

NORTH SHORE CHILD & FAMILY

GUIDANCE CENTER



PROJECT ACCESS

An Initial Study about Access to Mental Health/Addictions Care

A project of North Shore Child & Family Guidance Center

January 2018

ACCESS DELAYED IS ACCESS DENIED

Project Access is Supported by the
Long Island Unitarian Universalist Fund of the Long Island Community Foundation



Project Access Executive Summary

Project Access is an initiative to improve access to mental health and addictions care, supported by the Long Island Unitarian Universalist Fund of the Long Island Community Foundation.

ACCESS DELAYED IS ACCESS DENIED

These are words that ring true for far too many families across Long Island, many middle class and working poor, who have been unsuccessful in accessing timely and affordable quality mental health and addictions care through their health insurer.

During the final year of George W. Bush's administration the U.S. Congress passed the Mental Health Parity and Addiction Equity Act of 2008. This law states that it is illegal to treat diseases of the brain differently than those of any other part of the body. Two years later during Barack Obama's administration, the Affordable Care Act (ACA) passed into law. The ACA reinforced the parity requirement that health insurers and group health plans provide the same level of benefits for mental and/or substance use treatment and services that they do for medical/surgical care.

REPEAL AND REPLACE?

In 2017, threats to "repeal and replace" the ACA as opposed to improve it have put parity law in jeopardy. Congress attempted and failed to pass several versions of what was named the American Health Care Act (AHCA). Federal parity law requires health insurers to make sure that essential health benefits such as copays and deductibles, as well as visit limits, apply equally to mental health and substance abuse treatment and to other medical benefits. In contrast, the AHCA would allow states to waive certain federal protections, such as essential health benefits, which means that they would have the option to eliminate mental health parity and addiction equity in exchange plans.

NETWORK ADEQUACY

Regardless of the legislation, parity will do little good if it does not include routine enforcement of network adequacy. What is network adequacy? Network adequacy refers to the requirement of a health insurer to provide enrollees with timely access to a sufficient number of providers included in the benefit contract. Network adequacy has to do with individuals obtaining the timely, affordable and accessible care they need for their well-being.

If individuals cannot access mental health or addictions care, serious consequences, including death, may follow. Exacerbating the problem of individuals finding appropriate providers for mental health and addictions care is stigma and the shame it generates. The issue of network adequacy was the impetus for launching Project Access.

PROJECT ACCESS

Project Access, a new initiative launched by North Shore Child & Family Guidance Center, is exploring the problem of individuals gaining timely and affordable mental health and addictions care, identifying obstacles to accessing care and disseminating findings to activate change.

Participants of the current study, nearly 650 respondents from all across Long Island, were already receiving help at the time that they answered this survey, which can be assumed to be a factor in shaping their responses. Some responded in an online survey and most completed surveys provided by a diverse group of New York State licensed community-based mental health and chemical dependency agencies.

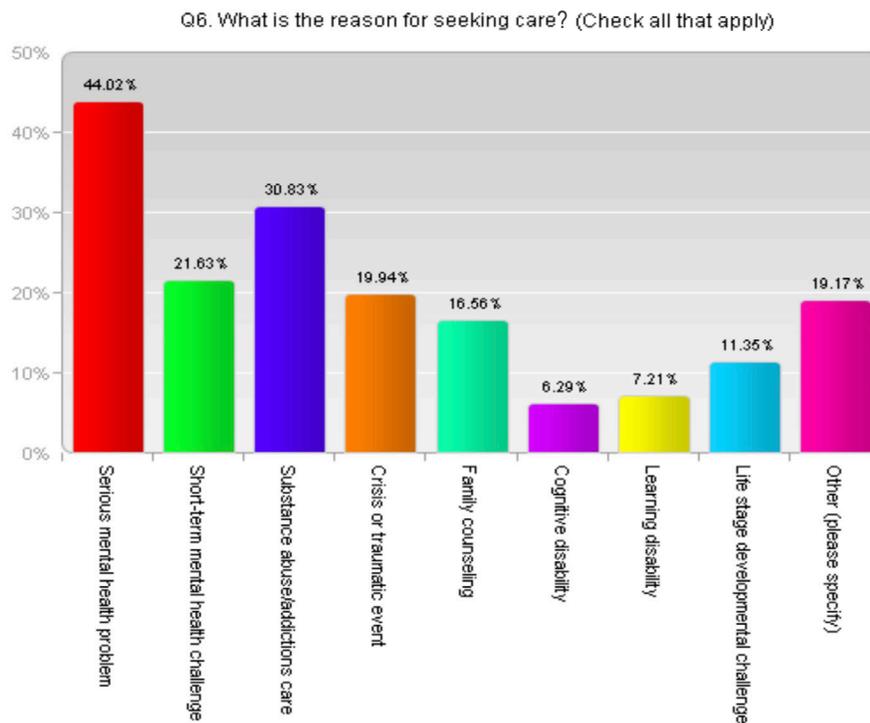
Accordingly, the data need to be interpreted with an appreciation of that influence. We cannot ascertain from this data the extent to which people who have not accessed care are experiencing obstacles to seeking and receiving care.

DIFFICULTY IN FINDING HELP

Almost half of respondents indicated that it was more difficult finding help for mental health or substance abuse/addiction problems than finding help for physical illnesses, and nearly 40% of respondents said that their insurance company did not have an adequate number of providers.

