

PATH Consumer Provider Network Expanded Guidelines for Consumer and Family Participation in the PATH Program

The Projects for Assistance in Transition from Homelessness (PATH) program is administered by the Center for Mental Health Services, a component of the Substance Abuse and Mental Health Services Administration (SAMHSA), one of eight Public Health Service agencies within the U.S. Department of Health and Human Services. PATH was authorized by the Stewart B. McKinney Homeless Assistance Amendments Act of 1990.

PATH is a formula grant to the 50 States, the District of Columbia, Puerto Rico, the Northern Mariana Islands, Guam, American Samoa, and the U.S. Virgin Islands. There are over 480 local organizations that provide PATH services. The National PATH Technical Assistance Center assists SAMHSA in providing support to the State and local providers.

PATH services are for individuals with serious mental illnesses and those with co-occurring substance use disorders who are homeless or at imminent risk of becoming homeless. PATH services include community-based outreach, mental health, substance use, case management and other support services, as well as a limited set of housing services. While PATH programs vary greatly, a typical PATH program employs outreach workers who spend time on the street and at meal sites and other service settings working to engage individuals who are disconnected from services.

The PATH Consumer-Provider Network (PCPN) is a group of individuals who were eligible for PATH services at one point in their lives and are currently employed by programs that receive PATH Federal and/or match funding. The PCPN was created in early 2008 and works under the mission “To ensure that consumers have a voice and are involved in the planning, design and delivery of PATH at the local, state, and national level.” The group meets monthly to discuss various projects and endeavors, including the development of these guidelines.

In 2009, Dorrine Gross, the Project Officer overseeing the PCPN at that time, charged the PCPN with developing voluntary recommendations to expand the Substance Abuse and Mental Health Services Administration (SAMHSA) Guidelines for Consumer and Family Participation in SAMHSA Funded Programs (The SAMHSA Guidelines). The SAMHSA Guidelines lay out seven areas to ensure consumer involvement, but they do not expand on what compliance with the guidelines might look like. During monthly teleconferences, PCPN members discussed how they envisioned implementation of the guidelines at the PATH Provider Agency and State levels. The following document consists of their recommendations.

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Notes about this document:

The SAMHSA Guidelines for Consumer and Family Participation are intended for all SAMHSA programs. Because of this, the guidelines include families and youth. For the purpose of this document, the PCPN focuses on consumers only. While a limited number of PATH programs serve families and youth, these are not the populations that PATH focuses on. The SAMHSA Guidelines are available on the SAMHSA website <http://www.samhsa.gov/grants/apply.aspx> under “Resources for Grant Writing.”

Throughout the SAMHSA Guidelines, the words *applicant*, *applicant organization*, *organization*, and *grantee* are used. For PATH, these terms refer to both the agency that receives PATH funds (the *PATH Provider Agency*, also often referred to as a *PATH Provider* or *PATH Program*) and the State level PATH grantee (the *State PATH Contact (SPC)*). The PCPN uses the terms *PATH Provider Agency* and *State PATH Contact (SPC)* throughout the recommendations. The terms are used together when referring to both or alone when referring to one or the other.

This document is organized with the text from the SAMHSA Guidelines in ***bold italics*** and the PCPN recommendations in plain text. Recommendations are separated in to recommendations for PATH Provider Agencies and recommendations for State PATH Contacts.

Introductory Text

SAMHSA is committed to fostering meaningful consumer, family member, and youth involvement in substance use and mental health policy and program development across the country. A key component of that commitment is involvement of consumers, family members, and youth in the design, development, and implementation of projects funded through SAMHSA's grant programs. The following guidelines are intended to promote consumer, family, and youth participation in SAMHSA's grant programs.

Applicant organizations should have experience and a documented history of positive program involvement by recipients of mental health and/or substance use services, whom they serve, and their family members. The term 'youth' is included in the guidance below but only applies to organizations that serve young persons and that are seeking grants to provide services and supports to youth. The involvement of consumers, families, and youth should be meaningful, influential, measurable, and span all aspects of the organization's activities as described below.

SAMHSA demonstrates its commitment to consumer involvement in PATH in the annual PATH application. States and PATH Provider Agencies are required to document consumer involvement in the expenditure of PATH funds in their States and PATH Provider Agencies. Past responses reveal that State PATH Contacts and PATH Provider Agencies vary in how they implement the involvement of consumers. Some agencies are consumer-run programs where every person, from line staff to executive director, identifies as a consumer. Other agencies may have consumers in roles such as peer providers or designate a seat for one consumer on the board (see Appendix A: PCPN Program Descriptions). These guidelines will help State PATH Contacts and PATH Provider Agencies think about consumer involvement in PATH funded programs. While consumer involvement will always differ among programs, all State PATH Contacts and PATH Provider Agencies should strive for meaningful consumer involvement when expending PATH funds.

