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Innovative Approaches to Increase Engagement in Mental Health Services among Youth Living with HIV

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Learning Objectives



1. To describe innovative mental health (MH) quality improvement initiatives
2. To identify methods for improving accessibility of meaningful MH services by conducting an interest and/or needs assessment with youth and their caregivers
3. To identify strategies for implementing and scaling up successful peer support groups for youth living with HIV

RW Program at Children's National



- Multidisciplinary team-Outpatient Clinic within hospital
 - 4 Physicians
 - 3 Nurse Practitioners
 - 1 Nurse
 - 4 Medical Case Managers (Licensed Social Workers)
 - 2 Psychologists
 - 1 Customer Navigator (Exposed Infants/Mothers)
 - 4 Research and data management staff
- Serving approximately 230 customers (ages 0-24)



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Mental Health, Youth & HIV/AIDS

Mental Health and People Living with HIV/AIDS



- Overall, people living with HIV/AIDS are at higher risk to develop some mental health conditions
 - For example, they are twice as likely to be diagnosed with depression ([Hyperlink for AIDSInfo FactSheet on Mental Health](https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/27/92/hiv-and-mental-health))
- Some etiology of symptoms/behaviors in children and adolescents
 - Managing adherence to medications
 - Disclosure experiences and sequelae
 - Coping with loss (death of parent or loss of relationships)
 - Coping with stigma and discrimination associated with HIV/AIDS
 - Coping with emotions associated HIV/AIDS diagnosis

MH Diagnoses in Children & Youth in the United States



- 1 in 6 children 2–8 years of age (17.4%) had a diagnosed mental, behavioral, or developmental disorder.
- The most commonly diagnosed MH disorders in children are ADHD (9.4%; ages 2-17), behavioral problems (7.4%; ages 3-17), anxiety (7.1%; ages 3-17), and depression (3.2%; ages 3-17).
- Behavioral disorders are typically found in younger children (ages 6-11) than older or younger children

Source: CDC-Data and Statistics on Children's Mental Health
[Hyperlink for CDC Data Sheet on Children and Mental Health
https://www.cdc.gov/childrensmentalhealth/data.html](https://www.cdc.gov/childrensmentalhealth/data.html)

MH Diagnoses in Children & Youth in the United States (cont.)



- Depression and anxiety are more common among older kids and tends to increased with age
- Diagnoses like anxiety and depression tend to co-occur along with behavioral problem
- Among children living below 100% of the federal poverty level, 22% had a mental, behavioral, or developmental diagnosis
- Age and poverty level affected the likelihood of receiving mental health treatment

Source: CDC-Data and Statistics on Children's Mental Health

[Hyperlink for CDC Data Sheet on Children and Mental Health](https://www.cdc.gov/childrensmentalhealth/data.html)

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MH and Youth Living with HIV



- A large cohort study found that 53% HIV-positive adolescents had been diagnosed with psychiatric disorders and 44% had chronic depression (Pao et al., 2000)
- Adolescent Impact Study conducted in three U.S .cities (n=164), 31% of HIV-infected adolescents presented with some psychopathology (Whitely et al., 2014)

MH and Youth Living with HIV (cont.)



- However, approximately one-third of the customers with clinical symptoms did not receive MH care although MH services were available (Whitely et al., 2014)
- Access to MH treatment may be even lower among Black youth living with HIV/AIDS, as they were less likely to receive mental health care than non-black youth (Wood et al., 2009)

Why does Mental Health Care Matter?



- Attendance and engagement during medical appointments
- Impacts adherence to medication—Viral Suppression
- Overall health and wellness –Quality of life

Mental Health Services: Provided during Medical Visits



MH Screening

- Customers ages 4-24 and caregivers
- Conducted annually

Substance Abuse Screening

- Customers ages 12-24
- Conducted annually

Consultations

- Guided by MH Interest Surveys
- Occurs during every clinic visit

Mental Health Consults



Consults

Pill Swallowing
Evaluations & Training

MH Crisis (SI/HI)