REASONS FOR SEEKING HELP

Almost 70% of respondents indicated that they were the persons with the direct experience seeking help, with just over 30% stating that they were answering on behalf of another individual, such as a child, who has received care. Among the respondents 51% were female and 45% male. Others identified as transgender or non-binary, gender-fluid or gender-queer. 62% sought mental health services, 16% substance abuse services and 22% both. The following table indicates the reasons why they were seeking care for themselves or their loved ones.



FACTORS RELATED TO SEEKING HELP

Although the participants in the current study represent a population that likely achieved access to care, when 25% or more of the population experienced an obstacle the finding can be considered very important. For instance, stigma (36%), affordability (nearly 39%), choice of providers were limited (39%) and long waiting lists (nearly 25%) are considered important findings indicating impediments to seeking care.

NUMBER OF AGENCIES OR PROFESSIONALS CONTACTED BEFORE OBTAINING HELP

As indicated above, it is likely that the respondents had obtained care. Consequently, this sample does not include

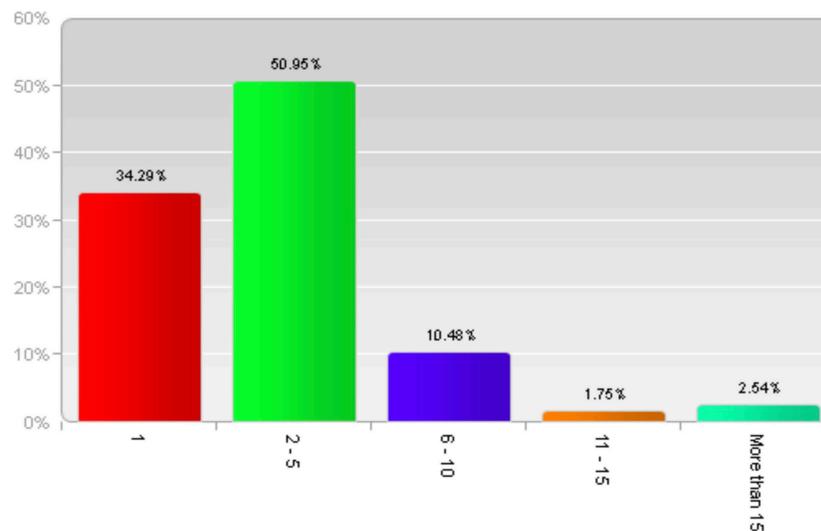
Project Access Executive Summary

those who attempted and failed to access care. Slightly more than 33% indicated that they were able to access care after just one contact. For the remainder of the respondents it took them anywhere from 2 to more than 15 contacts, 15% of whom required 6 or more attempts, including those experiencing a crisis or traumatic event.

ADDITIONAL IMPEDIMENTS RELATED TO SEEKING HELP

Given the fact that the participants in the current study represent a population that likely achieved access to care, when nearly 25% of the population of participants identify that particular impediments seeking care exist, the findings can be considered very important. For instance, almost 24% of participants could not find a provider that accepted their insurance, nearly 39% had a problem with affordability, 21.25% pointed to personal indecision as a factor, and slightly more than 24% of participants reported that they felt their attempts at accessing help were futile (24.06%). These should be considered important findings that reflect additional obstacles individuals experience when seeking care. These findings highlight the relative importance and centrality of these variables in facilitating or impeding progress.

Q7. Thinking back to when you first sought services, how many agencies or professionals did you contact before you were able to find treatment for yourself or your loved one?



ASSISTANCE IN FINDING A PROVIDER

Two-thirds of respondents indicated that their insurance company was not helpful to them in finding a suitable provider for themselves or a loved one.

ADDITIONAL INSURANCE INFORMATION

There are many more barriers highlighted that illustrate the challenges in accessing care in a timely manner. In particular, nearly 30% indicated that it took them more than a month and 15% between 3 - 6 months to secure services. Additionally, 50% of respondents said that it was more difficult to access mental health/addiction services than physical health services.

Range Of Experiences Shared

RANGE OF EXPERIENCES SHARED

155 participants shared their story about accessing services. The responses were both positive and negative. One overarching theme that emerged was the role that insurance played in both accessing and maintaining services. Another theme observed within participants' comments was a perceived sense of insensitivity when assisting individuals to access services.

FROM THE RESPONDENTS, IN THEIR OWN WORDS

• I did not get turned away once I figured out where to go to get help for my daughter, who was 15 years old at that time. However, it took a lot of research. It seemed as if no one had ever walked down this path before, which I find hard to believe. Now, there is more help out there (more literature), but mental illness is still not treated like any other disease. There is still a stigma associated with it, and this must change. It is a disease that the victim never did anything wrong to deserve. Mentally ill people and their loved ones should be treated with love and respect, given immediate help and people everywhere should be taught more about this disease. While there have been some improvements, we still have a long way to go.

• I feel that finding a therapist is the same as shopping. I need to find the right one that fits me!

• I have called recommended therapists who were not taking new patients. They were brusque on the phone with no alternative recommendations. I was very surprised by how much that hurt my feelings - I guess if someone is recommended to you, you expect a better, more personable response - a waiting list or alternative recommendation.

• I have never been turned away when seeking care. I think it's very good for myself plus anyone who needs care to get the help they need. I personally am happy to be a part of something where I can vent and discuss my issues to maintain clarity. It makes me feel like it's not so bad, like I'm not alone under all the pressure life brings daily. I think the best thing one can do for themselves is want

the help because that's the only really way it will work. I just want to be clear as I've been and maintain that with my effort and the great counseling I receive here it shouldn't be hard at all. I see and feel the improvement.

• I needed detox services and I had bad insurance. I was turned down by many places due to my insurance.

