**Introduction:**
The NH Children’s Mental Health Focus Groups were convened by The National Alliance on Mental Illness NH (NAMI NH) in New Hampshire. Three NAMI NH staff worked on this report; Claudia Ferber, Children and Family Services Coordinator; Annette Carbonneau, Community and Volunteer Developer and Patrick Roberts, Research Assistant; as well as Michael J. Cohen the Executive Director. The purpose of the project was to: provide the Endowment for Health (EFH) with family and youth thoughts, observations and attitudes towards NH children’s mental health service system (public and private) and; inform the EFH planning processes as they move forward the “Children’s Mental Health and their Families” Theme Grant Program. This project was consistent with the goals and objectives of the National Alliance on Mental Illness NH. It provided us, as well as the EFH, with a better understanding of the education and support needs of families dealing with a child and/or adolescent with mental illness. The information can help NAMI NH’s advocacy efforts to shape policies and programs that improve treatment outcomes for children with mental illness and their families. In addition, this project is consistent with the goals and objectives of the New Freedom Commission Report on Mental Health, in which the “promotion of children’s mental health” is listed as an objective for the nation. NAMI NH supports the New Freedom Commission Report and children’s mental health is one of NAMI NH’s priorities.

**Methodology:**
In January 2007, the Endowment for Health and NAMI NH staff met to identify potential areas of interest for the focus groups to address and demographic information to be gathered about the families receiving mental health services. It was decided that participants of the focus group or those who completed a web based questionnaire would be individuals who were the parent or primary caregiver of a child or adolescent, birth through 21 years of age who were currently involved in NH’s mental health system (public or private). Participants would be asked to anonymously complete a form to gather key demographic information and answer a set of questions. NAMI NH utilized its network of NAMI NH support groups/affiliates, community providers and family organizations to recruit participants and host the focus groups. Eleven communities were selected: Concord, Derry, Keene, Portsmouth, Tamworth, Manchester, Nashua, Berlin, Rochester, Lebanon, and Laconia.
NAMI NH staff facilitated the process and provided a record keeper for each group. Participants in the focus group were provided a stipend of $25. For those individuals who completed the questionnaire and demographic information online they were provided a stipend of $10. A third option was that families were provided the demographic information form and questionnaire in hard copy and given a self-addressed stamped envelope to return the completed forms to NAMI NH. Participants, if they requested, would be provided a copy of the results of the focus group responses. This report will be available to the public through the NAMI NH website [www.naminh.org](http://www.naminh.org) and the Endowment for Health website [www.endowmentforhealth.org](http://www.endowmentforhealth.org).

NAMI NH worked with its community partners to recruit and promote the events. Promotion strategies included developing a flyer which was mailed out to key stakeholders in each community (approximately 65 per site) including Parent Information Center, Family Voices, Division for Children, Youth and Family, Division of Juvenile Justice and NAMI NH parent support groups. Flyers were provided for distribution to each community mental health center through the Children’s Directors. Flyers were also available at all meetings and events in which NAMI NH staff participated.

The flyer was sent out electronically using NAMI NH’s e-mail distribution list and asking recipients to pass along to their distribution list. We utilized e-newsletters (NAMI NH, DRC, PIC, Upstream, NH CAN, Compassionate Heart, Department of Education), and NAMI NH’s e-news that is sent every 2 weeks. In addition, the schedule of the focus group meetings was on the NAMI NH website.

There were 11 focus group meetings scheduled between 2/1/07 and 6/30/07. The focus groups (2 hours long) were hosted in diverse settings: public libraries, YMCA’s, Community Centers, Family Resource Centers, and Medical Centers. One site was cancelled after it had been rescheduled twice. The focus group had a facilitator and a record keeper. All focus group participants’ comments were recorded. Outreach calls were made to individuals who registered but did not attend. They were encouraged to participate via website or complete a hard copy of the questionnaire and demographic information form.