Brief Clinic
Interventions

Diagnosis Disclosure

Mental Health Services: Provided Outside of Medical Visits



Therapy

- Individual and target family
- MH check-ins over the phone

Peer Support Group

- Monthly groups
- Two age groups (12-15 and 16-24)

Psychological Testing

- Case by case basis
- Assess changes in cognitive functioning after baseline

Psychiatric evaluations for medication management and collaboration with a specific psychiatrist

Challenges with Engagement



Customers and caregivers frequently decline traditional MH services such as outpatient therapy due to:

- HIV Stigma
- Mental Health Stigma
- Time-Competing obligations and priorities
- Readiness to engage in treatment
- Transportation

Innovations to increase Engagement in MH Services



During medical visits

- Prioritizing MH consults during visits
- Needs assessment to inform on-going clinic consults
- Curating developmentally appropriate brief, evidenced-based interventions
- Consistent follow up for identified needs/interest

Outside of medical visits

- Multidisciplinary team recruitment for peer groups
- Multidisciplinary team involvement in peer groups (nutrition and social work)
- Uber Health transportation
- Virtual peer support groups during COVID-19 pandemic and care packages

COVID-19 Response



- Quick transition to telehealth for existing individual therapy customers
- Targeted in clinic consults to address coping with stress of pandemic (social distancing)
- Suspension of screeners to decrease clinic visit duration-screening tools to converted to electronic format using REDCap

COVID-19 Response (cont.)



- Peer Support Groups transitioned to telehealth platform in April until social distancing restrictions are lifted
- Mental health resources for families and youth have been uploaded to the shared drive for all staff to use with customers
 - 24-7 hotlines and crisis intervention services
 - Resources for parents to explain pandemic to children
 - Home schooling ideas/resources

Staying Connected

- Providing stability during time of crisis (back to the basics)
- Directly addressing COVID-19 (staying abreast of news and cultural and social media trends)
- Targeted coping strategies (including adherence & COVID-19 precautions)
- Maximizing all customer/family touch points



MH Quality Improvement Projects

Needs Assessment Survey

Peer Support Group



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MH Needs Assessment Survey

Mental Health Needs Assessment Survey



Goals:

- Decrease mental health stigma
- Increase parental buy-in and show effectiveness of mental health
- Convey message that mental health is not always therapy
- Provide on the spot, short-term interventions
 - Dynamic and can include a wide range of topics
 - Increase rapport with customer and families
 - Improve overall mental and physical health

Needs Assessment Survey (MH Interest Form)



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Please check the mental health topic(s) you are interested in knowing more about:

- Depression (being sad or irritable)
- Anxiety (worrying too much about things)
- School problems
- Managing Anger
- Managing Stress
- Coping with bullies
- Losing a loved one (grief/bereavement)
- Identity (for example gay, lesbian, questioning, and transgender)
- Managing behavioral problems
- Parent and child relationship problems
- Violence between partners and friends
- Coping with taking medication
- Other: _____
- None

Frequency of Endorsed Topics



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Topic	Frequency per topic (out of 115 responses January to December 2019)
Depression	32/ 27.8%
Anxiety	37/32.2%
School Problems	16/13.9%
Managing Anger	29/25.2%
Managing Stress	29/25.2%
Managing Behavior Problems	11/9.6%
Parent/Child Relationship	15/13.0%
Grief	10/8.7%
Bullying	4/3.5%
Exploring Identity	4/3.5%
Coping with Medication	8/7.0%
Violence	0/0%
Other	6/5.2% (Fears, Mental health in general, Managing time/Study habits , Coping with emotions, Psychology/College Career, Toilet training)

Most Endorsed Topics by Gender



Topic	Male	Female	Transgender
Anxiety	10	23	0
Depression	11	18	1
Managing Anger	12	12	0
Managing Stress	7	19	0

Mental Health Interest Survey Follow-Up



- Out of the 88 people who have endorsed wanting to learn more about a mental health topic from January 2019 to December 2019, 68% have been provided mental health interventions (60 customers).
- Reasons for not providing MH interventions have been:
 - More pressing mental health concerns at later appointments (e.g., safety planning or annual MH screens due)
 - Customer or caregiver no longer need this information because their symptoms have abated
 - Transition to adult care
 - Customer has not returned to clinic since survey

