

Roadmap to Peer Support

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A. About the Roadmap to Peer Support

This roadmap offers general guidance on how to build and maintain a peer support program. Peer support programs help connect people who are dealing with certain health problems or situations with other trained peers (often called peer supporters) who have dealt with similar challenges. These programs bring together people so they can share experiences and support one another. Programs may be started by an organization, a group, or an individual person. Those who may find this roadmap helpful include:

- Researchers and program developers
- Health care and community leaders
- Health care and public health professionals
- Advocacy organizations and groups that actively support the interests of consumers and patients
- Patients, family members, and other caregivers

Development of the Roadmap

This Roadmap is the result of a two-year project funded by the Patient-Centered Outcomes Research Institute (PCORI). The purpose was to learn what is needed to make a peer support program work and to compile a general how-to guide to start and run a program. The project team included researchers, patients, family caregivers, peer support program leaders, health care leaders and workers, consumers of health care services, and patient and family advocates. To begin, the project team partnered with seven well-established peer support programs in the United States. These programs are well-known, diverse in the problems for which they provide support, and based in health care or community settings. The project team looked at (1) program structure, how programs are organized, and who is involved; (2) how peer supporters are recruited, trained, and supported; (3) how peer support is provided; and (4) success stories and potential challenges, and how these could be addressed.

To develop the Roadmap, the researchers on the team started by interviewing partner program leaders and persons giving and receiving peer support. Program handouts and materials were reviewed and results of the interviews were studied to decide what information should be included in the Roadmap. A national workshop was then held with program staff and volunteers from the partner programs and other people who were interested in starting peer support programs. Key questions about peer support and ideas about what needed to be included in the Roadmap were discussed by workshop participants. The project team used a collaborative process to draft, review, and revise the Roadmap contents, repeating this process until the contents were approved.

Rationale behind the roadmap

This roadmap was developed to guide people working in research, healthcare, and communities in forming peer support programs, and preparing peer supporters within the programs to provide peer support. Studies show that support from a peer may help a person to cope or deal better with problems, and equip or encourage them to do things that could improve their health and outlook on life. However, peer support programs are still not widely available and have been limited to a small number of health problems or situations.

Potential benefits of peer support

Potential benefits for a person seeking support are finding another person in a similar situation who has “lived the experience,” and being able to talk with them in a safe and judgement-free setting. People receiving support say they highly value a peer supporter who is a “living example,” of someone who has “been there” and has personal experience with the challenges they face, someone who is living proof that people can live well with, or despite, the underlying issue.

Peer support may provide people receiving it (referred to in this Roadmap as program participants) with:

- Practical information and advice about managing their health problem (or situation) and how to live with it. This type of information and advice may not be provided by health care professionals or may be more easily received from a peer.
- Hope and less isolation.
- Insight about what may lie ahead.
- Someone who takes the time to listen and understand.
- A sense that what they may be feeling or going through is normal (or expected).
- Information about services in the community.

People giving peer support may experience special benefits as well. These include:

- Feeling good about giving back and being part of something that matters.
- Feeling stronger and having more faith that they can deal with hard times.
- Improving social skills, such as good ways to communicate and encourage others.
- Remaining engaged in a peer support system that promotes recovery and well-being.

Family caregivers and friends may find many of the same benefits from peer support as their loved ones (program participants) and may also benefit from peer support programs if these provide:

- A local resource of materials, information, and education to better understand potential options and insight into what may lie ahead.
- A way to connect with relevant community services and with each other for emotional support.

Peer support programs can also help health care professionals by endorsing the advice or guidance that they have provided (for example, lifestyle changes, sobriety, etc.) helping motivate program participants to adopt their advice.

How you can use this roadmap

This roadmap may serve as a general guide for anyone who wants to start a peer support program. There are different ways to start and run a peer support program. This roadmap organizes the work involved into four parts: plan, implement, assess, and sustain. You may want to review and use all parts or just the sections that are helpful now, coming back to the roadmap as your program changes and grows. You may not have all four parts planned or outlined, and you may do some things differently, but the roadmap can be a reference with suggestions when you need it. This roadmap includes guidance from seven established programs. They all started small and grew to meet the needs of their participants and community, adding pieces included in this roadmap when they were ready.

The Four Parts figure depicts the four parts for building a peer support program and key points to consider within them. More details are included in the corresponding sections. The roadmap also includes sections on Tools and Resources, Peer Supporter Training, a Glossary, and a section describing the Partner Peer Support Programs.

Four Parts for Building a Peer Support Program

Below is a basic outline of information you will find in each part the Roadmap for building a peer support program. Go to each section for more details.

PLAN

Preparation

- Assess the need for a program
- Learn more about the target organization or community
- Secure “buy-in”
- Initial decisions in getting started
- Develop a start-up plan

Planning for program activities

- Program goals
- Program approach, scope, and content
- Program delivery (personnel, matching)
- Communicating about the program
- Potential challenges and how to address

IMPLEMENT

Program policies and procedures

Program leaders

- Roles and responsibilities
- Background, experience and preparation of the leader
- Motivation and inspiration

Peer supporters

- Role and experience as a peer supporter
- Providing support for peer supporters
- Core skills/competencies
- Recruitment and retention
- Orientation/Training

Building successful relationships with program participants

ASSESS

Assessment of peer supporter orientation, training and follow-up support activities

- Quality of peer support services
- Experiences of peer supporters in the program
- Outcomes of the overall program

SUSTAIN

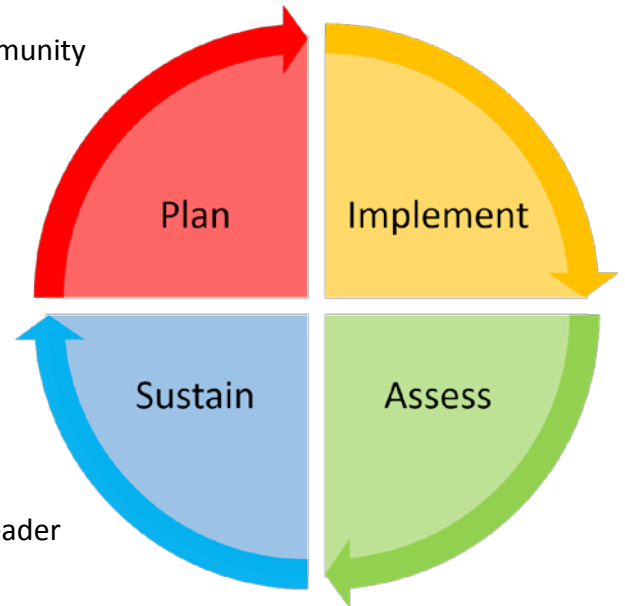
Financial sustainability

Organizational capacity (maintaining leaders, staff, volunteers and program champions)

Adaptability/flexibility

Evaluation methods (including consumer feedback/success stories, adherence to best practices)

Following the program guide and recommended guidelines and standards



B. Plan

Preparation

Assess the need for a program

To begin, make sure that there is a need for the program you have in mind and that you are not duplicating available services. Search the internet for similar programs and talk to the leaders who run these programs to find out if a program is needed. Ask people what they need and what they believe the program should offer. At this stage, it is important to think about **how you can engage people in your program and give them what they need so they stay engaged over time.**

Parent Connection learned about a need for postpartum support from registered nurses who said they were getting calls from new mothers after they left the hospital.

While defining your program, describe how program participants, or potential participants, may be helped by peer support. Keep in mind that some participants might only have a vague idea of what type or amount of support they want. Here are some examples:

- They may want to feel less stressed, or not feel alone and isolated by their problem or circumstance.
- They may want lasting relationships or a sense of community, a person who listens to them, or a place to feel safe and fully accepted.
- They may want information and resources to help them with health or other issues.

Continue to get potential participants' input in the planning stage with the aim of ensuring they have the best possible experience once the program commences.

Find key people who may benefit in a more general way from your peer support program and ask their advice about starting a program. People you may want to seek out, depending on whether your program starts in a health care facility or a community setting, include:

- formal or informal leaders in the organization or community who influence or make decisions; for example, clinicians in a health care organization, or leaders of a community-based program
- people who can relate to the problem you want to address; they may be clinical or non-clinical, and vary in education and experience
- leaders who see themselves as change agents, are interested in supporting your program, and can link to resources within an organization or in other partner organizations
- other experts within your organization who can help, such as a person in the budget or communications department

Learn more about the target organization or community

When building a program learn about the beliefs and practices of the organization or community where the program will be based to ensure that these are aligned with peer support. Read their mission or vision statement to make sure it matches your proposed

program. For example, is their statement consistent with the population you want to serve and the goals you want to achieve?

