Lancaster County Youth Behavioral & Mental Health Needs Assessment

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Presented by
Victor DeSantis, Ph. D., Dean, Millersville University
Adam B. Lawrence, Ph.D., Research Fellow, Millersville University
Kate Gallagher, MNM, Founder, coLAB

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Executive Summary

The Nonprofit Resource Network of Millersville University, working in partnership with coLAB Inc., is pleased to provide this final report for the Lancaster County Youth Behavioral & Mental Health Needs Assessment to the Lancaster Osteopathic Health Foundation (LOHF). LOHF contracted with the NRN and coLAB in January 2014 for this needs assessment with research implementation commencing in April 2014. The research project featured a robust mixed-methods design which included quantitative (random sample telephone survey and secondary data analysis) and qualitative approaches (focus group and key informant interviews). The final phase of the project was the telephone survey completed in November 2014.

The final report is organized around the five key themes that emerged from the mixed methods study. The five themes are broad categorizations of the data collected and provide a useful mechanism for presenting the findings. The themes are not meant to be mutually exclusive, but they are comprehensive enough to cover the variety of inter-related thoughts and ideas. The five themes are:

- Access and Availability
- Transitional Ages
- Lack of Specialists
- Communication and Collaboration
- Affordability and Insurance

The target age group under study in this research design is youth aged 0 to 25 living in Lancaster County, Pennsylvania. To provide some background on the youth behavioral and mental health topic, some selected data points from various sources are worth considering (references - page 23).

Youth Population

- Population of youth aged 0-24 years old in Lancaster County in 2010 was 179,653. This age cohort makes up 34.6% of the total population, and is in line with the national population (34%).

- The population of Lancaster County continues to grow, with a total population of 519,445 in 2010 that is estimated to increase to 526,194 by 2020 (1.30% increase).

Behavioral and Mental Health Needs

- In 2007, 13.4% of children in Pennsylvania, 2-17 years old, had one or more emotional, behavioral, or developmental condition.
- Among Pennsylvanian children, males are more than twice as likely to have an emotional, behavioral, or developmental condition.
- Suicide, which can result from the interaction of mental disorders and other factors, was the second leading cause of death among children aged 12–17 years in 2010.
- Almost one-quarter of children (22.4%) in Pennsylvania, age 4 months-5 years, are considered at moderate- or high-risk for developmental, behavioral, or social delays.
- Among children in Pennsylvania, age 2-17 years, with emotional, behavioral, or developmental conditions, 68.8% received needed mental health care.
- 29.8% of children in Pennsylvania, age 10 months-5 years, received a standardized developmental screening during health care visit.
- Across the US, the cost of services and decreased productivity of mental disorders for children 0 to 24 years is about $247 billion annually.
- In US, from 2007 to 2010, there was a 24% increase in inpatient mental health and substance abuse admissions among children
- In the US, the rate of hospital stays among children for mood disorders increased 80% between 1997-2010
- Children with mental disorders are more likely to have other chronic health conditions, such as asthma, diabetes, or epilepsy, than children without mental disorders.

Methodology

To gain a comprehensive understanding of youth behavioral and mental health needs in Lancaster County, a mixed methods study design was deployed. The power of this mixed method design is the ability to join the quantitative approaches (random sample telephone survey and secondary data analysis) with the more qualitative approaches (focus group and key informant interviews). Gathering both quantitative and qualitative data provides a much richer and more nuanced understanding of this important topic and allowed the research team to strengthen the later research phases (focus groups and telephone) based on data collected in the early phases (secondary data and key informant interviews). Mixed methods can improve the validity of a research design and allow for greater generalizability of research findings due to the multiple lenses involved in the process.

Key informant interviews are an excellent method of gathering data and insights from industry professionals, service providers, advocates and others that are intimately involved in the subject matter. Although working from a common set of questions, these open-ended face-to-face interviews provide valuable feedback and allow the researcher the opportunity for ask follow-up questions and gain a more thorough and clear perspective. A total of fourteen key informants representing a variety of stakeholders were interviewed as part of the project. See Appendix A for key information interview notes and Appendix B for key informant interview demographics.

Focus groups are another qualitative approach that allows a research team to gain more in-depth information on perceptions, insights, attitudes, experiences, or beliefs of a small group. The group interview of approximately six to twelve people usually share some similar characteristics, such as providers or parents. A trained facilitator guides the group based on a predetermined set of topics and questions, usually with specified time frames to keep the process moving effectively. The facilitator creates an environment that encourages participants to share their perceptions and points of view. A total of five focus groups were conducted at various locations with sizes ranging from 6 to

13 participants. See Appendix C for the results of the focus group discussions and Appendix D for focus group demographics.

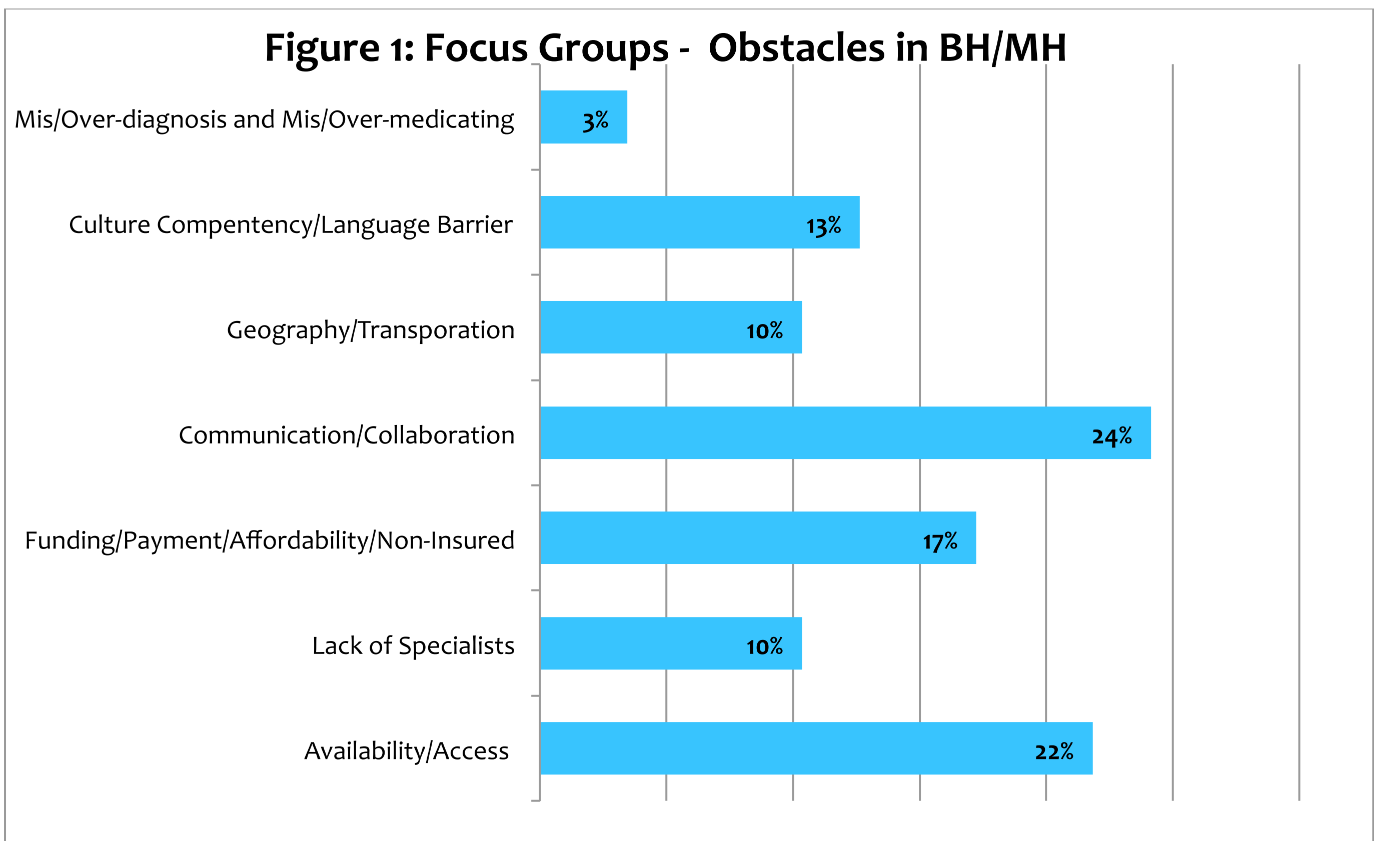
The telephone survey was the final research phase to be deployed for the project. The questionnaire was heavily informed by the results of the key informant interviews and the focus groups, with substantial input from the Children's Health and Wellness committee of the Lancaster Osteopathic Health Foundation. The results of the telephone survey are based on computer-assisted telephone interviews with 1,015 adult residents of Lancaster County, Pennsylvania, conducted from October 6 to November 7, 2014. The interviews were completed in the Millersville University Polling & Research Office under the supervision of Dr. Adam Lawrence, Director. The overall response rate for this survey was 21%.1 The sample consisted of telephone numbers randomly selected using Random Digit Dialing (RDD). For the results of this survey, the sample of 1,015 residents of Lancaster County has a maximum margin of sampling error of + 3.07 percent at the conventional 95% level of confidence. A profile of the respondents is provided as an appendix to this report. In addition to sampling error, the four primary sources of non-sampling measurement error include the following: interviewer effects (e.g., an interviewer fails to read a question precisely as it is written); questionnaire design (e.g., question wording, question length, and question order); the respondent (e.g., some respondents offer what they perceive to be socially desirable answers to particular kinds of questions); and the method of data collection (different methods of data collection—for example, face-to-face, by telephone, or by mail—may yield different responses to the same questions).

[1] The response rate for this survey was calculated using Response Rate 2 (RR2) as defined by the American Association for Public Opinion Research (A.A.P.O.R.).

Access and Availability

Focus Groups

Among the participants in the focus groups, when asked about obstacles within the behavioral and mental health (BH/MH) field, the most frequently occurring issue was access and availability. Roughly 20 times during the focus groups was this topic mentioned, encompassing just about one-quarter of the discussions around obstacles. Collaboration was the only obstacle discussed more often than access to and availability of mental and behavioral health services.



Overall, access and availability was the third most often mentioned or discussed topic area. In Lancaster, for children with the more significant needs and behaviors, psychiatric care is, as one

participant noted, hard to find. Most wait three weeks to one month to get treatment. In part, this is due to there not being a children's hospital in Lancaster, and more specifically, there isn't even a children's unit within a hospital. One social worker reported, "[In July] our psychiatrist is booking out until September, and that's good timing here." Even if a behavioral and mental health diagnosis is identified, the services aren't often available in a timely fashion. A focus group participant who self-identified as an administrator said, "Services are similar to tax breaks, they exist, but very few people know how to access them." A less common but widely accepted idea was that services already exist, but the field as a whole needs to reorganize and make them easier to access. A large barrier to receiving services was identified because of issues with insurance and affordability, and finding services but learned that waiting lists are at maximum capacity.

Additional barriers to access include:

- Language
- Transportation
- Culture and stigma

Key Informant interviews

Among the key informants interviews, when asked about obstacles within the behavioral and mental health field for youth, issues with access and availability were discussed about a dozen times, or encompassing nearly one-fifth of discussions around obstacles. Collaboration and lack of specialists were the only obstacles discussed more often than access and availability. When key informants were asked what comes to mind when they think of the behavioral and mental health field, nearly all reported a need for more providers in mental and behavioral health. Key informants cited a lack of services, especially for low-income children. When asked what the top unmet behavioral and mental health need is for children in Lancaster County, nearly all cited access and availability in a timely manner due to long waiting lists. Additionally, one interviewee reported the challenge with locating accessible, consistent, high quality services in Lancaster County.