Needs Assessment Survey

- Standard procedure
- Curated mental health kits
 - Binder with ready-to-go materials
 - Handouts
 - Adaptations from CBT Express
 - ✓ Short visual aids
 - ✓ Materials that can serve as reminders
 - ✓ Stories to explain abstract concepts
- Opportunity to also target parent education and provide them with support



Examples of Handouts from MH Kits



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Symptoms of Stress

Stress is one way that our bodies respond to the demands of our lives. A little bit of stress can be healthy—it keeps us alert and productive. However, all too often, we experience too much stress. Too much stress can result in serious physical, emotional, and behavioral symptoms.

Physical	Emotional	Behavioral
<ul style="list-style-type: none">✓ Fatigue✓ Sleep difficulties✓ Stomachache✓ Chest pain✓ Muscle pain and tension✓ Headaches and migraines✓ Indigestion✓ Nausea✓ Increased sweating✓ Weakened immune system✓ Neck and back pain	<ul style="list-style-type: none">✓ Loss of motivation✓ Increased irritability and anger✓ Anxiety✓ Depression or sadness✓ Restlessness✓ Inability to focus✓ Mood instability✓ Decreased sex drive	<ul style="list-style-type: none">✓ Unhealthy eating (over or under eating)✓ Drug or alcohol use✓ Social Withdrawal✓ Nail biting✓ Constant thoughts about stressors

Stress Management Tips

✂ Keep in mind that stress isn't a bad thing.

Stress motivates us to work toward solving our problems. Reframing thoughts to view stress as an acceptable emotion, or as a tool, has been found to reduce many of the negative symptoms associated with it. The goal is to *manage* stress, not to eliminate it.

💬 Talk about your problems, even if they won't be solved.

Talking about your stressors—even if you don't solve them—releases hormones in your body that reduce the negative feelings associated with stress. Time spent talking with friends and loved ones is valuable, even when you have a lot on your plate.

📅 Prioritize your responsibilities.

Focus on completing quick tasks first. Having too many "to-dos" can be stressful, even if none of them are very big. Quickly knocking out the small tasks will clear up your mind to focus on larger responsibilities.

🍏 Focus on the basics.

Stress can start a harmful cycle where basic needs are neglected, which leads to more stress. Make a point to focus on your basic needs, such as eating well, keeping a healthy sleep schedule, exercising, and other forms of self-care.

🧺 Don't put all your eggs in one basket.

People who are overinvolved in one aspect of their life often struggle to deal with stress when that area is threatened. Balance your time and energy between several areas, such as your career, family, friendships, and personal hobbies.

🕒 Set aside time for yourself.

Personal time usually gets moved to the bottom of the list when things get hectic. However, when personal time is neglected, everything else tends to suffer. Set aside time to relax and have fun every day, without interruptions.

🌐 Keep things in perspective.

In the heat of the moment, little problems can feel bigger than they are. Take a step back, and think about how important your stressors are in a broader context. Will they matter in a week? In a year? Writing about your stressors will help you develop a healthier perspective.

Success Story #1



- 19-year old female
- Reporting physical symptoms that she attributed to being on HIV medication
- Medical providers ruled out organic etiology of symptoms
- Mental health provider provided psychoeducation on psychosomatic symptoms
 - Stress symptoms handout
 - Circle your symptoms
 - Engagement in mental health treatment

Success Story #2



- 19-year old male
- Complex medical history
- Behaviorally acquired HIV - diagnosed in 2018
- Provided handout on symptoms of depression
 - Psychoeducation
 - Symptoms
 - Coping skills
- Build rapport
- Next appointment
 - Expressed it had been shocking to realize he felt depressed
 - Decided to engage in mental health treatment
 - Did not need to disclose HIV status within our team

Challenges



- Mental health stigma
- Follow-up appointments are 3 months apart
 - Symptoms might have abated
 - Customers do not remember why they chose symptoms
 - Parent/Child differences
- Short amount of time to complete interventions



