

Afiya Peer Respite

*Annual Report
FY '15*

Summary: Although Afiya is technically a separate contract with a separate budget, in practice, it is a part of the Western Massachusetts Recovery Learning Community (RLC). It is a three-bedroom home situated in downtown Northampton at 256 Jackson Street. Afiya's mission is to provide a safe space in which each person can find the balance and support needed to turn what is so often referred to as a 'crisis' into a learning and growth opportunity. It is funded primarily by the Massachusetts Department of Mental Health (DMH).

Afiya officially opened on Saturday, August 4th, 2012 and completed its third year of operation as of June 30th, 2015. It remains as the only peer respite in Massachusetts. In the broader national picture, it is now one of about two dozen respites. Although occasionally we hear of respites closing down, the general trend is on a substantial upswing. New peer respites are set to open in Wisconsin (moving from one fully operational respite house to three), Georgia (from five to six), and so on.

Team Overview: In Afiya's first year, there was no turn over. However, years two and three have offered more complex pictures of growth, change and challenges. Of the original team, the following people remain:

1. Dani, Director
2. Andy, House Coordinator
3. Wyatt, Team Coordinator

Of those who joined in year two, the following people remain:

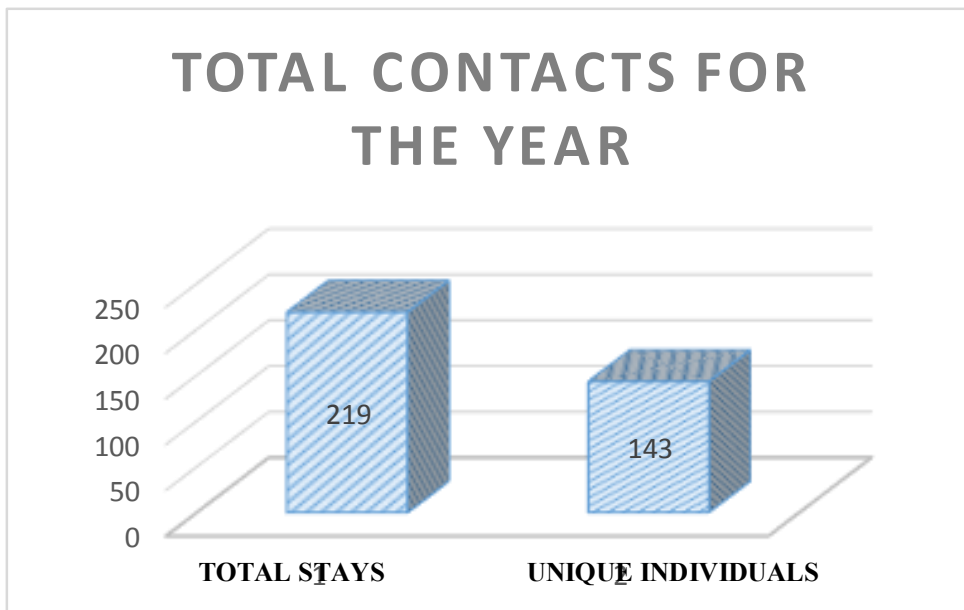
1. Ana, Advocate
2. Ely, Advocate
3. Kim, Advocate
4. Luna, Advocate
5. Ray, Advocate
6. Natan, Advocate

Several team members from the broader RLC also help out at the house periodically including Twan Henry, Sherry Brandford and Earl Miller.

All current team members (as well as most from the broader RLC) have been intensively trained in Intentional Peer Support which includes a 5-day basic training. The three original team members have also been through two additional IPS trainings (crisis and co-supervision). Another 2-day IPS crisis training is currently scheduled for the fall. Wyatt Ferrera is also an IPS trainer, and responsible for orienting all new team members to IPS concepts upon hire.

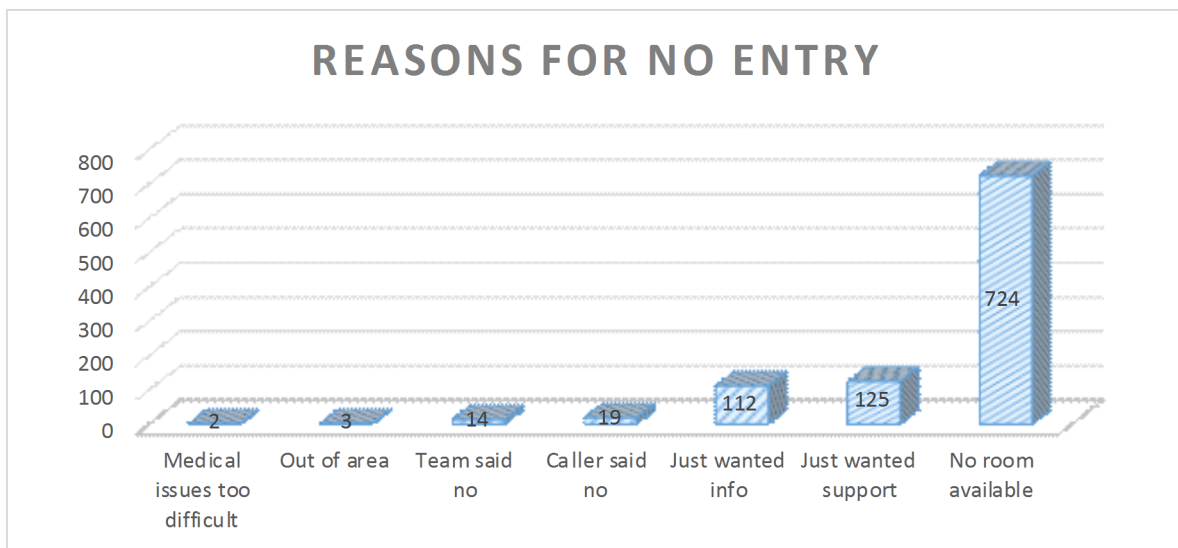
In addition to IPS training, three team members (Ana, Ray, Wyatt) have been through the Massachusetts Certified Peer Specialist training, with Andy Beresky scheduled to attend in the fall. Seven permanent team members have also attended a four-day Hearing Voices Facilitator training (Dani, Andy, Wyatt, Ana, Luna, Ray, Natan), and six have attended the three-day RLC Alternatives to Suicide training (Dani, Wyatt, Ana, Luna, Ray, Natan). Team members also seek out and attend a variety of other trainings and conferences (both to present and learn) whenever possible throughout the year.

Total Contacts for the Year: People have come to stay at Afiya 219 times between July 1, 2014 and June 30, 2015. Of those 219 stays, 143 (65%) represented unique individuals, and 111 (51%) represented individuals who were entirely new to the house (i.e, had not stayed in prior fiscal years either).

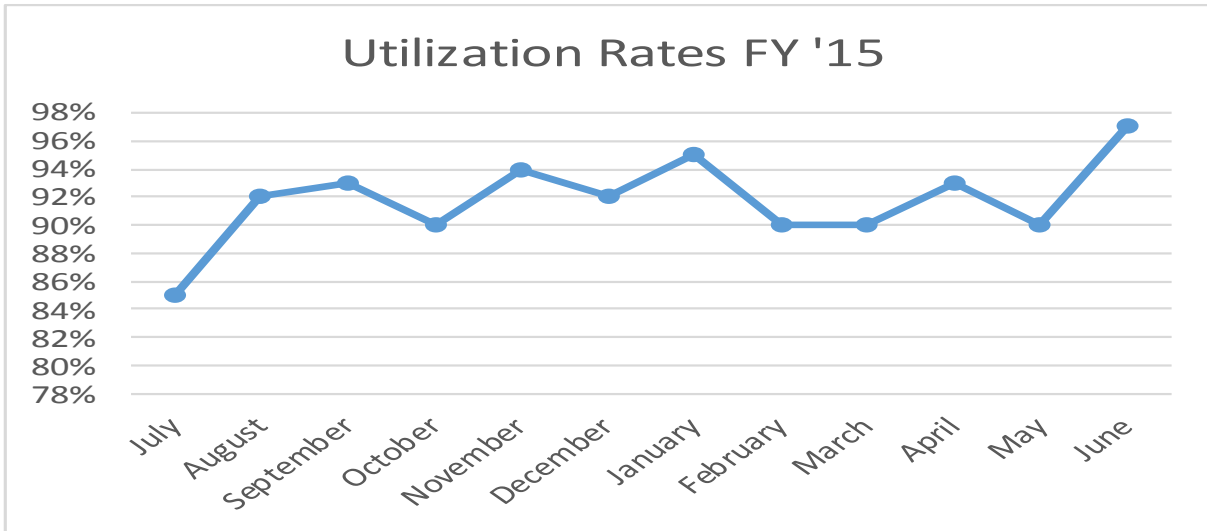


The repeat stays for the year represented 31 people. Of those 31, 12 people stayed a total of two times, 10 people stayed a total of three times, and nine people stayed three or more times throughout the year. Of the people who stayed three or more times, five receive other supports and services through DMH and some have been working on significant shifts in how they make use of those services and supports in their community.