Figure 2:
Key Informant Interviews - Obstacles in BH/MH

Communication/ Collaboration 23%
Funding/Payment/ Affordability/Non-Insured 14%
Other 27%
Culture Compentency/ Language Barrier 9%
Geography/ Transporation 7%
Mis/Over-diagnosis and Mis/Over-medicating 11%
Lack of Specialists 20%
Availability/Access 16%

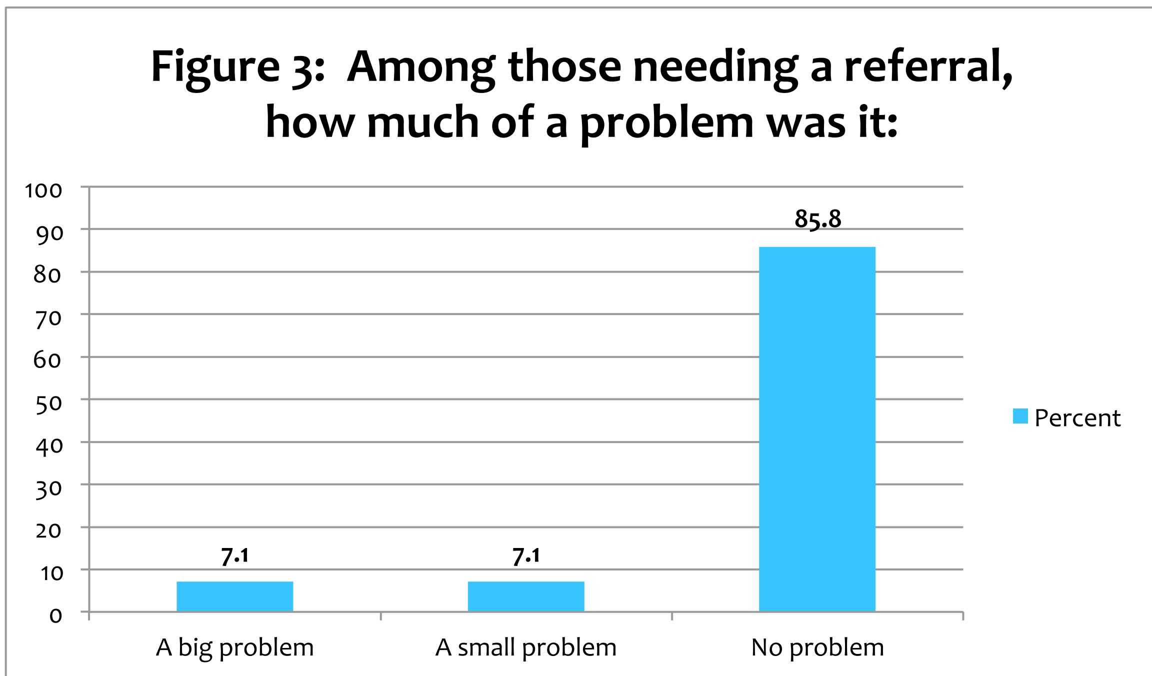
Telephone Survey

Our results revealed that 43% of the parents we interviewed said their children experienced at least one of the mental health challenges asked about in our survey. Remarkably, a full 25% of parents said their children experienced more than one mental health challenge. Among those parents whose children experienced a mental health challenge, only 45% said their child saw a health care provider for treatment or services related to the problem(s) over the past 12 months. Why is this percentage so low? Our data do not allow us to identify the causal factors with absolute certainty, but they are

suggestive. A number of factors related to access and availability may collectively help to explain this finding:

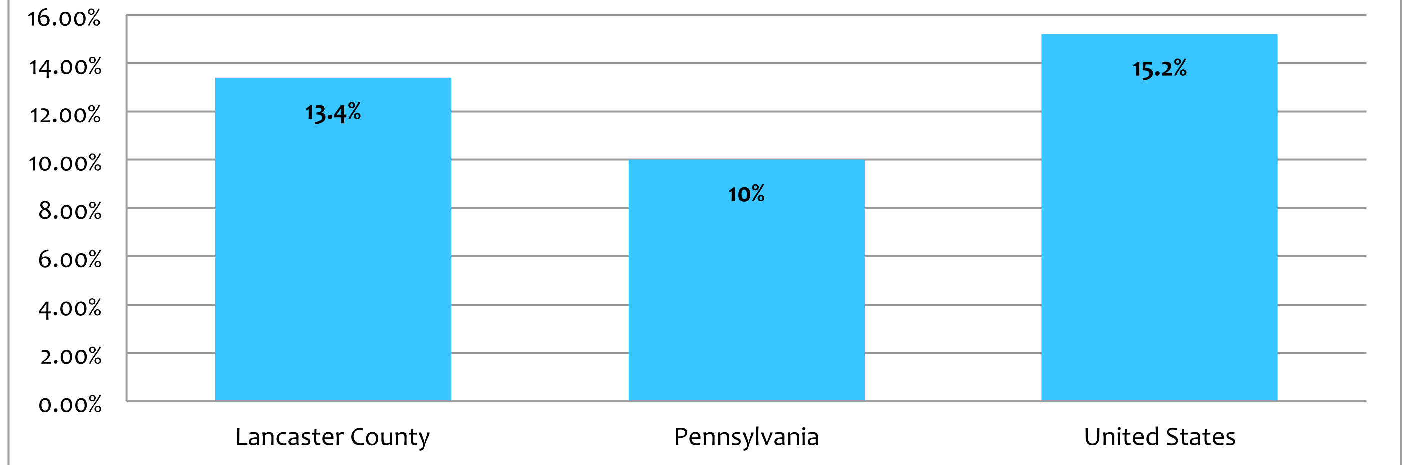
1. 10% of our respondents said their children do not have health insurance coverage of any kind.
   a. While 10% is relatively low, in a population as large as Lancaster County, this proportion translates into many thousands of children who are not covered by health insurance.
2. The necessity of securing a referral speaks to the difficulty of gaining access; for 14% of parents, getting a referral proved to be a problem (Figure 3).
3. A sizeable proportion of our respondents who were able to gain access to health care treatment or services experience difficulty coordinating their children's care.
   a. Slightly more than 65% of parents said there was no one helping them to arrange or coordinate their children's care to make sure their children get all of the health care they need.
   b. Not surprisingly, 37% of parents said they could have used more help arranging or coordinating their child's care among the different health care providers.
4. Respondents told us that it was often difficult accessing the information they needed in order to make informed choices about their children's health care.
   a. Only 35% said that they always got the specific information they needed from health care providers.
   b. A full 21% of respondents said they were only sometimes or never able to get this information.
5. Finally, we asked our respondents, "If you could make one suggestion to improve the process you went through to make sure your child received the necessary health care services or treatments, what would it be?" Although we asked no specific questions about the issue, a healthy number of respondents spoke about the problem of wait times. The following responses summarize their concern:
   a. "Getting into the doctor's office quick enough for well visits."

b. “Because of electronic medical records, appointment-making a pain if technology fails.” “Wait times need to be improved.”
c. “Quicker appointment.”



Secondary Data

From the Community Health Needs Assessment, Final Summary Report: Philhaven May 2013, those without insurance are the most underserved followed by public and then private insurance in Lancaster County. Lancaster County has a notably larger percentage of uninsured residents at 13.4% compared to neighboring counties, which range from 9.1% to 10.4%. The Pennsylvania average is at 10% while the United States average is at 15.2%.

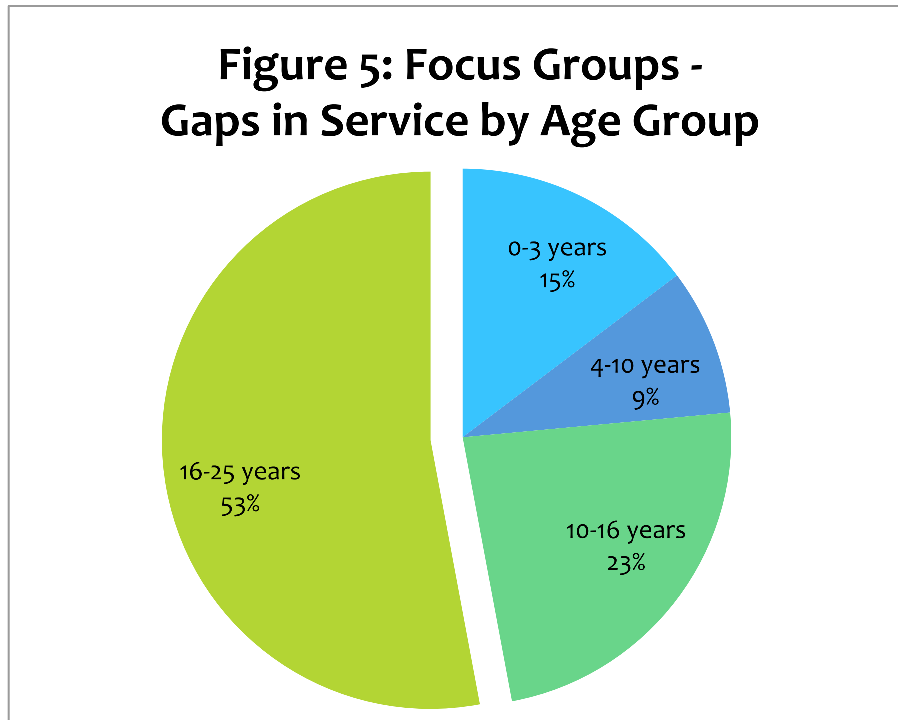


The largest barrier that is preventing families from accessing mental and behavioral health care is stigma, followed closely by awareness and availability of services, and then cost or insurance barriers. According to the United Way of Lancaster's 2010 Community Assessment, transportation is a major barrier for low-income individuals. "Access to health care is directly impacted by affordability of care, availability of health insurance, transportation, cultural competency, health disparities and language barriers."

Transitional Ages

Focus Groups

Among the participants in the focus groups, when asked about which age groups have the most gaps in services, transitioning age group, specifically 16 to 25 years, was mentioned more than half of the time regarding any questions or discussions around age groups with the greatest need for behavioral and mental health services.