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Peer Support Groups

Peer Support Challenges



- Recruitment
- Stigma
- Transportation
- Scheduling

Peer Support Group Recruitment



- During clinic visits (e.g., flyers, conversations by all providers)
- Medical Case Management collaboration (e.g., open house Oct. 2018)
- Nutrition Collaboration (e.g., co-facilitation of groups)
- Uber Health Transportation (e.g., round trip door to door service)

Peer Support Groups (PSG)

- Increased support for medication adherence
- Increase in coping, communication, and disclosure skills
- Increased engagement in overall treatment



(Photo: Making Coping Jars)

Logistics of Peer Support Groups

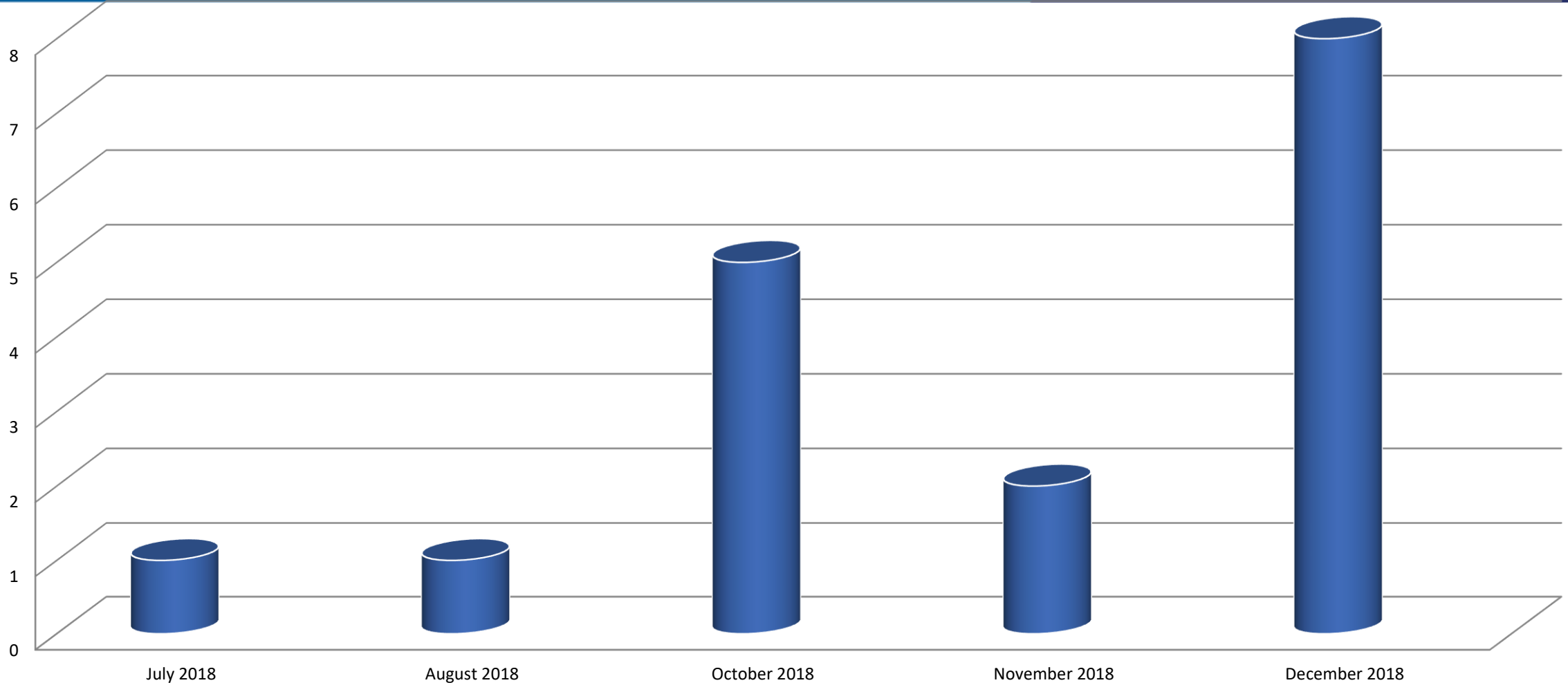


- Recruitment- Open Group (On-going during clinic visits)
- Text Reminders and Phone Calls (several contacts; including the day of...)
- Room scheduling (and set up)
- Scheduling and Coordinating Uber Health rides (watching dashboard for problems with rides, etc.)
- Developing agenda with activities (some coordination with dietician)
- Ordering food and coordinating food delivery
- Activity and food set up/preparation