It's also worth noting that the Afiya team fielded over 1218 contacts during this period, many not resulting in a stay at Afiya for a variety of reasons. However, the most common reason remains lack of space available at the house (72%).

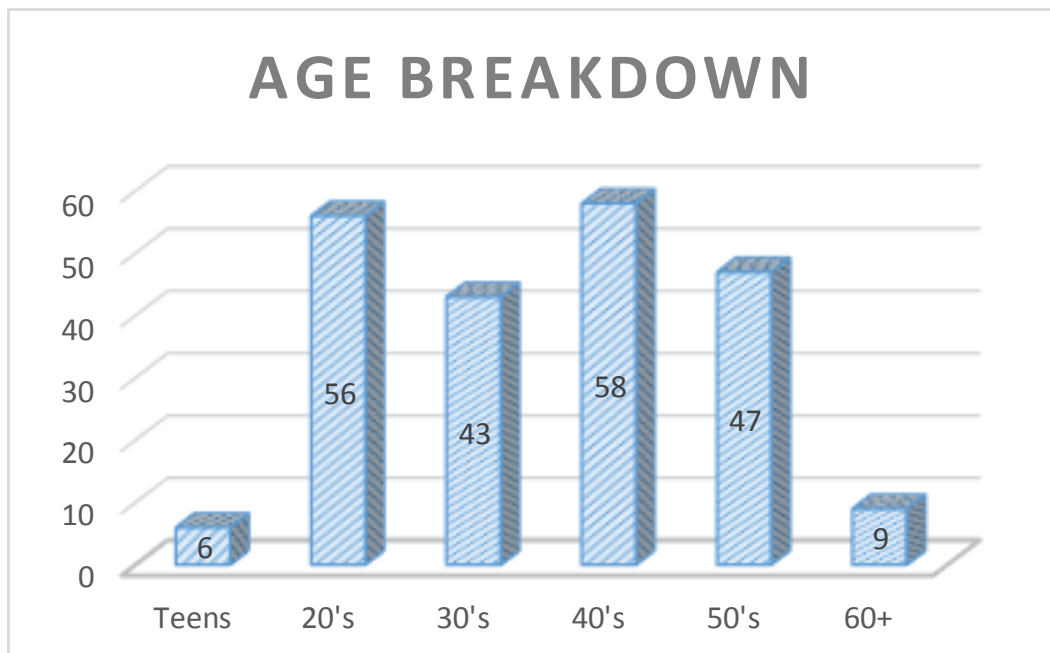


Utilization Rates: Overall, rates were over 90% the vast majority of the time. The lower utilization at the start of the year represents a period after the house had just re-opened following a month-long closure. Missing days in most months can primarily be explained by transition periods as one person leaves and another person is coming in.

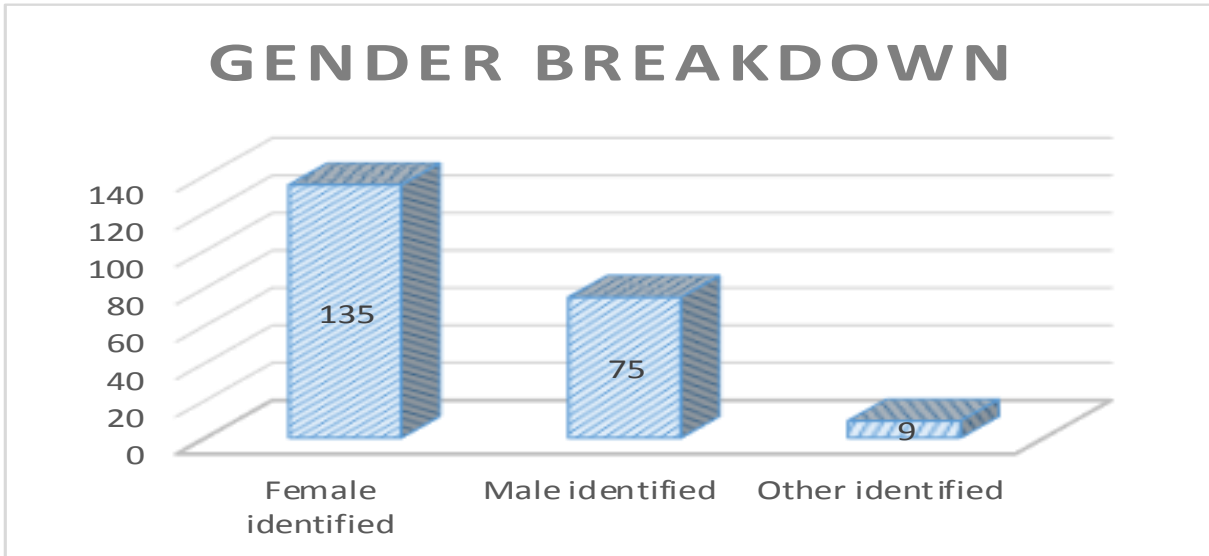


Demographic Breakdowns: Although outreach efforts continue in hopes to further diversify the individuals who are aware and make use of Afiya, people coming to stay are actually fairly diverse in a number of ways.

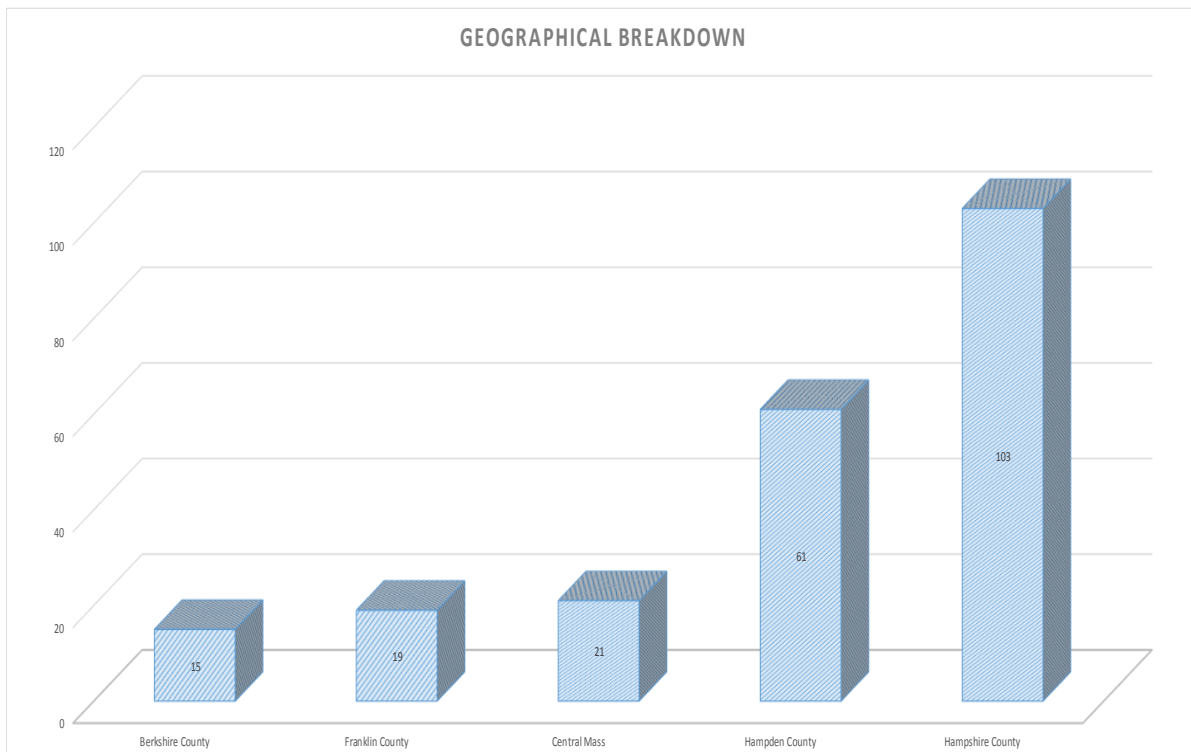
Age: Most people who stayed at Afiya (93%) were between the ages of 20 and 59, with people fairly evenly split between their twenties, thirties, forties, and fifties (although those in their 20's and 40's represented the largest groups). That said, people staying at Afiya throughout the year ranged from 18 to over 60.



