

The background of the entire page is a vibrant, abstract collage. It features thick, expressive brushstrokes in shades of red, orange, blue, and green. Interspersed with these are patterns of white and black, including a prominent white grid or lattice structure in the lower half. The overall effect is one of dynamic energy and artistic expression.

# Peer Respite Handbook:

## A Guide to Understanding, Building and Supporting Peer Respite

*Created by the Western Mass Recovery Learning Community  
in Collaboration with Intentional Peer Support*

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# PREFACE

The idea of peer respite has taken off, particularly in the United States, where new programs seem to be popping up nearly every month. It's wonderful when a new idea begins to make its way into common knowledge and practice. However, there's also tremendous risk at this stage.

The risk comes from trying to capture the idea before it is fully understood, or when there's more investment in outward appearance than in fully implementing a new effort in a genuine way. This handbook was developed to build understanding and support replication to increase access, and to do so in a way that safeguards the integrity of the essential elements of the peer respite vision.

This handbook has been written from the framework of systems in the United States of America. The authors of this handbook are connected to Afiya Peer Respite in Massachusetts, which is frequently used as a frame of reference. This was not done to exclude other perspectives, and we reached out to others for input as a part of the process. This handbook will be available as an online document that we can amend with new developments, and we will also create a forum for others to share their ideas and experiences. Whatever its limitations may be, we nonetheless believe that you will find much of the content to be widely applicable.

Readers may notice that this book uses primarily what grammar books will tell you are third person plural pronouns (they, their, them). This is not an error. It is done in recognition that many humans do not live within a gender binary system, and to use only 'he' and 'she' excludes them. So much of our work is about supporting people to find their own path and define their own lives and stories. We do not wish to take some piece of that away from anyone by failing to recognize the diversity we know to exist in gender identity.

We would also like to recognize the many people that contributed to bringing this book to life. A special thanks to Chris Hansen and Shery Mead for their fire and passion to see this project through, to Darby Penney for her editorial and librarian-like wisdom, to Andrea Alexis and Ana Keck for their wonderful artists' eyes, to Laysha Ostrow for her years of commitment to researching peer support and sharing her knowledge, to Opeyemi Parham for expanding our minds and understanding of diversity and multiculturalism, and to Second Story peer respite for going the extra mile to share what they've learned along their own journey



# What is a Peer Respite?



# MISSION OF A PEER RESPITE

There are several different ways that people have come to commonly describe the mission of peer respite. These include:

- **As hospital diversion:** A primary aim of peer respite is to support people through difficult times while avoiding hospitalization and other invasive and life-disrupting interventions. This may include supporting someone who has frequently been in and out of the hospital to break that cycle. For some peer respites, it includes supporting someone through a first experience and helping them avoid ever getting into a cycle of hospitalization in the first place.

While part of the motivation of hospital diversion is saving the community money, another reason is that hospitalization, especially when involuntary, can be experienced as traumatizing. Even when voluntarily chosen, hospitals can be unnecessarily restrictive or disruptive to someone's life in ways that are not helpful. For example, even a relatively brief hospitalization can impact someone's work or school, leave pets unfed, and bills arriving in the mail unable to be accessed. The option of peer respite, on the other hand, brings to life the promise of 'least restrictive' environments, and allows for people to determine for themselves where they stay.

- **As an opportunity to turn crisis into learning:** In general, people are taught that "crisis" is bad, and that the focus should be to get out of "crisis" and then avoid it in the future. Peer respites typically accept that humans can learn as much (if not more) when life is difficult than they can when everything's great. Therefore, a primary goal when someone stays at a peer respite is to support them in exploring how they've come to walk through the world in the way that they do, and how that is or is not working for them. That may include examining how they make meaning of their life experiences, how they define healing or "recovery," and what they do or do not want to change moving forward. It also means not assuming that experiences like hearing voices and self-injury are "symptoms" to be gotten rid of, but that they may be potentially meaningful ways of coping that could teach us a lot about what is going on for the person in that moment.



*Photo credit: Sera Davidow*

- **As a non-clinical alternative focused on peer-to-peer supports:** Some people who stay at a peer respite also regularly use clinical services. Others feel alienated from those services or have never used them and are trying to avoid doing so. Either way, the focus at a peer respite is on non-clinical peer-to-peer support, and the mission is based on the idea that there is great power and wisdom to be found in shared experiences between people who have all “been there.” Peer respites try to come from a place of mutuality, meaning that it’s assumed that everyone—regardless of their specific role – has the potential to learn and grow and contribute based on their connection with others, and that no one person is the “fixer” or “holder” of all knowledge.
- **As an opportunity to address issues related to social justice and marginalization:** Although this is not often where the conversation of peer respite begins, it’s important to mention right from the start. People with psychiatric diagnoses, people who are poor and limited to using public sector services, non-white folks and so many others who have experienced routine marginalization often lack any kind of choice at all regarding when, how, or where they seek support. Often, these consequences of racism, poverty, and ableism (etc.) have been traumatic themselves, and played a fundamental role in creating or adding to a person’s initial distress. As peer respites are rooted in choice and self-determination, they have the potential to become a part of a much broader network of change, but that requires awareness, intention and openness to ongoing learning from day one.

Ultimately, a peer respite combines these four concepts (and more) to create a space with the mission of supporting people who are struggling to learn from their experiences, grow, and stay connected to their worlds, based on the shared wisdom gained from their own lives and that of others who have faced similar challenges.

# HISTORY OF PEER RESPITE

The history of peer respite is not clearly documented in any one place, but one thing is clear: Advocacy for peer respites has come from human rights and self-help movements, and has largely been driven by people who have been harmed by, or had their rights violated by, existing systems. Although successful efforts to get new respites up and running often involves partnership with a variety of people and funders, it's important to remember those roots to help remind us why the design and values are so important.

Many agree that the Crisis Hostel in Ithaca, New York was one of the earliest steps toward creating a peer-supported environment that served as an alternative to hospitalization. Although not truly a peer respite (not everyone who worked at the Hostel identified as having personal experience with psychiatric diagnosis, trauma or other life-interrupting struggles), this early attempt received publicity in the New York Times in 1993 just as it was about to open.<sup>1</sup> Although it's difficult to find information about the Hostel, since it no longer exists, it is mentioned in a number of places, including the book *Alternatives Beyond Psychiatry*, edited by Peter Stastny and Peter Lehmann, as well as in an article that speaks to some of its outcomes.<sup>2</sup>

In 1997, the first official peer respite, Stepping Stone, was developed by Shery Mead and friends in Claremont, New Hampshire. Stepping Stone was considered a fully peer-run respite (meaning everyone working there identified as having personal experience with psychiatric diagnosis, trauma or other significant life challenges and it was not under the umbrella of a clinical organization). Rose House was the next fully peer-run respite, opening in 2001 in Poughkeepsie, New York. Additional peer respites opened after that, including the Georgia Peer Respites in 2008.

Meanwhile, the creation of “hybrid” peer respites (respites where everyone employed identified as having personal experience, but existed within the context of a clinical organization) were also underway. Sweetser in Maine was one of the first in 2002. Second Story was another hybrid peer respite that followed several years later in Santa Cruz, California. Some of these respites still exist, some have changed or evolved into other organizations, and some have closed.

Including full peer-run respites and hybrids (both in the United States and beyond), the number of peer respites in existence is changing nearly monthly.<sup>4</sup>

<sup>1</sup> *Crisis Hostel article viewable here* : <http://nyti.ms/2CAaCi4>

<sup>2</sup> *Crisis Hostel outcomes*: [www.hsri.org/files/uploads/publications/ot-03.pdf](http://www.hsri.org/files/uploads/publications/ot-03.pdf)

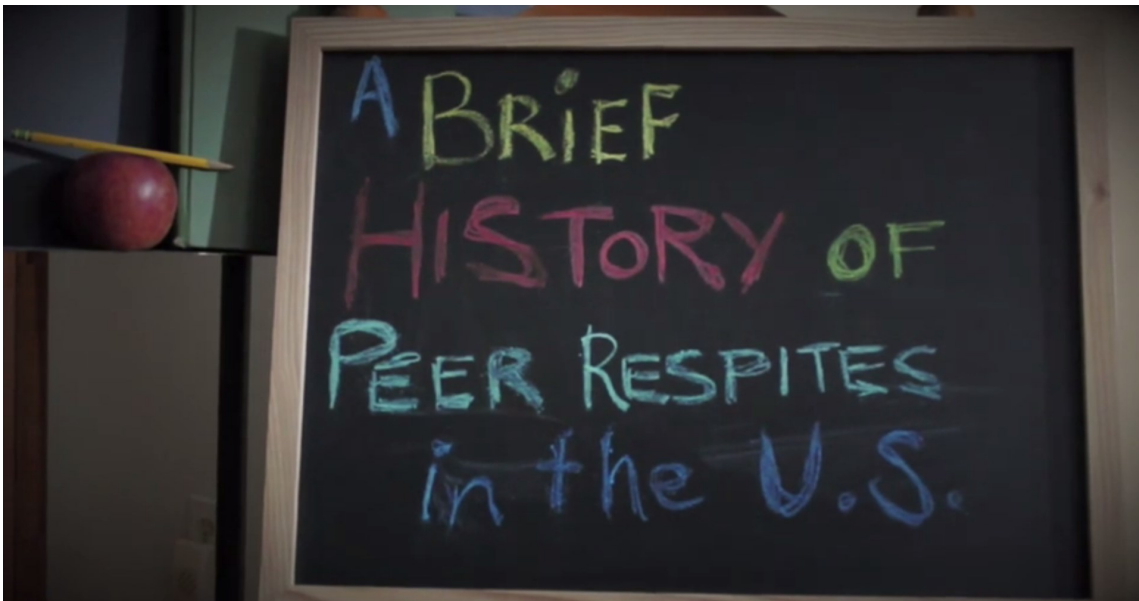
<sup>3</sup> *Stepping Stone Peer Respite*: [www.steppingstonenextstep.org](http://www.steppingstonenextstep.org)

<sup>4</sup> *Up-to-date listings of peer respites in the United States*: [www.power2u.org/peer-run-crisis-services.html](http://www.power2u.org/peer-run-crisis-services.html)

Further variations on peer-to-peer crisis alternatives have developed. For example, around 2013, New York City incorporated several peer-integrated respite houses (see the respite charter in the 'Framework of a Peer Respite' section for a description of what this entails) into a program called Parachute. Although this model didn't require leadership to identify as having personal experience, (which disqualifies the model from being considered a peer respite), the majority of employees were required to have psychiatric histories as one of their qualifications.

Additionally, a couple of peer-support-oriented models that fall just short of offering bedrooms and a place to go and stay have also surfaced. The most well-publicized version of this is called the Living Room model. The Living Room started as a hybrid peer respite in Arizona. It morphed into a new approach that is open 24 hours a day and offers peer support (although under clinical oversight, and with clinicians on-call as needed). It isn't intended as a place to stay, but rather a place where someone can drop in for support at any time with the goal of avoiding hospitalization. This model is now spreading across the country.<sup>5,6</sup>

Similar to the Living Room is Safe Harbor, based in Omaha, Nebraska. This fully peer-supported alternative offers people a place to go for 24 hours or less as a crisis alternative. Like the Living Room, it does not offer bedrooms, but has recliners where people can rest. Like all the supports mentioned, it is founded on the value of peer-to-peer support and the belief that people are often able to move through difficult places without needing to be pulled out of their lives and into a hospital.



<sup>5</sup> Article about the Living Room: <http://bit.ly/2CoQphB>

<sup>6</sup> A super quick video on the history of peer respites in the US: <http://bit.ly/2CqyG9o>

# FRAMEWORK OF A PEER RESPITE

Efforts to define peer respite have been underway for several years. In 2014, at a Mind Freedom Conference in Litchfield, Connecticut, a group representing at least five states who were following the peer respite track began developing a "charter." Charters are often effective ways of delineating the framework of a particular approach, while leaving room for the day-to-day details to vary and develop based on local needs and wants. <sup>1</sup>

The Peer Respite Charter builds on the work accomplished at that conference, as well as on national surveys, and feedback from the National Peer Leader Network (a US-based group of individuals with peer respite leadership experience). It is intended as a working document that can be periodically updated and made stronger as individuals have the opportunity to contribute.

While the charter continues the trend of categorizing peer respites into different types (fully peer-run, hybrid, and peer-integrated), this should not be seen as a statement of any particular respite's potential impact or worth. Peer respites will likely differ substantially from one another even within each of the three stated categories. Individuals who stay at a respite may find that factors beyond those listed in the charter are most important to their own experience (e.g., quality and training of employees,).

This document is an effort to protect the overall intent of the approach and prevent it from drifting, in order to preserve the core integrity of the peer respite concept. The charter is designed to support the idea of transparency. It is important to this movement and to healing the oppression and marginalization that many of us have experienced through voicelessness in the system for there to be transparency about who is in leadership. Whose voice are we truly hearing? People who've experienced trauma and psychiatric diagnosis and received services in the system? People in clinical roles? Both? We don't necessarily need to eliminate any mix of those options, but we do need to do our best to be upfront about who is in leadership roles.

## **Section I: Characteristics of All Peer Respites:**

1. All people in paid roles at the respite, including all those who are in direct leadership, identify as having personal experience with life-interrupting emotional distress and other significant life challenges and are willing to share some of that experience with others as a part of their work.
2. The respite's philosophy is rooted in the idea that crisis can be a learning opportunity.
3. Emphasis is placed on values and personal responsibility rather than on assessment and risk.

<sup>1</sup> Example of a similar sort of charter: [www.hearingvoicesusa.org/hvn-usa-charter](http://www.hearingvoicesusa.org/hvn-usa-charter)

4. The respite's philosophy is rooted in values such as self-determination, mutuality and the belief that healing and growth are possible for all.
5. The respite's design and approach are rooted in an awareness of the impact of trauma, including trauma experienced due to systemic oppression related to race, gender, sexual orientation, etc., and the practice of creating healing and accessible spaces that do not replicate these issues.
6. "Illness" is not assumed and a wide variety of ways of making meaning of distress and various unusual or difficult experiences are welcomed and may be openly discussed.
7. Routine person-specific paperwork is minimal and, where it exists, led largely by the individual seeking support.
8. Individuals working or volunteering at the respite are supported (through training, team work, co-reflection, etc.) to come from a peer-to-peer perspective.
9. Language used by people working or volunteering in the respite, and on any related paperwork, is non-clinical, everyday language that is inclusive and leaves space for a variety of perspectives.
10. There is no routine focus on psychiatric diagnosis, and it is only discussed when meaningful to a particular person or conversation.
11. There is an openness to discuss any and all healing paths and no one path (including psychiatric medications) is assumed to be the right or wrong one for any particular person.
12. People staying at the respite are supported to keep connected or get connected to their chosen family, friends and/or any providers/supporters *as they desire*.
13. There are no restrictions on coming and going freely from the respite, with the exception of limitations on how long someone can be gone from the respite before they lose their spot.
14. There is no required schedule of groups, bed/wake times, etc., and individuals staying at the respite take the lead in designing their stay in the way that will be most helpful to them.
15. There is openness to the idea that what often gets called a "symptom" (e.g., self-injury, etc.) can be a way of coping with or adapting to difficult life experiences.
16. Avoiding the use of force (calling emergency services or police against someone's will, etc.) is a priority, and there's a process in place for internal review and learning should force ever be used.
17. There is an emphasis on not talking about people without them present, even when releases have been signed legally enabling someone working at the respite to do so.
18. Tasks that are likely to create or enhance power imbalances, such as handling medications or Money, are avoided.
19. "Staff only" areas are minimized or eliminated altogether.

## Section II: Characteristics of Fully Peer-Run Respite:

In order to qualify as a “full peer respite,” the following terms must be met, in addition to all the peer respite characteristics listed in Section I:

1. Functions independently or as a part of a larger *non-clinical* organization.
2. Exists in a house, apartment or other homelike space, and not in a medical building or other structure that is simultaneously being used for clinical or other purposes that would represent a potential conflict with the mission of the respite.
3. The design of the organizational Board of Directors and any other advisory boards includes a commitment to having a majority of appointees who have personal experience with psychiatric diagnosis, trauma, addictions, homelessness, and other significant life challenges.
4. There is no requirement that someone be receiving any other particular services (at a particular agency, through a department of Mental Health, etc.) in order to access the respite.
5. There is no formal clinical involvement, including no clinical assessments required in order to access the respite.

## Section III: Characteristics of Hybrid Peer Respite:

Hybrid Peer Respite have all the qualities and characteristics listed in Section I, but do not meet one or more of the characteristics listed in Section II.

## Section IV: Characteristics of Peer-Integrated Respite:

Peer-Integrated respite are not technically “peer respite.” However, they may nonetheless meet all the qualities listed in section I, with the following exception:

While most people employed to work at the respite identify openly as having personal experience with psychiatric diagnosis, trauma, etc., the design does not require people in leadership roles (and possibly others) to have and/or share personal experiences themselves.





## **Piece by Piece:**

Because “peer respite” is still a relatively new concept and some of the concepts in the charter may feel new or confusing, we offer the reasoning behind each point below:

### **Section I: Characteristics of All Peer Respites:**

- 1. All people in paid roles at the respite (including all those in direct leadership) identify as having personal experience with life-interrupting emotional distress and other significant life challenges and are willing to share some of that experience with others as a part of their work.**

Although the support that happens in a peer respite is based on much more than simple commonalities in experience, that foundation can be a strong one, and can change the tone and direction of a connection. In order for that to be true, it’s important that someone both identifies as having personal experience and is willing to speak to some of it. Without that second part, the first part loses much of its meaning.

- 2. The respite’s philosophy is rooted in the idea that “crisis” can be a learning opportunity.**

Historically, within the system, many have regarded “crisis” as something coming out of nowhere as the result of a medical illness. However, for many people, the experience of “crisis” has meaning. It can signify that something in one’s life isn’t working, that they’re feeling overwhelmed, that they’re feeling disconnected or stuck, and so on. When supported to look for that meaning, and to think through how to learn from and move through it, the course of one’s life can be changed in invaluable ways.

- 3. Emphasis is placed on values and personal responsibility rather than on assessment and risk.**

So much of the mental health system is still defined by fear and assessment of risk. Getting stuck in that perspective can lead people in provider roles to take over responsibility and control of someone’s life in a variety of ways (medications, money, living situations, etc.). Although the initial intent may be to keep someone “safe,” the unintended and long-term outcome can be that that person feels disempowered and begins to see themselves as incapable of being in charge of their life in any meaningful way.

Peer respites, on the other hand, focus on values rather than rules, believing that even an adult who is in great distress is capable of taking personal responsibility for themselves and their end of any relationships in the respite. Similarly, the intent in peer respite is to support people to make their own meaning, rather than being assessed and having meaning put on them. This is not only because people know themselves best, but also because taking responsibility for making meaning of one’s own life is often a step in the direction of feeling empowered to make the choices and changes needed to go on living.

This process isn't always easy, and can feel scary for everyone involved, as it is a frank acknowledgement that no one has easy answers to many of the intensely difficult things people are experiencing. Yet, it's still a step forward that is important in the healing process for many people.

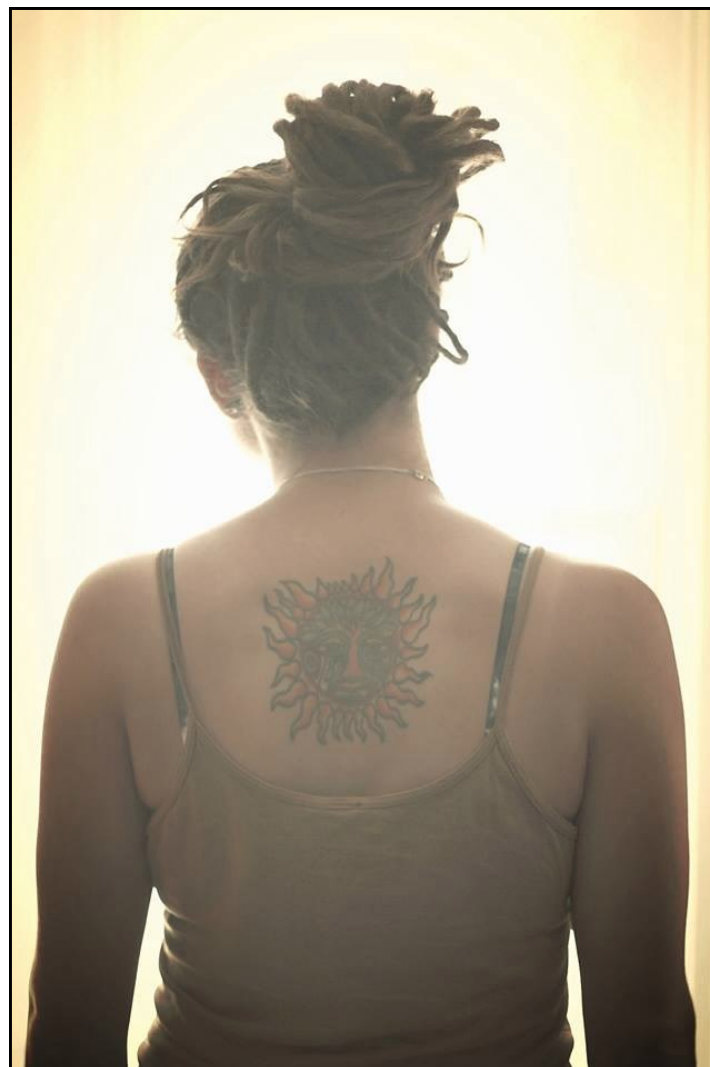
4. **The respite's philosophy is rooted in values such as self-determination, mutuality and the belief that healing and growth are possible for all.**

It's not enough to say that a peer respite is "values-driven" rather than "rules-driven." It's important for each peer respite to go beyond that and determine which values ring most true. Although that may differ from space to space, some of the most basic values that all peer respites hold in common include:

**Self-determination:** All peer-to-peer approaches are founded on the idea that each person should determine who they are, what their experiences mean, and how they want to move forward.

**Mutuality:** All peer-to-peer approaches are based in the idea of mutuality. However, mutuality is a confusing concept to many people, and is often misused. Mutuality doesn't necessarily mean that each person's role is the same, but it does mean that – regardless of roles – each person can learn from, be impacted by, and grow, based on the connection with the other. It also means that each person counts in the equation, and that it matters whether the interaction is working for everyone involved, not just for the person in distress at that moment.

**Belief that healing and growth are possible for all:** Without a fundamental belief in everyone's basic human and healing potential, peer-to-peer approaches just don't make sense.



**5. The respite’s design and approach are rooted in an awareness of the impact of trauma, including trauma experienced due to race, gender, sexual orientation, etc., and the task of creating healing and accessible spaces.**

Although peer respite does not mean assuming that trauma is the source or the sole cause of each person’s distress, it does mean having an awareness that many people have experienced trauma, and that that has shaped their beliefs about and ways of being in the world. Among the traumas many people have experienced are components of systemic oppression such as racism, sexism, transphobia, homophobia, classism, ableism and more. Building a peer respite environment that is aware of and invested in being a part of undoing systemic oppression is essential. Peer respite is about seeing someone as a whole person, and partnering with them to understand who they are in this world and why, as well as who they want to be moving forward. There simply is no way to do that without tending to these pieces.

**6. “Illness” is not assumed and a wide variety of ways of making meaning of distress and various unusual or difficult experiences are welcomed and able to be openly discussed.**

Some people hear this as ”anti-medical model.”

However, what it’s really about is choice and self-determination. Some people feel that an illness-based approach makes sense for them. Others do not. Peer respites make space for people to learn about, consider, and choose for themselves. Without the opportunity to make sense of your own story, how can there be any real self-determination?

**7. Routine person-specific paperwork is minimal and led largely by the individual seeking support.**

Paperwork is power. Many people have experienced what it’s like to have paperwork (diagnoses, assessments, incident reports, etc.) that follows them around for years and influences how others see them. Anyone who writes notes about someone else needs to know that what they write might impact that person’s life now and/or in the future. Given that people have had so many bad experiences with paperwork that follows them around, it’s a simple fact that paperwork at a peer respite can get in the way of building trust. Additionally, in an environment where there’s so much effort put into avoiding power imbalances, it’s important to be aware that writing notes about a person staying at the respite —when no notes are being written about the person working there— adds to the power imbalance. Any notes, records or referrals that exist for any reason should be done in an open and collaborative way with the person staying at the respite.

**8. Individuals working or volunteering at the respite are supported (through training, team work, co-reflection, etc.) to come from a peer-to-peer perspective.**

Although many roles are called “peer” some people in designated peer roles work for organizations that offer them the same training as all other employees, and often don’t fully understand the different job responsibilities that should be involved (see *Handbook on Peer Roles* for more information on development of peer roles in the broader system: [www.psresources.info/peer-roles-handbook](http://www.psresources.info/peer-roles-handbook)). In a peer respite, it is essential that the training and expectations of the team be well thought-out and based in peer-to-peer principles.

**9. Language used by people working or volunteering in the respite (and on any related paperwork) is non-clinical, everyday language that is inclusive and leaves space for a variety of perspectives.**

This ties in closely with number 5, above. It is impossible to leave space for people to explore and make their own meaning if all language used suggests a medical or clinical perspective. Again, the key isn’t to find language that excludes a medical perspective, but rather to find language that is open to any perspective. (See language section for more on this topic.)

**10. There is no routine focus on psychiatric diagnosis, and it is only discussed when meaningful to a particular person/conversation.**

In an environment that doesn’t assume illness, it’s important not to assume that diagnosis is meaningful. Any routine requirement for a particular diagnosis or even requiring someone disclose their diagnosis suggests that that diagnosis has meaning. In reality, many people who heal and move on to live full lives do find meaning in their psychiatric diagnoses, but many others who experience the same success do not. So, in an environment that prioritizes self-determination, it’s key to support people to figure out which path will be the right one for them.

**11. Involvement in conventional mental health services (including use of medication) is not assumed, and there is openness to discuss any and all healing paths and approaches.**

Similar to number 10, an assumption that everyone is or should be involved with conventional mental health services and/or psychiatric medication walks hand in hand with an assumption that there is a medical problem. Many people (even those who don’t interpret their experiences through a medical lens) find benefit in clinical supports like therapy, but in an environment that prioritizes self-determination, that choice needs to be their own. Additionally, the only way to truly support someone to find the right path is to approach them with curiosity about what works or might work for them, and not make assumptions.

- 12. People staying at the respite are supported to keep connected (or get connected) to their chosen family, friends and/or any providers/supporters *as they desire*.**

One of the benefits of respite over hospitalization is the freedom to maintain community connections. This can include anything from going to work to visiting with family and friends. It can also include continuing to see a therapist or other provider as desired. Or it can mean cutting connections with everyone for a while, or getting support to find new connections. The key is that there is a choice.

- 13. There are no restrictions on coming and going freely from the respite (with the exception of limitations on how long someone can be gone from the respite before they lose their spot).**

This goes back to the foundational element of self-determination, along with number 11, the ability to keep connections in the community. This doesn't, however, mean that if someone's comings and goings (due to lateness, etc.) are disruptive to the space, that that would not be discussed.

- 14. There is no required schedule of groups, bed/wake times, etc., and individuals staying at the respite take the lead in designing their stay in the way that will be most helpful to them.**

This point speaks not only to personal choice but to personal responsibility. Although part of the picture is leaving room for choice in how someone organizes their day, the other part is their need to take responsibility for making sense of and doing something with those choices.

- 15. There is openness to the idea that what often gets called a 'symptom' (e.g., self-injury, etc.) can in fact be a way of coping with difficult life experiences.**

In a medical model, actions like self-injury tend to get labeled as a "symptom" or seen as something that needs to be stopped. However, if crisis is truly to become a learning opportunity, space must be made to understand each part of someone's experience, including whether or not they see certain things as problems, how those things are impacting their life, why they do (or do not do) them, and what all that means. Jumping to calling something a symptom, or assuming it needs to stop, cuts off a whole world of conversation that is essential to developing a peer-to-peer relationship.

- 16. Avoiding the use of force (calling emergency services or police against someone's will, participation in forced medication or Involuntary Outpatient Commitment programs, etc.) is a priority, and there's a process in place for internal review and learning, should force ever be used.**

Force is the opposite of self-determination, and it is also something that many people have experienced a great deal of in the treatment system. Thus, it is something that peer respites strive

to avoid. In rare circumstances when force does happen (ideally only because there's a true medical emergency), it's important for the respite team to be transparent enough to look at what happened and to acknowledge whether they played any role in where the situation ended up, and to commit to working on developing personal and organizational strategies and practices toward non-coercive outcomes in the future. This is central to being a part of a movement that fights against oppression and abuse of power. It is advisable to have guidelines in place before such a situation happens that includes a process for an internal review. Even peer respites can find themselves moving too quickly toward force in some situations out of inexperience and fear, and having a structure to encourage learning and growth from that experience is critical.

**17. There is an emphasis on not talking about people without them present (even when releases have been signed enabling someone working at the respite to do so).**

Although it's legal to talk about people without them present if there is a signed release in hand, it misses the mark as far as making sure that people really are at the forefront of their own lives. Some people who've been in the system for a long time are used to signing away that right, but part of the mission of a peer respite is to support people to take that type of ownership back and reconsider the role they want to play in what happens to and is said about them.

**18. Tasks that are likely to create or enhance power imbalances (such as handling medications or money) are avoided.**

Tasks like holding someone's money or administering their medications are ones that are linked to a long history of force, coercion and power. These also feed into the idea that someone can't be responsible for themselves and various parts of their lives. For these reasons, it is not okay to take on these tasks within the context of peer respite.

**19. "Staff only" and locked areas are minimized or eliminated altogether.**

"Staff only" areas suggest power and separation. Although it can be necessary to have a place to work or store items to which everyone does not have open access, having large offices or forbidden rooms in a space generally increases any sense of divide, and can chip away at the idea of mutuality. Additionally, locking up items like knives (sometimes referred to as 'sharps' in clinical settings) breeds an automatic sense of distrust and misses the mark on treating everyone as adults who are ultimately responsible for themselves. This goes for refrigerators and general food access, too.

## **Section II: Characteristics of Fully Peer-Run Respite:**

In order to qualify as a “full peer respite,” the following terms must be met (in addition to all peer respite characteristics listed above):

### **1. Functions independently or as a part of a larger non-clinical organization –**

As is discussed in other sections of this handbook, when a peer respite is fully facilitated by people who have “been there,” it’s important to name that.

### **2. Exists in a house, apartment or other homelike space, and not in a medical building or other structure that is simultaneously being used for clinical or other purposes that would represent a potential conflict with the mission of the respite.**

Although some respites may be limited in their space selection due to local zoning laws, it is still valuable to have a non-clinical environment that represents and re-enforces the value of a non-clinical approach whenever possible.

### **3. The design of the organizational Board of Directors and any other advisory boards includes a commitment to having a majority of appointees who have personal experience with psychiatric diagnosis, trauma, addictions, homelessness and other significant life challenges.**

In a truly peer-run organization, it is relevant for people with personal experience to be represented at every level of the organizational structure.

### **4. There is no requirement that someone be receiving any other particular services (at a particular agency, through a department of Mental Health, etc.) in order to access the respite.**

Peer respite means moving away from the idea that there are the “sick” and the “well.” It also means that people who are having their first experience of deep emotional or mental distress can access the respite and potentially avoid a deeper relationship with the mental health system altogether.

### **5. There is no formal clinical involvement (including no clinical assessments required in order to access the respite).**

It can be difficult when a clinician with different training and priorities is involved in determining who is a fit for a peer respite. It can also get in the way of creating a non-clinical environment overall.

# MYTHS AND MISCONCEPTIONS

## **Myth #1: Peer respites are for people who need a bit of rest; NOT for people in serious distress.**

Peer respites will not be a good fit for everyone. That's the grain of truth in this particular myth. But, neither are traditional respites or hospitals a good fit for everyone. There are actually two issues with this particular myth. First, distress is entirely subjective; in a peer respite, team members try to make decisions that are not based on how much distress THEY believe a person to be in, but by how the person *themselves* defines their experience and whether they believe a peer-to-peer environment could support them through that struggle. For some, the loss of a beloved pet will be equally as distressing as the loss of a parent. Some thrive in a fast-paced, unforgiving work environments, while others will need to take a break. Some have spent years struggling with distress in and out of the mental health system, and others are experiencing a first major disruption to their lives and may not quite know what to make of it. So much of our ability to sit with stress has to do with what has come before in our lives, so flatly deciding that someone's self-defined crisis is "too big" or "too small" is presumptuous and not in line with the concept of meeting someone where they are at.

But, more importantly (where this myth is concerned), peer respites see people in any number of states. Some do call feeling stressed, near but not quite at a breaking point, and needing time off from roommates or work life. However, many others call because they are seriously thinking about killing themselves, hurting someone else, or taking some other action that could have serious negative impact for their lives. Others are overwhelmed by hearing distressing voices or disturbing thoughts, are being threatened with involuntary commitment to the hospital, and so on. All of these experiences would be a potential fit for peer respite. People working in peer roles are well-trained (by a mixture of life and on-the-job experience and many formal trainings) to support people moving through distress, and so peer respite is often a great fit for people who are struggling deeply.

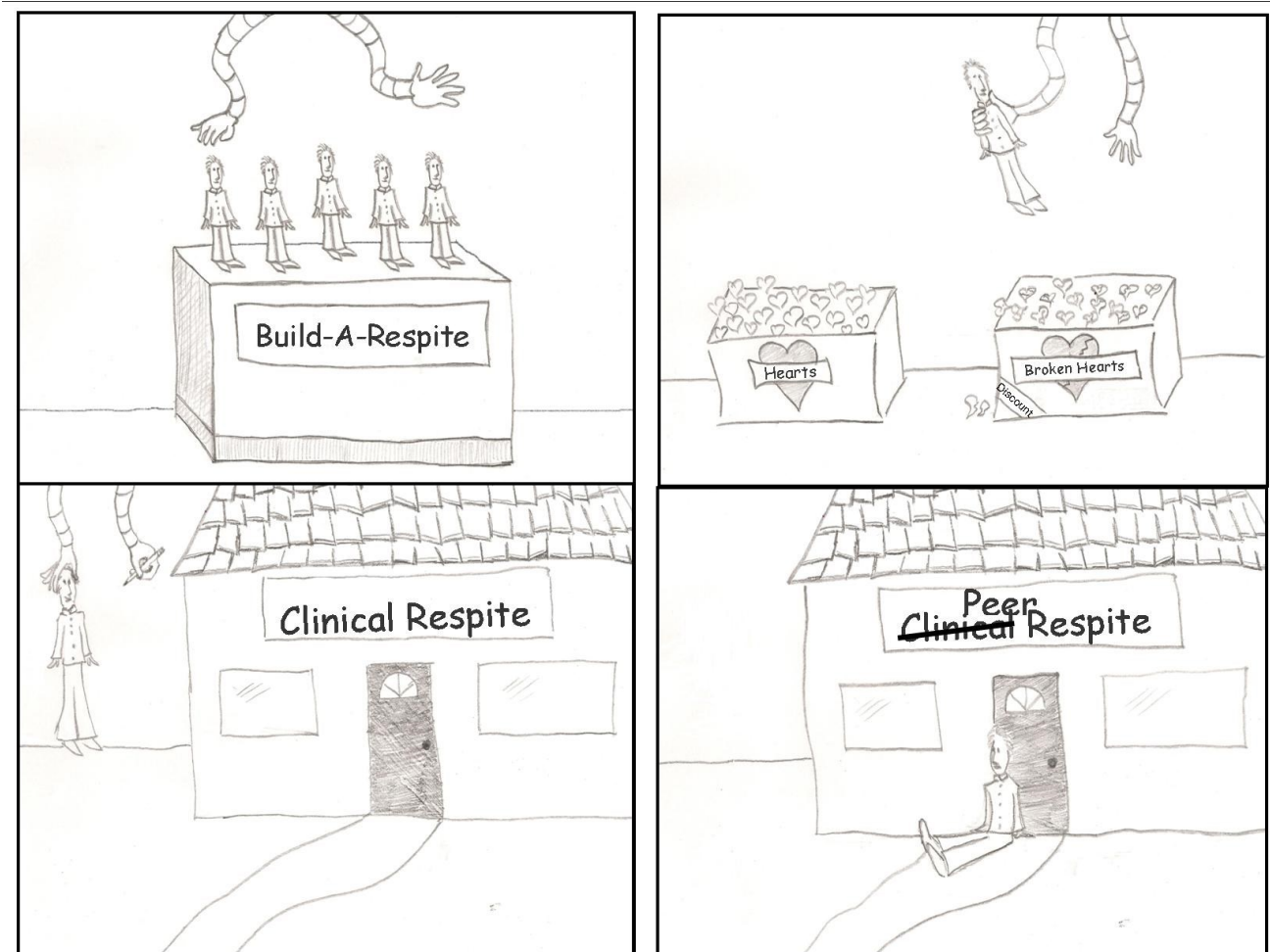
## **Myth #2: The main difference between a peer respite and a clinical respite is the identity of the people working there.**

A major qualification of working in a peer role is having been through significant life struggles (trauma, psychiatric diagnosis, addiction, homelessness, hospitalization, losing custody of one's children, etc.), and having an understanding of the marginalization and losses that can result. There is something extremely powerful about sharing one's story with someone else who has walked in their shoes (or, at least, been in the same shoe store) and has felt similar pain from the inside out. It's all the more powerful to then have that person be willing to talk about their story. In many traditional spaces, it is frowned upon to share too much of one's own history or life beyond the most superficial facts. There is a fear that it may burden the other person, making them feel worse. There also sometimes seems to be a



fear that respect for the person in the supporter role may be lost if they reveal their vulnerabilities. Whatever the reason may be for this closed-offness, the fact is that, time and again, it has been shown that offering up relevant bits of who one is in a genuine way creates a connection which helps others to feel heard and seen in deep ways, possibly in even deeper ways than if they were paying for a therapist to see them in a clinical light.

However, peer-to-peer support is about so much more than that. It's really a way of *being with* someone. Rather than assessing someone or their "level of safety," it's about hearing them out and keeping an open mind and heart so that judgment and fear don't get in the way of seeing that person for who they are and how they are struggling. It's about two people sitting side by side without a clinical veneer or power dynamics at play. There is no expert, and knowledge is a shared entity. It is about two people who have seen the depths of hell looking at each other honestly and building a connection from which *both* people can learn and grow.



Comic illustration by Sera Davidow

Other more concrete differences between peer respites and clinical settings may include the set-up, structure of the days, and (as briefly aforementioned) power dynamics. Peer respites are most commonly set up for each person to have their own private room. The structure is very open (as discussed elsewhere in this book) and the power dynamics between “staff” and “clients” are minimized as much as possible (including avoidance of those terms altogether). This is a result of the peer support model, but also because people in peer roles are not administering medication or holding people’s money, and are not trained to come from a place of assessment and diagnosis, all of which amount to having a great deal of power over someone (even when used with the best of intents).

**Myth #3: A respite can’t possibly be “safe” if there’s no clinician there to assess risk.**

Many peer respites have reported that some of the most difficult situations (people acting with disregard toward the space or other people, etc.) they’ve faced have involved people who *have* been assessed by clinicians who then encouraged them to stay. This is likely because peer support needs to be freely chosen. It is a relationship that asks for mutuality and trust. If someone is told to call a peer respite and stay there simply because they don’t have another place to go, or because their insurance has run out in a clinical environment, it is not an ideal starting point for a peer-to-peer relationship.

This calls into question the whole notion of assessing risk, especially since research suggests that the practice of risk assessment tends not to be particularly effective in any setting.<sup>1</sup> There are many stories of people who reportedly have “violent histories” staying at peer spaces where they do not end up having any issues of that nature and have built incredibly strong connections. Some of these same people also share stories of having only acted out physically when subjected to force and restrictive environments. While there are likely to be a number of factors involved, it seems worth considering how much environment might play into someone acting in “risky” ways.

<sup>1</sup> Wand, Timothy. *Investigating the Evidence for the Effectiveness of Risk Assessment in Mental Health Care. Issues in Mental Health Nursing. Volume 3, 2011—Issue 1.*



Comic illustration by Sera Davidow

**Myth #4: If people can still go to work or a group in the community, then they can't be in *that* bad of a place.**

The stereotype or media image of someone who is in a really bad place —thinking about suicide, experiencing an increase in hearing distressing voices, or whatever else is commonly portrayed— is of someone who can barely move or get around in the world. While this sometimes happens, it's just not true for many people. In fact, it may be the work or community connections that are supporting a person the most! Cutting someone off from their community based on an assumption that, if they were really suffering, they wouldn't be able to handle work or school or life, is simply nonsensical. And it can cause even greater distress, trauma and loss if that person is kicked out of college, fired from a job, or risks their living situation or custody of their children as a result of hospitalization.

A peer respite is one of the few environments that fully supports people to decide for themselves exactly what they need a break from and to what (and whom) they wish to stay connected. People who stay can go to work, school, and appointments and lead their full lives, if that's what they choose to do. On the other hand, if someone is looking to take a break from all that, a peer respite makes space for that, as well. In fact, when someone calls looking for anyone at a peer respite, confidentiality is upheld. A standard response will be something like "I cannot confirm or deny whether that person is here" (or similar), although messages are also taken and passed along, so that the relevant person can decide whether or not they would like to get in touch.

**Myth #5: The best thing for people who are thinking about killing themselves is to be in a locked place where they can't possibly cause any harm, not a peer respite where they are free to come and go.**

Studies show that suicide rates are highest directly after someone is released from a locked psychiatric unit.<sup>2</sup> How are we defining 'safe' and what does it mean for someone's life over the long-term? Many people who have thought about suicide will say that what most helped them get through their darkest times was space to talk about where they were at and the opportunity to feel connected to others who were open to hearing them and their pain. People who work in peer respites can be trained to stay present with people through these difficult conversations, but are ideally hired for their natural inclination to want to be "with" people through these times, rather than pressing the panic button. Imagine being able to say the "S" word without medications, assessments and hospitalizations being forced on you. Many people stay silent in clinical environments due to fear of what will happen if they say specific words. As a result, they find themselves struggling even more.

<sup>2</sup> Large, M. M., & Ryan, C. J. (2014). Disturbing findings about the risk of suicide and psychiatric hospitals. *Social Psychiatry and Psychiatric Epidemiology*, 49(9), 1353

It's important to note that the idea that there is a place where no one can cause any harm to themselves or others is simply wishful thinking. Many people have killed or done serious harm to themselves (or others) while *in* a locked psychiatric unit. Furthermore, sometimes when people are locked up and their freedoms are taken away, they can become angry and/or desperate to reclaim some of their power, leading them to lash out toward themselves or others in ways they wouldn't normally.



Comic illustration by Sera Davidow

#### **Myth #6: Respite bring dangerous people into the neighborhood.**

Most respites have a small area (a handful of cities, a few counties, etc.) that they are funded to support, and thus people are often limited in accessing the respite based on their geography. Therefore, if you happen to live in the same area, everyone who comes to stay at a particular peer respite will generally be your neighbor, a part of your community, your fellow human beings walking down the streets with you.

This myth suggests that people are somehow safer staying disconnected and leaving others who are struggling alone. However, most experience suggests that this is just not true. Instead, what experience suggests is that there is a need for *more* spaces that are welcoming and support people in transforming crisis into opportunity. *More* spaces are needed where people can talk about the big feelings they have, including wanting to die and wanting to hurt others (and maybe, just maybe decreasing the likelihood that people will act on those feelings). This society has become increasingly disconnected and spaces like peer respites hold connection above any other value and motivation.

# CORE DESIGN ELEMENTS

In addition to the difference between full peer-run respites and hybrids, there are also a number of different designs for the overall structure of peer respites. These include:

- **Exists as a part of a larger organization:** Many (if not most) peer respites are connected to larger organizations that also offer other supports. Some of those larger organizations are clinical in nature (not ideal where it can be avoided), while others are considered to be peer-to-peer. Potential upsides include:
  - ⇒ Can pave the way for a person seeking support to continue a relationship with the organization even after leaving the respite.
  - ⇒ Can create automatic partnerships and extra support for the respite team during difficult times and create easy access to additional resources.

Both of these points are particularly true for peer respites that are a part of peer-to-peer organizations. However, potential downsides or risks may include:

- ⇒ May be more likely to rest on connections and resources available internally and spend less time developing connections to the broader community.
  - ⇒ In places where the organizational mission holds some tension with the mission of the peer respite (most common under clinical organizations), it may be harder to keep the peer respite on course.
  - ⇒ There may be more competition with other parts of the same organization for grants or funds, especially since many grants only allow for one application per organization.
- **Exists independently with no ties to any larger organization:** Some peer respites have developed as their own organizations.

Upsides include:

- ⇒ The ability to focus all the energy on supporting the peer respite and holding to its mission.
- ⇒ Necessity —due to fewer internal supports— becomes a great motivator to learn about and connect with community resources.

However, some potential downsides include:

- ⇒ More complicated or taxing on the team to figure out ways to maintain connections with people who have left the respite. Ongoing connection is positive, but when pressured due to lack of resources, it can be challenging.
  - ⇒ Challenges involved with incorporating as a non-profit and managing all the related back office fiscal and personnel activities
  - ⇒ Increased challenge on getting grants as a new organization. (Many grantors look to organizational history as evidence of grant worthiness, although there are some grants available primarily to start-ups or very small organizations as well.)
- **Exists in the same building as clinical services:** Peer respites that exist within a clinical environment are, by definition, considered to be hybrid peer respites (though not all hybrid peer respites exist in clinical buildings). One upside of this model is that people who seek out traditional crisis services are much more likely to learn about the peer respite.

However, there are some substantial downsides, which include:

- ⇒ Tends to be much more challenging to hold to the mission of a peer respite when it's based within a conventionally clinical space. For example, it's much more challenging to stay out of a place of 'assessment' when assessment is the primary focus of what's happening on the other side of the wall.
  - ⇒ Associations with clinical environments based on past experiences may influence the ability to engage in a peer-to-peer relationship or may cause someone who feels alienated from clinical services to avoid the respite altogether.
- **Incorporates a drop-in center in the same space:** Some peer respites, including those that are both hybrids and fully peer-run, include daytime access to people who are not currently staying at the space. Some of the obvious upsides include:
    - ⇒ Creating a natural way for people who use the space during the day to learn about the peer respite.
    - ⇒ Creating a natural way for people who have stayed at the peer respite to stay connected after they leave.
    - ⇒ Offers people who are staying at the respite more opportunity to meet and connect with a wider variety of people.

On the other hand, commonly named downsides include:

- ⇒ It can be hard for people who are staying at respite, particularly those with trauma histories, to never be able to know who might be in the space at a given time, including both people they've never met and people they might know from other settings (some of whom they may actively not want to see or who pose a danger for them to be around).
- ⇒ Increased noise and traffic may also be seen as a negative factor, and there can be higher potential to be pulled off course from the main mission of the respite

• **Incorporates a peer support line or “warmline” in the same space:** Many respites incorporate a peer support line or “warmline” into their space. Upsides can include:

- ⇒ Both the person answering the line and the person working directly with people staying at the respite are able to offer each other additional support when difficult situations arise, in instances where the phone line is funded separately and different team members are responsible for covering each one.
- ⇒ Can create another easy way to stay connected to people who have stayed at the respite.
- ⇒ Can act as a resource and place to connect people who are calling the main respite line just to talk.
- ⇒ When the phone line is quiet, that employee is sometimes able to offer additional support and chances to connect with people staying at the respite.

Downsides include:

- ⇒ Privacy and sound issues (some respite walls are thin!).
- ⇒ Needing additional private space for phone calls to be received can be a drain on space for those staying at the respite.
- ⇒ Can create additional confusion as to which line is for what purpose. People might start calling numbers intended for the phone support line to access the respite and vice versa.
- ⇒ Can compromise the quality of relationships if attention is divided between calls and people staying at the respite.

• **Exists in a space that is independent and focuses only on being a peer respite:** Some respites only offer routine access to the space for people who are actually staying there. Others take it a step further; they do not offer routine access to people not staying, and also avoid other focuses beyond the peer respite (including no peer support lines, etc.). Clear upsides of this approach include:

⇒ Able to more easily avoid attentions getting divided and drawn away from people staying at the respite.

Downsides include:

⇒ Less opportunity to meet a wide range of people and form connections that might be meaningful both during and after one's stay at the respite.

⇒ Potentially less activity to get involved in during the day for those who are looking for something to do, simply due to fewer people being around.

- **Restricts access to people already receiving particular services:** Some respites only offer access to the respite for a set group of people who are already receiving particular services from a specific agency or governmental office. The clearest upside of this approach is related to research, which often requires specific parameters and controls to be in place; having a clearly defined group of people is not only helpful but required for some types of research. However, downsides include:

⇒ Perpetuates a lack of exposure of people who are already receiving services to anyone who may be living life in a different fashion.

⇒ Prevents supporting individuals facing their first experiences, and prevents peer respite from acting as a resource to help people avoid entering the mental health system.

- **Open access, regardless of other services received:** Most respites do not restrict access to people who are already receiving particular services. Upsides to this approach include:

⇒ Increasing the potential for learning within the space, simply by virtue of people being exposed to others who are living their lives in any number of different ways.

⇒ Creates an opportunity for someone who is new to the area or having a first experience of disruption to their life (for example, college students) to access a peer respite and divert them from landing in a hospital or getting caught —sometimes for a long time— in other services.

⇒ Creates an opportunity to better measure overall community need and desire for respite access, which can be used as advocacy for more peer respites in the future.

A possible downside to this design includes:

⇒ Greater potential for “mission drift.” While this type of open access may initially create room for the respite to meet its mission in very meaningful ways, if attention isn't paid to how things are



playing out, it could mean that some of the people who have the greatest need for the respite and the least access to other resources are getting excluded in favor of people who could reasonably be getting support elsewhere.

⇒ More likely to get a higher number of phone calls and inquiries about respite, which can be overwhelming and take away from being able to focus on people staying at the respite.

- **Requiring a “pre-crisis,” “proactive” or “pre-entrance” conversation or interview before accessing the respite:** A “pre-crisis” conversation or interview (now also known by other names, including “pre-entrance” and “proactive”) is essentially a meeting that occurs before someone identifies as being in “crisis.” The intent is to create a starting point for connection between that person and the respite team before they are in a difficult spot, and to also hear from them about what they feel would be helpful support when they do get in that place. It usually entails a face-to-face meeting where a series of questions (not unlike questions you might find in a Wellness Recovery Action Plan) are reviewed. Most typically, the responses to the questions are offered by both parties and get documented and filed. They are then reviewed when and if the person actually comes to stay at the respite.

As already stated, one of the major upsides of this approach is that a relationship has already begun to develop simply through the process of completing the conversation. Other upsides include:

- ⇒ Offers the opportunity for a person to think about what they may want from a respite before they’re actually in the midst of a difficult time (when they may be more likely to feel stuck or overwhelmed), and to think through and agree upon what they may find helpful, and/or how they may best be supported or challenged to move forward.
- ⇒ In some instances, the interview has been used as a tool for outreach and to let people know peer respite supports are available.
- ⇒ Creates an opportunity to make sure that the person has been able to ask questions and learn about what peer respite offers during a time when they’re able to really hear and consider the information.
- ⇒ Ensures that people are not meeting for the first time when someone is in a bad place.
- ⇒ Can help reduce misunderstandings and misconceptions about the peer respite before someone is actually staying there.

Downsides include:

- ⇒ Can significantly limit the number of people who have access to the peer respite, especially

when no exceptions are made and only people who have already completed the interview are considered eligible to stay.

- ⇒ Can lead to preconceived notions about what someone wants and decrease emphasis on asking them in the moment. It can even be somewhat coercive if someone is being pushed to work within a pre-agreed upon document.
- ⇒ Can re-enforce old ways of doing things, like learning about someone by reading a file.
- ⇒ Can re-enforce the notion that someone in crisis is incapable of making decisions or changing their minds, and must be protected from the consequences of their actions.
- ⇒ Some may feel mistrustful at the idea of a file being kept on them and may avoid the respite simply because of that fact.
- ⇒ Can put someone in the position of predicting that they are going to have a crisis, which may even limit how they think about their options when they do get into a bad place.
- ⇒ If the employee taking part in the conversation is not well-trained and highly skilled, it can shift from a conversation -the intention of the tool- into just another type of intake form where people give one or two-word answers.
- ⇒ Is extremely time consuming and takes away from supporting people who want help now.

Fortunately, many respites that employ the “pre-crisis conversation” do make exceptions for people who haven’t had a chance to fill one out. Additionally, whether or not a pre-conversation has happened, it’s possible to have conversations during (or even after) a stay that also allow for much of this same learning and relationship-building to take place moving forward.

- **Accepting funding streams that are specific to a particular person versus those that seek to fund the respite as a whole.** This is an incredibly complicated topic that is further muddied by the different ways funding sources function across the world. Some respites may receive funding that is by the person; for example, insurance payments that are attached specifically to an individual and the particular services or supports they receive, or “unit” contracts through governments that are similarly based on amount of time spent with a specific person. Others get “cost reimbursement” contracts that are based strictly on anticipated costs of operating the respite for a given period of time, regardless of who or how many people come to stay.

Mostly people strongly prefer funding streams that are not person-dependent because:

- ⇒ They are more likely to protect privacy and reduce or eliminate the need to report to the funder about specific individuals.

- ⇒ Even if there's a slow period where not many people are staying at the respite, funding remains consistent.
- ⇒ It's easier to plan and predict costs and funds needed to cover them.

However, there are a few benefits to a “pay by person” model, too. Most notably:

- ⇒ If the respite stays very busy, they may end up with extra money by the end of the year that they are free to use as makes sense (for renovations, supplies, team retreats, etc.).
- ⇒ Many “cost reimbursement” style contracts require that all funds be spent or returned by the end of the year. So, even if costs are kept down and money is left over, that money needs to be spent or given back to the funder. This sort of budgeting can be very stressful come end of year, as it's almost impossible to calculate everything correctly down to the penny!

It's also worth noting, however, that some respites have considered (and at least one has tried) to construct themselves around an approach where at least some stays are covered by the individual who is staying, on a pay by night basis. This sort of “pay based on individual” structure is completely different than ones driven by insurance or the government, and are likely to allow for the greatest freedom and privacy possible. However, such a structure also limits access to those with substantial financial resources, and can bring in other complicated interpersonal dynamics that are more likely to arise when money is changing hands.

Although not yet attempted within the context of a peer respite, there also some organizations that have employed models that exchange volunteer hours for support.. Those organizations are typically grant-funded (which pays for basic operational expenses), but people who wish to make use of their supports are asked to exchange documentation of volunteer activities in the community for access to services. At the time this book was being written, , one of the best examples of this model is Volunteers in Psychotherapy, based in Connecticut in the United States.

There are several other core design elements that are also being considered or implemented. For example, some respites are looking at how to offer a mix of on-site respite supports alongside the ability to go to someone's house and support them there. This can be ideal (and much less disruptive) for individuals who feel good about their current home setting, but are also feeling disconnected and isolated, or who live in very rural areas with sometimes hundreds of miles between cities. Other respites are considering adding a ‘bridger’ who can work with people on the wait list to come in, and/or people who've stayed at the respite recently and would like some additional support to make the adjustment back to their home or continue to build connections in the community. Both are options that will hopefully be explored further and employed with greater frequency in coming years.