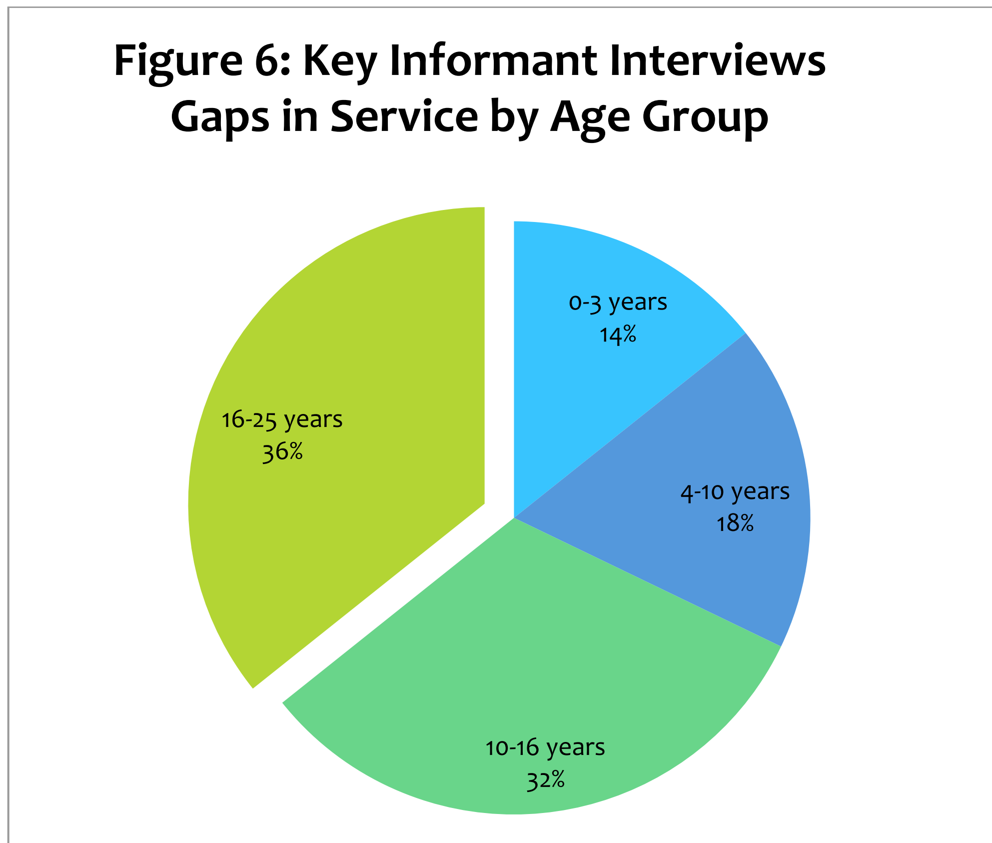
Across all focus groups, the transitional ages of 16-25 constituted the majority of the conversation regarding age groups, with one exception: the parents-based focus group focused on middle school aged children ranging from 10 to16 years the most. The majority of the parents had children with BH/MH needs and within this same age range of 10-16 years. However, the only other age group discussed by parents in that focus group was the 16-25 years population. Overall, the focus groups discussed this population only slightly less than access and availability, the fourth most common topic discussed. The youth aging out is going into the adult system and agencies cannot help them or give

case management anymore unless a major mental illness diagnosis has been documented. At the age of 21, access to care abruptly stops, and a number of professionals in the focus groups report that those transitional age youth are, “floundering with how to access and wondering what [to do] if they are not eligible for funding or insurance.”

There was an overall sense from all of the focus groups, except the parents' focus group, that youth are aging out of the system and there are limited to no services available. Those that are available tend to be services that are there for the late teenagers who are leaving the system as children and are, “all of a sudden being treated as adults with no guidance and support.” In additional to behavioral and mental health needs, transitional youth need help with housing, work, job placement and transportation.

Key Informant interviews

Among the key informant interviews, when asked about which age groups have the most gaps in services, transitioning age groups, specifically 16 to 25 years, were mentioned more than one third of the time related to any questions around age groups. The next third was the age group of 10 to 16 years old. The last third was split almost evenly between birth to three and ages 4 to 10. There was a more even spread across age groups among key informants than in the focus groups; however, transitional ages were still a clear focal point of the key informant interviews.



Much like the focus groups, the transitional age group was a concern for key informants because there are children leaving the youth system and moving into an adult system. One key informant said, "The transitioning age group has been neglected." Five separate key informants agreed with the idea that adolescence poses the greatest challenges, especially those that are transitioning from child system to adult system and have behavioral and mental health challenges. Another key informant who worked for a state agency said, "There is a greater need to consider for children in the foster care system or whose parents' rights have been terminated."

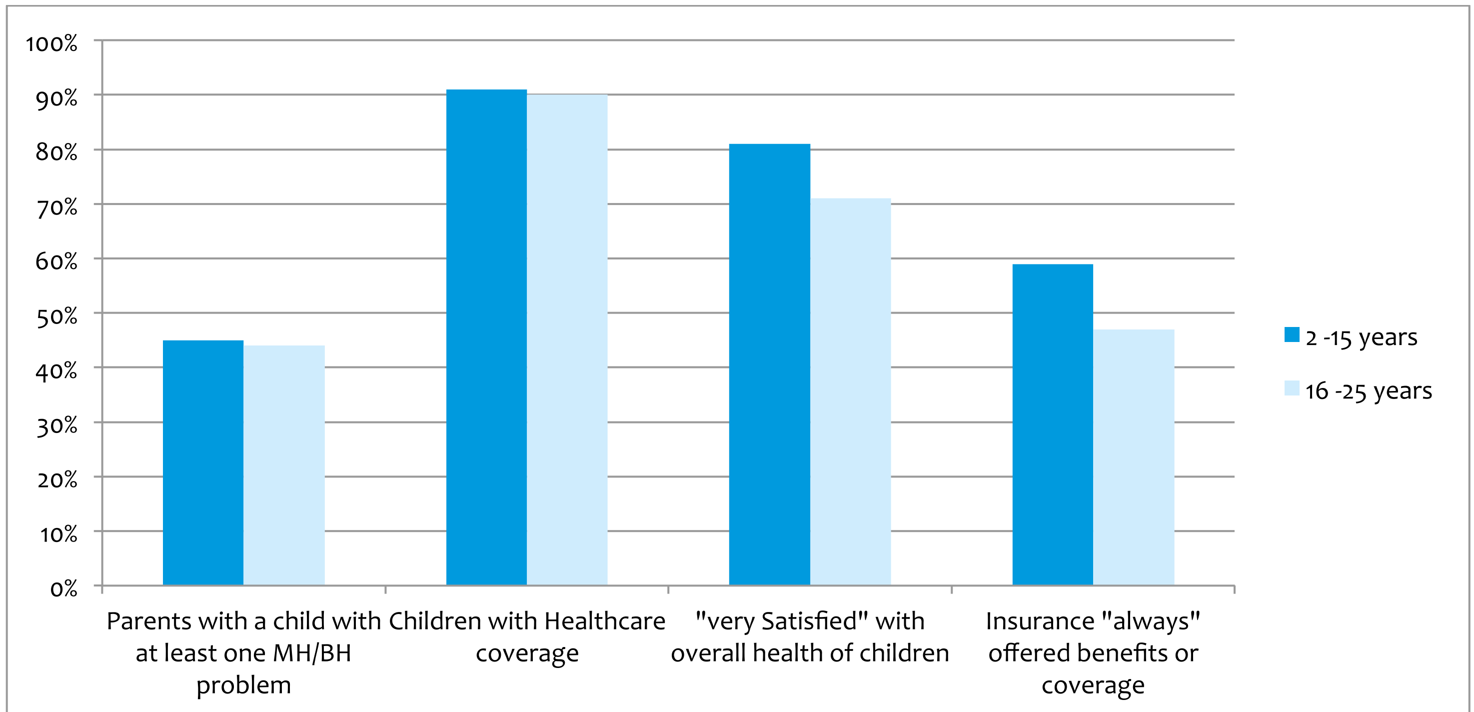
Telephone Survey

The results of the telephone survey confirmed the importance of transitional age groups. To explore the role of transitional age groups, especially the 16 to 25 years of age group, we divided our

respondents into two groups: parents or legal guardians with children 2 to 15 years old, and parents with children 16 to 25 years old. The comparisons revealed a number of similarities and differences:

- The numbers of mental health challenges reported by parents in both groups were statistically indistinguishable:
    - 45% of parents in the 2 to 15 age group reported a child with at least one mental health challenge;
    - 44% of respondents in the 16 to 25 age group reported the same.
- The children in both age groups enjoyed health care coverage at similar rates:
    - 91% of children 2 to 15 years old had health care coverage;
    - 90% of children 16 to 25 were covered.
- Despite similarities in the rates of mental health challenges and health care coverage, parents were less likely to say they were "very satisfied" with the overall health of their children 16 to 25 years old, in comparison to parents with children 2-15 years old:
    - 81% of respondents with children 2 to 15 said they were very satisfied;
    - 71% of parents with children 16 to 25 years old said the same.
- On the issue of health care coverage, although children in the two age groups were covered at similar rates, parents with children 16-25 years old were less satisfied with that coverage:
    - 59% of parents with children 2 to 15 years old said their insurance "always" offered benefits or covered services that met their child's needs.
    - 47% of parents with children 16 to 25 years old offered the same response.

Figure 7: Child Health Perceptions among Survey Respondents by Age Group



When it comes to parents' efforts to seek help for their children, several noteworthy differences between these age groups emerge:

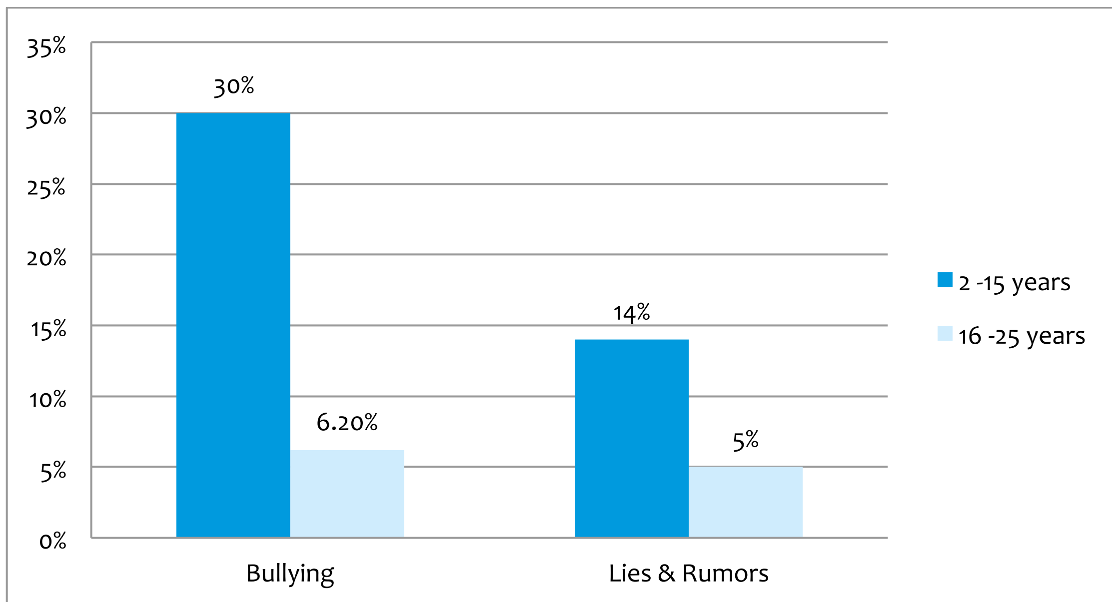
1. Parents with children 2 to 26 years old are more likely to seek advice about their child's health from "a friend or relative" (children 16 to 25: 12%; children 2 to 15: 4%).
2. Parents with children 2 to 26 years old are less likely to have seen a doctor, nurse, or other health care professional for any kind of medical care (children 16 to 25: 79%; children 2-15: 92%).
3. 27% of parents with children 16 to 25 years old who sought care for their children's mental health challenges said they needed a referral, compared to 17% of parents with children 2 to 15 years old.

4. As noted above, parents of children 15 to 25 years old were more likely to need a referral, but the data show that they had less help coordinating their child's care than parents of children 2 to 15 years old:
    a. 48% of parents with children 2 to 15 years old said they had help arranging or coordinating their child's care among the different doctors or services used;
    b. A considerably lower 24% of parents with children 16 to 25 years old said they were given similar assistance.
5. Not surprisingly, 34% of parents with children 16 to 25 years old said they felt they could have used more help in arranging or coordinating their child's care among the different health care providers and services.