Gender: In Afiya’s first year (and particularly in the first six months), many more people who were female identified came to stay at the house than those who were male identified. However, in the second year this was much more balanced. In year three, although there were still a substantial number of male identified individuals, the majority (61%) were female identified, with 4% of people not identifying on a gender binary.



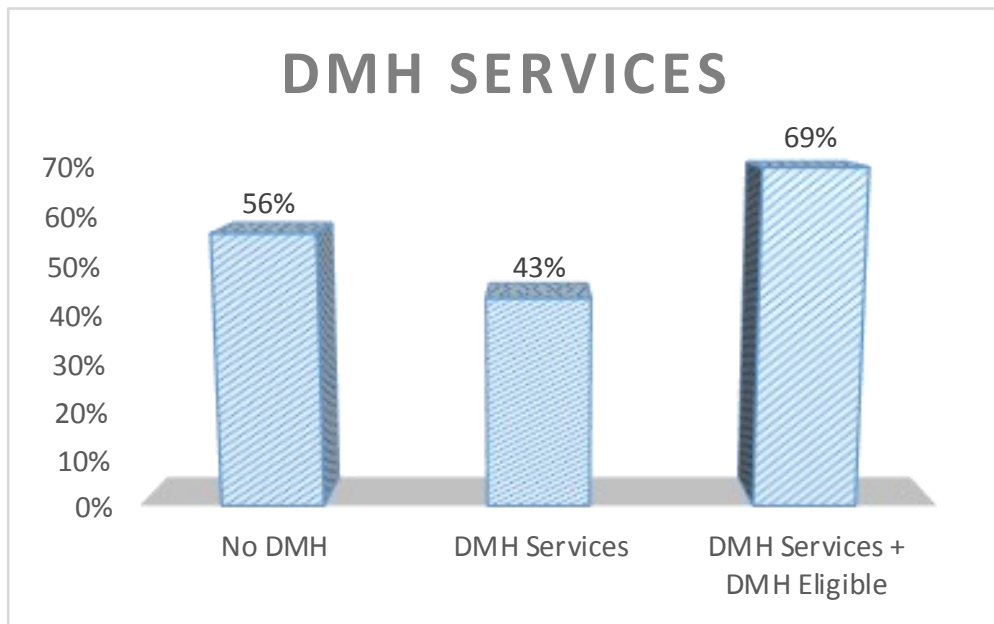
Geography: Similar to the prior two years, most people staying at Afiya also lived in Hampshire County (47%). Year three also continued the trend of an increase in the number of people coming from Hampden County (28%). The Berkshires continued to be the area making least use of Afiya with only 7% of stays representing individuals residing in that part of the region.



DMH Services: When looking at data of individuals who made up the group who stayed at Afiya in this past year, 43% reported receiving some other DMH-funded service ranging from Case Management to Clubhouse membership to Community Based Flexible Supports (CBFS), while 56% said that they did not (and 4% declined to say one way or the other).

Additionally, some individuals who were in the house who did not get counted in the figure for receiving DMH services were in the midst of the application process. In actuality, using statistical projections based on data from the annual survey and actual or risk of multiple psychiatric hospitalizations (as evidenced by at least one past hospitalization and self-reported risk of return) as the

predictor of likely DMH eligibility, an additional 26% of people at the house would likely qualify for DMH services. All told, this brings the likely number of individuals who use or would qualify for DMH services to 69%.



Fidelity to Structure: As noted in last year’s annual report, the overall structure to which we are attempting to maintain fidelity has many components including:

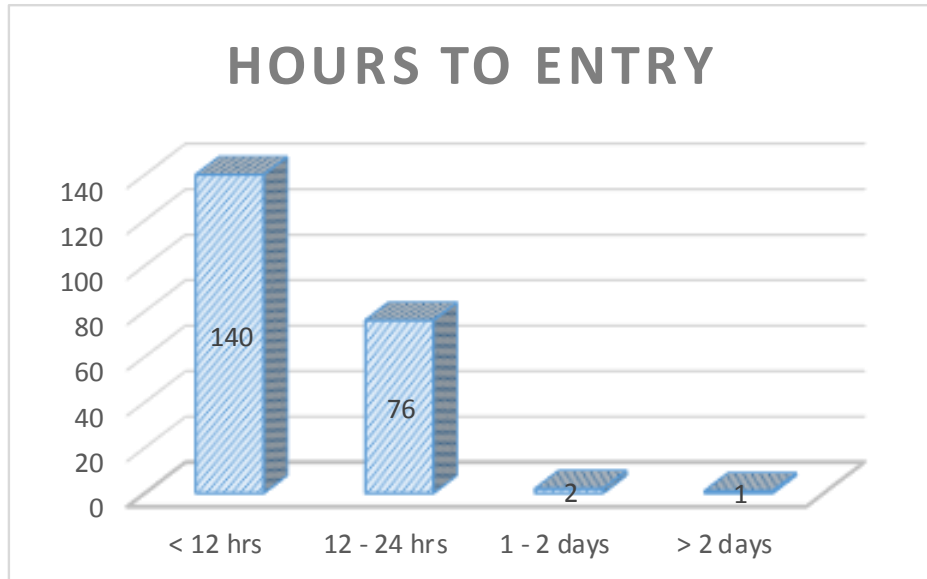
- Being run and facilitated by people who personally identify as having been psychiatrically diagnosed, experienced trauma, hospitalization, etc.
- Being in a completely residential location with no clinical supports
- Not using forced treatment or coercion
- Operating from a values-driven (rather than rules) driven place with no mandatory bed times, curfews, groups, meetings, and so on
- Approaching each person with genuine curiosity and learning about how they have made meaning of their experiences
- Not inquiring about diagnosis, psychiatric history, medications, etc.
- Not speaking for people, even when other providers call seeking information

These qualities require ongoing work and attention, but Afiya continues to have great success with them. Afiya continues to hire only individuals who identify as having their own personal experiences and are deeply invested in the values and approach of the respite. While the team has learned and grown in how they talk about the values and hold people accountable to them, they have not drifted or allowed themselves to fall into a rigidity about rules or ways of doing things that would interfere with the overall nature of the house. Although there are still periodic

