A Guide to Running a Mental Health Support Group By Josh Steinberg

ABOUT THE AUTHOR:

Josh Steinberg is a sophomore at the University of Pennsylvania who plans to major in psychology and ultimately pursue a career in clinical psychology. Originally from Massachusetts, Josh was diagnosed with Obsessive-Compulsive Disorder (OCD) in 2011. After completing an intensive course of Cognitive Behavioral Therapy (CBT) with Exposure and Response Prevention (ERP), Josh was pronounced as "in recovery" by his therapist in 2014 and continues to work on symptom management and relapse prevention. For the past five years, Josh has devoted much of his free time to mental health advocacy, outreach, and research. His passion for mental health has guided his trajectory both as a student and as a community member, culminating in the advent of T.E.A.M. (Teens Engaging Anxiety of the Mind) OCD, a support group for kids and teens with OCD. The group has evolved greatly over the past few years: it started out specifically as a resource for Josh's synagogue but was then expanded to his hometown. Soon, members of all ages began to join from neighboring towns, prompting Josh to divide his original group into two: one for middle schoolers and one for high schoolers. Josh has also begun to offer the opportunity for members to Skype into meetings in certain circumstances, such as where they live far away or do not have adequate access to mental health resources at home. The following guide draws upon some of Josh's experiences running this support group in hopes of helping others to develop their own mental health support groups.

A NOTE FROM THE AUTHOR:

The following guide has been created by Josh Steinberg based purely on his own experiences serving as the leader of T.E.A.M. OCD and dealing with his own OCD. Josh is not a trained clinician and is not qualified to treat mental health issues. All of the following information has been de-identified to protect the privacy of the persons referenced herein. All information presented herein is either Josh's opinion or the conclusion of a professional in the mental health field (cited where necessary). Although you can reach out to Josh at the email address listed at the end of this guide, some questions may be more suitable for a mental healthcare provider.

INTRODUCTION:

While undergoing intensive treatment for my own OCD from 2011 to 2013, I discovered how isolating and lonely it can be to fight a mental illness in the absence of peers who are able to understand the struggle. While many of my friends at the time were entirely sympathetic, it was hard to find true empathy and understanding; I believe that if I'd had the opportunity to talk to others like me, my experience fighting OCD may have been drastically different. It is on this premise that I founded my support group. I launched T.E.A.M. (Teens Engaging Anxiety of the Mind) OCD in early 2017 to help create a supportive space and a close network of kids and teens suffering from OCD. My group follows the GOAL (Giving Obsessive-Compulsives Another Lifestyle) format developed by Dr. Jonathan Grayson, a licensed psychologist specializing in OCD treatment who practices in California. Dr. Grayson started his own group with the help of Drs. Gayle Frankel and Edna Foa in the 1980s and published his support group format in a handbook entitled "The GOAL Handbook: Running a Successful Support Group." The following text provides knowledge that I have learned through launching my support group for OCD, but much of the information may also be relevant to support groups for a vast range of mental health issues.

I. Launching Your Own Support Group

A. Selecting A Format

Support groups can take many forms and each format connotes its own benefits and limitations. Generally, support groups can be <u>curriculum-based</u>, topic-focused, or open forum. Curriculum-based groups are informative and promote wellbeing through psychoeducation; typically, curriculum-based support groups employ readings such as articles and books in their meetings. Topic-focused support groups, as their name would suggest, focus on a specific subject that may or may not be changed depending on the needs of group members. Open forum support groups are the least rigid of these main types; facilitators generally do not pre-select topics and conversations are usually free-flowing and adapt to the interests of group members. Selecting the format (and many groups are a combination of different formats) of your support group is an integral first step that will dictate not only how the group runs but also the content discussed in meetings. As I previously mentioned, my support group follows the GOAL format. This format was created specifically for OCD support groups and is very popular, especially among peer-led support groups. When selecting a group format it can be useful to research different types of support groups and which types of groups are most efficacious for the specific characteristics of your members. Additionally, it may

be helpful to reach out to a facilitator of an existing support group that may serve as a model for your own. Collaborating with other facilitators can be a great way to learn more about what format will be a good fit for your group. You can find support groups in your area on the International OCD Foundation website here.