• I private pay for my therapist and psychiatrist. My insurance company won't reimburse for either but they provide the level of care I need. I am 31 and have been in treatment since age 15 and things are finally starting to get better but there are still roadblocks in insurance covering meds and doctors. Even hospitalizations when I was suicidal. I would get gigantic bills.

• I ran across several obstacles in finding a therapist. All insurance company did to help was plug in zip code and give names. No info available about handicap accessibility so I had to call many only to find out facilities were not handicap accessible. I was not even able to find one that was but was lucky to find a great therapist who agreed to see me in one of the other rooms in building. Otherwise not sure I could have found the help I needed. Additionally, every year, although insurance under my name and coverage for me is approved - every year my 2nd insurance tells my therapist I have no coverage for mental health and I have to straighten it out. Feel blessed to have found (name of worker).

• I sought private services (I preferred rather than community clinic for privacy) for my teenager who became addicted to [drugs]. After a

Range Of Experiences Shared

28 day rehab I could not find even one practitioner who accepted my insurance or was truly qualified. We settled on someone who misrepresented himself and did not have an adequate addictions background. My child ended up back in rehab and the therapist never even bothered to call. Very unprofessional and unethical.

- I tried last year to get care for my 12-year old son, who had his first mental break. He was hospitalized by choice and it was a VERY scary experience. He stayed in the hospital for a week and it was the longest week in the world. Thank GOD he was placed in the pediatric unit because in the adolescent unit there was a great deal of violence. After his hospitalization, we decided to put him in a partial hospitalization program. Unfortunately, that program only lasted for six weeks. That was NOT enough time to get him back on track to healing. How do you heal from a mental break in such a short time? Nevertheless, we were desperately looking for an appropriate school for him--one that was more therapeutic. By the grace of God, we found (name of agency). He only missed out on about 10 or 11 days of school while waiting for placement, but we are happy to report that, although things are far from perfect, he is finally in a school with supports that help him. He is finally staying in school and attending classes. He has a long way to go, but we feel much better that he is safe and on the road to recovery!

- I tried seeking mental health counseling but every time I tried getting help either my insurance wouldn't be accepted or it was a long waiting time. I was scared at first but got the care I need.

- I was never turned away from treatment.

- I was referred to a substance abuse counselor and he retired after 1 year of my

treatment. Found another therapist but it was through my insurance and they had no one on staff with experience treating both substance abuse and depression. It was a bad experience. I had come to the care center years before after an overdose on pills and alcohol. Rob was my counselor and I remembered how helpful he was. So I called and did an intake and have been doing well ever since.

- I wasn't turned away for services but I waited two months to see someone. They should get people in quicker.

• I work for a school district and we work with families on a daily basis where they cannot find a provider that will accept their insurance or they cannot afford the copayment. Personally, a family member within my household required therapy and we had difficulty finding a provider and when we did, scheduling was a nightmare because so many patients were trying to see him. I believe it was because he was one of the few willing to accept multiple insurance policies.

- It has been very difficult as a family member of someone with a mental illness to assist them in getting help. A major part of many serious mental illnesses is that those who are ill do not see that they need help. There needs to be a better way for family members of adults with mental illness to facilitate treatment.

- It is difficult to find treatment for tween eating disorder.

- The main problem was finding a provider relatively close with after school/evening hours that provided both counseling and medicine rx. Found wonderful counselor my son loved but he was LCSW and could not provide medicine. Looked but unable to find a provider to work with him to give needed meds. That was referred by health

plan. Another big issue is with insurance - every year they deny all mental health coverage and I have to fight them to cover it - what they eventually do is coverage is provided but it's time consuming and frustrating for myself and for. Thankful I found [name of agency] wonderful staff and counselors.

- When my mental health began to decline I searched online and through insurance to seek a provider/psychiatrist, psychologist, counselor I found a few but there were long waiting lists to be seen, or they were not accepting new clients once I find a provider. They did not take insurance so it was very costly. The provider was very cold and mechanical. So I was unable to get the help I felt I needed so I stopped going. Several months later I had a nervous breakdown and was hospitalized for it. Through hospitalization I was given temporary social worker who was able to find me a counselor I could connect with that took my insurance and was affordable even without insurance, I felt very upset that it had to be that, that was the way I found help when I had sought it long before, and feel I could have avoided my crisis if I had access to it sooner.

Implications

IMPLICATIONS

The problem of access for mental health and addictions care is complex and may begin with a family's hesitance to ask for help and to reveal that they are residing with someone who is living with a mental illness.

Families coping with mental illness or addiction do not as readily seek help as they might for heart disease, cancer or diabetes. Why? As the results of the Project Access survey suggest, it could be related to personal indecision, often stemming from stigma and the shame it generates.

STIGMA LOOMS LARGE AND CAN LEAD TO RELUCTANCE TO SEEK HELP

When there is a mass shooting and the perpetrator is labeled mentally ill, it casts a shadow on all people with mental illness, despite the fact that this group of people is disproportionately the victims of violence. 36% of survey respondents cited stigma as an impediment to seeking care.

Attitudes like this reinforce stigma and can lead to reluctance for those in need to seek necessary help in a timely manner to address issues including discrimination in school or in the workplace; and bullying, violence or harassment. These attitudes may lead to individuals believing that they can never improve their lot in life; and feeling let down by health insurance companies and providers that do not meet their mental health needs.

The United States has chronically failed to treat illnesses above the neck the same as illnesses below the neck. For example, a parent who would not hesitate to reach out for help if their child was in an accident and appeared to have broken an arm, might wait weeks and months, if not longer, to ask for help if it was a mental health crisis or substance abuse problem.

