral healthcare system.
- Parents and guardians feel involved in their child's care but many feel like the behavioral health system is the one in charge.
- Awareness of the Connecticut Behavioral Health Partnership (CT BHP) is low among discussion participants.
- Most participants did not know about the Connecticut Behavioral Health Partnership complaint and appeals process.
- Parents and guardians who take advantage of peer support programs report they are invaluable.

Recommendations

These findings lead the consultant to draw a number of conclusions.

- A more comprehensive, representative study is needed. This study is an excellent first step in interjecting client experience but has significant limitations. Qualitative studies such as this allow researchers to gain insight and develop a deeper understanding but they do not allow for generalization back to the entire population. A more comprehensive study would ensure that the study participants reflected all of the characteristics, needs and experiences of the population being served by CT BHP.
- CT BHP should develop a communications plan aimed at increasing clients' awareness and knowledge of the organization.

CT BHP may offer services that address many of the issues raised by discussion participants but because of the lack of awareness and understanding of the partnership these services are underutilized.

- Develop a follow-up procedure to ensure the behavioral health service information given to families during a crisis has been received and processed. Educating families on policies and procedures such as the complaint and appeals process would improve utilization.
- Issues surrounding continuity of behavioral healthcare need to be addressed. Many of the discussion participants believe that some of the symptom reoccurrences and hospitalizations could have been prevented if they had one professional overseeing care regardless of where the care was being delivered (general hospital, psychiatric hospital, residential facility, Intensive Outpatient Program).
- Develop a family mentoring program. Because participants report becoming increasingly involved/in charge of child's care with experience and because families that utilize peer support say it is invaluable, a 'Family to Family' peer mentoring program may be an additional way to provide advice and support to families new to the State's behavioral health care system

When considering the findings and recommendations it is important to remember that these three discussions are just one step toward understanding the experiences of HUSKY children receiving behavioral health services. Every step was taken to conduct an objective study using focus group methodology. Because study participants were self-selected and because of the limited number of conversations, the discussion participants are not necessarily representative of the entire population of families receiving behavioral health services through husky. This study provides a great deal of insight as to these families' perspectives on behavioral health services, but does not necessarily reflect the participant needs, level of services and experiences of the population as a whole.

Appendix A
Focus Group Topic Guide

Connecticut Behavioral Health Focus Group
Topic Guide - Final
Consumer Focus Group
Topic Guide

- I. Introduction
 - A. Welcome and introduce moderators
 - B. Explain purpose of the group and length of the discussion
 - C. Ground Rules – There are no right or wrong answers, you don't have to raise your hand – speak when you have something to share – it is OK to disagree - be courteous (let others finish talking first, one person speaks at a time)
 - D. Confidentiality of Responses
 - E. Notification of recording
 - F. Why we are here, group introductions and warm-up
- II. Let's start the focused portion of our discussion with a conversation about access to mental health services. First, can you tell me a bit about the process of getting your child services? Have there been times your child could not get services?
 - A. What about finding a provider – have any of you had trouble finding a provider whose qualifications matched your child's needs? Generally speaking, are you using private providers or community providers? How much choice do you have when selecting a provider? Were you able to find someone from the names you were given? (If not, did you get more names?) How about the time between finding a provider and being able to get an appointment for your child? Do you remember how long that was?
 - B. (Cultural Competency) Were you able to find a provider that met your family's needs? For example, were you able to find a provider or providers that spoke the language you are most comfortable with? Who understand your culture or traditions? Who has appointments during hours that you are available? Who treated you with respect?
- III. I'd like to shift our conversation and talk specifically about the intake and discharge processes. Let's start with the intake process. By intake I mean the beginning of a new service or new service provider. Explain the process to me. I'm interested in both how it is supposed to work and how it actually works?
 - A. Have you been asked to participate in your child's intake or treatment planning process? If so: Do you feel that the provider listened to you? What about the

discharge process - were you asked to participate? Did you understand the next steps?

I'm going to read off a few topics and I'd like you to tell me if they present any type of challenge either during intake or discharge – and if they do, tell me a bit about that challenge.

- B. Transportation (What would you say are the two or three biggest transportation issues?) What sorts of transportation do you typically use to get to appointments? (probe, if not mentioned: do you use medical transportation?) What about with regular appointments, are there different transportation issues when it comes to regular appointments?
- C. At one point there were some changes in the Husky plan that caused many families to have to change providers. Did this happen to you? If so, did you have difficulty when you had to change providers?
- D. Accessing pharmacy services? While we are on the subject of pharmacies and medications . . . I'm curious about the process of you and your child being introduced to a medication when it is prescribed. What type of information do you receive about the medication? Typically, does someone explain the purpose of the medication? Its side effects? The impact of not taking it regularly (sticking to the scheduled time or skipping a dose)?
- E. Coordination with community based services
- F. Did you have any concerns during the beginning or ending of a service? Did you share these concerns with the Drs. Or therapists? (If no, why not?) What happened when you did share the concerns (Did you feel listened to? Or Did you feel as if your concerns were given real consideration?)