B. Finding A Location

While what is done at a support group meeting is ultimately more important than the physical space in which the group meets, the effect of the meeting space should still be considered. When seeking a location for your support group you should evaluate some essential aspects of what makes an adequate meeting space. First, it is important to secure a space that is private. If you would like to conduct your support group in a public building like a place of worship or a library, you should ask to use a private room where members can feel comfortable sharing aspects of their personal lives without risking being overheard by passersby. Additionally, the space should either be free or reasonably priced to rent (charging members to attend meetings in order to pay for use of the room should be avoided if possible). I have found that if you explain that you are looking to host a support group to an appropriate staff member at a library, town hall, place of worship, or recreation center, they are often happy to accomodate the group free of charge. Finally, the meeting spot should ideally be convenient and accessible for all members. While finding a universally convenient meeting location may be hard for larger groups, leaders of smaller groups should attempt to accommodate members who are coming from far away by finding an equidistant meeting location.

C. Advertising To Potential Members

Effectively advertising my support group and recruiting members was, and continues to be, one of the hardest parts of the process. Due to social stigma surrounding mental illness, insufficient methods of reaching potential members, and the typical daily hardships that make consistent attendance difficult for members, I often struggle with recruiting members to my group. A related challenge I've encountered is needing to adjust my plan for a given meeting's agenda when actual attendance ends up being lower than the attendance I had expected. However, there are steps that I have taken that I've found very helpful to address some of these challenges.

One of the first steps that I took to advertise my group was to reach out to the International OCD Foundation to get my support group listed on their website in the Resource Directory. Having your group listed as a resource on the appropriate advocacy organization websites will help potential participants find your contact information and reach out regarding the group. This has been the most useful advertising method for my support group. Additionally, I found it can be helpful to create fliers and distribute them in your community in public spaces and on bulletin boards in restaurants and stores. Furthermore, I found it useful to reach out to local therapists specializing in treating the disorder of interest to make them aware of your group and ask them if they would be comfortable recommending it to members who could benefit from attending. Finally, it may be helpful to reach out to school counselors or administrators to make them aware of your group so that they can choose to pass information along to students who may need support and/or their parents.

As a general matter, recruitment is an ongoing process for support group facilitators and the best, yet most basic, advice that I can give is to get the group's information out to the most people possible in such a way that targets the population of interest. This usually entails being outgoing and assertive by making coldcalls and reaching out to individuals and institutions with larger networks than your own. Fortunately, I have found that most people tied to the mental health field are more than happy to help you find members. Because it is often difficult for providers to find appropriate support groups for their patients and for patients to find them on their own, any proactive advertising that you can do will go a long way.

A more in-depth discussion of how to handle members who do not consistently attend meetings despite having committed to the group can be found below in the section pertaining to communicating with members.

II. Group Topics

A. Selecting Topics For Group Meetings

While not every type of support group will have a specific topic, let alone a rotating schedule of meeting topics, it is important to have a general idea of the scope of topics that your group will cover. For example, even if your support group's format is open forum, will you entertain conversations regarding medications?

Will you steer conversations toward topics that are more directly relevant to the disorder of interest or let any topic be discussed? If your group's topic is a specific disorder like OCD, how will you handle members who have comorbid diagnoses? Will you discuss topics relevant to all stages of treatment or just remission? While there is not necessarily a correct answer to any of these questions, I have found it helpful to make the expectations of the group as clear as possible both to myself and to members from the onset. For example, in the case of my support group specifically, I am always sure to inform group members that the group is for people suffering from OCD at all stages of treatment and try to make my weekly meeting topics as relevant as possible to members regardless of their stage of treatment. In the past, the group has discussed the following topics that typically span the course of treatment: the therapeutic alliance¹, guilt, handling slips, communicating with family members, stress, advancements in OCD treatment methodologies, and more. It can also be helpful to research potential topics prior to meetings and survey members to determine topics of interest.