Regardless, the points mentioned on these pages are some of the most common differences. For the most part, they are not exclusive to one another, and the final design may include just about any combination of elements listed.

**Ultimately, when setting up a respite, it is most important to thoroughly consider:**

- Which of these elements are most consistent with the respite’s stated vision, mission and values.
- Which of these elements are within or beyond the control of those who are organizing and facilitating the space. Sometimes there are certain aspects that truly are out of the peer respite team’s hands, due to funding source requirements and so on. However, all too often, people give up their power or undercut themselves by either not asking for something different or not being strategic in their advocacy! It’s important that a lot of thought goes into this point before it is assumed that something is truly beyond control.
- How each element being selected intersects with the other, and with other available resources and supports in the area.

Additionally, for any element that is being required rather than chosen, it’s important to think through how to minimize the damage of that element on the overall vision and/or to consider how to advocate for change moving forward. Although it’s generally much more difficult to change something after it’s been set in motion, it’s certainly not out of reach in many instances!



# DAY-TO-DAY STRUCTURE

As noted in the charter, the intention behind peer respites is that there is no set structure to the days. There is no wake-up time or bedtime, and whatever happens in between those two points is decided by the person staying. During the initial conversation with someone who is seeking respite, there may be some discussion around what their time at the space might look like. This is primarily to get a sense of what they are seeking, and is also an opportunity to explain what sorts of supports and resources are readily available.

Additionally, when someone arrives to the space, there may be paperwork which asks if they have any specific aspirations or hopes for what they might do during their stay. These conversations and pieces of paper are just intended as signposts pointing toward what someone finds helpful during crisis. They are not binding contracts that force a person to fulfill whatever is said or written.

What might seem helpful one day may be the absolute wrong thing for a person the next day. It may be helpful to think about your own life when you're struggling. Sometimes you need friends, family, people around you to talk things out and think things through. At other times, that may be the last thing in the world that you want or need. So, quiet time with a cup of tea in the backyard may be more in order.

*“I was staying in a clinical respite, and one night I tried to go downstairs after 11:00pm, but the staff told me I had to stay in my room because it was after the house bedtime. However, I had a roommate who was screaming in his sleep which wasn't so restful, and was actually pretty distressing to be around. How is making me stay upstairs in my room supposed to help in a situation like that?”*

- Former guest at a peer respite

## **With no set structure, it leaves room for someone to:**

- Determine what it is they would like for themselves.
- Think about what has been helpful when moving through distress in the past.
- Examine even negative experiences and build understanding about them.
- Consider fears and places of “stuckness” without pressure to actually face those fears or make change in that moment.
- Experiment with resources, supports and ideas they've never tried or even heard of before.
- Grow, change and evolve during the course of the stay.

People will come to stay at peer respites for any number of reasons. Some may stay because of recent

trauma and loss; others might be avoiding hospitalization and overwhelmed by distressing voices or urges or disturbing or suicidal thoughts. Some may be overwhelmed by their current living situation or perhaps they are feeling very alone in the world and wanting to be around caring people. Due to the wide number of reasons people come to respite, there are a variety of things it will make sense for people to do once there.



**Some of these activities may include (but are certainly not limited to):**

- Talking with people working or other people staying at the respite.
- Meeting basic needs like catching up on sleep or eating healthfully.
- Getting support to address concrete problems with housing, legal issues, employment, etc.
- Continuing with school, work, community obligations (i.e., keeping engaged in one's life and responsibilities as desired and makes sense!).
- Playing a wide range of games and, generally, having fun.
- Hiking, biking and other forms of exercise, both indoors and outdoors.
- Gardening and getting out in nature.
- Processing recent trauma.
- Doing yoga or meditating.
- Cooking and sharing meals.
- Researching and trying out groups and events in the broader community.
- Learning and/or teaching specific skills or areas of interest.
- Learning about or developing a Wellness Recovery Action Plan (WRAP) or other similar approach.
- Writing, journaling, reading or making art or music.
- Taking space to clear one's thoughts.
- Re-evaluating or making new plans for moving forward.
- Watching TV and/or movies to distract from hard stuff.

- Learning about new ideas and community resources such as the Hearing Voices Network and Alternatives to Suicide.
- Trying a healing modality they've never tried (Reiki, acupuncture, etc.).
- Relishing the privacy of one's own bedroom.

**But some of the examples above sound way more serious than others. Is there really value in making art or playing games? Or does that just validate that the people staying in the respite aren't really in need of serious support?**

The reality is that "real" support can look like many different things. Some people benefit from talking directly about what's bothering them, and they're ready to talk as soon as they arrive. However, others either feel like more talking just keeps them stuck in the bad stuff, or are wary of too much, too fast before they've had a chance to develop trust with the person with whom they're speaking. In those instances, just being with someone or being open to engaging in something simple like playing cards can be exactly what is needed to form a connection that works. Many people also find that an enjoyable distraction can provide a non-threatening space to process and think.

Additionally, in some instances, people do want to speak but don't have the words for what they want to say, and drawing, painting, writing, or making music allows them to communicate their pain and other emotions in a way that makes sense to them. Feeling silenced when you want to speak can be extremely painful, but sometimes there needs to be room for the "speaking" to happen in non-literal ways.

**Okay, but what if the person literally wants to do nothing but sleep or sit around and watch TV. What then?**

It's hard to define doing "nothing," exactly. Some people find that they shut down completely (to the point of not being able to speak or respond to others) when they aren't eating and/or sleeping enough. Others report feeling more and more revved up and unable to sleep the less sleep they've been able to get. Still others say that those are the times when they think about suicide the most or hear the most distressing voices. In all of these situations, giving someone the time and space to simply sleep at length may be *exactly* what they need, and judging or chastising them for that could be extremely counterproductive.

Similarly, someone may simply appear to be watching an endless amount of television/movies, but underneath that, they may actually just be taking the break they need to recharge themselves in order to face a big challenge or trying to distract themselves from disturbing thoughts or voices until they pass. It's also important to note that our minds work differently, and some people (autistic or neurodivergent

folks, for example) may simply have a way of processing information or finding balance that means they benefit from lengthy periods focusing on outside stimuli (viewing a movie, watching a fire, etc.). It's hard to tell without asking, and asking is unlikely to generate an honest response unless the question comes with an open heart and mind to whatever the answer might be.

There may, in fact, be times when it really does seem like someone isn't making good use of the respite space. However, it's critical to not have cookie cutter rules about what that looks like, and to simply be open to figuring out what "good use" means for each and every person, and then to be willing to talk about that when it comes up.

**Alright, I hear you. But, what if someone just seems at a loss for ideas of what to do? Should I keep a list of ideas at the ready to share with them?**

Sure. Although it's important to not present lists of ideas as if they are the be-all and end-all of all possibilities, it can be useful to have some ideas on hand to share with someone *if they're interested*. All of us have the potential to lose touch with the things that we enjoy or find supportive when we're in a bad place, and sometimes all it takes to bring them back is a quick reminder. New ideas can be great, too.

However, there's a huge difference between having some ideas ready for those who want them, and pushing them on people who already have their own thoughts about how to use their time. Bear in mind that even presenting unsolicited ideas can sometimes come across as a demand, a rule, or as the only option available. This tends to be especially true for people who have spent a lot of time in a system where they're used to being told what they need to do. So it may be best to keep these sorts of tools aside unless they're requested, which doesn't preclude giving someone a tour and pointing out the various resources and supplies that are around, or inviting them to join you in a particular activity.

**What if someone *wants* more structure to their day? Some people *do* like that, you know.**

Absolutely. Some people really do like structure, and there are many reasons why. In some instances, people like structure because it's what they're most used to, and in those situations, they may benefit most from a conversation that simply explores what they like about that structure and if it's just that it's familiar or if it's actually what they want moving forward.

Others like it because it's how they find that they thrive. In those instances, and as noted on the following page, there are at least three choices about how to move forward.



- **Sit down and support the person to develop their own structure.** Just because there isn't a set structure in place for everyone who walks through the door doesn't mean that that particular person can't develop a specific schedule for themselves.
- **Combine peer respite with another support.** Occasionally, someone will choose to both stay at a peer respite and combine that with attending a day program or partial hospitalization program that offers structured activities and some clinical supports for part of the day, but leaves room for the person to return to the peer respite in the evening and overnight. For individuals who want the reassurance of structure for part of their day while still staying out of the hospital and not being alone later in the day, this option can be of use. **NOTE:** This should not be the norm or an expectation, and should only occur when someone truly is seeking and wanting clinical supports in addition to what the peer respite has to offer. Some people are also able to combine alternatives like meditation programs with and other healing workshops with a stay at peer respite, too.
- **Check out other options for support.** If someone truly wants a highly structured environment and they are not interested in creating that structure for themselves, then maybe peer respite just isn't the right place for them right now, and that's okay, too.

**Okay, let's say that we're good and the person's good with how they're choosing to spend their time at the respite, but we're required to take notes that demonstrate that the person's accomplishing certain outcomes. Then what?**

First of all, in a peer respite environment, it's really best if notes are extremely minimal or don't happen at all. This is a point where solid advocacy may be required during the initial set-up process. (See the documentation section for more on this topic.) However, if a peer respite team finds themselves in a place where there's absolutely no other choice, then it's important to start thinking creatively and to commit to collaborative and transparent processes so that you are still modeling the idea of "nothing about us without us."

To be creative in this way, it's important to know two things:

1. **What's the "worldview" of the person or organization that's requiring the note to be written?** Is there some specific outcome the funder's trying to track? Are they trying to prove "medical necessity?" Are they worried about liability? Are they somehow tied to clinical expectations of what a peer respite should be? (NOTE: These questions are not meant to indicate that proving "medical necessity," or other similar priorities are *good* things. In fact, they run quite counter to a peer respite's mission and values. However, it's nonetheless important to understand what's on someone's mind when they are pushing for things to happen in a certain way.)

**2. What’s the “worldview” of the person about whom the note is supposed to be written?**

Regardless of what someone else observes going on on the outside, what does that person say it means to them on the inside? What do they say their hopes are for being in the space? Does what others are seeing actually mean they’re lost and aimless, or do they have an idea of where they’re headed?

Having a clearer idea of the funder or organization’s goal will give team members a better idea of what constitutes more and less than is needed, and will help them define the “wiggle room.” Knowing the individual’s worldview will give them the words needed to take the next step.

For example, did someone sleep all day, or did they work on re-regulating their sleep schedule? Did they just sit around watching television, or were they exploring new ways of coping with their distress? Did they refuse to communicate with anyone, or were they meditating?

To be clear, this is not a suggestion to simply start making things up, but it is a suggestion to talk with the person, being transparent if you need to write notes, and, *at the very least, offering to do the notes with the person.* Most importantly, be genuine in your curiosity about what’s actually going on for them. Once you understand more about their worldview and what’s happening on the inside for them, then finding a way to create a note (or, better yet, having them do it) may get a lot easier.

# WHO USES A PEER RESPITE?

There have already been several references to who uses a peer respite in this handbook, but in short, many people of many different types and experiences have used peer respite.

From a demographic perspective, of course, people of any race, religion, sexual orientation, gender identity and age (18 and up) are able to access peer respites (although occasionally one is set up to cater to a particular demographic, such as people of certain ages). Although it can be a struggle to create a peer respite space that feels welcoming to people from varied backgrounds (this can include taking a hard look at the different backgrounds and characteristics represented on the team, the language used, the assumptions and biases carried, etc.), it is clearly something for which respite spaces should strive.

The experiences of and reasons motivating people to seek the support of a peer respite are equally as varied. Some examples include:

- Avoiding psychiatric hospitalization.
- Overwhelmed by distressing voices or disturbing thoughts or urges.
- Struggling with suicidal thoughts.
- Grieving and loss.
- Recent or resurfaced trauma.
- Struggling with addiction or substance use.
- Struggling with impact of taking or stopping psychiatric medications.
- Overwhelmed by a chaotic living environment.
- Difficulty taking care of basic needs (eating and sleeping regularly).
- Struggling with deep sadness or highs and lows.
- Overwhelmed by the stress of school and/or work.
- \* Struggling with the impact of racism, poverty, misogyny and other forms of systemic oppression.
- Struggling with the impact of homelessness. (Some respites will not accept someone who does not have a home to which they can return, and most others will not accept someone if they are strictly just looking for a place to crash, but the trauma and stress that can result from homelessness itself is a valid reason for some peer respite spaces.)



*Photo credit: Sera Davidow*

This is by no means a comprehensive list. As previously mentioned, what's more important than the "what is going on" for someone is the "how it's impacting them" piece, and whether or not they think a peer-to-peer environment might be a useful support.



# ESTABLISHING AN ADVISORY BOARD

One of the most fundamental components of a peer respite is that it be guided by the life experiences of those it seeks to support. As such, it would not be appropriate for a clinical organization or other group of people with no personal experience to engage in a visioning or start-up process without substantial guidance from an advisory board.

This is true even if the intent is to hire a team of people who do have personal experience and turn the reigns over to them at some point down the road. In fact, even if the group involved in the start-up has their own direct experience receiving services within the mental health system, an advisory board is still highly recommended. The more voices that can be involved in the visioning and start-up process, the more representative of different life experiences the respite is likely to become. The presence of an advisory board will also help the effort to remain in sync with a community-based, grassroots project, which is exactly what it should ideally be.

However, setting up a solid advisory board that is prepared to give meaningful input is easier said than done. Often, attempts to set up such a body fall into one or more of these traps:

1. **Group is made up of people who are uninterested or unprepared to offer input:** Sometimes, well-intentioned providers fill seats on advisory boards by instructing their staff to drive people from day or residential programs to the meeting location and/or luring people in with food. This can result in very quiet meetings where people don't know why they're there and don't have much to add.

While setting up transportation or offering people refreshments isn't necessarily a bad thing, it shouldn't be the only reason people are showing up. It's essential that those in attendance be clear on the purpose of the meeting *before* they arrive, and that they've made a conscious decision to participate, and are sincerely invested in the subject matter. Assistance with transportation, stipends, and food items should only be used to increase access and as a courtesy or extra thank you.

2. **Group doesn't include anyone who has a background in advocacy or giving critical systems feedback:** While all experience is valuable, people who have been given no support to think critically about what does and doesn't work about the mental health system or what it means to be an advocate for change are most likely to offer very skewed visions that strongly favor what already exists. There is often a process that people need to go through—especially if they've been voiceless or experienced marginalization—where they re-learn how to question, say no, build new understanding, and speak truth. Without that step, an advisory board may allow an organization to check a box, but won't lead to an empowered group that can fill the role in a genuine way.

3. **Group has no real power:** While it is a reality that advisory boards aren't, and shouldn't be, responsible for making every decision, they should have some real power, and there should be as much transparency as possible around exactly what that includes. This can be tricky territory with lots of gray, but any group that is consistently treated as if they only matter because it allows for another group to check a box is not going to be a group that is particularly sustainable or meaningful.

Of course, on the flip side, sometimes advisory boards can also run amok by having too much power. For example, it can quickly become extremely cumbersome if an advisory board insists on being a part of every day-to-day decision; deciding on the color of a new couch, for example. Rather than supporting an organization or project to hold to its mission and values, this level of micromanagement can become a distraction and actually prevent the core work from getting done.

4. **Group isn't clear on its purpose:** Even a group made up of people with past advocacy or board experience can slip into disarray if the reason for gathering isn't clear. Some of the common outcomes resulting from an advisory board that lacks guidance about its purpose includes:

- People —often those who have little or no other advisory board experience— treat it as a support group of sorts
- In-fighting and differences of opinion can become the main focus
- Members get bored or frustrated because they feel they're not accomplishing anything
- Attendance drops off for any of the above reasons

Unfortunately, all of these pitfalls, along with under estimating the amount of time and work that it takes to create and sustain an effective advisory board (which is substantial!), can not only lead to an ineffective group, but can also serve to re-enforce the idea that people with psychiatric diagnoses are not capable of forming organized and productive groups. So, how does one do things differently?

**Step 1:** Identify the starting structure and intent of your advisory board. Consider the following questions:

- Is the advisory board just for the purpose of setting up a peer respite, or will it also provide input on the broader organization or other related topics?
- Is it a temporary board? Will it only exist during the set-up process, or will it continue to serve in an advisory capacity indefinitely?
- Regardless of whether or not the board will be in existence indefinitely, for how long are people who join at the start being asked to commit to serve?
- How many people (minimum and maximum) do you want on the board?
- What is the board's actual power? Does it have the final say? Will the board be notified if its recommendation isn't followed?

- How often will the board meet, and where? Bear in mind that choosing a location that is central and easy to access by public transportation wherever possible can be important.
- Will you be able to offer reimbursement for travel expenses and/or a stipend? Some individuals who may want to participate will have very limited incomes, and may not otherwise be able to take part.
- Will you be able to or do you want to offer snacks or a meal at your meetings? Time of day may be an important determining factor.

As a part of this step, it can be really useful to create a brief write-up that includes a summary of the answers to these questions, as well as a statement of purpose and responsibilities for anyone who might choose to join the Board.

**Step 2:** Recruit for membership. Advisory boards should almost never be made up entirely of people from one group. Fresh, broad and critical perspectives are essential to an advisory board's purpose. It's also essential that the group be established with diverse backgrounds in mind. The ideal board will represent a variety of ages, races, gender identities, abilities, and experiences, and individuals building the board should go out of their way to ensure that groups that are typically under represented (people of color, trans people, deaf folks, etc.) have a substantial presence. Advertise at coffee houses, supermarkets, on Facebook, or in any other community location available. Ask friends, even those not otherwise familiar with the work you're doing, for suggestions. Put a notice on Craig's List or include mention of your need for advisory board members with a press release to various media outlets. The drive to attract new people, and especially people who do not generally have access to a lot of resources, is one reason to give serious thought to providing stipends for participation.

Note that it's often much easier to recruit and sustain membership during an exciting project. If the intent is to form an ongoing advisory board, significant work may be involved in keeping membership up when things are less exciting. It will also be important to be transparent with people when they're first joining about what things might look like on an ongoing basis.

**Step 3:** Determine roles and process. Consider the following questions:

- Will there be assigned roles like chair or vice chair, and what do those roles involve?
- Are there any meeting agreements that the board would like to put in place to guide interactions?
- Will paid employees offer any technical assistance, such as note-taking, meeting reminders, etc.?
- Will meetings be open to the public or only to voting board members?
- What other roles and decisions processes will board members be a part of? For example, do they have final say in approving a mission or values statement? Will they be a part of hiring committees?
- What happens when there's a substantial disagreement between the advisory board and paid employees?

**Step 4:** Set timelines and goals. This may be less important with ongoing boards, but particularly as a part of a start-up process, it's important to be upfront with any key dates or deadlines when things must be decided. It's also really helpful toward keeping things rolling to have some shared ideas about where the group is trying to head and when it's hoped that they might get there.

So, for example, what are there priority issues to be discussed? Is there a target date for finalizing a mission statement? What about a values statement? If advisory board members will be a part of the hiring process, when is that anticipated to take place? If the board is being set up in advance of funding being identified, is there a goal date for identifying funders?

**Step 5:** Check in routinely. Getting a little off course is normal. However, it's also normal to have trouble getting back on track if checking in on how things are going isn't a regular part of the equation. Advisory boards should regularly be considering the following:

- Are meetings generally feeling productive? If not, what might need to change?
- Is everyone in the room clear on the mission and purpose of the group?
- Has the group been keeping up with meeting agreements? Do they need to be edited?
- How is the group doing with any projected timelines?
- How is membership looking? Is it time to invite new people into the conversation?

Advisory boards can be challenging to set up and sustain, but little that's worth doing is easy. While it may be near impossible (and, in fact, undesirable) to construct an advisory board without any tension, following these steps may make it much more likely that what is created will have lasting positive impact on the shape of the peer respite that grows out of its efforts.

Note: It's important to understand the difference between an advisory board, a governance board (usually called a board of directors), and management of an organization. In brief:

**A Governance Board or Board of Directors:** A board of directors is responsible for and has the final say on the hiring and firing of the executive director, and is also expected to keep track of the organization fiscally. They also have input into (and generally have the final say in relation to) the overall direction of the organization. This may include substantial expansions, changes in geography (e.g., opening or focusing on a geographic area currently considered to be outside of the organization's area of focus), whether or not to apply for grants that would represent a substantial shift in focus area or supports offered, and so on. They are also generally responsible for final approval of major policies and procedures of the organization. While they generally are and should be interested in some of the day-to-day functions, they are not seen as responsible for them, and it can become extremely problematic when boards begin to micromanage at that level.



**Management:** Management includes the direct employees of an organization who are empowered to carry out the oversight and day-to-day activities of that organization. Although the executive director is hired by the board, all other management employees are hired, supervised, and evaluated by other leadership employees. Management of the organization also is responsible for development of programs, protocols, trainings, and other main components, and will generally make many leadership decisions throughout the course of a given week without consulting either a board of directors or an advisory board, particularly those decisions that are needed just to keep things running, and don't represent any major shift or change. Of course, in many peer-to-peer organizations, the hierarchy is flattened as much as possible, and people in managerial roles make decisions, shape approaches, and develop trainings in close collaboration with people in a variety of other roles, including non-managerial and community.

**Advisory Boards:** Advisory boards do not have the same legal responsibility as boards of directors. They are not legally responsible for fiscal oversight or for the hiring and firing of the executive director. There is a great deal more variability from board to board in their focus, as well as how much power they hold, and whether or not their recommendations are seen as binding in any way. Organizations that host advisory boards are not typically legally bound to listen to the recommendations of an advisory board, unless otherwise required by a particular funder through a specific grant negotiation.



*Illustration by Lianna Oddi from the 'Afiya House' film*

# DEVELOPING A VISION

As noted in the previous section, the first step to developing a vision is to actually begin developing a group that can go through that process together. For example, in Massachusetts, a group called the Groundhogs formed around 2009 to advocate for and begin developing the vision for peer respite in the state. Laysha Ostrow, a researcher and individual with her own history within the psychiatric system, wrote a case study about the Groundhogs process in 2010.<sup>1</sup>

The initial Groundhogs group had a statewide focus and continues to meet as of the writing of this book to discuss a number of priorities. Western Massachusetts also developed an offshoot of the Groundhogs that met independently for a period of about two years. This group spent a great discussing a number of issues and concerns including:

- What is the mission of peer respite?
- What are the underlying values of peer respite?
- What core design makes the most sense for this area?
- What basic guidelines are recommended (e.g., about ability to have visitors, drugs and alcohol, etc.)?
- What organization would make a good home for the respite?

## **MISSION**

In general, developing a good mission statement can be a key step toward clarifying the point of why such a group has gathered. Here are some sample mission statements from peer respites as they existed when this book was first printed (it shouldn't be assumed that these mission statements are necessarily endorsed by this handbook; they are only offered as examples):

**Afiya House (Massachusetts):** Afiya strives 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.

**Alyssum (Vermont):** The mission of the corporation is to provide a peer-operated, peer-staffed holistic approach to mental wellness, discovery and recovery for Vermonters who are experiencing a mental health crisis. This alternative will provide a safe, mutually supportive, non-judgmental, educational, and self-empowering environment. Alyssum will afford individuals the opportunity to engage in the principles of wellness, discovery, recovery and peer support so as to emerge from crisis with wisdom and the personal responsibility skills for living well.

<sup>1</sup> Ostrow, L. (2010) *A Case Study of the Peer-Run Crisis Respite Organizing Process in Massachusetts*. Master's project, Brandeis University Heller School for Social Policy and Management, Waltham, MA. Retrieved from [http://www.livelearninc.net/s/Ostrow\\_Groundhogs-case-study.pdf](http://www.livelearninc.net/s/Ostrow_Groundhogs-case-study.pdf)

### **Keya House (Nebraska):**

- Mental health consumers advocating for the needs of mental health consumers and groups in Nebraska
- To promote communication, education, and self-determination throughout the region and the state
- Outreach to consumers and groups of all cultural diversities
- To strengthen and maintain self-help and advocacy groups
- To offer education to diminish stigma and discrimination

The intent of a mission statement, of course, is to communicate what the project (or who the organization) is, and what some of the foundational values and goals are in about thirty seconds. Obviously, a mission statement won't answer every question, but it should at least offer a great start to doing so.

There are also lots of resources on the internet to support the writing of a solid mission statement. Although few of them will come from the same perspective or priorities, they can still be useful.<sup>2</sup>

### **VALUES**

Values are more than a statement that gets hung on a wall somewhere, although that's not an uncommon phenomenon in some organizations. An effective set of values will be used as a guide that will support a team in addressing any difficult situation that comes up and will offer a framework within which to talk with others working or staying at the respite about any related concerns, thoughts or ideas.

As a part of the original process of setting up the Western Mass Recovery Learning Community, a set of defining principles was developed that was also adopted by Afiya peer respite. These values are still actively in use today and can be viewed in the appendix section. The *Hospital Diversion Manual* developed by Peoples, Inc. in New York also offers examples of relevant values.<sup>3</sup>

Going through the process of developing a mission and identifying values (among many other conversations) prepared the local Groundhogs group to be in an excellent position to respond quickly and thoroughly when the Massachusetts Department of Mental Health put out a Request for Information (RFI) in 2010. An RFI is typically the information-gathering step that comes before a Request for Proposals (RFP) or Request for Response (RFR) is released and funding becomes available. See the appendix for a document detailing how the Groundhogs responded and for ideas on how others might respond to similar requests.

<sup>2</sup> One mission statement resource: [articles.bplans.com/writing-a-mission-statement/](http://articles.bplans.com/writing-a-mission-statement/)

<sup>3</sup> Hospital Diversion manual: [www.power2u.org/downloads/OH-Hospital-Diversion-Manual.pdf](http://www.power2u.org/downloads/OH-Hospital-Diversion-Manual.pdf)

### **Other worthwhile steps in developing a vision may include:**

- Visiting other peer respites.
- Interviewing other peer respite team members and leadership.
- Watching films about peer respite.
- Reading existing research (see outcomes section).
- Reading Shery Mead's book, *Intentional Peer Support, an Alternative Approach*. This book includes a number of essential points about the foundational philosophy of peer respite (available at [www.intentionalpeersupport.com](http://www.intentionalpeersupport.com)).
- Review Laysha Ostrow's and Bevin Croft's *Toolkit for Evaluating Peer Respites*. This document provides a great deal of information, including a summary of how peer respites have addressed a variety of questions and concerns.<sup>4</sup>

Some prospective peer respites or groups in visioning processes have interviewed existing peer respites by phone, a task with which an intern or volunteer can sometimes be very helpful. Some questions to consider asking:

- How many people can stay at your respite at a time?
- Does everyone have single rooms?
- Do you have people staying at the respite who are homeless?
- Are people working at the respite allowed to sleep during the overnight?
- What do you do if someone says they're suicidal? What do you do if someone self-injures?
- Do you have an office in the respite space?
- How many team members are working at any one time?
- What trainings do team members go through?
- Is your respite a part of a larger organization? If so, what kind of organization?

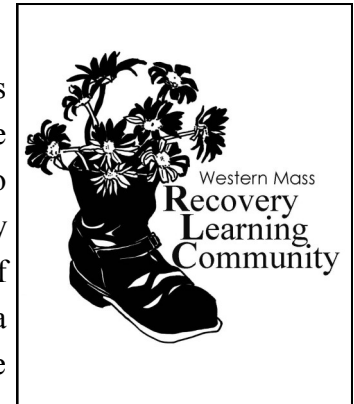
Those involved with starting Afiya engaged in this process and found that all respites that were contacted were very responsive and willing to answer questions. Overall, getting out in front of the funder and having a clear vision makes it all the more likely that the end product will be much closer to the ideal. However, that's not always going to be possible in many areas where funding is already or about to go out for bid. Nonetheless, in those instances, incorporating as much of this process as possible and involving people from the community will still have great value.

<sup>4</sup> Ostrow, L. & Croft, B. (2014) *Toolkit for evaluating peer respites*. Lawrence, MA: National Empowerment Center. [http://www.peerrespite.net/s/Peer-Crisis-Respite-Toolkit\\_FINAL-fpjd.pdf](http://www.peerrespite.net/s/Peer-Crisis-Respite-Toolkit_FINAL-fpjd.pdf)

# INDEPENDENCE VS. UNDER AN UMBRELLA

Determining whether it's best to partner with an existing organization to bid on a peer respite contract or attempt to get it funded is challenging and comes with many pluses and minuses on every side of the equation.

To return to the Massachusetts example, ultimately, the Groundhogs determined that they did want to recommend a partnership and the organization with whom they wished to partner to bring the peer respite into fruition was the Western Massachusetts Recovery Learning Community (RLC). Together, the Groundhogs, the RLC team and the Guiding Council of Western Massachusetts (the RLC's advisory board) joined to develop a response to the RFR document, and funds were formally awarded in the spring of 2012.



It's worth noting that this process of spending some years developing a vision and selecting a partner organization to host the final project was also similar to the genesis of the RLC itself. Specifically, the Guiding Council of Western Mass (GCOW) developed in 2005, and spent two years visioning the RLC before it was funded in 2007. GCOW also took it upon themselves to interview umbrella organizations with whom to partner and support the RLC's development. Their standards for selecting organizations for interview included:

- Must not provide any clinical mental health services.
- Must be well-established as an organization and a 501(c)3 non-profit, including the ability to hold state contracts and provide all the necessary fiscal and human resources support.
- Must be an organization that is already peer-to-peer or has substantial experience supporting peer-to-peer efforts.
- Must have a mission and values that are consistent with the RLC's own.

GCOW interviewed four different organizations that met these basic qualifications. Some of the questions they asked during interviews included:

- Can you tell us more about your values and mission?
- What experience do you have supporting peer-to-peer communities to develop?
- What administrative rate do you charge to the contracts you hold?
- What sorts of supports and resources might you be able to offer beyond the obvious (payroll, billing, etc.)?

- Although we are looking for mutual support and partnership, we also require a great deal of autonomy in how we will managed our hiring, budget and day-to-day facilitation of our work. How will you support this level of autonomy?
- If we choose to spin off into an independent organization at a later date, how will you support us to do that?

Through this process, GCOW ended up selecting the Western Mass Training Consortium ([www.wmtcinfo.org](http://www.wmtcinfo.org)), and the partnership has been a healthy one that was also advantageous during the peer respite application period. For example, the RLC was able to make use of an existing relationship the Consortium had with a landlord to obtain a desirable property for the house. For local and currently unaffiliated groups that are considering developing a peer respite under the umbrella of a larger organization, this process may also be worth considering.

Of course, as noted in the Core Design Elements section, there are several potential pitfalls involved with joining with a larger organization to create peer respite. These include:

- Even if the leadership of the organization is supportive at first, just one key change in leadership could significantly change the organization's direction.
- It may be harder to develop an independent identity under the umbrella of a larger organization, and especially if that organization is resistant to the respite's developing its own website, having a separate phone line or system, or has strict policies about inclusion of the umbrella organizations name on all documents.
- There's greater potential for loss of control related to hiring, budget and various administrative guidelines.
- There's greater risk for being pulled away from the values and mission of the respite.
- There's greater risk of energy being pulled away from the respite and toward other parts of the organization.
- There may be greater risk of potential competition for new grants and funding sources (many grant opportunities accept only one application per organization) or not qualifying for certain grants that have total budget limits due to the organization's larger collective budget.

Although these risks tend to be bigger when partnering with a clinical organization (it's difficult to implement a non-clinical approach when the organization supporting the respite is fully immersed in a clinical perspective!), this can happen even in peer-to-peer organizations.

On the other hand, the benefits are also many, including:

- Getting to skip over the process of incorporating as a non-profit and becoming eligible to

accept other types of funding, including state or federal grants.

- Being able to lean on the established credibility of the organization when applying for grants or soliciting new funders.
- Not having to worry about all the details of payroll, fiscal audits, billing, health insurance and so on.
- Not having to worry about obtaining independent liability insurance. Many larger organizations will be able to cover any new programs under established insurance policies.
- Having more checks and balances in place when there is a complaint or grievance filed.
- Having a broader network of support to call upon during difficult times.
- Not having to establish a full Board of Directors, although, it's still advisable to establish a separate advisory board, particularly if the larger organization is not peer-to-peer.

#### **About the Foundation Center**

**([www.foundationcenter.org](http://www.foundationcenter.org)):** Established in 1956, Foundation Center is the leading source of information about philanthropy worldwide. Through data, analysis, and training, it connects people who want to change the world to the resources they need to succeed. Foundation Center maintains the most comprehensive database on U.S. and, increasingly, global grant makers and their grants — a robust, accessible knowledge bank for the sector. It also operates research, education, and training programs designed to advance knowledge of philanthropy at every level. Thousands of people visit Foundation Center's website each day and are served in its five library/learning centers and at more than 450 Funding Information Network locations nationwide and around the world.

For groups that have considered all these pros and cons and prefer to set up an independent organization, there are several considerations including, but not limited to:

- How to incorporate as a non-profit.
- How to set up a Board of Directors.
- How to become eligible to accept contracts from the relevant funding source.
- How to develop all the necessary policies involved with hiring, paying and providing insurance to employees.

Although contacting other peer respites, or even other organizations that don't offer respites but focus on peer-to-peer support is always a great way to go, another potential source of support is the Foundation Center on-line.

In addition to providing a great deal of information about potential funding sources, the Foundation also sponsors a separate website called Grant Space at [www.grantspace.org](http://www.grantspace.org). Between the two sites, there is lots of information on topics like articles of incorporation, outcome measures, and more.

# DEVELOPING A BUDGET

Developing a realistic budget for a new project can be exciting, but challenging at the same time simply for all that is unknown. This is especially true for people who've never had to develop a budget before, and who may not be as familiar with the hidden costs involved.

It also means knowing some of the details involved with the project, or at least being able to make an educated guess. Some of the details it's hard to move forward without include:

- The number of people or Full Time Equivalents (FTEs) planned for hire (i.e., the total average number of employee hours being paid each week, regardless of how many individuals those hours are split among).
- The starting pay rates for each type of position.
- The likely cost of rent and utilities for a respite space.

Although developing the respite team will be discussed in more depth in a later section, there are two important points to consider here in relationship to budgeting:

1. **One person working alone (or too few) too often throughout each day doesn't work well.** The main support available in a respite is peer-to-peer support. This can look like long and in-depth conversations, a willingness to just sit with someone, the ability to go on walks together, and so on. On top of that, team members will inevitably have other responsibilities, including cleaning and maintenance, completing paperwork, and, quite likely, answering the phone, particularly if there is a strong support line component without separate coverage. Having someone working alone too often is not only likely to burn them out, but just isn't enough to focus on making peer support readily available to multiple people going through hard times. Bear in mind that, while part of the peer respite model includes people staying at the space also being able to support one another, the reality is that sometimes that works great and sometimes it doesn't work at all. In a perfect world, even in respites where only three or four people are staying at a time, two people would be available to support the space at least for the bulk of daylight hours. This also expands the potential for going with someone to explore community resources, etc.
2. **Low payrates don't generally pay off in the long-term:** Low payrates can lead to team members feeling under-valued. It can also leave people facing the reality that they simply need to



take additional jobs to make ends meet, which means their time will be divided, and the likelihood of burnout may be even higher. It's also worth noting that, while many people meet the basic qualification of having personal experience with emotional distress and receiving mental health services, far fewer people are truly talented at mastering all the nuances of peer-to-peer support. In fact, there's a relatively small pool of people who: a) identify as having personal experience; b) are willing to be open about identifying as having personal experience; c) are really good at peer-to-peer support; and d) want to do this work. Good employees really are worth keeping! It's also far more challenging to raise rates down the road than it is to simply start there in the first place. It may be worth considering a minimum starting rate of *at least* 60% per hour above the minimum wage for all permanent positions, at least in countries where there is still a substantial discrepancy between the legal minimum wage and what is seen as a living wage.

Ultimately, everyone's budgets look somewhat different. Line item titles vary and how funds are grouped can also be different from organization to organization. However, at a minimum, when developing a respite budget, the following lines (whatever they may be called and however they may eventually be grouped) should be included:

- **Salaried and hourly wages:** This includes all salaried or hourly employees, including if there are any employees in oversight roles who might just have an hour or two paid by the contract each week, and per diem/relief employees who will fill in when permanent employees are out sick or on vacation.
- **Fringe benefits:** This incorporates (at a minimum) health benefits, payroll taxes, workers compensation expenses, and other benefits that would be enjoyed by workers in respites or jobs with similar roles and responsibilities.
- **Real estate taxes/rates and property insurance:** This line will vary depending on the set up of your particular respite, whether you own or rent, and the by-laws and particulars of your geographical location.
- **Utilities:** Think gas and electric, but also phone, internet, and cable. This line may also include trash removal, sewer costs, water bills, and other fees specific to your location.
- **Repair and maintenance:** This line includes general maintenance and upkeep on the space, and also snow removal/plowing expenses and other weather or location-specific expenses where applicable.
- **Rent:** This line will include rent or mortgage payments. If you are in a part of the world where a mortgage is being paid in combination with property taxes, just be sure that property tax expenses aren't represented in multiple places within the budget.

- **Professional fees:** If any consultants will be contracted (to set up a web page, design marketing materials, offer learning opportunities, provide services or healing alternatives like acupuncture, etc.), then this is the line where that cost will show up.
- **Staff training:** This line will hold all expenses related to initial and ongoing training costs such as trainer fees, training space and supplies, and so on.
- **Mileage:** This is the line where mileage reimbursement for driving to outreach events, to trainings or meetings, or to explore the community with someone staying at the space land. This line also usually covers any related parking or toll fees.
- **Food:** This line represents the weekly food budget, as well as any extra food expenditures (occasional pizza, holiday meals, etc.) that are planned
- **Program supplies:** This line generally covers any planned expenditures on items that are primarily for the use of people staying at the respite (for example, books, yoga supplies, etc.)
- **Household supplies:** This line generally covers items like dishwasher detergent, laundry soap, paper towels, and so on
- **Office supplies:** This line usually covers all items that are necessary for the operation of the project and that are primarily purchased for an employee's use (computer paper, ink cartridges, pens, etc.)
- **Equipment rental:** If there is a rented copier or other similar equipment needed for functioning of the project, this is where that expense will usually land.
- **Dues and subscriptions:** If there are magazine subscriptions, dues paid to a wholesale club or local food bank, or other repeating fees of that nature, they will usually land here.
- **Advertising:** This line covers any fees associated with posting job ads, as well as any fees associated with paid advertisements of the respite
- **Indirect/Administrative expenses:** This line item represents the fee generally charged to a particular program or project that goes back to support the activities of the larger organization. In other words, it's this fee that helps pay for the salary of the person working in billing or payroll and so on. The administrative rate can vary substantially from organization to organization, but it's not unusual for it to fall somewhere in the 10% to 20% range. The administrative rate is usually charged against all program expenditures (except for those that are considered 'capital expenses'). If there is no larger organization, direct costs for fiscal and human resource support need to be factored in.

If property is owned, depreciation is another factor that may need to be accounted for in a budget.

Bear in mind that there are also substantially different types of contracts and ways that payment happens that can impact some of these calculations. As noted in a prior section, the two most common types of contracts include:

- **Cost reimbursement contracts:** This is where a set amount of money is designated by the funding source for a given year, regardless of how many individual people actually use the support. Billing happens as money is actually spent. Any overages become the responsibility of the organization, and any money unspent is lost back to the funding source.
- **Unit contracts:** This type of contract is set up so that a funding source agrees to pay a particular rate for each service provided and/or person supported. The major upside of this type of contract is that organizations can sometimes spend additional income above and beyond what was expected or needed to operate the program on anything they like. In other words, if the support is being used a great deal and income is higher than anticipated, the additional funds may be able to be spent at the organization's discretion with no expectation that they be returned if not spent on the project itself. However, this model comes with a huge risk which is that if the support goes through a slow period, there may not be enough funds available to sustain it during that time. Another major drawback is that unit contracts tend to require more documentation and proof of need for the particular person being supported.

There are many more variations as to what these contracts can look like. For example, some unit contracts have what is called an "accommodation rate," which bases payments on overall supports provided, rather than person by person, and can look very similar to a cost reimbursement contract in that way. Further complications can also be added when Medicaid reimbursement or other managed care gets involved. This is because there are often much more stringent regulations (such as determining "medical necessity" for any support provided, language that must be used, required documentation, etc.) involved in how the support is provided in order to qualify for reimbursement.

Many peer respites tend to prefer the reliability of the cost reimbursement-style contract. Also, since the values of peer respite support as minimal documentation as possible and don't really fit within a model of "medical necessity," the requirements of a unit rate or insurance-based contract can often be a deal breaker. However, as explorations with managed care continue, unit contracts are also being more deeply considered and creative ways to manage the drawbacks are being discussed in some circles.

# SAMPLE START-UP TIMELINE

The timeline for the start-up process can be highly variable, and often is at least somewhat impacted by the requirements of the funder. A one-year timeline, especially if you do not already have a space identified for the respite, is ideal and is a good starting point when making a proposal, but it may be a rare funding situation where that is possible.

Below is a sample of a 6-month start-up timeline that may be helpful at least as a beginning point for consideration. Bear in mind that it assumes that a peer respite is already established as an organization (or partnered with one), and a property has already been identified. Remember, taking the time needed to get everyone ready and set up well is important. It's hard to back track once the respite is up and running.

Timeframe	Activity
<b>Month 1</b>	Create cost center and address any other basic start-up needs for fiscal processing
	Formalize the lease/purchase agreement for the site
	Submit licensing application where applicable
	Post job ads for all peer respite positions
	Establish training plan for new hires
	Contract with web developer to set up website
<b>Month 2</b>	Begin any necessary property renovations
	Implement outreach plan to neighborhood
	Identify list of wants/needs and begin purchasing
	Conduct interviews
	Create flyer and brochure
<b>Month 3</b>	Complete property renovations
	Begin furnishing/decorating space
	Outreach to local police and legislators
	Process applications and making hiring decisions
	Print flyer and brochure
	Set up all utilities not already established
	Newly hired team members in leadership roles begin work

Timeframe	Activity
<b>Month 5</b>	Complete website
	All other peer respite hires begin work
	Formal training for peer respite team begins
	Advertise opening of peer respite through website, press release, etc.
	Implement (ongoing) intensive outreach plan to local providers, etc.
	Develop needed forms and guidelines
	Begin distributing peer respite brochures/flyers
	Complete any finishing touches on the set-up and decoration of the space
	Hold open house
	Complete development of all necessary peer respite guidelines and meet with team to review
<b>Month 6</b>	OPEN!
	Meet weekly as a team to evaluate initial opening process and make tweaks as needed

# ADVOCACY & FUNDING

The most common source of peer respite funding comes from local government budgets (states, cities, regions, etc.) geared toward healthcare and “mental health.” Other funding sources have included:

- The federal government (for example, in the US, Substance Abuse and Mental Health Administration)
- Individual donors
- Private foundation grants
- Managed care companies
- Larger organizations
- Pay by person

As mentioned in the core design elements section, there are pluses and minuses to each of these funding sources, some more than others. For instance, funding through managed care companies tends to come with the most strings, documentation requirements, and expectations of “medical necessity,” all of which are in conflict with the most basic respite values. For some people, these are deal breakers, and they’d rather see no peer respite than one that falls so far short of what the approach is intended to be. However, others have attempted to push and explore whether more creativity is possible within these systems.

In an ideal world, funding for each respite would be diversified. This comes with multiple benefits:

1. If one source is lost, others still remain and may even be willing to increase funding in some instances to help save the support.
2. If one funding source doesn’t like a particular activity or approach, it can simply be applied to another funding source that doesn’t have the same restrictions allowing for more flexibility all around.
3. New potential funders often like to see that an array of funds has already been secured. This is generally because they are more inclined to want to fund sustainable projects that are doing the work to ensure their future.

Unfortunately, there aren’t any magical tips for uncovering enough funding to startup a respite or to convince a government office that they should re-organize their budget in order to be able to do so. However, there are some activities that can be helpful in moving this goal forward including:

- Inviting government or other funding source leadership to visit a nearby peer respite alongside others who are already planning on taking the trip.

- Compiling research and any convincing statistics on decreased costs and improved quality of life.
- Developing a local or statewide advocacy group to expand and promote this agenda (see the building blocks section).
- Keeping an eye out for any federal or regional innovation grants. These may not be expressly for the purpose of starting a peer respite, but peer respite might fit within the possibilities. Additionally, some grants may only provide funds to further develop your plan, bring in training or similar but that's still a step in the right direction!
- Ask a local department or other funder to support a first step, like bringing in Intentional Peer Support training, or funding a local strategic planning meeting, or creating an event with a speaker or movie from a peer respite.
- Ask around for ideas about private donors. They're not easy to find, but they are out there!
- Search for grants that can at least help with some part of getting started.
- Develop relationships with local legislators and make sure they know about your idea.
- Brainstorm ideas on how to obtain property. A private funder may not want to provide the ongoing budget, but a one-time purchase of property may be more reasonably in reach.
- Talk with local organizations who are likely to be allies or potential partners down the road, and who can help with talking up the idea of bringing peer respite to the area.
- Schedule a screening and community discussion of an existing peer respite film. For example, the Afiya film is available on line.<sup>1</sup>
- Create a short film to promote your mission. For example, a group in Florida developed a promotional film about starting a peer respite and posted it on-line.<sup>2</sup>

Ultimately, just about any effort that moves things in the right direction is probably worth it!

<sup>1</sup> *Afiya Film*: [bit.ly/2El4lHq](http://bit.ly/2El4lHq)

<sup>2</sup> *Florida film*: [bit.ly/2BZeR5s](http://bit.ly/2BZeR5s)

# Setting Up House





# IDENTIFYING A SPACE

Finding the best spot for a peer respite can be an extremely complicated and imperfect process, and there is a great deal to consider along the way. Although this section has more questions than answers, hopefully it offers some help in the process of thinking it all through.

Although timeline and funding requirements may dictate more of this process than is ideal, it's nonetheless important to start with defining one's vision. In other words, if there were no practical barriers (cost, zoning, funding requirements, etc.), what would the ideal peer respite be like?

**Here are some questions that may be worth considering:**

- How many people will be able to stay at the respite at any one time, and will they have their own private bedrooms? There is a fine line between wanting to create enough opportunities and maximize the investment, and creating a 'mini-institution,' which may also be stressful and hard to manage in the spirit of peer respite, and may ultimately reduce its overall impact. It is highly recommended that everyone be able to have a private room. Sharing a room with a stranger can be very hard and even re-traumatizing for some people, and is likely to detract from someone's ability to freely set their own schedule. If that's absolutely not possible, it's recommended that there be a way to section off parts of rooms or have privacy screens in place.
- Are you looking for a space where everything is on one floor? Upside: All rooms can be made accessible. Downside: People may feel more on top of one another than if there were multiple floors.
- Beyond the bedrooms, bathrooms, kitchen and living room, what other rooms are you hoping to have available? It's definitely a plus to have multiple common areas so that people can have more flexibility around how they connect and what they're doing.
- What sort of space will you need for food and supply storage?
- How close do you want to be to neighbors?
- How will the space support access to private conversations that aren't easy to overhear and the ability to meet the needs of someone who wants to be sleeping at the same time that someone else wants to be up and moving around?
- How important is it that the space is easily accessible via public transportation?
- What geographical area are you trying to cover; where does someone need to be living in



order to access the respite, and what does that mean for where you want to be located?

- How important is it that you have a nice back yard, access to walking paths, etc.?
- How important is it that the area you're in be quiet and away from the center of any town or city?
- How important is it that there be at least some stores within walking distance?
- Will you want to steer clear of things like regular ambulance routes? If you're at all near a hospital, you'll find that some streets are regularly used by ambulances and other emergency vehicles, which could mean that sirens become a regular part of your backdrop.
- Do you want to be able to have a garden or space to be outside?
- Will people other than those staying at the respite have access? Will you be incorporating a general drop in space or will there be other regular visitors? If so, what kind of layout is needed to ensure that people staying at the respite still have some privacy? Is a room with a separate entrance ideal?

*“Overall, I’m really happy with the space we chose, but boy, do I wish I’d realized we were right on an ambulance route. The sirens are definitely an issue at times. Unfortunately, we didn’t even think to check for that.”*

- Respite team member

- How diverse is the community you will be supporting, and will a variety of people be likely to feel welcome in the neighborhood you're choosing? It is important to consider those who have been most marginalized in our communities, and select locations that maximize the potential for their needs to be met. Regardless of where the space lands, it will also be important for people working in the respite need to consider what they can do to make the space itself an environment that is welcoming to people from a variety of cultures and backgrounds.
- Will there be group meals some or all of the time? What sort of space will be needed to accommodate large group meals?
- What are your requirements and/or goals for making the space accessible? What sort of space will be needed to ensure doors are wide enough, and a ramp and wheelchair accessible shower can be added?
- What sort of space will you need/want for laundry?
- Will you need to be licensed by the state or some other entity? If so, what are the requirements for spaces of this nature? (e.g., two exits on each floor, etc.)
- Will you want to be able to accept donations like extra clothes to give to people who are staying, and if so, what kind of space will you need for that?
- Will you want to be able to offer any storage to people who stay at the respite if they're not able to take all their belongings with them when they leave, and if so, what sort of space will you want for that?
- Will people working at the respite be able to rest during the overnight, and if so, what sort of space will they need for that?
- Are you considering having an office space, and if so, what will that need to accommodate? (Per the Peer Respite charter, we highly recommend that "staff only" areas be eliminated or minimized as much as possible.)
- What sort of parking do you want to be able to offer both for people working and staying at the respite?
- Are there any areas where you're aware there's already been a community problem around residential or other similar programs moving in?

Beyond the overall vision, there are at least a couple of practical considerations including:

- Zoning issues
- To rent or buy

## **Zoning**

Zoning issues can be particularly challenging, especially as the various ins and outs are often not common knowledge. The zoning for a specific property can generally be found by contacting the local planning agency in the given area. Contact information for the local planning agency can usually be found by using the Internet to search on the term “planning,” along with the relevant city and state.<sup>1</sup>

The good news is that, in many areas, as long as the number of people staying at any one time is below the designated threshold, peer respites can typically qualify for areas zoned for single-family homes. Based on a brief review, it appears that the threshold is between 4 and 6 unrelated individuals at any one time in most regions (few peer respites have more than four bedrooms available), but it’s important to check local ordinances for applicable details.

It’s also important to note that it’s sometimes possible to apply for and receive a “use variance.” This is not a change in zoning, but a specific exception for a particular property to be used in a way that differs from the zoning. If one applies for and receives a use variance, there are likely to be conditions that come along with that from the particular municipality that is approving the variance.<sup>2</sup>

## **To Buy or Rent**

This is an issue that is often decided by available budget, available credit and other resources held by the organization or group starting the respite. When in a position to consider both options, though, here’s some food for thought:

The major plus with buying is fairly obvious: There’s no landlord who’s able to ask the respite to leave because the relationship has broken down, there have been problems and/or the landlord has decided to sell the property. There’s also generally much more freedom to make renovations or changes to the property as desired.

On the other hand, the major plus with renting often comes when there’s a problem with the structure (a leaky roof, etc.) and someone else is responsible for the expense and repair. However, sometimes landlords will still charge tenants for the cost of repairs, depending on the type of repair and the particular landlord’s practice. Additionally, should funding be lost for any reason and the respite needs

<sup>1</sup> Additional useful information for those based in the US may be found at: [www.sba.gov/content/basic-zoning-laws](http://www.sba.gov/content/basic-zoning-laws)

<sup>2</sup> Additional helpful information may be found at: [realestate.findlaw.com](http://realestate.findlaw.com)

to close or move, an organization can stand to take a much bigger financial loss if they're left holding property, as opposed to needing to break a lease.

As options are being considered, it's a good idea to consult with other organizations that have been through the process, especially if the organization currently considering this matter has never undertaken a project that involves property in this way, and to consult with someone who has the relevant financial knowledge needed to assess the capacity to make a purchase if that is being seriously considered.

Here is just a small sampling of how some respites were handling their spaces as of the writing of this handbook:

**Afiya (Massachusetts):** Afiya rents their house. Their umbrella organization had a pre-existing relationship with a landlord who was interested in searching with them for a house that worked for their needs. They found a house that was a good fit, the landlord bought it, led renovations on it and leased it to Afiya. This arrangement has worked well overall.

**Alyssum (Vermont):** Alyssum owns their house. Their state Department of Mental Health allowed them to use left-over funds to make the down payment (not something that is allowable in all areas), and now they're in a position where their mortgage payment is cheaper than rent would have been, not to mention that the house is now seen as a 'corporate asset.' They also have found that owning the property has paved the way to making renovations as suits the respite.

**Georgia Respites (Georgia):** Georgia now operates five peer respites, all of them on rented properties. In two instances, allies who wanted to see a peer respite in their area bought properties and now rent them as peer respites. The other three houses are through landlords that were found through a normal search for rentable property. All of their rental relationships have worked out well thus far.

**Second Story (California):** Second Story rents their house. This decision was based largely on financial reasons (the grant secured would not pay for property purchase), and there is still thought of owning property someday which they feel would be preferable. Their experience of the downsides of leasing includes the fact that the rent goes to the landlord and not to greater investment into the community and neighborhood. If they were able to own the property, they indicated that they would also feel more secure overall, although the landlord has been very responsive and supportive, and has allowed them a lot of flexibility with the property. They also noted that if the peer respite contract were ever to end, owning the property would enable them to make use of it in a different way.

# SETTING UP A SPACE

As with most interior decorating projects, putting together a respite is a LOT of work! One of the more useful first steps might be to enlist some help. Having a team chosen before putting the interior of the space together is a great way to get that help. Before the respite is open, that team will have lots of hours to devote to:

- Identifying what items are needed.
- Finding and purchasing those items.
- Selecting a color scheme and painting.
- Cleaning.
- Putting furniture together.
- Selecting and hanging artwork.
- Organizing the library.
- And so much more!



A.P. Grant, [www.gesturalphotography.com](http://www.gesturalphotography.com)

This can also be a great way for a newly hired respite team to bond with one another before they're officially needing to focus on other people in the space.

Another wonderful place to possibly get support is the local community. When people know what the inside of a space looks like, it can sometimes be less intimidating, and if they have a part in putting that space together, there could be a sense of ownership that gets built along with that. One respite put a wish list online and advertised it (with links to the specific items required) via social media and other websites. People who supported the venture were pleased to have the opportunity to contribute, and it created positive relationships with a wider group of supporters.

This is also where being a part of a larger organization may come in handy. Putting the word out and getting help from people working in other areas of the agency may not only reduce stress on the respite team, but is likely to help the rest of the organization become familiar with what the peer respite is all about. This is likely to come in handy down the road for purposes of outreach, support and so on.

Another place to look may be among funders. Not only is it nice for them to know what their funds are going to, but it can also be a great way to strengthen your relationship. Painting side by side in a hot space will do that for you!

*“To this day, we still like to point out which bedroom at the respite house that the Area Director from the Department of Mental Health was responsible for painting! It was definitely meaningful to both her and us.”*

- Respite team member

## **Purchasing:**

As an overall guide, it's great to choose calming colors, comfortable furniture and fun artwork for a peer respite space. While donations can be wonderful, there have been many instances where peer support programs have received second-hand furniture and other hand-me-downs because of lack of funding and/or interest. So, buying new furniture and decorations can be a nice way to respect the project you're starting and to show that both the space and the people who will be staying in it are valued as much as any other space or group. However, finding a person with a good interior decorating eye can make a creative and homey environment no matter what the resources.

