CONSUMER FOCUS GROUPS

Six consumer focus groups (2 of which were Spanish speaking) were completed this year in collaboration between DPH staff and family representatives of the Medical Home Advisory Council for a total of 35 participants. The focus groups were conducted virtually with consumers identified as utilizing MCH services. Of the 35 participants, 20% were men, 77% were women, and 1% did not provide a gender. For Racial/Ethnic composition, there was 54% Hispanic, 14% Black, 6% Multi-racial, 3% Middle Eastern, 3% Asian, and 20% who did not provide any race or ethnicity information.

The same ten questions were asked this year and last year.

Chart #1: "What type of services do you need or require?"

The most popular responses (26%) involved different types of therapy services and programs like speech therapy or swim therapy. This also included in home and out of home programs. Mental/Behavioral health services were the second most stated response at 21%. In the previous year, both mental health services and making other services more available were the two highest stated responses, both at 21%. Also identified this year was the need for specialty dental, optometry, and audiological services (18%; medical services, including services where the provider is specialized in working with CYSHCN (16%); and transportation services (7%). Other responses (12%) included a combination of needing waivers, more information about HUSKY, translation and housing services, and supplies.





Chart #2: "How can finding these services be easier?"

The number one answer this year was the need to have more providers and facilities (36%). This is up from last year when only 9% of respondents said there needed to be more providers. Families are experiencing very long waits to get services. The second most popular answer this year was to simplify what is available (27%). This includes making sure handouts are in plain language, making the 211 website user friendly, making sure phone numbers are available and easy to find, and having lists of providers and services available to families. This is very similar to the third most popular answer last year with 21% wanting more user-friendly hotlines and webpages. The third answer this year was more advertising (17%), which was the highest response last year with 44%. Participants also identified making services less expensive or covered by insurance (6%) and using support groups (7%). Other included expanding services that are available (7%). The number two answer last year was "education" for clients, providers and insurance with 24% was not mentioned this year.





Chart #3: "Who helps you get appointments?"

Just as last year, the top response was themselves with 67% this year and 58% last year. The second response was also similar to last year with a medical provider helping them with 12% this year and 15% last year. Both social worker and a hospital/clinic/agency received the same number of responses at 9%. Getting help from a friend was also mentioned at 3%.





Chart #4: "Who would you talk to if you had concerns about your child's behavior?"

This year, the primary response was a doctor or pediatrician at 38%. The second most popular response was organizations and schools with 19%. This is a similar answer to last year when school professional and community agencies 23% and 20%, respectively. Friends and the internet (social media parent groups) received 16% of the responses while talking to a therapist or psychologist received 14%. Other responses included talking to the child (5%), talking to nobody/not knowing who they would talk to (5%), and calling 911 (3%).





Chart #5: "Based on your concerns about your child's behavior has the conversation about evaluation ever come up?

Last year only 33% of the participants responded that they had conversations with a provider or the school about getting the child evaluated. This year 77%, said that evaluation was brought up in discussion.





Chart #6: "What would you do if behavioral or other health services were not working for you?"

Most participants said they would see other services like support groups (29%), specifically with one of our Connecticut Medical Home Initiative contractors, and look for different medical providers (20%). Last year, the most common response was to make a formal complaint (32%). Participants also identified that they would call the doctor (12%) and ask for a new plan or referral or tell them exactly what they needed from the doctor, call 211/911 (9%), and talk to friends and family (6%). Only 6% said they were not sure what they would do. Other (18%) includes making a complaint, paying out of pocket, and moving out of state.





Chart #7: "If you do not have insurance available through your employer, Medicaid, or the Insurance exchange, how would you access health insurance coverage?"

The answers this year were very similar to the previous year, with community organizations/clinics/state agency having the most responses at 38%. Last year community health centers/community agencies received 37%. Hospital services/ER received 19% this year and last year it received 20% of the responses. Participants also stated they would go without/don't know what they would do (19%) or pay out of pocket (12%). The Other category (12%) includes talking to people who know about health insurance, applying to grants directly from an insurance company, or talking to their workplace to get something covered under their employer provided insurance.





#8. "During the pandemic, has your child been receiving medical services?"