Clearly, as this study reveals, despite any progress made in eradicating stigma, we still have a long way to go with respect to public education and mental health awareness.

WHEN PROVIDERS DO NOT ACCEPT YOUR HEALTH INSURANCE

What makes the problem of stigma even more insidious is that once an individual or their loved ones pick up the phone to ask for help, they are told repeatedly by providers, "I'm sorry I don't accept that insurance any longer, I only accept cash," and there is a chance they will give up.

When a parent gives up they risk their child deteriorating further. This is also true for adults with mental illness and increases the odds that they will ultimately need more costly care or confinement, hospitalization or incarceration.

Almost 40% of survey respondents identified affordability as an obstacle to seeking care.

THE CHALLENGE OF FINDING ACCESSIBLE AND AFFORDABLE CARE

Almost 50% of respondents indicated that it was more difficult finding help for mental health or substance abuse/addiction problems than finding help for physical illnesses and most particularly when they were in crisis. Nearly 40% of respondents said that their insurance company did not have an adequate number of providers. These findings suggest that, despite federal parity law, more needs to be done to ensure adequate networks of providers for people living with mental illness and addiction.

THE COMMERCIAL HEALTH INSURANCE INDUSTRY

After reviewing the research, Project Access committee member Dr. Ilene Nathanson, Chair of the Social Work Department at LIU Post, concluded, "If the definition of insurance is protection then the gross inadequacies of our insurance system are laid bare in this study. Delays, unaffordability, outright inaccessibility - all courageously endured by human beings in need of mental health care. It is time that the insurance industry stepped up to the task of protecting."

Implications

MONITORING AND ENFORCING NETWORK ADEQUACY – A CALL TO ACTION

Governor Andrew Cuomo created the Department of Financial Services, charged with the responsibility to monitor private health insurers to ensure that they have adequate networks of care as a condition of their license. This means they must demonstrate the consistent ability to provide timely access to care for individuals and their families. Yet, data reveal that people experience long delays in obtaining necessary mental health and addictions care.

Private health insurers pay substandard rates of reimbursement for mental health and addictions care. Consequently, a growing number of providers, including community-based organizations, no longer participate in an insurance network because they cannot afford to accept such low rates. The insurers fail to carefully monitor their lists of providers and New York State fails to monitor and regulate the insurers for network adequacy.

According to New York State Senator Todd Kaminsky, an honorary Project Access committee member, “In this day it is disgraceful that mental health treatment is still not being taken seriously. Turning children and families in need away is simply unacceptable.”

Senator Kaminsky, who cited complaints from numerous constituents, wrote to the New York State Department of Financial Services (DFS) expressing his deep concern about that lack of commercial insurance coverage for mental health services for middle class families on Long Island. In his letter, he wrote, “This lack of access to care is alarming and I hope DFS will immediately respond to my letter by commencing a thorough investigation of this issue.” The lack of response led to the launch of Project Access.

We call on the New York State Department of Financial Services to launch a thorough investigation of this issue.

Our Committee

The Project Access Planning Committee includes:

- **Robert Basile**, PsyD, Director of Clinical Services, Chief Associate to the Executive Director, Metropolitan Center for Mental Health, NY, NY.
- **Millicent Garofalo**, Esq., LCSW-R, Clinic Coordinator of Families in Support of Treatment (F.I.S.T.)
- **Elissa Giffords**, DSW, LCSW, Professor, Social Work Department, LIU Post
- **Lee Holtzman**, LCSW, High End Services Coordinator, North Shore Child & Family Guidance Center
- **John Levitt**, Esq., AXA Advisors, Community Person and Parent
- **Andrew Malekoff**, LCSW, CASAC, Executive Director and CEO, North Shore Child & Family Guidance Center
- **Nancy Manigat**, MBA, LCSW, Chief Program Officer, CN Guidance and Counseling Services
- **Ilene Nathanson**, DSW, LCSW, Chair of the Social Work Department at LIU Post
- **Jacqueline Shelley**, LCSW, Danny's Dream Foundation
- **Sari Skolnik-Basulto**, PhD, LCSW, Assistant Professor at Wurzweiler School of Social Work
- **Troy Slade**, BA, VP of Business Development NFP/BWD, a leading force in the insurance industry
- **Michael Stoltz**, LCSW, Chief Executive Officer, Association for Mental Health and Wellness
- **Janet Susin**, MA, President, National Alliance on Mental Illness (NAMI) Queens/Nassau

Honorary Stakeholders:

- New York State Senator Todd Kaminsky
- New York State Assemblyman Charles Lavine
- New York State Assemblyman Michael Montesano
- New York State Senator Elaine Phillips

Supported by the Long Island Unitarian Universalist Fund (LIUUF) of the Long Island Community Foundation (LICF)

Many Thanks To All Participating Agencies

For more information on Project Access, or to participate in our survey, write to Project Coordinator Andrew Malekoff at amalekoff@northshorechildguidance.org

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Preface

PROJECT ACCESS is an initiative to improve access to mental health and addictions care.

Under both G.W. Bush and Obama administrations, Congress passed mental health legislation that requires health insurers and group health plans to provide the same level of benefits for mental and/or substance use treatment and services that they do for medical/surgical care. However, this policy will do little good if it does not include enforcement of network adequacy. What is network adequacy? Network adequacy refers to the requirement of a health insurer to provide enrollees with timely access to a sufficient number of providers included in the benefit contract. Network adequacy has to do with individuals obtaining the care they need for their well-being.