NAMI NH worked closely with the Community Mental Health Centers. We did provide the Centers with hard copies of the questionnaire and demographic information form with a SASE and they agreed to provide it to these families. Another site had 7 families registered and on the evening of scheduled focus group, no one attended. NAMI NH contacted the local mental health center and they agreed to distribute a hard copy of the questionnaire and demographic information form with a SASE to those and other families. In two communities, where the focus group had been rescheduled, we opted to run ads in their local papers. We also utilized the community access television stations. Press releases were sent to local and state papers two weeks before the event and a faxed copy of the press release was sent three days before the event.
Discussion:
There were 206 parent or primary caregivers who participated in this process (137 were focus group and 69 were web surveys). Some participants did not answer all the questions either by choice or they felt it did not apply to them. Participants were primarily Caucasian, married females between the ages of 30 and 49 with at least a high school diploma.

Participants were asked where their child received mental health services. 41.3% served through the community mental health center, 27.2% through a private provider, (these 2 previous values were significantly higher than what would be statistically expected), 11.2% through their primary care/pediatrician and 7.8% other providers (these latter 2 values were significantly lower than the expected values). These values do not total 100% because some respondents left the item blank. The respondents also noted, in some cases, that their children were receiving their psychiatric and therapy services in the private system while they also accessed other community services in the public sector. This practice was not widespread, however. A correlation was found between children receiving treatment at community mental health centers and lower ratings of the quality of service as compared to children who received treatment elsewhere (Pearson Correlation of .242 at the .01 level). A cautionary note is that while there is a correlation between receiving treatment at a mental health center and a lower rating of the quality of service that does not mean one factor conclusively causes the other.

Participants were asked how mental health services were paid for. 35.9% stated that payment was through Medicaid/Medicare, 29.6% through private insurance, 11.6% through self pay, 5.4% through the school district, 4.4% through other sources and less than 1% through court orders (DCYF or DJJS). As with the previous section, these values do not total 100% because some respondents left the item blank. In both cases we can not make a judgment why the item was left blank.

When asked if health insurance coverage impacted their access to services and choice of providers, 36.9% responded it did. Health insurance, public or private, had an impact on access to services and choice of providers. A moderate correlation was found with lower ratings of accessibility to mental health services (Pearson Correlation of .428 at the .003 level) and with lower ratings of the quality of mental health services received (Pearson Correlation of .468 at .001 levels). Participants with only private insurance were not able to access public mental health services such as case management or MIMS. They found the limit on office visits and co pays a financial challenge. Within the focus groups it was not uncommon to hear statements such as “we have changed from weekly appointments to bi-weekly appointments due to insurance” or “had to adjust diagnosis to get it covered” or “booted out of the hospital quickly with a limited stay”. Participants with Medicaid coverage reported they did not have a choice of providers. It appears, regardless of public or private insurance, families still struggled with accessing appropriate services for their child.
When asked if there was a connection between mental health and overall health, 59.7% responded, and all of those said yes. These responses were supported by statements from participants such as “when my child is struggling mentally it seems like his entire body is breaking down”. The discussion in the focus groups on this topic also had a broader, policy orientation reflected by the following participants’ statements. “I honestly think it’s about time that mental health issues were treated just like a cold or broken bone - mental health issues still carry a stigma” and; “If your mental health is suffering the rest of your life will be suffering”.

The majority of participants believed their mental health providers and primary care physician/pediatrician shared their view that mental health has an important connection to overall health. However, based on what participants shared, the practice of provider’s was not reflective of this belief about connection. Participants felt their role in bringing different providers together became their responsibility. One telling statement that reflected what many others said was; “yes, but that [mental health providers working together with PCPs] has come from many years of building a relationship and seeing my child on a repeated basis when ill - mentally or physically”. 28.6% of the participants also shared they would feel comfortable bringing to their PCP/primary care physician any concerns - mental or physical. However, a feeling among participants was that the PCP/Primary care physician did not have the knowledge or skills to address the mental health issues and they were also unaware of available resources and supports. 59.3% said that early identification of their child’s mental health issues was not identified by their medical provider. As one participant shared, “early on I had concerns and I think our pediatrician saw these, as less odd, than we thought they might be (sensitivity to sound, stimuli, etc.), but once things got really bad our pediatrician was very supportive and helpful”. 66.7% of participants said when medical providers made a referral to mental health providers it met their needs.