When planning for a new program, you may find the **SWOT** analysis approach useful. **SWOT** stands for **S**trengths, **W**eaknesses, **O**pportunities, and **T**hreats. This involves asking the following questions:

What strengths in the organization or community can help your program? (Examples: a meeting space; access to personnel; access to other potential partners in the community or organization or to their networks)

What weaknesses in the organization or community will you need to consider? (Examples: no place to store program materials; too far away)

What opportunities in the organization or community can help your program? (Examples: upcoming health fair at a community center; a clinic looking for a place to refer patient; the site will assist with outreach through their networks, members or partners)

What threats or challenges to the program are in the organization or community? (Examples: persons opposed to the program; shortage of resources; safety; lack of transportation; potential to be viewed as competition)

Secure “buy-in”

Step 1: Compose a short, clear description of your program and list the reasons why peer support may be needed.

Step 2: Determine who the key people are within the organization or community where you want to base your program. Think who may be affected by or interested in your program. Plan to meet them.

Step 3: Prepare for your meetings by gathering information or materials that detail the potential benefits of peer support. Here are some topics that may help you make a stronger case for starting your program:

- existing need for peer support
- lack of programs in your area
- aligns with organizational values and beliefs
- builds on existing organizational strengths and fills a gap in services currently offered

Initial decisions in getting started

Who will “own” the program and run it?

Find the department in the organization or community group that can potentially benefit from this program, and are able to offer administrative support, hands-on help, access to volunteers, or low-cost assistance.

Who will develop the program plan?

Try to form a team to help develop the program. Include potential program participants and their family members to offer input on what is needed as well as business-minded people to compose the business plan.

What format of peer support will be used?

There are many types of peer support (see the sub-section Program Approach, Scope and Content).

How will the program be paid for?

Peer support programs can be funded in a variety of ways. You may wish to search for grants and donations, possibly from local or state sources, such as the Department of Health or the Department of Education. Ask for small amounts of funding to start-up and show that the program really works. Use any potential success to encourage additional funding.

Example: *National Alliance on Mental Illness (NAMI)* – Many NAMI organizations look for private grant or governmental funding that is tied to the specific peer program. Most NAMIs seek unrestricted financial support (not government-related) to sustain their activities. This can include joint fund raising events such as walkathons. Most depend on individual donations including annual campaigns, workplace giving (such as United Way), and support from peers who have benefited from free NAMI programs.

All NAMIs seek in-kind and financial support by developing relationships with local community organizations, such as boys or girls clubs, faith congregations, or behavioral health providers. Some programs are completely volunteer-based with little funding; for example, those who partner with churches to host meetings.

Example: *Parent Connection* – Nurses at Beth Israel Deaconess Hospital discovered that more support was needed for new mothers. They applied to a grant program funded by proceeds from the hospital’s gift shop and received funding for one-year. During this period, they were able to collect data that showed the potential impact of the program. After the first year, the obstetrics department paid the social worker’s salary and the hospital paid the program coordinator’s salary.

Develop a start-up plan

Develop a plan	A simple business plan may work. Involve all team members (see <i>section d.</i> above) in composing the plan. Have key people review the plan and give input. Remember to include potential program participants.
Create a timeline	Decide on a realistic start-up timeline with milestones. Add projected dates to finish major pieces of the plan and assign a team member to each piece.
Create a budget	Create a simple budget (there are examples and templates that you can find on the web)
Plan to build relationships	Plan to build relationships and develop a process for input and support; both of these are high priority for a program in its early stages.
Motivate and engage key people	<p>If your program will serve people receiving health care, connect with a few nurses and physicians who take care of these patients and who could potentially benefit from your program. For example, in <i>Parent Connection</i>, the nurses refer new mothers to the program; the success of the program is dependent on this referral by nurses and other hospital staff.</p> <p>If your program is going to work with individuals of a particular target demographic (and/or their families), make sure you connect with groups that actively engage with, or are made up of key people from those demographics. For example, NAMI Maryland works with leaders in different faith and ethnic communities, veteran-serving organizations, and civic, fraternal and professional organizations.</p>
Communicate	Establish a communication path that flows back and forth to ensure that everyone is kept informed. Even small programs need a process to keep everyone involved. This practice may help with developing and maintaining a good quality program.
Plan for the future	<p>As part of your start-up planning, think about the long-term goals for the program. Invite everyone to contribute. You can seek diverse input from :</p> <ul style="list-style-type: none"> • people seeking peer support • professional experts or people with a business or human services background • patient- and family-centered care experts <p>This approach may produce new ideas and help with the development of the program.</p>

A process for when and how to spread the word should be included in the start-up plan, and mapping it on a timeline may be helpful. Questions to consider as you plan how to spread the word about your program most effectively may include:

- When will you be ready to get the word out?
- When and how will it be disseminated?
- Who are the key groups to target?
- What content should you relay and to whom?
- When and how should you relay this information?
- Are you able to respond to questions? If not, who will do this?

Planning for program activities

Program goals

Once the purpose of the program has been outlined and the need identified, write clear concise action-related goals. This will help you measure your progress over time. The goals may be based on the guiding principles and purpose of the organization, values and beliefs of the community, or the need for the program.

Here are a few examples of what some programs include in their goal statements:

- Help individuals and their families better cope with the illness or other difficult situation
- Connect people seeking support with a peer supporter who has similar experiences
- Fulfill requests for information and share stories of personal experiences
- Provide emotional and social support
- Provide peer services for individuals in a specific community.
- Offer practical daily living strategies from people in similar circumstances

It is helpful to write down a few action-related goals. These will help people involved in the program (or interested in it) understand what to expect from the program. There are a number of resources available online to help create clear and concise goals, such as SMART goals.

Program approach, scope, and content

Peer support can be provided using group or one-on-one support. The support can be guided and structured with planned discussions on specific topics, or be more free-flowing with flexible conversations that follow the interests of program participants. To meet the needs of the people you plan to serve, it is important to look at the benefits and limitations of these approaches.

Various program approaches are summarized in the Table below. Some programs offer multiple services using various types of approaches.

	Benefits	Limitations
Guided approach	<p>A main topic or theme can help keep the discussion focused, positive, and solution-oriented (participant may get more out of the conversation)</p> <p>May help peer supporters to follow the program requirements.</p>	<p>It may feel like a lecture. To avoid this, deliver content in an engaging manner. For example, invite participants to talk and share their story.</p> <p>Program leaders will have to spend time developing and periodically reviewing content.</p>
Flexible approach	<p>Program participants are free to ask any questions, share any concerns, or talk about resources offered through the program or in the community.</p> <p>The schedule is usually driven by what works best for the participant. (Some programs have a set number of sessions or a defined length of time for the peer supporter and participants to interact.)</p>	<p>Peer supporters need to be able to respond to a wide variety of questions about situations they may not have personally experienced.</p> <p>Program leaders will need to supply additional resources to help the peer supporter feel better prepared to help participants.</p>
One-on-one support	<p>May work well when the participant has specific needs.</p> <p>A participant may feel more comfortable sharing their thoughts and feelings with one individual than with a group</p> <p>The peer supporter and participant can build rapport over time and that may help the supporter better understand the emotional state of the participant.</p> <p>May offer more flexibility in how support is provided (telephone, in-person, email, or text).</p>	<p>Peer supporters or participants who want in-person meetings may find it challenging if they live in different towns, or even in different areas of the same city.</p> <p>Matching two people with similar experiences could prove challenging.</p>
Group support	<p>Members working through similar problems can share experiences, encouragement, and provide tips and resources that might help each other.</p>	<p>Participants may feel uncomfortable or unwilling to share their story in a group</p>

	Benefits	Limitations
	<p>The group format may bring a sense of community to participants showing that they are not alone, and that others have been where they are now and understand how they feel.</p> <p>Participants who are there to get their needs met may also find that even if their problem cannot be “solved”, they may be empowered and comforted by offering advice and support to others in the group. They may leave the group feeling better than when they arrived.</p>	<p>Group leaders often need training and practice on how to facilitate group conversations and manage group dynamics (example how to help the group avoid negative dialogue).</p> <p>To adapt, programs may need to develop their own way of providing group support.</p>

When developing a program, leaders might need to consider how their setting or community can impact their choice of approach to providing peer support. For instance, some rural areas might not have a large enough number of participants to hold group events. Also availability of resources, such as public transportation or access to technology, need to be considered.

“I think there are tons of people that are just not comfortable going into a group setting and revealing their emotional distress, or their concerns or issues and other people are willing to give that a try and see if it works for them...I think sometimes the one-on-one, is a little easier for people to ask their questions, and develop some trust with the person.”