One set of findings highlighted the prevalence of a risk factor among children in the 2 to 16 years old age group: school climate and safety:

- Only 6.2% of parents with children 16 to 25 years old said their child was called mean names, teased, or hit or kicked;
- An alarming 30% of parents with children 2-15 years old said their child was the victim of such behavior at least once a week
    - 25% of these parents said their children were the targets of such behavior more than once a week.
- Children aged 2 to 15 years old were also more frequent targets of lies and false rumors.
    - 5% of parents with children 16 to 25 years old said their child was the target of other students' lies and false rumors;
    - 14% of parents of children 2 to 15 years old indicated the same.

Figure 8: School-related Challenges Faced by Children



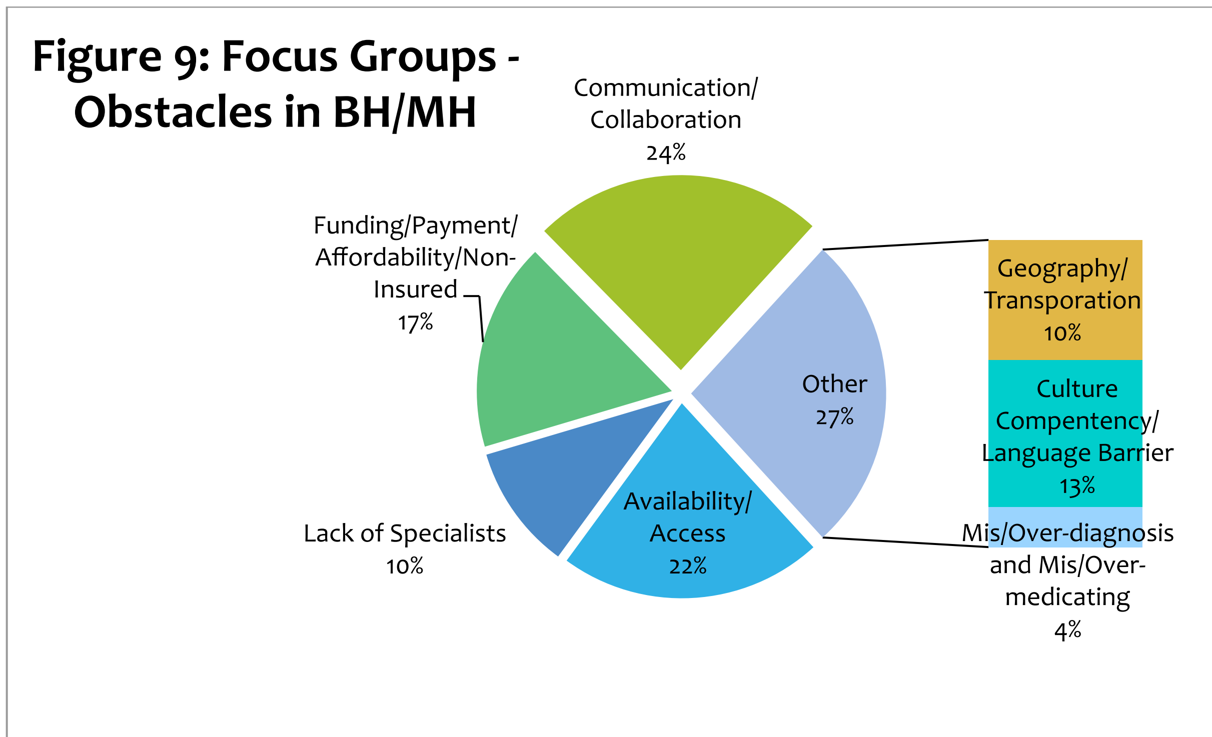
Secondary Data

From the Community Health Needs Assessment, Final Summary Report: Philhaven May 2013, the most underserved population: Young adults (18-29 years); followed seniors, then children (0-12) and adults (30-64) ranked the same, with teens (13-17) being considered the least underserved, not as underserved as the rest.

Communication and Collaboration

Focus Groups

Among the participants in the focus groups, when asked about obstacles within the BH/MH field, issues with communication and collaboration were discussed about a quarter of the time. Collaboration was the most discussed obstacle among all focus groups. Communication and collaboration was the most discussed item across all topics among focus groups. These two topics were discussed with regard to creating a "children's resource center." Nearly every participant agreed that communication and collaboration is key, and it is critical to not reinvent the wheel to solve the problem.



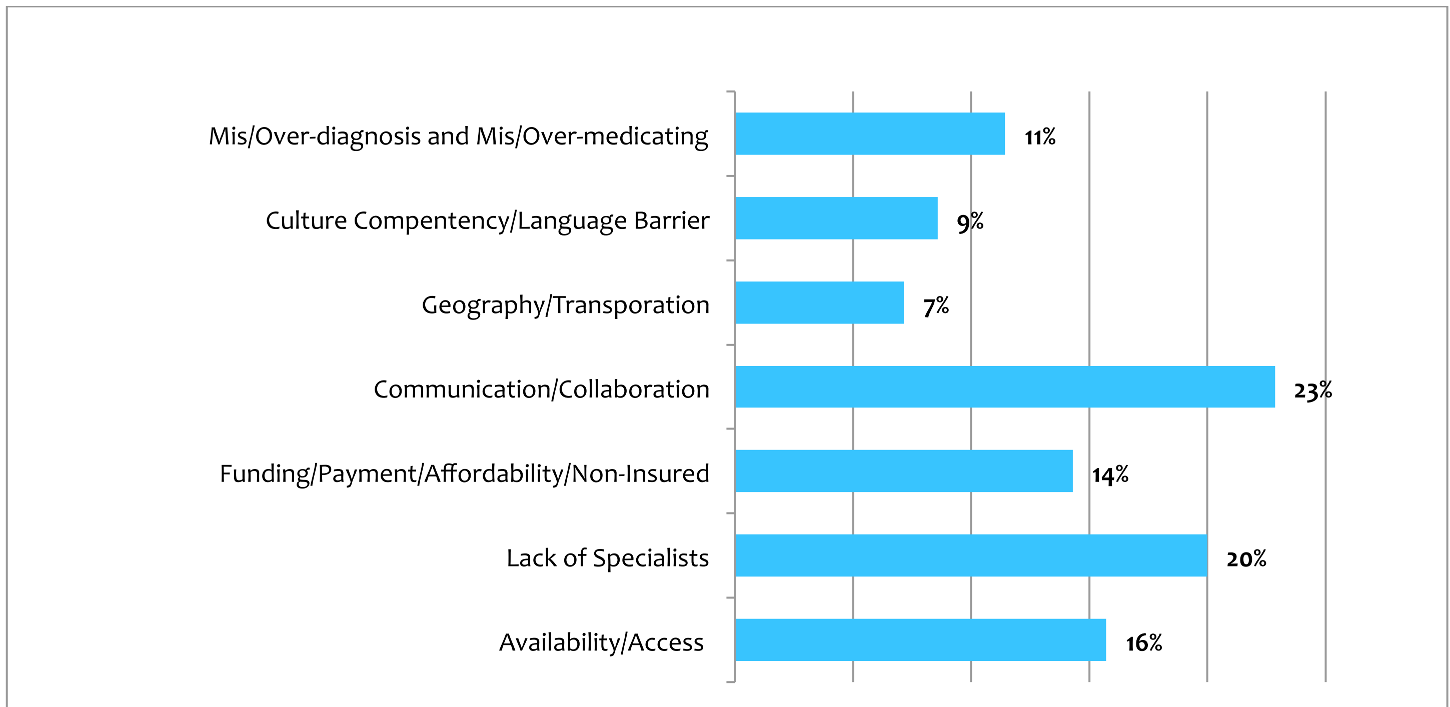
To demonstrate the issue is systemic, the focus group agreed that there is a problem with connecting to PCPs and hospitals, not just mental and behavioral health. A second focus group had a small group of participants that believed the behavioral and mental health services for youth are there, but

there is no coordination of efforts. That same focus group generally agreed that the system is too fragmented and common language changes all the time. Finally, that group went on to express a need for PCPs to have connection and coordination with mental wellness services. A third focus group reported their belief that youth behavioral and mental health is a complex issue and the different systems have not learned to work and communicate with each other. That same focus group went on to share their collective belief that it is difficult to get collaboration and integration going, despite people reporting they want it. Regarding the idea of a “children’s resource center,” a focus group's consensus was that it needs to be more of an integrative project with mental health and PCPs, so PCPs are not working outside of their expertise. This group presented a widely agreed upon and compelling idea that integrating behavioral and mental health and primary care is the way to go. They suggested and generally agreed that there could be a behavioral and mental health professional at PCP facilities for integrated and maximum impact.

Key Informant interviews

Among key informants that were interviewed, when asked about obstacles within the BH/MH field, issues with collaboration were the most discussed obstacle among key informants. Communication and collaboration was the third most discussed item across all topics among key informants. When asked what comes to mind when interviewees think of BH/MH, they reported that there was not enough consistency. For example, the PCP, therapist, support staff and parents may all be using different approaches. Parents have identified their need for more support in understanding mental and behavioral problems rather than deferring to a doctor or therapist to capture all of their information. Such information could come from the child’s school.

Figure 10: Key Informant Interviews Obstacles in BH/MH



Telephone Survey

Dissatisfaction with communication and collaboration was a recurring theme in the responses we received to the telephone survey. Among those parents whose children saw a health care provider for treatment of a mental health challenge, 65% received no help arranging or coordinating their child's care.

Responses to the question, "If you could make one suggestion to improve the process you went through to make sure your child received the necessary health care services or treatments, what would it be?" Frequently alluded to problems of collaboration and communication were:

- "Better communication about drugs."
- "Better information readily available."
- "No coordination of services."
- "Lack of communication between doctors and schools."

- "Doctors listening to concerns needs improved."
- "Easier communication with insurance companies."
- "Knowledgeable advocate to help guide through process, especially what questions to ask of doctors."
- "Physical health: talk on parents' level. Go into more of an explanation. Mental health: talk to the parent like they honestly know their own child, and really listen to the parent. Keep parents informed."
- "To follow through and make sure everyone is on the same page, … and things don't go overlooked. More communication."

Relatedly, many of our respondents spoke about the difficulty they experienced obtaining the information they needed to make informed decisions about their children's care.