If individuals cannot access mental health or addictions care, serious consequences, including death, may follow. Exacerbating the problem of individuals finding appropriate providers for mental health and addictions care is stigma and the shame it generates. We need to start treating illnesses above the neck the same as illnesses below the neck.

Project Access, a new initiative launched by North Shore Child & Family Guidance Center, is exploring the problem of individuals gaining timely and affordable mental health and addictions care, identifying obstacles to accessing care, and disseminating findings to activate change.

Notably, participants of the current study were already receiving help at the time that they answered this survey and that can assumed to be a factor in shaping their responses. Accordingly, the data needs to be interpreted with an appreciation of that influence. We cannot ascertain from this data the extent to which people who have not accessed care are experiencing obstacles to seeking and receiving care.

Many thanks to all participating agencies

For more information on Project Access, or to participate in our survey, write to Project Coordinator Andrew Malekoff at amalekoff@northshorechildguidance.org

Access Delayed Is Access Denied!

Project Access Data

Participant Information

Table 1: Participant status

Are you the person with direct experience trying to access mental health and substance use/addictions care?		
Count	Percent	
443	68.79%	Yes
201	31.21%	No, I am answering on behalf of an individual who has received care
644		Respondents

Table 2: Marital Status

What is your marital status?		
Count	Percent	
55	9.06%	Minor, does not apply
281	46.29%	Single, never married
112	18.45%	Married
35	5.77%	Separated
12	1.98%	Widowed
78	12.85%	Divorced
23	3.79%	Living together
11	1.81%	In relationship but living apart
607		Respondents

Project Access Data

Table 3: Household

How many people including yourself live in your household?		
Count	Percent	
100	16.81%	1
107	17.98%	2
122	20.50%	3
126	21.18%	4
64	10.76%	5
23	3.87%	6
9	1.51%	7
44	7.39%	8 or more
595	Respondents	

Table 4: Gender

Please categorize yourself in terms of gender		
Count	Percent	
307	51.34%	Female
273	45.65%	Male
2	0.33%	Transgender FTM (female-to-male)
1	0.17%	Transgender MTF (male-to-female)
5	0.84%	Non-binary/gender fluid/gender queer
1	0.17%	Not sure
3	0.50%	Prefer to self-describe (please specify)
6	1.00%	Prefer not to say
598	Respondents	

Project Access Data

Table 5: Race

Please categorize yourself in terms of race (Check all that apply)			
Count	Respondent %	Response %	
106	17.67%	16.33%	African American or Black
19	3.17%	2.93%	West Indian or Caribbean
16	2.67%	2.47%	American Indian or Alaskan Native
21	3.50%	3.24%	Asian
4	0.67%	0.62%	Native Hawaiian and Pacific Islander
421	70.17%	64.87%	White
62	10.33%	9.55%	Other (please specify)
600 Respondents			
649 Responses			

Table 6: Ethnicity

Please categorize yourself in terms of ethnicity		
Count	Percent	
85	14.76%	Hispanic or Latino Origin
491	85.24%	Not of Hispanic or Latino Origin
576 Respondents		

Project Access Data

Table 7: Subcategory of Hispanic

You selected Hispanic or Latino origin; please indicate which subcategory best defines you		
Count	Percent	
5	6.02%	Cuban
5	6.02%	Mexican
31	37.35%	Puerto Rican
25	30.12%	South or Central American
17	20.48%	Other Spanish culture or origin regardless of race
83	Respondents	

Table 8: Level of Education

What is the highest level of education you completed?		
Count	Percent	
2	0.33%	Less than elementary
16	2.67%	Elementary
14	2.34%	Jr. High or Middle School
48	8.01%	Some High School
200	33.39%	High School
46	7.68%	Secretarial/Technical without degree
110	18.36%	2 year College Degree (Associate)
106	17.70%	4 Year College/University Degree
44	7.35%	Master's Degree
13	2.17%	Doctoral Degree
599	Respondents	

Project Access Data

Table 9: Household Income

Which of the following best describes your annual household income?		
Count	Percent	
279	49.29%	Less than \$25,000
111	19.61%	\$25,000 - \$49,000
61	10.78%	\$50,000 - \$74,000
32	5.65%	\$75,000 - \$99,000
31	5.48%	\$100,000 - \$124,000
17	3.00%	\$125,000 - 149,000
15	2.65%	\$150,000 - \$199,000
20	3.53%	\$200,000 or more
566	Respondents	

Table 10: Services Sought

Please select the services you were seeking		
Count	Percent	
405	62.12%	Mental health services
105	16.10%	Substance abuse/addictions care
142	21.78%	Both
652	Respondents	

Project Access Data

Table 11: Court Ordered

Table 3: Did the court order you to seek treatment?		
Count	Percent	
116	17.85%	Yes
534	82.15%	No
650		Respondents

Table 12: Reason Seeking Care by Court Ordered Status

		Did the court order you to seek treatment?					
		Yes		No		Total	
		Count	Percent	Count	Percent	Count	Percent
What is the reason for seeking care (Check all that apply)	Serious mental health problem	41	19.16 %	242	26.13 %	283	24.82 %
	Short-term mental health challenge	20	9.35 %	119	12.85 %	139	12.19 %
	Substance abuse/addictions care	67	31.31 %	130	14.04 %	197	17.28 %
	Crisis or traumatic event	21	9.81 %	108	11.66 %	129	11.32 %
	Family counseling	15	7.01 %	91	9.83 %	106	9.30 %
	Cognitive disability	9	4.21 %	32	3.46 %	41	3.60 %
	Learning disability	4	1.87 %	43	4.64 %	47	4.12 %
	Life stage developmental challenge such as adjustment to marriage, parenthood, work or retirement	11	5.14 %	63	6.80 %	74	6.49 %
	Other (please specify)	26	12.15 %	98	10.58 %	124	10.88 %
	Total		214	100.00 %	926	100.00 %	1140

Table 12: Reason Seeking Care by Court Ordered Status represents people who gave a reason(s) for seeking care. For example, 283 participants reported they sought care for a serious mental health problem, 19% were mandated. Of the 197 people who were seeking treatment for substance abuse/addictions care 31% were mandated.