Quote from a peer supporter

Program scope and the content provided to peer supporters and participants can range from basic talking points to help supporters start conversations with a participant, to detailed pre-planned educational activities.

<p>Simple (for more flexible approach to peer support)</p> <p>Content for Peer Supporters and Program Participants</p> <p>Complex (for more guided approach to peer support)</p>	<p>Talking points and resources for peer supporters. These talking points can be used as starting points or ice breakers for peer supporters to use, to help start conversations and encourage discussion</p>
	<p>Contact checklists or summary sheets may be used for reporting back to program leaders, as reminders of previous conversations, and to keep a record of the program participants' history</p>
	<p>Resource databases by geographic area, issue, or health condition, for peer supporters to access to answer questions or provide referrals. (This approach requires effort to keep the resources up-to-date).</p>
	<p>Materials and links to resources for program participants, free of charge, through organizational websites</p>
	<p>Comprehensive content for peer supporters to use during conversation with participants and guidance on group facilitation</p>
	<p>Subject matter experts develop and refine content, record keeping documents, and feedback documentation for program leaders</p>
<p>Customizable program for participants, with weekly updates, web based content, apps for smartphones, and products</p>	

When choosing materials for your program, review ones that have been based on studies that show they work well, and adapt these materials to fit your needs. If you decide to create new materials, be prepared to spend a lot of time on finding relevant content. For example, *Weight Watchers* has a devoted team that develops content to share with participants and keeps it updated with new information and studies on weight management.

Another option may be to partner with a national, state, or local program that has similar goals and offers materials or resources to new programs. For example, *NAMI* and *P2PUSA* are national organizations that offer materials, training, and support for their peer programs.

Parent-to-Parent of Georgia (state-level *P2PUSA*) offers a searchable [database](#) of service providers for children with special needs

Program delivery

After you decide on your program approach, content, and scope, think about the program personnel you will need. For example, who will lead the program, who will coordinate the support activities, and who will provide peer support. You will need to also consider how the peer supporters (those providing support to other peers) will be prepared and supported. Also, depending on your program approach, you may need to decide how you will be connecting (or matching) the peer supporters with the program participants.

Program personnel

Program personnel including volunteers and any paid positions will vary based on your support activities, funding, and scope of the program. You will have to estimate how many participants you expect to serve, how many peer supporters you will need, and what program materials and supplies if any are needed. Consider what program services will require someone to coordinate the work and who will do that. Also, think carefully about who will guide and support your peer supporters.

Number of peer supporters needed

The number of peer supporters needed will depend on the scope and format of your support services. Some programs connect one peer supporter with several participants at once, others match them with only one participant at a time.

Questions for program leaders to think about regarding personnel:

- What funding is available to hire staff? Where will future funding come from? What work can be done by volunteers?
- What demand (or requests) for peer support do you anticipate in your area?
- How many personnel and/or volunteers do you need to meet that demand?
- Do you need to offer paid positions (for example, a social worker, nurse or more experienced program leader, who can guide and support your peer supporters)?
- As your staff or volunteer numbers grow, how will you maintain the quality of your program?
- How will you manage and support your volunteers?
- What is the optimal ratio of peer supporters to program participants?

There are several types of personnel that can be involved in peer support programs. They will vary based on the nature of services that you wish to provide and your

program setting. In addition to peer supporters, personnel in peer support programs may include paraprofessionals (persons trained and certified for their job, such as certified recovery specialists), program coordinators, trainers, and health care professionals (for example, nurses and social workers).

Below is a description of the support services provided by these different types of personnel.

Peer supporters

- The services provided by peer supporters are at the center of what peer support programs offer. The relationship between people who have had similar experiences is unique to peer support programs.
- Commonly, peer supporters are volunteers in programs so it is important to be aware that they may have limited time, competing priorities, or other commitments. Some may want to volunteer, but may not fit well in the role of a peer supporter. In that event, you may be able to find another role that they can play.
- If the peer supporters/volunteers will be working in a professional or health care setting, you need to consider whether you will face resistance from staff. Talk to the staff in these settings to find out their concerns and discuss potential benefits of the peer support program. Consider including peer supporters who can share the potential value of peer support when talking to staff, and provide pointers to those individuals.
- It is important to keep in mind that peer supporters may still be emotionally or physically working through their own problem (or recovering from it) and may need periodic support themselves.
- Be aware that the activity of providing peer support and being a resource to others can be extremely empowering, even transformative, for peer supporters.

Para-professionals

- These may be program leaders who work to get funding for the program (see Planning a Peer Support Program), or persons with special training who can offer a certain type of support to participants (for example, a community health worker can help with transportation questions.)
- Some para-professionals start as volunteer peer supporters and then go through training and certification in order to offer additional support services. (For example, a pathway may be provided between volunteer peers and community health workers).
- Some participants may not feel that para-professionals are their peers, even if they have shared similar experiences. They may see them as health professionals rather than a peer who is there to listen and understand what they are going through. This can often be addressed by clearly defining the para-professional's role and how they engage with peer participants.

Dee's Place has peer recovery coach training for staff who want to learn new support skills.

Professional-delivered services

- Peer support programs embedded in a health care setting often have health care professionals, such as nurses or social workers, to support the peer supporters. They also usually manage the day-to-day operations of the program, including matching a patient needing support with a peer supporter.
- Health care staff are able to link participants to other services, such as referrals for mental health or substance abuse, or screening for other illnesses.
- The salaries of the health care professionals are usually paid from grants or by a department with an interest in supporting the program. Program leaders may have difficulty finding funding to support these roles.

Matching peer supporters and program participants

In program using one-on-one peer support formats, peer supporters are sometimes ‘matched’ to program participants. People are commonly matched on similar health conditions, age, and other circumstances. Though the process may be time-consuming and challenging, achieving a successful match can produce very good results. Creating a good match starts with knowing your peer supporter (and some of their personal traits) and identifying the needs of the program participant.

Learn more about *Parent-to-Parent’s* [matching](#) practices and their network of supporters.

To ensure an optimal match over time, program leaders may need to match a participant to several peer supporters or change peer supporters over time depending on the participant’s stage of illness. This may be particularly relevant to programs such as *Parent-to-Parent USA* where a participant may be struggling with a very rare disease.

A poor match could leave a program participant with unmet needs. Sometimes this can be due to location. If the peer supporter lives in a different geographic area, they may not know exactly what resources can be found where the participant lives. Also, different types of communities (urban versus rural) may have more or less access to resources.

A peer supporter may decide that their match with a participant is not working well, or that the participant may need additional help. In those cases, they need to connect the participant with either another ‘peer supporter’ or with the program leader.

At *The Parent Connection* peer supporters are trained to identify the signs of post-partum depression. When they identify a participant with those signs they refer them to the program coordinators, who are social workers and skilled in talking to new mothers about post-partum depression and referring them for appropriate care.

In some programs, participants play a proactive role in seeking the peer supporter whom they get matched with. For example, at *Dee's Place*, the program participant seeks a 'sponsor' rather than the program leader providing a match (12-step program approach). At NAMI, a potential participant will contact the national, state or local branch and, after a conversation about their situation, will be connected with a local NAMI leader, or directly with a support group facilitator or course teacher.

Communicating about the program

The purpose of communicating about your program is to share information about it and make more people aware of the problem your program will help address.

Materials given to the general public about the program should be plainly written and have basic information, such as:

- Purpose of the program
- Who the program will serve
- Potential benefits of support
- A description of what participants can expect. For example, participation is voluntary, information is not shared, medical care is not offered, their feedback is welcome, how they will be contacted, and how often they will connect or meet with peer supporter.

Materials and information that are relayed to community or institutional leaders, possible funders, and other programs should include details and proposed outcome measures relevant to them (for example, estimate of need, number engaged or served, evaluation results, and/or budget).

To spread the word about your program, use multiple communication approaches, connect with other programs for support, connect peer supporters to key people, and find program champions:

Use multiple communication approaches

In order to reach all relevant parties, you will need to **spread the word through a variety of channels** and networks; for example, communicating information both in person and electronically. The table below lists some ways to spread the word and some of their potential benefits.