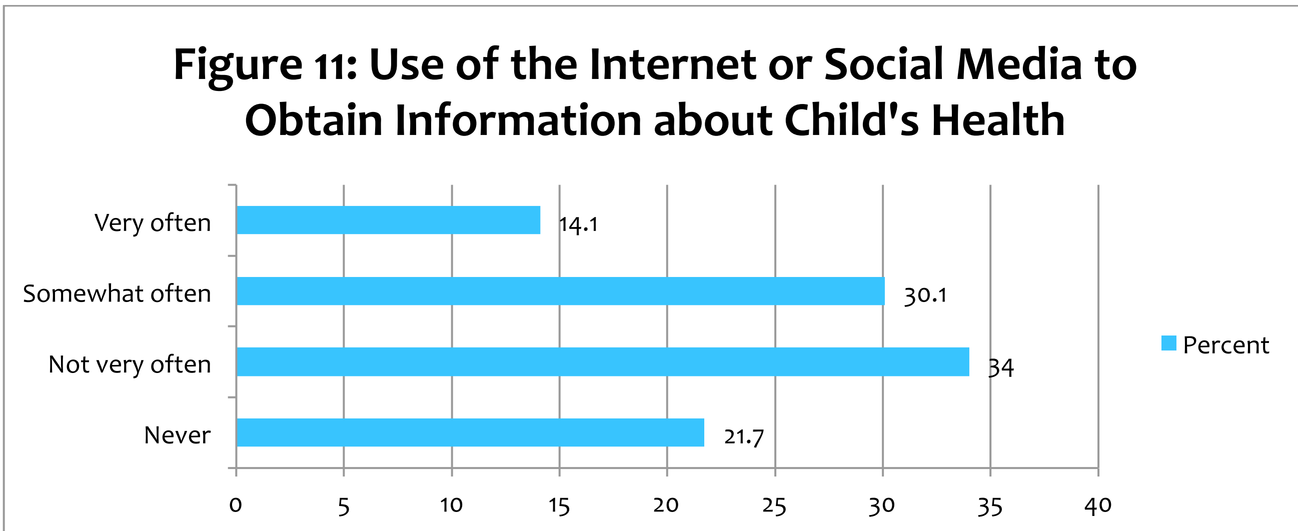
- Only 35% of parents said that they always got the specific information they needed from health care providers—information such as the causes of health problems, how to care for their children, and what changes to expect in the future.

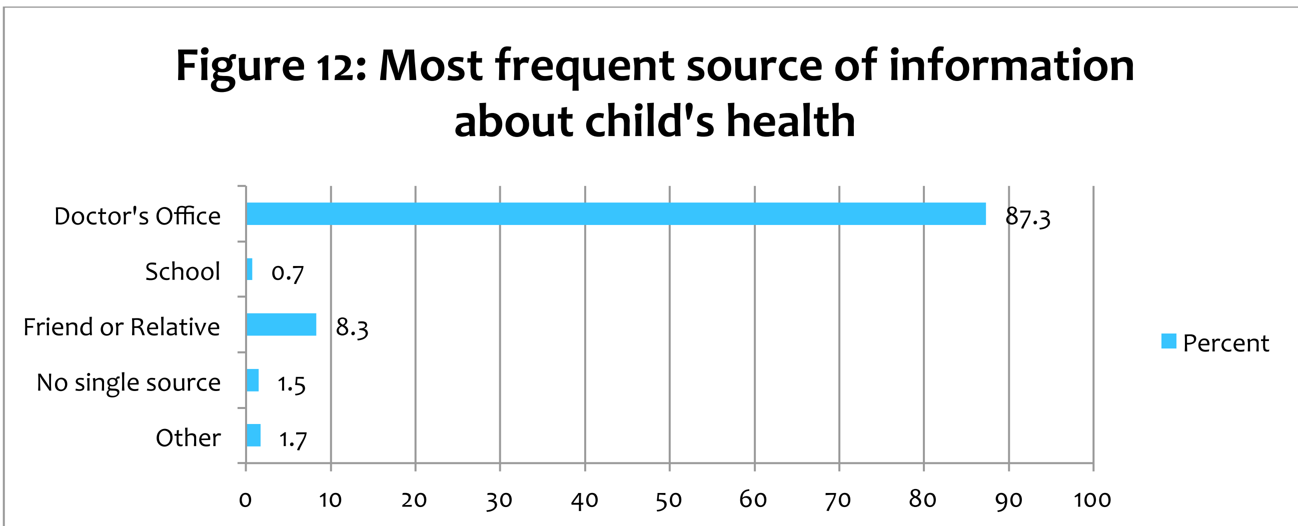
It is little wonder then, that such large percentages of parents sought information from other sources.

- Of the parents we surveyed, 44% used the internet or social media "very often" or "somewhat often" to get information about their child's health (Figure 11);
- 13% said they get advice about their child's health most often from a source other than a health care provider (Figure 12), with friends and relatives at 8%;

The frustration felt by parents about the difficulty of accessing information is summarized in the following responses to the question, "If you could make one suggestion to improve the process you went through to make sure your child received the necessary health care services or treatments, what would it be?" Responses included:

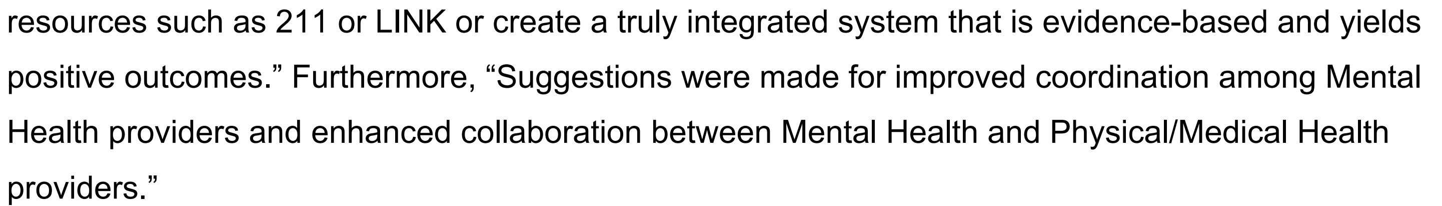
- "Better information readily available and insurance billing information."
- "Telephone numbers outdated."
- "Outdated information available."
- "Much research done on my own."





Secondary Data

From the United Way of Lancaster's 2010 Community Assessment, “The existing mental health system is segmented and difficult to navigate.” From the Community Health Needs Assessment, Final Summary Report: Philhaven May 2013, “The lack of a centralized clearinghouse of information and referral services was noted repeatedly. Suggestions were made to either build from existing

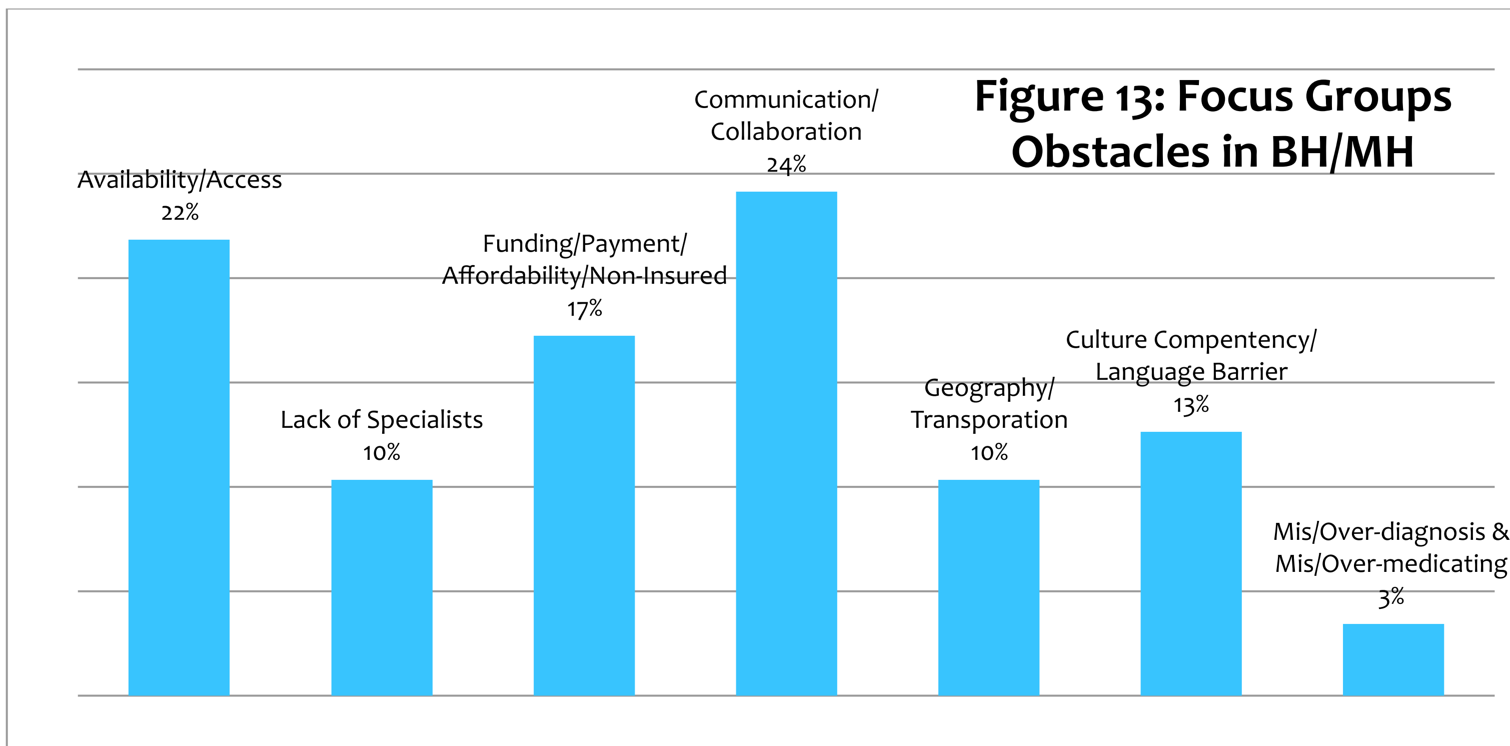


resources such as 211 or LINK or create a truly integrated system that is evidence-based and yields positive outcomes." Furthermore, "Suggestions were made for improved coordination among Mental Health providers and enhanced collaboration between Mental Health and Physical/Medical Health providers."

Funding, Insurance and Affordability

Focus Groups

Among the participants in the focus groups, when asked about obstacles within the BH/MH field, issues with funding, insurance and availability were discussed about one-fifth of the time. Funding/payment/insurance/affordability issues were the third most discussed obstacles among the focus groups. Funding/payment/insurance/affordability issues were the fifth most discussed item across all topics within the focus group. Parent focus groups did not discuss this topic at all.



One focus group suggested that the bigger issue is at the state level due to funding constraints. Another focus group discussed that insurance is an issue with obtaining referrals. The same focus group discussed that funding and integrating mental health into PCP services as a potential national model being looked into and modeled locally because PCP providers tend to be closer to families.

One of the focus groups discussed the idea that just because services are there does not mean that people can access them. This is often because of issues with insurance and affordability. That same group discussed their belief that Lancaster County has a rich array of services; the problem is that the population is rising and the funding is dropping. The need is growing disproportionately to the population growth. That same group discussed this being in large part a work force issue. There is a lack of psychiatrists nationally, and that trend is reflected here in Lancaster County. There was a general sense from the professional focus groups, and not discussed in the parent focus group, that a lack of funding is contributing to this problem.

Key Informant interviews

Among key informants that were interviewed, when asked about obstacles within the BH/MH field, issues with funding, insurance and availability were discussed more than 10% of the time. Funding, insurance and affordability issues were the fourth most discussed obstacles among key informants. When key informants were asked what comes to mind when they think of BH/MH, one interviewee said, "Who pays [for] their services? If there is a great specialist out there that one's insurance doesn't pay for, we shouldn't be sending patients to them." A key informant suggested that undocumented children do not have access to any insurance whatsoever or services outside of school.