B. Conducting Research On Meeting Topics and Incorporating Outside Sources

Even if the purpose of your group is not specifically psychoeducation, it is important to base discussions on a combination of research, expert opinions, and anecdotal evidence (I will be discussing the role of the facilitator's personal experiences in support group meetings below). Incorporating research into meetings, if done correctly, can be a powerful supplement to personal, and thus inherently subjective, discussions. Research findings should be sought out prior to meetings and map on effectively to the relevant topic. I have found it is most appealing to members if group leaders incorporate research to facilitate discussion, rather than exclusively present research when leading the group. This way, especially in support groups with children and adolescents, members will remain more engaged due to the personal relevance of the sources you provide. More importantly, research articles can often serve as a method of validating members' individual experiences by demonstrating that a phenomenon is being actively investigated, understood, and taken seriously by impartial professionals. Additionally, research may inspire hope among group members by showing them that mental health issues are being studied with the goal of improving the quality of life for sufferers.

¹ To learn more about the topic of the therapeutic alliance, consider reading further here.

Additionally, it can be helpful to sporadically incorporate op-eds and other more informal pieces found online into group meetings. Finding a strong voice that can eloquently articulate a complex issue can help members make sense of what they are experiencing and pick away at some of the isolation that often accompanies suffering from mental disorders. Furthermore, discussion of opinion pieces can help to facilitate a conversation regarding differing perspectives on mental health issues.

I usually like to begin support group meetings by introducing the topic, defining any potentially unfamiliar terms, and asking some conversation-guiding questions. From there, I like to present some handouts to group members and give them some time to read independently. For example, at a recent meeting I brought in an article from Psychology Today explaining the week's topic of the therapeutic alliance as well as a research publication on the topic. I asked members to read through the first article and then I summarized the findings of the research before asking members to share their initial thoughts and reactions. Usually, if the topic is relevant to members, readings will spark a relevant conversation that picks up well on the original guiding questions.

III. Conducting The Group

A. Creating A Welcome Handout

A welcome handout can be a great resource to create for your group to give members a better sense of the format, logistics, and potential topics of your support group. Welcome handouts typically include information regarding meeting times and locations. Additionally, these handouts may provide information regarding the rationale of the group's design and give some information regarding member expectations. I have adapted a handout that was offered by the creators of the GOAL format for my group, which can be found <u>here</u>. If you are using a support group format that has been created by others, I recommend searching for resources online relating to creating a welcome handout.

B. Creating An Emergency Contact Sheet

It is prudent to create an In Case of Emergency (ICE) Contact sheet for group members. This can be as simple as creating an Excel spreadsheet with a column for name, age, phone number and email (both for the member and their contact), and the member's relationship to their emergency contact. I have attached a sample version of an ICE spreadsheet <u>here</u>. You can ask new members to fill out this sheet at their first meeting to ensure that you have a course of action should an emergency situation arise. However, an ICE contact may not always be an appropriate substitute for contacting local authorities in the unlikely event that a member is in need of emergency assistance.

C. Ensuring Privacy And Confidentiality

The best way to ensure members' privacy and avoid breaches of confidentiality is to minimize the amount of personal information that is collected and shared at and in between group meetings. A practical step that is easy to implement is asking group members to introduce (and refer to) themselves with only their first names. Regarding ICE contact sheets, group leaders should be sure to restrict access to members so that only the facilitator can see the information. If group leaders want to send emails to group members all at once, they should send the email to themselves and BCC (blind carbon copy) members to maintain their privacy. Also, each member should be made aware that discussions during group are to remain confidential and not discussed outside of the group at their first meeting; reminders of this policy should be given sporadically.