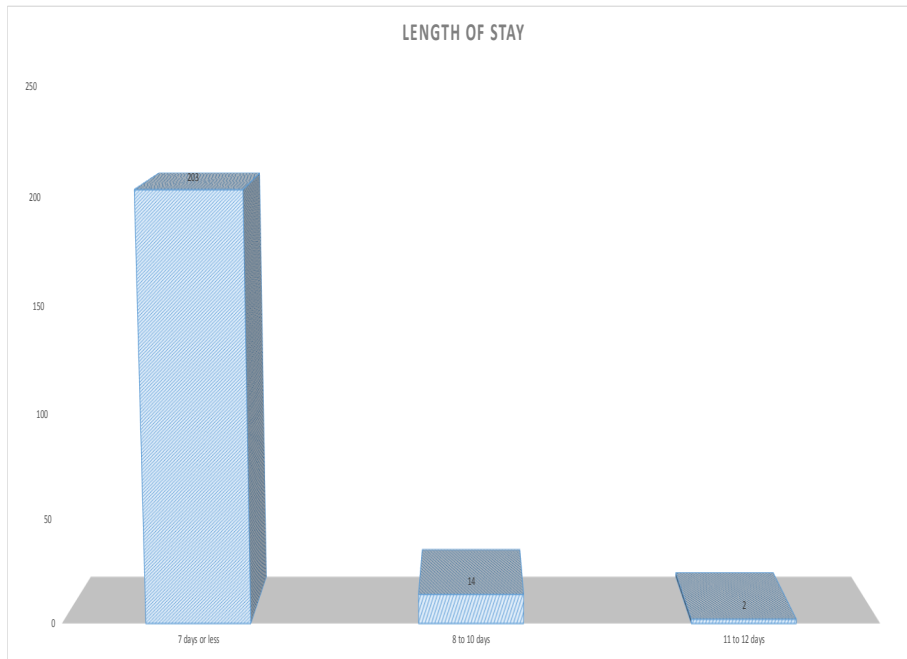
tensions with clinicians who would like us to give them more information about someone staying at the house (or would like to give us details or case files), many more providers now understand our approach.

Another aspect of the Afiya structure to which the team remains attentive is the amount of ‘red tape’ between a person in

distress and entering the house. The vast majority of people (64%) who were a good fit were able to come to stay at the house within 12 hours of being offered a space at the house. Another 35% were able to come into the house in under 24 hours, and only in three instances did it take longer than that. In most situations where it took over 12 hours, the delay was either at the request of the person coming to stay or due to transportation complications involved with getting to the house. (This does not include wait times involved with being on a wait list when the house is full.)



Afiya was also built around a structure that made space for people to come to stay for one to seven days, and expected them to be accountable for taking part in planning their stay in such a way that they were ready to leave at the end of that time. Of the 219 stays in the past year, 203 (93%) of them ended in seven days or less. (In fact, there were several more stays shorter than 7 days than in past years.) 14 of the extensions that occurred were for one to three additional days. Only two stays extended beyond that point to 11 to 12 days.

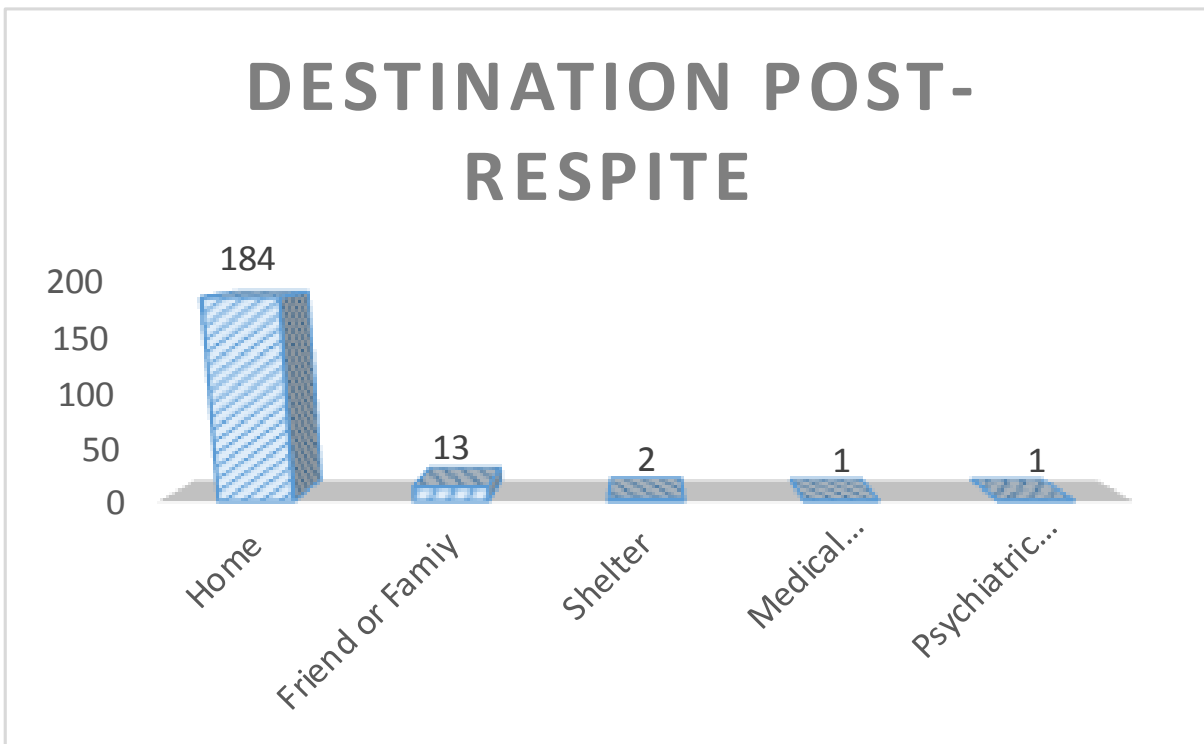


Outcomes: Outcomes continue to be tracked in multiple ways. For fiscal year 2015, outcome tracking methods included:

- Data entry in a collective database
- Completion of ‘Hopes for Stay’ forms by people staying at the house
- Voluntary surveys following departure from the house

We made one significant change in the way that we tracked outcome data this year. Specifically, we separated out our voluntary surveys into two. One survey can be completed directly at the end of the stay and reports on what was useful about the stay and how it compared to stays at more traditional locations. The other survey is sent out at a later date and asks people to speak to how their time at Afiya has (or has not had) longer term impact. The goals and apparent implications of this shift are discussed later on in this report.

Post-Respite Destination: Where someone goes after they leave Afiya is often (though not always) seen as reflective of how they were impacted by their stay. In the past year, the vast majority of people (84%) who were willing to state where they were headed upon departure returned to their own home. Another 6% went to stay with a friend or family (often due to housing issues). An additional two people (1%) went to some variety of shelter (domestic or homeless), and two went to the hospital (one for strictly medical reasons, and another for a combination of medical and psychiatric reasons), three (3%) to a medical hospitalization, and one (.08%) to psychiatric hospitalization. On 16 occasions, people declined to say where they were headed specifically, but they were clearly leaving of their own volition to a community location.



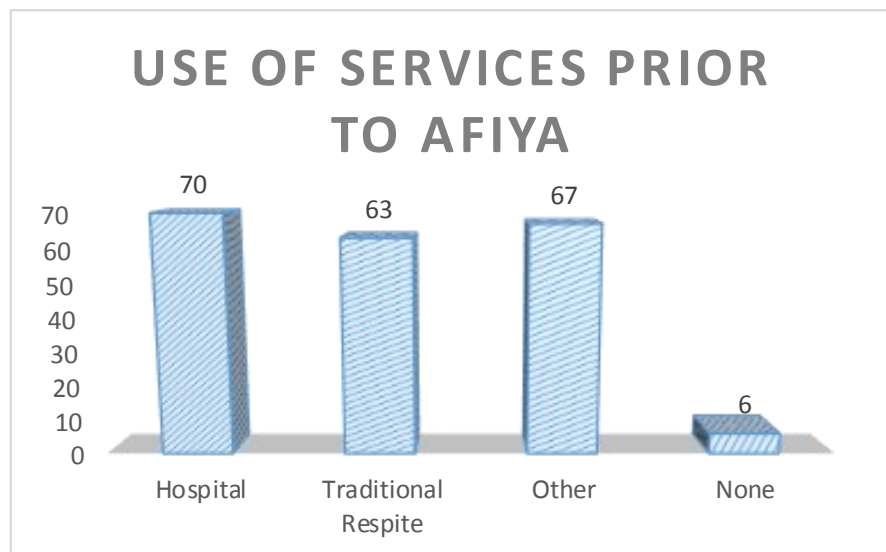
Meeting Goals: Afiya’s make-up is such that there is an intentional avoidance of structured treatment plans or emphasis on setting goals. These are generally seen as interfering in the process of meeting someone where they’re at, and really being able to be present with them as they explore how they want to move through their current distress. However, all people who come to stay at Afiya are asked to fill out a very basic ‘Hopes for Stay’ form soon after they arrive, and some individuals themselves have specific goals they want to work on even beyond that form. On 189 occasions (86%), individuals staying noted that they had met at least one hope for their stay. Of those times when no goal was met, two involved medical or psychiatric hospitalization and several others involved instances when team members had to ask someone to leave early due to the house not seeming to be a good match for them.