46.8% of participants said mental health screening is not a part of a well child’s checkup/annual physical. Not performing a mental health screening as part of a well child checkup was found to be weakly correlated with health insurance impacting access to services and choice of providers (Pearson Correlation of .295 at the .002 level). Not performing a mental health screening as part of a well child checkup was also found to be weakly correlated with mental health providers not working with participants to develop a written plan to move participants’ children into adult mental health services and supports (Pearson Correlation of .253 at the .009 level).

The majority of participants (71.9%.@001, significance) felt their mental health services were child centered and family driven. Although we provided a definition of these concepts, participants were not familiar with them. However, participants felt they were listened to and were supported when they shared their concerns. They also felt they had an active role in the treatment planning process. In one focus group a participant shared “any decisions made for my son are joint decisions. It’s not the doctor’s decision. It’s ours together. We also include our son in all decisions. When my middle child is with
us, he is allowed to give his input on how his brother is doing. We all have say in how things are going and the next step to take”. On the other hand, participants who answered in the negative gave examples that if the system was child centered and family driven there would be available respite and other needed supports. Appointments would be available around the child’s and family’s schedule and there would be no wait list for therapy or psychiatric appointments.

Participants were asked about transition planning - Early Supports and Services and Transitioning to Adulthood. 66.7% of participants had no involvement with Early Supports and Services. When discussing transitioning to adult services, participants varied in their understanding of the process and the role of the adolescent, family, mental health providers and school personnel. Most participants focused on school issues and stated they were using their time, energy and skills to access services and supports needed to get immediate results rather than looking long term. Participants report only 13.9% of their adolescent’s transition plan provided a written plan for mental health services and supports when the services moved from the child’s mental health system. Based on feedback from participants, the transitioning planning process varies from school district to school district and the mental health component is not addressed in either the school or mental health community. The following quote from one participant reflects the observation of most participants in the focus groups “... it's difficult to determine what the child will need and which direction they will move in. It's very easy to leave holes in a transition plan ....... I wish I had more information when we were building that ..... it seems as if organizations (schools especially) are hesitant to share information about what a child can get for support so they won't have to fund the plan or services.......

69% of participants said yes when asked if mental health professionals are involved in communicating, planning and consulting with other support and service providers involved with the child and family. It was found that mental health professionals’ being involved in planning and consulting with other support and service providers was moderately correlated with higher ratings of quality of service (Pearson Correlation of .391 at the .006 level). Examples of coordination provided by the participants included mental health providers attending a school meeting, a doctor calling a therapist and/or writing a letter to the school. Some participants report such barriers as: communication between mental health and other providers is seen as the parent’s responsibility; providers are overtaxed; large caseloads; turnover of staff; and services are not reimbursable according to providers.

Participants were asked if their mental health professionals provided them with education and support about their child’s mental illness. The affirmative response was 29.6%. Based on feedback from participants, there is no standard practice for providing education about child and adolescent mental illness. As one participant put it, “I needed to know more about what we needed and what we didn’t know about”. Only 15 % of the participants said they received information about community resources from their mental.
health providers. When asked what would help, participants talked about educational programs to learn about: diagnosis, treatment options, and strategies to manage symptoms or behaviors, community resources, and how to pay for services. It appears that participants “feel lost in a maze”. Although participants felt listened to by providers, they report a need for more support. Participants talked about the need to connect with other parents who face similar challenges - “talk to other parents who have been there”. They asked repeatedly for more support groups and options for childcare so they could attend the educational and support meetings.

When asked what mental health service or support met their definition of quality, the participants’ responses were subjective. It seems to be the person who provides the service or support and not the service or support itself. “Not driven by money, but need” was one definition of “quality” mental health services and supports. Integrated, accessible, timely, choices, consistent, good outcomes, affordable, responsive, and fidelity are words that repeatedly came up in the focus groups to describe quality.