Method	Details
Email and listserv communications	<ul style="list-style-type: none">▪ An effective way for program staff to communicate.▪ May offer an easy way to spread the word within an organization or to a large group of people▪ A listserv can be invaluable if you and your program actively and regularly expand it by proactively adding anyone who either has expressed interest in peer programming, has access to networks

	<p>or organizations that engage peers or potential community partners, or might offer funding or in-kind services. Leveraging such a constantly expanding listserv (and/or social media) can be very beneficial.</p>
Website	<ul style="list-style-type: none"> ▪ Easy, low-cost way to reach people seeking support and to post volunteer opportunities ▪ Wide reach to people in various geographic locations ▪ Program leaders and peer supporters can download materials (if you set up a private page)
Marketing materials	<ul style="list-style-type: none"> ▪ Printed materials (flyers, brochures) that advertise the program and provide contact information ▪ Handout those at health fairs, community centers, clinics, etc. ▪ Can be distributed by peers, volunteers, and community partners to their sites, and more broadly through their networks. ▪ Videos (more expensive) can offer personal stories online or in person (potentially more dynamic)
Newsletters	<ul style="list-style-type: none"> ▪ Can include program information in an organizational newsletter or make one specific to your program ▪ Can keep funders, peer supporters, and program participants involved and informed ▪ Can email, post on website, or send by regular mail ▪ Contain updates, accomplishments, opportunities ▪ Provide a way to attract new people and new funders ▪ Can be monthly or quarterly
News coverage	<ul style="list-style-type: none"> ▪ Requires that you contact media through press releases or “pitching” a story (letting them know you have a good story and people who would be willing to be interviewed) ▪ Reach a large number of people ▪ News spotlight or interview on TV ▪ Newspaper or magazine articles or advertisements; radio interviews

<p>Social media</p>	<ul style="list-style-type: none"> ▪ May help to attract new members or bring existing members closer together. For example, <i>Weight Watchers</i> has a platform called “Connect,” where members post and interact with one another. ▪ Social media platforms can be very useful for communicating about the program ▪ In some limited circumstances social media can be used to deliver peer support, however you need to consider confidentiality implications with this approach. ▪ Can keep everyone connected and updated (especially younger audiences) ▪ Fast way to promote and remind about upcoming events <p>Note: while social media can spread information quickly, some program participants may feel left out if they do not use social media but others do. You should consider whether you need to monitor these sites to be sure they are used in appropriate ways.</p>
<p>Social events</p>	<ul style="list-style-type: none"> ▪ Educate and inform the public about the program ▪ Recruit peer supporters and program participants ▪ Raise awareness and solicit donations ▪ Celebrate and recognize peer supporter efforts
<p>Conferences, conventions, workshops, webinars</p>	<ul style="list-style-type: none"> ▪ Platform to report on the program and its best practices ▪ Webinars allow programs to connect electronically; discuss the program, conduct training or coaching sessions ▪ Way to connect with others to discuss experiences, share best practices
<p>Testimonials</p>	<ul style="list-style-type: none"> ▪ Formal or informal statements describing program experiences (or example, narratives and stories) ▪ Written, video-recorded, or audio-recorded
<p>Annual reports</p>	<ul style="list-style-type: none"> ▪ Good document to support requests for funding ▪ Way to inform others about progress of program (for example, number of people served, number of participants that felt the program helped them)

Connect with another program for support

When programs are stand-alone in the community or even in an organization, it may help to partner with related programs for support, and to exchange advice and possibly resources. For example, a partner program could share in the planning, cost and delivery of volunteer

recognition events, or expand a network of contacts. They may also have a solution to a problem or advice about an approach that worked well for them.

Connect peer supporters to key people

Peer supporters may have a role in obtaining support for your program. By sharing their experiences and forming relationships they can increase buy-in. This role can strengthen connections inside and outside the program.

NAMI Peer Supporters speak to decision makers with a short personal story and they contact State delegates to advocate for mental health care funding at the State level

Find program champions

Program champions (physicians, staff, social workers, participants) can be potential leaders or key supporters of peer support programs. They can support a program, relate a vision/mission, get people involved, connect your program with partner networks, and help when change or flexibility is needed. They can also help expand a program by building peer interaction, and actively promote a program through outreach.

Champions at *Parent to Parent USA* reach out to regional centers to build relationships with support groups and other agencies.

Finding people to support the interests of your program, or assist in the program (but who are not program staff), may be very valuable. Key people that show strong interest in the program can be coached to be program champions; these people may be at the organization, executive, or community levels.

One of the best ways to create champions may be to involve them early when you are developing the program. This may make the success of the program personal to them and strengthen their commitment. For example, they can help screen or train volunteers or review marketing materials. Some champions may be excellent candidates for Board membership or participation in an oversight committee or council.

Potential challenges and how to address

It is important to learn about the potential challenges other organizations or programs have faced and how they dealt with them. What might your challenges be and are there potential solutions? Below are some challenges from existing programs. This list is not comprehensive and not all peer support programs will face such challenges:

Program resistance: Sometimes a person will resist and make it hard to start your program. If this is a key person with influence, find out their concerns and use creative means to address them.

Adequate peer supporter recruitment: At times, it can be hard to recruit the needed number of peer supporters. Programs use a variety of methods to recruit and boost their numbers.

Retaining volunteers: Keeping volunteers in the program takes time and effort. While most volunteers are personally motivated, having a strong personal relationship with other program leaders and staff may increase their desire to stay with the program.

Managing volunteers: Volunteers need to be trained, supervised, and supported. Occasionally, they will need to be counseled or even released from the program.

Matching options: Peer support programs offer a variety of people with many different conditions and needs. Sometimes it may not be possible to match a participant with one of your supporters. You might have to be flexible when looking for a good match. Many programs have geographic challenges; one option is to conduct support sessions through an online video chat (Google hangout, Skype, or by phone).

Fixing a poor match: Despite the best efforts of all concerned, sometimes a match will not work. Ensure a process is in place to connect the participant with another supporter. For example, the peer supporters may let the program leader know that the match is not working well, and the leader can then match the participant with another supporter.

“It's mostly by word of mouth...There's actually a little piece of the website there that talks about the volunteer group and has a bio of all of us who are on there and how we got started and what things we do and what things we're interested in, so certainly [it is] there if anybody has an interest.”

Quote from a program leader

“On the relationship end of things, I would say volunteers are like a garden. I mean, it's like what I said to you before, and you really have to know your volunteers. And you have to take good care of them. You can't just plant them and walk away.”

Quote from a program leader

“...when we make a match, we can make it based on the criteria that the parent is looking for. And it's not always based on disability, but sometimes it's based on some issue that the child is facing because of that disability...”

Quote from a program leader

“I think once or twice we've had some matches that did not go really well... I could recall one event where the support parent actually came to me and said, “This is way out of my league.” And we assisted them in finding some more formal resources.”

Quote from a program leader

Breaking program boundaries: Support programs may at some point have problems with boundaries they have set for the supporter-participant relationship. It is vital that supporters clearly understand the limits of their role. Many programs highlight the importance of boundaries and train peer supporters in different ways to manage participants who overstep

these boundaries and to avoid such boundary issues themselves. Despite these safeguards, boundary issues may arise and must be managed.

Since peer supporters may have had to grapple with a health problem or personal issue that might be ongoing or recurrent, they may also be in need of periodic support. Guidance must be provided to them on who they can turn to for support– for example, encouraging them to connect with the program leader, see their physician, or receive support outside of the program. They should not seek such support from the participants assigned to them.

Maintaining quality and following the plan: As programs are conducted, it can become challenging to ensure everyone follows program policies and recommended practices. This may pose a risk to the quality of your program. Even in smaller programs there needs to be a process in place to monitor quality and address any problems.

Example: *Weight Watchers* has a standard procedure for every participant that includes: A needs assessment; a wellness treatment plan; short and long term goals, and, plans to meet those goals. Upon meeting with participants, the goals and progress made towards reaching them is updated in individual counseling notes.

Managing expectation: Some participants may not experience benefits from peer support, or their expectations may differ from those offered by the program. At times, peer supporters may be disappointed if the participants are not engaged in program activities or lack the motivation to make desired changes to cope with their problems. It is important that program leaders remain aware of these possible scenarios and have relevant strategies in place that can resolve the potential negative effects of peer support on program participants and peer supporters.

Doubt about benefit of peer support: Professional staff may not see the benefit of peer support. Moreover, health care professionals may doubt the value of the program (which may limit referral to services). Therefore, educating and engaging your referral base is an important early step when starting your program.

C. Implement

Program policies and procedures

Privacy and confidentiality involve not sharing information about another person. Policies that describe the scope, limits, and boundaries of the peer supporter role should help set expectations. This means that they must be clearly stated and visible for your program, program leaders and peer supporters, and for the participants.