Additionally, even when the budget is high, it can be important to not go too far overboard and decorate the space so lavishly that people feel out of place and unable to touch anything and/or relax. It's also important to consider whose culture is being represented when putting a space together. This means bearing in mind both ethnic cultures and socioeconomic ones. It's impossible to get one space just right for every person who may enter it, but taking the time to consider all these pieces will go a long way toward helping the space feel respectful and accessible.

The list of what to buy is quite possibly endless, but the basics include:

**Furniture and rugs:** Comfy is good. Especially the beds and living room (or most frequently used common space's) furniture. Couches and chairs are good. Reclining chairs, rocking chairs and the like tend to be popular.

*"I wish I'd known that new furniture was a potential problem for people with multiple chemical sensitivities. I had no idea, but we learned quick when someone with MCS came to stay with us the first week we were open and couldn't stay as a result!"*

- Respite team member

### **A word of caution about new furniture:**

New furniture is recommended for a peer respite as a show of respect and value toward the work you will be doing and the people who will be coming to the space for support. However, one part of making a space accessible is to be aware of the chemical sensitivities that some people experience.

As it turns out, new furniture (rugs, too) comes with a new furniture smell that may be undetectable to some but unbearable to others. These items go through a process of what is called off-gassing—releasing the chemicals that were trapped, frozen or absorbed when the new furniture was made. This process can take a few months to a few years to complete.

Some new furniture is much more likely to cause a problem than others. Furniture that has been sprayed with stain-resistant chemicals is often the worst, but any furniture that is made with formaldehyde (common in particle board) is often problematic. Glue used to lay new flooring can also cause problems, though commercial ozonators can help clear the air.

Your options? Look for high-end used furniture, solid wood items, or ones that are labeled as "ultra-low-emitting-formaldehyde" or "no added formaldehyde." It's also possible to seal some items using non-toxic sealants or paint.

For more information about Multiple Chemical Sensitivities: [www.multiplechemicalsensitivity.org](http://www.multiplechemicalsensitivity.org)

Beds should be large enough to accommodate many shapes and sizes of people and to give people room to roll around on. A good quality mattress also goes a long way and could last a good long time. For the accessible rooms, people might be transferring from wheelchairs onto the beds, so make sure they are the right height for that purpose, but bear in mind that different heights are ideal for someone using a walker versus someone using a wheelchair. Removable bed risers may be good to have on hand for this purpose, and waterproof mattress covers are highly recommended. Also, for the accessible rooms, omitting the floor covering might make getting around a little easier, and reduce the likelihood of allergy issues arising. Durable furniture is important, as well. Remember, lots of people will sit on these couches, chairs, and beds. Testing them out in the store is a really great idea as opposed to buying them online, although, buying online can be very convenient. Talking with the team about what furniture they would like in the space can be a nice way to create that ownership of the space mentioned earlier.

For people with chemical sensitivities, new furniture and rugs can be really intense. Try to buy these new pieces early enough to give them at least a little bit of a chance to release the chemical scents.

**Appliances:** A big refrigerator is important. Depending on the food budget and whether or not people are also encouraged to bring some of their own preferred items, the refrigerator might be filled not only with the normal weekly food staples, but with those of several others. Having enough space for each person to have a shelf is ideal, but not always possible. Think about other common basics. For example, will you need a good-sized coffee maker? Tea-making tools? A toaster and microwave? A grill? An industrial strength washer and dryer is something to seriously consider, even if it seems a bit pricey. Laundry will be a frequent activity! Many respite find that a nice dishwasher is well worth the cost. It's also worth noting that getting warranties for appliances and other furniture can be a really smart decision. However, be sure to check the terms of the warranty, as some will be considered null and void if the company learns the appliance isn't being used in strictly a private, single family setting.

**Library:** Having a wide variety of books (history, art, healing practices, politics, etc.) available for people to peruse can be really valuable for their stay. In particular, some people find it very supportive to read books on human rights and social justice perspectives, as they can provide context and understanding for one's own life struggles. The generic version of WRAP, *Action Planning for Prevention and Recovery*, is available for download free on-line.<sup>1</sup> Books about hearing voices and other alternative ways of seeing distress are good, as are poetry and novels. Also, for the blind or sight impaired community (or for people who have trouble focusing on words on a page for any number of reasons), books on tape or CD are important. It's worth budgeting for some of this, but books are also a common donation item from book dealers, stores and the community at large.

<sup>1</sup> *Action Planning*: <http://bit.ly/1SHZ1hI>



**For fun:** A constant “crisis” focus can get a person down, so have some entertaining things around for everyone to do/use! Board (and other) games are a fun way to come together in the space. A ping-pong or pool table can be a great way of connecting. Also, good quality art and knitting/crocheting supplies and lots of paper are good. Art supplies should be meaningful and not of the ‘popsicle-stick crafts’ variety. This doesn’t mean that everyone needs to be a serious artist, but having old kid’s craft supplies can come across as insulting. Musical instruments (with headphones), crossword puzzles, word-searches, mandalas to color, and finger and full-size puppets will likely be well-used. Consider some outdoor games, as well, like bocce, volleyball, horseshoes, etc. Some respites have real and electronic (Wii, X-Box) exercise equipment that sees a lot of use, although finding an unobtrusive way to secure smaller electronics will also be important. Remember, these items may seem trivial or like they feed into the idea that a peer respite isn’t a place where people go when in real distress, but the truth is that these items are used to form connections, distract from emotional and physical pain, and express emotions when words aren’t possible or helpful, so they’re all pretty important in their way.

**Sensory tools:** In setting up the environment it will be important to consider the varied sensory needs of people who may stay there. This will mean prioritizing the availability of quiet spaces, as well as items like fidget and textured toys, weighted blankets, noise blocking headphones, and cushions.

**Computers (and software):** Computers can be an essential way that people stay connected to their families and friends and/or research resources. They can also be used for job and housing searches. Having not only computers, but also printers, scanners and the ability to send faxes can also be very helpful for related tasks. A wireless router is important for people who bring their own computers.

When thinking about computers, it will also be important to consider computer programs you may want. What programs will people working at the respite need access to in order to complete required tasks like keeping databases? What sort of security will there be on the computer? Security programs can be particularly tricky. It’s likely that, at some point, someone will download something that will contain malware (malicious software designed to cause problems or steal data from the computer). It’s also likely that, at some point, someone will look at content on the Internet that others might find offensive.

There are a wide variety of programs available that can block particular content, viruses and malware, and these programs are popular at public libraries and various other places where computers are made available. However, there are a number of pros and cons to deciding what is best for a peer respite. At a minimum, some sort of virus protection is essential, but content blockers are a bigger deal. Many people who’ve received mental health services are particularly sensitive to being treated like a child, and content blockers can leave people with that impression. This is particularly true because content blockers often fail to distinguish, for example, between a site that focuses on pornography and one that focuses on information about sexually transmitted infections.

**TV:** Depending on what someone is looking for from their stay, there might be a lot of television use. One of the more important things to think about in this case is placement and noise level. Some of the things people are watching on TV might be really challenging for others staying at the respite. Having two TVs some distance from each other may be useful. Also, having the TV room in an out-of-the-way space, rather than as the center point for the space can help, in terms of building connection and not having it take over, or leaving some people who aren't interested in television feeling alienated. Having televisions in each room is a possibility. A benefit to that might be that people get to watch what they want. However, a downside might be that people end up in their rooms not making too much connection with people working and staying. Be sure to consider the extras, such as DVD player, Roku, and video game console, if possible, so that people have more choice with how they use the television. A couple of sets of wireless headphones can also be a good investment if the space is shared.

**Safes:** In peer respites, it is a hope that not too many places will be locked or will be places where only team members can go, but there are some things that may need to go in a safe (for example, petty cash) regardless of whether there is a formal office area. Also, people coming in may have valuables or medication they want to keep locked up, so safes for each room can be helpful.

**Kitchen supplies:** A lot of cooking is likely to happen in the space and some of the less sturdy cookware will wear out quick. Consider some good quality pots and pans (perhaps stainless steel) and some heavy-duty baking dishes. Cooking is so enjoyable and calming for some people, so having great tools to do that with is very practical. A large wok can be important, as well, as there will sometimes be several people eating the meal together. And yes, knives will be needed, and no, they shouldn't all be locked up and kept in a separate sharps container, which presumes that people coming through the space are somehow unsafe and not responsible for themselves.

**The Art:** Whenever possible, there is great value in prioritizing art made by the community. It goes a long way toward adding spirit and ownership to the space, and bringing pride to the community. Note: It's also important to avoid signs like "staff only" or rule lists, and posters of the inspirational quote variety, as they also can come across as insulting and patronizing.

*"Every piece in this house was created by someone in our community. I love knowing exactly where it all comes from. Every piece has a story, and it's so nice to be able to share some of them when we're giving tours.*

- Respite team member

**Food:** This will likely be a week to week thing. However, buying dried goods and other non-perishables in bulk is a great way to make the food budget stretch. Some things that may go fast are mac and cheese, canned soups, coffee, olive oil, sugar, and snacks, so stock up. This is probably another one of the easiest places to get some donations to the space. Checking with local bakeries for bread, pizzerias

for pizzas once a week, farms for fresh vegetables and so on can be so helpful. Ask team members what connections they may have to local vendors and others that might be useful in this area. Knowing someone who knows someone is a good way to make a connection. Starting out with a fully stocked spice rack is also really helpful. Buying them piece by piece can get a bit confusing at the beginning, so getting everything at once at the start will make buying things individually later on a lot easier.

**Cleaning supplies:** This is another item that is useful to buy in bulk, if possible. Just like laundry, there will be a LOT of cleaning to do. Dishwashing soap, laundry detergent, glass cleaners and all-purpose cleaners are practical. Also, sponges and rags will be well used. A plug here for scent-free products can't be overstated. So many people will come through with chemical sensitivities and using products that do their best to limit these chemicals in the space can really help. Also, many cleaning products come in plastic bottles. Buying bulk products that you use to fill up the smaller plastic bottles (soap for the bathroom, etc.) will be the most efficient way of keeping these items on hand.

**The outdoors:** Having comfortable outdoor furniture will make it more likely that people will enjoy the great outdoors at the space. Lawn chairs, chaise lounge, picnic tables, and a hammock are all among the possibilities. An outdoor grill makes barbecues and other fun outdoor get-togethers possible. Buying a lawnmower could save a lot of money when it comes to landscaping. Also, gardening is another creative and relaxing activity for some, and having basic gardening tools can help keep things looking nice. If a garden space is being contemplated, consider asking for donations of seeds and seedlings, as well. A lot of farms and farmers' markets are happy to donate and team members who are gardeners often have extra plants! A garden can be yet another way to get the larger community involved and is a prime activity for volunteers who are looking for a way to help out.



### Other items needed/worth considering:

- Extra personal care items (scent-free shampoos and deodorants, toothpaste, toothbrushes, disposable razors, etc.) These are items that people will sometimes pick up from hotels and other sources and donate to the space.
- Beading and jewelry making supplies
- Old magazines for collages
- A place to put cigarette butts outside
- First aid kits
- Flashlights and batteries
- Fans and air conditioners
- Nice window treatments
- Light-blocking shades for the bedrooms
- Good-quality bedding, both sheets and comforters, enough so that team members aren't stressing about getting wash done before the next person comes to stay in a particular room
- Postage stamps
- Plungers
- Dishware (including at least some unbreakable items, as well as paper plates)
- Good shelving for extra storage
- A locking file cabinet for any confidential documents (preferably made of wood to reduce institutional look)
- Basic tools like hammer, screwdrivers, etc.
- Fire extinguishers
- Nail and hair clippers
- Desks and dressers for each room
- Clothes hangers
- An iron and ironing board
- Takeout menus for local restaurants that deliver
- Spare bikes and bike locks for riding around town
- Lighting and light bulbs, including full-spectrum bulbs
- A stereo system or other way to play music
- Headphones for computer and music
- Light box for light therapy
- Cell phones (and possibly pagers) for anyone who will be on-call
- Lots of paper goods (tissues, towels, toilet paper, etc.)
- Naturally scented oils, eye pillows, etc., for aromatherapy. Check for allergies first before using.
- Office supplies: copy paper, extra ink cartridges for the printer, paper clips, stapler and staples, envelopes, pens, etc.
- Phones, both corded and cordless
- Outreach supplies, like (brochures, business cards, folding display table, etc.
- An array of utensils, including a durable can opener
- Indoor plants
- Garbage cans for kitchen, bedrooms, bathrooms, etc.
- Lots of decent quality towels
- Alarm clocks
- Yoga supplies and meditation cushions

**And the list goes on!!**



# INTRODUCING THE RESPITE TO THE NEIGHBORHOOD

Introducing a new peer respite to the neighborhood can be one of the trickiest steps in this process, simply because people's reactions are unpredictable, and there are a number of decisions one needs to make along the way.

**Consider the following questions:**

***1. How many neighbors do you want to tell? The whole street or apartment complex? Only people within a certain distance? Why?***

Respite providers have taken a number of different approaches to notifying neighbors. First, it's important to verify that there are no requirements to notify neighbors based on city ordinance. In most areas, even residentially zoned locations, there is typically no requirement that neighbors be notified, provided the total number of people staying at any one time is under a certain count (often between 4 and 6). For the vast majority of respite providers, this will mean that there is no formal requirement.

From there, it becomes an individual decision. Do you:

- Tell no one?
- Tell only neighbors whose property directly runs up along your own?
- Tell only neighbors within a certain range?
- Tell neighbors in the whole building or on the whole street?
- Reach out even further to the broader community or city?

Unfortunately, there's no magic or 'right' answer, and even formal published reviews tend to suggest that arguments can be made both for and against each approach.<sup>1</sup>

Some arguments against telling neighbors include:

- Some studies have noted that advanced notice can backfire and increase the likelihood of community opposition even to the extent of preventing the space to get up and running at all.<sup>1</sup>
- Making a big production out of notifying everyone can come across as implying that there is something to worry about
- Making a big production out of notifying everyone can re-enforce stereotypes that people with psychiatric diagnoses are dangerous

<sup>1</sup> (See, for example, Zippay, A. (1997). Trends in siting strategies. *Community Mental Health Journal*, 33(4), 301-310.

- Some have argued that notifying a whole neighborhood is akin to violating people’s confidentiality as this immediately identifies them as someone who is struggling to all neighbors simply because they are staying at the respite
- There is some value in getting settled in and established so conversations can be based on what *is* happening and how things *are* going rather than what might be

On the other hand, some arguments in favor of notifying more people (and sooner):

- Neighbors may be more likely to be upset or feel mistrustful if they learn about the respite after-the-fact and feel like it was hidden from them
- Neighbors may have a very different perspective on how far you should have extended your net in terms of the distance from the respite and who you chose to speak to directly
- You may miss the opportunity to shape a positive understanding of the respite if neighbors hear about it from someone else first

## 2. *Once it’s been decided who is going to notified, how does one do it?*

If it’s been decided that some people are going to be notified, there are any number of ways to go about it including:

**Distributing a form letter with a brochure or other written information:** Well thought-out written information can help people better understand the respite’s mission and expected outcomes. However, bear in mind that – unless they’re already familiar with peer support, respites and other similar concepts – even the best-written brochure or letter might feel fairly foreign and raise more questions than it answers. Written materials don’t help develop a personal connection in the way a face-to-face interaction does. Thus, it’s likely best to use written materials only to augment, rather than replace, direct conversation. If there’s no time to speak to people directly, at least consider including contact information and, if available an invitation to an open house or similar event.

**Going door-to-door to speak to people:** This approach can be time-consuming, especially if notifying a large number of people, but can pay off as far as relationship-building goes. Just be sure that some time has been spent thinking about the questions that might get asked and how to answer them. Some questions that might be worth anticipating include:

- o What is peer support?
- o Are there other peer respites like this in the area/country?

- o What information can you tell me about how other peer respites have done?
- o Will this affect my property value?
- o What will you do to make sure the neighborhood stays safe?
- o Will you be taking in people who use drugs?
- o Will you be taking in people who are on the sex offender list?
- o What type of people will be staying there?
- o What if someone comes to my door looking for you?
- o How often will this mean the police/ambulance is here?
- o How will this affect noise in the neighborhood?
- o Will this make it unsafe for my child to play outside?
- o Why this neighborhood?
- o Will the respite be clearly marked? Why or why not?
- o Will an employee always be present?
- o Who do I call if I have a problem or complaint?
- o Are employees trained to handle emergencies?
- o Who decides who is safe to stay at the respite? Are clinicians involved?
- o Do you own or lease? Have you already signed the lease? Who is renting to you?
- o What should I do if someone staying at the respite comes onto my property?

Of course, no one person is likely to ask all those questions, and some may ask none, or come up with other inquiries no one could have predicted. Meanwhile, if there's more than one person going out to talk to people, be sure they've consulted with one another so that they're sending a consistent message.

It also doesn't hurt to bring a small gift along (cookies are a good and relatively inexpensive option), and – if possible – inviting people to visit the respite before it opens, during an open house or otherwise, can also help to reduce some of the sense of mystery and uncertainty.

**Inviting neighbors to an open house or similar event:** Open houses can be tough if the respite is already trying to be respectful of neighbors as far as noise, crowds, traffic and parking go. However, open houses can be a great time to bring in neighbors and let them see the space and to be exposed to others who are supportive of it.

If having one big open house feels like too much, another option is a rolling open house. With a rolling open house, the idea is to set aside a few days and schedule visitor slots every half hour or so so that smaller groups can stop by to look at the space and interact with people who will be working there. Although this approach doesn't create the same sort of party or community atmosphere, which has both its pluses and minuses, it can still accomplish many of the same goals.

Other types of events might also be worth considering, such as backyard barbecues or pot lucks. And, if scheduling an event at the respite seems like too much, or not a good fit for the space, securing a community location for a pot luck and inviting neighbors might also meet the needs of a friendly introduction. If there are talented entertainers within the community, consider including them, as well.

**Inviting neighbors to participate in a project or planning meeting:** If a garden project or painting party are being planned before the respite opens, it doesn't hurt to invite people who live in the neighborhood, especially if it's combined with a pizza party or similar event. Even if some neighbors don't come, it still conveys a sense of openness and community-mindedness that might be helpful in the long run.

**Posting a notice or press release in the local newspaper or otherwise engaging the media to help you get the word out:** Sometimes neighbors may expect that there be an effort toward public notification through the local press. This doesn't mean this is absolutely required, but if it does become a part of the plan, there are a couple of choices.

A paid notice or ad about the respite can be placed. This approach comes with a few downsides. The obvious downside is the cost, but more importantly, it gives less space to explain the project and is probably more likely to raise alarm, because it may appear that the advertiser was required to go through that step or felt the need to give notice.

A press release, on the other hand, is likely to offer much





more room to explain what a peer respite is, and to come from a place of excitement rather than warning. The downside is that the newspaper has to choose to print a press release, and that won't always happen.

A sample press release is included on the next page. This sample is, by no means, the only way to write up a press release, but it does incorporate the following points worth bearing in mind:

- o Clear contact information for the press. Be sure the phone number is one you can be reached at directly and, if possible, include two different contacts so you're sure not to miss the call.
- o The press release isn't too long -under a page- but covers a lot of ground.
- o It clearly describes some of the history and basis for the project.
- o It defines what is meant by "peer" and is clear that employees will receive specific training. (Whether or not people will be trained is a common question.)
- o It notes the geographical area covered. Knowing that the respite is largely geared toward helping your neighbor's neighbors and community may help.
- o It names specific people who are involved in the leadership of the project, including someone from the state funding agency and the person who will be in direct leadership of the project. It can be helpful if people have names to reach out to directly.
- o It includes a quote from someone who lives in the area. (If at all possible, this can be extremely helpful! If someone knows that their neighbor is not only not afraid, but *supportive* of the project, that alone may help them also not feel afraid.)
- o Direct contact information for the public is included. (If people have a clear place to reach out to, they're less likely to start reaching out more widely.)

When the press release is ready to go out, it's also good to bear in mind that the best bet to getting the press release published is to use media contacts with specific people one already knows in some way. However, if that's not possible, most media outlet websites will offer specific instructions and e-mails as to who to contact.

There are sources online that include details on how to write a press release. Some examples to check out include:

[www.wikihow.com/Write-a-Press-Release](http://www.wikihow.com/Write-a-Press-Release)

[www.cbsnews.com/news/how-to-write-a-press-release-with-examples/](http://www.cbsnews.com/news/how-to-write-a-press-release-with-examples/)

[www.businesswire.com/portal/site/home/how-to-write-press-release/](http://www.businesswire.com/portal/site/home/how-to-write-press-release/)

## **SAMPLE PRESS RELEASE**

**Contact:** Lead Contact's Name  
Your organization's name  
Your phone # & Your e-mail

### **FOR IMMEDIATE RELEASE**

#### **Cutting Edge “Peer Respite” Approach Comes to Yourneckofthewoods** *Peer-to-peer supports saving tax payer dollars while offering a critical resource*

Your City Name Here – Peer Respite is a relatively new approach geared toward supporting people who are going through difficult times while helping them to stay (or grow) connected to community. The respite focuses on creating a homelike environment supported by people who themselves have been through difficult life experiences. On top of their own personal experiences, employees will also have received training designed to facilitate the use of their wisdom gained to support others in healing and moving forward.

The Newname respite will be based in Yourneckofthewoods and facilitated by X organization. It follows in a growing line of about two dozen peer respites across the country. The first Peer Respite, Stepping Stones, came into being in New Hampshire in 1995. However, in spite of its success and the success of those that followed not long after, the idea didn't fully take hold until much more recently when new peer respites seemed to start popping up every few months.

“We're so excited to bring a peer respite to the local area. Everything we've learned about the other peer respites in the country suggests it will be life changing for so many people,” said local Department of Mental Health Area Director, Marjorie Manager who was joined by Geoffrey Guide, the soon-to-be Director of the project, at a recent planning meeting. In fact, peer respites across the nation are consistently reporting outcomes that include reduced tax payer dollars going toward unnecessary emergency room and hospital usage, and an increased sense of satisfaction and personal growth from those who stay. “This is going to be such a great resource for our community. I'm proud to be a supporter of this effort,” said Norman Neighbor who lives just a mile away from the planned respite site.

Newname respite will open its doors on X day/month. Stays of up to X days will be available to people living in X area who go through the initial process to determine – through mutual agreement - if they are a good match for what the house has to offer. Prior to the start date, an open house will also be held on X day. For more information, please visit [www.yourorganization.org](http://www.yourorganization.org) or e-mail [info@yourorganization.org](mailto:info@yourorganization.org).

### 3. *Beyond the neighbors, who else might you want to be talking to?*

Other people worth putting on the notification list and/or involving in some way:

- **The Mayor, local congressional representatives and senators, city council members, and other local politicians:** These are people that upset neighbors are likely to call, and having them be able to say they're already familiar with the Peer Respite will generally work in the respite's favor!
- **The local police department:** Again, this is a place where upset neighbors are likely to call, and so giving them some information to work with ahead of time can be helpful. It also may be helpful in the event the police are called to the respite for any reason to have them understand the nature of the space, including asking them to take as trauma sensitive an approach as possible such as not banging on doors unexpectedly, etc.
- **Other local emergency services (fire department, etc.):** It's not unusual for respites to have false alarms that bring the fire department, so it's good for them to know ahead of time what they're walking into for the same reason as it is useful for the police to know. Additionally, while it's rare for an ambulance to be called to a peer respite for reasons related to emotional distress, most respites will experience calling an ambulance for a medical reason at some point or another (chest pains, respiratory difficulty, etc.), and it can be good for first responders in the medical realm to be well-informed and educated by the peer respite team before a first encounter.
- **Local potential allies:** As noted above in the press release, it can be incredibly helpful to have people who live near the respite positioned to speak up on the respite's behalf.
- **Other local community leaders:** Are there any other people in the local area who are well respected by the community? Think about cultural and religious leaders, academic faculty, and so on. Again, having someone of this nature who is well-informed and supportive of the respite's work and mission can be priceless.
- **The neighborhood watch group:** If there is a neighborhood watch group in the area, it may (or may not) be to the respite's advantage to notify them ahead of opening. At some point, it may be worth making a connection or even joining the neighborhood watch in order to communicate the respite's own investment in the local community's safety.
- **School principals:** If there is a school near the respite space, it may be worth considering sitting down with the principal. A likely concern of neighbors is the safety of their children and this will almost certainly come up if the respite is under a mile away from a school. Giving the principal the information they need to respond to parent concerns may be a benefit all around.

# DEVELOPING COMMUNITY RELATIONSHIPS

Some important community relationships have already been mentioned in previous sections, but there are likely an endless number of creative ways to develop a peer respite's place in and sense of belonging to the local community. Although it's easy enough to get caught up in the reality that many people don't truly understand what a peer respite is (or are even afraid of the concept), taking an active role in the community is likely to benefit everyone involved.

**Some of this is about what the community may be able to provide to the respite. For example:**

- There may be local bakeries that are willing to make regular donations of baked goods.
- Farmers markets and other local resources may have a process for donating fresh fruits and vegetables.
- Gardening supply stores (or just about anyone in the neighborhood) may be able to contribute seeds or seedlings for a garden.
- Local pizza shops may be willing to donate periodically or even as often as a pizza per week in some instances.
- Local animal shelters or boarding services may be willing to temporarily house the pets of people staying at the peer respite at no or reduced cost or offer volunteer opportunities that could make for great opportunities for people who find time with animals healing.
- There may be a local lawyer or Disability Law Center who is willing to offer some consultation services to people staying at the respite for free.
- Local gyms may be willing to give out free or reduced short-term passes for people staying at the respite and/or access to yoga and other classes.

At the very least, even if it's not about donations or free services, getting to know the local people in the community can go a long way when you're telling someone staying at the respite about a local resource. For most people, it's far less intimidating to check out a resource when you have a specific name to offer and an experience to share.

**However, some of this is also about what can be given back. For example:**

- Is there a neighborhood clean-up project going on that people working and/or staying at the respite could get involved in?

- Is there a local walkathon happening to raise funds for a good cause (it doesn't need to be mental health)?
- Is there a neighborhood watch that it might be worth someone who works at the respite joining?
- Could the opportunity to volunteer at another local community resource (soup kitchen, food shelf, community garden or conservation project, neighborhood clean-up, etc.) become one of the regular ways that people working and staying at the respite can give back?

Incorporating ways that the respite can give back to the community can support the idea that it's not the drain on resources some may view it to be, and also helps to counter the idea that people who are struggling can't also find ways to and even benefit from supporting others.

**And, in the best of circumstances, community connections can be about mutual relationships that involve both give and take. Here are two examples:**

- A positive relationship with the local police department may lead to opportunities for you to offer training to their officers (on being trauma-sensitive, understanding and supporting people in distress, etc.). It may also lead to officers being more inclined to connect struggling people with your space, rather than automatically taking them to the police station or hospital. Keya House in Nebraska is well-known for developing this type of relationship with their local police department. See their website for more information <sup>1</sup>
- A positive relationship with a local college or a particular professor may result in an offer of free space for trainings and events, along with access to students for outreach, while the respite may be able to be a critical support for students on their campus.
- A seat on a local community service, health or mental health planning board, or advisory and networking groups can raise your profile and help ensure your voice gets heard while you also give valuable input.

Of course, developing connections to local mental health services, so that you can, at the very least, be able to inform people you're supporting about one another, is also essential. It's also important to connect with less obvious places, such as cultural groups, churches, schools, substance abuse treatment centers, domestic violence services and other community resources, particularly for peer respites that are not restricted to supporting only people who are receiving mental health services.

Ultimately, the sky —and time— is the limit as far as what sort of connections can be pursued.

<sup>1</sup> Keya House, Nebraska [www.mha-ne.org/keya/](http://www.mha-ne.org/keya/)



# HIRING

As with all the tasks associated with setting up a peer respite, hiring is difficult when one doesn't fully understand what it will all truly look like. This includes the person applying for the job who may just be hearing about peer support for the first time themselves, and aren't sure quite what they're getting themselves into.

Sometimes, the opportunity to start a peer respite comes along relatively quickly, so the people in the lead need to figure out quickly exactly what it is that they are trying to do and who can best support that mission along the way. And, even for those who have had the luxury of a long visioning process, sometimes that process has been so focused on the bigger picture that people still haven't had a lot of time to really think through what qualities an ideal peer respite employee would possess.

One key starting point for anyone responsible for peer respite hiring is understanding this: While first-hand experience with psychiatric diagnosis, trauma, and so on is required, it absolutely is *not* enough. Working in a peer respite is an intense job that requires a great deal of skill and intentionality. These are not positions for the 'faint of heart' or for anyone who is still so focused on their own healing, that they don't have space for others. In addition to those points, one of the most essential qualities in a peer respite employee is understanding the basic philosophy. Just a small handful of examples of this include:

- Do they consistently use non-clinical, everyday language (and understand why that's important)?
- Do they understand perspectives beyond a medical model/mental illness frame, and understand that part of their role is to support people to explore different perspectives and make meaning of their own experiences?
- Do they get the reasons why many people find being hospitalized to be harmful or disruptive to their lives?
- Do they believe in the power of connection and just being with someone through difficult times?
- Do they understand the impact of systemic oppression in the lives of so many people who will stay at the respite?

These and other points are incredibly important, because it is generally much harder to unlearn than to learn. Of course, understanding particular concepts on an intellectual level doesn't guarantee that someone will be fully prepared for the rest of what is required, but it's a start.

**Here are just some of the other qualities worth considering during the hiring process:**

**1. Reliability:** The reality is that all jobs require that employees be on time and consistently available for their scheduled shifts. That's no different at a peer respite. Sure, space can (and

should) be made for people to take time off, but there should be no assumption —simply because someone has a psychiatric history of some sort— that room should be made for less reliability. See the ‘Additional Hiring Considerations’ section for more on this.

2. **Energy:** Peer respites tend to have longer shifts, given that the main focus is forming deep connections that require time. So not only does someone need to show up on time and be physically and emotionally present, they also need to be able to stay awake and alert during awake hours and not regularly require excessive breaks. This can disrupt the ability of the space to function and/or leave other employees holding an unfair share of responsibility.
3. **Ability to stay present -really, really present:** This can be a tough ask for anyone, especially given the long shifts that form the structure of many peer respites. Yet, being able to really be with people in their pain means being able to sit for relatively long periods of time and truly hear them without getting too distracted by one’s own stuff.
4. **Ability to stay out of the “fix it” role:** Many people’s very human reaction to another person’s suffering is to want to make it stop. However, the bind here is that sometimes we are truly powerless to do so; for example, we won’t always have housing for someone who is homeless. More importantly, sometimes our efforts to “fix” actually get in the way of what someone most wants and needs: connection, being heard, and so on. Given that most peer respites will see people in desperate situations that people at the respite will be powerless to solve, it will be essential to truly understand the difference between having compassion and taking responsibility for someone in order to keep things sustainable.

One way of thinking about responsibility that is quite different than most traditional systems is that peer respite employees will have a responsibility *to* people staying at the respite to remain present, be with, share with them, and so on. However, they will not have responsibility *for* (or over) them, and thus will have no power to control them or their situation.

5. **Confidence:** Everyone working at a peer respite needs, expects, and likely wants training. Beware of those who don’t want training or think they already know everything. However, given adequate training, it’s critical that team members are able to quickly develop the confidence needed to act independently and to think on their feet when something difficult happens. This doesn’t mean that a good employee won’t ever reach out for help, but it does mean that, in order for a respite to function day-to-day, everyone needs to feel pretty clear on their job, and able to make solid decisions without asking someone else what to do.
6. **Ability to set personal limits:** Peer respites will vary in the limits that are set for employees



about how they can interact with people staying at the respite, such as whether they can develop outside friendships, or what to do when a friendship already exists. However, in most instances, those limits will intentionally be looser than in conventional mental health settings. This is because there's so much emphasis on genuine connections and being human with one another. While the power of the relationships that get formed within this framework can be incredibly healing, it really requires that each team member be self-aware about what their limits are and how to express them. This should also include the ability to set limits related to sexual harassment, racist remarks, and so on (though does not need to exclude the ability to support people making those remarks to explore impact or where it's coming from for them.)

**7. Awareness of broader social justice and human rights issues:** It is extremely important that individuals working in a peer respite have a basic understanding of oppression and how that plays out for people in the mental health system. They also need the ability to relate that to other social justice issues, like racism, sexism, homophobia, transphobia, and so on. While people may need support to further develop their understanding of a range of intersecting social justice and human rights issues, a general openness and investment in these points is critical.

**8. Ability to communicate with other team members and outside organizations:** A solid peer respite employee will be great at developing connections with people staying at the respite, and will also be willing to apply the same approaches to fellow team members. They will be willing to work through conflicts with curiosity and compassion, and will understand why it's important to avoid gossip and other destructive trends. They'll understand the importance of building relationships with other organizations, while navigating the tricky waters of holding to the values and integrity of the peer respite. They'll be able to use the tools available to keep up with team communication; for example, if your team communicates primarily through e-mail, it's essential to hire employees who are able to use e-mail.

All these factors should be considered right from the point of hiring, and questions should ideally be asked that get at their essence. Ignoring all but the "big vision" piece is likely to land a start-up peer respite in the position of having a team full of really well-intended people who aren't otherwise going to be able to hold up the tasks of actually making the respite successful.

Once you have explored and developed some sense of the skills and responsibilities of the employees you'd like to hire, posting a compelling job ad that helps people make sense of that job is a good next step. (See sample job postings in Appendix 2.) Another next step involves setting up the interview committee. Having at least three people with diverse perspectives (paid employees, advisory board members, community members, etc.) is likely to be of value. If interviews will include people who are bilingual, having someone on the interview committee who can also speak that particular language is often helpful, too.

Once the interview committee is set up, it's time to develop the list of questions. For personnel law and practical reasons, it's important to ask the same basic questions of each applicant. (This doesn't preclude asking follow up questions of particular people based on their responses.) Here are some possible questions to consider along with the reasons for asking them:

- **Did you get a chance to view the respite's website? If so, what were your thoughts?** Someone who's really excited and intrigued is more likely to take the time to research what the respite is actually about.
- **Say you did start working at the respite and had to explain to your family and friends what this work is all about. What would you say?** This is an opportunity for the interviewee to demonstrate any existing understanding they have about the respite.
- **What if one of your friends asked, "Aren't you scared of what could happen without any clinical support around?" How would you respond?** This is an opportunity for the interviewee to demonstrate their understanding of discrimination and stereotypes of people with psychiatric diagnoses and how they might respond to that.
- **Can you tell us about a time when you were working and didn't get along with your supervisor?** The responses to this question are often telling. Most people can come up with at least one example, but if the example offered is concerning, that might be a red flag worth noting.
- **Can you tell us what you think about the language in this sentence? "The mentally ill can be dangerous, but schizophrenics and bipolar people may still benefit from peer respite."** This is another opportunity for the person to demonstrate their understanding of discrimination and stereotypes. It's also an opportunity for them to show whether or not they understand the value of not using clinical language and labels in a peer respite setting. To be clear, an ideal answer here would include that language like 'the mentally ill' is damaging and distancing, that people in peer roles avoid labeling and clinical language like 'schizophrenics' and 'bipolar,' and that the belief that people with

*"We hired most of our team through an ad on Craig's List. The majority of them hadn't really heard of 'peer support' before, but the critical thing was that they each had that essential spark and passion for the idea of it and a real willingness to learn. That made all the difference and was worth far more than if they'd already been trained. Three years later, we still have more than half of the original team left. That's kind of unusual for an effort like this, and so I feel good about how we approached things. I'd do it the same way again."*

*- Peer respite team member*

Psychiatric diagnoses are dangerous is a dangerous idea itself, and ultimately a myth. If the person doesn't recognize any or all of those points (especially with some prompting), they are likely not a good fit for peer-to-peer work at that time. At the very least, if their answer seems off, it would be good to ask some follow up questions.

- **Can you tell us about a time when you had a job that felt draining or hard to sustain for you? What were the conditions that were draining, and how did you handle that? What other sorts of environments are you likely to find draining?** This is an opportunity to ask someone to really think about conditions that have been and would be hard for them to sustain
- **When we ask your references about your history of reliability and punctuality, what will they say?** This is an opportunity to get at someone's ability to show up for the job if they are hired, without just asking, "Are you reliable?" (That is to say, it's likely to get a more honest answer.)
- **What would you expect the role of 'advice giving' to be at a peer respite? How does advice giving differ from sharing experiences?** This is an opportunity to begin to get a sense of whether or not someone has at least a beginning awareness of staying out of a 'fixer' role, and the importance of listening and supporting them to find their own way.
- **Are there any specific ways that you're comfortable sharing that you can imagine using your own life story and wisdom gained as a tool?** This is an opportunity for interviewee to talk about their own experiences and how they believe that will impact their work at the peer respite.
- **Do you prefer to work in environments where you are on your own or around other team members with whom you can check in as needed? How do you do in each of those environments?** This is one possible way to get at a better understanding of how someone might do working independently.
- **What do you do to re-energize and take care of yourself? How do you make sure you have enough time away from work to do the things you want to be doing?** This is one possible way to get at setting limits and sustainability.
- **What do you think are the most important factors for supporting a person who has been caught up in the mental health system to move on with their lives and live well?** (This is an opportunity to see how much someone understands the impact of living within a system, and how that on its own can create barriers to moving forward in life.)
- **What is your understanding of how racism, classism, homophobia, transphobia and other issues of systemic oppression may play out at the respite, and how might you approach that?**

**And/or How does racism (and other types of systemic oppression) show up in the mental health system?** This is an opportunity to gauge someone's awareness and openness, as well as how much they may have already thought about systemic oppression overall.

- **What have you done to participate in the undoing of racism and/or other types of systemic oppression?** This seeks to understand more about the person's investment in issues of injustice, and creates space to delve deeper into their understanding of what systemic oppression looks like and what might be required to impact or change it.
- **Are you familiar with the phrase 'trauma informed' or 'trauma sensitive'? Either way, what do you think it means in this context?** This is an opportunity to gauge if someone has already developed any understanding of the impact of trauma on the lives of people in the mental health system and in general.
- **Do you speak, read or write any other languages? If so, which ones and how well?** Creating a space that is accessible means hiring people onto the team who speak other languages, particularly those that are common in the respite's local community.
- **Can you share some about your experience with using e-mail, the Internet, and (other relevant computer programs)?** This is especially important if a substantial amount of communication between the team happens on-line.
- **A man staying at the respite shares with you that, although he's been diagnosed as bipolar, he doesn't believe in mental illness and sees himself as a trauma survivor. How would you respond to that?** This is an opportunity for the interviewee to demonstrate whether or not they are open to different perspectives and understandings of emotional or mental distress. This openness is key to the type of work that happens in a peer respite setting.
- **While staying at the respite, a woman shares with you that she is actively hearing voices and seeing visions. What would you do?** This is an opportunity for the interviewee to demonstrate how they might respond to an experience that is typically painted as being scary in the media. Do they react out of fear? Are they willing to sit and learn more about the voice hearing experience? Do they come across as at least being open to the idea that voice hearing may be more complicated than it's painted to be on television?

Often, the scenario questions are the ones that are most helpful, especially since peer respites benefit greatly from having team members whose gut instincts include 'out-of-the-box' thinking in a variety of situations. Additional ideas for interview questions for peer support roles are available in Appendix 2, as well as in the *Provider's Handbook on Developing and Implementing Peer Roles* at

[www.psresources.info/peer-roles-handbook](http://www.psresources.info/peer-roles-handbook)

There are many other questions that also might be of value, but it's always good to have a sense of why a particular question is being asked. It's also worth avoiding questions that can be answered with a simple "yes" or "no" or that are likely to elicit a canned answer (a question that every applicant is likely to respond to similarly, regardless of their actual fit for the job).

Once interviews are complete, it's important to look not only at each individual applicant, but at the bigger picture of the team being created. The ideal team will include team members who represent a range of:

- Ages
- Socioeconomic backgrounds
- Race and ethnicities
- Languages spoken
- Experiences with the mental health system

It also tends to be helpful if at least some people on the team have experienced other common challenges and hardships like homelessness, criminal justice involvement, domestic violence, physical or other disabilities, and addiction/substance misuse.

Of course, before the hiring process can happen, those involved with the program start-up already need to have established how many people they plan to employ, the structure of the schedule and shifts available, as well as job descriptions (see included samples). It's not advisable to routinely have only one person on at a time. At least 8 hours (and ideally, 10 or 12 hours) of double coverage can be critical to sustaining the quality of support in the space.

Another issue, and one that has not been addressed so far in this book, is the standard length of each shift. While some respites lean toward a more traditional first, second and third shift approach, others have chosen to go with longer shifts of 12 hours.

### **Who 'qualifies' to offer peer support?**

Some peer-to-peer organizations, programs and projects have spent a great deal of time attempting to define exactly what life experience qualifies someone to be employed in a peer role.

Some groups have said that experience being hospitalized should be included. Others simply ask that someone have been through diagnosis, and some sort of treatment experience. Still others believe that all that matters is that someone has been through some substantial life disruption or extreme states, whether or not they landed in the mental health system in any way.

Although this point is for each group to decide themselves, many people find that what is indeed most important in hiring for a peer respite is that each employee truly be willing to come from a place of their own experience, that they have a real understanding of the losses and distress that traditional interventions can bring, and that they are really, truly willing to live and practice the values upon which the respite is founded. Experiencing hospitalization doesn't guarantee that someone will support the mission or values of a respite. That said, most also agree that having team members with a mix of experiences, including hospitalization for at least some, is also of great value.

The benefits of longer shifts include longer periods to develop connections, avoidance of mirroring the scheduling style of hospital environments, and shorter work weeks for team members.

Of course, there are some downsides as well. These include that such long shifts may not work with many people's schedules outside of work, and that some people find the exhaustion of a long shift not worth the shorter work week. Whatever the program decides, it's important to know the overall plan before going in to interviews so that can also be explored with each applicant.

Determining how much room there is for job sharing, and how many part-time and full-time team members are desired, is also an important part of the process. Remember that having more part-time people will automatically create a pool of people who can often easily fill in for one another. It also can be of benefit when supporting people to start working who may not have worked for a while, who have disabilities that prevent working a lot of hours (at least initially), or who can't exceed a certain amount of income at the moment due to other benefits.

However, having multiple part-time people can increase the budget, because there are more people to train and more people who come to each team meeting. It also may mean that the team loses members who are ultimately looking for full-time work and end up taking other jobs to meet their needs. Perhaps most important, it can be very jarring for people who are staying at the respite to constantly be meeting new people, and can prevent them from developing solid connections with any one person.



# POTENTIAL ROLES

Peer respites across the country are set up differently, with different job titles and types of roles available. However, all of them have at least one designated leadership role and several primary peer supporter positions.

Some incorporate multiple leadership roles, as well as volunteers and interns. Here's some food for thought for each of those positions:

**Leadership:** All peer respites have at least one person in a designated leadership role, whether that role is titled as Director, Coordinator or some other title. Choosing what to call the roles can be a more important decision than it initially appears. It's important to remember that any peer-to-peer support may already be taken less seriously by outsiders, and so—as far as external relations go—the stronger title of Director may be the best way to help counter that. However, internally, where minimizing power differentials is useful even between paid roles, a title that does less to set someone apart may be better. On the other hand, titles are most commonly used and relevant outside of the space, so what is most effective for external relationships may ultimately bear the most weight.

At least some respites also employ multiple people in leadership roles. This style has developed for a number of reasons, including sharing on-call responsibilities, creating growth opportunities, and flattening the hierarchy as much as possible and in ways that are consistent with peer-to-peer and community-based approaches. Where on-call duties are concerned, it can be extremely helpful to have more than one person involved in the rotation. That said, some respites have included employees in non-leadership roles as a part of that rotation as a way to empower them to take more responsibility for the space, although, with employees who are paid hourly, this can present budgetary issues.

Most peer respite leadership roles also include time offering direct support in the space. In peer-to-peer communities, it's of value for leadership team members to stay connected to the work in very real ways wherever possible.

**Peer Supporter roles:** There are many titles used to name this position that makes up the bulk of the peer respite team including Peer Advocate, Peer Worker, Peer Supporter, and so on. Some peer respites have dropped the word "peer" from all job titles, to emphasize that the role is about the *relationship* more than about the identity of the employee. In these environments, the position may simply be titled Advocate or similar. Although there are downsides with the term Advocate as well, including the fact that some perceive this to mean advocating *for* rather than *with* someone. Meanwhile, don't forget per diem workers in all this. Having a solid pool of people who are well-trained and available to fill in when permanent employees need time off is essential to the survival of the respite and

should be budgeted for right at the start.

**Administrative & Technical Assistance:** Especially for peer respites that don't operate under an umbrella organization, there will be a number of background roles, such as processing payroll, managing billing, and so on. Finding someone (whether within the leadership of the peer respite or outside of the primary team) who is skilled in writing grants and other fund development tasks can also be critical to the survival and growth of the respite. Some peer respites will work to make sure that these roles are filled by people who have psychiatric histories, and others will waive that requirement for individuals not working in direct leadership or support of people. Either way, even though these roles won't constitute the most visible work, it is key to have them filled by people who are highly skilled in these areas.

**Volunteers & Interns:** Volunteers and interns are often involved with peer respites. They can bring added support without additional funds, increase the community's sense of involvement and attachment to the respite, impact the academic world with a new and different approach, and so on. Some of the activities volunteers and interns might be involved in at peer respites includes offering extra coverage, helping with outreach, researching how other respites approach particular issues, distributing flyers and brochures, organizing gardening and other sorts of projects, art, and so on.

However, there are a few cautions to bear in mind. First, both interns and volunteers need to be well-trained and supported, which may mean that what seems like an opportunity for additional support to the respite at no cost becomes a lot of work for short-term benefit. Additionally, with interns, it's important to remember that many people who stay may also have experienced feeling studied, watched, and assessed and so it's important for interns to be willing to really participate in the approach and not come from a place of simply studying everyone. Ideally, interns will come with a similar list of qualities as people in paid roles. Volunteers can draw from a wider pool, provided they get the values and principles of the overall approach.



# ADDITIONAL HIRING CONSIDERATIONS

**Paid Leave Time:** Organizations handle leave time differently. Some combine all sick and vacation time, keeping only holidays separate, and some combine all three. Others have a separate bank for each, and, depending on the particular geographical location, there are widely varying laws about required time off in general and for life events like having a child.

However an organization manages paid time off, approaches should be consistent across all employees, and not based on whether someone is hired because they have a psychiatric history. Although there may be some specific considerations that are more common with people being hired into peer roles (such as managing financial benefits received due to inability to work for a period), it's a fine line between awareness of those considerations and discriminatory treatment, even if well-intended. Overall, it's advisable for any organization that wants to sustain its workforce to be prepared for varying needs, and to develop policies that are compassionate and respectful of those it employs.

Additionally, offering generous amounts of time off is particularly important in roles where people are expected to give a great deal of themselves on a day-to-day basis. Being available to give of one's self on such a personal and emotional level naturally requires more time to rejuvenate and re-energize off the clock.

Many times, peer respites will be hiring people who have experienced a great deal of disruption in their life, and who have done a great deal of work to figure out what works to keep them on the path they want to be on. In those instances, it will be in both the employer's and employee's best interest for the employer to work creatively with that team member to support them to use their time off in a way that they have learned works for them, provided it also works reasonably for the space and the basic requirements of the job.

Other times, however, particularly due to the nature of the job qualifications, it's possible that someone being hired may not have worked for an extended period of time. In those instances, it will be important to develop an open line of communication around use of leave time. It can also be helpful for the employer to have resources on hand that might help someone assess their needs and the potential impact on other benefits of going back to work. In some instances, people may need time off expressly to figure out a plan to transition from benefits to paid work, or to avoid losing those benefits before they are ready.

**Criminal Record/Background Checks:** Most jobs where one is working directly with people in a vulnerable place require criminal record checks. This can be a very sensitive process, as some people

may feel embarrassed or afraid for a potential employer to learn about any past legal difficulties. A criminal record or background check should never be done without notifying the potential employee, volunteer or intern - usually, they will need to fill out paperwork to allow you to do so- *and* explaining what to expect if something does show up on their record, including that it can typically be worked through.

It is important for each employer to become familiar with the laws around criminal record checks for employees and to develop a system for following those laws. For example, in some areas, a criminal record check is required for all peer respite positions, including interns or volunteers who will have unsupervised access to people supported, but can only be done after someone has been formally offered a particular position. In other words, criminal record checks would not be done on each person who applies, but only for the candidate who is selected and offered a position.

Fortunately, while this process used to take days or even weeks, it can now be completed in a matter of hours for organizations who are linked to criminal record check databases. However, it's also important to be familiar with what is actually being checked. For example, most criminal record checks are only searching for arrest records and convictions in a particular state or country, and even serious issues might get missed if they occurred outside of that region.

From a values perspective, it's also important to remember that many people have done things in the past about which they are ashamed, and it's certainly consistent with a peer respite's approach to hold to the belief that someone is able to move beyond the past, as well as to hold the value of respecting their privacy in doing so. This holds true of people who work at the peer respite just as much as anyone else. Additionally, it's vitally important to remember that the legal system—just like all other systems—is often influenced by racist, classist, ableist, and other discriminatory attitudes, so sometimes who ends up with a record and who does not has more to do with that than anything else.

In truth, this is also a job where a history with the criminal justice system can actually be a benefit. Without a doubt, there will be people who stay at the respite who have had—or are trying to manage or stay out of— legal trouble. Having an employee who can speak from a place of personal experience in that area is as useful as being able to share personal experience around emotional distress.

With all that in mind, it's important to remember that, in most instances, a criminal record does not need to be a deal-breaker. Specific laws will guide each peer respite around what can and cannot be considered on someone's record (e.g., if something is over 10 years old in some areas, it may not be considered as a barrier to employment), or what is so serious or recent that that person simply could not be considered. However, in most instances, there will be a process for notifying or negotiating with a funder, particularly if that past experience would be useful to them on the job, and if they appear to have addressed whatever issues may have led to those problems.

**Overall Expectations:** It's important to be sure that an employer is hiring and ultimately supporting a team with the right expectations. It's essential that expectations not be set so low, based on someone having a psychiatric diagnosis, for example, that bad employee behavior becomes acceptable. For example, it shouldn't be acceptable for employees at a peer respite (or anywhere) to:

- ⇒ Fall asleep on the job, unless time is actually set aside for sleep during an overnight.
- ⇒ Show up late without notice
- ⇒ Miss so many shifts that they're constantly running out of paid leave time
- ⇒ Act disrespectfully or abusively towards others
- ⇒ Show up to work so sedated that they aren't able to connect with others

Sometimes, when hiring, organizations make the mistake of setting the bar so low (based on misconceptions about peer support) that they continue to employ people who just aren't doing the job, or are consistently not doing it well. That should never happen. However, it also isn't reasonable to expect that everyone will be able to fit easily into conventionally corporate ways of being in a role, particularly when they've followed unconventional paths, and may have survived a great deal of trauma that requires them to be in the world in very creative ways just to survive. In fact, some of that creativity that they've developed is precisely why they'll be great at supporting others.

Considering a creative approach to supporting employees to do a job well is *completely* different than just employing people who aren't doing the job. For example, it is reasonable for employers of peer respite to have naturally more flexible ideas and policies around:

- ⇒ How, when, and why people take time off, within reason
- ⇒ Changing schedules to suit changing needs
- ⇒ Willingness to increase or decrease number of hours worked, if it works for the respite, too
- ⇒ Added debriefing or paid time off after moving through a particularly difficult situation. Often people who feel deeply in this world are the best at this work, but are also inevitably deeply affected by all the pain they're asked to hold

Some respites or other organizations include a paid hour or two in people's regular schedules to practice some of the healing techniques that they might share about during their work, like yoga or therapy. This will vary, but again, high creativity should always still entail high expectations for how people do the work, and should not come with expectations that people will constantly be falling apart.

It's also worth noting that the following are flatly unacceptable:

- ⇒ Questions about (or requests to see) an employee's treatment plans
- ⇒ Questions about (or requests to see) one's WRAP or other wellness plans
- ⇒ Questions about use (or non-use) of psychiatric or any other kind of drugs or any request to be notified of changes in one's drug regimen

Such questions may violate the law, and are insulting and a violation of one's personal privacy. Employers that start off believing that they have a right to know this information—or that their employees will necessarily even have such plans, be taking such drugs, etc.—are far more likely to making hiring mistakes because of the bad assumptions that underlie such a belief.

Overall, getting clear about where expectations lie right from the start is an essential part of the hiring process.

# SUPERVISION

Supervision is an essential support in any healthy work environment. It helps people stay on track with their job responsibilities, and supports them to feel appreciated for a job well done and to address any hurts and concerns in a timely fashion. In a peer-to-peer environment, it's valuable to leave space for feedback to go in *both* directions.

It's important to note that some supervisors may feel tempted to ask more personal questions during supervisions because the nature of the job requires that people have gone through many personal struggles. While it's fine to ask people how they're doing and to care if they seem to be having a hard time (just like anyone might with any other human being), it's critical to not treat employees as fragile and to not get into a place of monitoring or assessing their well-being. It is also not advisable to require employees to complete wellness plans of any kind; this is a discriminatory practice and feeds into the idea that people working in peer roles are less capable than anyone else.

Because so many people struggle to directly celebrate the positives *and* face potential conflicts, it can be handy to have a tool that serves as a reminder of the various goals of these meetings. A sample tool is included in Appendix 4.

And, of course, managers and administrators of peer respites need support, too. It can often present an ideal supervisory structure when peer respites are connected to a larger peer-to-peer organization, so that the supervisor of the supervisors is familiar with and deeply invested in the peer respite approach. In situations where this is not possible, because the peer respite is independent or connected to a more clinically oriented organization, it can be useful to form partnerships with other organizations (nearby, nationally, and even internationally) doing similar work. In situations where there is a supervisor with a clinical background, it can be particularly useful to attend trainings and events together that might help build common understanding of the work being done at the respite space.

There are also online networking groups for individuals involved with peer respites. For example, there is a US-based online group facilitated by the National Empowerment Center. There are also trainings and handbooks available online that can be useful to individuals in non-peer roles who are responsible for supervising peer-to-peer efforts. (For example: [www.psresources.info/peer-roles-handbook](http://www.psresources.info/peer-roles-handbook).)

# CO-REFLECTION

While supervision is an important management and administrative practice, it's also important to offer all people working at a respite the opportunity to reflect upon the relationships they are developing with the people coming to stay at the respite and with one another. This is sometimes called “co-reflection.”

Particularly in a peer-to-peer environment like a peer respite, finding ways to incorporate the Intentional Peer Support (IPS) approach of co-reflection (formerly referred to as co-supervision) can be incredibly useful. This approach encourages everyone, regardless of their role, to work together as a team to support one another and to build understanding and grow through their work.

In some settings, the practice of co-reflection is incorporated into regular formal co-reflection meetings anywhere between weekly and monthly. The intention is to reflect upon interactions and connections that have gone well, and learn from what contributed to that. They also offer an opportunity to reflect upon difficult situations or disconnections, how people responded in the moment, and other possible responses. The hope is that self-reflection might bring to light old patterns and create opportunities to support one another to think through and try something new.