Peer Support Group Attendance 2018



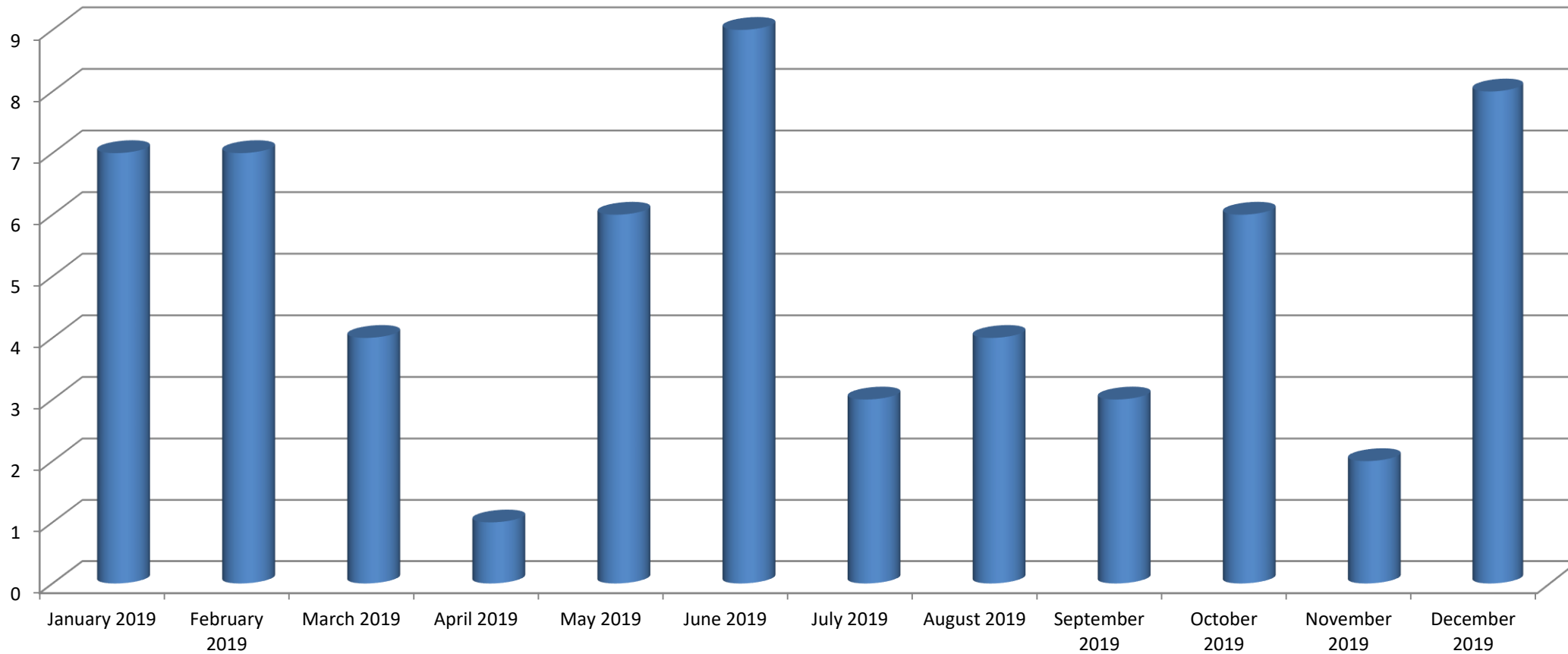
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Peer Support Group Attendance 2019



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Peer Support Group: Agenda



- Group Meeting Time : 6:00-8:00pm (third Thursday of the month)
- Sign-in, Dinner, and Review of Rules
- Icebreaker Interactive Activity (e.g., topic relevant bingo and pass to the left)
- Psycho-education or speaker
- Discussion
- Closing game/activity
- Satisfaction Surveys
- Clean-up and Uber Health scheduling/coordination