Every program needs a set of policies that guide how people should behave and what procedures should be followed when conducting the program. Programs that operate within an organization will most likely have to follow their policies and procedures (such as volunteer orientation and training). In a peer support program run by a health care organization, peer supporters and other program staff will have to learn and follow the rules of HIPAA to protect patient privacy and confidential information. Confidentiality and privacy is still a part of the work and needs to be respected, whether or not HIPAA regulations apply to the organization. Outside of a healthcare system, program will need to determine the best method for formalizing privacy and confidentiality expectations.

A well-defined set of policies and procedures may be helpful for everyone involved in your program. One focus area is liability and many organizations have procedures that describe how employees, volunteers, and others (including program leaders) conduct themselves. Program leaders must work out what policies and procedures work best for their particular program, and may need to adjust them over time as the program matures. Visit the [Resources and Tools section to see examples of specific policies and procedures](#). Below is a description of areas where a policy or procedure may prove to be helpful.

- **Managing the support activity:** Some things to consider are how to connect peer supporters and program participants; how to manage potentially difficult group dynamics; the number of attempts a supporter should make to reach a participant; the number of participants they should support at one time; how long peer support services should be offered to the participant; who should be contacted first if there is a problem; and what to do in case of an emergency.
- **Support for peer supporters:** Many programs have 24/7 support for peer supporters to help them fulfill their role. Some offer support groups or regular discussions where peer supporters can discuss important ideas, ask each other questions, and share concerns. These can be in person, online, or by phone.
- **Health and safety:** This may include basic training and refresher courses on potential health related issues (e.g. if peer mentors will be in a hospital they would need information about hand hygiene policies). There may be a need for procedures or guidance on how to handle specific safety matters such as when a supporter notices warning signs (*red flags*) of impending participant problems, and ways to address those. Other areas to consider include how to manage an urgent situation; *checking-in* on the

health or emotional needs of staff, volunteers, and participants; and, the health or emotional state of peer supporters.

- **Feedback to program leaders:** There are several benefits to routinely reporting feedback to program leaders. This includes having information to continuously improve the program, providing feedback and guidance to peer supporters, and helping maintain program quality assurance and control.
- **Check-in meetings between program leaders and peer supporters:** Holding these meetings may be one of the most important ways that leaders can support peer supporters and sustain the program.
- **Use of tools and technology to organize the work:** Technology can make program activities easier and communications efficient. However, program leaders need to consider any issues stemming from using specific technology solutions. For example, privacy of information may restrict program leaders in health care-based programs from using online platforms to facilitate peer communications. However, it is possible to build protection into the platform to help overcome this issue.

Program leaders

One staff position that is essential to running your program is a program leader or coordinator. The information below on program leaders covers their roles and responsibilities, elements that may prepare a leader (such as their experience), and what can motivate and inspire them.

Roles and responsibilities

Decide where the leader fits in the community or organization

The program leader should be an equal peer to other leaders in the organization or community so they can form strong partnerships and supportive relationships.

Determine the leader's responsibilities

What the leader will be responsible for will depend on the size of your program and the availability of other staff that support the program. Also, the way a leader is defined will vary among programs. There are three levels of tasks for which a leader may be responsible. Smaller programs may mean that leaders will have to take on duties across all three levels. Larger programs may involve leader duties at the high level and possibly at the mid-level. The table below provides a description of duties at each level.

Direct Service	Mid-level	High Level
Counsel peer supporters Documentation and other paperwork	Recruit and screen peer supporters Hiring and managing personnel Personnel and peer evaluation Matching peer supporter to participant Training peer supporters Problem-solving with peer supporters	Policy development Funding Program development Marketing Program evaluation Sustainability

Write the program leader's job description

Your best resource to help write a job description may be human resources. You may wish to partner with this department in an organization or with a person in the community who has this background. The resources section has examples of job descriptions.

Background, experience and preparation of the leader

Background and experience

If the program is in a clinical setting, it is useful for leaders to have a healthcare professional background in nursing, social work, or counseling. Larger programs may require that the leader have some form of leadership training or education. A leadership and project management background can also be very helpful particularly for larger programs.

Larger programs expect their leader to have experience in managing programs. Also, many leaders have personally experienced the health condition or situation that the program aims to address. This personal experience often helps them in their role as a leader.

“...if they don’t have some type of a business background, or human service background, I think it can be very challenging. We have seen a lot of programs fail because of that. They have the best of intentions as a parent, but they don’t have the skills to actually manage running a program. So, I think professional expertise is needed as well. That combination seems to work really well.”

Quote from a program leader

Building the program leaders’ skills

Initial training

The extent of the training will depend on the structure of your program. Larger programs often have training that covers a lot of information and may use train-the-trainer models that offer certification. Smaller programs tend to provide less structured training and will build on the skills leaders already have acquired as peer supporters or in other roles. Sometimes program leaders benefit from looking at other programs and meeting with other program leaders to learn what worked for them. They may also review best-practices from other programs and information from research studies.

“So for instance, taking peer to peer or family to family [programs], those are the individuals that once they get their life situation settled want to become board members or want to become involved...with policy activities.” [or become state or national trainers or mentors for new peer supporters]

Quote from a program leader

Ongoing development

Refresher training is sometimes offered in larger organizations. Some hold conferences or workshops that present new ideas or new research information about health conditions or life situations. Others may keep

track of issues raised from providing peer support; hold refreshers with peer supporters to address these issues; reinforce content from the original trainings; and review policies and procedures of the program (often as they evolve.)

Feedback

Many leaders are the head of their program and do not report to others. Thus, getting input from participants and peer supporters about their performance is helpful to their understanding of what they are doing well and areas where they need to improve. Simple input forms can be used. Everyone in the program needs to feel that their input to the leader about the program and staff performance is welcome at any time and highly valued (refer to Assess section).

Motivation and inspiration

Leaders often say their inner *passion* is what motivated them to start a new program or lead an existing one. Such passion may be what drives them to remove barriers and devote their time and skills to the program.

Maintaining support for program leaders

Build support for the program leader into your program plans. Types of support may include providing someone to do day-to-day office work, paying for conference fees and educational events, or giving them resources to work on program barriers.

The Internet can also serve as a means of support for leaders. Larger programs that have local groups in many places can form a network with email list serves and websites. Stand-alone programs can use public list serves and targeted searches to find people or resources that may support them (for example, to identify an organization that teaches how to support or advocate for a cause).

Leaders can also be connected with local partners, such as a person in the community, or a local chapter or program (this is particularly important for stand-alone programs). Connecting new leaders to experienced ones is another form of peer support for leaders, and may also reflect the mission of the program.

“It’s a joy to see people come in and they are broken. And they stay, you know, like you say, the seed has been planted. As they stay you can see their growth, their progress. So that’s one of the biggest joys to me.”

Quote from program leader

Other ways leaders may be inspired:

- A desire to help others and see people benefit (similar to peer supporters)
- They personally experienced self-healing
- They see a need in their community or may enjoy using their skills to start or develop a program

Peer Supporters

Role and experiences of peer supporters

The main role of the peer supporter is to help a person cope or deal better with problems, and equip or encourage them to do things that could improve their health and outlook on life. Peer supporters may have a certain health problem or difficult personal situation that is similar to the program participant. The fact that they have lived through similar challenges (a “practical living example,” someone who *has been there*) may help them share their experience, provide non-judgmental support, and bring encouragement and hope for positive outcomes.

Another key part of the peer supporter role is to provide practical information that health care professionals may not offer as part of formal treatment services or clinical practice. This information may be especially important to help participants adapt to and cope with the changes and new challenges in their life.

Peer supporters may benefit in a number of ways from their relationship with program participants, as described below:

- ***Giving back:*** Peer supporters may feel a sense of satisfaction by giving back to people in a similar situation and *making a difference* to their lives.
- ***Reciprocal benefit:*** The act of giving practical and emotional support to a person can also benefit the peer supporter.
- ***Means of coping:*** Supporters may build upon their strengths and insights to sustain their own recovery and help themselves cope with their own health challenges.

Peer supporters could also face a number of challenges, some of which may not be visible or known at first. Programs can guide supporters by helping them understand what could be potentially challenging to them. These challenges may include:

- ***Communication issues:*** There may be difficulties in discussing sensitive or difficult subjects (this could occur on the part of the participant or the supporter).

“If I can be a sounding board or someone to listen or to share, I think it's useful. And so in whatever capacity, I'm willing to do that for people. People have done it for me...it's better to give than to receive.”

Quote from a peer supporter

“...when you listen to others going through the difficult situations...it's a win-win situation. You feel that you are doing something for somebody else and at the same time, you are doing something for yourself.”

Quote from a peer supporter

“... people don't usually wanna talk about tough subjects...sometimes it can be difficult to talk to a complete stranger...especially if you're unsure, you know, if you're not confident ...”