It's important to highlight the fact that these meetings *do not* focus on talking about people who are staying or have stayed at the respite, but instead focus on responses, feelings, and thoughts that are coming up on the team as a result of some of their interactions. For example, rather than focusing on what the policy should be when someone talks about suicide, or how a particular person staying at the respite was doing when they brought that topic up, a co-reflection-oriented meeting may focus on what feelings are coming up for the team when suicide comes up (Fear? Anger? A sense of being paralyzed or needing to fix it?), and where that might be coming from (A past bad experience? A lack of feeling supported to know what to do?). The purpose is to encourage self-reflection to examine patterns and responses in relationships, as well as to explore and practice new ways of seeing and responding to difficult situations. Supporting each other to set and hold limits, especially in the face of abusive situations is also important.

Similarly, if a particular person staying at the space is really getting to one or more people working there and leaving them feeling burned out, that might get explored, too. The trick, however, is to explore it in a way that is talking less about what that person is doing (it's not even necessary to mention names), but rather about what the experience is bringing up for people who feel impacted by it. One essential concept that goes hand-in-hand with the co-reflection process is this: A person who feels burned out by another individual, but who hasn't taken the time to examine why, also holds responsibility for that connection becoming a disconnection.

Co-reflection can also be practiced very effectively between two team members or in small groups, and in some settings, this is all that is possible, due to lack of funding for a full team meeting with this focus. Whether practiced in groups or one-on-one, this approach can be essential to staying out of the “fixer” role, understanding each other’s worldview and supporting growth and a stronger team.



*Reflection of Lake McDonalds, Wikimedia Commons*

# TRAINING

There are at least two phases to any good peer respite training plan. Those phases include:

- The start-up training plan
- The ongoing training plan

**The start-up training plan:** It's very important that any start-up timeline leave adequate time for the team to get trained prior to opening. This training phase is not just about gaining knowledge and practicing skills. It's also about giving the team a chance to get to know and bond with one another. A close team that's willing to stretch and support one another is a critical building block to keeping things running well.

Beyond formal trainings, some of the activities worth building into a start-up training plan include:

- **Visiting other peer respites:** If funds are available, taking a road trip to one or two peer respites in neighboring states can be a great way to see a respite in action and to provide a great bonding opportunity for new hires. Overnight trips are especially effective where bonding is concerned.
- **Setting up the space together:** As noted in the Setting up Space section, painting and putting furniture together as a group can make for some great "get to know you" times. It can also have the additional and desirable effect of bonding the team with the physical respite space.
- **Visiting and learning about community resources together:** Individuals working in peer respites aren't expected to become walking, talking encyclopedias of local community knowledge, (although the ongoing willingness to partner with others to find out information as needed is invaluable). However, some familiarity is helpful, and learning together has many benefits including more opportunity to connect with fellow team members, as well as the likelihood that more will be learned in a group, where different people inevitably ask different questions, than when alone. Note: A great project to work on together at this point is building a resource book based on everything that gets learned!
- **Watching relevant films, reading books, or listening to radio interviews together:** People who are just starting out in a peer role may see that there's value in being open to different perspectives, yet, they may not have had the opportunity to learn about many of them. Fortunately, there are a number of films, radio interviews, and books available that can support that learning.



Meanwhile, the most common and comprehensive core training available at this time for peer respites is Intentional Peer Support (IPS). IPS was founded by Shery Mead and has grown into a thriving approach that has been offered to people around the world.

### But, what exactly is IPS and why is it useful to people working in peer respites?

Here's an excerpt from the IPS website ([www.intentionalpeersupport.org](http://www.intentionalpeersupport.org)) that begins to paint a picture of what this approach is all about:

*Intentional Peer Support is a way of thinking about and inviting transformative relationships between people. Practitioners learn to use relationships to see things from new angles, develop greater awareness of personal and relational patterns, and support and challenge each other in trying new things.*

**IPS is different from traditional service relationships because:**



Art by Ana Keck; [www.anastasiakeck.com](http://www.anastasiakeck.com)

- *IPS doesn't start with the assumption of a problem. With IPS, each of us pays attention to how we have learned to make sense of our experiences, then uses the relationship to create new ways of seeing, thinking, and doing.*
- *IPS promotes a trauma-informed way of relating. Instead of asking "What's wrong?" we learn to ask, "What happened?"*
- *IPS examines our lives in the context of mutually accountable relationships and communities — looking beyond the mere notion of individual responsibility for change.*



- *IPS relationships are viewed as partnerships that invite and inspire both parties to learn and grow, rather than as one person needing to ‘help’ another.*
- *IPS encourages us to increasingly live and move towards what we want instead of focusing on what we need to stop or avoid doing.*
- *At the end of the day, IPS is really about building stronger, healthier, interconnected communities.*

**The Intentional Peer Support approach rests on three principles, which are essentially about shifting focus:**

- ⇒ From the intention of ‘helping’ to a focus on learning and growing together
- ⇒ From the individual to the quality of the relationship
- ⇒ From fear-based responses to hope and possibility

**And on four key concepts or “tasks”:**

- Connection
- Worldview
- Mutuality
- Moving toward

**These four tasks can be summarized as follows:**

1. **Connection**— In order to be in relationship, attention needs to be paid to creating connection and noticing disconnects. Without connection, it’s hard to get anywhere together, and with it, possibilities emerge. Since no connection is constant, Intentional Peer Support does not view disconnection as a “bad” thing, but instead as an opportunity to consider what reconnection might look like, possibly in a stronger way than before.
2. **Worldview**— Our knowledge of ourselves and our worlds comes from a combination of culture, family, and all of our individual experiences including trauma, privilege, and success. This means there are multiple truths and many valid ways of understanding experiences. It’s also the underlying reason for most disconnects. Supporting each other to better understand our own worldviews— “how we have come to know what we know,” as well as staying curious about each other’s worldviews, feeds the compassion and connection we each need to grow. It also opens up ways to re-think the stories we’ve learned to tell and re-imagine our future.

3. **Mutuality**– In IPS, “help” is re-defined as a co-learning and growth process where the relationship has to work for both people. Mutuality means both worldviews in the relationship need to be present, and that giving and receiving goes both ways. This might look like sharing a part of one’s story, asking for something needed (including being able to say when something isn’t working), or negotiating how to be together in a way where both people are present and connected. It can also look like building enough trust that people can challenge one another to consider other angles on their own experiences.
4. **Moving Towards**– Often the mental health system focuses on moving away from negative experiences (or “symptoms”), or frames moving forward as no longer doing or experiencing something that was identified as “bad” Instead of a relationship being based on what’s wrong or problem-solving, “moving toward” means putting intention into what two people want to create together and keeping the focus on learning and growth.

The Intentional Peer Support Core Training is a 5-day introduction to this innovative framework designed to have participants practicing right away. In a highly interactive environment, participants learn the tasks and principles of IPS, examine assumptions about who they are, and explore ways to create relationships in which power is negotiated, co-learning is possible, and support goes beyond traditional notions of “service.” IPS is all about opening up new ways of seeing, thinking, and doing, and here we examine how to make this possible.

The IPS Core Training is for anyone interested in mutual support and has been widely used as a foundation for training people working in both traditional and alternative mental health settings, and in peer respites throughout the world. Specific topics include:

<b>The 4 Tasks: Connection, Worldview, Mutuality, and Moving Towards</b>	<b>The 3 Principles: Helping to Learning, Individual to Relationship, Fear to Hope</b>
<b>History of the Movement</b>	<b>Listening Differently and With Intention</b>
<b>Rethinking Old Roles and Ways of Relating</b>	<b>Working Toward Shared Responsibility</b>
<b>Understanding the Impact of Trauma</b>	<b>Moving Beyond Problem Solving</b>
<b>Examining Power and Privilege</b>	<b>Negotiating Boundaries and Limits</b>
<b>Navigating Challenging Scenarios</b>	<b>Looking at Crisis as an Opportunity</b>
<b>Using Co-Reflection to Maintain Values</b>	<b>Creating Vision</b>

Several other IPS trainings are available to build on the initial 5-days, including:

- Crisis and Advanced Trainings
- Co-Reflection Trainings
- Refresher Trainings

A 5-day IPS Train-The-Trainer is also available periodically. This training prepares individuals to offer the IPS Core Content (which composes the Core Training) to co-workers within their organizations. Many peer respites have supported team members to become IPS Organizational Trainers in order to support new team members as they are hired.

The IPS team is available to travel to any location and offer training onsite, and is happy to negotiate training setups to meet a variety of location, budgetary and practical needs. Both IPS Core Training and Train-The-Trainer are also hosted by the IPS team on a “pay-by-seat” basis each year.

For more information on IPS trainings, visit their website at [www.intentionalpeersupport.org](http://www.intentionalpeersupport.org).

### **Rounding out the Start-up Training Plan**

To round out a start-up training plan, the team needs to be informed of and trained on all the critical guidelines and procedures of the respite space, including the process for someone coming to stay at the respite, documentation requirements, and so on. Where time allows, involving the team in the development of these guidelines is ideal.

### **Ongoing Training Plan**

The ongoing training plan has two parts:

- A training plan for new hires
- A training plan for continuing employees

It’s advisable to develop a basic checklist for all new hires that details all the topics to be covered and the minimum amount of time involved in on-site training. Points that should be included are:

- Review of any existing guidelines
- Commitment to and learning related to multiculturalism and principles of anti-oppression
- Sexual harassment
- Overview of peer support concepts
- Process for entering the respite
- Required documentation, including timesheets
- HIPAA and any other relevant privacy guidelines
- On-call and emergency contact procedures
- Expectations for cleaning and other shift responsibilities

This is just a brief start to what will likely develop into a substantial list of items that should be discussed before someone would expect to be working more independently in the space. Also, for many respites, much of the training is about shadowing or working in the space as an extra person, to witness for themselves how the space runs and to try things hands-on with support from a more experienced team member.

Regardless of how seasoned a team member is, ongoing training will always be of value, not only for what is learned directly, but for the emphasis it puts on the idea of lifelong learning. There are many trainings available that can augment someone's existing skills and deepen their understanding and confidence when particular issues arise.

**Some of these trainings include (but are certainly not limited to):**

**Hearing Voices Facilitator training:** Although these trainings are geared toward people who wish to start a Hearing Voices group, they can be extremely useful to individuals who are looking to build their understanding of the experience of hearing voices, seeing visions or other unusual experiences. The training can also support people to come away with new ideas and approaches to talking about voices with someone else, including in a peer respite setting. The Hearing Voices approach is fully in line with peer respite values, and can be very re-enforcing in that way.<sup>1</sup> Facilitator trainings are available through the Western Mass RLC, both in Massachusetts and on-site throughout the country, as are shorter trainings for individuals wanting to use the approach in a broader context. For more information on these trainings, visit [www.westernmassrlc.org/hearing-voices](http://www.westernmassrlc.org/hearing-voices). Additionally, online Hearing Voices-related trainings are periodically available through Rachel Waddingham at [www.behindthelabel.co.uk/training/online-training/](http://www.behindthelabel.co.uk/training/online-training/).

**Alternatives to Suicide Facilitator training:** Similarly to hearing voices, suicide is an often fear-invoking and frequently misunderstood topic that can drive people to disconnect without the proper tools to be in conversation with somebody. Although these trainings are geared toward individuals wanting to facilitate Alternatives to Suicide peer support groups, just like with Hearing Voices, many people go through the trainings who simply want to explore the topic, and gain understanding and confidence about how to talk with someone who's struggling. Three-day Alternatives to Suicide and two-day Conversations about Suicide trainings are available in Western Massachusetts and on-site throughout the country. For more information, visit [www.westernmassrlc.org/alternatives-to-suicide](http://www.westernmassrlc.org/alternatives-to-suicide).

**Trauma-Informed Peer Support:** While it's become increasingly popular to talk about the framework of trauma and trauma-informed approaches, there is still a lot of work to be done by most

<sup>1</sup> For more information on the Hearing Voices approach visit: [www.hearingvoicesusa.org](http://www.hearingvoicesusa.org) or [www.intervoiceonline.org](http://www.intervoiceonline.org)

groups to truly understand what it looks like to practice trauma-informed peer support. Given the level of trauma experienced by people who enter the mental health system, including trauma caused within the system itself, it's a critical point to develop. <sup>2</sup>

**Rights & Advocacy Work:** While people working in peer respites do not need to be legal experts, it is essential that they have some sense of what people's human and legal rights are overall and specifically in their particular region. It's also important for people to have an understanding of what to do when someone feels their rights have been violated, and how to effectively advocate *with* (as opposed to *for*) someone. For people in the United States, the federally funded Protection and Advocacy organizations in each state can be a useful training resource to understand local rights. Listings by state can be found on the National Disability Rights Network website at [www.ndrn.org](http://www.ndrn.org).<sup>3</sup>

**Diversity & Allyship:** There are a number of diversity and cultural competence trainings available, and they range from superficial to in depth explorations of the many differences in background and experiences of violence and oppression. The best trainings for individuals working in a peer respite environment will help build understanding of people's different perspectives and experiences, including the oppression and discrimination (and thus trauma) they may have faced. It will also help team members explore how they may have internalized certain beliefs of oppressive systems, and support them to consider how to be better allies to people who have had life experiences that are different than their own. Any organization that does work in this area for one or more groups of people can be a good resource, including disability rights organizations, commissions for deaf or blind individuals, networks working to heal racism, transgender rights organizations, and so on.

**Peer Respite-Specific Training:** It's hard to beat getting training and/or technical assistance from a group that's "been there and done that," and has thought through how to share what they've learned with others. This training can include support to make use of the tools in this book, and much more. Contact the Western Massachusetts RLC at [info@westernmassrlc.org](mailto:info@westernmassrlc.org) for details.

**Certified Peer Specialist training:** Most states in North America now offer some version of a Certified Peer Specialist training. While these trainings can vary from state to state, and some are much more consistent with peer respite values than others, they can be useful for additional skill development and increasing understanding of how the overall mental health system works. <sup>4</sup>

<sup>2</sup> *Engaging Women in Trauma-Informed Peer Support* is a useful on-line resource <http://bit.ly/2zY3Srm>. Trainings on Trauma-Informed Peer Support (for all people not just women), are also available by contacting the trainers at [community@capital.net](mailto:community@capital.net).

<sup>3</sup> *A good on-line resource for rights information: [www.chrusp.org](http://www.chrusp.org)*

<sup>4</sup> *A compilation listing of peer specialist training programs, compiled in 2014 by the Texas Institute for Excellence in Mental Health, is available at: <http://bit.ly/2C5osrJ>*

**Wellness Planning:** Wellness Recovery Action Planning is the most well-known tool to assist people to create their own plans on how to support themselves to live well, and how to get the support they want and need when in a difficult place. Although it's not the only option or way of going through this process, it has been useful to many, and it will be helpful to have people working at a respite at least be familiar with the basic components of WRAP and how to support someone to develop their own plan.<sup>5</sup> Mad Maps (developed by the Icarus Project) are another format of wellness planning that is gaining notice and has integrated more of an anti-oppression perspective.<sup>6</sup>

**Advanced Directives:** Many people who have experienced force within a mental health system fear experiencing that loss of power again. Thus, it can be very important to support people in a peer respite to develop tools that will help them retain as much control as possible, even if they are in a place where they are having difficulty speaking for themselves or being taken seriously. In many countries, there is a process for developing an Advanced Directive. This document is developed when someone is in a good space and details what they would want to have happen during a crisis of any kind, including who they would want to support them, what services they would absolutely want or not want, etc. It is a document that is intended to have legal standing and to prevent decisions from being made in a way that someone would find harmful. Local disability rights organizations are often a good resource for training in this area, and there are a number of online resources including, for the United States, a page on the National Disability Rights Network's website: [www.ndrn.org/issues/mental-health/advance-directives.html](http://www.ndrn.org/issues/mental-health/advance-directives.html)

**Withdrawing from Psychiatric Drugs:** Many people coming through a peer respite will have some relationship with psychiatric drugs, whether they are interested in starting, increasing, changing, lowering or getting off them. This is often seen as a taboo topic, and peer respites can be very quickly pegged as being "anti-medication," because they're willing to discuss options. However, regardless of that risk, and although it's not our role to decide for anyone what they should or shouldn't do, it is very important for people working in a peer respite to be willing to have the conversation and to have some tools and resources to offer. In some instances, this may look like going with someone to an appointment or helping them think through exactly what they want to communicate beforehand. It may also include discussing harm reduction approaches to withdraw from psychiatric drugs, and helping people understand the potential risk of making changes too quickly.<sup>7</sup>

<sup>5</sup> More about WRAP can be found at: [www.mentalhealthrecovery.com](http://www.mentalhealthrecovery.com).

<sup>6</sup> More about Mad Maps can be found at: <http://theicarusproject.net/for-peers/>

<sup>7</sup> One valuable resource is the Harm Reduction Guide to Coming Off Psych Drugs which is available in 12 languages at: [www.theicarusproject.net/alternative-treatments/HarmReductionGuideComingOffPsychDrugs](http://www.theicarusproject.net/alternative-treatments/HarmReductionGuideComingOffPsychDrugs) Other relevant information can also be found at [withdrawal.theinnercompass.org](http://withdrawal.theinnercompass.org).

**Benefits Training:** It is incredibly common that people coming into peer respite will have questions about or need assistance with applying for or maintaining a variety of benefits related to food, housing, and basic income. For example, in the United States, it is incredibly useful for individuals at the respite to have training on the ins and outs of Social Security Disability Income (SSDI) and Supplemental Security Income (SSI).

**Restorative Justice:** This approach is an alternative way to address conflict and when harm has been experienced by a person or community, and damage done to relationships. It shifts the focus away from the action itself, and to the people and connections involved. It also regards the way forward as involving any person seen as causing harm, those that experienced harm, and the community around them. In communities where people in power have generally been seen as responsible for mediating any problems and requiring people to adhere to any rules or practices, it can be particularly powerful to turn the responsibility for addressing issues over to the community wherever possible.

Annual conferences can also offer valuable opportunities for learning and networking, although again, the content is often highly variable and sometimes more consistent with peer respite values than others. See the Appendix for some suggestions on annual conferences that may be worth attending.

# SUSTAINING THE TEAM

In any job where you find yourself supporting others, it is important to remember to support yourself as well. This might be especially true where peer-to-peer supports are considered. Let's be clear that this is NOT because people working in peer roles are especially fragile people, as has been suggested by some. On the contrary, individuals who do this work have survived tough situations and have made it through to the other side. There's a case to make for people like that to be even *more* resilient than those who haven't been through those struggles. There are several reasons, however, that people in peer roles may have added stressors that are simply different and often in addition to those in other supporter roles. Some of these reasons include (but are not limited to):

- **The lack of clinical "boundaries":** "Boundaries" —at least in relationship to the mental health system— are often based on an organization or particular profession's beliefs, rather than being about personal limit-setting by an individual or in the context of a given relationship. However, in peer-to-peer relationships, there's generally a shift away from system-set boundaries and toward individual limits set by people directly involved in a given situation.

In particular, there's a call on individuals in peer roles to open up their personal lives in a way that simply isn't expected of others. No one is the expert here, and both people are giving of themselves in big ways. This means making yourself vulnerable at times and, possibly, sharing from your own life experience. That is very different from people in clinical roles, at least in most conventional settings, who rarely talk about their private lives, considering that "unprofessional." When you make yourself vulnerable in this way, it can take a lot out of you energy-wise -mentally, emotionally, physically, etc.

- **Possibly being one of only a few people working in peer roles in the organization.** This will not be true in a purely peer-run respite, but in other versions of a respite model, this may be so. In those situations, you might have to witness your co-workers doing and saying things that go against your values on a daily basis, and this can absolutely be draining. It also takes a lot of effort to stay clear about your principles when you are surrounded by people who are doing things differently.
- **Being in a position to constantly explain and justify peer roles.** Whether or not you work in a peer respite that is also part of a peer organization or if you work in the traditional system, you will need to explain over and over again what peer-to-peer support is and what someone in a peer role does with their time. This might look like



explanations to your co-workers or answering calls from providers, and doing outreach about your respite. Although this movement has come a long way and gotten a fair amount of attention lately, there are still many people who have no idea what we do. Worse, there are many people who believe they do understand, but still have misconceptions about what we do.

- **Supporting those who are experiencing or have experienced similar difficulties as you've faced.** The very nature of being in a peer role means that you've experienced some substantial difficulties in life. Your experience could include childhood trauma, and it's likely that at some point someone (or many someones) will share with you about their past abuse. You may have also experienced your own intense struggles with hospitalization or force, and this is another likely topic that you'll hear about when working at the respite. We've all experienced that moment when someone is seeking support from us and their story is eerily close to our own. It can touch on some really raw or vulnerable places, whether you're in a peer role or not. It's also likely at some point that you'll cross paths with someone in this setting who reminds you of people who have hurt you in the past.
- **Working in similar environments where you may have previously been hurt or experienced trauma.** People have experienced trauma in any number of settings. Some may be similar to the respite you find yourself working in, or even the organization by which you are now employed, particularly if working for a traditional agency. When doing outreach for the respite, you may find yourself in a wide array of spaces that could bring up difficult feelings and memories, from police stations to hospitals and beyond.
- **Supporting people in extreme states/difficult times.** This is true for all people working directly with other struggling people, but for people offering peer-to-peer support, it can be especially hard. We are trying to change the way people are supported and have been supported through crises for decades. Sometimes this means that the people seeking support at a respite may come with expectations that they will be taken care of or have things done for them or that the people working at the respite will have all the answers. When that turns out not to be true it can bring up anger and confusion that needs to be talked about and moved through before space can be made for change. As with any paradigm-shifting movement and work, it is hard; worth it, but difficult. We constantly need to look at the work we're doing and ask if we are holding to our values and if things could be better. This is an evolving art.

- **Having some sort of clinical or social service training/background.** While many people consider this an asset or believe it will help them be good at the job, this is rarely the case. Peer respite work requires such a paradigm-shift that having this sort of training or experience often means there is at least some unlearning to do. This can feel similar to being asked to work with one's non-dominant hand. There are significant differences in philosophical understandings about the roots of distress and crisis, reflected in language (non-medical or clinical) and ways of working with people. The strict "boundaries" demanded in many traditional "helping" roles also come from a very different place and perspective than what limit setting looks like in a peer-to-peer setting.
- **Being completely new to the field.** While this is often an easier starting point than the bullet above, being completely new to working with people and offering peer-to-peer support means there is a significant learning curve ahead. This is particularly true given that the same concepts and approaches taught in clinical trainings are also conveyed through popular media all the time, so most of us have picked up some of those ideas. Furthermore, if a respite is starting out, there may be several people in this category working together all at the same time, making it hard to really get one's bearings and build confidence.

And while each person working in a peer respite is navigating these various challenges, there's also the rest of their life with which to contend. Fortunately, there are some ways you can support yourself through all of this both by taking good care of yourself during your shifts in the respite and outside of work.

The peer-to-peer relationship is based, at least, in part, in mutuality. That means that both people's wants and needs matter. So, don't be afraid to take some time to think about what would support you in those moments when you're supporting others. Some examples of those moment-to-moment activities might be:

- Taking deep breaths
- Noticing what's happening in the periphery of your vision while talking with someone; this relaxes the eyes and often deepens breath
- Relaxing the muscles in your face, neck and shoulders
- Taking frequent bathroom breaks, even if just to splash some water on your face and take a moment

*"When I first started, I wouldn't take breaks to eat or even to go to the bathroom because I thought supporting someone struggling was more important than taking care of myself. I now know that BOTH of these things are equally as important and, when paid attention to, support the relationship to grow."*

*- Respite Team Member*

- Clearly stating how you're feeling in the moment. Sometimes just labeling a feeling can loosen its hold and begin to help it dissipate; an example of doing this tactfully might be, "Hey, I'm noticing I'm feeling really overwhelmed right now. I'm just going to take a minute to pause and breathe."
- Drinking plenty of water. Water helps flush stress chemicals that can stay in your system for up to three days after the stressful event.
- Having a hot or cold drink. Sometimes the making of the drink is as important of a ritual as what is actually being consumed.
- Asking the person you're supporting if they'd be willing to talk outside/go for a walk/garden
- Being aware of what recharges you personally
- Eating protein or whatever works for you
- Asking for a brief co-reflection conversation with a colleague
- Engaging in a spiritual practice
- Following a personal ritual to clear out the stress and enable moving on. For example, one person would open and close a window to symbolize letting go of the negative or tension.

Everyone has some sense of what supports them in trying times, so this is by no means an exhaustive list, but here are a few examples of what some people working in peer respites have offered that they do to take care of themselves outside of work:

- Hiking, biking or other exercise
- Dancing
- Time with friends/family/partner
- Cooking delicious food
- Reading
- Making or listening to music
- Writing or blogging
- Crocheting/knitting/sewing
- Going on retreats or vacations
- Spending time with children/animals
- Watching television/movies
- Making art or crafts
- A yoga practice
- Spending time on the computer

*"At first, I thought it was great that people I'd supported were reaching out to me on Facebook, and I more or less still do. However, when I started receiving daily messages at all times of the day and night about really heavy stuff, I realized that what had been a place for me to relax and connect with friends was becoming something different, and I needed to set some different limits."*

– Respite Team Member

- Spending time on the computer
- Developing a spiritual practice
- Exploring a new hobby/interest
- Involvement in community groups and politics

Another unique characteristic of many peer-to-peer roles is that, depending on your particular organization's policy, you're freer to give out your contact information, which might include phone numbers or social media accounts. This is an important part of having a genuine human relationship with someone. It's worth remembering, though, that the people coming into the respite are going through some hard times. They may be in a place in life where they are needing some extra supports, as we all do at times, even after they leave. Thinking about whether or not you are able to give that extra support indefinitely might be useful.

Being really clear with whoever you're giving your contact info to (about your availability, times of day you are or are not available, how long it might take you to return a message, whether or not you're okay receiving work-related messages on social media accounts, etc.) can be critical not only for supporting yourself, but for decreasing the likelihood that the trust that's already been established in that relationship will be broken.

This also includes being as clear as possible about what your intentions and hopes are for the relationship, so that, for example, if you just mean to be offering a way to reach out if someone wants to talk on occasion, they are less likely to mistake that for an offer of daily contact. Transparency is a big part of what it means to offer peer support, so don't be afraid to ask for what you need and to be honest if you need to ask for some changes to the relationship/level of contact. If you don't ask, then you become just as responsible as the person on the other end of the relationship for getting burned out. See the section on supervision and co-reflection for more on this concept.

It can also be helpful to seek out others who work in peer roles, no matter where they are based. In some states, peer initiatives are very strong, while in others, opportunities to connect may be lacking. Reaching out, even beyond your own locality, to other peer respites and people working in peer roles may help sustain you in the work you're doing. Trainings, conferences and events are a good way to touch in with people doing similar work, as well. In some areas, people have intentionally formed 'peer networks' to connect people working in a variety of peer roles to one another through newsletters, regular meetings and regional events. <sup>1</sup>

# WHEN ITS NOT WORKING OUT

It's essential that people working in peer respites be held to high standards, and that expectations for what it means to hold space in a respite and in peer-to-peer relationships be clear. Unfortunately, that means that sometimes things just won't work out. This may happen for any number of reasons, just like with any job. For example, the person may realize that the job just isn't something they enjoy. Even some who are good at this sort of work may also ultimately find it too draining, or that it's too painful to be a part of holding so much pain from so many people. Other reasons that it doesn't work out might include:

- Someone's learning curve is just too steep, or the need for unlearning is too great on one or more topics, whether that relates to non-clinical perspectives, racism, how to respond when someone is talking about suicide, and so on.
- Someone's life is turbulent at the moment and it's coming into the workplace
- The pay isn't high enough for them to make ends meet, and they're struggling to meet basic needs or having to take on other jobs to close the gap
- They discover they have a fundamental disagreement of some sort with how things operate at the respite and bridging that gap is not feasible
- Something in their life is preventing them from coming to work and/or being on time
- There's an interpersonal conflict on the team that people are unable or unwilling to move through and that is impacting the space

And, of course, sometimes—even if everything else seems right—there are things that come up that raise ethical or other concerns that prevent someone from continuing in the workplace.

Perhaps what's most tricky about navigating situations where someone's employment is not working out is how to address concerns, and—if it comes to it—end employment in a way that is consistent with the values of the work. This is further complicated by employment law, documentation requirements, and other elements that can reinforce power differentials and hierarchy in an environment where the tendency is to work as collaboratively as possible.

One point to remember is that it's essential to be as upfront as possible about concerns when they happen. Except in rare circumstances where action is required based on a one-time event, someone should have been involved in conversations about concerns with their employment well before the point of termination. This is, of course, good practice in any place of employment. It's also important to remember that hard feelings or abrupt disappearances can quickly become rumors among co-workers and the community of people who use the support. Whenever

possible, it's useful to talk with the person about how their departure will be communicated with others, and to give everyone space to process their sadness and discomfort when there are bad feelings or a difficult situation that can't fully be discussed with everyone who might want to know what happened. Leaving this hanging or unrecognized can have long-term negative impacts on the community and breed a sense of secrecy and mistrust.

Some other points to consider that are more specific to a peer-to-peer environment:

- **The person working at the respite may also have built their own support community and friends within the same community where the respite is held.** In these instances, it's important to be clear about whether the person is being asked to step away from their work role or from the community altogether. Can those two be separated out, and how? What are the barriers, and can they be overcome? If they can, how can the respite team intentionally welcome the person to continue participating and being connected in a different way?
- **It may be even more important for everyone involved to have a clear way to say goodbye.** Often, in the conventional system, people just disappear without any thought to how re-traumatizing that can be for people who've not had much that is steady in their lives. It can also create a sense of powerlessness and open or re-open a wound for the person who's being asked to leave. As a result, some peer-to-peer organizations have been intentional in trying to create space, such as going away parties, gatherings or circle conversations for people who are leaving to talk with and say goodbye to others (at least within the context of their paid role), even if they are leaving on bad terms with the employer.
- **The person leaving may want to use the respite supports in the future:** Whether or not an employee can also use the peer respite supports offered either during or after employment is a valid conversation for all respites to have. While some funders may prohibit people from being paid and formally supported by a peer respite, there's often more flexibility around this topic with peer roles than in other contexts. When someone's leaving, though, there will often be real benefit in having intentional conversations with them and the rest of the team about how to move through hurts so that the support can be accessible to them in the future. Of course, some space may be required post-separation in order for people to want to genuinely engage in that process, but hopefully the door can be held open to that possibility.

Loss of a job can bring up a tremendous amount for people both because it can raise old traumas and because loss of pay brings up very real fears and concerns. These are just a few of the considerations respite teams may want to think about, even in advance of finding themselves in a situation of this nature.

# Documentation

you have a voice

our harmony

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for

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little of all

# INITIAL CONSIDERATIONS

Record-keeping is a tricky topic due to the number of potentially conflicting interests and requirements involved. From a most basic standpoint, creating files on people is not consistent with peer-to-peer values. This is because one of the essential aims of a peer-to-peer relationship is to keep power differentials at a minimum. At a peer respite—and with most peer roles—where there's already the differential of some people getting paid, it's important to do everything possible not to add to that. Certainly, writing notes on someone staying at the respite (when they, of course, don't get to write routine notes on the person working there) inevitably increases power for the one doing the writing.

Additionally, many people who've received mental health services have been negatively impacted by documents that have been created about them and placed in their files. These documents can follow people around for years, whether or not they represent who that person is in the present, and even if they were inaccurate from the beginning. Documentation can also serve as a real disconnection point in the moment, especially when forms are designed to ask a set of artificial or routine questions that may not always feel particularly relevant or genuine.

When considering documentation, people commonly remark that they need to write things down in order to remember them, and that expecting people to never make personal notes is unrealistic. This is true, and personal notes to oneself should be understood as substantively different than routine notes *about* someone else that go into a permanent file. Personal notes that include other people's details, of course, should still be kept confidential and shredded or otherwise destroyed when no longer needed.

Some people also worry that if certain information isn't documented (what psychiatric drugs someone is taking, for example), this could lead to harm in a medical emergency. While it's true that, for example, not knowing that someone is taking a particular medication, or that they're allergic to bee stings can mean that you're unable to react quickly in a medical emergency, this is simply a truth of life in the vast majority of places in the world. Just as we might not know a medical detail about someone at a peer respite, so might we not know what medications our own close friends are taking. And, while it's true that not knowing this might mean that we can't respond ideally if they were to collapse on the ground while we're out to lunch, somehow most of us understand that, as much as we'd want to be able to help in that situation, it's not our responsibility to track our friend's medical details, and trying to do so would likely change and potentially damage that friendship.

This is also true in a peer respite where the energy is around shared responsibility, rather than responsibility *for* or *over* another human being. That said, if someone wants to inform a peer respite worker of a particular medical concern or other issue, that is different and situational rather than



representing overall policy. There are ways to create this sort of opportunity without it needing to become a permanent or routine document. Examples are available in Appendix 1.

Of course, there are many reasons that documentation does occur, including, but not limited to, for research purposes and outcome measures, as well as basic requirements of a funding source. Yet, taking the time to carefully negotiate funding requirements right from the start is very important. All too often, people assume that funder requirements are non-negotiable when, in fact, funders can sometimes be just as flexible as anyone else. When attempting to negotiate, it's a great time to ask "why." This is often one of the most powerful questions that can be asked, because sometimes the answer is that the person asking doesn't actually know and is just requesting something out of habit. And, at the very least, knowing what is behind a particular requirement offers a great deal of information about how to think about things creatively.

It can also be useful to know what other people are doing for documentation, both in peer respites and in other programs and approaches that have similar values and goals. Below is an excerpt from the original Afiya grant proposal in response to the Massachusetts Department of Mental Health's documentation requirement .

Record-keeping is a charged issue for peer-run supports. Peer-to-peer values suggest that detailed files should not be kept by organizations about individuals who have received support. This practice not only replicates clinical system approaches, but also serves to enhance the same power differential that peer-to-peer supports seek to eliminate. Storage of documents like one's Wellness Recovery Action Plan (WRAP) also goes against the explicit values of WRAP itself. For these reasons, we would suggest that only minimal documentation (HIPPA forms and basic program entrance records) be kept as a matter of standard practice in a locked file cabinet at the Peer Respite site. However, any action plans or other personal documents developed during the course of one's stay will be turned over to them at the time of their departure. Similarly, any forms completed ahead of one's entrance to the program (e.g., forms geared toward orienting an individual to the Peer Respite and determining the benefits to them) will generally be held by the individual, as well.

These practices are similar to the practices of a variety of other programs nationally and internationally, including PO-Skane ([www.po-skane.org/ombudsman-for-psychiatric-patients-30.php#](http://www.po-skane.org/ombudsman-for-psychiatric-patients-30.php#)) in Sweden and the Western Mass Recovery Learning Community.

As the Peer Respite will prioritize person-centered supports and because some individuals who use or anticipate using peer respite supports may want their plans or other documentation to be stored on their behalf, the Peer Respite will develop a website-based system where individuals can receive assistance from Respite staff to store their documents in an individual account on-line. This will allow them to personally access these forms (WRAP, action plans, advanced directives, etc.) from any computer, regardless of their location. This will further allow individuals to control access to these documents, as they will have the liberty of sharing their account password with whoever they choose and changing that password as they desire.

While Afiya was ultimately required to keep slightly more documentation than represented in their original proposal (three documents in total), the fact that they put their ideal plan out to funders had two important affects:

1. It was an opportunity to educate funders about other alternative approaches, For example, PO Skane in Sweden.
2. It meant that the team wasn't already starting from a point of compromise when negotiating where they would land.

For any routine documentation that does exist, it's important to think about how it is approached. Peer-to-peer environments will commonly not push most kinds of documentation when refused. Additionally, for any notes that do get taken, it's standard practice for the person to be offered the opportunity to write the note themselves, or at least state what they'd like it to say.

Consideration should also be given to how many papers someone is handed upon arrival. In many traditional environments, there's often a stack of papers handed over and most people simply never truly read through them. While offering information and being transparent about expectations is important, so is avoiding this sort of set up. In an attempt to keep paperwork to a minimum (both documents requiring person-specific documentation and documents that are simply for informational purposes), it's helpful to list what's absolutely essential. This may include:

1. A basic HIPAA notice or any other legal confidentiality expectations for the nation where the respite is located and signature page (*kept on file*).
2. A basic entrance agreement detailing resources and responsibilities (*signed and kept on file*).
3. A basic sheet about the mission and values of the respite.
4. A basic sheet about community resources.
5. A basic sheet documenting someone's hopes and aims for their stay (where this sort of documentation is required) (*completed and kept on file*).
6. An additional voluntary sheet where someone can offer any details they want peer respite team members to know and emergency contacts. This is a sheet that would generally not become a part of someone's permanent file and is only kept so long as they are staying in the space.

See Appendix 1 for a variety of sample forms and documents.

Whatever documentation requirements end up being, it's important to keep an eye on not having them get in the way of the true intent of the space, which is to build connection and support people to learn from and move through places of deep distress. This can mean giving someone some space when they first arrive and before paperwork is introduced, being willing to meet and review paperwork outside or wherever the person is most comfortable, and generally letting them take the lead as much as



*Photo credit: Dani Scott*

possible. Giving them some space to work on the paperwork alone can also be helpful. Other important points to keep in mind include:

- Explain why the paperwork exists. Is it useful to the team? A requirement of the funder? Be willing to answer questions. This can lessen the power differential that paperwork can create.
- Consider adding explanations for paperwork on the document itself, especially where a funder may be requiring information to be given that doesn't feel entirely in sync with everything else.
- Give the person open access to any paperwork about them, either by making a copy for them to keep or by offering electronic access.
- Ensure a collaborative process. Even if paperwork is absolutely required, people staying at the respite should have as much control and responsibility for the paperwork as possible.
- Train respite employees on how to handle paperwork. If no training is offered, people are more likely to fall back into old habits. Good training on how to do paperwork collaboratively should be offered, and the team should check back in on the process on a regular basis.
- Beware of old habits. Particularly if someone is coming from working in a traditional environment, it may be easy to slip into old ways of doing things, including where paperwork is concerned. Team members should get in the habit of checking in with themselves and each other to be sure they're staying on track and keeping conscious about this issue.
- Don't let paperwork slip too far. While giving someone space to do the paperwork in their own time is important, it is also important that they receive information in writing about what the respite is all about and what is expected from everyone staying and working there. If someone is a few days into their stay and there are ways in which they are not respecting the values, but they have never looked at the entrance information, it is unfair on both sides and can be a real connection breaker. Setting some basic guidelines around when paperwork should be done may be helpful to all involved.

# Developing Guidelines



# INITIAL CONSIDERATIONS

Traditional spaces tend to have many blanket rules and protocols in place. These may have been created based on one or a couple of incidents where things did not go as well as they could have. This practice tends to place blame on the person receiving support, rather than focusing on shared responsibility, mutuality, and the uniqueness of each situation. In spaces that value self-determination, respect and optimism, it seems more appropriate to have guidelines that can flex and change based on the individual situation. Similarly, in spaces where conversation and connection are the focal point of the design, talking through disagreements and difficult situations, rather than simply having a black-and-white rule to fall back on, is also of value. A space may have a few very concrete guidelines, such as asking people not to bring alcohol or weapons into the respite, or to not disclose who else is staying there. Having *some* clear limits makes sense. But, overall, it's more about meeting each person where they are at and not developing protocols based on a couple of situations that look similar.

As the respite changes and grows and finds its feet, it's likely that any guidelines that are developed at the start will need to change, including getting rid of some and creating new ones. Building guidelines with the respite's particular values in mind is a process that requires a lot of integrity and constant reflection. When done well, the values themselves can support the process of understanding a difficult situation and making decisions about what to do next. This is fundamentally different than coming from a place of "I'm right and you're wrong, because that's the rule."

The way guidelines are developed for a peer respite is an important process. Generally, having as many team members as possible be part of the process is good practice. These team members are the ones who will be putting these guidelines into place, after all, so it makes sense that they would have some say in how they are written. Being a part of development also helps people truly learn and know what the guidelines are all about.

Some of the guidelines that might be useful for a peer respite include:

1. **Limit-Setting Guidelines**—In traditional environments, limit-setting is often referred to as setting 'boundaries' and focuses on rigid rules like withholding information about where you live or not sharing your phone number. Instead, respite guidelines tend to prioritize awareness and exploration, and how to define and set one's own limits. For example, a respite will commonly have expectations that someone working at the respite not attempt to date or be intimate with someone staying at the respite, but would support their employees to decide for themselves whether or not they want to share their phone numbers or interact with someone on social media.
2. **Initial Conversation Guidelines**—Although peer respites generally avoid the language of "intake" and "admission," there still needs to be a process for talking with someone about whether or not

peer respite is a good fit for them and coming to a decision together about whether or not they will stay.

3. **Waiting List Guidelines**—If a peer respite is going to have a wait list of any kind, it's essential to have a set process for managing and tracking the list so that people don't get lost in the shuffle. It's also important that people be given a realistic idea of how long they might be waiting.
4. **Visitor Guidelines**—Respite vary tremendously on who can visit when and in what part of the space. Although emphasis is placed on respecting the value of being able to maintain personal connections, a balance is also sought between that and respecting the privacy of others staying at the respite. Wherever a peer respite lands on this issue, it is important that there be transparency about what the guidelines are, so that no one feels surprised by it.
5. **On-call Guidelines**—Any 24-hour space will benefit from a back-up support system, which means people working at the space need to know who to call, and the person being called needs to know what might be expected of them.
6. **Asking Someone to Leave the Space**—Inevitably, there will be times when a stay just isn't working out. Giving people information upfront about what is likely to lead to them being asked to leave is important, as is supporting the team in thinking through in advance how they will handle the often difficult process of asking someone to leave.
7. **Service Animal Guidelines**—Animals are very important in many people's lives, but they can also be disruptive to a respite if they are not well-trained, if they are not being kept with the person who brought them, and/or if someone else working or staying in the space is allergic or afraid. It's important that people working at a peer respite understand the local laws about service animals, as well as the difference between service animals, support animals, and pets, and how the respite is going to respond to each one.
8. **Communication Guidelines**—It's essential that a peer respite have safeguards against falling into the trap of routinely talking about people without them present, as this is not in line with peer respite values. However, sometimes it will be necessary to communicate about particular situations or a team member's own need for support. It is helpful for the team to have thought through how they want to handle communication overall, and what sorts of resources and methods may be used.
9. **Medical Emergency Guidelines**—Overdoses (intentional and otherwise), chest pains, etc. happen anywhere and everywhere in this world, and sometimes there will be a medical emergency in the space. It's important that everyone in the space knows how to respond to situations like overdoses (intentional or otherwise), chest pains, etc. and that they are familiar with where to find local emergency numbers and other relevant information.

10. **Drug and Alcohol Use Guidelines**—Some respites have a zero-tolerance policy for any alcohol or illicit drug use while staying in the space, while others have a more liberal policy that acknowledges people may drink, etc. during their stay when off the premises, provided they do not return to the space heavily intoxicated. Whatever the guidelines may be, it's important that both people working and staying in the respite are clear on the expectations and what will happen if they are not followed.
11. **Guidelines about Interacting with Police or 911**—Generally, there is a real effort in peer respites to not jump quickly to calling the police or 911 when there is difficulty in the space. This is because the police are not often well trained to manage situations where someone is in emotional distress. There is also a well established history of increased likelihood of violence for non-white folks or people with psychiatric diagnoses when the police get involved. Thus, their presence can raise tensions and make a situation more volatile. Additionally, many people who will stay in a peer respite have experienced being taken to the hospital against their will by the police, and so even the sight of a police car and uniform can bring up past traumas and fear and agitate a situation.

That said, most peer respites will support team members to call for emergency help if a situation arises that truly feels dangerous or can't be managed in any other way. Thinking through when to reach out for this sort of help, what alternatives there are before it gets to that point <sup>1</sup>, and what to do when it does is an essential part of ensuring that it doesn't get over- or under-utilized. (It's also possible that the police may start stopping by the respite just to see if someone they're looking for is staying there. Thinking through how to respond in those situations is also important.)

It can be helpful to have advance (and regular) conversations with the local police about avoiding more disruptive practices like showing up at the space unannounced, banging loudly on the door, or coming in the respite unless absolutely necessary. It will also be helpful for you to develop a common understanding of what information you can and can't share with each other so that bad feelings are less likely to arise in already tense moments.

Additionally, it is essential to have a guideline for an internal review when any coercive incident occurs, including if the police or other emergency services are called against someone's will. This is not meant as a punitive measure, but rather as a way to ensure that the peer respite does not drift too far. It is important that those involved consistently check in with themselves as to how their actions meet the respite's mission and values, and that they consciously work toward developing non-coercive practices that work for all.

See Appendix 3 for a sampling of guidelines, including several of those mentioned in this section.

<sup>1</sup> Lots of information on what to do instead of calling the police can be found here: [bit.ly/29ZwIQO](https://bit.ly/29ZwIQO)

# MAKING GUIDELINES ACCESSIBLE

As a way to keep things simple and in order, it may be a good idea to develop a guidebook to keep all guidelines and any other important information for new and existing team members reference together. In addition to guidelines, this book also might include a list of ideas for things to do when the respite is quiet, training sheets for new team members, information on the principles of Intentional Peer Support, and other resources. Here is a sample Table of Contents for a guidebook:

## Contents

### Get to know the respite/organization:

- Defining values/principles of the respite
- Intentional Peer Support Principles

### What to do on shift:

- Conversation opener ideas for peer support interactions
- Things to check on during your shift
- What to go over with new team members
- How to fill out timesheets

### Space information:

- Phones (frequently used numbers, how to transfer lines, etc.)
- Utilities information
- Lock box information

### Check out our guidelines:

- Guidelines for initial conversations
- On-call guidelines
- Communication guidelines
- Wait list guidelines
- Medical emergency guidelines
- Asking someone to leave the respite
- Limit-setting guidelines
- Drug and alcohol guidelines
- Visitor guidelines
- Guidelines for service animals

**Note:** This guideline book should not be something that needs to be locked up. Although there's no reason to ask people staying at the respite to look through it, it shouldn't be a secret and should be open to anyone who wants to see it. For this reason, any documents that include passwords or private phone numbers and so on may be best kept in a different location.





# Language

# Language in a Peer Respite

It's common to discredit the importance of conversations about language or to say it doesn't matter, but the truth is that using terms like "mental illness" and other clinical language should be considered a serious red flag in an environment that is called a peer respite.

**Consider the following key language points:**

- **Making meaning of one's own experiences:** Above all else, peer respites are designed to be spaces in which people can explore and move through their experiences of emotional and/or mental distress. They are spaces where someone is meant to be free to make their own meaning of what has happened to them. However, the moment that someone speaks to them in medicalized language, it sends the strong message that there is only one way, or a very limited number of ways, to define their experience.
- **Seeing oneself as having the potential to move beyond dependence on the mental health system:** Respites are intended to be spaces where someone may begin to see themselves as more connected to the world, and able to move beyond the mental health system or a cycle of going in and out of hospitals. To that end, there is no value in referring to someone as a "client" or "consumer" (or even "guest" or "peer" or some of the other more benign-sounding terms that sometimes come to be rigidly used to mean "someone receiving our services"). Consider: What message do we send to someone when we are supporting them to think about moving *beyond* the system, while referring to them as a label based specifically on their relationship *to* the system?

It's also worth considering the Stanford Prison Experiment ([www.prisonexp.org/](http://www.prisonexp.org/)) in relation to this conversation. The Stanford Prison Experiment was a psychological study conducted in 1971 by Stanford University. The study involved assigning some volunteers to be prison guards and some to be prisoners. The study had to be shut down because the volunteers took on their roles so deeply that it was considered unethical to continue the project. Applying the same principles, what potential effect do we have on everyone involved when we rest too strongly on terms like "client" and "staff?"

- **Creating an environment where one has choice and voice:** Problems consistently arise when peer support becomes divorced from an understanding of social justice and psychiatric oppression. This is a concept that can be scary or off-putting to many funders and providers, but the truth is that even they talk about elements of oppression that exist in the mental health system on a fairly regular basis. They just don't name them as such.

For example, many systems have invested time and resources in developing a "person-centered" approach in recent years. They wouldn't need to do so if they didn't recognize that the voices of

people receiving services have been habitually silenced. And, of course, not having a voice is a symptom of systemic oppression. Yet, making the leap to examine the system from a perspective of historical oppression is hard for many people, often because they perceive themselves as getting blamed or attacked in the process.

Peer-to-peer supports can perpetuate or replicate that denial in many ways, and one is through language. By using words like “compliance” (which almost always refers to one person doing things the way another person wants them to), or relying on clinical terms, we do take at least some degree of someone’s choice away (or at least, teach them not to expect choice in the first place). Instead, people working in peer respites should consider it their responsibility not to use those sorts of words, and when they hear someone staying there use a clinical word, they should be trained to ask them what that means to or looks like for them. It’s only through that sort of process that real choice and voice are found.

**Words not to use:** So, where does that leave us? There truly are not any word lists that people should or must use, but there certainly are words and ways of speaking that people working in peer respites should steer clear of. These include:

- Labels for individuals that are based on their relationship to the system (client, consumer, patient, person served, etc.)
- Language that promotes a medical model/disease model way of understanding distress (mental illness, mental disorder, etc.)
- Diagnostic terms (bipolar, schizophrenic, etc.)
- Clinical interpretations/judgments of experiences (hallucinations, psychoses, delusions, manic, etc.)
- Clinical interpretations of behavior (manipulative, splitting, decompensating, compliant or non-compliant, high or low functioning, etc.)
- Referring to people as if they are their behavior (cutter, offender, convict, etc.)

**What to say instead:** Some people may feel overwhelmed by the prospect of speaking in this way if all they’ve known is a clinical system. They may even question if they’ll be understood if they do not use these sorts of words. However, the goal of not doing so is to use everyday language that pretty much anyone could understand.

For example, instead of someone being a “client,” they might just be someone staying at the respite, or someone you’re supporting. And instead of having “hallucinations,” someone might be hearing voices or seeing visions. Similarly, instead of being a “cutter,” someone might be described as a person who sometimes uses self-injury as a way to deal with stress, and so on.

**Do we challenge everyone's language?:** Of course, this leads us up to the following question: If someone staying at the respite uses some of this language, is it the role of people working at the respite to challenge them on it? The answer is no. At least not directly, and particularly not if they're speaking about themselves.

In other words, it should never be the intent of someone working at a peer respite to take words away from someone they're supporting. However, it's absolutely their job to ask the person what that word means for them, and to encourage them to figure out if it's a word that is helpful to them and that they want to keep using.

For example, if someone says "I'm bipolar," a peer supporter could simply say, "What does that look like for you?" or "How do you feel about that label for yourself?" or "How has thinking about your experiences in that way worked or not worked?"

Similarly, if someone says "I'm psychotic," a peer supporter could simply say, "What are you experiencing?" or "When you say that, what does that mean is happening for you right now?" or "When you've been in similar states in the past, what has that meant for you?"

**One final note:** Everything research tells us about how people learn and take in different messages tells us that the absence of negative messages can be even more important than positive ones. For example, let's say that someone thinks they're a complete failure at life. Now, let's say that 99 people tell them how wonderful they are and list out all of their successes, but one lone individual agrees with them that they're a failure. That person is much more likely to hear, believe, and remember the one who agrees with them than the other 99.

There are lots of implications for this information, but the most important for now is this: It is critical that everyone in a peer respite environment be consistent with speaking in non-clinical, everyday terms or else there simply won't be room for someone to truly re-evaluate how they see themselves. And, if that room doesn't exist, then the peer respite will fail at a fundamental part of its mission.

# Language & Traditional Providers

**What do we do if we're working under a provider or funder who insists on clinical language?:** Sometimes, peer respites exist under funders who use clinical language, and that can be a tough spot to be caught in. There are two main approaches to bear in mind when in this position:

1. **Change Agent:** There is at least an element of being a “change agent” in any work that involves creating alternatives. When working with a provider, you may often find yourself in the awkward but sometimes rewarding position of being a change agent for the organization that pays your salary. Some organizations will be more open to consider change than others. For those that are less open, here are some common ways you may find that your objections to particular language are discredited:
  - **That's just the new “PC” (politically correct) word:** When someone says this, it's often a way of saying, “We might have to use this word to appease someone, but it doesn't really have any deeper value or meaning.” Statements like this can also be a way of expressing very real frustrations that language can feel like an ever-moving target without any real explanation. However, for people who have invested time in the language conversation, the meanings run deep and have great impact.
  - **No one will understand me if I talk like that:** When someone says this, sometimes it may express a concern that the language has gotten too flowery, generalized, or detached from the familiar system lingo. However, more often, a statement like this reflects that person's lack of a sense of connection to the word(s) they're being asked to use. Interestingly, *most* of the accepted language in the mental health system is also fairly generalized (“mentally ill,” “schizophrenic,” etc.) and non-descriptive of an actual person, and the sense of understanding what people mean when they use those words can be a bit of an illusion. In actuality, using everyday language, even when it means a change in the standard way of speaking in that setting, actually communicates more detail and nuance about a situation. And, in reality, when a switch is made to using every day, non-clinical language, people almost always understand.
  - **It makes it hard to speak if I'm always worried I'll say something wrong:** Often, this is an expression of frustration at the frequency of language conversations and/or the way they're being approached. It's natural for people to feel uncomfortable when they're being asked to change something that's ingrained in how they move through their day-to-day. It's important to recognize that there will be a time when the language feels more awkward until a different way of speaking becomes the automatic. Tension, discomfort, and awkwardness are a natural part of the experience of change.

- **You're just the language police:** Labeling someone as the language police often reflects frustration from someone who feels like language issues are being raised too often. However, it can feel very silencing to the person who gets so labeled. It is important to remember that it can get difficult to hear if someone is constantly harping on a particular topic. However, it is also hard to be one of a few people (or sometimes the only person) whose primary role includes bringing up these sorts of difficult topics. Ideally, the responsibility for paying attention to language should fall on the whole organization. Constructing a practice where everyone holds this responsibility makes change all the more likely and makes everyone's job easier.
- **It doesn't matter what words someone uses, it's what they mean that counts:** People want to be recognized for caring and doing a good job, and rightly so. Sometimes language corrections can feel like a slap or an accusation, and that can make the message harder to hear. However, at the same time, language really does matter and the *intent* can be different than the actual *impact*. Words carry powerful messages, and often people on the hearing end of them are hearing what that word has meant in their own lives, and not what someone else might mean by them.

Responding to these objections can be tough, we offer some ideas that have led to at least measured success some of the time.

- **Choose your battles.** It probably isn't worth commenting every single time a specific problematic word come up.
- **Use your own story.** Share how certain words have negatively impacted you. Sharing a real event can make your point much harder to ignore or argue against.
- **Get others involved.** If you have allies in the organization who are willing to back you up and will also start challenging some of the language, that can be huge.
- **Ask questions.** Asking people in clinical roles why they are concerned about language change may be an interesting conversation that will be much more productive than arguing over a word.
- **Personalize the issue.** Ask people to think about times when someone talked about them in a way they found hurtful or held them back, and support them to draw the connections.
- **Validate concerns.** Even if you can't agree with what is being said, there may be ways to validate some of the feelings around it. For example, even if you believe wholeheartedly that change needs to happen, it may be helpful and validating to talk about how hard change is and give someone a chance to vent about other changes they might be getting asked to make at the same time.
- **Request outside training.** It can be useful when the voice that's saying something doesn't have to be yours (or, at least, when it reaffirms what you've been saying). Language trainings from people outside your organization can be helpful in this way.