D. The Role of Personal Experiences When Conducting A Meeting

It is not uncommon for support groups to be peer-led given the personal nature of the topic at hand. As a result, group facilitators may have personal experience with the disorder which the group targets (such as in the case of T.E.A.M. OCD). Therefore, facilitators may have a breadth of personal experiences that they can employ in order to better connect with and help members. However, it is important for facilitators not to grandstand or become overly liberal in doling out advice and life lessons based on their own experiences. I have found that the best way for me to toe the line in this respect is to view myself as merely a senior member of the group. This means that beyond organizing the group and selecting meeting topics, I take a relatively unassuming role in groups. Yes, I of course steer conversations and ask guiding questions, though I try to let the other members sway discussions as much as possible since meetings are supposed to be about the members of the group and what is most helpful to them. Specifically, once a conversation is off the ground, I contribute only when necessary (i.e., to break an awkward or prolonged silence, or to steer

us back on track if we digress too much) or when hearing a personal anecdote may be helpful for others. I have found that this style allows the group to develop the most natural conversations possible and helps ensure that discussions are personally relevant for group members.

E. The Non-Role of Therapy In Support Groups

By definition, support groups are not therapy; support groups are a special resource for those with mental health issues because they can provide a safe, open space for people to share and connect with others while supplementing their own course of psychotherapy. Therefore, group leaders do not need to be licensed therapists. This presents an opportunity for groups to be run by a peer who may have some insider knowledge of a specific psychological disorder or a professional in the mental health field. If the group leader is not a licensed clinician (as is the case in the group that I lead), then group members may be more apt to share their thoughts about therapy; specifically, members may be more likely to share their doubts about therapy with peers as opposed to their treatment providers (and thus have them be addressed by other members). I believe that T.E.A.M. works well for its members because it provides a unique opportunity to destigmatize OCD and reduce the feeling of isolation that is common among those who suffer from psychological disorders. By not incorporating therapy into meetings, the environment feels more relaxed and collaborative.

F. The Role Of Parents and Siblings In Support Group Meetings

Some support groups are geared toward those directly suffering from a given disorder, some are for their loved ones, and some are directed toward both of these populations. In addition to selecting a clinical population of interest for the group, it is important to explicitly understand in your own mind, and make clear to participants, for whom the group is intended. My support group is specifically designed for children and teens who suffer from OCD (I have split my group into two different age groups of 8-13 and 14 and older). Therefore, in this case it would not be appropriate for a parent to consistently sit in on meetings; this may interfere with the group dynamic by making other members uncomfortable. If you plan to create a support group solely for the clinical population (i.e., not their parents, siblings, and/or friends), it is important to anticipate that some loved ones may want to sit in on the first meeting or two. This issue has arisen a couple of times in my experience, and I am typically apprehensive about permitting parents to sit

in on group meetings because it could make members uncomfortable if they aren't expecting this change and could result in them feeling embarrassed about sharing personal aspects of their struggles with those who they perceive as unable to understand their challenges. If this comes up in your group, I would recommend talking with the parent and/or the child that brings it up privately prior to a given meeting, or even every meeting, to give them a chance to voice concerns and ask questions. Additionally, reiterate to the loved one that, as advertised and explained to the members at the time of joining the group, the group is not intended for family and friends. You can even elaborate on some of the considerations above to explain why the presence of family members could be counterproductive. However, be sure to always be respectful and offer to help them find a resource that would appropriately serve their needs.

It may at times be appropriate to invite friends and family to group meetings if the topic is relevant to them (i.e., how to communicate with family members) but make sure to give members ample notice if you intend to host a meeting like this so that they can freely voice any objections or decline to attend the meeting in advance.