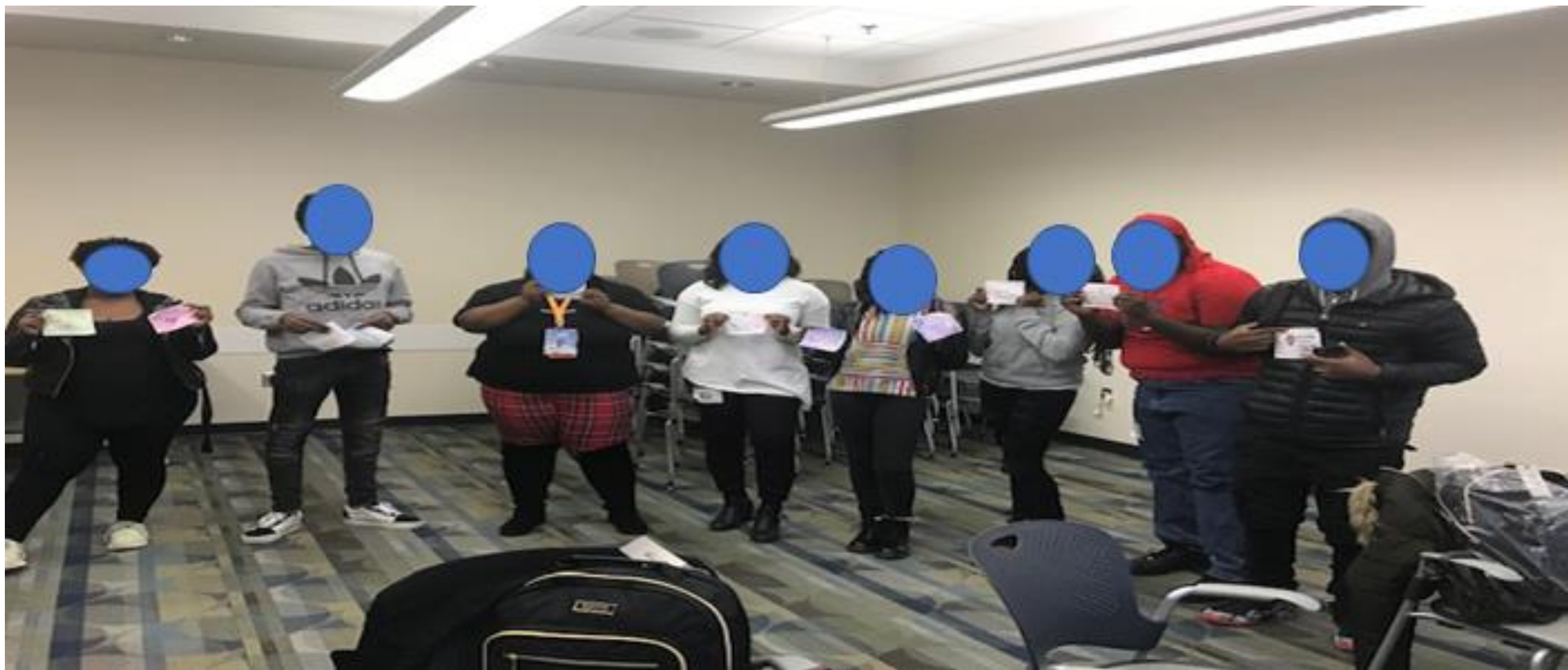
Ugly Christmas Sweater Party



Love Quilt Squares



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Collaboration with Nutrition