Survey Feedback: As aforementioned, each year, we distribute two surveys to people who have stayed at the house. Both are available electronically (through Survey Monkey) and on paper. As aforementioned, we now give the first survey to someone at the end of their stay. The follow-up survey is distributed by mailing people who have stayed hardcopies with self-addressed, stamped envelopes, by e-mailing those who have stayed a link to the on-line survey and by posting the survey in our newsletter, and on the RLC’s Facebook page.

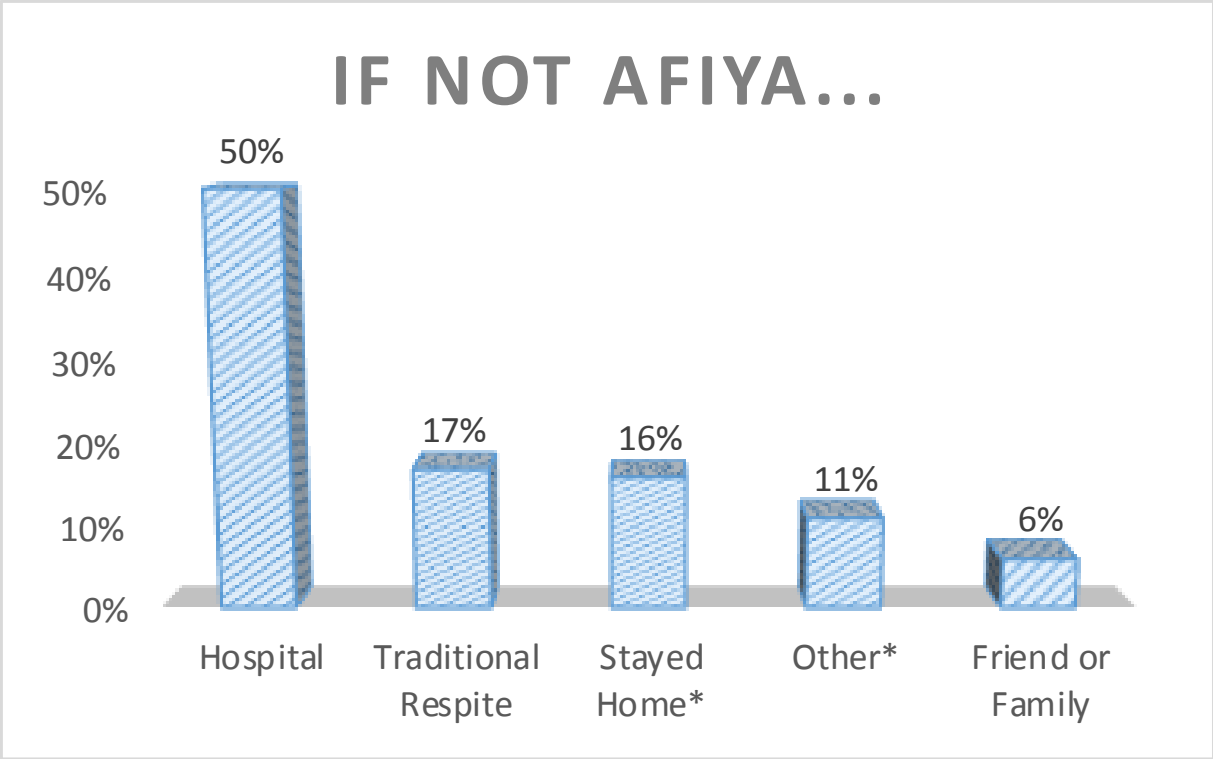
The hope was that this new approach might increase the number of responses received, but overall the percentage of responses is down a bit this year for the initial survey portion. For example, although we received 11 more of the initial survey portion back this year (for a total of 64 responses), that represents only 29% of stays (while last year’s 53 responses represented 37%). The secondary (longer-term outcome) survey response rate was down to 31% (or 44 of 143 unique individuals responding). It is possible that this shift is due, at least in part, to the team’s own adjustment in getting accustomed to provide the initial survey to people at the end of their stay and/or to individuals being confused about how the second survey is different than the first when they receive it later on.

Results:

Prior Service Usage: Of the 64 people who completed the initial survey, 70% reported prior hospitalization, 63% reported prior experience in a traditional crisis respite program, 67% reported using other mental health services and only 6% reported not having used any other mental health-related services prior to Afiya. Of those who reported having used other services, therapy and residential program were named, but the majority did not offer details as to what ‘other’ entailed.



If Not Afiya: The most common response to where someone would have gone if Afiya were not available was to the hospital (50%). Several others (17%) said they would have gone to a clinical respite. Four (6%) said they could have stayed with family or a friend. Ten (16%) said they would have stayed home, and seven (11%) offered other responses that ranged from “I don’t know” to “die”. Also of note, several of the people who said they would have ‘stayed home’, cited bad experiences in the traditional system as a reason they would have continued to avoid going to a clinical setting. Some of these same people also said they would not be alive today if not for the availability of Afiya. See the comments below for more details.



A selection of responses to: If Afiya had not been available, what would you have done instead?

“Be on the street.”

“I would not have lived to get to Afiya without the peer support line, and I would not have survived this week without this incredible resource. As a psych survivor, I have no willingness to ever go to a hospital again and be told the answer to a crisis stemming from abuse in my life is abuse and human rights deprivation in an institution.”

“I would die over re-entering a hospital after the severity of abuse I’ve experienced. With that trauma, it’s hard to trust any type of even radical support, but I’m so glad I finally made the call.”