Figure 14: Key Informant Interviews Obstacles in BH/MH

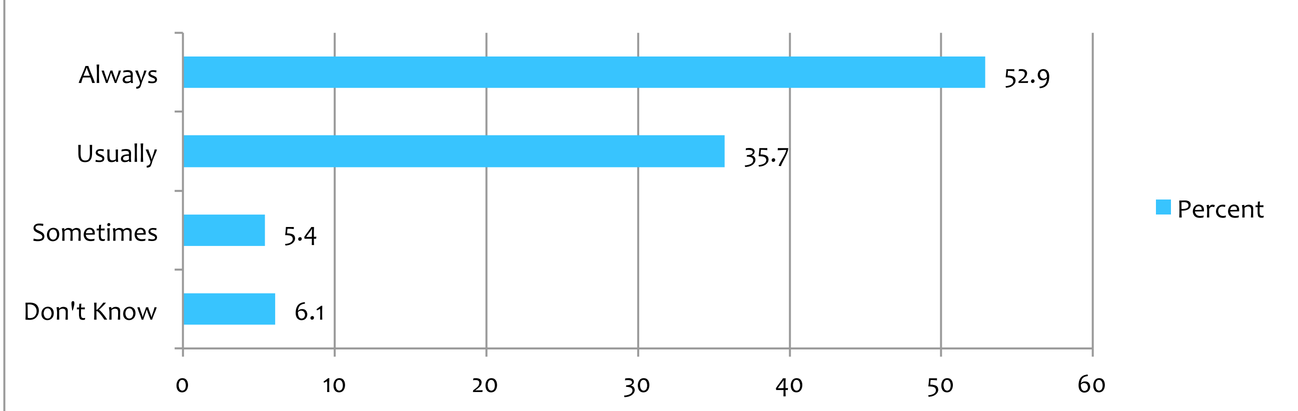
Mis/Over-diagnosis and Mis/Over-medicating 11%
Culture Compentency/Language Barrier 9%
Geography/Transporation 7%
Communication/Collaboration 23%
Funding/Payment/Affordability/Non-Insured 14%
Lack of Specialists 20%
Availability/Access 16%

Telephone Survey

The criticism expressed most consistently by parents seeking mental health care and services for their children concerns the cost of insurance. Data from a wide variety of questions asked in a number of different contexts speak to this fact.

1. 10% of parents said their children do not have any kind of health care coverage.
2. Even for those children who are covered by a health insurance plan of some kind, significant percentages of their parents reported difficulty trying to maintain insurance coverage.
    a. For 14% of parents, insurance wouldn't cover a treatment or service;

b. For another 14%, a specialist a parent wanted their child to see was not accepted by their insurance;
c. 9% of parents had to drop coverage at times because premiums were too expensive.



3. Concerns about the affordability and funding of health insurance emerge strongly in the responses to the question, "If you could make one suggestion to improve the process you went through to make sure your child received the necessary health care services or treatments, what would it be?" In fact, the cost of insurance is the problem most frequently referenced by the respondents to our survey. The responses below summarize the wide variety of concerns related to the cost of health insurance voiced by our respondents.
    a. "Cheaper access."
    b. "More affordable plans."
    c. "Cheaper health insurance."
    d. "Inaccurate billing."
    e. "Health insurance rejects claims."
    f. "Changes in insurance price premiums."

g. “Less expensive.”
h. “Lower cost rates.”
i. “Lower costs.”
j. “Lower premiums.”
k. “Making insurance payments easier to get.”
l. “More providers that take medical assistance.”
m. “Make obtaining insurance easier.”
n. “Poor children are neglected because of insurance coverage.”
o. “The insurance needs to be more affordable for people’s jobs.”
p. “Paying for physical exams.”
q. “Would want to see health care available for everyone.”

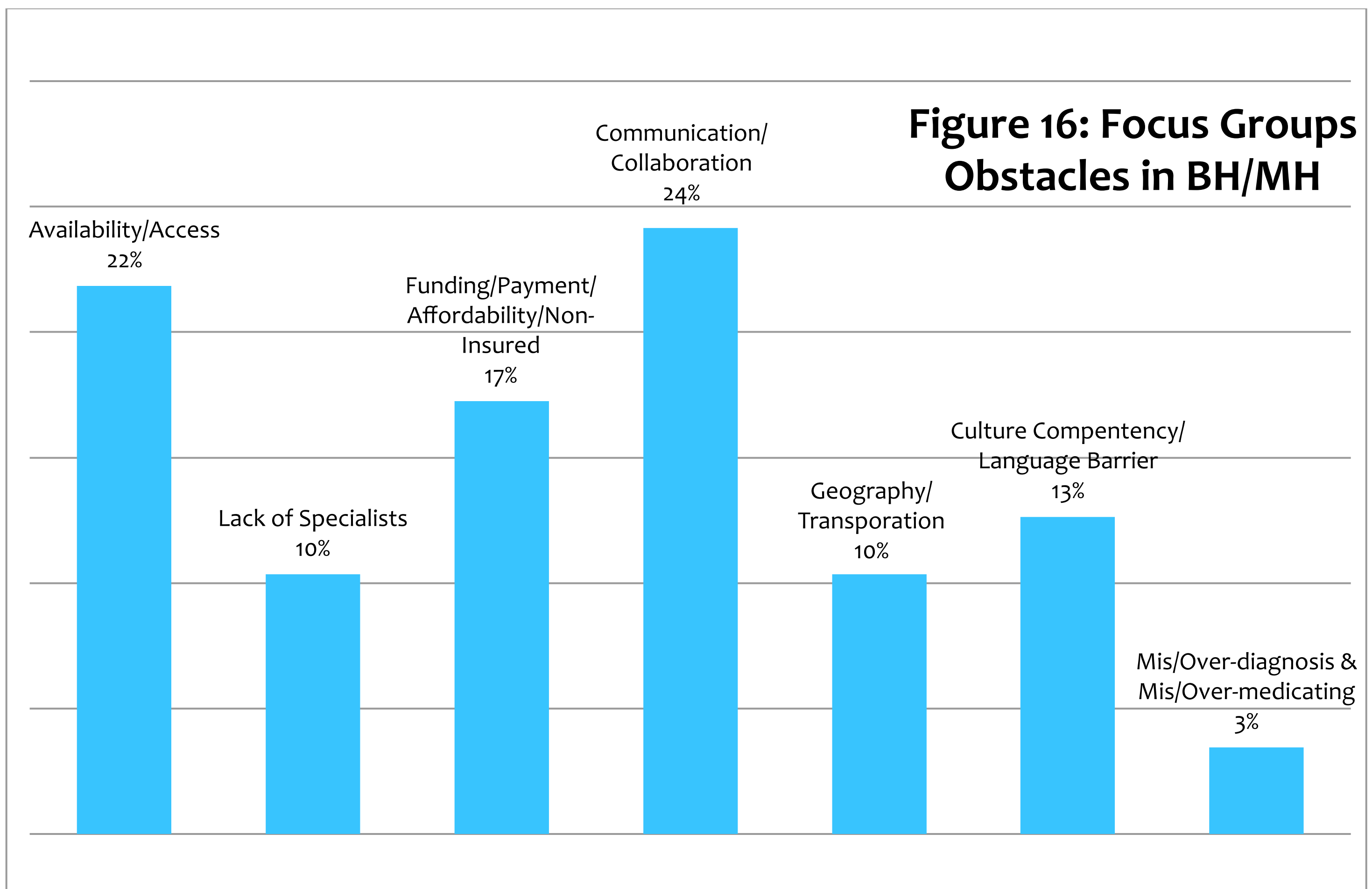
Secondary Data

From the Community Health Needs Assessment, Final Summary Report: Philhaven May 2013, “All attendees were in agreement that funds continue to decrease for Mental and Behavioral Health services, while the demand for services has escalated.” African Americans rank highest as the most underserved group in Lancaster County followed by Asian, Latino/Hispanic, and White.

Lack of specialists

Focus Groups

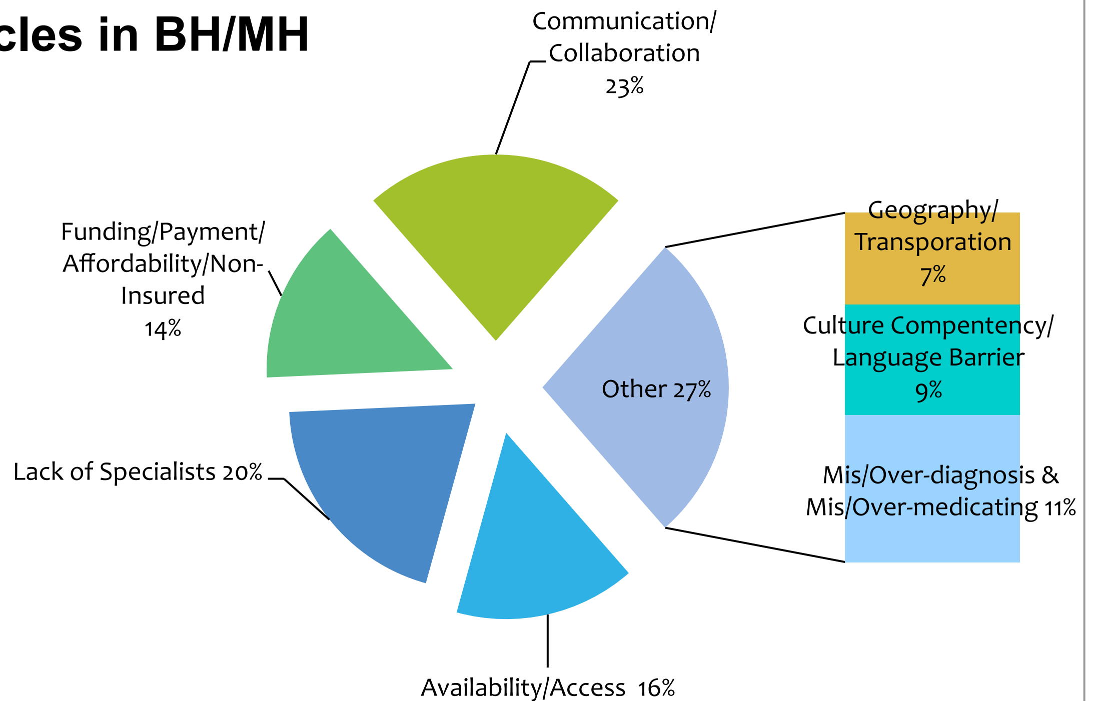
Among the participants in the focus groups, when asked about obstacles within the BH/MH field, the lack of specialists within the county encompassed about 10% of discussions around obstacles. There is a lack of specialty providers in the area, though a small percentage of participants believed they are not coming to Lancaster County because they cannot receive competitive pay here.



One focus group discussed the concept that doctors are more willing to work with adults due to it being a less complex dynamic since you are not dealing with parents, schools, and pediatricians. One focus group reported a strong need for more child psychiatrists in the field, and even more specially, two focus groups expressed agreement for a need for more trauma informed care practitioners. In part, this is a work force issue as there is a lack of psychiatrists nationally. In summary, between four focus groups containing many layers of professionals in the behavioral and mental health field, it was reported that a lot of providers in Lancaster County are not fully staffed, the field is not getting new recruits and that general funding is contributing to this problem.

Key Informant interviews

Among the key informants interviews, when asked about obstacles within the BH/MH field, the lack of specialists within the county were discussed one fifth of the time. Collaboration was the only obstacle discussed more often than lack of specialists among key informants. When asked what comes to mind when key informants think of BH/MH, they generally reported a need for more providers in mental and behavioral health, and more specifically, that the first need is child psychiatrists and psychologists. When asked what the top unmet need in the behavioral and mental health field was, about half cited specialty providers in the BH/MH field and a lack of specific child psychiatrists and psychologists.