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Satisfaction Survey Data

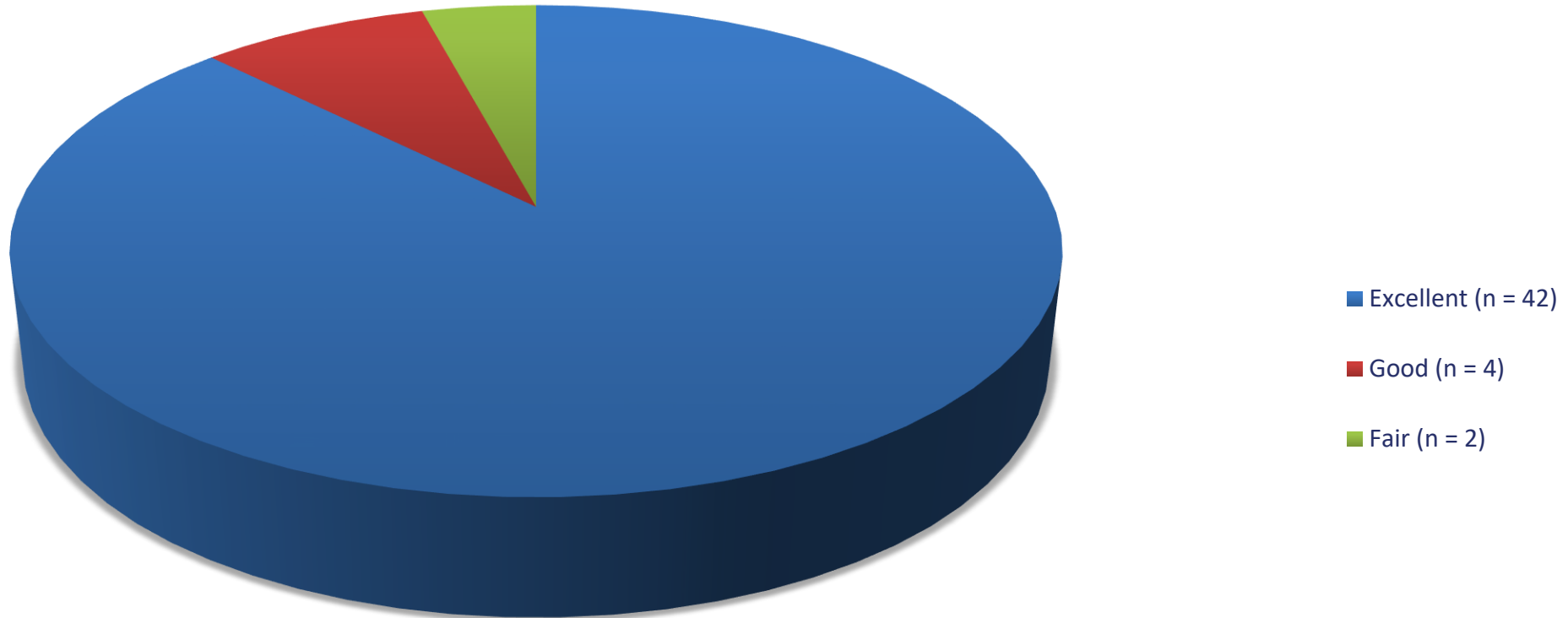
Satisfaction Surveys



1. How would you rate your experience today in group?
2. Tell us at least one thing you liked about your experience in group today.
3. Is there something you did not like about your experience in group today? Yes _____ No _____
If you answered yes, please describe.
4. Please tell us what improvements you think need to be made to improve the group experience. For example, activities, topics discussed, etc.

Question 1: How would you rate your experience today in group?

Overall Experience Ratings



Question 2: Tell us at least one thing you liked about your experience in group.



“Being here for the first time and meeting new people that are just like me”

“I loved how everyone felt comfortable to speak!”