Quote from a program participant

- **Change in availability:** Supporters may need breaks from their role because of time constraints or other demands, or because they personally need support.
- **Challenges with role:** Supporters may experience a fear of revisiting difficult or traumatic periods (the potential return of painful memories that may resurface by supporting someone else going through a similar experience).

“I think sometimes for some of these conversations I have to sort of gear myself up, because it takes me back to a very traumatic period in our family's life.”

Quote from a peer supporter

Additional issues that peer supporters may face include:

- Feeling guilty because they cannot follow up regularly with their participants
- Concern that the participant is feeling obligated to talk, and the supporter is not sure how to get them to open up
- Frustration in continued efforts to reach a patient/participant but not being able to connect
- Making a connection and getting concerned about how a participant is coping, but then not being able to reach them to check on them.
- Grief and emotional distress when a peer backslides, becomes more ill, or dies.

[Providing support for peer supporters](#)

Programs need to have a way to provide ongoing support for the peer supporters. For example, supporters may have questions, or need help addressing challenging situations. They may need personal support if experiencing distress or any negative impacts from providing peer support.

Examples of ways for peer supporters to get support:

- Positive reinforcement from program leaders and other program staff
- Recognition of peer supporters through organizational and other opportunities
- Events for peer supporters to talk about their disappointments, worries, and challenges
- “Ebbing and flowing” type of reciprocal support between the peer supporter and the program participant
- Family networks/friends
- Specific religious and spiritual beliefs
- Mutual support through social gatherings (to promote connection) and social media (private peer supporter page on Facebook)
- Buddy system: pairing two peer supporters to look out for each other
- Psychological support from clinical professionals when needed

Provide support in times of emotional stress

Peer support programs should have a clear plan for supporting peer supporters during times of emotional stress. Of particular note are health care-based programs that serve people

with sensitive or severe illnesses or conditions. One-on-one counseling sessions may sometimes be needed to help supporters work through instances of emotional distress. Peer support groups for the peer supporters can also be formed and led by experienced program leaders.

Programs should routinely check the wellbeing of their supporters to find out how they are feeling and make it clear that they can take breaks from their role as a peer supporter. In some cases, program leaders might encourage them to attend another support group as a program participant, see their physician, or receive support outside of the program.

Examples: Dee’s Place stresses the reality of “burnout” and how vital it is for peer supporters to take some time off and receive ongoing, continuous support. NAMI teaches that peer supporters cannot seek support from their peer support group participants. They recommend that peer supporters attend other NAMI peer support groups as participants, and seek support from other program coordinators and leaders.

Core skills/competencies

A peer supporter often needs to acquire certain core skills to prepare them to successfully provide peer support. There are general skills that apply to all programs and specific ones that depend on the health condition and/or people that the program is intended to serve. Programs should anticipate what their peer supporters will need or may potentially encounter when working with participants and include these matters in peer supporter training.

The general core competencies for a peer supporter are listed below:

- Describes Peer Supporter role and responsibilities including limits, defining role boundaries, maintaining privacy and confidentiality
- Demonstrates how to initiate and end the support relationship
- Describes the role of the program participant
- Demonstrates well developed communication skills including active listening, and ability to provide respectful empathetic responses
- Applies strategies to stimulate open conversation with a focus on the other person
- Uses personal experiences to strengthen relationships and stimulate dialogue
- Demonstrates ability to provide constructive feedback
- Displays non-judgmental attitudes, stays positive, and provides affirming responses
- Identifies how to manage potential or real emergency/crisis situations
- Follows a partnership approach

Recruitment and retention

Peer supporter recruitment: It is important to devote both time and attention to recruiting the right [appropriate] peer supporters. This will be key to ensuring strong and successful peer supporter-program participant relationships and the overall success of the program.

You can advertise about need for peer supporters with flyers and pamphlets that includes information about your program. Another approach to recruit peer supporters is to reach out to people who have received services from your program. For example, NAMI tries to recruit new peer supporters who have benefited from its peer programs rather than from the general public. In hospital settings, clinicians can also serve as referral sources.

Screening applicants: Part of the recruitment process should include screening to ensure the applicant is (or can become) a good peer supporter. Below are possible factors to look for and questions to ask:

- Do they want to become a peer supporter for the right reason? (Example question: Why do you want to become a peer supporter?)
- Do they have the required personality or skills to support others? (Example question: If I asked your best friend to describe you, what might s/he say?)
- Do they have experience as a peer supporter?
- Are they at a place in their journey with the underlying issue/health problem that they can devote the time and energy to provide support to others? (Example questions: How does being a peer supporter fit into your life now? Do you have time to do this with everything else that you are already doing in your life? What do you think some of the challenges of being a peer supporter might be for you?)
- Do they understand and agree with the values and philosophy of the program?

Survivors Helping Survivors has criteria for selection in their volunteer orientation manual. *NAMI* has “red flags” in interview materials to help screeners decide if the person is a suitable candidate at that time.

Pathway to becoming a supporter: A transition period may be used to prepare someone to become a peer supporter. For example, supporters may start by leading an informational session and eventually become a peer supporter; think of this as building blocks to becoming a peer supporter. If a supporter is not believed to be physically or emotionally ready for the role, they may require more coaching or may be directed to other volunteering opportunities. Program leaders should be ready to re-direct volunteers to another task or assignment where they can volunteer successfully.

Retention methods: Retaining peer supporters may help ensure a well-trained and experienced group of supporters. However, at times it can be difficult for programs to meet the needs of peer supporters and to keep an adequate number trained and available. Programs use a variety of methods to boost their numbers:

Roadmap to Peer Support

- Programs can retain supporters by respecting their needs. For example, *Parent Connection* knows that peer supporters have other commitments (children, work, etc.).
- Keep peer supporters engaged and interested in the program. *NAMI* coordinators try to keep mentors updated even when they are not involved with the program by sending newsletters and training updates.
- Foster a positive environment that makes supporters feel valued and lets them know that “their work matters.”

Some ways to recognize supporters:

- personal feedback from program leaders
- gift certificates, e-gift cards
- certificates and awards at events (for example, *NAMI* gives awards for program supporters each year at its state conferences and recognizes program supporters for length of service at its national conference)
- retreats or quarterly dinner meetings to celebrate contributions
- meal vouchers

Training

Peer supporters need to acquire the core skills needed for providing peer support and need to be prepared for the challenges that they may face. For example, knowing how to recognize crises or ‘red flags’ for participants and themselves. Training and guidance can help them learn and be effective sources of support. Many programs will use existing staff (nurses, social workers, program leaders, or experienced peer supporters) to conduct their training.

Initial Training:

- Initial formal training may differ among programs. The Resources section has training materials to help meet the general competencies for providing peer support. Each program will have to adapt these materials to include information that is specific to their program to ensure their peer supporters are prepared to handle specific issues for program participants.
- Key areas to cover in peer supporter training include:
 - The concept and methods of peer support, including benefits and limitations of peer support
 - The role of the peer supporter
 - Setting and maintaining boundaries

- Identifying when self-care is needed and how to seek support
- Navigating challenging conversations and keeping an open mind
- Core communication skills for peer support: Active listening, showing empathy, asking open-ended questions, and showing willingness to provide ongoing support
- When and how to share your lived experience

Role play may be a good way to enhance peer support skills. Experienced supporters can role play real events to help train new peer supporters. For example, a program may have experienced supporters perform a role play at a training session. Ideas that peer supporters think of while viewing the role play are discussed as they arise, allowing the new supporters to draw on prior knowledge and develop new skills.

“The training opened me up to looking at my son’s illness’s from a more sympathetic perspective...my perspective is not necessarily the only perspective...it generally wasn’t even the right perspective.”

Quote from a peer supporter

Refresher Training:

Refresher training can be done through follow-up and supervision meetings; both are critical parts of ongoing learning.

Examples:

At Survivors Helping Survivors where breast cancer treatments change rapidly, peer supporters attend continuing education activities. Guest speakers are invited to present updates on changing technology and methods for treating breast cancer.

Monthly national teleconferences are held for peer supporters in each of the NAMI peer programs. Topics are chosen partly based on debriefing forms completed by peer supporters after a peer support group.

On-the-job Learning:

You can help peer supporters become prepared on-the-job using the following approaches:

- Shadowing an experienced supporter (*Survivors Helping Survivors*)
- One-on-one guidance from someone who can explain and show how the program works

Challenges to Training:

- If a program grows too quickly, new recruits may not be properly trained and ready to support others

- Training (for example, extensive HIPPA online modules) may be a burden and deter people from becoming supporters
- Covering all the training needed to provide certain types of support
- Infrequent or varied types of refresher training

Feedback and Assessment of Training:

It is helpful to ask those going through the training to provide feedback on the training, whether they have found it helpful, and what they would like to learn more about.