- **Share blogs and articles.** There is a lot of material on language and the mental health system out there. Mad in America is one great resource: [www.madinamerica.com](http://www.madinamerica.com). If you don't have access to live trainings—or even if you do—this is another way to get the conversation going.
2. **Harm Reduction:** When there's an aspect of language in the organization that you can't change (yet), you can also practice harm reduction. This can look like:
- **Offer explanations:** If you're required to use paperwork, or be in or near a facility where someone else is using very clinical language, it can be useful just to explain the reality of your situation. This might mean offering transparent explanations about why you use different language, or why you may still be required to work with paperwork that uses language that is different than what you would choose.
  - **Use it as a tool:** If it's useful to explore the meaning of various words in the moment, then it may even be possible to use someone else's language or words on paperwork as a prompt to say, "So, when you see/hear that, what is your thought on what that means for you?" "What do you think the system means when they use that word, and how does that affect you?" And so on.
  - **Use it as an opportunity:** If you know that someone you're supporting has decided that they don't want a particular word used in reference to themselves, situations where that language is being used can be an opportunity to support them to practice saying 'no.' In other words, such situations might create a chance for that person to practice explaining that they don't want a particular word used in reference to themselves and why. Similarly, if the format allows, you can support them to cross out words they don't like on paperwork and write in alternatives.
  - **Offer counter-balance:** If you're in an environment where clinical language is being used, it may be all the more important to be sure that there are books, movies, and other opportunities available that expose people to the alternatives.

Ultimately, people working in peer respites can act in the role of guide or facilitator at times, in the sense that they are accompanying someone on a deeply personal journey of learning, exploration and growth. If that guide or facilitator uses language that cuts off that process, then growth and learning may be stunted, and that gets in the way of the peer respite's mission.

**A final note:** This section addresses issues regarding clinical language, but there are also many intersections between the language that gets used in clinical systems and gender, race, sex, disability, and so on. For example, the paperwork, practices, and environments in the mental health system often fail to recognize the needs and identities of transgender or gender non-conforming people. They commonly fail to recognize the trauma that can be experienced by receiving services in a system where one's language isn't commonly used in conversation or written documents, or where there's no room made for someone's spiritual or cultural beliefs. Peer respites should also look for opportunities to explore and find ways to do things differently in these areas of language, as well.



# Trauma



# TRAUMA BASICS

Conventional mental health approaches tend to focus on psychiatric diagnosis and the bio-medical model for understanding emotional and mental distress. Even in clinical settings that are working toward becoming more trauma-informed, misunderstandings and tensions almost always remain between a truly trauma-informed approach and a clinical one if for no other reason than the tendency in a clinical environment to define someone's problem for them. Peer support approaches, on the other hand, help people to explore and make their own meaning of what is happening for them. Some of the ways in which people may make meaning beyond a conventional medical model include:

- Nutrition, food allergies or reactions, etc.
- Spiritual emergency
- Supernatural causes
- Energetic fluctuations

However, one of the most common ways that people understand their experiences is through a trauma lens. Many people identify as having experienced trauma, even if that is only a part of how they understand what has happened to them. Because trauma is so prevalent among people experiencing life-interrupting distress, it becomes particularly important that people setting up and working in a peer respite consider how they create a space and interact with people in a way that is healing and makes every effort to avoid re-traumatization.

## **But first, what is trauma?**

Many people understand trauma only in the context of a major event like physical or sexual abuse, a life-threatening accident, or war. But, the reality is that people can experience trauma in a number of situations or circumstances. One definition of trauma that makes space for all of this is:

*Trauma means that someone has experienced one big event or a series of events that has damaged their belief that the world is able to meet their basic needs (for safety, warmth, sustenance, etc.), often leading them to make adaptations in order to survive.*

Therefore, trauma includes racism, poverty, verbal abuse, homelessness, abandonment, and a variety of other events or circumstances that shake someone's sense of the world and their own place in it. This can include experiences within the psychiatric system, such as restraint or seclusion, as well as experiences with the police and criminal justice system. Coming from a trauma perspective, it's important to note that many actions or experiences that get defined as "symptoms" by the psychiatric system are instead understood as ways of coping or adapting. This includes everything from hearing voices to self-injury.

## **Trauma Research**

Although there are many studies supporting the idea that trauma leads to being labeled with a psychiatric diagnosis, one of the most well-known pieces of research is the Adverse Childhood Experiences (ACE) study. Although this study has its limitations (including the fact that the initial research was conducted with largely white, middle-class individuals), it nonetheless has important implications. Conducted by Kaiser Permanente, a health insurance company, and the Centers for Disease Control (CDC), this study looked at 17,000 people from primarily middle class backgrounds and asked them to identify which adverse experiences they had been through as children from a list of ten items (including having an incarcerated parent, neglect, and so on). The findings indicated that there was a direct correlation between the number of adverse experiences in childhood and a variety of negative outcomes including medical conditions, incarceration, problematic use of substances, psychiatric diagnosis, and early death.

In fact, the study not only found that there was a correlation, but that there was a graded correlation, which means the higher number of traumatic experiences someone has, the more likely they are to experience certain negative outcomes. For example, when compared with someone with an ACE score of 0:

- An individual with an ACE score of 4 is 240% more likely to contract Hepatitis
- An individual with an ACE score of 4 or more is 460% more likely to be diagnosed with depression
- An individual with an ACE score of 4 is 1,200% more likely to attempt suicide
- A male child with an ACE score of 6 is 4,600% more likely to become an IV drug user
- An individual with an ACE score of 7 is 500% more likely to develop the experience of hearing voices

### **A Brief Word About Trauma’s Impact on the Body**

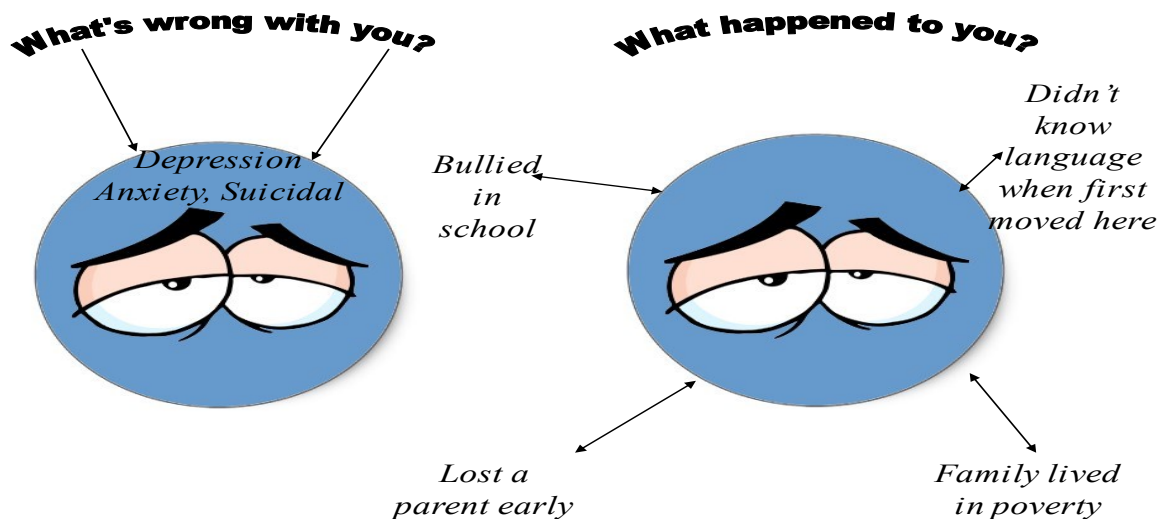
Trauma can have a profound impact on someone’s body, both in the moment and over the long-term. Trauma is typically thought of as putting someone into a “fight, flight, or freeze” mode, either at the point of the initial trauma, or when someone experiences a situation that reminds them of that trauma. (Some add ‘appease’ to this list because of the tendency that many people have to do whatever they need to do in the moment to make things ‘okay.’) This means that someone may immediately be pulled into either getting ready to fight a perceived threat or running away from it in either figurative or literal ways. When the body goes into this mode, it’s important to understand that blood goes to the parts of the brain that are responsible for fighting or running (etc.), and away from those parts that are responsible for conversation and the ability to stay fully present. There are exercises that can help people stay present—or return to being present—when this switch gets flipped unnecessarily.

# TRAUMA-INFORMED APPROACHES

There's a great deal that goes into developing a trauma-informed approach, but it's important to understand that a trauma-informed approach is completely different than a trauma-specific approach. People often confuse these two points. In an environment that is employing a trauma-specific approach, there are often specialized assessments to identify past trauma, and a variety of specific trauma-oriented therapies that may be offered.

On the other hand, trauma-informed approaches assume that everyone may have been impacted by trauma at some point in their lives, and so the environment is designed based on that assumption. This is a similar philosophy as that of "universal precautions" in a medical setting. For example, a nurse who is practicing universal precautions will assume that every person with whom they interact may carry a communicable infection of some sort. As a result, and without any need for assessment of risk, rubber gloves and other related safety practices are used routinely. We realize we're using a medical analogy here, but we do not mean to suggest that there is a "medical" element to trauma or that trauma is communicable like a disease.

Another common feature of trauma-informed practices is to shift away from asking "What's wrong with you?" and to move toward asking "What happened to you?" instead. For some, the difference between those two questions may seem immediately obvious, but it can be confusing. Consider the diagram below to help illustrate how these two questions are meant and what is most different about them.



This diagram is meant to illustrate that there are two ways to approach someone who is deeply sad. If you ask the person "What is wrong with you?" the starting assumption is that what is wrong is inside their head, and that diagnoses need to be made to explain it. However, if one asks "What happened to you?" that may elicit a rich exploration of things that have happened in that individual's life that have

led them to feel very sad or struggle in their current environment.

Although trauma-informed approaches and environments are based on straightforward principles, the process of shifting to a trauma-informed way of being requires a great deal of intentional work, both at the beginning and on an ongoing basis.

As a starting point, some questions that can be worth considering when creating a trauma-informed environment include <sup>1</sup>:

**Safety:** Am I doing all I can to be mindful of the physical and emotional safety of others?

**Trustworthiness:** Am I being clear and consistent with my expectations and interactions with others? Am I creating an atmosphere of respect and acceptance free of judgment?

**Choice:** Am I helping to create conditions so those with whom I interact experience opportunities of choice and control?

**Collaboration:** Am I mindful that an approach of collaboration and sharing is at the center of my interactions?

**Empowerment:** Am I fostering an environment where an individual's own strengths, experiences and uniqueness can be highlighted and built upon

It's worth noting here that, in the mental health system, "safety" is most commonly interpreted to mean whether someone presents a "risk to self or others," but this is not what is meant in this case. Rather, it means things like paying attention to whether or not a physical environment looks like a psychiatric unit, which may be re-traumatizing for someone who has felt traumatized while hospitalized on psychiatric units; whether people need to go through locked doors, which may be re-traumatizing for someone who has stayed places where they had no control of when they could enter or leave, or who feels like the locked doors signal lack of overall safety and trust; whether they're asked to sit with their back to a door, which may feel re-traumatizing for people who've been physically abused and want to know what's behind them, and other elements.

<sup>1</sup> Adapted by the Western Massachusetts Training Consortium in July of 2008 from R. Fallot, PhD and M. Harris, PhD, 'Community Connections, [www.ccdcl.org](http://www.ccdcl.org), [www.wmtcinfo.org](http://www.wmtcinfo.org)

# TRAUMA-INFORMED PEER RESPITE

Although the basic principles are relatively simple, it’s likely that a training —or at least a clear and guided process— will be important in order to explore what “trauma-informed” truly means, and identify and unlearn beliefs and practices that may interfere with it.

First and foremost, any trauma-informed peer respite will find multiple and ongoing ways to prioritize:

- Self-determination, including how it relates to and intersects with personal responsibility
- The ability to control one’s own identity and meaning-making process
- Transparency about what is offered and what is expected, and any clear limitations of the space (for example, that meals are not routinely prepared by paid employees, etc.)

The chart below shows a number of other qualities and examples to bear in mind in any environment:

<i>Action/Condition</i>	<i>Why Someone Might Struggle with This</i>	<i>Alternative Actions/Conditions</i>
<b>Yelling or loud voices</b>	May remind someone of abuse in their family (witnessing domestic violence, conditions that occurred right before someone hurt them, etc.).	Being intentional about not raising voices, keeping an even tone, or yelling, even when not done in anger or when just trying to get someone’s attention who is further away.
<b>Blocking someone into a small space</b>	May bring someone back to a time when they were hurt and couldn’t escape; may put them into ‘fight or flight.’	Set up conversations and meetings in spaces where people are not likely to feel trapped.
<b>Requiring “lights out,” being in bed, or bed times at particular times</b>	Many people who’ve experienced abuse, particularly childhood sexual abuse, were abused late at night, in the dark in their beds.	Support people to find bedtime rituals that help them create a sense of personal safety. Support people to re-organize furniture in their rooms. Support them to create sleeping nests in places other than on the bed; etc.
<b>Requiring someone to stay in their room</b>	Many people associate particular rooms, especially bedrooms, with being abused.	Give people choices about where to be, even when —and perhaps especially when— they’re having a hard time; etc.
<b>Asking someone to sit or sleep with their back to a door</b>	Many people have learned to be on guard in their environment. Being forced to sit in a place where someone could easily approach them from behind without being seen could put someone in “flight or fight” mode.	Help people re-organize meeting rooms, bedrooms, etc., so that they are never asked to have their back to a doorway. If there’s a circle where someone might have to have their back more to a door, ask for a volunteer who doesn’t mind being in that position.
<b>Referring to people as “client,” “patient,” etc.</b>	A great deal of trauma is rooted in being/feeling out of control or someone else having power over you. This sort of language can replicate those power roles.	Refer to people by their names and without any system-based or clinical labels. Use person-first, non-clinical language to describe experiences.

<b>Forcing or telling people they need to stop self-harm or other ways of coping</b>	Many people use self-harm <i>as a way of coping</i> . Taking that away or acting as if it is bad and must be stopped not only takes away a way of coping, but also replicates a sense of having no power or choice.	Instead of assuming self-harm is bad or must be stopped, ask someone what it means for them, <i>how</i> it's impacting their life and if they <i>want</i> to stop.
<b>Dark, dirty or broken spaces and furniture</b>	People who have experienced trauma, especially related to abuse, have often felt dehumanized and devalued. These environments can have the same effect and leave someone feeling hopeless and like they have nothing more to lose. Environments where everything looks the same can also add to a sense of losing themselves and becoming anonymous and objectified.	Look for every opportunity to make environments more home-like, brighter, and more humane. Choice of different spaces to go into is critical, as is opportunity to see and go outside and get fresh air. Environments that allow for personalization of room decorations, bedding, etc., can also be helpful.
<b>Focusing primarily on problems, weaknesses, and diagnoses</b>	People are complex beings and always more than their problems. Talking about people as if they are their problems and not creating space to focus on their strengths and other topics can replicate the same sort of dehumanization and sense of being objectified that they have experienced as the result of trauma.	Create lots of space to focus on activities and topics that have nothing to do with an identified problem, often more space than that which is spent on any specific concerns; Support people to build connections and peer groups based on their talents and interests; Be intentional about seeing and naming the positives and strengths.
<b>Lack of access to personal belongings</b>	Personal belongings can be incredibly important to someone, especially when they don't have access to their own space or the freedom to come and go or live where they want. Loss of personal belongings can add to the sense of being powerless and feeling hopeless, and having your world shrink around you.	There should never be any routine removal of personal belongings. Any 'safety' concerns connected to personal belongings should always be weighed carefully against the importance of having access to those items, with a great deal of importance given to the latter. If access to personal belongings is to be withdrawn, clear information should be given about why and for how long.
<b>Entering Someone's Physical Space</b>	People who have experienced trauma may quickly enter "fight, flight, or freeze" when they feel like people are too close or have touched them without permission. This is based on how they've learned to survive in response to past trauma.	Recognize that moving too close to someone in an uninvited way even if you're doing so for "safety" reasons, is likely to make the situation worse or push the person toward violence. Ask people before you hug or touch them. Avoid multiple people gathering around someone.

<b>Changing and Unpredictable Rules</b>	People who have experienced trauma have often lived in very unpredictable and chaotic environments. Thus, feeling like their current environment is unpredictable is likely to bring that back up.	If there are rules, be clear about what they are upfront and be willing to talk to someone about them. Rules should not be arbitrary and you should be ready to talk about why they exist. Rules should be available in writing and in different languages. Rules should not come as a surprise to someone; for example, they shouldn't be learning about a rule because they're being penalized for breaking it. In the healthiest of environments, there are ways for each and every person to have some say into any rules; values are prioritized over rule-setting in general.
<b>Lack of choice overall</b>	Most trauma, especially abuse-related trauma, involves lack of choice or voice. Any time an environment does not offer choice, it can replicate that sort of sense of being powerless and hopeless.	Prioritize choice, even where it seems trivial; there should be choice around food, TV programs watched, etc. Avoid forced treatment of any kind, and never make that a starting point. Be transparent about any situations where there is lack of choice and explain why.
<b>Lack of access to privacy in showering, dressing or sleeping</b>	These are times when someone is likely to feel much more vulnerable and times when they are likely to have experienced abuse in the past.	Prioritize ensuring that people have privacy; avoid roommate situations. When they are not going to be given privacy, be clear with them about why and for how long. Look for options to offer, even when the situation isn't ideal. Be sensitive to gender identity and other conditions that may make the situation feel even more or less safe to the person. Brainstorm with the person about how to make the situation more tolerable.

These examples are applicable to any environment, but should be given even more consideration in a peer respite setting. Some additional ways to build a trauma-informed environment include:

1. **Avoid “employee only” areas.** Most people have had the experience of being talked about in rooms that are off limits to them, and that can reduce their trust and damage connections.
2. **Be transparent about who you’re calling during a conflict or difficult situation.** Many people have had the police or 911 called on them behind their backs. If there’s a difficult situation going on in the space, and you’re just calling for some extra support, let people know that’s what you’re doing so they don’t make assumptions. If you feel the need to call some sort of emergency service, talk to people at the respite about why and who they think should be called, if at all possible.


3. **Ask permission before having visitors tour the space:** Being able to be confident about who will be in the space and when can be very important to some people staying at the respite, and feeling like they have no control or choice about that can feel re-traumatizing and diminish their ability to benefit from the support. Consider implementing a practice where people staying at the respite collectively decide who may visit for a tour. This isn't meant to indicate that the people should be able to refuse visitors of others who are staying in the respite, and primarily refers to individuals who wish to tour the respite who aren't connected to someone staying. It is often advisable to have separate space for people visiting individuals staying at the respite, so that they do not need to be in common areas every time they stop in.
4. **Have any "policies and procedures" manuals that exist out and available to anyone staying at the respite:** Again, transparency is essential, and there should be no reason that people staying at the respite shouldn't know expectations for those who are working there and how they'll be held accountable if something is wrong. This shouldn't include access to the personal contact information of individuals working at the respite. They have as much right to privacy as anyone else.
5. **Avoid routine note-taking about people staying at the respite, and be clear what access they have to any files that do get kept:** Most people in the system have had the experience of someone writing notes about them. Many have felt negatively impacted or experienced a sense of loss of control in relation to files kept about them. In a peer respite, it is essential that this sort of power imbalance be avoided or minimized where complete avoidance isn't possible. If notes are taken, the person about whom the note is being written should ideally be the one writing the note or saying what they want written, and should have access to them. If they give additional information about themselves in writing that isn't a required part of a file, it should be made clear that they own that information and can take it back at any time. If they want to read what's been written, they should always have access. Again, ultimately, routine note-taking on people at a peer respite should be avoided altogether, but if that is not possible, every effort should go toward having the notes be under the control of and accessible to the person about whom they are written.
6. **Hold the highest standards for talking to providers about people staying at the respite:** Even if there is a release signed by a person staying at the respite, trauma-informed peer respites will avoid talking with anyone about a person staying at the respite unless they are present *and* have said that they want the conversation to happen (even if that means talking together with a provider on speaker phone or what have you). All too often, people have gotten very used to signing away their rights for privacy, even though it leaves them feeling mistrustful and out of control. A peer respite should focus on supporting people staying to re-find their voice and sense of power, and that makes releases of information used in the conventional mental health system fairly meaningless.



7. **Hold the highest standards for respecting privacy in general:** In addition to what we've said above about sharing information with providers, it's also important to have similar standards for family members, friends, and romantic partners. Sometimes staying at a peer respite involves deep exploration of all relationships in one's life. It is important that people working at a peer respite give someone the space to do that and to be in charge of who they do and don't talk to or see in the process. That said, there will also be times that peer supporters can meet with someone staying and their family/friends in ways that can be useful, particularly in supporting the person staying at the respite to be heard. It's also important to note that respecting privacy includes even disclosing if someone is staying at the peer respite at all. While people answering phones and doors can always take messages in case someone is there, disclosing to anyone who calls —whether providers, family, friends or other— is a violation of privacy. It should always be up to someone staying —who is, of course, an adult— whether they let someone know that they're there. This doesn't preclude someone working at the respite from talking through with them who they'd like to let know, or the potential consequences of not telling people who might be looking for them, but this should only be in support of the person working that out for themselves.
8. **Hold a person's space and belongings in high regard:** This means avoiding invasive practices like searching someone's belongings. This may seem tempting as a way to create more of a sense of safety. However, it can be traumatic to feel watched and searched in that way. The reality is that people are able to come and go from a respite, which means they'll always have access to the rest of the world and all that's in it. By searching them, all that will have been accomplished is conveying a sense of lack of trust, and they still can go right back into the world and get whatever it was the person who searched them is afraid they might have in their bags. Generally speaking, the barrier created simply isn't worth what is ultimately only an illusion of safety. Similarly, asking someone to turn over their belongings to be heat-treated for bed bugs conveys a very strong sense of mistrust about their cleanliness, and should be avoided unless they've indicated there's a reason to be concerned about that. Not entering someone's room at the respite without permission is also a way of communicating trust and respect for their personal space, even if the room is only theirs temporarily.

Ultimately, it is important for a peer respite to remember the following two points:

- A peer respite's job is not necessarily to support someone to avoid being uncomfortable or feeling difficult emotions, but to co-create space where it's safe to go through that process together.
- A peer respite's job needs to be about *both* creating a trauma-informed environment that minimizes re-traumatization *and* supporting someone to build the resiliency necessary to thrive in spite of living in a world that is full of difficult situations.



# Difficult Situations

# INITIAL CONSIDERATIONS

In any place where people come together, some difficulties will arise. Some of these will be quite small – people not cleaning up after themselves, disagreements about what to watch on television, someone eating someone else’s food in the refrigerator. Hey, it’s hard to have housemates, and especially ones that a person didn’t select themselves! When these kinds of issues arise, generally, the next step would be for the person noticing the issue, whether a team member or someone else staying, to talk with people involved. For example, this might include talking about the values of the space and why there are certain expectations around cleanliness or respecting someone’s property.

The greatest challenge in addressing these issues is to do so in a way that is not condescending or shaming, and does not treat someone like a child. One approach that tends to help is to talk about how the particular issue is affecting other people working or staying in the respite, or the environment overall. Either way, even if it is uncomfortable, it is important to address issues as they happen, rather than growing quietly resentful toward someone or saying indirect things to them in hopes that they will make the change desired. In peer-to-peer support (and in life in general), it’s good to move toward directly addressing the issue at hand and coming from a place of transparency.

Another way to work with conflict might be to ask those having the issues if they would be willing to sit down and talk to each other, with or without someone in a paid role being present. This could involve two people who are staying and having conflict, a person staying and a person working, or even two people who are working together. No matter who the conflict exists between, asking people to directly address the issues together is really important and really different than what is done in many workplaces throughout the world.

Part of respect is trusting that people can deal with disagreements that arise. Along the same lines, in

## **Responding to Media Inquiries:**

On occasion, it’s possible that the media may reach out to ask about the peer respite. This may happen because they are doing a special interest story on the peer respite concept, but it’s particularly likely to happen if there’s been a difficult situation at the respite.

Either way, it’s extremely important to identify who on the team will be the designated media contact. That should be someone who is relatively familiar with how common it is for the media to misrepresent what is said, and who is confident and able to be thoughtful about when it is helpful to share information and when it is best to not respond, or to redirect a particular conversation. Usually that will be the Director or someone else equipped to keep the bigger picture, and the needs and wants of team members, funders, and community in mind. Some media training may be a worthy investment.

Others who work at the respite should be given a clear response to give when they are contacted. For example:

“I’m not able to offer any information right now, but I can give your contact information to x and they will get back to you.”

some traditional spaces, people who are in paid roles tend to be the only ones to settle disagreements. It can be very powerful and rewarding not to take that on as paid workers —both for people working and people staying. Of course, none of this means that people in leadership roles shouldn't hear someone out if they have a complaint or concern. A setting where only paid team members' voices are heard by those in leadership also represents a power imbalance and should be avoided.

There are, however, several other situations that are a bit harder to navigate. Some of these are because of things that people choose to do while in the space, or the deep distress that they are experiencing, and others are more about the unfortunate realities of the world, like poverty and lack of resources. Regardless of the source, it can be helpful to a peer respite team to have space to talk about difficult topics, think through how they intersect with the values of the respite, and develop confidence in how they might respond.

This does not mean trying to come up with a policy or protocol for every last “what if” that someone can dream up. That's an endless task, and people will always end up surprising you, anyway. But it may mean team conversations or trainings around a variety of topics.

# TALKING ABOUT SUICIDE

One of the most difficult situations that will likely come up in a respite is talk of suicide. There is an ongoing myth that people go into peer respites for less serious issues and that real “crisis” means going to hospitals and other traditional places. While it’s true that there are some things that aren’t a fit for a strictly peer-to-peer space (detoxing, for example, due to the medical issues involved), people will reach out to a peer respite in very extreme states. These states include when someone is thinking about wanting to kill themselves.

Part of what makes this situation understandably difficult is the fear and uncertainty that it can elicit from people working in support roles. Talking about death can be a lot to hold, especially if someone doesn’t feel like they have a many tools or much confidence to draw upon. Furthermore, most of us have been exposed to the more traditional, liability-averse system, which is geared toward avoiding talk about what is really going on and to intervene in coercive and often very traumatizing ways whenever suicide or death is mentioned.

When supporting someone in this space, some useful concepts, growing out of the Alternatives to Suicide approach started by the Western Mass Recovery Learning Community are Partnering, Transparency and Continuity.

**Partnering:** Let the person experiencing distress know that you are on their side and want to support them in whatever way you can. Ask questions and explore their worldview to understand what they really mean when they say they’re “suicidal.” People use that language for many different reasons (because they’ve learned it’s what they need to say to be taken seriously, because they’re feeling stuck and hopeless, etc.), only one of which is that they actually want to kill themselves.

Remember, suicide is an action, not a feeling. If someone is talking about ending their lives, they are doing it for a reason, and there are a lot of strong underlying feelings. Thinking about death and suicide are, for many, a language for those feelings. They are reaching out and hoping for a response from you— a connection. They are not choosing to take actions toward dying in that moment. If they were, they wouldn’t be talking to you. So focus on the connection and think about what the feelings and experiences behind the pain might be.

**Transparency:** It’s okay to be honest about how someone’s words are impacting the other person in the conversation. If a team member is feeling scared, they can say that. If they’re feeling sad, that’s okay, too. This is not to bring up any feelings of guilt in the person who is already feeling

upset. Often, however, if supporters are not naming their own feelings in difficult situations, they can get caught in those difficult emotions and lose the ability to offer support at all.

Although less than ideal, some peer support occurs in situations where there is a policy that anyone who talks about suicide needs to be reported to a supervisor. One way to work in an environment where this is the case is to be upfront about the fact that if a person talks about “being suicidal,” that the team member has an obligation to report this, and to ask if there is a way that would work for both/all involved to talk about what’s going on in language that allows the supporter to stay in the conversation. It’s also useful in those situations to provide other resources (such as a peer support line, for example) that are not as strictly limited in what they can discuss.

**Continuity:** As mentioned elsewhere, respite stays are short-term. If someone is still in a rough space upon leaving the respite, it can be valuable to let the person know that they can contact the respite for a stay, or reach out to the warmline/peer support line (if available). Also, if the peer respite is connected to a larger organization, it may be possible for people in paid roles outside of the respite to continue a relationship with the person once they leave. And, if for some reason, that person does end their stay prematurely to go to a more clinical setting, people from the peer respite may offer to visit them there. The basic idea is that, regardless of the hard things the person came to the respite with, they are welcome in that community, and that community doesn’t wash their hands of that person when things are at their hardest, or just because someone leaves the physical space.

Often in traditional agencies, and in the world at large, when someone starts talking about wanting to kill themselves, panic is the response. That might mean the “authorities” are called, even when someone just needed a space to vent. It is not uncommon that at some point or another in everyone’s life, they might think to themselves, “It’d be easier to just end this.” Life is really hard! So, part of the work in the peer-to-peer world seems to be creating spaces where it is okay for people to talk about the experience of wanting to die. If the automatic response is to call 911 or Emergency Services when someone dares say the “S” word, they may be unlikely to reach out again.

And, of course, there may be times when someone does take steps toward ending their life. This could happen at the respite space, or it could be someone who stayed in the past calling the respite line to say they have overdosed. To be clear, this is *not* going to happen the majority of the time. In fact, it’s quite rare. But, if it does, calling 911 is okay.

There is a difference between the *emotional* crisis of talking about wanting to die and the *medical* crisis of swallowing an overdose of pills (etc.). So, if someone has taken action to end their life, it does

become a medical emergency and it's okay to treat it in that manner. BUT, the three principles of partnering, transparency and continuity should not get lost in this situation! In fact, in some ways, they become even more important, because 911 may be getting called against someone's wishes.

Here's an idea of what these concepts might look like in this situation:

**Partnering:** Ask similar questions as above, but they might be, "In telling me this, what response are you hoping for?" or "I feel like I need to call 911, given what you just told me. Is that a call you're willing to make or make with me?"

**Transparency:** It's important not to call 911 behind someone's back, and to be available to talk with them about what to expect once 911 has been called. Some people go to peer respites specifically to avoid hospitalization, so having 911 called may feel very upsetting to them and may potentially break some of the trust that had been building during their stay. Most of us, even when thinking about suicide, are still quite rational and capable of taking responsibility in our lives, and respond positively to being expected to do so. Being treated as fragile can be demeaning, and can send the message that this is a dangerous place to be in, rather than one that, though difficult, can be worked through. If someone is upset about 911 being called, sharing honest reasons why can help. For example, you might say "I care about you and wouldn't be able to sleep tonight if we hadn't called" or "I feel totally stuck, and I know this isn't a great answer, but I at least want us both to be around in the future to figure out how to do it better." Acknowledging that there are hurt feelings and broken trust can be helpful, as well.

**Continuity:** When someone is taken to the hospital, it's important that some effort be made to keep in touch with them. Ideally, the contact will be made by people who had a connection with that person and genuinely feel invested in what happens to them next. It is possible that if 911 was called against someone's wishes, they may not wish to stay in touch. That is their choice to make, but an effort should be made to see if they are willing.

It's also worth noting that it can be especially difficult when someone who has taken action to end their life while at the peer respite wants to come back and stay again. The truth is that trust may have been shaken in both directions, and the peer respite team may be wary of how things might be different during a next stay. It's okay to own this as well, and to meet with someone to talk about how everyone can be a part of moving forward together, and to learn and grow from what happened. This is an opportunity to agree upon what might work better in future. With a good connection, it can also be an opportunity to own that this was a difficult and distressing time for everyone involved and to work together to find other ways to deal with each other's intense pain and distress.

Read on for a brief note on being a "mandated reporter," along with some relevant questions that might be useful when supporting someone who is in a such a difficult place.

**Note:** It is worth noting here that sometimes people in paid roles feel that they are unable to talk about suicide and/or are restricted in how they respond because they are “mandated reporters.” While it’s true that many people working in peer respites will be considered mandated reporters, there is a common misunderstanding about what that means. Specifically, in many areas, being a “mandated reporter” means that one is required to report suspected or actual abuse or neglect by a caregiver toward someone who is considered a child, elderly, or disabled. By that definition, ‘mandated reporter’ simply does not apply to suicide.

Ultimately, the laws will vary from place to place as related to a peer respite employee’s responsibilities if someone is talking about suicide. However, more often than not, how a respite employee is expected to respond to someone who is talking about suicide is going to be dictated by that organization’s own policies, and/or that of their funders, tolerance for risk around liability, and so on.

It’s important to know each of these details because this sort of knowledge is exactly what will give a respite power and the tools needed to discuss this issue, influence policy, and ensure that there is room to have deep discussions about suicide and how to move through such dark places.

### **Possible Questions, Statements & Strategies for Supporting Conversations Around Suicide**

This document has been developed over time through many community dialogues and ongoing learning and experience. The following values are its guiding force:

#### **During the interaction, the support person will take great care to:**

**NOT** make promises that can’t be kept, such as guaranteeing that the support person(s) will be present with someone throughout an entire intake process if they’ve chosen to go to the hospital, etc.

**NOT** interpret cutting, burning or other self-harm that is not life threatening as an ‘emergency,’ unless the person who has self-injured identifies it as one.

**NOT** going beyond one’s own limits in terms of staying beyond the time they are available, etc. That doesn’t mean that someone can’t choose to stretch and go above and beyond, but there should be an awareness of not burning out and a sense that it is okay to be human and set limits.

**NOT** to call emergency services unless it is the preferred choice of the individual experiencing distress.

**NOT** to be overly alarmed by uncomfortable conversations. Be ready to sit with crying, talk about emotional pain, anger, etc. Sometimes just being given the space to talk through one’s pain is incredibly powerful!



Below is a list of suggestions that one might say or ask when talking with someone who is struggling with thoughts of suicide. No one suggestion will always be right. This should simply be used as a guide, and what is actually said should be based on what you know of the person and your unique connection with them.

***Possible Questions/Helpful Statements-***

- What's going on?
- That sounds really painful.
- It sounds like you're feeling really (reflection of what they've said... abandoned, hurt, overwhelmed, etc.).
- How well are your basic needs being met lately (i.e. sleeping, eating)?
- Is there anything you'd want from me right now?
- Do you want to talk more about what's going on?
- Did something happen that made you feel this way?
- Have you felt this way before?
- What has worked in the past to help you take care of yourself when you're feeling like this?
- Do you have any tools you've learned that could help you take care of yourself while you're feeling like this?
- How long have you been feeling this way?
- What does it feel like in your body when you feel this way?
- Do you feel this way more at certain times or places?
- Is there something you need to let go of or something that needs to end to move forward?
- Is there anything that's been bringing you joy?
- Do you have someone in your life that you could trust to help you get through this?
- Would it help to hear about some of the things I've done to take care of myself when I've been feeling like I might want to hurt myself?
- It's normal/common for people to want to die when things are really hard.
- If you were going to die, is there anything you'd really want to do first?

***Possible Ways to Connect and Support -***

- Explore what might make them feel safer or nurtured in their current environment (being covered by a blanket, going in a room where there are no other people, music, increased or decreased light, a pillow to hold, etc.). If in person, offer to help adjust their environment in that way
- If in person, offer something to eat or drink.
- Reflect (eg., "It sounds like your...") and validate (eg., "After everything you've been through, it makes total sense to me that you'd be feeling this way," etc.).

- Develop a plan between the person experiencing distress and the support person that should typically include a concrete step to check-in in person or by phone later that day and the next day.
- Offer resource information to help brainstorm supports that are available through at least the next day to week, including information about mutual support groups, warm lines, friends or mentors, outpatient supports, the local emergency services, etc.
- Offer to review tools, journaling or art that could support the person
- Offer to go for a walk or hike, if in person.
- Invite to come meet in person, if speaking by phone.
- If you feel comfortable, offer to meet in the community.
- Share some of your own story, including (if applicable) your experience that these feelings can come and go, what has helped you, etc.
- Ask what supports the person feels like they need at the end of your conversation. If they say something might be helpful, offer to make the call with them.

# SELF-INJURY

There's a common tendency to confuse self-injury with attempts to kill oneself. However, for many people, self-injury is actually a way of coping with difficult emotions and to avoid suicide, and the vast majority of self-injury is not life-threatening in any way. It's possible that someone might self-injure while staying at a respite, and this doesn't need to be a difficult situation if team members are supported to feel confident in how to react.

Remember that almost all of us engage in behaviors that might be called self-injury—whether with food, other substances, abusive relationships, unsafe sex, risk-taking, exercise, work, and even excessive use of internet and video games.

Most peer respites do not prohibit self-injury, but what they do ask is that self-injury (and, often, graphic conversations about self-injury unless all parties present have agreed to be a part of that talk) not occur in common spaces, because of how they might impact others. It's also important for people working in a peer respite to be able to talk with someone about self-injury, if it's something they want to discuss.

Some possible questions to explore someone's worldview on and how they make meaning of self-injury might include:

- What's coming up for you that makes you think of hurting yourself?
- Why do you self-injure? What does it do for you?
- Are there other things that you sometimes do that have the same effect?
- When you self-injure with the hopes that it will [REASON THEY'VE SAID THEY SELF-INJURE], does it usually work?
- How else does it impact your life?
- Is it something that you want to stop?

These questions are not meant to be asked one after the other or all in one sitting. They're only meant to be used where it seems helpful to explore and better understand why someone self-injures and what it means for them. It's also incredibly important that these questions be asked without any agenda. The goal should not be assumed to be trying to stop someone from hurting themselves. They should only be asked from a place of curiosity and exploring what self-injury means to someone, how it's impacting them, and how they do or do not want to change that.

# HOMELESSNESS

Homelessness and lack of housing resources are major issues in many places across the country. And, of course, not having one's basic needs met (e.g., not having enough food, clothing, sleep, shelter, etc.) is often enough to send someone into a place of crisis or an extreme state. Excessive lack of sleep is enough to do that for many people. Unfortunately, that means that there are lots and lots of people living without a home who are also in some level of "crisis."

When someone is living without a home, they can understandably feel desperate for a safe, warm place to stay. Add to that the fact that many homeless shelters are overcrowded and experience regular violence, and a peer respite can look more and more inviting. However, many funders prohibit peer respites from accepting people who do not have a stable home to which they can return. This is usually for two reasons.

1. The funder doesn't want to be seen as responsible for putting someone out on the street at the end of their stay.
2. The funder doesn't want the peer respite to drift from its mission and turn into a homeless shelter

Both of these are reasonable concerns that people working in peer respites often share, too. It's also true that a short stay at a peer respite is extremely unlikely to afford enough time to search and secure housing, so it's almost guaranteed that someone who comes to stay at a respite from living on the street will be returning there after their stay is over.

Peer respites are likely to be called upon to make a decision about whether they will advocate for people living without a home to be able to stay at their respite from the early stages of planning. Below, see a sample response that the Western Mass Recovery Learning Community offered to the Massachusetts Department of Mental Health when this issue was raised in their state.

**Homelessness as a Basis for Exclusion:** We have heard and can imagine the risks and concerns of offering respite supports to individuals who are homeless including:

- That they would over use services simply for somewhere to stay
- That they would refuse to leave or resist making progress for lack of anywhere to go
- That they would stay for longer periods of time than average for lack of somewhere to go
- That the respite could become a homeless shelter of sorts with individuals learning how to answer questions to manipulate the 'system' for somewhere to stay

However, a trauma perspective would suggest that an individual whose basic needs (shelter, food, sleep, etc.) are not being met is in fact vulnerable to crisis and extreme emotional states and that assisting someone to meet those needs can be a powerful step toward helping them regain the balance they need to move forward in other ways. We also know that research has consistently demonstrated the overlap

between individuals who experience psychiatric diagnosis, those who experience homelessness issues, those who are incarcerated and so on.

In essence, the fears and worries are valid, but so are the needs of these individuals. **Ultimately, we would recommend not making homelessness an automatic reason for exclusion, but that individuals who are homeless be supported to articulate how the peer respite would benefit them, and that those reasons should include more than simply a place to sleep for the night.**

At this time, Afiya, the peer respite that is a part of the Western Mass RLC, is able to accept people living without a home if—as their original response to the state suggested—they are able to describe needing the support for reasons other than just wanting a place to sleep or search for housing. This isn't an easy process, but when people who are living without a home do come to stay at the peer respite, they are asked right from the beginning to understand that lack of housing will not be a reason that they would get an extension to stay longer. At least one peer respite was said to have closed specifically because they allowed people who were homeless to stay for extended periods, and drifted into becoming a shelter more than a respite, so the risk is real.

Watching someone leave to go back to living on the streets after their stay has ended can be heartbreaking for team members, but so can a black-and-white policy to never accept anyone in that situation. Ultimately, this is just one situation of many where peer respite team members need to be supported to practice acceptance of their lack of control over many people's suffering and focus in on their ability to be with someone for as long as they have together and be a connection point and bright light in all of the darkness. That gift is surely of much more value than yet another closed door because team members aren't willing to face the discomfort of not being able to fix the situation for someone.

# ADDITIONAL SITUATIONS

**There are many other difficult situations that arise. Some of these include:**

**Theft:** Sometimes people take things that do not belong to them because it's a large part of how they've learned to survive in the world. Other times, it's a show of lack of respect, anger or retaliation. Either way, the impact on the space and other people staying there can be substantial when people intentionally take items that do not belong to them, because it breeds mistrust and suspicion and may bring up old traumas. Addressing this issue can be particularly challenging, because it's rare that someone will admit to taking an item that wasn't theirs to take. Once again, it may be tempting to ask to search people's belongings. However, this is a real show of power over another human being that is likely to leave both the person doing the searching and the person whose belongings are being searched feeling uncomfortable and violated. Additionally, the likelihood that the item won't be found, either because the person hid it somewhere else or because they did not take it, is relatively high, and leaves everyone in a bad position. As in most situations, it's generally best to have honest conversations, but to always stick with respecting people's personal space and belongings.

**Drinking or sharing alcohol or doing non-prescribed drugs in the space:** Different peer respites have different takes on how to approach drugs and alcohol. Some prohibit any use of non-prescribed drugs or alcohol at any time during one's stay, even when off the property. However, another approach that's consistent with peer respite values is to ask that someone avoid smelling of drugs/alcohol while in the space, clearly appearing to be high or drunk, or bringing drugs/alcohol (or paraphernalia) onto the property. The thinking behind this approach is that the goal is less to judge what someone chooses to do on their own time, and more to ask them to be respectful of the impact on their environment. In relatively minor situations where someone simply smells of liquor, it may be simple enough to just ask them to take a shower, change clothes, or hang out in their room. However, when someone is clearly using or bringing drugs/alcohol/paraphernalia onto the property, and/or sharing them with others, it becomes a much larger issue. This is because they are impacting the sense of respect and trust in the space, and may also be impacting others who are struggling to stay sober. See the guidelines section for more details. One of the most common issues with drugs and alcohol is when someone returns to the space after drinking or using, and is acting in a way that impacts the space, such as falling down, arguing, being loud, etc. It's important that each respite decide what its limits are, under what circumstances someone would be asked to leave (versus being asked to stay out of common spaces), and so on.

Also worth noting: It has always been challenging to separate out the impact of prescribed drugs versus alcohol or street drugs (or prescription drugs that are not prescribed to the person who has ingested them). As laws change (including laws about medical marijuana, for example), deciding what is and

isn't allowable is growing more complicated. It's important to know the laws in the area where the respite is located and to think through what that means for the space. For example, perhaps edibles are allowable for someone who has a medical marijuana prescription, while smoking marijuana may still need to be done off property because of how the smell might impact others.

**Leaving and not coming back/not making contact for an excessive amount of time:** What counts as "excessive" may vary from place to place, but most respites will have guidelines about how long someone can be gone without communication and still be able to keep their spot. With conversation and planning, some respites will go so far as to support someone to spend a test night at home while still holding their spot at the respite, but that is usually discussed beforehand. When someone simply disappears, it can be very hard on the team and others staying at the space to not know where someone is or to worry that they're going to return and expect their spot back after it's already been given away to someone else. Making sure that guidelines around this issue are addressed right at the start of a visit can help head off problems.

**Someone is on the sex offender registry:** Some respites accept people who are listed on sex offender registries and some do not. Some who do not accept people on the registry also make a point to check the registry before inviting a person to stay. On the other hand, other respites may simply inform all callers that they're not able to have someone who is listed as, for example, a level three sex offender stay at the space, and then let the caller determine if they fit that or not. This is based on the idea that it's truly the person who's on the registry's responsibility to know where they can and can't be, and to avoid implying that the peer respite is in a position to be responsible for that. This can be an uncomfortable situation if, for no other reason, the sex offender registries are just as likely to be influenced by racism and classism as any other system, and it may mean turning away people who would truly be helped by a stay.

Whatever decision a peer respite makes about this issue, it's important to know a couple of things: First, what are the relevant laws in a particular respite's geographical area? For example, there may be specific laws or ordinances requiring that people who've been convicted of certain crimes or who are listed at a certain level on a sex offender registry can't be within a certain distance of a school.

Second, what is the required process when someone who is on a sex offender registry is considered to be residing at a particular address? For example, in some areas, if someone who is listed as a sex offender, particularly those who are deemed at risk of repeating a sex offense, stays at a particular address even for a few nights, that information may be posted in the newspaper. Under these circumstances, this may mean that a peer respite's address may show up in the newspaper as housing someone identified as a sex offender, which can cause upset and concerns in the neighborhood.

Thinking through what each of these points means for the respite space ahead of time is important to making the best and most thoughtful decisions.

**Physical assault and verbal threats:** These are very rare, especially physical assaults. Unfortunately, some people have faced years of living with abusive relationships or in environments where yelling and speaking violently toward one another is the norm. While peer respite team members can have compassion for that, and be willing to discuss the impact and other ways to be with one another, it's important that people working and staying at the respite not be asked to share space with someone who just assaulted another person. The system also has a history of giving people a pass because it's believed that someone "can't control themselves." However, peer respites operate on the assumption that people are responsible for themselves, so it's important to hold them accountable for their choices, even if space is also held for things to be different in the future.

**Medically unable to care for self:** On occasion, someone may come to stay at the respite who is or gets very physically ill, withdrawing from drugs or alcohol, and so on. Not only can these situations affect the energy in the whole household, but in some instances, there's real medical danger. While the non-clinical nature of a peer respite is generally a part of its appeal, this doesn't make sense when there's a clear and serious medical issue happening. In these situations, although it can be difficult, it's important to support someone to seek the kind of help that will address their medical needs.

**Making racist, sexist, homophobic, transphobic, or ableist comments:** Racism, sexism, homophobia, transphobia, religious discrimination, and ableism (discriminating against people because of disabilities or certain perceptions about them) are forms of violence, and are often experienced as trauma by the people who are subjected to them. Religious or political proselytizing (forceful attempts to convert someone's views) can also be extremely harmful. People making these remarks may also have been subject to trauma, and those remarks may be a sign of that, so it's important to have compassion and willingness to explore what they mean or what is underneath their statements. However, at the same time, it's at least as important to be clear about setting limits. An environment where these sorts of remarks go unchecked cannot be a healing environment.

**Not being in a place to hold to the values in some way:** People in all sorts of different and extreme places have stayed in peer respite environments and still been able to hold to the basic values of the space. However, occasionally some people get into a frame of mind where they're simply not able or willing to take on the responsibility of doing so. This may look like someone yelling, smoking in the space, or engaging in other activities that are unsettling enough that they significantly impact others working or staying in the space. These issues are often shows of disrespect (even if unintentional) to the respite and its mission, and should be taken seriously, particularly since people who are actively demonstrating a lack of high regard for the space or people in it may also be more likely to show



disregard in more serious ways if not addressed. Setting limits here is also an important step toward demonstrating respect toward other people staying at the respite whose ability to benefit from the space may be significantly impacted when problems aren't addressed.

**Someone is very angry and yelling at people:** In a trauma-informed environment, yelling and raised voices can be very hard. However, a trauma-informed environment is also one that makes space for anger, and doesn't treat it as a symptom. This can be a tension that is extremely hard to hold. Often it comes down to talking with someone, validating their anger, letting them know that you want to hear it, but also asking them to be aware of the impact on the space. It may also mean getting creative. Can you go for a walk with them somewhere where they can yell? Can the respite keep a stock of plates around that it's okay to go outside and smash? Can there be a punching bag? Expressing anger is as important as getting to express every other emotion.

**What's next?:** In some of these situations, when all else fails, someone may have to be asked to leave the respite, and it's important that team members know that it's okay to do that, even if someone is homeless or otherwise struggling.

When these issues come up, it may be useful to involve someone in leadership as a part of the conversation, even if just to talk it over and think through whether this is a big enough issue to be addressed in that way. If it's been determined that someone has done something that does warrant them leaving the space, there are several ways to go about asking them to leave. Some general points to consider include:

- **A deep, thoughtful conversation is needed about what happened.** This might include those who were working at the time, an on-call supervisor, people staying who were affected, and/or the person who is being asked to leave. This last piece is quite important. One of the battle cries of this movement is "Nothing about us without us!" This can become especially important when there are negative consequences for someone's actions. A traditional paradigm would hold that the opinions and beliefs of those in paid roles are more important or more correct than those of the person who is in the non-paid role. As stated before, paradigm-shifting is hard and uncomfortable, but necessary. Try to include the person potentially being asked to leave in the process whenever possible, and when it doesn't seem possible, try to at least ask each other why and explore whether it seems impossible simply due to fear and discomfort or a valid and clear reason.
- **If asking someone to leave, explain very clearly why and offer this explanation in writing.** Transparency is key. Be honest with someone about what exactly happened that went against the values of the respite and be clear that they are being asked to leave. Talk with them about how much time they might need to pack and leave. If needed, support them in finding transportation. Try to be compassionate, as well. We ALL make mistakes. Remember, people who are being asked to leave

may have nowhere else to go and/or they may have been asked to leave other spaces before and may be feeling really critical of themselves. Team members should do their best to remember to include their whole heart in this process.

- **If asking someone to leave the space, put this in writing and have your Human Rights Committee review the letter.** Letters are a way to make both the team and the person asked to leave clear about what happened, why it didn't work for the space, whether an extended break is being suggested, and what would need to be different during any subsequent stays. The organization's Human Rights Committee should generally be involved in reviewing letters as a sort of check and balance, so that the team is also held accountable for approaching situations fairly. This is good practice, as our work is part of a human rights movement, and we want to make sure we're holding ourselves accountable to the values just as much as we are holding someone who stays with us to these values. Also, within the body of the letter, information should also be included about how to make a complaint if the person feels they were treated unfairly.
- **Ask for a follow-up conversation to take place before the person comes to stay at the respite again.** This is not to belabor a point and cause a person to feel even worse about what occurred. It's about making sure everyone is on the same page and asking what will be different about future stays. In-person conversations tend to be better, but if someone lives far away or it's really inconvenient for them to get there, conference calls or Skype can also work.
- **Opportunities to debrief—in a group or separately— after something big has happened in the space and/or someone has been asked to leave, is important for everyone involved.** This doesn't have to mean talking at length about someone else or criticizing them behind their back, but it should mean that there's space to talk about the impact on the environment and the people in it. This should include both people working at staying at the respite.

Of course, if there comes a point where many people who stay are receiving letters and/or breaks, it might be a sign to the team to look at their own practices and what they are bringing to these situations. Also, it might be a useful time to review guidelines and check out if they're too stringent



# Diversity & Accessibility

# PRIVILEGE & ACCESSIBILITY

Creating a safe haven for people in crisis requires us all to address issues of cultural sensitivity. We need to acknowledge painful realities: that many of us have experienced trauma in our lives, and when we've sought help within the conventional bio-medical model of mental health. The last thing we want is to re-traumatize individuals under the guise of helping them.

We who travel at the forefront of this movement for peer-led respites know that this is a human rights movement, which means that we are called upon to support people not only to move through their most distressed moments, but to find their voice and agency in a society where they've often felt powerless.

We can begin to look at the essentials by first examining privilege and roles that traditionally operate with more or less power, simply for having been born with certain qualities or access to particular opportunities.

## **Examples of qualities that come with privilege include:**

1. Being white-skinned
2. Being born biologically male
3. Being born cisgender (i.e., born into a body where your sex assigned at birth matches your gender)
4. Being able-bodied
5. Having a brain that functions in a "neurotypical" way
6. Being Christian (at least in most Westernized nations) or of the dominant religion in one's culture
7. Being a legal adult
8. Being financially comfortable/wealthy
9. Being heterosexual (or involved in a heterosexual relationship)
10. Having gone to the right schools and/or having access to good education
11. Being physically attractive by our culture's standards
12. Being a person who uses their words and their mind to cope when stressed
13. Being literate and/or a fluent speaker of the local language (e.g., English-as-first-language in English-speaking countries, etc.)
14. Being seen as "smart" or "intelligent"
15. Being born in the country where you currently live

## **Conversely, examples of qualities that put one at a disadvantage in our society include:**

1. Being darker-skinned
2. Being born biologically female
3. Being physically disabled

4. Having a brain that works or processes information in a different manner (neurodiverse)
5. Being other than Christian (in Western societies)
6. Being a child
7. Being financially poor
8. Being lesbian/gay/bisexual
9. Being born transgender (your sex assigned at birth does not match your gender)
10. Being unable to read or write
11. Being physically unattractive by cultural standards
12. Being a person who uses “body wisdom” or emotion to cope when stressed
13. Being perceived as having learning or developmental differences
14. Being ‘other’ than the dominant culture
15. Being someone who was born in another country and immigrated to where you currently live

The main point here is that the more qualities you have from the first list (which is by no means a comprehensive list), the more this society has been put together with people like you in mind. It means your way is more likely to be free of barriers to living the life you want to live, and accessing resources in the community around you without interference. It also means that those currently in power are more likely to be familiar with your needs and wants, and to have your way of being in the world in mind when they advocate for new policies, laws, and so on.

This idea of “privilege” can often be hard for people to hear. That is especially true for those who have worked hard to get where they are or who have experienced many hardships in their own lives. However, “privilege” does *not* mean that people don’t deserve what they’ve worked for, and it isn’t meant to invalidate anyone’s very real struggles or pain. It simply speaks to the ways in which this world is—or is not—set up to meet one’s basic needs or facilitate their success.

In reality, many of us are born into a mix of privileges *and* disadvantages. Some may succeed despite being faced with many barriers. Others may struggle deeply despite what appears to have started out as an easy (or easier) path. But understanding that some of us begin life with a clearer path to success and having our needs met is an important part of creating environments that are designed to recognize *everyone’s* needs and undo or heal some of the inequities people have experienced in the past.

**It is not enough to simply invite people in to what already exists. There needs to be real consideration for how to meet people where they’re at in every way.**

It's also essential to work very intentionally at understanding how difficult privilege is to see when you're the one who has it. Seeing a *lack* of barriers can be as difficult as seeing the air, and it does require work and commitment.

We can begin in our respites by acknowledging that the various parts of our identities affect how we interact with one another and how we seek to create those genuine human relationships we so desire. All of the values presented in our Developing a Vision section are impacted by the factors of privilege and oppression presented here. In respite work, it *will* matter whether a person in a paid role is male- or female-identified, white or a person of color, Christian or Muslim, as they listen to others share stories of "what happened to them." "Cultural competency" is the current catch phrase for educating ourselves about people who are different from us. In our respite work, we want and need to look at —not turn away from— difference.