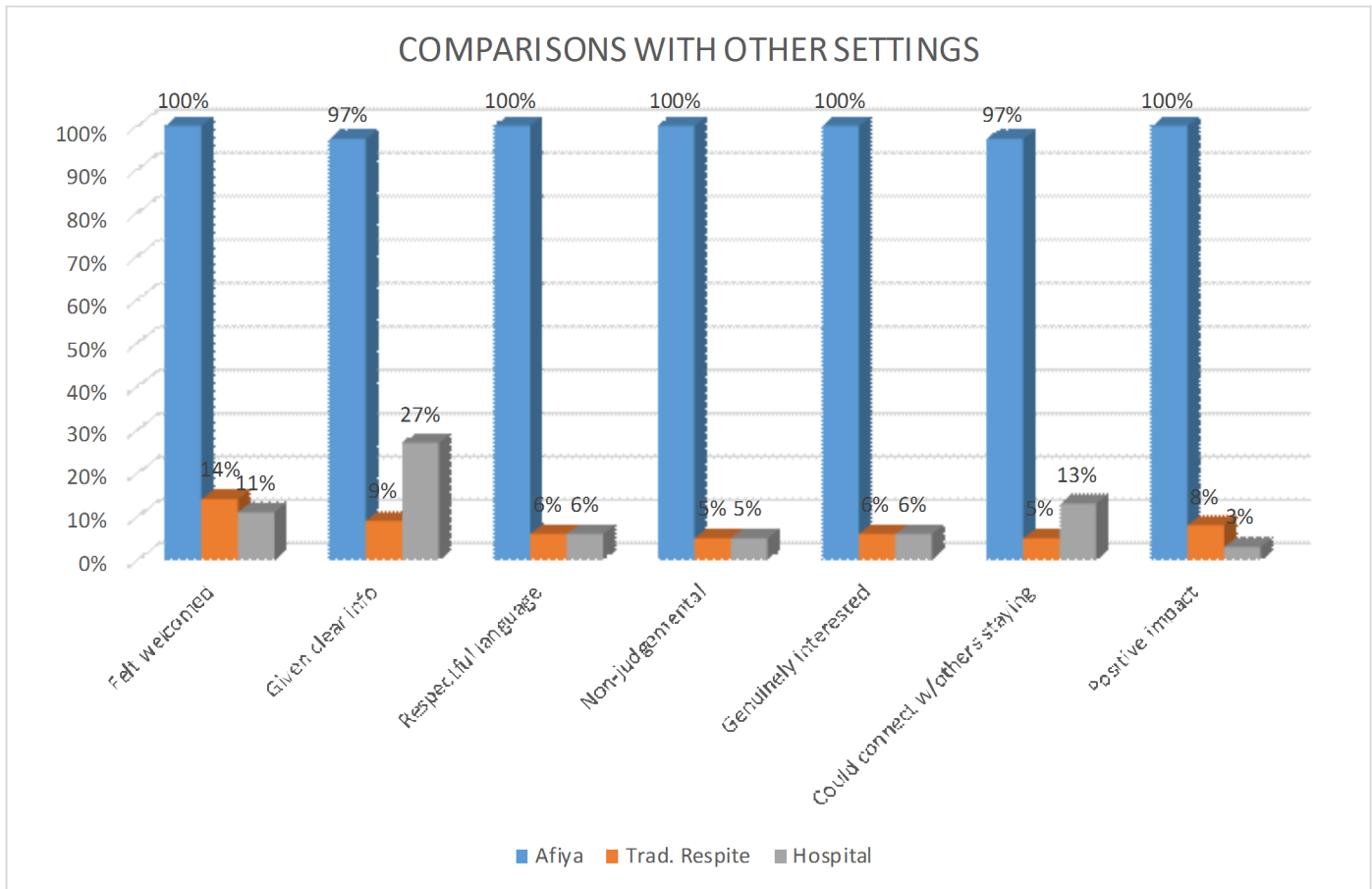
“I will never again utilize a hospital or traditional services after repeated abuse. If Afiya wasn’t available, I wouldn’t have another option, and that is life threatening.”

“I’d be dead without Afiya.”

Comparisons with Other Settings: People responding to the survey were also asked to compare Afiya to other settings; Namely, to hospitals and clinical (traditional) respites. In one section of the survey, they were asked to say in which of the settings (Afiya, Clinical Respite, or hospital) they experienced the following:

- I felt welcomed when I entered this setting
- I was given clear explanations and information about the space and supports available.
- People working there consistently used respectful, recovery-oriented language.
- People working there treated me non-judgmentally.
- People working there were genuinely interested in learning more about me and my perspectives, fears, challenges, hopes, wants and dreams.
- There was opportunity for me to connect with and engage in mutual support with others who were staying in the space, not just those working there.
- My state there had a positive impact on my life.

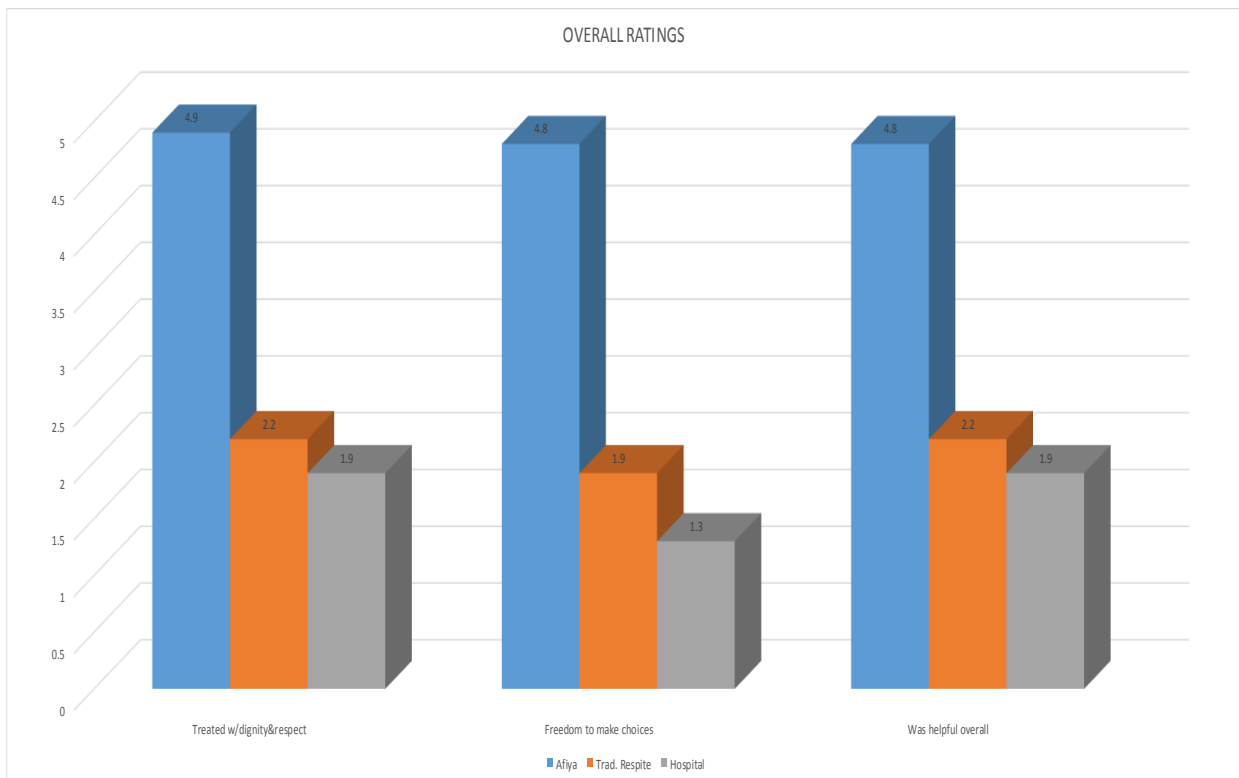
Although nobody scored ‘perfect’, there was a substantial difference in how people reported their experiences between the three settings. In all areas, Afiya scored at least 3 times higher than both hospitals and clinical respites.



People were also asked to rank the following statements based on how true they were for each environment:

- Overall, I was treated with great dignity and respect in this space.
- Overall, I had a lot of freedom to make choices and really be myself.
- Overall, my stay at this location was helpful, and I left feeling better than I arrived.

Again, no one scored perfectly, but Afiya continued to stand out. Interestingly, responses based on the above criteria were often more closely scored between hospital and clinical respite than one might expect (although this is consistent with last year’s results, as well).