Telephone Survey

While none of the questions in the telephone survey directly addressed the role of specialists, our respondents did speak out of frustration about their inability to access the services and treatment they offer. For example, fourteen percent of our respondents said they were unable to see the specialist they wanted because it wasn't covered by insurance. Also, in response to the open-ended question, "If you could make one suggestion to improve the process you went through to make sure your child received the necessary health care services or treatments, what would it be?", a number of respondents have reported concerns about specialists. A few representative responses to this question are illustrative:

- “We need more mental health professionals in the area needed by my child.”
- “Services for a 16 year old with bipolar need to be improved.”
- “More providers that take medical assistance.”

Secondary Data

From the Community Health Needs Assessment, Final Summary Report: Philhaven May 2013, there are too few Mental Health providers, particularly psychiatrists. In particular, “Psychiatrists who accept Medicaid were seen as too few in number.” The outcome is that a lack of providers means longer wait periods for youth.

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Appendix A: Key Informant Interview Demographics

Key Informant Interview Demographics

Organization/Affiliation	Gender	Occupation
Lancaster County public school	3 Males	2 nurses
Family Doctor, private practice	11 Females	1 physician
Lancaster County Behavioral Health and Development Services		8 admin
IU13		1 psychologist
Autism Solutions		2 parent of child with BH/MH diagnosis
Project Access Lancaster County		
Special Kids Network		
Community Services Group		
Youth Advocacy Program		
Boys and Girls Club		
Lancaster General Hospital		
Project Access Lancaster County		
Department of Public Welfare		

Appendix B: Focus Group Demographics

Focus Group Demographics

Organization/Affiliation	Gender	Age	Racial/Ethnic Group	Marital Status	Education	Children	Children's ages	Home Zip Code	Work Zip Code
Barley Snyder/ LOHF	Female	45 - 54	Caucasion, non-Hispanic	Married/Domestic Partner	Professional Degree	Yes	15	17543	17602
Brethren Village	Male	45 - 54	Caucasian/ non-Hispanic	Married/Domestic Partner	Master's Degree	No		17522	17606
COBYS Family Services	Female	45 - 54	Caucasion, non-Hispanic	Married/Domestic Partner	Master's Degree	Yes	20; 25	17557	17602
College Ave. Family Medicine	Male	55 - 64	Caucasian/ non-Hispanic	Married/Domestic Partner	Professional Degree	Yes	24; 27	17543	17603
Community Service Group	Female	45 - 54	Caucasion, non-Hispanic	Single, never married	Master's Degree	No		17102	17110
Community Service Group	Male	35 - 44	Caucasion, non-Hispanic	Married/Domestic Partner	Bachelor's Degree	Yes	13;10		17602
Community Service Groups	Female	25 - 34	Caucasian, non-Hispanic	Married or domestic partnership	Master's Degree	No		17516	17602
Community Services Group	Female	55 - 64	Caucasian/ non-Hispanic	Divorced	Bachelor's Degree	Yes	32	17603	17602
Community Services Group	Male	35 - 44	Caucasian/ non-Hispanic	Married/Domestic Partner	Master's Degree	Yes	8; 6 months	17543	17602
Compass Mark	Female	55 - 64	Caucasion, non-Hispanic	Married/Domestic Partner	Bachelor's Degree	Yes	22; 26	17070	17601
Friend	Female	45 - 54	Caucasian, non-Hispanic	Divorced	High School/Equivalent	No		17566	17566
High	Female	45 - 54	Caucasion, non-Hispanic	Married/Domestic Partner	Bachelor's Degree	No		17601	17601
Lanc. Co. BH/DS	Female	45 - 54	Caucasion, non-Hispanic	Single, never married	Master's Degree	No		17603	17601
Lanc. Co. BH/DS - EI	Female	55 - 64	Caucasion, non-Hispanic	Married/Domestic Partner	Bachelor's Degree	Yes	28; 30	17601	17603
Lanc. Co. Community Foundation	Female	45 - 54	Caucasian, non-Hispanic	Divorced	Master's Degree	Yes	20, 24	17602	17603
Lancaster General Hospital	Female	35 - 44	Caucasion, non-Hispanic	Married/Domestic Partner	Master's Degree	Yes	7; 9	17543	17601
Lancaster Mental Health Society									
Lancaster Regional Medical	Female	25 - 34	Caucasion, non-Hispanic	Single, never married	Bachelor's Degree	No		17543	17603
LOHF	Female	55 - 64	Caucasian, non-Hispanic	Married or domestic partnership	Master's Degree	Yes	33, 29	17601	17601
LOHF	Female	65 - 74	Caucasian, non-Hispanic	Married or domestic partnership	Doctorate Degree	Yes	50, 38	17545	17601
Mental Health America of Lanc. Co.	Female	45 - 54	Caucasian, non-Hispanic	Married or domestic partnership	Bachelor's Degree	Yes	9, 11	17022	17601
Menthal Health America	Female	55 - 64	Caucasian/ non-Hispanic	Married/Domestic Partner	Master's Degree	Yes	27; 28	17543	17601
Naeems Dream	Female	45 - 54	Caucasian/ non-Hispanic	Married/Domestic Partner	Associate Degree	Yes	6; 8; 8; 16; 20	17601	17601
PA Office of Mental Health	Male	55 - 64	Caucasian/ non-Hispanic	Married/Domestic Partner	Doctorate Degree	Yes	32; 26	17036	17105
Parent	Female	45 - 54	Caucasian, non-Hispanic	Separated	Master's Degree	Yes	23; 20; 17; 14; 11	17050	
Parent	Female	55 - 64	Caucasian, non-Hispanic	Separated	Some college	Yes	35; 33; 24; 16	17543	17543
Parent	Female	45 - 54	Caucasian, non-Hispanic	Married/ Domestic Partner	Bachelor's Degree	Yes	15; 13	17584	17584
Parent	Female	35 - 44	Caucasian, non-Hispanic	Married/ Domestic Partner	Associate Degree	Yes	9	17563	
Pressley Ridge	Female								
Pressley Ridge	Male	35 - 44	Caucasian/ non-Hispanic	Married/Domestic Partner	Master's Degree	Yes	10; 6; 4	17601	17601
School District of Lancaster	Female	55 - 64	African American/Black	Single, never married	Doctorate Degree	Yes	36, 31, 19	17603	17602
School District of Lancaster									
School District of Lancaster									
SE Lancaster Health Services	Female	55 - 64	Caucasian, non-Hispanic		Doctorate Degree	No		17603	17603
SE Lancaster Health Services	Female	55 - 64	Caucasian, non-Hispanic	Married or domestic partnership	Master's Degree	Yes	25, 23, 19	17512	17604
Southeast Lancaster Health Services	Female	35 - 44	Caucasian/ non-Hispanic	Married/Domestic Partner	Bachelor's Degree	Yes	10; 13; 16	21911	17605
Spanish American Civic Assoc.									
The Steinman Foundation									
TW Ponessa & Associates	Female	35 - 44	Caucasion, non-Hispanic	Married/Domestic Partner	Doctorate Degree	No		17601	17603
Unknown	Female	55 - 64	Caucasion, non-Hispanic	Married/Domestic Partner	Master's Degree	Yes	25; 27	17584	17602
Unknown	Female	45 - 54	Caucasion, non-Hispanic	Single, never married	Master's Degree	No		17522	17601
Unknown	Female	35 - 44	Caucasian, non-Hispanic	Married or domestic partnership	Master's Degree	Yes	8, 11	17520	17601
Unknown	Female	35 - 44	Caucasion, non-Hispanic	Single, never married	Master's Degree	No		17603	17601
Unknown	Male	75 years or older	Caucasian, non-Hispanic	Married or domestic partnership	Master's Degree	Yes	49, 50	17603	17602
Unknown									
Unknown									

Appendix C: Telephone Survey Data

CALL RESULTS & FAMILY CHARACTERISTICS

Call Result	Count	Percent
complete	536	9.6%
refused	958	17.2%
terminated early	181	3.3%
business	207	3.7%
answering machine	1029	18.5%
language/deaf	21	0.4%
No kids 2-25	669	12.0%
Government office	2	0.0%
non-working	1050	18.9%
busy	70	1.3%
no answer	830	14.9%
admin use only	3	0.1%
Total	5556	100.0%

Q1. Are you the parent or legal guardian of a child or young adult between the ages of 2 and 25 years old?

yes	58.89%
no	41.11%

Q.2 For HOW MANY children living in your household are you the parent or legal guardian?

1 child	33.9%
2 children	37.2%
3 children	17.0%
4 children	6.3%
5 children	0.5%
6 children	3.4%
7 children	0.9%
9 children	0.3%
10 children	0.5%

Mean: 2.14

Q.3 Age of child(children):

Child	Mean Age
1st	14.45
2nd	13.03
3rd	10.42
4th	9.94
5th	11.83
6th	12.17
7th	11.67
8th	17.00
9th	16.00
10th	2.00

HEALTH CARE

Q.4 First, in general, how satisfied are with the overall health of your child?

very satisfied	75.7%
somewhat satisfied	19.9%
somewhat dissatisfied	3.8%
very dissatisfied	0.6%

Q.5 Does your child currently have any kind of health care coverage?

yes	90.8%
no*	8.4%
don't know	0.9%

*If no to Q.5:

Q.5a During the past 12 months, was there any time when your child WAS covered by any health insurance?

yes**	20.7%
no	79.3%

**If yes to Q.5a:

Q.5b When your child WAS covered by health insurance, did that health insurance offer benefits or cover services that met your child's needs? Would you say always, usually, sometimes, never?

always	50.0%
usually	50.0%

Q.6 Does your child's health insurance currently offer benefits or cover services that meet your child's needs?

always	52.9%
usually	35.7%
sometimes	5.4%
don't know	6.1%

Q.7 Which of the following challenges, if any, have you experienced in trying to maintain insurance for your child and making sure they the continue to receive treatments and services? Please choose all that apply.

at times I had to drop health coverage because premiums were too expensive	7.8%
insurance wouldn't cover a treatment or service	13.6%
a specialist I wanted to see wasn't accepted by my insurance	14.2%
none/don't know/refused	64.5%

HEALTH CARE (Continued)

Q.8 When you need advice about your child's health, where do you get that advice from MOST OFTEN?

doctor's office	87.2%
school	0.6%
friend or relative	8.2%
other	1.7%
does not go to one place most often	1.5%
don't know	0.9%

Q9. How often have you used the internet or social media to get information about your child's health?

very often	14.0%
somewhat often	30.0%
not very often	33.8%
never	21.6%
don't know/refused	0.6%

Q.10 During the past 12 months, did your child see a doctor, nurse, or other health care professional for any kind of medical care—including sick care, well check-ups, physical exams, and hospitalizations?

yes	85.4%
no	10.8%
don't know	3.8%

SCHOOL CLIMATE & SAFETY

Q.11 During the last school year, in what kind of school was your child enrolled?

public or private	77.7%
preschool	0.6%
home-school	2.6%
not enrolled in any school	16.7%
don't know/refused	2.3%

Q.12 Based on what you know, during the past school year…

Q.12a How often was your child called mean names, teased in a hurtful way, or hit or kicked?

Several times a week	1.9%
About once a week	3.1%
2 or 3 times a week	2.3%
Once or twice a week	12.6%
Never	61.7%
Don't Know	17.2%
Refused	1.1%

Q.12b How often did other students tell lies or spread false rumors about your child?

About once a week	1.9%
Once or twice a week	7.7%
Never	60.5%
Don't Know	29.1%
Refused	0.8%

Q.12c How often did students use the internet or cell phone to threaten or embarrass your child by posting or sending hurtful messages?