Project Access Data

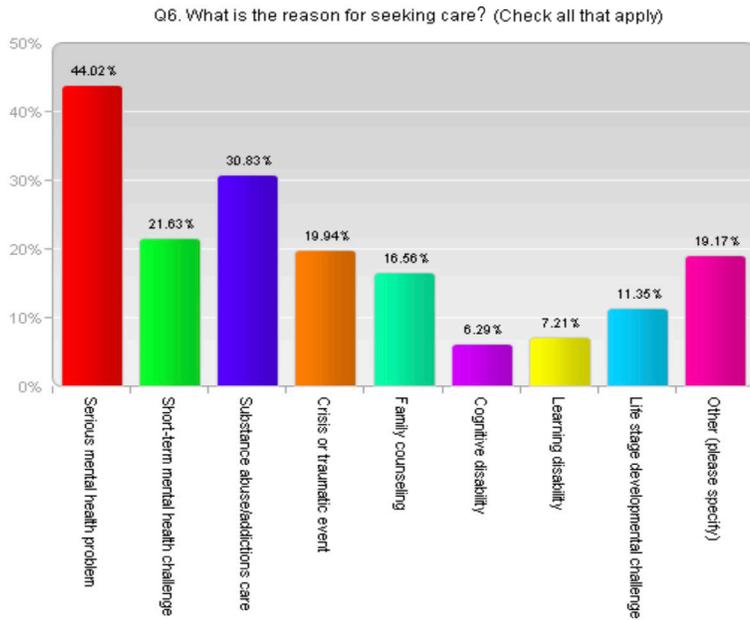


Figure 1: Reported Reason for Seeking Care

Other reasons for seeking care included dealing with chronic pain, eating disorder, housing, trauma, menopause or issues that should fall into the other categories.

Q7. Thinking back to when you first sought services, how many agencies or professionals did you contact before you were able to find treatment for yourself or your loved one?

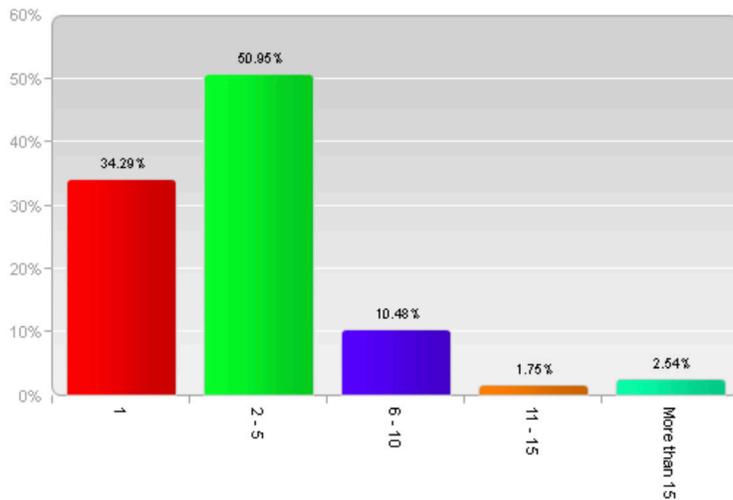


Figure 2: Reported Number of Agencies or Professionals Contacted Before Obtaining Help

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The dataset below (Table 13: Reported Number of Agencies or Professionals Contacted Before Obtaining Help by Reason for Seeking Care) represents how many agencies/professionals were contacted before seeking treatment for their specific reason. For example, of the 277 participants seeking treatment for serious mental health problems, 23% found a provider after 1 contact, 25% after 2-5 attempts, 28% after 6 – 10 attempts, 35% for 11-15 and nearly 24% more than 15 attempts.

Table 13: Reported Number of Agencies or Professionals Contacted Before Obtaining Help by Reason for Seeking Care

Thinking back to when you first sought services, how many agencies or professionals did you contact before you were able to find treatment for yourself or your loved one?													
		1		2 - 5		6 - 10		11 - 15		More than 15		Total	
		Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent	Count	Percent
What is the reason for seeking care (Check all that apply)	Serious mental health problem	81	23.23 %	143	25.09 %	35	28.23 %	7	35.00 %	11	23.91 %	277	25.00 %
	Short-term mental health challenge	53	15.23 %	63	11.05 %	14	11.29 %	3	15.00 %	3	6.52 %	136	12.27 %
	Substance abuse/addictions care	65	18.68 %	95	16.67 %	23	18.55 %	4	20.00 %	2	4.35 %	189	17.06 %
	Crisis or traumatic event	34	9.77 %	70	12.28 %	15	12.10 %	3	15.00 %	6	13.04 %	128	11.55 %
	Family counseling	27	7.76 %	62	10.88 %	10	8.06 %	1	5.00 %	4	8.70 %	104	9.39 %
	Cognitive disability	13	3.74 %	21	3.68 %	3	2.42 %	0	0.00 %	3	6.52 %	40	3.61 %
	Learning disability	10	2.87 %	24	4.21 %	5	4.03 %	0	0.00 %	5	10.87 %	44	3.97 %
	Life stage developmental challenge, such as adjustment to marriage, parenthood, work or retirement	25	7.18 %	32	5.61 %	6	4.84 %	2	10.00 %	7	15.22 %	72	6.50 %
	Other (please specify)	40	11.49 %	60	10.53 %	13	10.48 %	0	0.00 %	5	10.87 %	118	10.65 %
	Total	348	100.00 %	570	100.00 %	124	100.00 %	20	100.00 %	46	100.00 %	1108	100.00 %

Note: Percentages reported are percent responses.