Answers this year were similar to last year with 59% of participants saying their child has been receiving medical services. This was 56% last year. This percentage could be higher because in the next question, many of the people who stated they did not receive medical services did say that they did utilize telehealth appointments. There could have been confusion by what is considered medical services. Even though people were getting services, there were still needed services like home health aides and special education services that they were unable to have.





#9.a. "Are you receiving telehealth or Tele-audio services?"

This year, most of the participants had utilized telehealth or tele-audio services (69%). We did not separate which type of service they were receiving, unlike last year.





#9.b. "What do you like or dislike about it?"

Participants provided their likes and dislikes of telehealth and tele-audio. Many people had things they really appreciated about telehealth but recognized some limitations of it. People liked that they did not need to travel to appointments, that it was easy and convenient, and that it was better for some people with certain health issues so they did not need to be around people who were sick. The things that people disliked about telehealth is that there could be privacy issues, lack of technical knowledge, appointments being too short, and it being hard to express yourself over video/telephone. These responses were the same as the previous year.

#10. "As the pandemic has continued, have the services you have received improved over the last year?"

This year, only 32% of people said that the services had improved. This was 41% last year. Many people felt that the services were very similar from the previous year, with their PCPs being open more. Participants noted that while there are fewer cancelations, there are much longer wait times to get appointments.



CONSUMER READER INPUT

Biography

I am a Business Management Professional and have specialized in Human Resources and Payroll for over 23 years. I am also a mother to four children, ages 19, 14, 8, and 5. My 8-year-old son was born with a very rare gene mutation that resulted in over 22 surgeries, 2 open heart surgeries, 2 major strokes, and needing 24 hours of care each day. This situation has created me to be the best advocate I can be for him and to help others.

My challenges and thoughts after reviewing the Block Grant

The biggest challenge I have faced throughout this process is not being able to find the help or resources needed. Which is very sad because I have dealt with so many providers and hospitals that should have known about all the resources and programs through the CT Title V Program to pass along to parents like me; yet this is the first time I have ever known that they exist. In many ways, after reviewing this grant and all that it offers, I feel like parents like me, have been abandoned. Many Parents do not qualify for much because they have a career and make an income just a bit over what would qualify them for help or assistance. How many providers may have picked out the parents and families that they thought needed this information instead of all families? I represent those parents and families that have been neglected from our communities' resources that could have positively impacted our lives and situations if I had known. Awareness is so important. Making sure that proper communication and tools are available for everyone is essential.

State Title V Program Purpose and Design pages 34

In my observation I must ask a few questions. First, what community are you referring to in this paragraph? It seems unclear. I have never heard of any of these programs. Secondly, do these programs find woman and children in need or are these programs only for those who happen to receive information about these programs? This is unclear as well. Do any of these Priority needs include Mental Health and are the personnel positions trained to see the signs that may suggest Mental Health is needed before some of these other needs listed?

I think the purpose and design of the plan should not leave readers to question some areas.

Women/Maternal Health - Annual Report Page 67

What are the efforts being made to create a general awareness around pre/interconception care and specifically around the OKQ screening tool? How successful was the training for the staff at DMHAS? There is nothing in this information to show that the main goal of this initiative was successful or what impact it had on the women involved. While reading this, I found myself wanting to know this information.

Perinatal/Infant Health - Annual Report Page 87

This sounds just like page 67. I do not see a difference and would still have my same questions needing answers as I stated for Page 67.

Child Health Annual Report Domain Page 106

I am taken back by the Report Numbers. It states training and support was provided "once again" to 2,000.00 families and 3,500.00 professionals...Does this apply to all of CT? If so, these numbers are extremely low compared to the 3.6 million people we have in CT. This is confusing to me because

this page then speaks about CT Learn the Signs Milestones is in the "Sparkler App" and is now available to all CT families with Children 0-5 years old and to all the programs serving those families. Does this mean you will have more reported numbers, or can you anticipate this being able to reach more families?

Adolescent Health-Annual Report Page 122

I would say this reads well however, as a parent of a special needs child that is in the CT School system, I have never heard of SBHC or received any additional special screenings. It is very nice that DPH supported 90 school health service sites in 27 communities in CT, but many communities are still not being reached. Maybe you can include information on how many other communities can be added soon?

Children with Special Health Care Needs - Annual Report Page 148

I believe this is written very well. It answers all the questions I would have had. It is very informative.