Mission Statement

Program Mission—The organization's mission reflects the value of involving consumers, family members, and youth. The stated value should demonstrate why meaningful participation is important to the organization, how it improves outcomes, and generally how it is accomplished.

PCPN recommendations for PATH Provider Agencies:

- Involve consumers in the development and modification of the mission statement.
- Ensure that the mission statement communicates a message of value and respect for consumers.
- Use person-first language; talk about “people experiencing homelessness,” not “the homeless.”
- Include the concept of consumer involvement in the mission statement.

PCPN recommendations for State PATH Contacts:

- Review the mission statements of current PATH Provider Agencies and assist PATH Provider Agencies in revising mission statements that do not follow the recommendations for PATH programs. Person-first language in mission statements is indicative of programs that value consumer involvement.
- Ensure that the mission statements follow the above recommendations when selecting new PATH Provider Agencies.

Examples of mission statements and tag lines:

- PATH Consumer Provider Network. Ensure that consumers have a voice and are involved in the planning, design, and delivery of PATH at the local, state, and national levels.
- West Virginia Mental Health Consumer Association. To promote the rights, representation, respect, and responsibility of consumers of mental health services.
- Housing for New Hope. Preventing and ending homelessness, one valuable person at a time.

Program Planning

Program Planning—The Applicant’s submission must show how consumers, family members, and youth will be involved in substantial numbers in the conceptualization of initiatives, including identification of community needs, goals, and objectives; identification of innovative approaches to address those needs; and development of budgets to be submitted with applications. Approaches should incorporate peer support, recovery-oriented self-care, holistic wellness, and trauma-informed methods.

PCPN recommendations for PATH Provider Agencies:

- Invite consumers to attend all planning meetings and invite a consumer to co-facilitate these meetings. Find a way to share information and solicit feedback from consumers who do not attend meetings (e.g., hold public luncheons after meetings to obtain consumer feedback about meeting decisions).
- Distribute regular consumer satisfaction surveys and/or establish peer grievance committees to obtain feedback.
- Establish peer governing boards, peer planning committees, accessibility committees, or consumer advisory boards to encourage consumers to take ownership of their program. Ensure that the guidance of the board/committee is taken into account and implemented.
- Require that consumers review and have an opportunity to comment on program changes before implementation.
- Involve consumers in the development and implementation of community needs assessments. Consumers may have the ability to engage their peers better in discussions about their needs.
- Seek out information and provide training on peer support, recovery-oriented self-care, holistic wellness, and trauma-informed methods.

PCPN recommendations for State PATH Contacts:

- Develop a State Advisory Committee of Mental Health Services where 51 percent of members are consumers or family members.
- Establish and promote consumer-run programs. In PATH consumer-run programs, every employee has experienced homelessness and is living with serious mental illness. These programs are often very successful in engaging consumers who are disconnected from services and send a strong message that “Recovery is Possible.”
- Require PATH Provider Agencies to demonstrate that PATH consumers have meaningful involvement in program planning.
- Ensure that program planning follows the above recommendations when selecting new PATH Provider Agencies.
- Seek out information and provide training on peer support, recovery-oriented self-care, holistic wellness, and trauma-informed methods.

Training and Staffing

Training and Staffing—The Applicant’s submission will demonstrate how the organization staff has or will have substantive training in, and be familiar with, consumer, family, and youth-related issues and programs, including innovative approaches developed by consumers, family, and youth leaders. Attention should be placed on staffing the initiative with people who are themselves consumers, family members, or youth. Such staff should be paid commensurate with their work and in parity with other staff.

PCPN recommendations for PATH Provider Agencies:

- Create peer provider staff positions and make peer support a core part of the program. Provide appropriate training and supervision for these staff and compensate the positions equally with comparable existing positions. Remember that all consumers are unique and do not expect peer providers to be the voice of all consumers in your PATH Provider Agency.
- Hire consumers in roles at all levels of the PATH Provider Agency, not just in designated peer specialist positions.
- Make meeting with one or more consumers part of the interview process for all prospective applicants, from front-line staff to project directors.
- On all job postings, include some variation of the following statement: “Individuals who have formerly experienced homelessness or risk of homelessness and/or who are in recovery from mental illness and/or substance use disorders are strongly encouraged to apply.”
- Hold regularly scheduled consumer panels at staff meetings.
- Conduct or send staff to consumer involvement trainings. Training can be included as a part of staff meetings over the course of several weeks or a stand-alone event.