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Table 14: Participants' Feelings about Seeking Care

How did you first feel about seeking mental health or substance abuse/addictions care services (select all that apply)?			
Count	Respondent %	Response %	
160	30.48%	29.47%	Did not feel good about seeking help
291	55.43%	53.59%	Felt really good about going for help
92	17.52%	16.94%	Other
525 Respondents			
543 Responses			

Please note this was not a forced choice so some participants selected more than one option.

The other responses in the dataset above (Table 14: Participants' Feelings about Seeking Care) related to themes such as denial, shame and stigma.

Table 15: Participants' Feelings about Seeking Care by Services Sought

If you did not feel good about seeking help, please tell us why									
		The stigma associated with mental health and/or addictions		Personal indecision		Other (please specify)		Total	
		Count	Percent	Count	Percent	Count	Percent	Count	Percent
Please select the services you were seeking.	Mental health services	70	56.00 %	48	55.17 %	60	54.05 %	178	55.11 %
	Substance abuse/ addictions care	20	16.00 %	16	18.39 %	26	23.42 %	62	19.20 %
	Both	35	28.00 %	23	26.44 %	25	22.52 %	83	25.70 %
	Total	125	100.00 %	87	100.00 %	111	100.00 %	323	100.00 %

Note: Percentages reported are percent responses.

In Table 15, the response "other" reflects themes such as denial, shame, stigma, anxiety, insurance did not pay and felt scared.

Project Access Data

Factors Related to Seeking Help

Table 16: Impediment to Seeking Help - Lack of Transportation

Did any of the following make it difficult to seek help?		
- Lack of transportation		
Count	Percent	
157	24.76%	Yes
477	75.24%	No
634	Respondents	

Table 17: Impediment to Seeking Help - Availability of Treatment Hours

Did any of the following make it difficult to seek help?		
- Hours available for treatment did not meet my needs		
Count	Percent	
148	23.60%	Yes
479	76.40%	No
627	Respondents	

Table 18: Impediment to Seeking Help - Availability of Child Care

Did any of the following make it difficult to seek help?		
- Lack of child care		
Count	Percent	
55	8.93%	Yes
561	91.07%	No
616	Respondents	

Project Access Data

Table 19: Impediment to Seeking Help - Stigma

Did any of the following make it difficult to seek help?		
- Stigma associated with mental health or substance abuse/addictions care		
Count	Percent	
225	36.06%	Yes
399	63.94%	No
624	Respondents	

Table 20: Impediment to Seeking Help - Affordability

Did any of the following make it difficult to seek help?		
- Affordability		
Count	Percent	
243	38.88%	Yes
382	61.12%	No
625	Respondents	

Table 21: Impediment to Seeking Help - Language Barrier

Did any of the following make it difficult to seek help?		
- Language Barriers / Finding a practitioner who speaks your language		
Count	Percent	
29	4.61%	Yes
600	95.39%	No
629	Respondents	

Project Access Data

Table 22: Impediment to Seeking Help - Accessibility

Did any of the following make it difficult to seek help?		
- Accessibility/Handicapped access		
Count	Percent	
36	5.75%	Yes
590	94.25%	No
626		Respondents

Table 23: Impediment to Seeking Help - Participants' Perception of Discrimination

Did any of the following make it difficult to seek help?		
- Discriminated against based on diagnosis		
Count	Percent	
66	10.56%	Yes
559	89.44%	No
625		Respondents

Section Summary: Given the fact that the participants in the current study are a population that likely achieved access to care, when 25% or more of the population experienced an obstacle the finding can be considered very important. For instance stigma (36%), affordability (nearly 39%), choice of providers were limited (39%) and long waiting lists (nearly 25%) are considered important findings indicating impediments to seeking care. Lack of Transportation (24.76%) and availability of treatment hours (23.60%) are widely construed as obstacles. Two areas that require further inquiry relate to language barriers (4.61%) and accessibility (5.75%). Although the percentages of participants perceiving obstacles in each category are minimal, we would need to know the total number of people for whom English is a second language and similarly the total number of people who face accessibility challenges in order to infer any conclusions from the present findings.

Project Access Data

Additional Impediments Related to Seeking Help

For the following questions participants indicated their level of agreement with the following statements on a scale of 1 - 5, in terms of how they reflect their experience seeking services, with 1 representing Strongly Disagree (little to no relevance to their experience) and 5 representing Strongly Agree (extreme relevance to their experience).

Table 24: Impediment to Seeking Help - Discouraged from Seeking Help Due to Insurance

I was discouraged from seeking help because I could not find a provider who would accept my insurance		
Count	Percent	
74	12.48%	Strongly agree
66	11.13%	Agree
117	19.73%	Neither agree nor disagree
64	10.79%	Disagree
272	45.87%	Strongly disagree
593		Respondents

Table 24 indicated that nearly 25% of participants reported they were discouraged from seeking help because they could not find a provider who would accept their insurance.