Examples:

Parent Connection asks for feedback during the training process.

At NAMI, State trainers (experienced peer supporters who have gone through additional training to be trainers) provide evaluation of the trainees and determine if someone is certified, provisionally certified or not graduated.

Building successful relationships with program participants

Building a positive and supportive relationship with the participant is key to a successful peer support experience. Programs need to outline the parameters, such as maintaining appropriate boundaries in the relationship, and setting expectations to ensure peer supporters understand and adhere to their role. These parameters and expectations need to be clearly defined and communicated from the start. Many programs highlight the importance of both in early training. Peer supporters may also need training on how and when to end a relationship with a program participant, although this can be difficult at times.

Peer supporters need to:

- Clearly define their role at the beginning of a relationship so participants know what to expect.
- Accept that there may be differences in status, personality, experience, and opinion and avoid trying to *fix* the participant.
- Become familiar with their program’s approach to ‘boundaries’. Some programs advise against personal relationships, and others accept it occurs as a natural result of the peer support process.

“I have talked to a lot of people, I feel sorry for a lot of things that people are going through, but I try not to get too emotionally involved in it, I try to stay on a more professional side of it.”

Quote from a peer supporter

- Be aware of how to end a peer support relationship. The structure of some programs may make ending the relationship easier.
- If a participant is moving in to a supporter role, there may be need to provide a transition period before they commence their new role. This is very condition dependent, For example, a recent cancer survivor may not be ready to provide support for others just yet and may need a year or more to pass before they can do so. Both the peer supporter and participant need to be ready for the relationship.

What we counsel is that if they're getting to the point where it's not about living with the ailment, that it's about everything else, then it may be time to end the relationship... we have to be clear about when that role ends, and then they can be a friend in a different way if they choose to."

Quote from a program leader

D. Assess

Reasons to assess your program

There are multiple reasons to assess your peer support program. It can help answer questions such as:

- Is the program making progress in meeting its goals?
- Are the participants satisfied with the program? What do they like the most? What do they like the least?
- What impact is the program having on the people being served? What are its key benefits?
- What parts of the program are not working well? Can they be fixed by adjusting the program?
- Are the people with various supporting roles in the program satisfied with the program? What do they feel is most effective? What do they feel is least effective? Is there anything they need to be more effective in their role?
- Is this program cost effective? Is this program saving money for the organization?

Answers to these questions can help you:

- 'Make the case' for continuing the program.
- Report useful information to key stakeholders (such as a non-profit organization that has funded the program; key people who helped with the program start-up).
- Include specific information about the impact of your program in communications and marketing materials. This can encourage more people to participate and may bring in more funding.

There is no standard assessment approach or evaluation used by peer support programs. Evaluation plans vary among programs, and are often limited by few resources and lack of

personnel with the skills to conduct a formal evaluation. What to evaluate will depend on the services offered and the program.

At a minimum, you need to have a process for participants and peer supporters to share input, complaints, and suggestions. Such feedback may help you to improve the program, decide what needs to be done next, and plan for the future.

Peer support programs often use simple feedback forms, such as surveys conducted after a meeting or when participation in a program ends, to collect information about satisfaction and experiences with program services.

Below are commonly assessed areas:

Assessment of Peer supporter orientation, training, and follow up support activities

All peer support programs hold orientation and training activities for peer supporters and many collect information about those activities in order to continuously improve them. You can collect this information via survey that you give peer supporters at the end of the training. The survey could include a mix of questions with multiple choice or rating scale responses, with a few open response questions to gather comments you did not consider. A good example of such a question is “what activities were most helpful to you in this training?”

During follow-up meetings, some program leaders ask questions to peer supporters to assess how ready they are to provide peer support services and how to better prepare them. Sample questions include:

- What has it been like talking to program participants?
- What challenges have you faced?
- Can you describe how the training worked for you?
- What parts of the training have you used recently?
- What can we do to better support you?

Quality of peer support services

Program leaders and staff can look at a range of program activities to assess the quality of the program. Quality may be defined by how well the service is meeting the intended effect described by the program. Some programs continuously assess their services.

The information above may be collected from program participants through surveys, short feedback forms, listening sessions, random phone calls, or unplanned visits to the program. Participants may provide informal feedback to group leaders or staff, but it is also helpful to have formal feedback.

Examples of what to assess include:

- How the support activities are being conducted.
- Are participants satisfied with their 'match' with a peer supporter?
- Do the participants feel that the program has helped them? In what ways?
- How involved with the program do participants feel?
- What activities or features do participants find most helpful?
- Ideas on how to improve a program and its services.
- Have there been specific and measurable improvements in quality of life indicators, adherence to treatment, loss of weight, self-image, etc.?

In healthcare organizations where data is maintained on patients, databases can serve as a source of information and show the clinical impact the program is having on peers, such as re-hospitalization rates. Feedback from clinicians who see patients in the program can also be helpful.

Both program participants and peer supporters need a mechanism to share what was helpful, and share any complaints and ideas to further improve services. For participants, this can occur while receiving peer support. The input from either the participant or supporter can help improve how peer support is provided (for example, a peer may be re-matched with another supporter). They can also be surveyed once they finish the program (what was most helpful?).

When peer support services are being provided, program leaders need to assess the performance of the peer supporters in the program and provide guidance as needed. Performance checks allow a program to assure participants and other key stakeholders that the program is providing the highest quality of support possible. Because peer support programs sometimes involve emotionally difficult topics, performance checks offer an opportunity to find out whether a supporter is coping well with their work, or if they are becoming overly stressed

or emotional. If problems arise in any of these areas, supporters need an easy and quick way to report concerns to the person coaching or supervising them.

Example: At *P2P USA*, the program leader calls the parents (the program participants) and the peer supporter they have been connected with two weeks after making the match to determine whether both sides are satisfied and feel that the connection is helpful. If concerns are raised (for example, the peer supporter lives in a different State from the parents and is not familiar with the services within that State), then another match is made (if possible).

Experiences of peer supporters in the program

Peer supporters are at the frontline of any program and getting feedback from them is very important to make sure the program is successful. Supporters can provide information about their efforts and offer suggestions about running the program to continuously improve it. Find out how peer supporters are doing and feeling and what they think about the services the program has asked them to offer. Here are some examples of potential areas to obtain feedback about:

- Do they feel prepared to “do their job”?
- Are they getting enough guidance, training, and support from the program? (This information could be obtained via a periodic survey and/or discussions in meetings.)
- Are they satisfied with the services that they are offering?
- Are there areas in the program or their performance that they feel could be improved?

This type of information can help program leaders better support their peer supporters. Feedback from peer supporters as well as various leaders and staff within the program is vital to continuously improve the program. For example, peer support leaders at *NAMI* complete forms after a support group session to describe what issues arose in the group, what methods they used to assist the group, the need for more resources, and other issues.

Some programs have program-related meetings to discuss their work and any concerns. This type of meeting is a good way to gather wisdom and an opportunity to “brainstorm” solutions. *NAMI* holds appreciation events and teleconferences where peer supporters discuss the program and their thoughts about it.

Here are some additional areas to assess as applicable (on a periodic or regular basis):

- Are peer supporters readily available to answer program participant's phone calls/questions?
- Is enough time allowed for peer support activities? Is the program ended sooner or later than the program participants want it to end?
- Do participants feel stressed by the number or content of questions asked by peer supporters (for example, probing too much or asking things that the participant is not yet ready to provide)?
- Are program procedures being followed (for example, are peer supporters completing the required forms or note taking for the program)?
- Are participants satisfied at the end of the group meetings? Is everyone in the group given time to speak? (this information can be collected via surveys at the end of the activity, via someone attending and observing the meeting, or through debriefing forms submitted by the peer supporters after a meeting)

Outcomes of the overall program

The overall impact of your program can also be assessed. Such an assessment may keep track of the number of participants served, or the number of patients referred from providers of the health care or other organization that partnered with your program. Here are some other possible ways to assess the program:

- Seek input on satisfaction and experiences of peer supporters and program participants.
- Seek feedback from clinicians who see patients in a hospital program.
- Assess the impact on the condition that the program sought to help or improve (for example, weight loss in a weight loss program, sobriety in an addiction recovery program).
- In health care organizations where data is collected on patients, databases can serve as a source of information to describe the clinical impact the program has on peers, such as re-hospitalization rates.
- Assess whether the program achieved the overall goals it set out to achieve?
- Assess whether the program achieved the action-related goals described in the program plan? (For example, number of participants attending groups, number staying on the program Website for more than 10 minutes.)