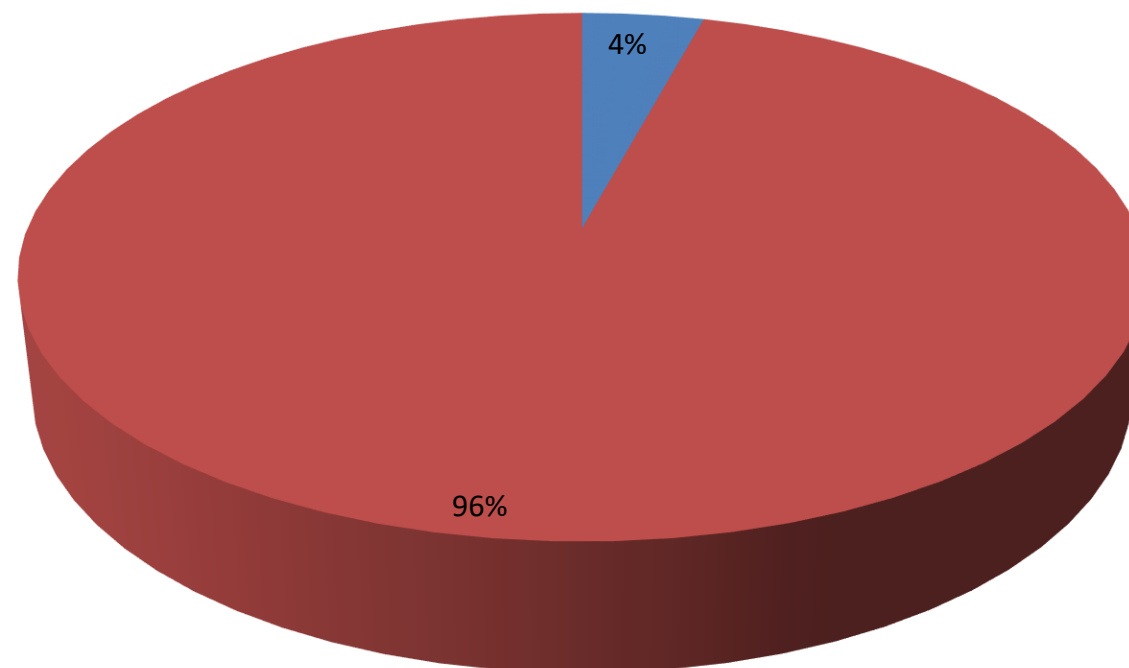
“I felt comfortable speaking and I would like to come back often.”

“Effective Communication, free food, familiar faces.”

Question 3: Is there something you did not like about your experience in group today?



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■ Yes (n = 2)

■ No (n = 46)

Question 3: Is there something you did not like about your experience in group today? (cont.)



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“Yes – I feel like we need more time for group.”

“Yes – We should get gift cards at least once.”

Question 4: Please tell us what improvements you think need to be made to improve the group experience. For example, activities, topics discussed, etc.



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“Longer time to discuss more topics.”

“More games – More gift cards, more prizes. Chipotle!!”

“Bring more people into the group.”

“Nothing I luv the group.”

Super Saturdays Peer Support Group



- Held monthly along with Cooking Class and Parent Advisory Council (PAC)
- Expanded to boys and girls ages 12-15 (somewhat flexible)
- The purpose of the group is to increase support, health knowledge, coping skills, and overall treatment engagement
- Topics include HIV, stigma and discrimination, communication skills, empowerment, and sexual health.
- Social work team will be included to increase team feeling and allow for parenting classes in collaboration with PAC

PSG COVID-19 Response



- Transitioned peer support group (ages 16-24) to telehealth starting in April until social distancing restrictions have been lifted
 - Three virtual peer support groups
 - Focus on coping during pandemic and most recently impacts of racism
 - Adherence
 - Mental Wellness
 - Each participant receives an e-gift card for delivery or carry out

PSG COVID-19 Response (cont.)



- Younger peer support group (ages 12-15) will be suspended-Interim plan includes bimonthly care packages for youth and parents to their homes



“During this time, it is easy to let our minds wander and focus on some of the negatives in our lives. Therefore, we need to actively fight against these unhelpful thoughts and lift our spirits by engaging in soothing activities. Creative activities and art can change your brain in many positive ways. It helps with expression, emotional healing, building empathy, and critical thinking. And let’s be honest, it also helps with boredom! Please use these art tools as you wish. You don’t have to be perfect at art because art can literally be anything! If you would like, I encourage you to choose your favorite creation and bring it to our next meeting to show the others. I hope you are all staying safe and that you know that we are hoping to see you in person very soon. Feel free to reach out to any of us if you need our support. We are here for you! –Dr. Gretchen”

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Questions?

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