The focus group question that asked participants what mental health services and supports would improve outcomes for their child and family produced the same recommendations regardless of the participants’ economic, social, geographical and cultural differences. The recommendations below are listed in no particular order of importance and are a compilation of the responses collected:

- Have a child psychiatrist to meet the needs of each community/region
- Eliminate Wait List for services
- Decrease staff turnover in the public mental health system
- Specialized training for public and private providers
- Provide home and community based services accessible to all families
- Provide respite services (funded as a discreet service)
- Availability of crisis response teams (trained in children’s issues, accessible and timely)
- Available Resource Specialists to coordinate care and provide resource information
- Standard practice of transitioning youth to adult mental health services
- Childcare providers trained to work with SED (after school programs, recreational activities and summer programs)
- School personnel educated about children’s mental health issues
- Available education programs for parents of children with SED
- Available & accessible Sibling Support Groups
- Available & accessible Peer Support Groups for Youth
- Available & accessible Parent Support Groups
- Collaboration and coordination between all providers and systems
Conclusions:
The focus groups and other data sources not only served as sources of information for this report but it had an unintended consequence of allowing parents to vent their frustrations about the mental health system and share their personal experiences with others in the focus groups. Sometimes their responses did not answer the question posed but rather they used the question to share their frustration and pain and at times, an opportunity to ask for help. We heard about the fragmentation in the system and the “sinking” feeling many participants experienced as they tried to negotiate within and across the systems. In their own words, they were clearly asking for an integrated and coordinated mental health system that offered services and support based on need rather than ability to pay. It appears that the processes of communicating, planning and consulting used by some providers are not standard practice for all mental health professionals. Nor is screening for early signs of mental illness. Participants seemed uninformed of the role the mental health professionals can have in these processes.

The recommendations from family respondents, noted in the previous section, demonstrate reasonable changes that providers in the mental health field and/or informed policy makers already know. Parents who are coping with a child with mental illness, we guess, are not that different from what we all see is needed to improve the effectiveness of the children’s mental health system.

We heard from focus group participants that parenting a child with mental health issues presents specific needs and unique challenges. Many parents want and try to offer their child with mental health issues, the same opportunities as other children (music lessons, soccer, art classes) and are not able to for a myriad of reasons. For families of children with SED, accessing affordable and quality childcare is a challenge. Families believe this service would, at times, help facilitate access to community and social activities.

Many participants shared that they feel that the quality and availability of services and supports for a child with mental health issues does not compare to the seriousness of the illness and the impact on the family. They shared that the lack of consistent providers and individualized services negatively affects their child. Services and supports are not available in all communities and insurance coverage (public or private) is a major barrier for families. Middle class families are struggling with the financial impact of co-pays for medication and office visits as they don’t qualify for sliding scale or public benefits assistance.

Although parents want improved services from their providers, it is clear they want and need to be empowered to help their child and their family. Repeatedly, parents spoke to the need for more support and education on children’s mental health issues and the necessity to talk to and learn from other parents and family members. They pointed out that the expected and hoped for life course of the family is changed by a child’s mental illness. The family searches for a substitute life course that still provides the same joy, learning and growing experiences for their child. Parents of children with a mental
illness love their child and want the best for their child as much as parents who are raising a child without a mental illness. Learning from other parents is one of the services the responding parents in this study said would be helpful to them.

A very important and final note is to acknowledge that the parents and caregivers who participated in this process, wanted to be part of the solution. They were able to acknowledge the challenges their providers faced working within the constraints the delivery system places on them. Participants expressed their belief that their contributions to this process would move the system positively forward.

From the NAMI NH point of view we want to thank the EFH for the opportunity to do this project and we hope the information will be helpful in shaping the grant making for the new theme. In addition, we want to commend the Endowment for recognizing the importance of family inclusion in shaping the mental health system. Through this project the Foundation has certainly operationalized the principal of a consumer and family driven system as articulated in the New Freedom Commission Report.