2 or 3 times a week	1.5%
Once or twice a week	1.9%
Never	80.4%
Don't Know	15.4%
Refused	0.8%

PROTECTIVE & RISK FACTORS

Q.13 Please tell me how much you agree or disagree with the following statements…

Q.13a We watch out for each other's children in this neighborhood

Definitely agree	66.7%
Somewhat agree	19.2%
Somewhat disagree	3.5%
Definitely disagree	6.5%
Don't know	4.1%

Q.13b There are people I can count on in this neighborhood

Definitely agree	77.4%
Somewhat agree	11.3%
Somewhat disagree	1.2%
Definitely disagree	7.1%
Don't know	3.0%

Q.13c If my child were outside playing and got hurt or scared, there are adults nearby who I trust to help my child

Definitely agree	76.0%
Somewhat agree	13.9%
Somewhat disagree	0.6%
Definitely disagree	7.1%
Don't know	2.4%

Q.14 In which of the following activities or organizations, if any, has your child participated? Please choose all that apply.

sports teams	57.6%
boy scouts or girl scouts	31.0%
4-H clubs	7.2%
religious services or other faith-based activities	53.4%
boys' and girls' clubs	3.6%
none/don't know/refused	15.8%

Q.15 Generally speaking, do you feel you are getting the support you need to cope with the everyday demands of parenting?

yes	83.8%
no	13.8%
don't know/refused	2.4%

MENTAL HEALTH CHALLENGES

Q.16 To the best of your knowledge have any of your children experienced any of the following:

Q. 16a What about hearing problems?

no	89.2%
yes	6.7%
don't know/refused	4.1%

Q.16b What about Vision problems that cannot be corrected with glasses or contact lenses?

no	83.6%
yes	10.8%
don't know/refused	5.6%

Q.16c What about Anxiety problems?

no	71.3%
yes	23.7%
don't know/refused	5.0%

Q.16d What about Depression?

No	78.7%
Yes	15.8%
don't know/refused	5.6%

Q.16e What about ADD or ADHD?

no	79.2%
yes	14.4%
don't know/refused	6.5%

Q.16f What about Behavior or conduct problems, such as oppositional defiant disorder or conduct disorder?

no	85.9%
yes	8.2%
don't know/refused	5.9%

Q.16g What about Autism, Asperger's, or other autism spectrum disorder?

no	88.3%
yes	6.7%
refused	5.0%

Q.16h What about any developmental delay that affects your child's ability to learn?

no	85.92%
yes	9.09%
refused	5.0%

MENTAL HEALTH SERVICES

Q.17 During the past 12 months, did your child see a health care provider for treatment or services related to ANY of the health concerns I just mentioned?

yes	45.0%
no	55.0%

Q.18 Did your child need a referral to see any doctors or receive any services?

yes	22.2%
no	68.3%
don't know	9.5%

Q.19 Was getting a referral a big problem, a small problem, or not a problem at all?

a big problem	7.1%
a small problem	7.1%
no problem	85.7%

Q.20 Did anyone help you arrange or coordinate your child's care among the different doctors or services you used?

yes	34.9%
no	65.1%

Q.21 During the past 12 months, have you felt that you could have used more help arranging or coordinating your child's care among the different health care providers or services?

yes	37.1%
no	61.3%
don't know	1.6%

Q.22 Was getting transportation to and from the location of your child's appointment a big problem, a small problem, or not a problem?

a small problem	1.6%
no problem	98.4%

Q.23 During the past 12 months, how often did you get the specific information you needed from health care providers—information such as the causes of any health problems, how to care for your child, and what changes to expect in the future?

always	34.9%
usually	39.7%
sometimes	17.5%
never	3.2%
don't know	4.8%

MENTAL HEALTH SERVICES OPEN RESPONSE

(Compiled open-ended responses; where help would be sought for various mental conditions)

Hearing Problems:

Count	Grouped Responses
233	Doctor, Family Doctor, Pediatrician, Primary Care Physician, General Practitioner
12	Doctor for a Referral, Doctor then a Specialist
32	Ear/Nose/Throat Doctor, Specialist
3	Health Campus
6	Unknown, Unsure
3	Insurance
2	Medical Center
1	Hospital

MENTAL HEALTH SERVICES OPEN RESPONSE (cont'd)

(Compiled open-ended responses; where help would be sought for various health conditions)

Vision Problems:

Count	Grouped Responses
116	Doctor, Family Doctor, Pediatrician, Primary Care Physician, General Practitioner
6	Doctor for a Referral, Doctor then a Specialist
107	Eye Doctor, Optometrist or Ophthalmologist, Specialist, Eye Specialist
26	Optometrist
7	Ophthalmologist
5	Vision Center, New Holland Vision Center
11	Unknown, Unsure
3	Health Campus
5	Infrequent Responses: Insurance Network, Medical Center, Hospital

Anxiety:

Count	Grouped Responses
174	Doctor, Family Doctor, Pediatrician, Primary Care Physician, General Practitioner
11	Doctor for a Referral, Doctor then a Specialist
6	Mental Health Professional, Psychologist or Psychiatrist, Specialist
3	Psychologist
9	School, Guidance Counselor, School Counselor
7	Counselor
9	Church, Pastor, Family and Church
3	Health Campus
8	Unknown, Unsure
3	Infrequent Responses: DuPont in Delaware, Hospital, Medical Center

MENTAL HEALTH SERVICES OPEN RESPONSE (cont'd)

(Compiled open-ended responses; where help would be sought for various health conditions)

Depression:

Count	Grouped Responses
202	Doctor, Family Doctor, Pediatrician, Primary Care Physician, General Practitioner
24	Doctor for a Referral, Doctor then a Specialist
5	Mental Health Professional, Psychologist or Psychiatrist, Specialist
4	Psychologist
1	School, Guidance Counselor, School Counselor
7	Counselor, Family Counselor
3	Health Campus
8	Church, Family & Church, Bible, Jesus
2	Unknown, Unsure
6	Infrequent Responses: Friends, Hospital, Medical Center, Physiologist, Quest, Work Referral

ADD or ADHD:

Count	Grouped Responses
197	Doctor, Family Doctor, Pediatrician, Primary Care Physician, General Practitioner
13	Doctor for a Referral, Doctor then a Specialist
4	Specialist, Psychologist or Psychiatrist
2	Psychologist
16	School, Guidance Counselor, School Counselor
5	Counselor, Counseling Service
3	Health Campus
4	Philhaven
3	Therapist
12	Unknown, Unsure
5	Infrequent Responses: Hospital, Medical Center, MHMR, Neurologist, Self-Prescribe

MENTAL HEALTH SERVICES OPEN RESPONSE (cont'd)

(Compiled open-ended responses; where help would be sought for various health conditions)

Behavior or Conduct Problems:

Count	Grouped Responses
169	Doctor, Family Doctor, Pediatrician, Primary Care Physician, General Practitioner
16	Doctor for a Referral, Doctor then a Specialist
6	Mental Health Professional, Psychologist or Psychiatrist
9	Psychologist, Child Psychologist
17	School, Guidance Counselor, School Counselor
5	Psychiatrist, Doctor or Psychiatrist
11	Counselor, Family Counselor
3	Lancaster Co MHMR
3	Health Campus
9	Family, Parent, Parents and Doctor
4	Philhaven
4	Therapist
22	Unknown, Unsure
8	Infrequent Responses: Insurance Benefits Information Line, Church, Internet, Quest, Medical Center, Hospital, None, Phone Book

Autism Spectrum Disorders:

Count	Grouped Responses
200	Doctor, Family Doctor, Pediatrician, Primary Care Physician, General Practitioner
21	Doctor for a Referral, Doctor then a Specialist, Doctor then CAD
6	Mental Health Professional, Psychologist or Psychiatrist
4	Psychologist
5	Counseling, Counseling Service, Counselor
12	Specialist
18	School, School Counselor, Pediatrician or School Counselor, IU13
3	Health Campus
4	Autism Society
10	Not Sure, Unknown
4	Infrequent Responses: Therapist, Hospital, Insurance Company Provider Assistance, Medical Center

MENTAL HEALTH SERVICES OPEN RESPONSE (cont'd)

(Compiled open-ended responses; where help would be sought for various health conditions)

Developmental Delay:

Count	Grouped Responses
155	Doctor, Family Doctor, Pediatrician, Primary Care Physician, or General Practitioner
15	Doctor for a Referral, Doctor then a Specialist, or Doctor then CAD
52	School, Doctor and School, or School Counselor
4	Psychiatrist
2	Psychologist
12	Mental Health Professional, Psychologist or Psychiatrist
6	Specialist
3	Health Campus
2	Intermediate Unit
4	Tutor, or Special Tutor
4	Internet
15	Unknown or No Answer
5	Infrequent Responses: Therapist, Quest, Medical Center, Hospital, Church

Q.24 If you could make one suggestion to improve the process you went through to make sure your child received the necessary health care services or treatments, what would it be?

COUNT	COMPILED OPEN-ENDED RESPONSES
16	Better communication between clients and providers including: better listening by physicians, more detailed information about services and treatment options, better communication about drugs.
17	Better communication and coordination between service providers, between primary and specialists, between school and health providers.
7	Providers need to adopt a more customer service oriented attitude toward clients.
27	Insurance processes including communication, billing, claims/approvals, and appeals need improvement with the goal of easier access, easier use, and greater flexibility in treatment options.
44	Reduce costs of insurance and/or care.
27	Increase accessibility of healthcare: accept insurance plans provided by Medicaid, lengthen office hours, reduce the time between scheduling and appointment, reduce client paperwork.
17	Non-specific remarks about altering or repealing the ACA.
105	No comment, No response, No opinion

DEMOGRAPHICS

ZIP CODE	
17022	3.8%
17453	0.4%
17501	0.9%
17502	0.7%
17508	0.7%
17512	2.0%
17516	1.1%
17517	3.1%
17518	0.4%
17519	1.3%
17520	1.1%
17522	4.7%
17527	0.9%
17532	1.8%

ZIP CODE	
17536	1.3%
17538	0.7%
17540	2.0%
17543	12.0%
17545	5.8%
17547	1.8%
17551	2.7%
17552	5.6%
17554	1.1%
17555	1.1%
17557	2.9%
17560	1.3%
17562	0.4%
17563	0.9%

ZIP CODE	
17566	1.6%
17568	0.4%
17569	2.9%
17572	0.7%
17581	0.7%
17582	0.7%
17584	0.4%
17601	15.1%
17602	3.6%
17603	9.6%
17673	0.9%
17751	0.4%
17752	0.4%

Hispanic Or Latino	
yes	3.9%
no	95.6%
refused	0.4%

SEX	
male	37.4%
female	62.6%

Race (choose all that apply)	
White	90.4%
Black/African-American	4.6%
American Indian	0.9%
Native Hawaiian	0.4%
other	6.1%
refused	1.3%

EDUCATION	
less than high school degree	6.7%
high school graduate	25.3%
some college, but not degree	13.4%
associate's degree	13.9%
bachelor's degree	25.5%
advanced degree (e.g., master's, law, medical)	14.3%
refused	0.9%

INCOME	
$0 - $20,000	2.8%
$20,001k - $40,000	12.5%
$40,001 - $60,000	20.4%
$60,001 - $80,000	17.9%
$80,001 - $100,000	9.2%
$100,001 +	25.2%
don't know/refused	12.0%