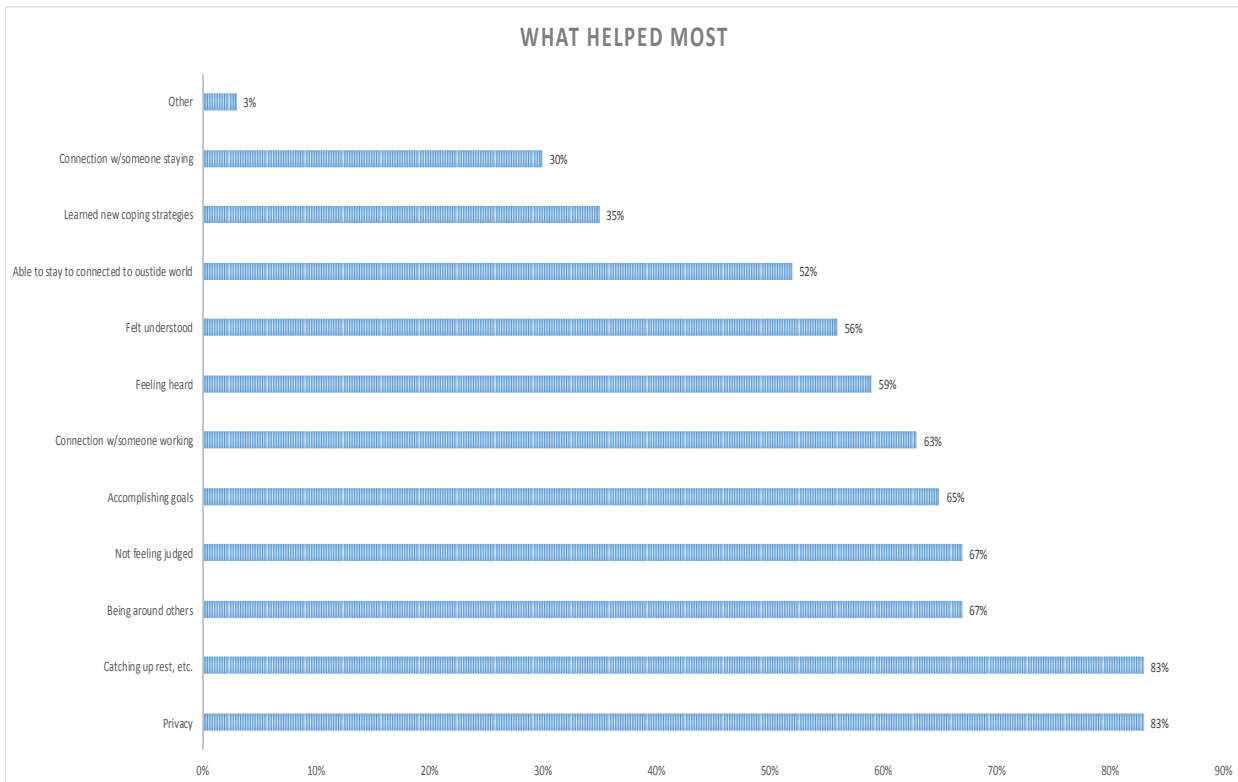
What helped the most: Respondents were also asked to name what elements of Afiya were most helpful during their stay. Elements listed included:

- Just being around others
- My connection with someone WORKING at Afiya
- My connection with someone else STAYING at Afiya
- I had privacy
- I felt understood
- I felt heard
- I didn’t feel judged
- I learned new tools / coping strategies
- I was able to accomplish specific goals
- I was able to catch up on sleeping / eating /taking care of myself
- I had freedom to stay connected to work / school / friends / etc. while getting extra support

Respondents could check as many elements as applied. The top five results were as follows:

- #1: Having privacy and the opportunity catch up on sleep/eating/taking care of self (Tied)
- #2: Just being around people and not feeling judged (Tied)
- #3: Accomplishing specific goals
- #4: Connection with someone working at the house
- #5: Feeling heard

A few people also wrote in other answers including the skill of the team overall, and access to the library of books available at the house.



Would You Return?: At the end of the first survey, people were also asked specifically whether or not they would again choose Afiya over hospital or other support options. An overwhelming majority (98%) said they would. When asked their reasons for this choice, some respondents shared the following:

“This service was life saving.”

“It's a great environment. People here are helpful. You're not forced to do anything. You can pace your communication. You don't feel trapped.”

“The staff at Afiya is beyond amazing. Also, out of the very many places I have stayed, Afiya is by far the most welcoming and comfortable.”

“I appreciated having my autonomy and privacy which I probably would not have had in a more traditional setting.”

“It is so different to be in a place like this than a hospital.”

“Getting to take care of myself and have support saved my life.”

“Definitely. It's a no judgement zone. Allows people to be themselves while giving them space to work on their individual programs and goals. Always available, accessible for just about everything.”

“I was supported to be me, but in a healthier, happier way.”

“Being here made a huge difference in my life.”

“Hard to imagine going somewhere else if this is available.”

“Everywhere else, they have rules about when you can sleep or be in your room, and what else they want you to do. Getting to design all that based on what I actually needed in the moment made a huge difference.”

“Having my own room means a lot.”

“No one made any assumptions about me, who I was, or why I was there. I'm so tired of people thinking they know who I am, and telling me what I should be doing to get better.”

“No labels given, no clinical records, no preconceptions based on the above. I also appreciated the absence of a clinical/mental illness-label-biased mentality among Afiya workers.”

The individual who said they weren't sure if they would return indicated that sometimes more structured environments are helpful to them.

Areas of Change: In the second survey, people were asked to specifically focus on what areas of their life have changed for the better since their stay at Afiya. The areas of possible change listed on the survey included:

- Housing
- Mental/Emotional/Spiritual Health
- Eating Habits
- Recovery Substance Use
- Physical Health
- Relationships
- Sleep Habits
- Setting Personal Goals
- Coping Skills/Tools
- Self-Advocacy
- Less Contact with Police

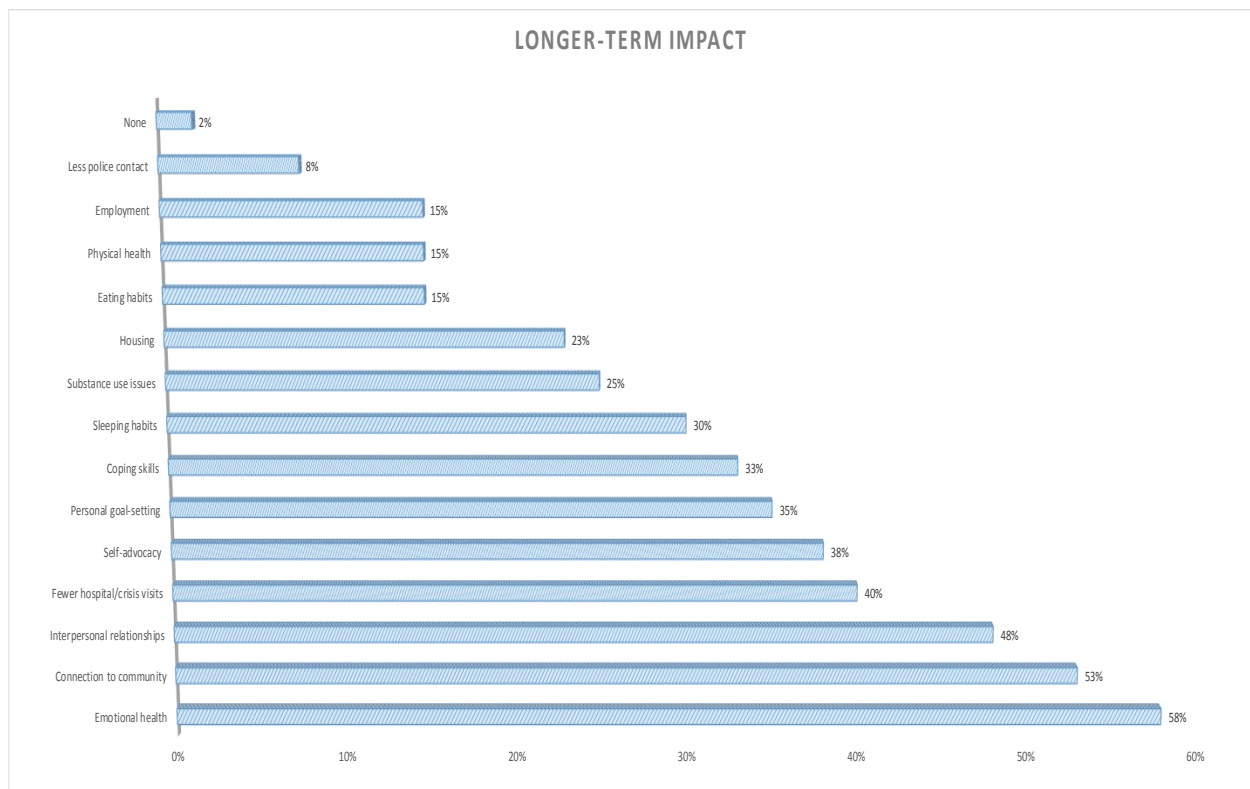
Individuals were encouraged to check as many areas as applied. Of the 40 people who answered this question, only 2 (5%) said there hadn't been any longer-term positive change in their life since their stay at the house.

Specific responses are detailed on the following page.