Once you actually got services - were the services offered the right services for your child? Were they for the length of time needed?

IV. I'd like to pass this bowl around the table. When I say stop I'd like the person with the bowl to pick 1 piece of paper and read what is on it. Then I would like everyone to tell me if they agree or disagree with the statement and why. These statements refer to your overall experience with getting and retaining behavioral health services for your child.

Statements:

- My child's perspective is considered in making decisions about his or her care.
- I feel in charge of my child's care
- I am comfortable expressing my concerns when care decisions are being made.

- When it comes to making decisions about my child's care I am involved in the decision making process.
 - I feel that providers listen to me and really hear my concerns.
 - I know who to call with a behavioral health question about my child.
- V. Obviously there is a lot to coordinate when it comes to providing care for your children. Again, I'm going to throw out some issues and I'd like to know if coordinating any of these presents challenges and what those challenges are:
- A. Coordination of Care between your pediatrician and other doctors.
 - B. What about coordinating medications?
- VI. One issue that often comes up when I talk to people about issues with services is missed appointments. First of all, what are some reasons that you've missed your child's appointments with their psychologist, psychiatrist, therapist . . in the past? What happens when you miss an appointment? If you're going to miss an appointment do you usually cancel the appointment – if not why not? Does anyone follow-up with you after your child has missed one of these appointments?
- VII. Complaint and appeals processes
- A. From what I understand, there is a grievance process you can go through . . . Is this something you are told about in the beginning? How do you find out about something like this?
 - B. Do you know how to file a complaint?
 - C. What about if you are denied transportation – what do you do?
 - D. What about if you are denied services; what would you do?
- VIII. I'd like to switch gears and talk about potential resources. Who do you call when you have a behavioral health question or you are in need of services?
- A. Have any of you heard of the CT Behavioral Health partnership? If you had to explain Connecticut Behavioral Health Partnership to someone unfamiliar with the organization, how would you describe it?
 - B. What role does CT Behavioral Health Partnership play in accessing services?
 - C. What about in the discharge process?
 - D. Have you ever taken advantage of the partnerships peer support programs? (If not, did you know about them?)
 - E. Have you used the CT Behavioral Health partnership website? Was it helpful? Easy to use? Was there anything you would add to or change about the website?
- VI. WRAP UP -
- A. How should it work? We've talked a lot about how things actually work but I also want to know how you think it should work. If you could suggest one change to the process or one area to improve what would that be?

- B. We've talked a lot about what is challenging about the behavioral health system. Before we wrap-up I'd like to give you a chance to tell me what you like about the system or if there is anything they do well.
- C. Summarize overall comments
- D. Thank participants

Appendix B
Recruitment Letters

Behavioral Health Partnership Oversight Council

Legislative Office Building Room 3000, Hartford CT 06106
(860) 240-0321 Info Line (860) 240-8329 FAX (860) 240-5306

www.cga.ct.gov/ph/BHPOC

Dear HUSKY Family Member,

The Connecticut Behavioral Health Partnership is conducting an evaluation of its effectiveness and we are interested in your opinions as a member of the HUSKY insurance program. An independent consultant has been hired to hold several focus groups to ask for feedback on important areas with which you have had experience. Some of the topics covered may include things like: how easy or difficult it has been to get services; your involvement in your child's treatment; was transportation to services provided; and how the services were coordinated, etc. To help us with this effort, you have been randomly selected to participate in a focus group in Wethersfield on March 5, 2009 from 7:00 - 8:30PM.

Here are a few things you may want to know before making a decision about voluntarily participating in the focus group:

- ➔ a \$75 stipend will be provided for participating;
- ➔ transportation will be provided if you need it;
- ➔ no child care will be provided and you should not bring your child to the focus group;
- ➔ translation services between English and Spanish will be provided in one group;
- ➔ the group size will be approximately ten people.

The group will be recorded for the purposes of summarizing the comments expressed in the discussion and then destroyed. No personally identifiable information will be included in the report. The focus group will be facilitated by a consultant who is independent from the HUSKY program.

If you would like to participate in the focus group process or you have questions, please call Brooke at 1-800-448-1569 Ext. 106. We look forward to hearing from you.

Sincerely,



Jeffrey Walter
Co Chair of the Behavioral Health Partnership
Oversight Council

Behavioral Health Partnership Oversight Council

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Here are a few things you may want to know before making a decision about voluntarily participating in the focus group:

- a \$75 stipend will be provided for participating;
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Sincerely,



Jeffrey Walter
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Here are a few things you may want to know before making a decision about voluntarily participating in the focus group:

- ➔ a \$75 stipend will be provided for participating;
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If you would like to participate in the focus group process or you have questions, please call Cathy at (203) 322-5996. We look forward to hearing from you.

Sincerely,



Jeffrey Walter
Co Chair of the Behavioral Health Partnership
Oversight Council