Project Access Data

Table 25: Impediment to Seeking Help - Personal Indecision

I found a provider pretty quickly but hesitated to follow through because of personal indecision		
Count	Percent	
61	10.37%	Strongly agree
64	10.88%	Agree
124	21.09%	Neither agree nor disagree
92	15.65%	Disagree
247	42.01%	Strongly disagree
588		Respondents

Table 25 above demonstrates that the majority of the participants did not report personal indecision as a factor.

Table 26: Impediment to Seeking Help - Practical Aspects

I found a provider pretty quickly who would accept my insurance but I could not work out certain practical aspects, such as transportation, scheduling		
Count	Percent	
61	10.43%	Strongly agree
60	10.26%	Agree
105	17.95%	Neither agree nor disagree
90	15.38%	Disagree
269	45.98%	Strongly disagree
585		Respondents

Table 26 above demonstrates that the majority of the participants did not report practical aspects as a factor.

Project Access Data

Table 27: Impediment to Seeking Help – Ambivalence about Seeking Help

At first I was looking forward to getting help but after several futile attempts at obtaining services, I started to question whether it was the right thing for me to do		
Count	Percent	
72	12.20%	Strongly agree
70	11.86%	Agree
103	17.46%	Neither agree nor disagree
66	11.19%	Disagree
279	47.29%	Strongly disagree
590		Respondents

Table 27 above indicated that the majority of the participants did not question whether seeking services was the right decision after facing several challenges.

Table 28: Impediment to Seeking Help – Limitations on Insurance Payments

I am currently receiving help but my insurance payments will run out and I cannot afford to continue without support		
Count	Percent	
56	9.56%	Strongly agree
33	5.63%	Agree
95	16.21%	Neither agree nor disagree
66	11.26%	Disagree
336	57.34%	Strongly disagree
586		Respondents

Table 28 above showed that while the majority of the participants disagreed that insurance payment were an impediment to seeking help, nearly 90 people (approximately 16%) did experience difficulty with insurance payment.

Project Access Data

Section Summary: Again, given the fact that the participants in the current study is a population that likely achieved access to care, when nearly 25% of the population of participants identify that particular obstacles to seeking care exist, the findings can be considered very important. For instance, participants could not find a provider that accepted their insurance (23.61%), affordability (nearly 39%), personal indecision (21.25%), and participants reporting that they felt their attempts at accessing help were futile (24.06%) should be considered important findings that reflect additional obstacles individuals experience when seeking care. An area that requires further inquiry relates to affordability (15.19%). Although the percentages of participants perceiving this as an obstacle is minimal compared to some of the other findings, consideration regarding cost barriers for those seeking mental health and or substance abuse/addictions care suggests there is insufficient access to needed care.

Additional Insurance Information

Table 29: Type of Insurance

Please indicate your type of insurance coverage (check all that apply)			
Count	Respondent %	Response %	
377	62.94%	50.20%	Medicaid
152	25.38%	20.24%	Medicare
222	37.06%	29.56%	Private
599	Respondents		
751	Responses		

Project Access Data

Table 30: Copayment Parity

Was the copayment the same for mental health / substance abuse/addictions care as for medical providers (such as cardiologist, pulmonologist, ob/gyn)?		
Count	Percent	
373	70.24%	Same
65	12.24%	Higher
52	9.79%	Lower
41	7.72%	I do not know
531		Respondents

Table 31: Adequate Number of Providers

Did your insurance company have an adequate number of providers for mental health / substance abuse/addictions care services?		
Count	Percent	
342	57.19%	Yes
238	39.80%	No
18	3.01%	I am not sure, I did not check with my insurance company
598		Respondents

Table 32: Insurance Company Support in Search for Provider

Did your insurance company help you in your search for a provider?		
Count	Percent	
202	33.28%	Yes
405	66.72%	No
607		Respondents

Project Access Data

Table 33: Mental Health/Substance Abuse/Addiction Care vs. Physical Health Access to Services

Were mental health/substance abuse/addictions care services more difficult to secure than physical health services?		
Count	Percent	
300	49.92%	Yes
301	50.08%	No
601	Respondents	

Table 34: Length of Time for Participants to Secure Services

How long did it take for you to secure services?		
Count	Percent	
63	10.55%	Same day
144	24.12%	Less than a week
218	36.52%	A week to one month
84	14.07%	Less than two months
55	9.21%	Three to six months
33	5.53%	More than six months
597	Respondents	

Project Access Data

Table 35: Impediment to Seeking Help – Could Not Find a Provider Experienced in Treating Participant’s Diagnosis

I couldn't find a provider experienced in treating my diagnosis		
Count	Percent	
48	8.21%	Strongly agree
37	6.32%	Agree
86	14.70%	Neither agree nor disagree
76	12.99%	Disagree
338	57.78%	Strongly disagree
585	Respondents	

Table 35 above indicated that the majority of the participants did not have a problem finding a provider experienced in treating someone with their diagnosis, but nearly 85 people (nearly 15%) agreed this was difficult.

Section Summary: Again, given the fact that the participants in the current study are a population that likely achieved access to care, there are many barriers highlighted that illustrate the challenges in finding an appropriate provider. In particular, nearly 30% indicated it took more than a month and 15% between 3 - 6 months to secure services. Additionally, 50% said it was more difficult to access mental health/addiction services than physical health services. Nearly 15% reported that they could not find a provider experienced in treating their diagnosis. While the percentage of participants perceiving this as a specific obstacle is minimal compared to some of the other findings, it is prudent to note that these responses are from people who have already interacted with the mental health/substance care system. It may be useful for future studies to explore providers’ level of experience treating various diagnoses related to those in need of mental health and or substance abuse/addictions care, since this may pose an additional barrier for individuals seeking access to needed care.



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