E. Sustain

A goal of most, if not all, support programs is to sustain the program (keep it running) and make it a permanent service in the institution or community where it operates. Sustaining a program includes planning for the future, always looking to adapt to meet the needs of those you serve, being willing to change, and if desired, expand the program. All of this requires a committed team of program leaders, peer supporters, key people who have some stake or interest in the program, and program champions.

To sustain your peer support program, the following may be needed:

Financial stability

At some point your program may need financial support. Funding can be secured by attracting funding organizations, applying for grants, charging for services, or requesting donations (both from satisfied participants and others).

Organizational capacity (maintaining leaders, staff, volunteers and program champions)

Organization capacity involves having enough people to run the program. One way to maintain or increase the number of supporters in your program is to recruit previous program participants to become peer supporters. Having program champions (leaders who can support a program in the larger organization or community) may also be helpful. Champions may be physicians, staff, social workers; or in community-based organizations, experienced peers who have been supporters but have “graduated” to be trainers or coordinators.

To ensure the program has the capacity to successfully serve participants, it is very important to **retain a motivated program team**. This may include leaders, staff, and volunteers. There are a variety of methods that your program can use if you find it difficult to meet the needs of peer supporters (and to keep an adequate number trained and available). New or creative tactics may be needed to keep them engaged in the program. A sufficient number of new peer supporters to manage unexpected dropouts and allow for expanded services may be needed. Below are some examples:

- Create a positive space, such as an awards dinner to help your supporters feel valued and appreciated.
- Have your program leaders provide personal feedback to peer supporters as an incentive to continue in their role.
- Form a strong personal relationship with program personnel, which may increase their desire to stay with the program.
- Greet program participants in a welcoming and friendly way, without judging their ability to improve their situation (may help engage them in being a supporter in the future).

- Keep track of your program participants after they have used peer services and offer them opportunities to be engaged in the program (for example, reaching out for more participants, helping with fund raising, assisting with program logistics, training to be a peer supporter)

Adaptability/flexibility

A program must have the ability to evolve, maintain, and expand in response to continuous updates and improvements. Many organizations or program leaders develop their program to better serve peer supporters and program participants. Such changes may be small (for example, adding a best practice to training on support services). Other changes can be much larger and can mean completely changing the program. Program leaders need to consider whether their current program is effective and how volunteers and participants are responding to it. For example, *NAMI* has advisory groups that include past participants, current supporters and program leaders to help identify and secure a group of experts in the field. To remain flexible, programs should take a proactive problem-solving approach, rather than a reactive one. Staff need to keep the needs of possible participants in mind when creating a program and as the program evolves.

Evaluation methods including consumer feedback/success stories, and adherence to best practices

An evaluation can help ‘make the case’ for continuing your program. For example, the information and feedback collected on the quality of peer support services (from both program participants and peer supporters) can prompt changes to improve services and help your program evolve and succeed. As the program develops, participants may find that some practices work well and others do not work quite as well. Their input can be invaluable and help guide further development and changes to the program.

An evaluation can determine whether the program has achieved what it hoped to do. If your program met its original purpose and goals, and adhered to best practices in training and development of support activities, you can use these achievements to support your argument to continue the program and also to support applications for funding.

Collecting and sharing success stories also strengthens support for your program. These personal accounts can get the organization or community behind the peer support program. Engaging key people or groups with an interest in the program in this personal way may be a very effective way to build a supportive culture.

“At the end of my talk our very own cardiologist pulled me aside, and said...it really opened her eyes to the importance that maybe not everyone wants to talk with another parent, but many do, and so the importance of educating the staff and having the hospital buy into this as another tool in their toolbox for treating not only the patient but treating the whole family, because when the parents are feeling heard and supported they're going to be better able to care for their child.”

Quote from a program leader

Following the program guide and recommended guidelines and standards

It is important to follow your program guide and also revisit guidelines or standards to see if any recommend changes as you sustain the peer support program. For example, ‘experts’ in relevant fields can be involved in an advisory board to consider how well your program is following recommended approaches. Further, a new program site that will offer an established program can look to other sites to model their approach (the idea of not reinventing the wheel), thus making it easier for new sites to start up and succeed.

Questions to consider in your work to sustain the program

Who are possible program champions?

How efficient and effective is the program?

What is the plan for maintaining the program?

How feasible/acceptable is the sustainability plan?

Are there recommendations for expansion? If so, what are the criteria?

F. Resources and tools

This section provides materials to help you plan, implement, assess, and sustain your program. The Roadmap program partners have shared materials that you can adapt and use in your program.

Type of Tools/Resources	Examples provided by partner programs
Roadmap to Peer Support	Adobe PDF of the Roadmap to Peer Support
Tools to Help Program Leaders Develop and Organize a Program	Program policies and confidentiality policy ¹ Creating an elevator speech ² - Mission statement ³ Matching and first contact protocols ⁴ Matching endorsed evidence based and best practices ⁵ Permission for release of information to peer supporter template
Role and Job Descriptions (for Peer Supporters and Program Coordinators)	Peer Supporter role description ¹ Program Coordinator job description ³
Recruitment Material for Peer Supporters	Peer supporter recruitment brochure ⁶
Screening Tools for Peer Supporters	Peer Supporter application and interview questions ³ Peer Supporter criteria ⁴ Guidance for recruiting screening and training peer supporters ⁵
Peer Supporter Training Material	Material from the Roadmap to Peer Support - Workshop on providing peer support <ul style="list-style-type: none"> • Sample Agenda - 13a • Core Skills and Competencies - 13b • Peer Supporter Training Workshop Slides - 13c • Peer Supporter Training Workshop - additional material - 13d • Post Training Workshop Survey - 13e
Recruitment Material for Program Participants	Participant recruitment card ⁴ Request for peer support form ³ Participant recruitment brochure ⁶
Documentation Forms for Peer Supporters, During or After Support Activities	Peer Supporter contact notes ³ -
Evaluation Forms (e.g. Participant Survey of Experience with the Program)	Participant survey example ⁶

Documents Provided By:

¹ The Parent Connection

² Kate Farinholt, Executive Director for NAMI, Maryland

³ Stanford Healthcare Peer 2 Peer

⁴ The Johns Hopkins Breast Center Survivors helping Survivors

⁵ Parent2ParentUSA

⁶ Parent to Parent of Pennsylvania

G. Program Partners Section

The Roadmap program partners were an integral part in helping develop the Roadmap to Peer Support. Seven well-known peer support programs in the United States shared information about their programs and offered their experiences, including success stories and challenges. This section describes these programs.

H. Project Team

I. Glossary

Confidentiality: Relates to privacy, and is a demonstration of respect for individuals and the sharing of personal information, stories, and testimonials. Confidentiality is an important component of training; peer supporters should be trained to maintain privacy and confidentiality.

Ethical Practices: Ethical practices are commonly shared beliefs and values related to an organization's operations and strategies. These practices create a positive environment for programs that extends beyond legal requirements to influence an organization's overall activity.

Health care professional: A person who qualified through education and training to provide a health care service to a patient (for example, nurses, social worker).

HIPAA: HIPAA stand for the Health insurance portability and accountability act. This act was passed in 1996 to protect patients' health information and personal identity. It emphasizes "informed consent", privacy, and not breaking confidentiality. Includes compliance with practices and understanding boundaries. Peer support programs working with patients educate their peer supporters about HIPAA either in-person or through online modules.

Liability: Defined as "the state of being legally responsible" for results of the program's operations.

NAMI: National Alliance on Mental Illness. NAMI Maryland is one of the program partners

P2P USA: Parent 2 Parent USA is the name of one of the Roadmap program partners.

Para-professional: A person who is trained and completed the required certification for their job (for example, a certified recovery specialist).

Patient-Centered Outcomes Research Institute (PCORI): PCORI was established to fund research that can help patients and those who care for them make better-informed decisions about the healthcare choices they face every day, guided by those who will use that information. Learn more about PCORI at www.pcori.org

Roadmap to Peer Support

Peer: A person who shares similarities with others which help form relationships. These similarities may be personal characteristics (for example, age), social groups (for example, sports team), or life circumstances (for example, health condition).

Peer supporter: A person who has personally experienced a health condition (or other circumstance), who is trained and in some way supervised to support another 'peer' who is experiencing a similar condition (or circumstance).

Privacy: Ability to keep personal information protected. Privacy may be reinforced in peer support programs through mission statements, program objectives, and training/operational procedures.