G. Allowing Time For Socializing

This step is fairly straightforward: you should decide the role that informal socializing will play in your support group. Following the style outlined by the GOAL format, I try to allow the last few minutes of every meeting to serve as a time for socializing. By allowing for socializing in your group (whether this occurs naturally throughout the meeting or time is formally carved out at the beginning or end for chatting), you are allowing members to get to know each other and develop a bond. As a result, members will feel more comfortable in the group setting. Additionally, socializing enables one of the key aspects of a mental health support group to occur: the elimination of social isolation by means of showing members that they are not alone in their struggles.

H. What To Do When Members Consistently Elect Not To Contribute

One of the most challenging aspects of running a successful support group is creating an environment where group members feel comfortable enough to share what they are thinking. In an ideal world everyone who comes to support group meetings would be equally willing to share their own ideas and listen to others. However, many members are apprehensive about sharing their personal experiences and thoughts as a result of shame, fear of judgement, inability to articulate a complicated concept, or difficulty connecting with the facilitator or other members. If this happens in your group, first off, you should never pressure a member to speak at meetings. This will make them uncomfortable and less likely to share of their own volition in the future. Additionally, it can be helpful to keep in mind that support groups by their very nature do not require participation of all members right from the onset. In fact, many members require attending a few meetings before they are comfortable enough to contribute openly to the group. I have found that the best way to foster an environment in which members are comfortable speaking openly is by beginning conversations myself, asking specific questions, and sometimes posing multiple choice answers to my questions.

Usually, after an opening icebreaker activity, I begin meetings by explaining the topic of the day in as simple a way as possible, and asking for very general impressions of the topic at hand before moving into a broad discussion of any outside source that we may be discussing together. By making the opening conversational prompt open-ended and digestible, I've found that members can simply spitball ideas, flexing their abilities to converse with the group, and acclimating themselves to sharing their thoughts until something sticks.

If and when this method fails (as it often does in my group for younger kids), I ask increasingly specific questions that more directly guide the conversation. In a support group meeting on the therapeutic alliance (the relationship primarily based on trust between therapist and client), the process may look something like this: I begin with general remarks about the concept (i.e., providing definitions and the implications of the topic on the lives of those with OCD) as it may be a new term to some members. Next, I hand out a reading on the topic and ask for the members' general impressions (e.g., what caught your eye while reading this? Did anything surprise you?). If participants are hesitant to respond, I would then ask a more concrete question such as "based on this reading, do you think that the therapeutic alliance or the specific type of therapy conducted in a session is more important?" Thus, it can be helpful to generate a list of potential questions (even if they are yes/no or multiple choice opinion questions) to ask members in advance if the conversation cannot carry itself on its own or is slow to get started.

I. Handling Difficult Topics

It is almost inevitable that some topics that are challenging to discuss will arise at a mental health support group. For instance, a member may appear to be—or indicate that they are—in crisis during a meeting. Crises are better left to be handled by professionals; thus, in most cases, the role of the support group facilitator will be to provide resources to the person in need if a crisis arises. If it seems a member is in need of more help than what can be reasonably provided in a support group setting, use your judgment in deciding how much time to devote to this member's struggle during the group. I would recommend thanking them for sharing and offering to speak with them after the group ends, keeping in mind that peer support groups are better suited for longer-term support rather than crisis intervention. When speaking with the member after group, recommend that they seek professional help and share appropriate resources with them. The following links may be useful to share with individuals in crisis:

- National Suicide Prevention Lifeline.
- The National Domestic Violence Hotline
- The National Sexual Assault Hotline
- Crisis Text Line

IV. Additional Tips From The Author

A. Making The Group Fun

A support group is not a form of traditional psychotherapy, even if the group is being run by a licensed therapist. With that in mind, the group environment will work best if the leader creates an environment that is respectful yet relaxed. An easy first step at the beginning of each meeting is to open with an icebreaker activity, especially if new members are present. Support groups should allow members the space to express themselves and interact with peers in a semi-structured environment that allows for open conversation surrounding a formally selected discussion topic. In my group, I often encourage members to not be afraid to veer away from the topic if they would like to discuss a tangential topic. Additionally, the use of humor and refreshments are great ways to ensure that members are comfortable and continue to come to meetings!