It is likely that a majority of people reading this book will be white, as that would reflect who has been the most vocal advocates in this movement in many areas of the world. To those readers, stepping outside your comfort zone on issues of race and class might present particular challenges to your belief systems. Robin DiAngelo --a white woman of Italian descent-- has suggested some ideas about this process attached to the phrase "white fragility."

**Here's an excerpt of what she offers:**

*"Challenges to this identity (being labelled "white and privileged") can become highly stressful and even intolerable. The following are examples of the kinds of challenges that trigger racial stress for white people:*

- *Suggesting that a white person's viewpoint comes from a racialized frame of reference (challenge to objectivity);*
- *People of color talking directly about their own racial perspectives (challenge to white taboos on talking openly about race);*
- *People of color choosing not to protect the racial feelings of white people in regards to race (challenge to white racial expectations and need/entitlement to racial comfort);*
- *People of color not being willing to tell their stories or answer questions about their racial experiences (challenge to the expectation that people of color will serve us)*
- *A fellow white person not providing agreement with one's racial perspective (challenge to white solidarity);*
- *Receiving feedback that one's behavior had a racist impact (challenge to white racial innocence);*

- *Suggesting that group membership is significant (challenge to individualism);*
- *An acknowledgment that access is unequal between racial groups (challenge to meritocracy);*
- *Being presented with a person of color in a position of leadership (challenge to white authority);*
- *Being presented with information about other racial groups through, for example, movies in which people of color drive the action but are not in stereotypical roles, or multicultural education (challenge to white centrality).*

*Not often encountering these challenges, we withdraw, defend, cry, argue, minimize, ignore, and in other ways push back to regain our racial position and equilibrium. I term that push back white fragility.”*

Simply put, if you are white —or possess some of the other privileges named on the previous pages— expect this work to bring up feelings in ways that you might not have anticipated. And if you possess any of the qualities of someone who often experiences oppression or disadvantage in this world, expect the same issues to follow you to your work within the peer respite world.

What is exciting is that we often find ways to grow into bigger, more beautiful beings when we sit at the edges of our comfort zones, bring our vulnerabilities and challenges with us, and work together to make meaning of the prickly places of bumping into others seeking genuine human relationships. It is absolutely *not* enough to maintain a general openness to learn about and respect cultures, beliefs and backgrounds other than one’s own. One has to proactively seek out information about common experiences of oppression as offered by people who have lived it. Without clear signs of this sort of efforts, many people won’t ever feel welcome enough to call or step through the door of a peer respite, or, if they do, they’ll be far more likely to be on guard, thus benefiting much less while there. Even the best-intended team members will drift from consciousness of cultural issues and sensitivity if this topic is not intentionally kept on the surface.

Ultimately, while it’s literally impossible to ever know all there is to know about other people’s experiences, histories and beliefs (and assuming one does know can cause a great deal of damage), creating a respite culture of openness and interest is essential. Fortunately, this is consistent with the overall emphasis on curiosity that every good peer respite holds at its foundation.

# PRACTICAL SUGGESTIONS

The following are suggestions about how to incorporate cultural awareness, as well as visible signs of openness, interest, and investment in diversity at multiple layers of the peer respite's start-up and ongoing operation:

## *Visioning:*

1. **Advisory Board:** Right from the start, seek out membership from other groups with similar or well-aligned goals and priorities to join your advisory board and give input on creating an accessible space. For example, is there someone from a local Black Lives Matter chapter or LGBTQQIA\* rights group that might be interested in joining? While most advisory boards overseeing the development of peer supports require a majority of people present to identify as having personal experience with psychiatric diagnosis, there is also a benefit to having a few people who don't, especially if they bring other valuable experiences with oppression, social justice work, and so on. And, of course, there are many people who identify as having personal experience who also are a part of other groups as well. (Note: LGBTQQIA\* stands for "lesbian, gay, bisexual, transgender, queer, questioning, intersex, and asexual. The asterisk is meant to acknowledge that is not a comprehensive list of terms and identities that are often included within that spectrum. However, it's also worth noting that there is much debate about this acronym. One reason is that there is a risk in extending the acronym too far or including too many identities. For example, individuals who are questioning or asexual are not generally targeted in the same way that gay, lesbian and trans people tend to be, and including them all as if they are equal can contribute to further marginalizing people who are already the most marginalized. )
2. **Mission and Values:** When developing mission and values statements, consider naming a commitment to fighting or undoing many types of systemic oppression. This generally should be something stronger than the standard statement against discrimination or acceptance of differences that is present in almost every organization.

## *Hiring, Supervision, and Training:*

**Job Advertisements:** Job ads that include statements about seeking employees who are committed to social justice and undoing racism and other systemic oppressions send a strong message, and may bring in applicants who might otherwise have not thought peer respite would be a good fit for them. Where a job is advertised is also very meaningful. Whenever possible, take the time to translate ads into languages that are common in the local area, and post the ads to websites, social media groups, or newspapers that are in that language. Find local LGBTQQIA\*, Black Lives Matter, or other relevant social media groups, and post jobs there.



Each of these steps can go a long way to reaching people who would otherwise be missed, and sending clear messages about who is welcome and encouraged to apply.

2. **Interview Questions:** Interviews should include questions about diversity, culture, and social justice. Here are just a few examples of questions that might work:

- What do you think “white privilege” means, and how might it come up as an issue in a peer respite setting?
- If two people staying at the respite were sharing sexist jokes about women, what might you do?
- What signs do you look for to signal that a space or group are committed to diversity and being open to different cultures?
- What sorts of trainings have you attended on diversity or cultural competence, and how have they impacted you?
- What sorts of topics or issues do you hope your next training on diversity or cultural competence cover, and why?

3. **Hiring a team that represents diversity:** Diversity does not simply refer to race, but also to age, gender identities, physical abilities, sexual orientation, languages, and a variety of other experiences in life, such as education, histories of struggle with substances, homelessness, or incarceration. Although there is no perfect balance, paying attention to who makes up a peer respite team, and doing one’s best to not have all the faces and experiences look similar, is essential. It’s especially important to recruit for employees who are representative of the racial, ethnic and immigrant groups in that area.

4. **Direct supervision:** It can be tough to keep up with direct supervision, but even if these meetings happen regularly, a great deal can be missed if the door is not intentionally opened to talk about potentially difficult issues on an ongoing basis. For example, it can be helpful to have a set list of questions that specifically invite people to raise concerns or ideas around conflicts, racism, sexism, or other issues of systemic oppression in the workplace. Incorporating these sorts of questions into routine conversation can also be a part of changing the overall culture and helping people grow more comfortable in making it a regular topic.

5. **Performance evaluations:** Having culture, diversity, and systemic oppression show up in performance evaluations keeps the conversation going, and helps drive home the point that each employee is responsible for and accountable to the peer respite’s growth and forward momentum in this realm.

6. **Creating regular opportunities to talk as a group:** Talking as a group about how the team and respite are doing with issues related to accessibility, privilege, and culture is one more way to remind the team of shared responsibility and create opportunities to learn from one another. Trainings, in-services, and guests from outside the team also help keep perspectives fresh and prevent understanding from getting limited by getting stuck in the team's own bubble. While trainings and conversations that incorporate multiple issues can be useful, it's also really important to focus in on a particular type of oppression at times. For example, if given room to do so, many groups, particularly when mostly made up of mostly white people, will avoid talking about racism if they're able to divert the conversation to talk about topics that feel less heated or challenging.

### *Setting Up the Space*

1. **Physical structure and furnishings:** Making a space physically accessible can be challenging, but is so important, and really hard to go back and do once a peer respite has opened. Adding ramps, widening doorways, and building accessible bathrooms, including grab bars and accessible showers, are the most obvious adaptations. However, having lighting that isn't fluorescent and paying attention to scents and chemicals on furniture should also be at the top of the list. Having other adaptive equipment (like bed risers) is a sign that people setting up a space have given forethought to what might be needed.
2. **Items available at the respite:** Fidget toys and weighted blankets may not seem like priorities, but can make a space much more useful and welcoming to autistic people or those with sensory issues and differences. Large print books, books in braille, and audio books create access for people with impaired sight. Magazines and books in different languages, and those that speak to an array of different cultures and religions, send clear messages that the respite anticipates and welcomes people who speak those languages or hold differing beliefs. The best way to find out what might be useful to have around is to talk with and get the advice of people who come from different cultures. A few other examples include avoiding rugs and other unnecessary objects that would get in the way of people in wheelchairs or who have difficulty seeing, as well as visual fire alarms, phones with enlarged numbers and extra volume, and so on.
3. **Décor:** Decorations are a key part of what can make a peer respite feel homey and have character. It's both important to represent different faces and cultures in art and décor, and to avoid appropriating from other cultures. For example, decorating an entire space with a Native American theme—particularly when no one on the team is Native American—may feel like taking advantage of a culture without having any real connection to the history, and may be offensive or alienating to some. Here's another place where getting lots of input from others can be really useful.

4. **Visible signs of commitment to social justice:** In general, peer respites avoid instructional signs because they can come across as treating people as children or make spaces look more institutional. However, a Black Lives Matters sticker on the fridge, or an LGBTQQIA\* triangle, or other recognizable signs and symbols of commitment to social justice can be a huge part of setting the tone in the space. They can help people who connect with those struggles feel more welcomed and safe within the walls of the respite, and can lead people to think twice before saying offensive or discriminatory things.

### ***Practices***

1. **Eliminating gendered materials:** Most peer respites will try to keep paperwork to a minimum, and have dialogues based on the natural flow of connection, rather than scripted conversations. However, especially during the process of figuring out if someone is a good fit to stay at peer respite, there are usually some routine things that get said and some basic paperwork provided. As a sign of awareness and openness to varying gender identities, it can be important to shift gendered language (he/she, her/him and so on) to non-gendered language. Although individuals concerned with grammar might find it awkward, a common way to avoid gendering standard materials and conversations is to refer to “they/them,” or use words like “person,” unless you are speaking about someone and already know what pronouns they use. Another way to increase access is to make it a common practice to ask people what pronouns they use as a part of the initial process of entering the respite. Although some people might be surprised by the question, it sends a clear message that it is acceptable at the peer respite for people to identify in the way that makes sense to them, and prevents putting people who have already experienced trauma around this issue from having to take what can often feel like the risky step of bringing it up themselves.
2. **Recognizing holidays beyond those that represent the majority:** Recognizing holidays at all can be a tricky issue for a number of reasons, but recognizing only what are seen as the dominant holidays can alienate a number of people, many of whom have already felt ignored and marginalized in the broader world. It’s impossible to guess what holidays or other important dates people might have in their lives, so one possible way of approaching this is just to ask people who are staying about their own practices and beliefs. Another is to make sure the team is educated about local communities and opportunities to celebrate a variety of holidays and cultures.
3. **Buying foods that are popular among different cultures:** Many respites can only afford basic food items. Additionally, people from different cultures have different tastes, and just knowing their ethnicity won’t offer much information about their food preferences. However, when looking at basic staples around the space it is useful to consider what are considered

employees were biased or more welcoming to people from particular backgrounds? Were there points where they felt excluded based on their cultural needs, beliefs or background?

**5. Give thought to how the team wants to respond to common problems ahead of time:**

Although there's no point in playing the "what if" game, it is likely that people who stay at the respite will sometimes make racist, sexist, homophobic, politically or religiously laden, or other culturally insensitive or discriminatory remarks.

Therefore, it's valuable for the team to think about how they want to respond right from the start. At what point is it okay to just be curious about what someone's said and help them explore where those thoughts or beliefs come from? For example, someone who makes a nasty remark about people of color may, with support, be able to discover that that belief comes from a family member, or from one particular incident in their past, and that discovery may be key in helping them to change their views. At what point does the team want to draw a line and ask someone to leave? Who will be responsible for having these conversations? The person most directly impacted, or someone else to whom the comment was not directed who can have the conversation without it feeling personal in the same way?

In the vast majority of instances, a peer respite that is doing its job well won't have rigid answers to most of the questions, and will be guided by their overall values and the relationships and circumstances that exist in the moment. However, having these conversations right from the start can help people feel more prepared and confident when these issues arise, as they inevitably will.

# PRINCIPLES OF ALLYSHIP

Another important practice in creating environments that are accessible and welcoming to diverse groups of people rests on the principle of allyship. Allyship refers to the partnership that can form between people who are part of a specific group that has experienced systemic oppression, and those who are not of that group but take responsibility for being a part of undoing the oppression they experience. It is based on the belief that it is unfair and ineffective to expect a group that has directly experienced oppression to be the ones responsible for changing it. In fact, since systemic oppression only occurs where there is an imbalance of power, it is precisely those people who are members of the group that has historically held power who will be key players in fighting for change.

The Anti-Oppression Network defines allyship as follows:

*Allyship is not an identity—it is a lifelong process of building relationships based on trust, consistency, and accountability with marginalized individuals and/or groups of people.*

The principle of allyship flows through all the suggestions in this section. True allyship is an ongoing practice that involves lots of listening, openness to hearing about and being held accountable for one's own missteps, and an interest in ongoing learning. Where peer respites are concerned, it can be useful to have trainings and conversations on the topic of being a good ally, and even to form ally agreements about how the team will share in addressing issues of racism, sexism, classism, homophobia, transphobia, ableism, etc.

This should never mean that allies drown out the voice of people who have direct experiences of a particular type of oppression. If people want to speak for themselves, they should always be given space to do so. It also doesn't mean that allies assume what battles they should be fighting on someone else's behalf. For example, if someone is being misgendered, it is important to first ask them how they'd like to be supported, before jumping in and saying what you think. As with peer support itself, allyship is about doing whatever we can to raise up someone's voice, wants and needs, while helping to tear down barriers and create environments where we all stand on equal ground.

It's also worth noting here that allyship is also sometimes seen as an insufficient or problematic word, because often people call themselves allies without being willing to stand beside the people with whom they say they're allying when things are at their most difficult, or without being willing to risk anything. People who are impacted by systemic oppression stand to lose something every day, and the best allies will be willing to stand next to them and risk losing something themselves, whether that means losing friends or supporters or what have you. It's also tricky to use 'ally' as a noun. In the end, it's truly about taking action.



## **Tips for Providers On How to Work with Peer Respite**

# A CALL FOR ALLYSHIP FROM PROVIDERS

It's not uncommon for peer respites or other peer-to-peer supports to get painted as "anti-psychiatry," or otherwise intent on being at odds with clinical providers. In truth, it *is* important to name the oppression and abuses that have often been experienced by people receiving services in the mental health system. It's also undeniable that some elements of peer respite are informed by those experiences, including the extra care taken to use non-clinical and non-labeling language, and the high level of sensitivities to people's privacy. However, many people working in peer roles are fully aware that people have experienced positives in the system as well, and that there are many very good and well-intended people working in clinical roles. People working in peer respites tend to have a mix of experiences themselves, both good and bad, with mental health services. Most know that some of the biggest problems have more to do with the cogs of that system and not the people trying to do good within it.

One of the greatest potential sources of ongoing conflict between respite team members and clinical providers is that the manner in which a peer respite operates truly is different, and in ways that may not always immediately make sense to someone not trained to work there. On a day-to-day basis, this can include phone calls or in-person meetings with providers that involve requests that the peer respite is unable to accommodate. For example:

- **Peer respites tend to have stricter standards for disclosing information about someone staying at the respite.** Even if a release has been signed, team members will generally not discuss someone without them present. This is because, historically, people have been expected to sign away their privacy and other rights as a matter of course. Thus, a signature often isn't enough to indicate thoughtful consent. Given that the respite's goal is to keep the person at the center of what's being discussed or happening related to them, regardless of what paper they've signed, this is a key issue. This means that when a provider—or anyone else—calls asking if the person is at the respite, they're likely to be told that someone's presence can't be confirmed or denied, but a message can be taken in case they are there. This also means that if someone calls asking how a person staying at the space is doing, that the most likely response they'll receive is a suggestion to contact that person directly and ask them.

## HIPAA Vs. Privacy

While peer respites will generally fall under the Health Insurance Portability and Accountability Act (HIPAA), this is not what drives their focus on respecting privacy. Rather, many people who have received services in the system have—to their detriment—become accustomed to people talking about and/or for them.

In trying to do things differently and supporting someone to find their own voice (as well as avoiding power imbalances), it becomes all the more critical that someone be able to speak for themselves whenever possible. So, while HIPAA laws are respected, they are generally seen as secondary to an overall value around privacy and someone having the opportunity to speak for themselves.

**Peer respites prioritize supporting people to get their voices heard.** So many people have experienced treatment plans with which they don't agree and people in their life who discount what they say because they're seen as "sick." Peer respite team members are trained to support someone to get their voice back as an integral *part of their healing*. This may include supporting someone to advocate for something that the provider system finds problematic or even frightening. This may leave providers feeling like peer respite team members are purposefully being difficult or stirring up trouble, but supporting someone in this way is a part of the job. It's also worth noting that it's generally *not* a part of the job for someone in a peer role to advocate for something on someone else's behalf simply because the peer supporter has decided it should be that way. This isn't about the peer respite's opinion, but about the individual's wants, feelings and needs getting heard.

What may be most challenging about the relationship between providers and respite team members is that both are often simply doing what is required of them in their role, but those requirements can sometimes seem at cross purposes. This has the potential to leave everyone frustrated. More importantly, it can also mean that the person seeking support at the peer respite is done a disservice, because those who should be supporting them are distracted by their own frustrations with one another. It may even mean that providers stop sharing information about the peer respite with people who might really benefit from it, due to hard feelings.

So the question then becomes: What next? What might help smooth over some of the misunderstandings and support people to benefit the most from what a peer respite offers?

Ultimately, most people in all roles would do well to take more time to understand others around them. This includes applying some of the principles of Intentional Peer Support, particularly exploring each other's worldview (see the Training section). That will mean taking time to ask each other questions, rather than going on assumptions.

However, the reality remains that providers continue to hold much of the power and credibility within the mental health system, while peer-to-peer groups are likely to have to fight to get heard and taken seriously. In fact, some research has shown that peer support programs need to work harder than conventional programs to be seen as doing a good job. (See the Outcomes section for more on this.) Providers who are willing and interested in being allies may want to consider the following:

- **Take the time to learn enough about a peer respite to be able to share information about it and to participate in dispelling some of the myths and misconceptions** It can get exhausting to always have to be the one who is explaining something, especially when often in a position of not being taken seriously.



- **Take the time to examine personal reactions and where they're coming from when feelings of anger or frustration come up.** Are they truly the result of a peer respite team member's actions, or are they possibly connected in some way to the responsibilities and expectations of the provider role, too? Is this about two people or two approaches clashing?
- **Take the time to ask questions when something that seems confusing comes up.** This goes back to the worldview idea, and the fact that there may be motivations and requirements that a provider might not be aware of unless they ask.
- **Give the benefit of the doubt, even when there's conflict or differing opinions.** Often, conflict arises when someone in a provider role and someone in a peer role are each doing exactly what they're trained to do as a part of their job and it happens to be at odds.
- **Even if you disagree with the peer respite approach, be sure to know enough about it so that you can share resource information with others who might still want to check it out.** It's hard for any human being to want to share information about a support they don't agree with, but overall, people really do benefit from choice, and peer respites count on the people around them in the community to help get the word out.
- **If a conflict feels personal or confusing, be willing to name it and talk it through.** Sometimes naming a problem truly is the first step to reaching a place of better understanding.
- **Don't share negative opinions with other providers or funders if those opinions are based on hearsay or assumptions.** As mentioned earlier, providers are usually taken more seriously, so sharing negative opinions about a peer respite can have farther reach and higher impact than one might initially realize. All too often, conflicts are based on misunderstandings, so it's important to check that out before saying something to someone else that might leave a lasting impression.

Most people working in the mental health system and at peer respites share at least one common goal, and that is to support people to heal and move forward. Taking the extra effort required to be an ally in these ways can make everyone's jobs easier in the long run and lead to increased likelihood of attaining shared goals.



# GENERAL TIPS FOR COLLABORATION

Just like with any community project, you will want to work with local groups, organizations and people to form connections and allied relationships. Although peer respites are very different from traditional spaces, developing relationships with those spaces is important for a number of reasons:

- Often they are able to get the word out about a peer respite to a large audience: the people using their services.
- A peer respite worker invited to speak in traditional settings may present the only opportunity that people who use those services have to hear about alternatives.
- It's a prime opportunity to clear up misconceptions about what respite is and what supports it offers.
- Word of mouth is a good way to develop a reputation in a community. You will want to develop as strong a reputation as you can and that includes being congenial with your organizational neighbors whenever possible, even if also challenging them at times.
- Some providers are strong allies in spreading peer support ideals and values within organizations.
- If you are a 'hybrid' peer respite, housed in a clinical space, part of your role is to act as a change agent for that provider, which will work best if you can develop a positive relationship along the way.

## **Some specific ways of developing connections with traditional providers:**

- **Conversations when providers call the respite line.** This is the most common, ground-level way you will be connecting with providers in the area. There may be several reasons why they are calling: seeking information on your space, resources, to see if there are spaces available for people they provide services for, etc. These conversations can be rich and enlightening for both parties. Be as clear with providers as possible about what your respite space is all about. Offer to send them brochures and ask if you can come in some time to a team meeting or to a meeting with those using their services and let people know more about the space. Correcting any misperceptions about the respite will be important. Some common misunderstandings could be that you are a shelter for people without homes, a "step-down program" for those coming out of the hospital or traditional respites, a "clubhouse", etc. Answering questions in the least defensive manner possible will help spread the word accurately and not perpetuate any false beliefs.

Sometimes providers will call the respite line and wish to talk about someone staying in the space. The answer for these situations is often "I cannot confirm or deny whether or not that person is here, but I'm happy to take a message down and get it to them if they are here." This does not always go over so well. The hard truth is that confidentiality is broken regularly by different organizations, especially among those whose funding originates from the same source. The provider may also say, "Well, we have a release." This may be true, but peer-to-peer supports make a special effort not to

talk about anyone without them present. Explain this philosophy to those calling and offer that, if the person they are supporting would like to do a conference call with them and the peer respite employee, that might be a possibility, but it is one that should be initiated by the person in question.

Even though some of these calls can be full of tension, they can also be great opportunities to ask a person in a provider role questions about their job, and to validate their frustrations. For example, you could acknowledge that you recognize that this may put the provider in a bad position, and ask more about that so you can understand better. Although this doesn't change the fact that you can't give the information the person might be seeking, it may help build a relationship that will make space for mutual respect rather than anger.

- **OUTREACH!** People can't support you if they don't know who you are. Be in touch with leadership people in local organizations to ask if you can come give a short presentation on what you do and what people in provider roles can do to be helpful for your place. It takes a lot of time and energy to build community recognition, and some (if not most) people seeking services will never have heard of the alternatives, even if they've been getting conventional services for years. So at least making sure that the organizations where they get their services can offer some of that information is key. Having the widest number of options available to support someone through their distress is an essential part of truly informed consent and a big part of what we're all about as a movement.

Another reason to do outreach regularly: People will often give misinformation out about your space, so going in to speak for yourself about what you offer is a way to combat that.

- **Offer trainings or participate in trainings in other organizations.** This can be a great way to network with people from other agencies. It can also be a way to spread the word about how you are doing things differently in your organization. The providers may not know about all the options available to people they support. Letting them know about peer supports can be helpful for everyone involved.
- **Joining committees or Boards and inviting providers from other organizations to do the same.** Working side-by-side with someone in a provider role, where both of you are focusing on something *other than* your normal day-to-day work, can be a great way to get to know someone and develop the sort of relationship that will lead them to be interested in what you do. Positive relationships and interest can make outreach and information offered much more memorable. Supporting another organization's project or cause, if you truly believe in it and it's consistent with your values, can also be a great way to develop the sort of relationship where they'll feel inclined to want to support you back. Similarly, inviting someone to join a committee for your own organization can be a great way to get them personally invested in what you do.

# AN INTERVIEW WITH 2ND STORY RESPITE

2nd Story Peer Respite opened in 2010 with 50% of their funding coming from the Substance Abuse and Mental Health Services Administration (SAMHSA), contingent on the expectation that they would participate in research to demonstrate the efficacy of the peer respite approach.

The respite house is based in Santa Cruz, California and exists under the umbrella of a traditional mental health organization, Encompass, Inc. Following an interview with

Adrian Camp-Bernard, who started as a part of the original Client Core Advisory Group, and, at the time of this writing, serves as a House Manager, and Yana Jacobs, Chief of Adult Outpatient Services for Encompass at the time of the grant application and through the respite's first four years of existence.



*Photo credit: Jen Conrad*

**Please note:** While ‘Second Story’ is an important example of a successful peer respite ‘hybrid’ (a peer respite existing under the umbrella of a conventional mental health organization), this mental health organization also had senior leadership that had previously been involved with the development of alternatives and were well-versed in that process. For example, Yana was involved with the first Soteria Project developed by Loren Mosher and operated in California. It is important to bear this in mind when reading about Second Story’s success, as without Yana’s prior exposure, the path to developing a peer respite that operated with integrity might have been much more challenging.

## **What first led administrators at Encompass to be interested in applying for a peer respite grant?**

**Yana:** At the time, a State Advocate (Delphine Brody) from the California Network of Mental Health Clients wrote a letter to the County’s Director of Health Services (Rama Khalsa) requesting that Santa Cruz County apply for a grant to create a peer respite house. Rama passed this letter on to me and asked me to apply for the SAMHSA grant.

At the time, I didn’t know anything about peer respites, but I was well connected with an international group of people who were like minded in the area of seeking alternatives, the International Network Toward Alternatives and Recovery (INTAR—[www.intar.org](http://www.intar.org)). I reached out to INTAR for

brainstorming ideas and several people contacted me and supported me in learning about respites, provided me with the history, and so on. It seemed to resonate with my prior work experience at Soteria House and thus we were off and running.

**Did you partner with anyone during the visioning and grant-writing process?**

**Yana:** I was working on the visioning process with a few members from INTAR, Shery Mead, Chris Hansen, Peter Stastny, Laysha Ostrow and Seana O’Callaghan (who also became my ‘co-grant writer’). Locally, I worked with a longtime advocate, Sylvia Caras, who was an ally and quite vocal in the peer movement.

**How important was it to have others who ‘got it’ working with you to develop the project?**

**Yana:** I mostly did this on my own and with the support of people from out of State. Santa Cruz was sorely lacking an organized peer movement, which was actually written into the grant (to help stimulate the coming together of people with lived experience). My hope was that the respite would inspire the natural forming of a local movement.

However, Sylvia Caras (local consultant) had a great deal to do with framing the program description and making sure it reflected the sentiments of people with lived experience, based upon her many years of working in advocacy both locally and nationally.

**If you could go back to that time and do anything differently, what would it be?**

**Yana:** I would hold more focus groups, and advertise to bring people together to discuss what I was envisioning and gather more input.

**When writing the grant, did you include any measures that were specifically intended to help hold the integrity of the respite and keep the voices of people with personal experience in the system primary?**

**Yana:** Yes, the grant stated that we would have a Client Core Advisory Group composed of people who worked at the respite and former guests who had stayed there. In addition, we also planned to have an Advisory Committee which was to be (at a minimum) 51% people with lived experience. There were also large sections in the grant that described in detail what the role of the Client Core and Advisory Committee were intended to look like.

**Adrian:** I actually started with 2nd Story through the Client Core. After going to my first Alternatives Conference, Yana found me on Facebook and we met. She asked me to be the facilitator of the Client Core. I was new to the mental health community then. We managed to forge the program’s

personality before it opened. We met weekly, and in spite of sometimes intense personality clashes, we kept coming back for a year and more. We were also approached a number of times from the County (not just Yana) to give input into other mental health programs. I cannot speak enough about how important the Client Core was. Before it, the peer community was spread out and somehow voiceless. This body brought people together. A bond was created going into 2nd Story, and now many of us are working throughout the local system. Four of us are still working with 2nd Story.

Now, we also have an anonymous feedback survey that allows people to let us know how we did. We have volunteers and former guests connected to the house who believe in its dream and push forward. We also invite guests to join our team meetings. And, we have posters on the wall for people to add their thoughts about what the house is, can become, and even was.

**What about skeptics? Were there any people in the organization that didn't think the respite was a good idea?**

**Yana:** Yes, there were skeptics everywhere, including the Mental Health Director at the time. Although she considered herself to be quite progressive and supportive, she was also quite political and wanted to be cautious. I originally wrote the proposal as an alternative to the hospital, envisioning that people who would typically be taken to the emergency room/acute hospital intake unit and then would be diverted to the respite. This idea was nixed by the Director. I also heard from some board members of the local National Alliance on Mental Illness (NAMI) chapter that they didn't like the idea of all/only peer staff. They wanted me to include licensed staff (non-peers) and a doctor.

I was able to argue that this request did not fit the peer respite model I was envisioning, and was not transformational. However, I did have to revise the intake plans to work from a more prevention (rather than acute/crisis) focus.

**During the start-up process, what approach did you take to hiring, development of house guidelines, and so on?**

**Yana:** The start-up process began by me putting together a hiring team and interview panel that included myself, the Community Support and Services Director from Encompass and three people with lived experience who were members of the Client Core Advisory Group. We first hired the House Director, and then the House Director was added to the hiring committee to hire the rest of the staff. We used a consensus model to determine who our choices were for staff selection. All staff had to have "lived experience," with preference given to people who had experienced coercive and/or forced treatment. The process was extremely challenging as there were many, many applicants.

I continued to play an active role at start-up since I was the one who held the vision. I needed to educate the community, providers, administration, and new staff on what the house was all about. Throughout this period, it made it much easier that the Director from Encompass was already someone who held a strong value in hiring people with lived experience. She was a natural ally, rather than being someone we needed to convince.

Once the staff were all hired, their next job was to begin to create the house guidelines together. The House Director reached out to other respite in the country to gather examples of their guidelines to share with staff as models. Encompass was also willing to allow us to deviate a bit from some of their Human Resource protocols because we were a “transformational grant” and needed to do things differently from business as usual in some instances. So there was flexibility and much interest in what we were creating.

And, still there were the skeptics, but they sat back and watched, seemingly waiting for us to fail. Instead, they started hearing many positive stories from people who stayed at the house, as well as traditional provider staff who witnessed so many positive changes with their clients that the skeptics quickly began to mellow out, and many even became voices of support.

**Did you lose what you thought were any key battles during this period in terms of how you thought the house should be run versus what administrators or funders wanted?**

**Yana:** Clinical notes were not required, since there was no billing. However, basic data was gathered as a requirement of the grant and to enable us to do the required evaluation piece. We also had some battles about who met ‘criteria’ to be allowed to stay at the respite. House staff wanted it to be open to anyone in the community regardless of whether or not they’d ever used mental health services, and including people who were homeless. Unfortunately, because this particular grant required a research and evaluation component, we had to stick with a “target” group -people receiving local mental health services- in order to track outcomes.

**Adrian:** The greatest battle and most crushing blow was that we could not form a board of directors within the grant's requirements. It felt at the time that this exclusively prevented us from becoming or moving toward peer-run. The biggest challenge to our success was not feeling peer-run, that we were somehow discouraged from moving toward this status. I wish we could have gotten to the point of creating our own Code of Ethics. At this point, we have been informed that, if we create one, the code would go to the Encompass Board for approval. As a peer community, we have asked for less stringent rules around spending time with people who stay at the house. We have gotten the support we requested to be able to be freer to spend time together after hours, on social media and in friendships.



**Has there ever been a point where the respite’s umbrella organization (Encompass) considered backing off from a peer-to-peer approach for any reason?**

**Adrian:** No, we’ve always been peer-driven only, and we’ve only felt support from most organizations throughout our growth. At this point, we are considering non-peers working as volunteers, but we continue to have complete support to be who we are.

**What have been some of the respite house’s greatest challenges as related to being under the umbrella of a clinical provider?**

**Adrian:** When I first came to this work, I was so green that I knew not the difference between a clinical provider and a peer-run organization. I was excited 2nd Story was coming to town. I was excited and energized to be able to know the peer community, something I had waited for since my first “collapse” at 19 years-old). I was grateful to be included in any way I could. For me, a clinical provider meant an organization that would keep us somehow accountable to standards.

Over time, though, we hungered for more agency. We wanted to have true decision-making power. We often felt disempowered when our peer manager would go to meetings, and then return only to inform us of the way things were. It created conflict among staff and grief toward her. The House Manager role is not a prized position, because the post is essentially serving two organizations [the respite and the umbrella]. I can remember a number of times when I felt voiceless. This is a natural human aggravation of wanting more inclusion and wanting it all now, instead of being mindful of the fact that change was happening through us, though unbeknownst.

Being attached to Encompass also meant that we could not develop our own Board of Directors, even though the grant requires us to have one. This became a struggle that eventually ended the Client Core Advisory Group, although some of that had to do with our own difficulties in pushing through and taking advantage of the loopholes that were present and would have allowed us to continue on that path.

At times, I also heard talk of some of the other employees at Encompass speaking negatively of our presence at “all staff” meetings. Of course, it is human nature to say negative things. We’ve said plenty of negative things at times about providers.

**And, what have been some of the benefits?**

**Adrian:** Initially, our point of contact with Encompass was minimal. The only time we shared with other staff in the organization was at “all-staff” meetings. However, over time, our voices got louder. We connected with others and became known as an alternative program to and within the system. Over four years of business, we became respected as representing the peer voice. It was effortless in some ways, because as a part of the umbrella organization, we were expected to join

trainings offered to all Encompass staff. Being at trainings, we got to know folks outside of the house. We came to be seen as their peers, not simply mental health peers. Our voices grew steadier and we were welcomed as people. It feels to me that we are seen as equals.

It also helped that we had a glaring spotlight on the program. Our success was a success not just for peers, but also for the Santa Cruz community and the nation. The current Encompass Director has openly acknowledged across the system, the gifts that we have brought.

**Yana:** Speaking from my obvious bias, I'd say the benefit has been working closely with clinical providers that have had an opportunity to experience the reality of the benefits of peer staff, and just how positive that has been for people they've worked with who have made remarkable changes as a result. I also think by working collaboratively, peer staff have had a strong voice in the agency's meetings as they are now part of this agency and have a place in those meetings as equal partners, representing another program under the umbrella. This has had significant influence and effects on the clinical providers. It has opened their minds, and for some, I believe it has busted some stigmas of the "us and them."

**What strategies have you employed when there's been conflict between the perspective of the team working at the respite and administrators at Encompass?**

**Adrian:** We employ direct communication, negotiation, and an expectation of openness on both sides. We have resisted at times and gotten what we wanted. Other times, Encompass has had requirements that we have honored, sometimes begrudgingly. I imagine it is like this in all workplaces.

The most effective strategies for conflict between 2nd Story and Encompass have been the realizations that we want this program to thrive and be successful. We have worked collaboratively as much as is humanly possible. We follow Encompass policies and procedures as much and as equal to any other mental health program within the Community Support Services (CSS) division.

The team was at greater odds with each other for the first four years than with CSS. Our CSS directors have offered an objective angle of ration that we found difficult to understand. We were sometimes troubled by the amount of workplace tolerance for seeming abuses taking place. We didn't think about labor laws as the reason for such tolerance.

**Has 2nd Story ever considered spinning off into its own organization?**

**Adrian:** We started talking about independence from the beginning of the project. However, the 2nd Story team seems steadier, for now, remaining with Encompass. Though we know that the future

likely means an independent respite house, right now we are navigating this with key stakeholders with caution, wisdom, and spirit.

**What advice might you give to a group that is about to embark on this same process of starting up a peer respite that is connected to a clinical provider? Do you have any specific cautions?**

**Yana:** Make sure that you have a clear distinction that you are creating something new and different, and that while you may work collaboratively, your commitment is to the identified guest first, and this will lead your decisions. Be clear that you won't be using treatment plans or history, and that you want to meet people without all that clinical baggage. Specifically, I guess I'd caution any "hybrids" from being allowed to share clinical history, as I believe it would only pollute the beauty of peer respite supports.

**Any last words of wisdom?**

**Adrian:** For any groups about to embark on this type of collaboration with a provider, I suggest having an advisory group like the Client Core. Make certain that house leadership is coming from a heart-centered lens. Make certain that they have gone through their own healing journey, and are open about who they are and why they want to work with the community.

Make certain that when hiring, you do so with a spirit of kindness, vulnerability and openness. Have a wonderful communication model like Intentional Peer Support as a guide. Work on values and ethics that act as a living guide instead of just paper on the wall with meaningless words.

Work toward building your community wherever you are. And most important, do it in the way you feel is most appropriate. Make certain to be sensitive to your community's needs, honoring the culture of your town or city. Guide yourself and your friends and families and providers with the faith that we move toward the way.



**Common Pitfalls &  
Other Things We Wish  
We'd Known**

# THIS WORK IS HARD!

Nobody who starts working at a peer respite goes in thinking it will be easy. However, few realize just how hard it can be. Some people operate under the misguided belief that peer support is mainly about keeping each other busy and just hanging out. But, the truth is that tough stuff comes up and deep distress rises to the surface. In fact, sometimes this is the *only place* someone feels safe enough to bring up certain topics, and so things can get particularly heavy at times.

People working in peer respites are also pretty much constantly expected to be explaining and justifying what they do to the outside world. While it's not the outside world's fault that they're unfamiliar, it can be especially exhausting to work hard, discuss tough stuff, and then finish one's day not being valued for the good work being done. On top of all that, there aren't nearly enough peer respites to go around, and so people working in these spaces are having to turn people away on a daily (and sometimes hourly) basis.

For all these reasons and beyond, it's more important than anyone who doesn't work in a peer respite could imagine to be able to gather as a team, support one another, decompress, smell the flowers, reflect on successes, bond, and just have fun whenever possible!



*Photo credit: Sera Davidow*

# COMMON PITFALLS

Although some of these issues are also addressed elsewhere in this handbook, it seems worthwhile to have a list of the most common pitfalls that peer respites experience all in one place. While this is an evolving list, it includes:

- ◆ **Being so focused on filling the space that the mission gets lost:** Sometimes there is real or perceived pressure from funders to keep a peer respite full. This can even be interpreted as evidence as to whether or not a peer respite is “successful” or “needed” in a community. However, particularly in the beginning, there should be no expectation that a respite will be close to full much of the time, as people are just learning about its existence. Eventually, a trend toward fullness will happen based on positive reputation and the quality support offered. Getting to this point, though, requires real trust in the process, both on the part of funders and those working in the space.
- ◆ **Either having no limits or too many regarding whether or not someone who is homeless can stay at the peer respite.** Housing is a major issue in many areas, and whether to have people come stay at a respite space if they have no permanent housing to return to is a common topic of debate. The risk of having no limits is that the respite drifts from its intended mission and becomes a shelter. On the other hand, blanket refusal of anyone living without a home often has to do with the team’s discomfort in asking someone to leave back to the street. In truth, there are many people living without homes who are legitimately also experiencing deep emotional distress and would truly benefit from a peer respite environment. Finding a balance is challenging, but many have found it to be very worthwhile.
- ◆ **Becoming a bed and breakfast or vacation spot of sorts.** Peer respites tend to be very nice spaces that offer a great deal of freedom and flexibility. However, they are meant as alternatives to hospital for people who are truly going through difficult times in their lives. Being careful to be clear about this during initial conversations with someone interested in coming to stay is an important part of preventing this type of drift. It’s also important to be wary of policies that allow someone to make an advance reservation to come to stay. This should not be confused with waiting lists (in instances where someone would come now if space were available), although even waiting lists should not be allowed to be excessively long or they then become meaningless, as well.
- ◆ **Becoming a “go-to” spot for clinicians who are desperate to find a spot for someone.** Most of us have found ourselves in a spot where we feel desperate to help someone find a resource that will work for them in an environment where that resource simply doesn’t seem to exist. Clinicians face

this issue quite frequently, particularly because of the level of responsibility they are expected to take on for someone else's well-being. This may mean that they are in a position to try and find someone a place to go when their insurance runs out at a clinical respite or hospital, when they are homeless, or when there isn't space or willingness to work with them in other environments. Out of desperation, they may start sending people in the peer respite's direction who aren't particularly good fits or aren't all that interested in being in a peer respite. Ultimately, it is essential that someone truly want to try peer respite. If they are simply being pushed in that direction by someone else (no matter how well-intended that push), difficulty and conflict are likely to follow.

- ◆ **Becoming a “step down” for a local hospital or other clinical service.** Often, this phenomenon is driven by the same motivations described in the previous section. However, this may also occur because there is a misunderstanding about peer respite, and a belief that it is not able to support people who are truly in deep distress or “crisis.” Although there may occasionally be good reasons to have people come stay at a peer respite following a stay at a hospital (e.g., they realize the hospital is not working for them), routinely having people use the respite in this way, rather than as intended to avoid a hospital stay in the first place, fundamentally changes the peer respite's purpose.
- ◆ **Becoming overwhelmed or burnt out by aggression and negative interactions in the space.** When people are in deep distress, it is reasonable to expect they may have difficulty interpersonally. It's also reasonable to expect that people who are just coming to understand peer respite and how it is different from conventional mental health services may have a real learning curve and need to adjust to what is expected there. It's also common that people who've experienced trauma and difficult relationships in the world may bring that way of being to a peer respite. However, it's important to hang onto the fact that peer respites are intended to hold to a value of mutuality. That means speaking up and holding people accountable to different expectations and the needs of everyone in the space. While this takes energy, it can be an essential part of team members feeling heard, not becoming verbal punching bags, and staying energized about the work.
- ◆ **Being under-utilized.** As noted in other sections, it should be anticipated that use of a peer respite will be slower at the start, although just how slow will vary from area to area and will be somewhat related to how involved the broader community was in the start-up process. However, it will also be important to have an active strategy and plan for educating the community on an ongoing basis about the respite, and addressing fears about the respite's abilities and purpose to be sure it grows in the way that it should. Most other services have been around for decades in most communities. Ensuring that people are aware of and truly understand a peer respite will be a long-term process

- ◆ **Seeing it as failure when team members leave, or not paying attention if there is a string of resignations.** Some jobs are the kind that people typically stay in for many years or a whole career. While it's great to have at least a few people who are in it for the long haul, having some team member turn-over should not automatically be seen as a bad thing. It's hard to be with people in their most difficult times, and it's particularly hard to keep staying curious and engaged with people who are in that place. Sometimes, the best thing is for someone who's excited by this work to come in, do it for a few years, and then move on to something else and make room for someone with fresh energy. It doesn't mean that it was a mistake for them to be hired or that they chose the wrong job for themselves. It may just mean that it was the right job for them until it wasn't anymore, or that it was an important but temporary stop on their career pathway. Paying attention to that shift and addressing it when it starts to happen can be the most important part of this process, so that things aren't left to completely fall apart by the time someone makes the decision to leave. On the other hand, if there are a string of resignations, that may also be a sign that the peer respite should check in with how values like mutuality are being held. It's always good practice to do exit interviews with departing employees to get a sense of why they're leaving and get input on what they think is going well or might be different.
  
- ◆ **Not thinking through the interpersonal issues that may arise between people staying and working at the respite.** For example, some respites make space for people who work in the peer respite to also stay there, while others prohibit that, (or are prohibited by funder policies). Similarly, some peer respites have guidelines about family members of a team member staying and whether that team member can work during that period, and others do not. The same goes for partners (or ex-partners), good friends, and so on. One way or another, there will inevitably be interpersonal concerns between people working and staying at the respite, and decisions will need to be made about how to handle them. Free-for-all (no limits and no forethought) don't generally benefit anyone, so the peer respite teams who take time to think through these concerns ahead of time, or discuss them thoroughly when they unexpectedly arise, will be best equipped to move through them in the healthiest possible way.
  
- ◆ **Accepting funding with too many strings and/or feeling pushed by funders to drift from the mission.** Almost all funding comes with some strings attached, some more than others. For example, Medicaid funding tends to come with strings like needing to prove medical necessity, writing notes, diagnosis, and a host of other requirements that are not in sync with peer respite values. Other times, funders who seemed open may change their minds mid-way through and start pushing for a shift in who and how people are accepted into peer respite settings. It is important for peer respites to go into any funding relationship with eyes open about the potential for these situations to arise. It's also important to ensure that contracts are as clear as possible and have as



many protections as possible in them to protect against this. When it does start to happen, it can also be useful to reach out to other peer respites to learn how they've handled similar situations rather than just assuming that the respite needs to give in to the funder without question or discussion.

- ◆ **Being too large.** There is a fine line between a home-like, community-based respite and a mini-institution. Most peer-run respites can accommodate between two and six people, and even six can sometimes be pushing it, depending on how many people in peer roles are working at a time. The primary offering in a peer respite is deep connection. Too many people can lead to a chaotic environment that gets in the way of connection. Additionally, everyone may feel pulled in too many different directions and not really be able to offer any one relationship enough time. Team member burnout and frequency of conflicts between people staying are also likely to go up.
- ◆ **Having difficulty saying no to people who live far away but want to come to the respite.** For several reasons, many peer respites have geographical limits on who can stay at the space. A common reason is that the funder only wants to fund support for people in the local area. Another concern is that when people are from far away, it can be much harder to support them to make valuable connections in their own community that can support them when they leave the respite. If the stay does not go well and if the person is asked to leave, it can be particularly challenging if they have no way to get home. Thinking all of this through and deciding where the respite can reasonably stretch and where it wants to set clear limits is important to navigating this issue successfully.
- ◆ **Going too far or not far enough with “nothing about us without us.”** Not talking about people without them is a core value of the peer respite approach, but teams have fairly regularly found this value difficult to navigate. In general, team meetings and shift change check-ins should *not* be about routinely running down what's going on for each person staying in the space, although letting the person coming on shift know who's in the space, and who might be returning late is certainly reasonable. But when something serious has happened in the space, that doesn't mean that team members aren't allowed to share that with one another. Ultimately, it's finding the line between the occasional sharing of urgent information versus routine talking about people that can get blurry, and requires frequent check ins. There are a number of approaches that can help people navigate this, including co-reflection, or meetings where both people working and staying talk with one another. Sometimes addressing this issue means just sitting down and having a group conversation about what the team is afraid of if a certain thing doesn't get discussed, or if it gets discussed *with* someone rather than in their absence. While some concerns are certainly valid, most teams find that much of this stems from old practices and/or fears about addressing conflict directly.
- ◆ **Taking all responsibility for people.** Many people have spent years going in and out of hospitals

and being treated as fragile and incompetent. The result can be losing housing, custody of children, friends and relationships, the ability to continue to contribute and a sense of citizenship. Part of the intent of peer-run respites is to keep people connected to their lives, communities and responsibilities, and to treat one another as capable adults. Most peer-run respites expect the people staying to bring and organize their own food, do their own laundry, and/or to contribute to the cooking, cleaning and domestic responsibilities. When it is assumed that people are incapable of doing these things, it can create a sense of learned helplessness which makes it much harder to reconnect to their lives, families, and communities.

- **Conflicts between co-workers:** Conflicts between employees are relatively common in any work environment. However, conflict between people in peer roles can be even more frequent. Conventional system wisdom might mislead us into believing that this happens because people in peer roles lack ‘professionalism,’ or that they are more troubled than other employees. This would not be an accurate assumption.

First, it’s important to remember that sometimes the idea that conflicts are more common between co-workers in peer-to-peer settings is more appearance than reality. In other words, people working in these settings are trained to speak up about interpersonal difficulties, which means that they may simply be more visible than all the conflicts that get stuffed or talked about only in a hushed manner in other spots. However, when considering what might be happening, be sure to also bear in mind that offering peer support requires that people give of themselves at a much deeper and more personal level than most other jobs. Peer supporters are asked to bring much closer to their whole selves to the workplace. This is part of what allows for such deep connections, and those connections form not only with people coming in for support but with fellow team members. While this is a large part of what makes peer support so positively impactful, it also means that relationships tend toward a more intense quality, and thus they are more likely to also experience overt and sometimes bigger conflicts at times. This doesn’t have to be a bad thing, but will inevitably get messy at times.

There’s also a certain reality that peer respites tend to hire people who excel at critical thought and pushing back against power. While also ultimately a positive that allows them to do their job well, it can be easy enough for pushing and criticism to take over internal organizational interactions, as well. Pushing co-workers (including leadership) to question and be their best selves isn’t a bad thing, but care needs to be taken to ensure that what is a strength doesn’t begin to be used to tear each other down.

# WHY PEER RESPITES SOMETIMES FAIL

The truth is that peer respites don't fail often. On the whole, research suggests that this approach is incredibly successful and impactful on many lives. However, it happens sometimes. It may not always look like flat-out shutting down failure, but sometimes respites falter and at least need some reminders of why that might be happening.

- **There's too much focus on saving money.** Yes, peer respite is much cheaper than hospitalization, and that's great. However, if savings are the only focus, then everyone's lost sight of what is truly most important: People. People and the quality of the lives they are living is what counts the most. Even when money is being discussed, this must not be forgotten.
- **Mission drift has happened.** Mission drift can occur based on pull from two different directions. In some instances, it happens when a funding source or a host organization has too strong of a say in how the respite is operating, particularly if they lack full understanding of the respite's values and approach. This might look like a peer respite being pressured to limit who it accepts in ways that don't make sense, or being pushed to accept other people to fill the place (a particular risk when first opening up and a very slippery slope that can be hard to undo), or people that the clinical system is simply angling to find a place to put. However, mission drift can also occur from within. For example, when a peer respite starts accepting people who are homeless without doing the work to prepare for the fact that they won't be able to fix the homelessness, this can mean that the peer respite becomes a shelter with people living in it for months at a time, excluding all the other people who need it for what it was really meant to be.
- **The team forgot to keep reminding the community and funders of the importance and impact of their work.** While it's not necessary to invest in formal research, it is important to keep everyone in touch with why the peer respite's work is valuable. That means visiting with local politicians in their offices and inviting them to tour the respite, attending legislative breakfasts, and making sure that legislators are getting to hear from people who are directly impacted by the respite's supports. It also means putting out press releases when there's something positive to report, and developing compelling annual reports that speak to the difference the respite is making. If, when budget cuts are looming, everyone thinks of the respite as some sort of extra or add-on, it will be at much higher risk of disappearing, and it may be too late to convince anyone that that's a misperception rather than a reflection of the truth. Other strategies can include ensuring a regular presence at local conferences (not just peer-related conferences!) and in local health/social services/mental health and strategic planning networks.

- **Peer respites have to work harder than traditional services to be seen as doing a good job.** Unfortunately, the world “gets” clinical work, so clinical work doesn’t have to constantly prove itself. On the other hand, peer respites are unfamiliar and can be met with suspicion. This is particularly an issue when something bad happens, such as violence. Violence can, unfortunately, happen anywhere, and happens not infrequently in clinical settings. However, while an incident of violence in a clinical setting is most likely to lead to questions about whether or not the clinical approach was being followed properly, one isolated incident of violence in a peer support setting can be seen as proof that the whole approach itself is a failure. As with the previous point, the only real remedy to this is to get out there, educate people, and, above all else, develop relationships so that people start to give the peer respite the benefit of the doubt, too.
- **Administrative, management and financial accountability challenges.** A peer-run respite requires the same administrative, management and fiscal skills as any other organization. One common pitfall is hiring people because they identify as someone with personal experience of diagnosis or hospitalization, without taking into account the need for the other skills and qualifications required to do the job. It can be challenging to find people with just the right mix of skills, passion, vision, and life experience to oversee a peer-run respite. Some organizations keep a reserve of funding for consultancy to help cover any gaps that emerge in the skill-set of the people they employ.

In the end, it will take lots of people and lots of peer respites working together to shape national perception and make each of these points less of a risk. Fortunately, it appears they’re well on their way.



# THE BASICS

*“The probability of using any inpatient or emergency services after the respite start date was about 70% lower among respite users than non-respite users. For those who used any inpatient or emergency services during the study period, a longer stay in response was associated with fewer hours of inpatient and emergency service.”*

**- Study on ‘Peer Respite Impact on Emergency Service Use’ conducted by the Human Services Research Institute (see more research in appendix 6)**

Measuring outcomes can be tricky. In part, this is because it can be quite challenging to balance the demand for what would be considered scientifically valid research with avoiding overly invasive measures or damaging the support you’re trying to offer simply through your attempts to conduct research at all. This is particularly true when it comes to researching peer-to-peer supports. Here are just a few reasons why :

- Many people who seek out peer-to-peer supports have felt alienated from conventional services and may feel uncomfortable with more traditional research approaches as a result
- Peer-to-peer supports often emphasize the importance of privacy and not asking some of the more invasive questions that research may require
- Peer-to-peer supports thrive on trust and connection, and many peer supporters fear breaking that trust and connection when research becomes the focus
- Many people who have received mental health services have felt taken advantage of particularly in research settings, and may feel mistrustful of anyone who approaches them with research in mind

That said, research can have significant value when it comes to funding, advocating for more of a particular approach, and in efforts to shift paradigms and perspectives. Participatory research, in particular, can help ease some of the discomfort and mistrust by involving people from the community in the design. It’s preferable to use members of a research team to conduct the research itself, both to prevent bias in the information collected and to protect the relationship team members have with people they’re supporting.

When considering data you may want to collect, it’s important to differentiate between outputs and outcomes. Outputs are the concrete supports you have provided. For example:

- How many people seeking support called the peer respite in a given period of time?
- How many providers seeking information?

- How many outreach visits (to providers, colleges, churches, etc.) did you conduct?
- How many people actually stayed at the respite and for a total of how many days?

Keeping this sort of data can be very useful in order to demonstrate demand for the support you're providing. Other demographic data can also be useful such as:

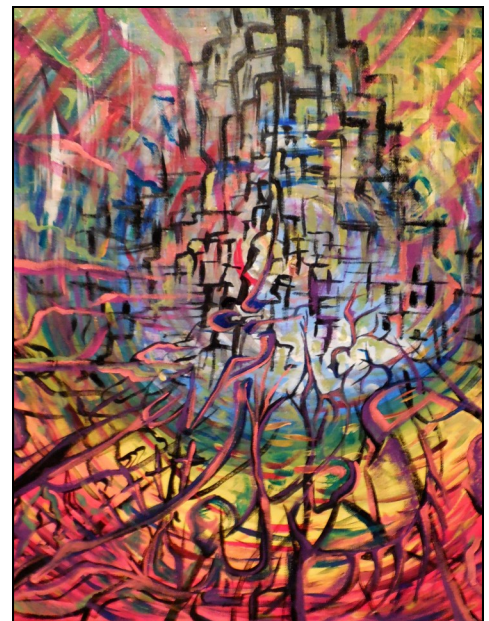
- Gender
- Race
- Age range
- Geography (where callers and people who stay at the respite live)
- Whether or not people who stay at the respite are using conventional mental health services (and, if so, which ones)
- Whether or not the person staying at the respite is new or has stayed before

However, it's important to note that even asking for demographic information (especially depending on how and when it's requested) can be a connection breaker. Similarly, guessing at this information (particularly gender and race) simply based on someone's appearance can be experienced as very disrespectful.

As opposed to outputs, outcomes look at the *impact* of the supports offered. One basic outcome that is very valuable to track is where someone goes after their respite stay. Although it's difficult to draw broad conclusions from this data in isolation, it can be helpful to at least counter any fears that peer respite is dangerous and that hospitalization and/or police involvement are likely outcomes. (See Appendix 5 for sample outcome measures and surveys from existing respites.)