The top five areas named by respondents were as follows:

- #1: Overall emotional health (58%)
- #2: Connection to a broader community (53%)
- #3: Relationships (48%)
- #4: Fewer hospitalizations and/or crisis visits (40%)
- #5: Self-advocacy (38%)

Setting personal goals, which had been in the top 5 the year prior, came in as number six this time round with 35% of people saying they were impacted in this way. This (along with the fact that ‘accomplishing specific goals’ was noted as one of the most helpful aspects of people’s stay in the initial survey) continues to be of interest because Afiya (and the Western Mass Recovery Learning Community as a whole) is so intentional in not pushing routine ‘goal setting’ or ‘treatment planning’ as a part of their process.



The survey also asked respondents to indicate whether or not they thought the positive changes were, in any way, related to their stay at Afiya. 90% of individuals felt their was a connection. Some of their comments included:

“It helped me bounce back from some really terrible times in my life.”

“This has introduced me to a big community of people like me.”

“I still attend one of the groups they connected me to every week.”

“Being at Afiya allowed me to re-set a lot of things in my life.”

“Being a part of this community - just knowing it’s there - makes a big difference, even when I’m not using it.”

“I got a lot out of just learning to speak for myself.”

“I learned a lot from people working there. There was one team member in particular who had been through a lot of the same things as me and was really helpful.”

“I had room to get some important things done that have had long term effect on my well being.”

“I was really struggling with my job, eating issues, spiritual issues, sexual orientation and hearing voices. Afiya gave me a stable, non-medical, peer support approach and environment that utilized Intentional Peer Support in an extremely professional manner. My time at Afiya was invaluable to me and helped me make sense of and quiet the voices, as well as lower the anxiety and psychotic symptoms I was facing. It also greatly helped with wanting to self-harm. My stay at Afiya definitely helped me keep my employment.”

“My friendships have improved through my ability to have more supports other than just them and better ways to express boundaries and state needs.”

“I found my current job while at Afiya and got a better idea of what it would entail. My relationship with my suicidal thoughts has changed drastically. They can just be, and are not the end of the world. Also seeing my experiences in the mental health system in a new frame work and as part of social justice movement have made me feel less fundamentally flawed.”

“I am now part of the RLC community where I can talk about all my experiences and they have value. I can be my weird special self and be liked reasonably well, which is a strange and beautiful experience. I have a new purpose and meaning in my life. I don't know what the future holds but I feel good about where I am now.”

“Afiya gave me an escape from a hostile alcoholic environment to allow me time to set in place a suitable living situation. Without the supportive staff at Afiya I would have probably landed back in the hospital and on more meds as my only recourse.”

“During my stay I reassessed my job and living situation and now have a new job and a new apartment. Afiya was a fulcrum for change.”

“The house gave me the space to uncover how my relationships, housing, and employment were impacting my wellbeing.”

Areas for Improvement: People were also given a chance to say what they didn’t like about the house. Those who responded included feedback on the following:

- Noise issues (loud television, hearing people talking/moving around a lot, etc.)
- More support planning for what to do after someone leaves Afiya (one respondent felt that there wasn’t enough discussion to help them plan out next steps)
- More ‘check ins’ (a couple of people noted that, while they appreciated the freedom in the environment, they sometimes found it hard to initiate conversations or say when they weren’t ‘okay’ and thought team members should more regularly approach people to ask in some way)

Interestingly, a couple of people also said that they wished for more direct support around goals and particular issues. This runs a bit contrary to the general results that suggest people are feeling they can accomplish a number of goals in an environment that offers so much space and flexibility. Ultimately, this may speak to the fact that that space and lack of force and artificial focus is helpful, but that some people still really would benefit from more focused check ins that help them think through what they need or want to do next.

A few people also suggested that there should be more flexibility in length of stay, although it's worth noting that we saw a trend toward shorter stays this year on the whole. However, by far, the most common complaint (30% of respondents) was that it is difficult to get into Afiya due to the house regularly being full and having no space available.

Although wait times are out of the Afiya team's control, they have already begun to work on addressing some of the other concerns. Specifically, in regards to noise, we moved the television on the first floor from the living room (right at the center of the house) to a side room that only shares a wall with the kitchen. The hope in doing this was also that it might help facilitate more opportunities to connect directly (or less distraction away from doing so), thus also potentially addressing concerns about not enough 'check ins'.

Narrative Comments: Both surveys offered an opportunity at the end to leave narrative comments as desired. Here is some of what was offered:

"Making connections at Afiya made me feel accepted and cared for."

"I felt as though I thrived and was able to use the resources available which helped meet some of my overall goals I had when I arrived. I had no idea how much I would accomplish while I was here and also how empowered it would make me feel. Thank you!"

"Unable to express in words my gratitude."

"Staff members were respectful and shared stories of mutual healing which really affected me positively."

"I am deeply grateful to all who listened and used their skills and education to help me in an extremely difficult situation."

"I'm so grateful that this place is in our backyard and so well run and fragrance free (non toxic) so that it's physically safe for me. If this was cloned across the country so that everybody had local access ,we'd be a nation of shiny, happy people!"

"Afiya worked for me because it overtly follows its own core values. They are actively followed, and it was conceived by people who understand the meandering nature of the recovery process."

"I do not know where I would be without Intentional Peer Support, Afiya and the Western Mass RLC. Thank you so much for all you do."

"Connecting to people who had lived through similar things and could sit with me in the pain from the vantage point of mutuality has been and continues to be life saving. I may not be alive today if Afiya didn't exist."

Challenges & Lessons Learned: Year three has continued to bring many challenges and rewards. Although we hear and see for ourselves the great impact staying at Afiya can have on peoples' lives, we are also acutely aware that there are still so many people who get missed.

As noted in the feedback we received on our surveys, it is hard to get into the house. There are nine psychiatric units based in Western Massachusetts with dozens of 'beds' in between them, but only three bedrooms at Afiya (open not only to Western Mass, but also Central). While a primary intent of the house is to support people to avoid hospitalization, it is extremely difficult to do that when there is commonly a wait period to get in of up to a week. More than once over the last year, we have learned of people who have tried to hang on for our wait list before going to the hospital, but have been unable to hold out and have ended up in the hospital. This has been very painful for both the team and those who end up hospitalized.

We have also been challenged by the number of people in our community who are struggling with housing, and/or who identify as being on the LGBTQ+ spectrum (and have been through a great deal of trauma as a result) and who are experiencing deep feelings of hopelessness. It has been very difficult for us to support people in these places without having the resources necessary to create new housing, or address the broader mental health system's lack of resources available to individuals who are transgender, and so on.

On one occasion during this past year, these sorts of issues did lead to a suicide attempt that took place at the house (the first serious suicide attempt in the house's three years of existence). Fortunately, the team was able to pull together and support not only this individual, but each other through the experience, and come out stronger on the other end. It was also particularly helpful during this time that Afiya is connected to the broader RLC, as people on the bridging team (who work in hospitals to support people to transition back to community) were able to connect with the person while they were in the hospital, and there are many other ways they've been able to stay connected with the community beyond that, as well.

Budget also continues to be a challenge over the years. The long shifts and intensity of time spent with people in deep distress takes its toll, and we are not able to pay the house Advocates at an adequate rate to ensure longevity. Budget also makes it difficult to have adequate double coverage. Two people are available at the house most days only between 2pm and 8pm, which can make long days even more tiring (particularly when both people in the house and people calling in to stay want your attention). Finally, the budget impacts the team's ability to meet regularly. Currently, the team is only able to afford to meet once per month. This is particularly difficult for maintaining a sense of team in a job where people are already often working on their own.

On a positive note, we have continued to be an active part of the national (and even international) peer respite community, and are frequently told we are seen as a leader in the type of work that we do. In December of 2014, Sera Davidow (Director of the RLC) and Dani (Director of Afiya) were invited to present on Afiya in Denmark. The house has also continued to attract visitors from across the country and beyond, as well. Also, toward the end of the year, the RLC started a collaboration with Intentional Peer Support, Inc. to develop a handbook on peer respites. It is anticipated that the book will be finished by the summer of 2016.