B. Seating Arrangements

I conduct my support group in my town's library and have minimal control over the general setup of the meeting space. However, I always arrive at the meeting space a few minutes early to ensure that there are enough chairs for the members and that they are arranged in such a way that all members can see one another; the best way to do this, I've found, is to make a circle of chairs, whether around a table or not. If you are going to meet in a larger space, encourage members to move in as close as possible to encourage participation.

C. Effectively Communicating With Members

When running a support group it is important to communicate consistently and clearly with members (and/or their parents if the members are minors). By communicating regarding logistical items as well as simply taking the time to check in to see how the members are doing in between meetings, you will demonstrate that you are a conscientious facilitator, thus making members more likely to benefit and want to keep coming back. Personally, a couple days before a meeting, I like to send out email reminders to group members (and/or their parents) to provide information regarding the meeting time, location, and topic. Additionally, to combat the common occurrence of members telling me in person, at a meeting, that they plan to attend the next meeting and then not showing up, I like to ask for an RSVP one to two days in advance of each meeting to get more updated numbers and hold members accountable for their attendance. I also always encourage them to reach out to me with any questions that they may have. I have found this type of proactive communication helps me foster strong relationships with the members.

V. CONCLUSION:

A. Summary: Action Steps

Because this guide covered a wide array of information I have attempted to synthesize some of the above information into some concrete action steps (based on the order that they appear in this guide, not necessarily indicating a specific chronology in which one should complete them) that may be helpful to follow when creating and facilitating your group. The following are simply short-hand notes to make the process easier; I recommend that you refer back to the more fulsome sections in this guide for more specific information:

- Determine the format of your group (potentially by talking with other group facilitators), including aspects such as the role of socializing and psychoeducation. You should also determine which clinical population(s) your group will serve as well as the age range of your members.
- 2. Find a suitable location in which your support group can meet.
- 3. Advertise your group in the community though flyering, word-of-mouth referrals (i.e., connecting with therapists, school counselors, etc.), and online postings.
- 4. Research the issues that your clinical population(s) often experience and then brainstorm some potential relevant topics and guiding questions to be discussed at meetings. Make it clear to members that some topics are not appropriate for the group setting.
- 5. Explore the group's topics further by selecting relevant research articles and op-eds to share with group members.
- 6. Create a Welcome Handout.
- 7. Create an Emergency Contact Sheet.
- 8. Establish clear guidelines for your support group to ensure confidentiality for your members.
- 9. Be wary of the overuse of personal experiences when conducting a support group meeting; use any personal experiences to guide discussions, but remember that the group should be about the members, not just the facilitator.
- 10. Create an environment different than what a member would experience in traditional therapy by emphasizing an atmosphere that is relaxed and relatively casual.
- 11. Make clear the role of parents, siblings, and friends in your support group. For example, if your group is not intended for parents, it would be inappropriate for a parent to observe or participate in meetings.
- 12. Allow time for socializing to foster friendships between members.
- 13. Encourage quieter members to contribute to the dialogue by changing your method of prompting discussion, not by pressuring them directly.
- 14. Be aware of important crisis management resources at your disposal in the event of an emergency situation.
- 15. Make the group fun for members by encouraging members to express themselves openly without fear of judgement. Snacks help too!

- 16. Create a seating arrangement that encourages open discussion and participation in meetings.
- 17. Communicate with your members (and/or their parents) via email regarding the support group.

B. A Final Note

It is my sincere hope that you have found this guide to running a support group helpful so that you may seek to serve the mental health needs of the members of your respective communities. Please feel free to contact me personally with any questions or comments about the content of this guide at <u>mentalhealthguideinquiries@gmail.com</u>.