Cost savings are, of course, high on most people's lists out of outcomes worth following. This is another area that can be challenging to document if for no other reason than it's hard to measure how often someone is truly not using a more expensive service due to the existence of peer respite. However, as a starting point, it is generally useful for each peer respite to know two things:

1. How much does a day at that peer respite cost
2. How much does a day at a local psychiatric unit cost



Art by Ana Keck; [www.anastasiakeck.com](http://www.anastasiakeck.com)

To capture an estimate for a peer respite, it is usually as simple as taking the annual budget, and dividing it by the total number of days in the year, and then dividing that second figure by the number of people who can stay at the respite at any one time. To calculate the average cost of a stay, the respite will then need to identify the average length of stay (usually from the last year's data, or if there's no past data, then the anticipated length of stay can be used), and then multiple the daily cost by that number. For an even more accurate evaluation of cost per night, a respite can look at its last year of utilization (number of nights that each space at the respite was actually in use) and divide the total budget by that figure. (For example, if Afiya has three bedrooms, then 100% utilization would mean that spaces were in use 1095 times through the year or 365 nights multiplied by three. However, if the utilization rate was only 92%, then the number becomes 1007 [1095 multiplied by .92] and that figure is then used to divide the total budget into a per day cost.)

Capturing the cost of the average psychiatric hospital stay can be a bit trickier. While some data is available on-line, it doesn't always differentiate between psychiatric and medical stays, and may offer figures that are somewhat higher or lower than local costs if based on national or statewide averages. Additionally, numbers given are often based on average total stay and without enough information to establish what that might mean per day. However, simply calling your local psychiatric unit and finding someone there who is willing to talk to you about their numbers can also be very useful. However you approach this, establishing a cost per day at the respite and being able to compare it to the cost per day of psychiatric inpatient care will be important information to have on hand to share in grant proposals, and with legislators and funders. Considering related costs of emergency room visits, and first responder (police, ambulance, etc.) interventions is also valuable.

Ultimately, a well done output and outcome measure structure can result in a very informative and meaningful annual report. Most peer respites won't be asked to go beyond that point, but for those interested in more formal research it will be necessary to find additional support including funding and professional researchers. While this sort of research can result in extremely valuable documentation that all peer respites can draw upon, it can also come at significant cost including the need for additional financial resources, the intrusiveness of inviting outsiders into the process, and (in some situations) additional restrictions. For example, one group had to limit their respite to only people receiving services from a particular organization for the duration of the research period.

If headed down this path, it will be important to take care in selecting a research partner. Sometimes universities make ready partners from a financial perspective, but individuals and groups who have their own psychiatric histories may make for the most effective and respectful process.



# FIDELITY

Fidelity measures are quite different from outcome measures; they seek to examine how closely one is holding to the established model, rather than exploring the impacts of that approach. However, they tend to be closely linked, because, without fidelity, outcome measures lose much of their relevance. In other words, if a peer respite no longer holds to the basic framework of being a peer respite, then whatever outcomes it is producing are no longer necessarily related to being a peer respite either.

Below is a basic fidelity tool developed from the charter. It is not comprehensive, and is meant only as a starting point.

<b>Basic Peer Respite Fidelity Tool</b>	Y	N
Are all people (including leadership) in paid roles individuals who have personal experience with life-interrupting emotional distress/other significant life challenges and is that required as demonstrated in the job description and other relevant hiring paperwork?		
<i>Notes/Recommendations:</i>		
Are more volunteers or interns working at the respite people who have personal experience with life-interrupting emotional distress and other significant life challenges?		
<i>Notes/Recommendations:</i>		
Does everyone who works at the respite (including leadership, volunteers, and interns) periodically share pieces of their psychiatric history and other life experiences, as well as lessons learned?		
<i>Notes/Recommendations:</i>		
Does the respite's mission, values, and any other written documents or practices reflect the concept that what gets called 'crisis' can also be a learning opportunity? If yes, how/where does this show up?		
<i>Notes/Recommendations:</i>		
Does the respite avoid focus on assessment or risk?		
<i>Notes/Recommendations:</i>		
Is the concept of personal responsibility present in the space? (In written documents, protocols, etc.) If yes, how/where does this show up?		
<i>Notes/Recommendations:</i>		
Are the values of the respite clearly stated and available to anyone working or staying at the space?		
<i>Notes/Recommendations:</i>		

Do the values include all of the following concepts: Self-determination, mutuality, and the belief that healing and growth are possible for all. If yes, how do these values show up?		
<i>Notes/Recommendations:</i>		
Is the impact of trauma consistently recognized in the respite's training and written materials? Does this include consistent awareness of trauma related to systemic oppression including racism, homophobia, ableism, transphobia, sexism, etc.? How/where?		
<i>Notes/Recommendations:</i>		
Do people who work at the respite avoid an 'illness' interpretation of people's experiences and maintain an openness to a variety ways of making meaning of distress and other experiences?		
<i>Notes/Recommendations:</i>		
Does the respite make space for people to talk openly about difficult and unusual or taboo experiences without negative consequences?		
<i>Notes/Recommendations:</i>		
Is routine person-specific paperwork kept to a minimum? What does that look like?		
<i>Notes/Recommendations:</i>		
Is the person staying at the respite in charge of leading management of any paperwork that does exist? (If any note is required, do they write it, etc?)		
<i>Notes/Recommendations:</i>		
Do individuals working at the peer respite (including leadership, volunteers, and interns) receive training and ongoing support to understand and consistently come from a peer-to-peer (non-clinical) perspective?		
<i>Notes/Recommendations:</i>		
Do people working at the peer respite (including leadership, volunteers and interns) <u>consistently</u> use non-clinical, everyday language that is inclusive of and leaves space for a variety of perspectives?		
<i>Notes/Recommendations:</i>		
Do people working at the peer respite (including leadership, volunteers and interns) consistently avoid asking about diagnosis or using diagnostic language, unless brought up by a person staying at the respite?		
<i>Notes/Recommendations:</i>		
Do people working at the peer respite (including leadership, volunteers and interns) consistently express an openness to many healing paths (including psychiatric medications or no medications, therapy or no therapy, alternative healing practices, etc.), and avoid expressing that any one path or the other is 'right' or 'wrong' for any particular person (unless talking about themselves)?		
<i>Notes/Recommendations:</i>		

Are people staying at the respite supported to keep connected to their chosen family, friends, and/or any providers/supporters as they desire?		
<i>Notes/Recommendations:</i>		
Are people staying at the respite free to come and go from the respite, and are any exceptions kept to a minimum and based only on preventing serious disruption to the respite's ability to function and support others?		
<i>Notes/Recommendations:</i>		
Is the person staying at the respite free to design their own day (with or without support as desired), including determining their own bed/wake times, whether or not they attend any available groups, and so on?		
<i>Notes/Recommendations:</i>		
Is the person staying at the respite able to decide for themselves what is a 'problem' and what is not? (For example, are they free to determine that self-injury is an acceptable way of coping for them at this point in their life if they so choose)?		
<i>Notes/Recommendations:</i>		
Does the respite intentionally avoid any use of force (calling emergency services or the police against someone's will, etc.)?		
<i>Notes/Recommendations:</i>		
Does the respite have a review protocol in place if they ever did act against someone's will (call 911, etc.) for any reason? (To review what could have been done differently, what was learned, etc.) Does that protocol include input from the person whose will was acted against?		
<i>Notes/Recommendations:</i>		
Is there a clear and transparent complaint process available to everyone staying or otherwise in contact with the respite?		
<i>Notes/Recommendations:</i>		
Does the respite have an intentional emphasis on not routinely talking about people without them present (even if a release has been signed)? If there are exceptions, what do those look like and do they still include mindfulness about this issue?		
<i>Notes/Recommendations:</i>		
Does the respite avoid tasks that are likely to create or enhance power imbalances (e.g., handling medications or money, etc.)?		
<i>Notes/Recommendations:</i>		
Are 'staff only' areas avoided or minimized? What does that look like?		
<i>Notes/Recommendations:</i>		

**Below are some other tools that might be helpful in this process:**

**FACIT Tool:** The Substance Abuse and Mental Health Services Administration (SAMHSA) also funded the development of a fidelity tool called the Fidelity Assessment Common Ingredient Tool (FACIT) specifically designed for peer-to-peer groups and supports. Although not geared toward peer respites, many of the items are applicable. <sup>1</sup> Additionally, in 2011, the FACIT tool was adapted for a fidelity evaluation of Second Story respite in California. A copy of that adaptation is available in Laysha Ostrow and Bevin Croft's *Toolkit for Evaluating Respites*. <sup>2</sup>

**IPS Core Competencies Measure:** Although not a fidelity tool for peer respites either, the Intentional Peer Support (IPS) Core Competencies measure is nonetheless a useful instrument for a peer respite. It supports a team that has been well-trained in IPS to examine how it's doing overall with implementing the tasks of IPS. <sup>3</sup> Additionally, Cheryl MacNeil and Shery Mead wrote a useful article on the topic of fidelity measures called *Discovering the Fidelity Standards of Peer Support in an Ethnographic Evaluation*. <sup>4</sup>

Much like outcomes research, formal fidelity reviews are best done by an outside party to ensure an honest report. However, integrating informal checks and balances into day-to-day practice may be even more important to keep things on track overall. This might look like setting aside time at team meetings to review the charter and ask questions about how people feel the respite is measuring up. It could also look like inviting people from other parts of the organization, or who have stayed at the respite before, in periodically to take a look, ask questions and give feedback.

Regardless of the methods used, it's important to not just trust that things will stay on track, or that it will be easy to see when things have strayed. It's common to veer off course when no time is taken to check in, especially for people who are so close to the day-to-day goings on. It can be hard to step back and see the big picture.

<sup>1</sup> The FACIT tool can be found here: <http://bit.ly/1UEJi82>

<sup>2</sup> The *Toolkit for Evaluating Respites* is available here: [www.peerrespite.net](http://www.peerrespite.net).

<sup>3</sup> A tool to measure IPS fidelity can be found here: <http://bit.ly/2C6WETM>

<sup>4</sup> *Discovering the Fidelity Standards of Peer Support in an Ethnographic Evaluation* by Cheryl MacNeil and Shery Mead is available at <http://bit.ly/2qfYErX>



Stories from People  
Who Have Stayed  
at Peer Respite

# MARTY'S STORY

I was going through a hard time and did not want to go back on lots of medication. I especially wanted to avoid antipsychotics. Initially, my psychiatrist and therapist were supportive but as the days turned into weeks, they began to raise the idea that I should be hospitalized. I asked them if they could promise me that I would not lose everything I had gained by going into the hospital and going back on medication. They both replied that they could not make that promise, but that they believed I would find myself again over time and that what was happening needed to stop.

My mind was like a computer with too many programs running that was beginning to lock up and shut down. I was losing my words and found it difficult to be around people and very difficult to engage in any conversation. Eventually I was threatened with forced commitment and I headed off into the woods. I like to kayak and being in the woods did not make things any better or worse, but then it rained for two days straight and I was wet and miserable.

Ultimately, someone suggested peer respite, and I was able to go there instead of being committed. I did not know if it would be helpful or not, but I wanted to try and make it through this extreme state without being extremely medicated. When I got there, people asked me what they could do to support me. I did not have any words, and, at first, I was freaked out by the question. I thought to myself that if they did not know how to help me I was in deep trouble since I clearly did not know what I was doing.



Photo by A.P. Grant, [www.gesturalphotography.com](http://www.gesturalphotography.com)

But, the question *did* make me think, and it caused me to realize that I needed to become the expert on my own experience. I thought about what parts of being in the hospital had been helpful. I was already clear on what parts were not, including the whole process of sitting in an emergency room for hours and even days, having my clothes removed, and having strangers stare at me.

Usually when I would be hospitalized I would end up in the “quiet room” for days at a time. I did not like having my clothes removed and being locked in a room, but the quiet and lack of demands on me did seem to help. So, at the respite, I spent time in a beautiful room with a nice big bed. It was also ok with the people there when I chose not to sleep on the bed and felt safer on the floor. In the hospital this was a big issue that had not ended well for me. I could also leave the room and attempt to be with other people or sit outside and return to the room when I thought it would be helpful. I did not need to be locked in a room. I could be around other people and not be judged or labeled for not engaging in conversation.

There was one late night at the house when I had energy and words and I asked the person working if we could talk. They responded in a mutually excited way about the prospect of talking. If I had been in the hospital, this opportunity to connect would have been met with hostility as it had in the past – and likely with medication being forced on me for being so awake in the middle of the night. This sort of connection and acceptance of where I was at in the moment made a tremendous difference in my ability to move forward and through such a difficult place.

Since staying at peer respite, I have learned that I can make it through extreme states without extreme interventions being forced on me. I have also learned that I can get support before things get so overwhelming. And, when I forget that I can make it through, there are other people with whom I am not connected that can hold the optimism that I can make it for me. It is really different to have people treat you like a person and not a patient – to see you as someone who is struggling versus defective or diseased. This different approach provided me with hope at moments that were otherwise hopeless.

Since going to peer respite, I have not been hospitalized. It has been 4 years and that is the longest time in my adulthood that I have gone without inpatient treatment. I continue to move forward in learning how to navigate my own life.

**Learn more about Marty’s story in the ‘Afiya House’ film available at: [www.afiyahouse.org](http://www.afiyahouse.org)**



*Illustration by Lianna Oddi from the ‘Afiya House’ film*

# JONATHAN'S STORY

I stayed at a peer respite about a year ago for one week. I stayed there because I work in the Medical Field and in Hospice-like settings very often. I have been working as a Personal Care Assistant (PCA) for 13+ years and a Certified Nurse's Assistant (CNA) for 5 years. Frankly, holding people's hands as they passed away took a huge toll on me: I think it is natural to feel what I felt due to the gravity of each situation, although, as the years went by, I needed a respite to renew my reservoir of energy to get back to work.

The respite was like 1,000 therapy sessions in one week. I knew I could have stayed in my room the whole time, although I chose to venture out and see the community and interact within the house to see what I could do to help. I was also able to meet with a favorite author of mine, who invited me to his house (thanks to the house having Wi-Fi).

Meeting my favorite author and the people who worked at the peer respite changed my life in all good ways and helped in all aspects of life. Within two weeks, I got back to work and found a girlfriend.

The fundamentals upon which peer respites are built help guide wellness and recovery: when you arrive, there is immediate mutuality and respect. No 50 pages of signing your life away. You can leave whenever you want. The respite really wants to help and does through it's very design. It is the most American ideology of wellness and recovery because peer respite respects freedom.





# DANIEL'S STORY

May 31 of this year marked two years since my entry into the psychiatric system—in short, I told someone how I was feeling, they called the police without telling me, and in the end I was told I could “voluntarily” sign myself into an inpatient psych unit, or they would commit me. At eighteen, I just wanted the pain to stop, and actually was a bit relieved that someone was taking it seriously. I panicked as I entered that inpatient unit, yet, deep down, desperately hoped it would “fix” me.

No treatment plan “fixed” me. It didn’t “fix” me because there was nothing to fix—I, as a human, and my life experiences, thoughts, and feelings, are not inherently wrong or in need of “fixing”. In traditional psychiatry, I wasn’t valued as an individual, but rather, reduced to a set of symptoms and diagnostic labels that erased my humanity, and, with that, any form of genuine human connection, equality, or respect between the mental health professionals and me. That did *not* yield a trusting or healing environment.

When I was planning for discharge from that hospitalization, a social worker actually told me to look into a local peer respite—I called them as soon as I finished reading their pamphlet. I was asked an open-ended question about what was going on in my life and why I wanted to stay at there. I started to answer with diagnostic labels, but was told those didn’t matter—they wanted to know what *I* thought and how *I* felt. Within a week, I was out of the locked ward heading in a cab to something called a “respite” and despite the phone conversation, I didn’t know what to expect. I thought it would be pretty similar to the psych unit, just without locked doors. But it was nothing like that.



When I was admitted to the inpatient unit, a nurse ran through a long script of pathologizing questions, and didn’t even make eye contact as she asked them. I recently got a copy of my records, and the psychiatrist’s notes read, “He was educated repeatedly about mood disorders and the fact that his level of functioning was... significantly decreased because of biological illness... and that he needed to follow up with treatment.” I was told many times that I needed to listen to doctors, therapists, and social workers whose “clinical expertise” could diagnose, medicate, treat, and save me. I bought into the idea that I had a biological illness and that the solution lay in the right mix of chemical substances (prescription psych meds) and intensive therapy programs. Repeatedly asked if I was “safe” or confined to a locked unit if deemed a “danger to myself” by professionals who talked to me for 15

minutes and decided they knew more about me than I myself because they had fancy letters after their names, I lost my trust in myself.

At peer respite, I was asked what *I* needed, what *I* found helpful, what *I* wanted. I was seen as a human, instead of a diagnostic label; an equal, instead of a “client” or “patient.” Being empowered to make my own decisions, and having my voice valued and encouraged, I started to believe in myself and my ability to get through difficult times. My first night was perhaps the hardest: having spent the last month and a half on a locked unit, I didn’t yet trust myself at all. I told a team member that I was having significant thoughts of suicide – and I expected the automatic, “Do you have a plan? Do you have intent? Are you safe?” Instead, she spoke from a place of genuine human connection; she asked me what was beneath that, then told me about a time she had felt similarly – and gotten through it. For the first time, someone told me that I *could* get through it – I didn’t need to be locked up for my own “safety”. When someone believed in me, I started to believe in myself – and I got through that night, and the next, and the next.

Two years later, I’m *still here*. I have learned how to not just survive, but to thrive, and found value in myself, my lived experience, and my ability to help others by sharing my story and supporting them in their journey. Sometimes, I still feel deep despair and pain – but there’re are also many good times that make life worth it. Those valuable, *real* things were never written on a prescription pad or taught as a DBT skill.

In my times of deepest despair, I sought death because I was in so much pain that I wasn’t really living, but merely existing in the world where others seemed to live. Being confined to a locked ward I could only look of through grated windows – with my rights, values, and self-determination stripped away – made me feel even less alive. I have learned that the best way to make sure I stay here is to *really live*. The point isn’t just to be breathing, or even “functioning”, but to have a life worth living.

Right before being inpatient, I wrote a song that, at the time, was about giving in to and justifying suicide. The title and refrain is, “Falling isn’t Failing.” When I played and sang that song one morning, a respite team member told me it was absolutely beautiful and its hope spoke to her. Confused, I explained what the song had meant to me when I’d written it. She responded that she heard that, too, but asked if perhaps there could also be another meaning – that it’s okay to struggle and that that doesn’t mean everything has to end: I could fall, and someone could catch me, and together we’d get back up again. In that moment, something truly shifted for me: I realized I was resilient and strong, I wasn’t alone, and I could choose to live in a new way. The peer respite was where I began to reclaim MY life – and thus far, life’s been quite an amazing, challenging, beautiful journey.



# ANA'S STORY

When I came to peer respite, I had recently lost the illusion that I was "cured" from my psych diagnoses and suicidal ideations. When push came to shove, it all came back, and my sense of self and recovery narrative could no longer hold. All I knew for certain was that I was not going back to the psych ward.

Instead, I got lucky and wound up at the local peer respite. It's not that I found some magical cure at that house. What was useful was that I could just be a human being even as a human being in distress; I didn't have to be that sick person who can't handle life. I could talk about myself without fear of losing my liberties, and I could also have conversations about other people's engagement rings or roller derby. I didn't have to choose between my life, employment opportunities, friends, and going to the respite. I could have the power to do what I wanted with my day.

More than anything, staying there gave me a new perspective. Instead of vilifying and attempting to eradicate my thoughts, my thoughts could also just be. I met people who lived with suicidal thoughts or voices in their heads or any number of other things and who lived important, meaningful lives. When suicidal thoughts popped up after the stay, it was no longer the end of the world. My brain wasn't the problem; the problem was the pinning my suicidal and otherwise unacceptable thoughts against a fabricated image of sanity. Nobody wins the sanity game, and the expectation to never have a "bad" thought only made mine more prevalent. For once, I could be just as valid as the person sitting next to me in the supporter role. They weren't pretending to be a pillar of sanity who could fix my life; they were just another person who had been through some hard things, too.



My stay at peer respite also led to employment at that same house, which is not how that would have worked out in more traditional settings, but I'm grateful that it did. It's empowering to be part of a community where I could be seen in a rough spot and also be able to come back and support other people. Unlike other jobs I'd had at traditional mental health agencies, I could be part of something I believe in and be a useful part of someone's journey.

I am able to be honest about myself and my story and step out from the veneer of being a provider. I can be real and genuine, and even be silly at times. Peer respite isn't the magic bullet for anybody, and we are small and underfunded in comparison to the rest of the mental health system. It can be hard to witness when people who have stayed at the house continue to have a hard time and have to fight against impossible odds like homelessness, physical health problems or joblessness. Someone's world can't be righted in seven days, but it can hopefully provide a space to begin that work.

# ANDREA'S STORY



Peer respite is a place that is suspended in time.

I first stayed at a peer respite last year when it seemed like there was no hope, nowhere else I could go to, and no way that I could possibly overcome the struggles I had been going through.

I first was introduced to the idea of peer respite through community bridgers who met me in the hospital. The hospital where I was an absolute nightmare to stay at, but community bridgers offered other alternatives. They came in, talked to the group I attended, and mentioned different groups all across the region for people who are survivors of mental health issues... as well as the local peer respite.

I didn't have the transportation to get there, so one of the community members brought me. Everybody was so helpful and understanding of my situations in life and easy to talk to. I settled in to my own private room, and was given the space to work out paperwork and issues in my life that I hadn't had the time to take care of.

Whenever I needed somebody to talk to, they were there.

Whenever I needed something to do, it was there.

If I needed rest, I got to rest. If I felt like I wanted to go out, but was too anxious, I was encouraged to go out and explore. It was well worth it. The local city was gorgeous. If I wanted art supplies to draw with, they had them. If I wanted a book to read, there was a bookshelf stocked with books. If I wanted to relax in the grass or on a bench and watch the sun set... No, really, seriously, there it was.

Everything I needed or wanted in life was there. The conversations late at night hanging out on the porch while my mind was racing too fast to sleep were some of my favorite memories I've ever had.

It doesn't cost anything. You don't owe anybody anything.

Afiya is simply there for you when you need it. That's all.

# Frequently Asked Questions



# FREQUENTLY ASKED QUESTIONS

Below are some questions that are commonly asked, most of which have not already been addressed (or addressed fully) in other parts of this handbook.

- 1. Are peer respites anti-psychiatry?** No. Peer respites are focused on creating a paradigm shift, which means they often are doing things very differently than traditional systems might. However, peer respites have not formed with the intent of getting rid of psychiatry or preventing or discouraging anyone who stays at a peer respite from accessing psychiatric services if they would like to do so. In fact, the most significant change that peer respites are trying to make is that of choice and self-determination. This means being a part of sharing information and options with someone, but that someone is ultimately just as free and welcome to choose psychiatric services from among those options as they are any other type of support. Any peer respite that attempts to get in the way of someone seeking the support of a psychiatrist, a therapist, or any other clinically oriented worker has lost sight of their own most important principles and values.
- 2. Are peer respites anti-medication?** No. Peer respites don't handle psychiatric drugs or other medications because doing so wouldn't be consistent with a peer-to-peer environment. However, many people stay at peer respites who take medications, and that's perfectly fine. They just need to be able to manage them independently or have someone from the community who can help them do so. Most peer respites provide a locked box in each bedroom where people can store small or valuable items, including medications, as needed. There's also usually a mix of people working at peer respites, including those that do and do not take psychiatric drugs.
- 3. Should a peer respite be willing to talk with someone about psychiatric drugs at all? What if they want support to get off of or reduce them?** People who work at peer respites are trained to support someone in exploring their goals, and if getting off or reducing psychiatric drugs is among those goals, they can support someone to think that through, too. While no one working at a peer respite is in a position to make specific recommendations of a medical nature, support at the peer respite can include talking about reasons, pros and cons, sharing personal experiences, and looking at resources online, in books, etc. It can also include helping someone find and connect with a doctor or others who may be able to support their goal.
- 4. Do peer respites support people to go to work and school while they're staying at the respite?** Yes, the vast majority of peer respites support someone to design their own day. For some people, a break from work is absolutely needed, but for others, a forced break would only make things worse. Choice and self-determination are cornerstones of the peer respite approach.

5. **Can people smoke at a peer respite?** There's a growing trend among hospitals to prohibit smoking for people on psychiatric units. This is not a popular decision among smokers, and particularly those who are hospitalized against their will. While everyone knows that smoking is bad for a person, no one wants to be told what to do or forced into making "healthy" decisions, especially when they're already in crisis. While peer respites don't generally allow people to smoke inside the space, most consider smoking a choice and offer an outside area for that purpose.
6. **Do team members cook for people staying at respites?** This varies somewhat, and can be impacted by local ordinances around food handling. However, the spirit of a respite emphasizes choice and personal responsibility. In many respites, that means that each individual staying or working at a peer respite must be able to prepare their own meals, or at least that there is no routine expectation that the person working be responsible for it all. However, that also means that people can choose to share meals when they wish to do so. In settings where this occurs, it may be someone in a paid role *or* someone staying at the respite (or everyone together) who prepares a meal. But, most of the time, people are making their own food.
7. **Should peer respites provide regular transportation?** This will vary based on budgets and the number of people scheduled to work at any one time. For many peer respites, it's not realistic to be able to promise regular transportation. However, some respites have more team members on at a time, have volunteers available who can offer rides, or are connected to larger communities that they can call upon for help as needed. The way rides are prioritized may also be influenced by the availability of public transportation in an area, as some respites are very near public transportation and more than willing to help someone figure that out, while others are situated in rural areas without an easy way to get around unless someone has a car. Ultimately, it's important to keep checking in to make sure that the work that is at the heart of the mission of the respite isn't getting lost in day-to-day busyness, no matter what can be offered.
8. **Will people who work at a peer respite attend appointments with someone staying there?** This also varies, for reasons similar to those described above. In most instances, people working at respites are willing to take part in advocating with someone at various appointments, but may be limited in their availability, based on number of people available to cover the respite space during that time. However, even when going to appointments is more difficult, most respites will support people by making phone calls with them and/or at meetings that might occur at the respite space. The biggest caution is the risk of moving from advocating with to advocating for someone, slipping into talking about them without them (not advisable even if a release has been signed), and so on.

9. **Should spouses or children ever be allowed to stay with someone at a peer respite?** Peer respites really aren't designed to have families stay with people. Although it's very understandable that it can be difficult to leave a child behind or find somewhere for them to go, having children at a respite also has the likelihood of being very difficult for others present and putting unfair responsibilities on respite workers. Rarely, and when the needs of others staying can still be met, exceptions have been made for nursing mothers.
10. **What kinds of opportunities should peer respites offer for volunteers?** Peer respites vary substantially in how they incorporate volunteers. Some bring volunteers in to help support the space, just like a paid worker, but often with shorter shifts. However, bear in mind that this means that a volunteer needs to be trained and supervised similarly to permanent employees. Other peer respites invite volunteers primarily for special projects or working on the space. This might include gardening, painting, or cooking a holiday meal. Volunteers may be primarily people who have stayed at the space before (who also may be hired to work at the respite in a paid role), or may be people from the broader community, or a mix. Ultimately, it's up to each peer respite to figure out what works for them, but it's important that that respite think through all the implications and time requirements of whatever choice they make.
11. **Should a respites have a policy about how soon someone can come back if they already stayed recently?** Some peer respites do and some don't. It's important, though, to avoid creating a policy or guidelines for everything under the sun. In most instances, issues of people wanting to stay more frequently than seems helpful can be addressed person by person. This is more consistent with the spirit of a peer respite, where the focus is on connection, transparency, and respecting different paths. If it feels like someone is calling too often or wanting to stay too regularly, it may be best to simply ask to meet with them to talk that out, rather than having a policy that might only serve to get in the way of exploring why that's happening.
12. **Should peer respites require people to share rooms?** A few peer respites offer shared rooms, but even they tend to have singles, too. Most peer respites offer only single rooms, because it can be so hard to truly rest and feel at ease when sharing a room with a stranger. Wherever possible, this is clearly the way to go. Sometimes, people may complain that that's decreasing the number of people that can be supported throughout the year. While that's certainly true, the volume of people supported with shared rooms versus single rooms is usually not astronomically different. However, the impact of the respite when someone is able to have their own space can be substantially higher than when they are required to share space, and so the cost of sharing just doesn't seem worth it most of the time. At the very least, finding a way to delineate with screens or alcoves can help create a sense of individual space where separate rooms is absolutely not possible.



13. **Do most peer respites accept donations?** Absolutely! Items like food of all kinds, from fresh fruits and veggies to baked goods to pizza donations to non-perishables, clothing, unopened personal care items, and more are appreciated at the vast majority of respites. Peer respites are also typically under a non-profit organization, so donations are tax deductible, as well.
14. **Should people be allowed to discuss religion or spirituality at a peer respite?** Yes! Religious and spiritual beliefs are often a huge part of who someone is, and there's no reason to try and cut that off. The idea that this topic should be off-limits tends to come from a clinical perspective that believes that religious talk might feed into someone's unusual beliefs, or fears that it might sever connection if there's a disagreement in perspective. However, peer respites focus on celebrating individuality and relishing whatever supports are meaningful to someone. Provided everyone is respectful of different belief systems, talk away!
15. **Do peer respites usually limit access to individuals with specific diagnoses?** No, peer respites don't typically focus on diagnosis at all, and generally won't even bring it up unless a person seeking support brings it up themselves.
16. **Should peer respites ask people who want to stay about their diagnosis or any psychiatric drugs they're taking?** No, generally these are not questions that are routinely asked. Occasionally, some related questions may be asked if associated with a particular research study. These are questions that tend to get in the way of the intended mutuality in the space, and make it more difficult for people to understand that the respite is a non-clinical environment that is intended to create space for people to make their own meaning of their experiences.
17. **Do peer respites save money?** Yes! For example, at Afiya (Massachusetts, USA) around 250 people stayed in 2015. When surveyed, about half of those who responded said that the hospital was the only other option for them. The average stay for a day at the hospital is \$2,695. Let's say that the 125 people who came to Afiya instead went to the hospital for one week (the maximum length of stay at Afiya). That would cost \$2,358,125. Compare that to the average cost of running a peer respite for a year = \$365,000. We are talking about saving the state quite a lot of money. And, that's with one peer respite. Imagine if we had them across the state and across the country! Numbers like these can be especially helpful when you are speaking with your local legislators.
18. **Do people need to be "medically cleared" to stay at a peer respite?** The short answer is no. The process for entering peer respite mostly involves making sure the person wanting to stay is clear about the values of the space and the peer-to-peer model, and that they want to be there and

uphold those values. That said, there might be times when someone's medical condition prevents them from staying at a peer respite. If someone needed to be checked every hour on the hour, or if someone needed medication administered many times throughout the day, it's likely that a peer respite might say that it was not a good fit. This is because, as peer supporters, we do not step into the role of giving medications or checking people's medical equipment or anything of that nature. That comes with inherent power dynamics that make the peer relationship impossible.

**19. Should there be restrictions on how often the same person can stay at a respite?** This answer is similar to question 11. This should be decided on an individual basis. Think about it this way: we all have gone through periods of struggle where we need more support. Making a blanket rule that says the same person cannot stay more than twice in the same month would discount the fact that some periods in our lives are harder than others. Someone could leave peer respite, only to lose their job or have a family member pass away. Would it really be useful to then have a rule that says, "Welp, you've reached your max for stays, sorry!" Flexibility and creativity are paramount in the peer respite world. That said, if someone is calling every week to stay, it might be time to sit down and talk with that person. Questions that might be helpful to ask include: What needs of yours are being met by peer respite? What needs of yours are NOT being met by peer respite? If someone is unable to move through their crisis during their stay, it's possible that a peer respite is not providing what they might need at that time.

**20. Are there usually any required meetings or groups?** Self-determination and choice are key values at any peer respite. Telling someone they have to do something would not be in line with this philosophy. So, no, there are no required meetings or groups. However, there might be times set aside during the week for optional meetings. This could be a space for people to talk about how things are going for them, name if there are any hard things arising for them, and check in with the values and how they are being upheld by people staying and working.

**21. Do peer respites accept interns?** Much like volunteers, interns are welcome in the space. It is suggested they go through an interview process with the team and possibly with someone who has stayed at the respite, to make sure it is a good fit for the space and that their values coincide with those of the peer-to-peer world. They also might need some training, possibly in Intentional Peer Support or other trainings that make it possible for them to be with people in similar ways to how people in paid roles are trained to be with folks. Also, accepting interns can be a great way to introduce someone who might be headed into a clinical role to this movement and to the concept of peer respite. Sometimes there can be misunderstandings that arise between providers and peer efforts, and someone who has actually spent time in a peer respite would be in a better position to dispel those misunderstandings. Lastly, someone who is training in a clinical role might be introduced to

rigid models of diagnosing and medicating as a part of their education. Interning at a peer respite would be a great opportunity for an intern to be introduced to that more flexible and common sense way of supporting people. That said, an intern's education should not come at the cost of being able to focus on the support being offered.

22. **Do people staying in peer respite usually need to sign releases?** No. As mentioned previously, even with signed releases, people working at peer respite will often not talk about people without them present. If someone staying needs a peer supporter to speak with their clinical providers for some reason, the ideal situation would be for the person staying to be present either on a conference call or face-to-face with the provider.
23. **Will peer respites store people's belongings after they've left?** This can vary. Some spaces do not have the room. Others might have the space and might agree to store the belongings for a period of time. Reasons someone might not be able to take all of their things with them could be that they are leaving without a place to stay, or are headed into a rehab program or something of this nature. It is wise to have a clear time limit for when someone's belongings must be picked up from the respite (say, a month or so), or else you might end up with a very full basement or storage space. If you do have a time limit on how long you will store someone's things, donating to Goodwill or another charity organization or creating a donation bin for people who come through the respite might be a good idea. Whatever you decide, be sure to clearly mark someone's belongings with their name or initials, and keep their contact information on record.
24. **Are people staying at peer respite generally required to set goals?** At some spaces, due to funding, there may be some requirement of "setting goals." If this is the case, it is always best to let someone know that this is required by your funders and find creative ways to make that document work for the person who is staying. Also, naming the document "hopes for stay" or "aspirations" or something other than "goals" could be useful. Often, in traditional spaces and groups, people are asked to create goals for themselves and are rewarded (or not) for achieving those goals. Sometimes, goals are set for them by providers. Language does matter and choosing something that does not have that connotation and energy can go a long way toward someone feeling supported. Of course, changing the language is not the only part to that. One must also change the intention. Being clear that any list of hopes or aspirations can look like whatever the person staying needs it to look like is what is most important.
25. **Are people staying at a peer respite required to focus on their 'problems'?** Focus is flexible. Imagine spending a few days or a week or more focusing on your trauma or your voices or your grief. People staying, just like any of us, might choose to talk about what brought them in in the

first place or they may choose not to focus on that at all. If your best friend overdosed in your arms, it's safe to say that focusing on that nonstop would not be supportive, relaxing or helpful. Sometimes we all need time to relax, distract, and get space from the things that are troubling us in the world. It's only then that we can get some perspective and find ways to deal with those situations that actually work for us.

**26. Are people staying at a peer respite allowed to have sex in their room (with other people staying, with friends or a partner, with someone working at the respite, etc.)?** People are sexual beings and this topic will likely come up at some point. Because many people who stay at peer respites have histories that include sexual trauma and/or abuses of power, it is important that people in peer roles, who will be seen as having some power simply for being in that role, not cross that line and engage in sexual intimacy with someone staying at the respite. While the issues may be very different when it comes to two people staying at the respite, or when someone's friend or partner comes to visit them, most respites also do not encourage sexual activity within the peer respite space. This is because hearing sex-related noises through the walls or knowing there are strangers in the areas where the bedrooms are locating in a respite can bring up trauma issues for people. However, that does not mean that people staying at the respite (or visitors) are generally prohibited from developing relationships that may lead to sex or from being physically affectionate with one another. Additionally, people working at the peer respite should be willing to talk about sex (unless the nature of the conversation or relationship feels somehow unsafe or not respectful), as it is an important part of people's lives that is often ignored or negatively impacted by the psychiatric system and its treatments. Conversations can include information about safe sex and access to supplies like condoms, negative impacts of psychiatric drugs, finding relationships, and so on.

**27. Should people working at peer respites be required (or asked) to have "wellness" or WRAP plans?** No! Asking people working in a peer role to maintain a "wellness" plan is discriminatory, as most employees in most roles in the world are not asked to do so. If someone who works at a peer respite happens to find having a wellness plan useful, that is entirely fine, but even if they have such a plan, they should never be asked to share it with their employer.

**28. Should people who work at a peer respite be required to be certified as a "peer specialist" before they're hired?** No (though some regions may require it). While some training and experience in peer roles can be extremely useful, what's most important is their investment in this work, their understanding of core concepts, and the ability to develop connections in skillful and meaningful ways. This may be enhanced by training, but is often present in some way before that point in people who are most successful in these roles. Trainings geared toward peer support are

also incredibly variable across regions, and some are much better than others. Online trainings or certifications can be particularly problematic, as this work is about relating to one another, and trainings on computers require none of that, nor do they provide any space for people to truly think about or shift why they believe what they believe about the world, emotional distress and how human beings relate to one another. Restricting people who can be hired to only those who are certified in these sorts of trainings can also be extremely limiting when the pool of people who will be good at these jobs is already quite small. Such restrictions may make it more difficult to reach a diverse applicant pool that comes from different age groups, ethnicities, and so on, as these training programs are still relatively new and not always reaching or accessible to a variety of people. Ultimately, it is best to be open to a range of applicants, and to decide as a team what trainings are most important to require once they've been hired.

It's also worth noting that there are many people who find the idea of training people in peer support objectionable. This is based on the belief that peer-to-peer support is about being human with one another, and that training does little but get in the way of that. However, it's worth remembering that even people who've never been through clinical training have been exposed to clinical ideas through media and a variety of other sources (including their own experiences receiving services). Good training for peer support will help people examine their worldview, and understand what assumptions and beliefs they might be bringing to the respite, regardless of where they come from. It will also give people a chance to talk through any fears they might have, practice ways to connect or address conflict, and so on. Ultimately, training is about giving space for people to learn together and build confidence, and should not be discounted.

# Appendices

**The following section is designed to be easily updatable as future editions of this handbook or on-line versions are revised.**

**If you have a suggestion, resource, form or other idea please contact us at [info@westernmassrlc.org](mailto:info@westernmassrlc.org).**

# Appendix 1: Resources

## Websites

The sites noted below are, by no means, meant as an exhaustive list. It's meant just as a starting point. As with all resources and trainings, it's also important to look at everything with a critical eye! Some of these resources will be strong in some areas, but still have a long way to go in others.

### **Sites with listings of peer respites and general peer respite information:**

Peer Respites—Action & Evaluation: [www.peerrespite.net](http://www.peerrespite.net)

National Empowerment Center: [www.power2u.org/peer-run-crisis-services.html](http://www.power2u.org/peer-run-crisis-services.html)

### **Sites with information about peer roles in general:**

Peer Support Resources: [www.psresources.info](http://www.psresources.info)

### **Peer respite training sources:**

Intentional Peer Support: [www.intentionalpeersupport.org](http://www.intentionalpeersupport.org)

Western Mass Recovery Learning Community: [www.westernmassrlc.org](http://www.westernmassrlc.org)

### **Alternative perspectives on emotional distress:**

Mad in America: [www.madinamerica.org](http://www.madinamerica.org)

Mind Freedom: [www.mindfreedom.org](http://www.mindfreedom.org)

Madness Radio: [www.madnessradio.net](http://www.madnessradio.net)

The Icarus Project: [www.theicarusproject.net](http://www.theicarusproject.net)

Intervoice: [www.intervoiceonline.org](http://www.intervoiceonline.org)

The Law Project for Psychiatric Rights: [www.psychrights.org](http://www.psychrights.org)

### **Alternative perspectives on psychiatric drugs:**

Harm Reduction Guide to Coming Off Psychiatric Drugs and Withdrawal:

[www.theicarusproject.net/resources/publications/harm-reduction-guide-to-coming-off-psychiatric-drugs-and-withdrawal/](http://www.theicarusproject.net/resources/publications/harm-reduction-guide-to-coming-off-psychiatric-drugs-and-withdrawal/)

Inner Compass Initiative: [withdrawal.theinnercompass.org](http://withdrawal.theinnercompass.org) and [www.theinnercompass.org](http://www.theinnercompass.org)

### **Trauma resources:**

The Sidran Institute: [www.sidran.org](http://www.sidran.org)

The ACE Study: [www.cdc.gov/ace/index.htm](http://www.cdc.gov/ace/index.htm)

### **Sites focused on combating homophobia, sexism, transphobia, racism, ableism, etc.:**

Black Girl Dangerous: [www.blackgirldangerous.org](http://www.blackgirldangerous.org)

For Harriet: [www.forharriet.com](http://www.forharriet.com)

Feministing: [www.feministing.com](http://www.feministing.com)

Black Lives Matter: [www.blacklivesmatter.com](http://www.blacklivesmatter.com)



## Websites

The Movement for Black Lives: [policy.m4bl.org](http://policy.m4bl.org)

The Root: [www.theroot.com](http://www.theroot.com)

Trans 101 with the Sylvia Rivera Law Project: [www.srlp.org/resources/trans-101/](http://www.srlp.org/resources/trans-101/)

Everyday Feminism: [www.everydayfeminism.com](http://www.everydayfeminism.com)\*

The Body is Not an Apology: [www.thebodyisnotanapology.com](http://www.thebodyisnotanapology.com)

Autistic Self Advocacy Network: [www.autisticadvocacy.org](http://www.autisticadvocacy.org)

*\*Please note that while *Everyday Feminism* is a website that has lots of useful information on many topics, it is generally **not** on target when it comes to psychiatric oppression.*

### **Information about relevant conferences:**

National Association for Rights Protection and Advocacy: [www.narpa.org](http://www.narpa.org)

National Empowerment Center: [www.power2u.org](http://www.power2u.org)

International Association for Peer Supporters: [www.inaops.org](http://www.inaops.org)

International Drug Policy Reform Conference: [www.reformconference.org](http://www.reformconference.org)

International Network Toward Alternatives and Recovery: [www.intar.org](http://www.intar.org)

Intervoice: [www.intervoiceonline.org](http://www.intervoiceonline.org)

National Conference on Peer Support: [www.ncps-canada.com](http://www.ncps-canada.com)

The Copeland Center: [www.mentalhealthrecovery.com/the-copeland-center/](http://www.mentalhealthrecovery.com/the-copeland-center/)

# **Appendix 2:**

# **Sample Hiring Documents**

Job descriptions and job ads will vary with the particular needs and design of each peer respite, but many fundamental elements should look similar across respites.

As noted in the hiring section, starting with materials that speak in language consistent with the values of peer respite is important, even if they will be under the umbrella of an organization that has a broader or more clinical focus.

Attached are some sample job ads and job descriptions. As with other samples offered in the appendices, if you intend to use all or part of a sample to create your own document, please be in touch with that respite directly. Do not use samples without contacting those responsible for developing them.

In almost all instances, it will be better to simply take what you've learned and use it to inform and build your own material.

## **Job Ads:**

**Example 1:** Advocate at Afiya (20 to 32 hours), the Western Mass Recovery Learning Community's peer respite based in Northampton. Offer peer-to-peer support to people staying at the respite, partner to explore resources, work as a part of a team to create a homelike and healing physical environment, etc.

Your own experience living through trauma, psychiatric diagnosis, homelessness, addiction and/or a variety of other life-interrupting challenges required. Understanding and commitment to examining and undoing systemic oppression related to racism, gender, psychiatric diagnosis, etc., also required. Intentional Peer Support, Certified Peer Specialist training and other trainings relevant to peer-to-peer work (Hearing Voices, Alternatives to Suicide, etc.) a plus. Bilingual/bicultural (English/ASL or English/Spanish) a plus. AA/EOE.

Applications that do not include a cover letter may be discarded.

**Example 2:** The Rose House is a 24 hours service. Shifts available are 9am-5pm, 4pm-12am, 12am- 9am. Overnights and weekends may be required.

The Per Diem Crisis Diversion Peer Companion staff will support the daily operations of our Rose House Crisis Respite. She or he provides peer support for each Rose House guest. The Peer Companion is available to instill hope, support wellness and demonstrate that recovery is real and does happen. Peer Companions model and utilize trauma informed techniques and tools, help guests set goals and engage in community and social events.

## **DUTIES AND RESPONSIBILITIES:**

- Provide support for guests during interview, intake, arrival and departure.
- Share personal experience and encourage mental health wellness and recovery.
- Assist in connection to mental health services, community resources, entitlements, and other services as needed.
- Model and utilize Trauma Informed techniques and tools as out lined in : Intentional Peer Support (IPS), Wellness Recovery Action Plan (WRAP), Mental Health First Aid, Emotional CPR (eCPR), Motivational Interviewing, SafeTALK, Applied Suicide Intervention Skills Training (ASIST), PEOPLE, Inc. In-House Peer Advocacy Training, and Crisis Diversion / Respite House Training
- Transport guests to store or appointments when needed, using company car.
- Provide telephone support to peers in the community through the 24 hour peer warm line.
- Help maintain a clean, safe and secure environment. Some cleaning duties may be assigned.
- Manage downtime with Guest and Rose House program focused activities and duties.
- Work cooperatively Rose House team and maintain clear, honest and respectful communication with team members.

## **REQUIREMENTS:**

- Honesty, respect for diversity, high personal standards, language and behaviors reflecting such values.

- Demonstrated ability to recognize the need for and facilitate connections between consumers and the community.
- Understanding of available community supports.

Qualify for New York State Peer Specialist Certification. <http://nypeerspecialist.org/>

- Working knowledge of confidentiality requirements related to records pertaining to Mental Health and Chemical Dependency laws.
- Must have good time management skills and be self-directing.
- Must have reliable transportation.

#### QUALIFICATIONS:

- High School Diploma preferred.
- At least two years in recovery from acute care environment
- Shared vision of hope for people experiencing crisis
- Work or Volunteer experience providing peer support, advocacy or human services.
- Able to delineate behaviors behind values of critical care and recovery (preferred)
- Basic knowledge of community support services/resources
- Completion of Wellness Recovery Action Plan (WRAP) training (preferred).
- Understanding of recovery vs. illness based system (preferred)
- Professional demeanor.
- Bilingual English/Spanish strongly preferred.

## Sample Job Description

### **Job Title: Advocate**

### **Job Summary:**

The Advocate will provide trauma-sensitive peer-to-peer support within the context of the Peer Respite. Supports offered will include advocacy, providing information and opportunities to connect to local resources, support around housing and benefits and 1:1 mutual support. Some outreach or group facilitation responsibilities may also be required, as well as support to the Peer Support Line.

### **Supervisory Relationships:**

The Advocate will be supervised directly by the Peer Respite Director or Coordinator.

### **Employment Status:**

Regular employee (hours/FTE may vary)

### **Principle Duties and Responsibilities**

- Mutual Support
  - The Advocate will maintain a consistently accessible presence at the Peer Respite for as needed/desired support with individuals staying at the respite
  - The Advocate will support individuals at the respite to self-determine and advocate for their needs and desires
  - The Advocate will partner with individuals at the respite to identify and connect with resources
  - The Advocate will partner with individuals at the respite to maintain desired existing natural supports and services in the community
  - The Advocate may accompany or provide transportation to appointments, meetings or community resource settings in an effort to support the above goals
  - The Advocate will support individuals at the respite who seek to identify goals, dreams and desires for moving forward
- Community Outreach
  - When available, the Advocate will participate in general outreach to community groups and organizations to share information about the respite
  - When available, the Advocate will participate in the facilitation of informational meetings about the peer respite to interested individuals
  - When available, the Advocate will participate in presentations about the peer respite at conferences or other similar opportunities
  - When available, the Advocate will assist in the development of supportive relationships with community resources
- Team Collaboration
  - The Advocate will maintain clear communication with fellow team members through the avenues provided
  - The Advocate will attend all required team meetings within the Peer Respite and broader organization

- General
  - The Advocate will be responsible for holding and exemplifying the values of the Peer Respite and trauma-sensitive practice
  - The Advocate will be responsible for respecting the privacy of individuals at respite and HIPPA-related requirements
  - The Advocate will maintain documentation as required
  - The Advocate will participate in the respite entrance process as needed
  - The Advocate will participate in the general upkeep of the Respite space which may include periodic cleaning, meal preparation and maintenance of the exterior of the space (shoveling, raking, mowing)
  - The Advocate will share responsibilities for answering the respite phone
  - Other duties as agreed upon

**Minimum Qualifications:**

- Education and/or Experience:
  - Personal experience having been given a psychiatric diagnosis, going through extreme states and/or trauma required
  - Intentional Peer Support preferred. Certified Peer Specialist training, Trauma-Informed training a plus. (Training will also be offered post-hire as available and needed)
  - Some experience in advocacy, group facilitation and/or peer support preferred
- Abilities:
  - Access to reliable transportation (with access to your own vehicle strongly preferred)
  - Bilingual/bicultural in English and American Sign Language or Spanish a plus
  - Ability to act as an advocate and support individuals to take leadership in their own healing and growth process
  - Ability and willingness use own life experiences in an open and intentional manner
  - Ability to participate in physical tasks involved in household upkeep which may include general cleaning, laundry, raking, mowing, shoveling and similar
- Attributes:
  - Calm and approachable, including when under pressure
  - Willing to sit with/talk through difficult situations and conversations (e.g., talk about hearing frightening voices, thoughts of suicide, etc.)
  - Respectful of and compassionate toward other people's thoughts, behaviors, ideas and needs
  - Self-aware and able to take responsibility for own mistakes, successes, weaknesses and strengths, as well as being able and willing to seek support when needed
  - Optimistic and confident in approach and outlook
  - Curious about and open to all perspectives, with a focus toward keeping up-to-date with information about peer-to-peer support and developments in the broader movement.

## Sample Job Description

### **Job Title: Peer Respite Director**

#### **Job Summary:**

The Peer Respite Director will provide trauma-sensitive peer support and team leadership within the context of the Peer Respite. Duties will include substantial direct support and administrative responsibilities.

#### **Supervisory Relationships:**

The Peer Respite Director will be supervised directly by the organizational Director or designee.

#### **Employment Status:**

Regular employee at 1 FTE (40 hours)

#### **Principle Duties and Responsibilities**

- Direct Support
  - o The Peer Respite Director will maintain a consistently accessible presence at the Peer Respite for as needed/desired support by individuals staying at the space
  - o The Peer Respite Director will support individuals at the respite to self-determine and advocate for their needs and desires
  - o The Peer Respite Director will partner with the individuals at the respite to identify and connect with resources
  - o The Peer Respite Director will partner with the individuals at the respite to maintain desired existing natural supports and services in the community
  - o The Peer Respite Director may accompany or provide transportation to appointments, meetings or community resource settings in an effort to support the above goals
  - o The Peer Respite Director will support individuals at the respite to who seek to identify goals, dreams and desires for their wellness, recovery and/or futures
- Community Outreach
  - o The Peer Respite Director will lead efforts to offer general outreach to community groups and organizations to share information about the respite
  - o The Peer Respite Director will collaborate with the team in the facilitation of orientation meetings about the peer respite to interested individuals
  - o The Peer Respite Director will collaborate with the team to provide presentations about the peer respite at conferences or other similar opportunities
  - o The Peer Respite Director will lead efforts to develop supportive relationships with community resources
- Team Collaboration
  - o The Peer Respite Director will engage in clear communication with fellow team members and ensure that all team members have access to the necessary communication tools to communicate with one another
  - o The Peer Respite Director will lead facilitation of Peer Respite team meetings and will attend all other required organizational team meetings.

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- Leadership & Coordination
  - The Peer Respite Director will be primarily responsible for all funder reporting requirements or designating them appropriately
  - The Peer Respite Director will be primarily responsible for representing the Peer Respite at all required funder meetings
  - The Peer Respite Director will collaborate with other leadership to investigate additional funding opportunities
  - The Peer Respite Director will provide budget management for the Peer Respite
  - The Peer Respite Director will share supervision and training responsibilities of all relevant positions including Advocates, Peer Diem Workers and volunteers
  - The Peer Respite Director will share on-call duties with other Peer Respite leadership
- General
  - The Peer Respite Director will be responsible for holding and exemplifying the values of the Peer Respite and trauma-informed practice
  - The Peer Respite Director will be responsible for maintaining confidentiality of individuals at respite and HIPPA-related requirements and ensuring that the site meets requirements to make this possible
  - The Peer Respite Director will be responsible for ensuring that the respite site meets all relevant licensing requirements
  - The Peer Respite Director will maintain documentation as required
  - The Peer Respite Director will develop and support the peer respite entrance process
  - The Peer Respite Director will participate in the general upkeep of the Respite space which may include periodic cleaning, meal preparation and maintenance of the exterior of the space (shoveling, raking, mowing)
  - The Peer Respite Director will share responsibilities for answering the respite phone
  - Other duties as assigned by a supervisor

**Minimum Qualifications:**

- Education and/or Experience:
  - Personal experience having been given a psychiatric diagnosis, going through extreme states and/or trauma required
  - Substantial experience in advocacy, group facilitation and/or peer support required
  - Substantial experience in management (including staff supervision) required
  - Certified Peer Specialist, Intentional Peer Support and Trauma-Informed training preferred (training will also be offered post-hire as available and needed) and familiarity with related values and principles required
- Abilities:
  - Ability to mentor and foster growth and leadership in fellow team members
  - Access to reliable transportation (with access to your own vehicle strongly preferred)
  - Bilingual/bicultural in English and American Sign Language or Spanish a plus
  - Ability to act as an advocate and empower individuals to take leadership in their own healing
  - Ability and willingness to use own experiences in an open and intentional manner
  - Ability to participate in physical tasks involved in household upkeep which may include general cleaning, laundry, raking, mowing, shoveling and similar

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- Attributes:
  - o Possesses a leadership style that is consistent with peer-to-peer values (e.g. ‘Servant Leadership’)
  - o Calm and approachable, including when under pressure
  - o Respectful of and compassionate toward other people’s thoughts, behaviors, ideas and needs
  - o Self-aware and able to take responsibility for own mistakes, successes, weaknesses and strengths, as well as being able and willing to seek support when needed
  - o Optimistic and confident in approach and outlook
  - o Curious about and open to all perspectives, with a focus toward keeping up-to-date with information about peer support and developments in the broader movement.

# **Appendix 3: Sample Guidelines**

Having written guidelines is an important part of developing a peer respite, and ensuring consistency. It's also a part of providing support to team members who shouldn't always be expected to hold all knowledge in their heads, or explain guidelines to new team members without a written reference point.

That said, it's also important to not create guidelines that are unnecessary or get in the way of relationships that develop naturally or the flexibility of considering the particulars of each situation.

What follows are some sample guidelines that you might find useful in developing your own. As with samples provided in other sections, it will generally be best to consider these, but write your own based on the particulars of your situation.

If you do choose to use some or all of these guidelines at your respite, please be in touch with the respite that developed them to talk about what led up to the development of the relevant guideline, what was meant by it, and how it may have changed over time. Please do not use any samples as your own without first discussing your plan with the respite that was responsible for developing them.

## Guidelines for Entrance Conversations at Afiya

This is intended as a guide, not a script. The purpose of the conversation will be:

- Giving information about what a person's stay at Afiya will look like
- Clearly relating the Defining Principle's of the RLC
- Learning about what the person's hopes and thoughts are regarding time spent at Afiya

**PLEASE NOTE:** This is the conversation that will orient someone to what it means to stay in our space. That said, it is very important to be clear and thorough in describing the Principles and going over all points on the paperwork so that someone has a good understanding of what Afiya can and cannot do and what their responsibilities are to the house and to the community.

### BEFORE STARTING THE CONVERSATION:

1. Show the person their room and ask if they would like anything to drink or a snack to eat while having the entrance conversation.

**\*If someone does NOT want to do the entrance paperwork when they arrive initially, this is okay. Please be sure to do the paperwork within 4 hours (or when they next wake up if they're asleep), however, because it is very important for people staying to understand what we do at Afiya and what we expect from them during their stay. If the entrance paperwork has not been completed on your shift, please let the incoming person know.**

### STARTING THE CONVERSATION:

**Give the person an idea of what the entrance paperwork and process looks like.**

- A. Show them all paperwork.
- B. Let them know you will be going over the Defining principles and the RLC calendar for that month.

\* Be mindful that people may have had difficult entrance conversations at more traditional spaces with possibly intrusive paperwork in the past. Likely their experience with us will be quite different, but it might be useful to state our intention to make the entrance process different than those experienced in other spaces and have some conversation around why we are trying to do this. Speak from your own experience as much as you feel comfortable.

### SHEETS TO GO OVER WITH PEOPLE:

#### 1. Welcome to Afiya sheet:

- A. Go over sheet in entirety.
- B. When discussing the Defining Principles, please have on hand the full descriptions and answer any questions people may have about what they mean. Also, it may be helpful to ask what a few of the principles mean for them.
- C. Show them where they can find a paper copy of the Principles in the house and show them the posted Principles on the wall.

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## **2. Entrance Acknowledgement sheet:**

- A. Please be sure to go over this sheet in its entirety, paying particular attention to reasons why someone might be asked to leave Afiya.
- B. Let the person know that their room will be forfeit if they leave and do not contact us within 24 hours. Within that, let them know that if they do end up staying somewhere besides Afiya for several days of their 7 day stay, we will check in with them and discuss whether or not Afiya is a good support for them.

## **3. Hopes for Stay sheet:**

- A. We have realized we've become very lax and inattentive with this sheet on entrances. Please discuss what "hope for stay" means and support the person in getting a clear idea of what it is they are hoping to get out of staying at Afiya.
- B. Let the person know that during their stay, team members will be checking in with them asking if there is something they can do to support them with their hope.
- C. Also, be sure to mention that the day before someone leaves our space, we will sit down and chat with them about how the stay went, overall.

## **4. Preferred Contact & Support Sheet:**

- A. This is an optional piece of the packet, but be sure to ask someone if they would like to fill out part or all of this sheet.
- B. \* Sometimes people who initially said they did not want to fill it out realize that they do, in fact, want a support person's name on it or have some information about their process that they want us to know. If we don't offer the sheet or glance over it as unimportant, we are not giving that person a chance to decide what they need for their stay.

## **5. Other Information You May Want sheet:**

- A. Be sure to show people the back of this sheet that discusses human rights issues and complaints and tell them who the human rights officer for Afiya is.
- B. Also, if someone wishes to talk with someone outside of the RLC about human rights issues, please point out that information to them.

## **6. Privacy Practices sheets:**

- A. Give the person the Notice of Privacy Practices packet to keep.
- B. Ask them to check the box to the left of Signature on the Privacy Practices Acknowledgement Form, then sign and date.

**\*If during the course of this entrance conversation, it becomes clear that this is not a fit, please check in with another team member, then contact the person on-call.**

## **WHEN YOU'VE FINISHED THE ENTRANCE PAPERWORK:**

1. Ask the person if they have any questions or concerns.
2. Give them a tour of the space.
3. Show them where the Guiding Principles are posted in the house and where the spare paper copies are. Also, show them where they can find spare RLC calendars.
4. Complete a tracking sheet with the person's entrance date on it.

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## Relationships & Potential Conflicts of Interest

Our hope is to be available to as many people as possible who may benefit from a peer respite environment. Inevitably, there will be times when that may be complicated by pre-existing relationships between someone working at Afiya and someone wishing to stay there (or two people staying there). These situations will often not lend themselves to clear-cut answers, but should lead to thoughtful consideration that bears in mind the needs and wants of each person impacted (both directly and indirectly) and the overall intention of the space. As a part of the process, the following guidelines will apply:

- In all instances, we will hold our mission as primary: “Afiya strives 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.”
- Bearing that in mind, if a person with direct ties to someone working at Afiya (a current or former partner, a direct relative, etc.) expresses interest in coming to stay and otherwise seems like a good match for the space, the following people should be involved in the conversation about if and how to move forward\*:
  - oThe individual in question who works at Afiya
  - oThe individual in question who would like to stay at Afiya
  - oThe on-call supervisor
  - oAt least one other team member

This group will be responsible for coming up with a plan which may include moving forward as normal, incorporating suggestions from the parent/child section of this document or other parameters as makes sense according to the group decision.

\* **Please note:** Inclusion of all people named above does NOT necessarily mean that all must speak together. However, at a minimum, there should be transparency about the conflict and input from each should be sought and considered, with responsibility for a final decision ultimately resting with at least one member of the leadership team. The only exception would generally be if involving the person who would like to stay at Afiya poses a serious safety risk to the person working at Afiya (such as when there’s a restraining order or similar).

- The parent/child relationship has inherent power dynamics that cannot be overlooked, as they have the potential to impact not only the parent/child involved but those around them as well. (The parent/child relationship should be understood to also include caretakers, guardians and stepparents.) If the child or parent of someone working at Afiya wishes to stay there, the team member who has a connection to that person will have the option to\*:

- oUse personal leave time
- oSwitch shifts with another team member who is willing to do so
- oWork with the team and individual in question to arrange for a stay that does not include their normal work days
- oTake unpaid leave time

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- In the event that paid leave time is not available to the person giving up a shift(s) *and* all other options have been thoroughly explored and found not to be viable *and* the budget allows, paying the person for the shift(s) they are giving up may be considered.

\* **Please note:** All options must be discussed in collaboration with other team members relevant to the decision, overall coverage of the house and related budget issues and the final decision must be workable not only for the situation but also for the broader needs of keeping the house operating reasonably. In addition, permanent team members will have the option to state that the presence of the person being considered for a stay at Afiya would have a detrimental impact to their overall ability to work in the house and can therefore determine that the person is not a good fit for the house at that time. (This should not be used capriciously and is intended for situations where someone feels their ability to work in the environment would be seriously damaged.) In the event that a per diem team member feels that they do not want to give up a shift for a similar reason, their input will also be considered and taken seriously in the decision making process, though the leadership team will retain the right to make a final decision on how to move forward. **Additionally, if anyone is not invited to stay at Afiya for this reason, it should not be considered a permanent ban and should be re-evaluated at each opportunity.**

#### **Other points to keep in Mind:**

- In the instance of married, partnered or dating couples, only one person from the couple will be invited to stay at the house at a time. (Similarly, couples working at Afiya will not be scheduled to work at the same time.)
- If a person calls Afiya wanting to stay, and you realize that you have ‘close ties’ to that person that would make it difficult to be a part of the process, you would explain that due to the ‘close ties’ it would be best if another advocate (if another person is working with you) takes the call, or an ‘on call’ team member would take the call.
- Additionally, the team will be asked to be particularly aware of privacy issues in all of the above situations and to avoid special treatment and access as a result of team relationships. In particular:
  - Team members calling to check in on family or friends (or even people with whom they’ve developed a close connection during their time at Afiya) staying at the respite will be asked to call them directly
  - Although we avoid talking about particular people without them present, if a conversation about a situation does happen between team members (at a team meeting or otherwise) that pertains to a team member’s close family or friend, they may be asked to step out during that time



## Asking Someone to Leave Afiya

**Summary:** Although people are able to stay at Afiya for up to 7 days, they may also be asked to leave sooner than that if they are not able to hold the values of Afiya and/or otherwise do not seem like a good fit.

### Examples of Reasons Why People May Be Asked to Leave:

- Repeated demonstration of disregard for the space/people in the house (Including but not limited to, smoking in the house, watching pornography in common spaces, etc.)
  - In ability to take care of basic personal needs (including but not limited to, inability to feed self at all without assistance, inability to properly use the bathroom, inability to take care of personal medical needs, etc.)
  - Stealing and/or damaging property
  - Racist, heterosexist or other hate speech (particularly if an individual speaks in this way repeatedly and isn't open to conversation about how they are affecting others)
  - Threat of or actual physical violence
- Drinking or using drugs on the property (or returning to the space high/drunken in a way that significantly impacts the space)

### Asking Someone to Leave the Space:

#### *This process will typically include:*

- A conversation with the on-call supervisor and other relevant team members
  - Establishment of a plan of how/when/what to say (this must include having at least two team members present at the house)
  - Typically, this will include giving the individual clear information about what is not working about their stay in the house
  - Request the best contact information for a follow-up conversation
- Establish a time by which they must leave

#### *After the person leaves, this process will typically include:*

- A notation in the handwritten comm log for team members just entering the space and a notation in the orange binder for future reference
- An opportunity will be offered for debrief to each team member and other people staying in the house who may have been directly impacted
- A conversation between relevant team members (including a supervisor) about whether asking the person to leave was just for this stay or if they are actually going to be asked to not call Afiya for an extended period
- Typically, if being asked to not come to Afiya for an extended period, this will be documented clearly in a letter and communicated as soon as possible to the individual using their preferred contact information

If someone is being asked to leave because of inability to care for own medical needs or other issues that present ongoing needs for other support, this will be a part of the conversation and planning when asking someone to leave

*\* The police will not typically be involved in asking someone to leave unless that person has refused to leave and/or the reason they are being asked to leave also poses a clear and ongoing threat*

## Communication Guidelines

**Summary:** Ultimately, in our team communications, we are responsible for holding two values that may sometimes feel as if they conflict. These are:

- ‘Nothing About Us Without Us’ (or not routinely talking about people who aren’t present)
- The need to be able to communicate with one another about our own concerns and responsibilities related to holding the values of the house

**We value ‘nothing about us without us’ for several reasons, including:**

- It helps us avoid replicating power dynamics that put other people in charge of what happens with someone
- It allows for individual relationships to develop naturally and more meaningfully than if already informed about someone through another person’s lens Etc.

**We have two forms of communication for the entire team – the email Comm Log and the hand-written Comm Log. Some examples of what would be in the email Comm Log are as follows:**

- Updates on trainings and meetings
- Maintenance issues
- Help with filling shifts
- Kudos for people helping out with things
- Brief explanations of larger incidents that refer people to the written Comm Log or Orange Binder for further details
- Anything people would need to know BEFORE coming on shift, etc.

**Examples of what might go in the hand-written Comm Log are as follows:**

- When someone steals from someone else (even if just a small item) in the house
- When someone puts their hands on someone else in any unwanted or aggressive manner
- When there’s any direct threat of violence made toward another person
- When someone has threatened to do immediate and life-threatening harm to themselves and is not willing to talk that through
- When someone has been using drugs or alcohol in the house (or has come back to the house noticeably intoxicated/high)
- When someone yells extensively in anger at someone else in the house\* (\* This isn’t intended to invalidate anger, but yelling/raising voices at others is not consistent with the values of the house)
- When someone is invading another person’s personal space in anger or in a sexual way
- When someone has damaged or is threatening to damage property in the house
- When someone is creating a disturbance in the house (listening to music too loudly and refusing to turn it down, repeatedly yelling or banging even if not in anger, etc.)
- When someone has been smoking in the house
- Upkeep issues happening in the space (people not cleaning up after themselves, food being left out, etc.)
- If someone hasn’t physically been in the space often during their stay
- If there is anything someone staying in the space wants everyone on the team to know
- If someone is not able to hold the values in some way
- General information about things happening on upcoming shifts (what time people will be coming to stay the next day, what time people will be coming for in-person conversations the next day, if we’re expecting a delivery, visitors, etc.)

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# Medical Emergency Guidelines

**Summary:** Overall, we avoid reaching out to the police, ambulances and other emergency responders when there is not a true emergency occurring. However, we want people working at Afiya to feel empowered to call for emergency support when there is a potentially life-or-death medical emergency.

**As much as we prioritize self-determination and avoid force, it is not consistent with the mission or values of the house for people to kill themselves there and it is okay for us to reach out for support and take action if that is happening.**

**Definition:** There are times in the house when someone might be experiencing a life threatening emergency. ‘Life threatening emergency’ should be understood to be defined as any medical issue (whether intentionally caused or not) that has serious potential to lead to death or serious injury. Examples include (but are NOT limited to):

- Having chest pains and then passing out
- Cutting one’s self deeply with bleeding that can’t be stopped
- Taking an overdose of any sort of prescription or not-prescription drugs

**Immediate Actions:** When a life threatening emergency is taking place in the house, people working in the house are encouraged to:

- **Keep in mind principles of partnership** (working with the individual directly affected as much as possible), **transparency** (being honest about your concerns, your limitations and any actions you are taking), and **continuity** (looking for a way for the connection to be continued even if they leave the house due to an emergency)
- **Consult with your co-worker, the on-call supervisor, and the person directly effected by the emergency for support and brainstorming for what to do in situations that are unclear or wherever you feel uncertain** (remembering to be transparent about any calls you are making and why)\*
- **Call 911 for emergency help in situations where the emergency is clear and any delay may have life threatening consequences** (where possible, encourage the person to call themselves and/or be a part of the decision to call)\*

**Follow-up Actions:** After the immediate emergency has been addressed, people working in the house should:

- Notify the on-call supervisor (if not already done)
- Seek support that you need to debrief (This may involve taking a break from your work day, calling in an additional team member to relieve you, a phone conversation during or after your shift, an in person debrief with another team)

# THE D.E.E.R. FRAMEWORK\*

The D.E.E.R. framework is a general guideline developed by the Western Mass Recovery Learning Community (RLC) toward supporting team members through the most difficult of times in their work.

Area of focus	What it means	Examples of what it might look like
<b>DEBRIEFING</b>	Providing team members with formal and informal opportunities to talk about what happened, both immediately after and as much as needed down the road.	<ul style="list-style-type: none"> <li>• Offering a formal, facilitated debriefing opportunity geared toward healing the trauma of what happened (such as what is offered by the Community Crisis Response Team based in Greenfield, MA) as soon after a particular incident as possible</li> <li>• Supervisors making themselves available for extra phone, text, or in-person support (<i>and</i> supervisors making time to gather and support one another)</li> <li>• Reminding everyone of the availability of Employee Assistance Program supports</li> <li>• Creating opportunities to debrief as a whole community (people in paid roles, volunteers, people who come for support, etc.)</li> <li>• Ensuring that team members have language and overall support to talk with others who might ask about what happened</li> </ul>
<b>EXTENDING</b>	‘Extending’ refers to extending ourselves and creating opportunities to connect, <i>not</i> to talk *about* any particular incident, but because connecting just to connect and being around others who have been through similar experiences is healing.	<ul style="list-style-type: none"> <li>• Creating an opportunity for a community meal</li> <li>• Setting up a team training or teambuilding opportunity <u>that focuses on team connection</u> (NOT to be confused with trainings around practical skills related to an incident, etc.)</li> <li>• Creating opportunities for group healing activities that are suggested by and/or meaningful to the team (e.g., a smudging/energy cleansing ceremony in the space where an incident happened, a creative writing/poetry group, etc.)</li> </ul>
<b>EMPOWERING</b>	‘Empowering’ refers to making space for and supporting people to take charge of their own healing.	<ul style="list-style-type: none"> <li>• Empowering team members to take additional paid time off</li> <li>• Creating access to alternative healing opportunities like acupuncture, Reiki, and Eye Movement Re-sensitization Processing Therapy (EMDR), etc.</li> </ul>
<b>REFLECTING</b>	‘Reflecting’ refers to creating honest opportunities to reflect on what happened, any role team members may have played, what was handled well and what could have been done differently, and what it all means for how the team wants to move forward.	<ul style="list-style-type: none"> <li>• Developing and using a tool that can be used routinely for any serious incidents and calls upon the team to review a situation from a number of directions</li> <li>• Re-evaluating team values, mission and job roles within context of a particular incident</li> </ul>

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## TIPS & REMINDERS WHEN IMPLEMENTING THE D.E.E.R. FRAMEWORK

- **Violence can happen anywhere.** Violence should be no more expected just because someone has been given a psychiatric diagnosis than it is with anyone else.
- **The expectation of violence can lead to violence.** It is critical that people who've experienced violence or another traumatic situation be supported to remember that violence and exposure to trauma should not be the expectation. Individuals who are consistently acting from a place of fear or need to control others are likely to contribute to future violence.
- **When considering what connection-building activities to offer in the 'Extending' portion of this approach, it's important that you be open to ideas that do not make sense to you.** People come from different backgrounds, cultures, and belief systems. What might be most helpful to them may not feel helpful to you at all, and vice versa. To support a diverse team, support offered must also be diverse.
- **Do not promote secrecy about what happened.** Many people working in this field (in any role) have experienced trauma, and the expectation of secrecy has often been a part of that. Thus, secrecy about current events can bring up old traumas and/or stunt people's ability to move through the current situation. It's far better to be open and honest about what happened, and focus on learning from it.
- **Be willing and open to look at systemic issues of oppression (psychiatric oppression, racism, sexism, transphobia, etc.) that may have played a role in what happened.** Doing so can feel hard, and is also likely to bring up feelings from a variety of directions. However, in the long run, it's also likely to support the development of a strong and health team that comes from diverse backgrounds and feels valued for that.
- **Avoid being reactive.** It's a natural human reaction to want to take immediate action to prevent future tragedy when something really awful happens. However, often the actions taken when people are in that 'reactive' place do little more than create the *illusion* of protection, and can even serve to actually make things worse/more dangerous in the long run. (For example, people can sometimes react violently in self-defense when they are forced to do something, so increasing forced treatment may be with the *intent* of decreasing violence, but a likely *impact* is to increase the likelihood of violent reactions.) It can also be really hard to undo restrictive policies and other actions taken out of fear or reactivity, even once people have calmed down and are thinking in a more balanced way.
- **Make it a regular practice to consider the team's role in anything that is not going well by integrating tools to do so in a variety of situations, not just when there's been a larger tragedy.** For example, when a team uses force (forced hospitalization, etc.) against someone seeking support, create an automatic review system to look at the team's/organization's role in what happened. Remember that people receiving services get harmed (emotionally, physically, shortened life spans, etc.) within the system with much more regularity than do people in paid roles, but that often goes unrecognized. Recognizing and valuing everyone's health and exposure to trauma – whether they are in paid roles or not – is essential to creating a healthy environment for us all.
- **Invest substantial energy and time building a values-driven approach that emphasizes the personal responsibility and mutual respect necessary to support a non-violent environment.** This means consistently being willing to unpack issues associated with power imbalances and conflict, intentionally using language that doesn't focus on control or 'power over' (e.g., avoiding terms like 'non-compliant' that are essentially 'violent' terms for the force and control they imply), developing habitual transparency and openness to learning *on all sides*, assuming the importance of choice and self-determination, and regularly measuring values and mission against day-to-day actions and choices. Environments that intentionally engage in these practices are naturally likely to be less violent.

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# Internal Review Guidelines

## *Western Mass Recovery Learning Community*

**Overview:** When there is any instance of an RLC team member using force (calling 911, etc.) or situation resulting in an incident report, an internal review will be conducted. The purpose of this internal review is intended as an opportunity to learn from the situation. If there is an employee-specific supervisory concern related to a particular incident that is also subject to internal review, it should nonetheless be kept separate from this process. The primary focus of this review will be to:

- Review and consider whether some aspect of the situation or relationship could have been approached differently leading up to the use of force/serious incident
- Review and consider whether some aspect of the situation could have been approached differently during the incident itself
- Review and consider how team and organizational values (including RLC Defining Principles, principles of Intentional Peer Support, and guidelines for being present with someone who is considering suicide as applicable) were or were not applied throughout
- Gather feedback and consider how the team might want to approach similar situations differently in the future

This review should be conducted by someone in a leadership role who was *not* directly involved with the situation in question. It should be conducted as soon as possible after the incident in question (starting no more than one week after the incident occurred). Any team member or volunteer involved (including on-call supervisors) should be interviewed, as should the person(s) against whom force was used (or who was otherwise involved) if they are willing. Other community members who were present may also be interviewed as makes sense and as they are willing.

As this report is intended for overall review and not employee-specific concerns, names should not be used in the final document. Rather, people should be referred to as ‘Employee 1,’ ‘Employee 2,’ ‘On-call supervisor,’ ‘Member of community 1,’ etc. as makes sense within the context of the situation at hand.

### **Questions for consideration during the interview process may include:**

What is your understanding of what happened?; Is there anything that happened leading up to this situation that you think was related?; Is there anything you can think of that someone could have done (or not done) to prevent this situation altogether?; What efforts do you feel like the team member(s) involved made to partner with the person they were supporting?; Was everyone involved transparent about what they were doing and going to do?; After [force], were there any efforts made to keep (or rebuild) the connection?; When everything was happening, did the team member(s) make an effort to ask questions to learn about the perspective/wants/needs of the person they were supporting?; When everything was happening, did the team member(s) make an effort to state their own needs/wants/hopes?; What are your thoughts on what could have been different? Are there any specific needs or recommendations you have for moving through similar situations in the future? (etc.)

**The final report should be documented on the attached form.**

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# Internal Review Form

**Provide a brief overview of the incident?** (e.g., *A community member was staying at the peer respite for three days. On the fourth day, she took an overdose of her prescription medications, and notified the team member on duty, stating that she was planning on leaving and didn't want them to call for help. The team member notified on-call and called 911, and was able to convince her to stay at the house. The ambulance came and she was transported to the hospital.*)

**Provide a basic key for all individuals involved** (e.g., *Employee 1: Person who called 911, Employee 2: Also present at house during incident, On-call supervisor: Notified of incident, Member of Community 1: Person who overdosed, Member of Community 2: Person also present during incident*)

**Did anyone involved identify any concerns or notable issues leading up to the incident?**

**Did anyone involved identify any clear points they feel could have been handled differently *during* the actual incident?**

**Did the team's actions appear to reflect the value of 'partnership'?** (See 'Possible Questions, Statements, & Strategies for Supporting Conversations Around Suicide' guideline even if the situation was not specific to concerns of suicide)

**Did the team's actions appear to reflect the value of 'transparency'?** (See 'Possible Questions, Statements, & Strategies for Supporting Conversations Around Suicide' guideline even if the situation was not specific to concerns of suicide)

**Did the team's actions appear to reflect the value of 'continuity'?** (See 'Possible Questions, Statements, & Strategies for Supporting Conversations Around Suicide' guideline even if the situation was not specific to concerns of suicide)



**Did the team's actions appear to reflect an Intentional Peer Support approach?** (E.g., Did they report asking questions to explore the other person's worldview, wants, needs, etc.? Did they prioritize connection even during challenging moments? Did they indicate that they were able to share their own wants/needs/etc. in the situation? See 'Core Principles of Peer Support' section in RLC Basics handbook )

**Did the team's actions appear to reflect awareness of the RLC's Defining Principles?** (Genuine human relationships; Self-determination and personal strength; Mutuality; Optimism; Healing environments; Respect)

**Did racism, sexism or any other type of systemic oppression appear to play a role in what happened?**

**Identify any recommendations for the future.** (Attach additional paper as needed.)

# Appendix 4:

# Sample Forms & Documents

The following six documents (see samples on the pages that follow) comprise the entrance packet for Afiya peer respite in Massachusetts.

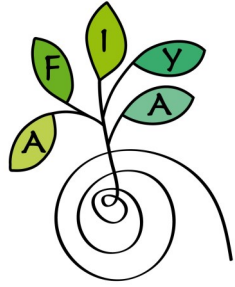
- ◇ Basic description page
- ◇ Overview of what's offered
- ◇ Entrance acknowledgement form
- ◇ Area information and resources sheet
- ◇ Preferred contact form
- ◇ Hopes for stay form

The only other document given to people when they arrive is a Health Insurance Portability and Accountability and Accountability (HIPAA) form that is required by the United States government to inform people of their rights to privacy whenever they give personal and identifying information of any kind to an organization seen as providing a health service.

Other sample forms that hold integrity to the peer approach (both related to entrance paperwork and beyond) have been included as they have been made available and with permission from the organizations that developed them.

If, when reviewing forms, you see something that you would like to use, please consider contacting that respite to talk about your plan, and make sure that you fully understand the intent and design of the form. Often, it is best to take what you learn and integrate it into your own newly developed form.

Please ***do not*** take any forms from this section and use them as is without first contacting the respite that developed them and discussing your plans.



**Afiya (A-FEE-yah)** is a Swahili word that means emotional, physical and spiritual health and wholeness.

### **Afiya's Mission:**

Afiya strives to provide a healing 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.

### **Afiya's Values:**

Afiya is a part of a larger community called the Western Mass Recovery Learning Community (RLC), and holds the RLC's Defining Principles including:

- Genuine Human Relationships
- Self-Determination & Personal Strength
- Mutuality
- Optimism
- Healing Environments
- Respect

# Welcome to Afiya!

## What You Can Expect While Staying at Afiya:

- **Your own private space** (with unlimited access to common spaces including a living room and kitchen)
- **The ability to come and go as you choose** (all stays are completely voluntary)
- **Access to basic community food items** (we have a very limited food budget, so supplementing with your own food is helpful if possible)
- **Access to visitors** (may be in designated spaces to protect the privacy of others)
- **An opportunity to rest and re-group** (while we might talk with you about a schedule that could best support your needs, you determine your wake, sleep and eating times)
- **Access to 1:1 peer support** (as well as the opportunity to connect as a group or individually with others staying at the peer respite as you desire)
- **Access to a variety of items including books, art supplies and more**
- **An opportunity to learn about and/or access local resources**
- **Uninterrupted access to your own existing supports and scheduled activities** (e.g., If you have a therapist you like and want to see or a job that you wish to keep working, you may do so throughout your stay)
- **Support to brainstorm and establish next steps for when you leave the respite**
- **Team members use written forms of communication at times to make sure they are on the same page**

## Limitations:

- **If you take medications, please be reminded that we are not able to hold or handle them.** However, we will provide you with a storage box to keep them yourself or you can have friends or family visit to help you as needed
- **We are generally not able to accommodate stays longer than seven days**
- **We do not offer any clinical services such as therapy or psychiatric services** (though we may be able to help you connect to those services if you desire)
- **We are not able to provide transportation.**

**Ultimately, our goal is to partner with you to create a healing environment through intentional peer supports and the opportunity to learn and grow.**

***Please ask if you have any questions!***

## Entrance Acknowledgement

**Summary:** Afiya is based in a residential neighborhood, .3 miles from a school and within walking distance from a supermarket, bike path and two bus stops. Because the space only works if everyone working and staying here works together, everyone staying here will be asked to review and sign this acknowledgement.

**First Name:** \_\_\_\_\_ **Last Name:** \_\_\_\_\_ **Date:** \_\_\_\_\_

By signing below, I acknowledge that:

- **I believe that a 24-hour, peer-supported environment will benefit me at this time.**
- **I have been given a copy of and understand the overview of Afiya's purpose, values and mission and am able to be responsible for my part in holding to the intent of the space.**
- **I understand that the Afiya community values respecting each other's privacy and that I am being asked to be sensitive to that and not share information about or stories shared by others staying or working at Afiya with any persons outside of the house.**
- **I understand that the standard stay at Afiya ranges from 1 to 7 nights and that during my stay I will be invited into having a conversation about transitioning out of Afiya.**
- **I understand that Afiya is primarily funded by the Department of Mental Health (DMH) and that they may, upon request, periodically review our space and documentation.**
- **I understand that Afiya strives to be scent free and that I will be encouraged to use scent-free products as much as possible while here.**
- **I understand that, although Afiya will support me to keep my personal items safe and secure by providing me with a lock box and a general house expectation that people not enter each other's private space without an invitation, Afiya and the people working here cannot take responsibility for preventing the theft of or replacing any missing or broken personal items.**
- **I understand that, although we hold the value of nothing about us without us, there are times when we use written communication with the whole team.**
- **I understand that I have a right to:**
  - ⇒ Follow my own schedule and have access to private and common spaces and community food
  - ⇒ Access peer support and resource information during my stay
  - ⇒ Leave Afiya at any time
  - ⇒ Have visitors throughout the day with limitations related only to the privacy of others and that I also have the right to refuse visitors
  - ⇒ Be in charge of any documentation connected specifically to me
- **I understand efforts will be made to work through most conflicts, but I will be asked to leave if:**
  - ⇒ I leave the space and do not make contact within 24 hours about a plan to return
  - ⇒ I bring drugs, paraphernalia or alcohol to Afiya and/or return to the house smelling of alcohol or drugs or acting in a way that significantly impacts the space.
  - ⇒ I do anything to show disregard for the space such as smoking in the house, stealing or damaging property, etc.
  - ⇒ I do anything to show disregard for the people at Afiya including yelling in anger at people, making threats, bringing weapons to the house, etc.
  - ⇒ I have medical or other needs that I am not able to manage independently or with community supports\*
  - ⇒ I am otherwise not in a place where I can hold the values and mission of the space or cannot benefit from the supports offered

\_\_\_\_\_  
*Signature*

\_\_\_\_\_  
*Date*

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# Other Information You May Want:

## Area Info:

**Neighborhood:** Afiya is located in a residential neighborhood across from an apartment complex and .3 miles from Jackson Street School. The nearest intersection is with Bridge Road only 299 feet away. Because we are on a relatively busy street just over a mile from Cooley Dickinson Hospital, you will often hear traffic which may also include sirens.

**Supermarket:** The closest supermarket is Big Y (.3 miles by foot and .6 miles by car) located at 136 North King Street. It is open every day from 7am to 10pm.

**Pharmacy:** The closest pharmacy is located at the Big Y (.3 miles by foot and .6 by car), 136 North King Street. Their pharmacy is open Monday through Friday, 9am to 7pm and 9am to 5pm on Saturday. It is closed on Sunday. There is also a CVS at 366 King Street (.4 miles away, open Monday through Friday 8am to 10pm, Saturday 8am to 8pm and Sunday, 8am to 6pm) and Walgreens at 225 King Street (about 1 mile away, open 9am to 9pm Monday through Friday, 9am to 6pm Saturday and 12pm to 6pm on Sunday).

**Gas/Convenience Store:** The closest gas/convenience store is the Pride Station at the intersection of Bridge, King and Damon Roads (375 King Street). It is .3 miles away on foot and about 1 mile by car. It is open 24/7.

**Bike Path:** We are about .6 miles from the Northampton Bikeway, a 1.75 mile paved bike path that runs from State Street through Florence and Leeds to the Look Park area. (To access, travel southwest on Jackson Street .1 mile to Gleason Street; Turn right on Gleason and travel .2 miles to Prospect. Travel .3 miles and turn right on path.)

**Bus Stops:** There are two bus stops very close to Afiya. The closest is at Hampshire Heights at the intersection of Jackson and Gleason, just 338 feet away. There is also a stop at the Big Y/Walmart plaza, .3 miles (by foot) away. You can find out more about local bus routes by going to [pvta.com](http://pvta.com) (Pioneer Valley Transit Authority), [frta.org](http://frta.org) (Franklin Regional Transit Authority) or [maps.google.com](http://maps.google.com) and selecting bus as your mode of transportation. [Peterpanbus.com](http://Peterpanbus.com) will also offer travel information for farther destinations.

**Employment Support:** There is a one-stop career center (the Franklin Hampshire Career Center) located at 178 Industrial Drive, Suite 1, about .6 miles from Afiya. Their hours are Monday through Thursday, 8:30am to 5pm and Friday 9:30am to 5pm. They offer a variety of supports for people seek jobs, training and support getting a GED.

**Library:** Forbes Library is about 2.0 miles (and a 20 minute busride) away from Afiya at 20 West Street. They are open 9am to 5pm on Monday, Wednesday, Friday and Saturday and 1pm to 5pm on Tuesday and Thursday. They are closed on Sunday.

**Banks & ATMs:** The closest freestanding ATMs that we're aware of are a Florence Savings Bank outside of D'Angelos at 388 King Street (.3 miles) TD Bank ATM at 304 King Street (.6 miles) and a Bank of America ATM at 192 North King Street, near the Walmart plaza (.3 miles). The nearest full service banks are Citizen's Bank at the Stop & Shop Supermarket, 228 King Street (about .9 miles) and Easthampton Savings Bank, 297 King Street (about .6 miles).

**YMCA:** The Northampton YMCA is located at 286 Prospect Street (.65 miles) and offers access to a variety of equipment and classes. Guest passes are available at a rate of \$10.00 per day.

*There are a variety of other stores, restaurants, entertainment and services available in the local area!  
Check in with us if you would like help finding any other resources.*

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## Emergency Services:

If, at any time, you feel that you would prefer to be in a setting that offers medical and/or clinical support, please be aware that you can contact Emergency Services 24 hours per day, seven days per week by dialing (413) 586-5555. (*This is your choice and not a call we plan to make if you are not interested in clinical services.*)

This number will get you to the emergency services offered by Clinical & Support Options in Hampshire County (where Afiya is located). Emergency Services is designed primarily to evaluate you for services at a traditional crisis respite or hospital.

## Human Rights Issues & Complaints:

You should always have the right to express any concerns or make a complaint about any service or support you receive, including at Afiya.

You are always welcome to talk to anyone working at Afiya about concerns or problems you are experiencing. However, if you would prefer to make a complaint, we have Human Rights Officers available to support you in doing so.

### *The Human Rights Officer at Afiya is:*

Ana Keck: Confidential Phone number: 413.539.5941 x 317

E-mail: [ana@westernmassrlc.org](mailto:ana@westernmassrlc.org)

### *If you would prefer to talk to a Human Rights Officer who consults to the RLC, but is not a direct employee:*

A human rights officer for the RLC and is available as needed to support people in understanding their human rights and making complaints about the RLC (including Afiya). They receive a stipend to honor their work, but are not a direct RLC employee. They are available to anyone throughout the RLC community who would prefer to talk to someone who is not a direct RLC employee.

To reach the person currently in this role use the information below.

Call Phone number: 413.539.5941 x 320 E-mail: [hro@westernmassrlc.org](mailto:hro@westernmassrlc.org)

**Please Note:** Afiya is committed to maintaining an environment that is free of discrimination based on ethnicity, sexual orientation, gender identity and expression, size or other aspect of their appearance, religious beliefs and so on. We consider this amongst your our basic human rights. A handbook will always be available at Afiya detailing your human rights according to DMH and call also be reviewed at [mass.gov/dmh](http://mass.gov/dmh).

## DPPC Complaints:

If you feel that you have witnessed or become aware of the abuse or neglect of someone (yourself or someone else) who is under 18, elderly or considered to be disabled you can report your concerns to the Disabled Persons Protection Commission (DPPC). To make a report, call their toll-free number 24-hours per day. Although they may ask you for identifying information, you are entitled to make an anonymous report.

Their 24-hour hotline is 800-426-9009.

PLEASE NOTE: Our funder requires us to offer the number for emergency services, etc. If you have questions about any of these services, please feel free to ask.



## Preferred Contact & Support Sheet:

**This sheet is completely voluntary and is only intended to make sure that you have a voice in what happens if a situation arises where you are not able to express your preferences in the moment. Complete all, none or part!** Use the backside as needed for additional space. Please write as clearly as possible.

If I become unable to express my preferences in the moment for any reason, I would like you to know that:

**I have the following community support(s) that I would like you to call on my behalf:**

**Name:** \_\_\_\_\_

**Contact #:** \_\_\_\_\_

**I'd like this person to be called if/when:** \_\_\_\_\_

**Name:** \_\_\_\_\_

**Contact #:** \_\_\_\_\_

**I'd like this person to be called if/when:** \_\_\_\_\_

**If there is a medical emergency, you should know** (any medical conditions, allergies you have or other related info that you would want us to pass on to a medical professional.):

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**If I would choose hospitalization in a given circumstance or if it is required due to a medical emergency, you should know** (under what circumstances you would choose hospitalization, if you really want to avoid hospitalization, if there's a hospital that you prefer or want to avoid, etc. *For example:* 'Although it is very rare, I have epilepsy and very occasionally have a brief seizure up to x minutes long. It doesn't require medical attention unless x and I would want to avoid the hospital.')

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**Additionally, I would like you to know that** (anything you'd like us to know about how to support you, your preferences, particular vulnerabilities, etc. *For example:* When I get really sad, sometimes I stop talking for as long as a full day. When this happens, I may not respond to you but I can still hear you. If I get to that place, it would help if you would call my friend Sally and ask her if she can come for a visit, but just sitting with me helps, too.):

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*If you have a WRAP or other plan, you are welcome to share that with us if you think it would be helpful. We can also work with you to create one if you would like. Any WRAP or other plans you share (as well as this sheet) will be returned to you when you leave Afiya!*

Name: \_\_\_\_\_

Date of Stay: \_\_\_\_\_

**Hopes for Stay:**

**Instructions:** The person whose name is at the top of this paper should be in charge of how it gets filled out. Nothing should be written below until its purpose and format have been reviewed with that person.

**Moving toward hopes, wants and/or needs\*** (include any updates you wish to note on any hopes, wants and/or needs you are moving toward. Some areas to consider may include empowerment and advocacy; emotional support; support accessing community resources; support in accessing those who can help you to develop a recovery plan; linkage or growth of involvement with natural supports and other local services):

<b>During this stay at Afiya, I hope/want/need to:</b>	
<b>I have met my own hopes/wants/needs during my stay:</b>	
	Yes   No
<b>Comments:</b>	

I have been in charge of how this form has been completed, and have been provided with a copy to take home with me.

**Signature:** \_\_\_\_\_

**Please note:** At present, our funder requires some basic planning and documentation. It is our goal to keep structured planning and documentation as minimal as possible, unless it is something that you find helpful. If there is any planning or note taking you would find helpful beyond this form, we can also work on that together and that additional documentation would be yours to take at the end of your stay.

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## Supervision Meeting Tool\*

Both people in the meeting should review and respond to the following questions at each meeting. If one or both people have nothing to offer in regards to a particular question, that is fine, but the question should at least be noted out loud and it should be acknowledged that there is no concerns or information in that area at that time.

Please also bear in mind our values as these conversations happen. Both people involved are responsible for doing their best to hold values around transparency, compassion, how they're talking to and about each other and others, etc.

1. Beyond the questions below, what other agenda items do **each** of you bring to today's meeting?
2. What are some of the contributions, strengths, etc. that you have noticed and/or appreciated about the other person since your last meeting?
3. Are there any positive interactions, strengths, etc. that you've witnessed in **other team members** (who are not at this meeting) and of which you think the other person should be aware?
4. Is there anything each of you need from the other to make your job/work/community run more smoothly or feel better supported?
5. Do either of you have any lingering hurts, upsets or concerns **with each other** that you'd like to address at this meeting?
6. Do either of you have any lingering hurts, upsets or **concerns with someone outside of this meeting** that you'd like some support on thinking through how to address?
7. Have you noticed anything (concerns and/or successes) related to the team's awareness of racism, sexism, transphobia, homophobia, classism, ableism or other social justice-related issues that you want to check in about?
8. What are you both agreeing to do/work on between now and the next meeting?
9. How did you each do with holding RLC values throughout this meeting?

\* *Although not something that needs to be reviewed at each meeting, please be sure to at least periodically talk about thoughts, feelings and hopes for future job development, personal growth, etc.*

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**Service Dog Agreement for Respite**

\_\_\_\_\_, Respite Guest, is permitted to bring his/her Certified Service Dog into Respite at the Decatur, GA Peer Support and Wellness Center (PSWC) under the following conditions.

1. Respite Guest is 100% responsible for the feeding and general care of the dog.
2. Respite Guest is responsible for cleaning up after the dog.
3. Respite Guest is liable for any damages caused by the dog.
4. Respite Guest must not leave the dog unattended unless the dog is in a crate or in the Guests' Respite Room
5. Respite Guest is responsible for keeping the dog in his/her respite room if there are any complaints of barking, perceived threats, or allergy claims from anyone present at the PSWC. If the situation is not resolved, Respite Guest is responsible for removing the dog from the premises, and possibly leaving respite sooner than planned.

I, \_\_\_\_\_, understand the conditions under which my service dog is permitted to stay with me during my respite experience.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

# **Appendix 5:** **Sample Outcome Measures**

Sample outcome measures and satisfaction surveys have been included in this section to assist other peer respite in developing their own materials.

As noted in other sections where samples are provided, it is often best to learn from these examples while still developing your own.

If you would like to use part or all of one of the samples, it is generally best to contact the respite that developed the sample to talk with them about how and why it was developed, and if there have been any changes since it was shared here.

Please do not use samples without talking to someone from the relevant respite and discussing your plan.

**AFIYA PEER RESPITE SATISFACTION SURVEY**

Please complete this survey with your last stay at Afiya in mind. Please complete it either right at the end of your stay or shortly there after if possible!

**Please note:** It is very important that we NOT receive duplicate surveys from people. (Surveys may be completed on paper, on-line or in person or by phone if requested.) **Please write, “This is not a duplicate survey” on the line below to confirm you have read and understand this!**

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1. When did your most recent stay take place? (Circle one):

**Before July 1<sup>st</sup>, 2013      Between July 1, 2013 – Dec 31, 2013      Between Jan 1, 2014 – June 30, 2014**

2. About how long has it been since your stay took place? (This will help us to interpret some of the longer-term impact questions):

**Less than one month      1-2 months      3-6 months      7-9 months      10-12 months**

3. Which of the following traditional services have you used in the past two years? (Circle all that apply)

**Psychiatric Hospital      Crisis Respite      Other Traditional Mental Health Services      None**  
*(Therapy, group home, clubhouse, etc.)*

4. If Afiya had not been available, what would you have done instead? (Circle one)

**Go to hospital      Go to traditional respite      Go to family/friend’s house      Stay home**

**Other:** \_\_\_\_\_

5. Help us understand your experience when staying in traditional settings verses Afiya. Read each statement and circle **all** settings for which the statement is true.

I felt welcomed when I entered this setting

**Hospital      Crisis Respite      Afiya      None**

I was given clear explanations and information about the space and supports available

**Hospital      Crisis Respite      Afiya      None**

People working there consistently used respectful, recovery-oriented language

**Hospital      Crisis Respite      Afiya      None**

People working there treated me non-judgmentally

**Hospital      Crisis Respite      Afiya      None**

People working there were genuinely interested in learning more about me and my perspectives, fears, challenges, hopes, wants and dreams

**Hospital      Crisis Respite      Afiya      None**

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.

**Hospital      Crisis Respite      Afiya      None**

My stay there had long lasting, positive impact on my life

**Hospital      Crisis Respite      Afiya      None**

6. Please rate each of the following on a scale of 1 to 5 based on how true the statement is (1 = not at all true and 5 = completely true. Mark N/A if you've never used that service.):

A. Overall, I was treated with great dignity and respect while in this space. (*1=Not at all; 5=Completely True*)

\_\_\_\_\_ Hospital      \_\_\_\_\_ Traditional Respite      \_\_\_\_\_ Afiya Peer Respite

B. Overall, I had a lot of freedom to make choices and really be myself. . (*1=Not at all; 5=Completely True*)

\_\_\_\_\_ Hospital      \_\_\_\_\_ Traditional Respite      \_\_\_\_\_ Afiya Peer Respite

C. Overall, my stay here was helpful, and I left feeling better than I arrived. . (*1=Not at all; 5=Completely True*)

\_\_\_\_\_ Hospital      \_\_\_\_\_ Traditional Respite      \_\_\_\_\_ Afiya Peer Respite

7. Overall, what was most helpful during your stay at Afiya? (Circle all that apply)

Just being around others      My connection with someone else **staying** at Afiya

Had privacy      My connection with someone **working** at Afiya

Felt understood      Learned new tools / coping strategies

Felt heard      Able to accomplish specific goals

Didn't feel judged      Able to catch up on sleep/eating/taking care of self

Freedom to stay connected to work/school/friends/etc. while getting extra support

Other: \_\_\_\_\_

8. What could have been improved during your stay at Afiya? (attach additional paper as needed)

If you want support in the future, would you choose Afiya over a traditional respite or hospital?

**YES**      **NO**      **NOT SURE**

Please tell us why:

9. Additional comments (If you would like to, please feel free to include a story of how Afiya has impacted you here. Although we try to keep this survey brief, longer stories are much appreciated!):

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AFIYA IMPACT SURVEY

**This survey is specifically intended for individuals who have stayed at Afiya between July 1, 2015 and June 30, 2016.**

It should only be completed 30 or more days AFTER your most recent stay at the house, as it is attempting to measure how staying at Afiya impacted you over the longer term in your life.

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1. When did your most recent stay take place? (Circle one):

**Before July 1<sup>st</sup>, 2015    Between July 1, 2015 – Dec 31, 2015    Between Jan 1, 2016 – June 30, 2016**

2. About how long has it been since your stay took place? (This will help us to interpret some of the longer-term impact questions):

**Less than one month    1-2 months    3-6 months    7-9 months    10-12 months**

3. Which of the following traditional services have you used in the past two years? (Circle all that apply)

**Psychiatric Hospital    Crisis Respite    Other Traditional Mental Health Services    None**  
*(Therapy, group home, clubhouse, etc.)*

4. If Afiya had not been available, what would you have done instead? (Circle one)

**Go to hospital    Go to traditional respite    Go to family/friend's house    Stay home**

**Other:** \_\_\_\_\_

5. Since your stay at Afiya, has your life improved in any of the following areas? (Circle all that apply)

**Housing**

**Mental/emotional/spiritual health**

**Eating habits**

**Recovery from substance use**

**Physical health**

**Relationships**

**Sleeping habits**

**Setting personal goals**

**Coping skills/tools**

**Self-advocacy**

**Less contact with police**

**Fewer hospital or crisis visits**

**Employment**

**Greater connection to community supports**

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6. Did this area improve, in part, because of your connection to Afiya?

Yes

No

Not Sure

7. If yes, describe how Afiya impacted you in that area (attach additional paper as needed)

8. Any other comments?

Please give us your opinions and impressions of your time spent at the Peer Support and Wellness Center. *All answers are anonymous.*

Date \_\_\_\_\_ First time completing this form? Yes \_\_\_ No \_\_\_

Birthdate \_\_\_/\_\_\_/\_\_\_ County of Residence \_\_\_\_\_

What services did you use? Respite \_\_\_ Wellness Activities \_\_\_ Warm Line \_\_\_ Computers \_\_\_

How many days did you spend in respite at the Peer Support and Wellness Center? \_\_\_

Before coming to the Peer Support and Wellness Center, had you ever been in a psychiatric hospital?

Yes \_\_\_\_\_ No \_\_\_\_\_

Since coming to the Peer Support and Wellness Center, have you been in a psychiatric hospital?

Yes \_\_\_\_\_ No \_\_\_\_\_

Has the Peer Support and Wellness Center prevented a psychiatric hospitalization for you?

Yes \_\_\_ No \_\_\_

Will you tell us more about this?

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How would you compare respite to hospitalization?

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What would you have done if you had not contacted us for respite? \_\_\_\_\_

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Please check. I am:

- currently employed Yes \_\_\_ No \_\_\_ \* want to be employed Yes \_\_\_ No \_\_\_
- seeking employment Yes \_\_\_ No \_\_\_ \* in supported employment Yes \_\_\_ No \_\_\_
- actively interviewing for employment Yes \_\_\_ No \_\_\_

Which part of the Wellness Center did you like the best? \_\_\_\_\_

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Which part of the Wellness Center did you like the least? \_\_\_\_\_

1. How effective was the Wellness Center toward reaching your personal recovery goals?

←—————→  
Excellent                      Good                      Fair                      Poor

2. How well did peer staff interact with you?

←—————→  
Excellent                      Good                      Fair                      Poor

What can we do to improve the Peer Support and Wellness Center?

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Do you have any additional comments, impressions, or opinions?

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(Optional)

<p><b>I am (check one):</b></p> <p><input type="checkbox"/> African American <input type="checkbox"/> Asian <input type="checkbox"/> Caucasian <input type="checkbox"/> American Indian/Alaskan Native <input type="checkbox"/> Multiracial <input type="checkbox"/> Other (please specify) _____</p> <p><b>Ethnicity:</b> <input type="checkbox"/> Hispanic <input type="checkbox"/> Non Hispanic</p>	<p><b>What is the highest level of education you have achieved (check one)?:</b></p> <p><input type="checkbox"/> High School Grad/GED <input type="checkbox"/> Some College <input type="checkbox"/> College Graduate <input type="checkbox"/> Post Graduate Degree (Masters, MD, PhD)</p> <p><b>Gender</b> <input type="checkbox"/> Male <input type="checkbox"/> Female</p>
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*The Peer Support and Wellness Center is a project of the Georgia Mental Health Consumer Network in partnership with and funded through the Georgia Department of Behavioral Health and Developmental Disabilities*

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# **Appendix 6: Relevant Research**

# EXISTING RESEARCH & DATA

There is a growing body of research in support of peer respite programs. One of the most recently completed studies was conducted by Bevin Croft and Nilufer Isvan of the Human Services Research Institute on Second Story Peer Respite based in Santa Cruz, California. As noted at the start of the Outcomes section, key results included:

*“The probability of using any inpatient or emergency services after the respite start date was about 70% lower among respite users than non-respite users. For those who used any inpatient or emergency services during the study period, a longer stay in respite was associated with fewer hours of inpatient and emergency service.”<sup>5</sup>*

## Other relevant research:

- Greenfield, T. K., Stoneking, B. C., Humphreys, K., Sundby, E., & Bond, J. (2008). A randomized trial of a mental health consumer-managed alternative to civil commitment for acute psychiatric crisis. *American journal of community psychology*, 42(1-2), 135-144. Retrieved from: [www.ncbi.nlm.nih.gov/pmc/articles/PMC2782949/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2782949/) This is the only randomized research on record in relation to peer respites, and concludes that it is “at least as effective as standard care.”
- Dumont, J., & Jones, K. (2002). Findings from a consumer/survivor defined alternative to psychiatric hospitalization. *Outlook*, 3(Spring), 4-6. Retrieved from: [www.hsri.org/files/uploads/publications/ot-03.pdf](http://www.hsri.org/files/uploads/publications/ot-03.pdf) This article, adapted from a NASMHPD Research Institute Conference presentation by Jeanne Dumont) found that “access to and actual use of the Hostel significantly contributed to healing, empowerment and satisfaction with services [But] in ...vying for continuing funds before all the results were in, the service was held to a higher effectiveness standard than pre-existing services.”
- *The Real Key We Way Story*. Retrieved from: [www.wellink.org.nz/pdf/Key\\_We\\_Way\\_The\\_Real\\_Story.pdf](http://www.wellink.org.nz/pdf/Key_We_Way_The_Real_Story.pdf) This document details the experience of a peer respite in New Zealand, and includes a brief section on statistics and outcomes. A key finding includes 100% report of positive impact on mental health from individuals who have stayed at the house.
- *Peer Support Wellness Centers Presentation*. Retrieved from: <http://bit.ly/2CosnUs> This presentation offers information about several different respites. Most notably, it includes some of the initial outcomes identified by a study of Rose House in New York State, conducted by the College of Saint Rose. Key findings included significantly higher satisfaction with Rose House peer respite over more traditional environments.

<sup>5</sup>[www.hsri.org/files/uploads/news/Peer Respites Impact on Emergency Service Use.pdf](http://www.hsri.org/files/uploads/news/Peer_Respites_Impact_on_Emergency_Service_Use.pdf)

- *Crisis Services: Effectiveness, Cost-Effectiveness, and Funding Strategies*. Retrieved from: <http://bit.ly/2CrnzNp> Includes a brief section on peer crisis alternatives that refers to at least one otherwise unpublished study of a crisis hostel (very similar to peer respite) that reported both better outcomes and lower costs
- *Afiya Peer Respite Annual Reports*. [www.westernmassrlc.org/outcomes](http://www.westernmassrlc.org/outcomes) Annual reports documenting a number of outputs and outcomes identified as Afiya Peer Respite in Massachusetts.
- Fenton WS, Hoch JS, Herrell JM, Mosher L, Dixon L. Cost and Cost-effectiveness of Hospital vs Residential Crisis Care for Patients Who Have Serious Mental Illness. *Arch Gen Psychiatry*. 2002;59(4):357–364. doi:10.1001/archpsyc.59.4.357. Looking at some of the key values found in offering community-based supports.
- Ellison, Ayla. *Average cost per inpatient day across 50 states*. Becker’s Healthcare, 13 Jan, 2016, <http://bit.ly/1164eEq> Information relevant to the cost of hospital stays in the United States.
- Stranges, E. (Thomson Reuters), Levit, K. (Thomson Reuters), Stocks, C. (Agency for Healthcare Research and Quality) and Santora, P. (Substance Abuse and Mental Health Services Administration). *State Variation in Inpatient Hospitalizations for Mental Health and Substance Abuse Conditions, 2002–2008*. HCUP Statistical Brief #117. June 2011. Agency for Healthcare Research and Quality, Rockville, MD. <http://bit.ly/2EtEX2b> More on the costs of hospital stays in the United States.
- Substance Abuse and Mental Health Services Administration. *Crisis Services: Effectiveness, Cost-Effectiveness, and Funding Strategies*. HHS Publication No. (SMA)-14-4848. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2014. <http://bit.ly/2CrnzNp> Supporting evidence of the reduced cost of peer respites.
- Thomas KA, Rickwood D. Clinical and cost-effectiveness of acute and subacute residential mental health services: a systematic review. *Psychiatric Services* 64:1140-1149, 2013. <http://bit.ly/2C8v0pD> Evidence supporting reduced cost and improved outcomes for all community-based efforts.
- Beach, MC. Sugarman, J. Johnson, RL. Arbeleaz, JJ. Duggan, PS. Cooper, LA. *Do patients treated with dignity report higher satisfaction, adherence, and receipt of preventative care?* *Annals of Family Medicine*. 2005 Jul-Aug; 3(4):331-8. <http://bit.ly/2IBngoQ> Research documenting the importance of treating people with dignity and respect.

- Bologna, Michael. Pulice, Richard. *The Impact of a Consumer Run Hospital Diversion Program on Quality of Life and Recovery: A Comparative Study*. Institute for Community Research and Training. 2008. [www.power2u.org/downloads/STUDY-QualityLife.pdf](http://www.power2u.org/downloads/STUDY-QualityLife.pdf) Research documenting the value of peer-run hospital diversion programs.
- US Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy. *An Assessment of Innovative Models of Peer Support Services in Behavioral Health to Reduce Preventable Acute Hospitalization and Readmissions. 4. Case Study Findings and Conclusions*. 2015. <http://bit.ly/2lxi7PA> Evidence of the value of peer support in reducing hospitalization rates.
- J. Duxbury. *An evaluation of staff and patient views of and strategies employed to manage inpatient aggression and violence on one mental health unit*. *Journal of Psychiatric and Mental Health Nursing*, 2002, 9, 325–337. <http://bit.ly/2lxWogu> Begins to demonstrate some links between mental health environments that lack choice and a sense of respect and aggression.



# Special thanks:

Thank you to the many people who took the time to answer incessant questions, offer input, model for photos and contribute in your various ways:

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Morgan Rhodewalt

Natan Cohen



'To Catch a Falling Sky,' by Ana Keck: [www.anastasiakeck.com](http://www.anastasiakeck.com)