PCPN recommendations for State PATH Contacts:

- Hire consumers at the State level.
- On all State level job postings include some variation of the following statement: “Individuals who have formerly experienced homelessness or risk of homelessness and/or who are in recovery from mental illness and/or substance use disorders are strongly encouraged to apply.”
- Conduct, or have an outside agency conduct, consumer involvement trainings for PATH Provider Agencies.
- Invite consumers or peer providers from PATH Provider Agencies to speak about their experiences during staff meetings or at luncheons for people at the State level.
- Review the hiring policies and procedures of PATH Provider Agencies to ensure that they follow the above guidelines.
- Ensure that consumer involvement in training and staffing follows the above recommendations when selecting new PATH Provider Agencies.

Informed Consent

Informed Consent—Applicant submissions will show how recipients of program services will be fully informed of the benefits and risks of services and make a voluntary decision, without threats or coercion, to receive or reject services at any time. Recipients will have an opportunity to serve in an advisory capacity to provide input on the services received. SAMHSA’s Confidentiality and Participant Protection requirements are detailed in the SAMHSA Grant Funding Announcements (GFAs). These requirements must be addressed in SAMHSA grant applications and adhered to by SAMHSA grantees.

PCPN recommendations for PATH Provider Agencies:

- Revisit informed consent procedures and forms annually. Make sure to obtain consumer feedback when conducting the review.
- Make sure consumers fully understand the purpose and details of the consent form and why they need to sign it. Ask consumers to reflect back what they heard to ensure that they understand the consent form (for example consent forms, see Appendix B: Informed Consent for Participation in PATH Site Visit Conversations and Appendix C: Authorization to Release Information).
- Create multiple places for the consumer to sign or create multiple forms to break down all the items requiring the consumer’s consent. This way, it is easy to make sure that there are explanations for all items requiring the consent of the consumer. In addition, the consumer can opt out of some items while opting in for others, rather than having to consent to all or nothing.
- Utilize time-limited consent forms; revisit consent forms with the consumer every six months or annually.
- Do not present consent forms until consent is necessary.
- Have peer providers explain consent to consumers. Consumers are more likely to ask their peers questions than staff.
- Allow consumers to revoke their consent form (selected items or the entire form) at any time. Make sure this is stated on the consent form.

PCPN recommendations for State PATH Contacts:

- Review the consent procedures with PATH Provider Agencies to ensure that they follow the above recommendations.
- Ensure that new PATH Provider Agencies adhere to the above recommendations regarding informed consent.

Rights Protection

Rights Protection—Applicants must demonstrate how consumers, family members, and youth will be fully informed of all of their rights including those related to: information disclosure, choice of providers and plans, access to emergency services, participation in treatment decisions, respect and non-discrimination, confidentiality of health care information, complaints and appeals, and consumer responsibilities.

PCPN recommendations for PATH Provider Agencies:

- Discuss consumer rights, including the right to respect, upon program entry (for an example rights protection form, see Appendix D: Grievance Policy and Procedure).
- Utilize agencies that specialize in legal issues to inform consumers about their housing and disability rights. Refer individual consumers to these agencies or invite the agencies to present at the PATH Provider Agency.
- Establish a peer grievance committee and designate a staff person to handle rights violations, so consumers are aware of options available to them.
- Post consumer rights where consumers can access them. Include contact information for the staff person dedicated to addressing rights violations and contact information for rights advocacy organizations.
- Provide staff training on consumer rights at staff meetings or hold stand-alone trainings.

PCPN recommendations for State PATH Contacts:

- Include consumer rights protection as a topic in any statewide PATH meetings.
- Provide training on consumer rights protection for PATH Provider Agency administrators.
- Keep a list of advocacy organizations in your State that can assist Provider Agencies with consumer rights protection. Distribute this list to PATH Provider Agencies and ask them to distribute it to their staff and post it where consumers can access it.
- Review the rights protection procedures of PATH Provider Agencies to ensure that they follow the above guidelines.
- Ensure that new PATH Provider Agencies adhere to the above recommendations regarding rights protection.

Program Administration, Governance, and Policy Determination

Program Administration, Governance, and Policy Determination—Applicants must demonstrate a plan to hire consumers, family members, and youth in key management roles to provide project oversight and guidance. Consumers, family members, and youth should sit on all Boards of Directors, Steering Committees and Advisory bodies in meaningful numbers. Such members should be fully trained and compensated for their activities.

PCPN recommendations for PATH Provider Agencies:

- Require the board to designate seats for consumers.
- Provide, or provide compensation for, childcare, telephone, and transportation for any committee or board member who needs it in order to attend.
- Allow for frequent breaks. Provide food and beverages at meetings. Do not request that attendees bring their own food to meetings.
- Consider consumer obligations the same as any other board member obligations when scheduling meetings.
- Match all new board or committee members, including consumers, with a seasoned board member to act as mentor and guide. Board membership can feel intimidating and a mentor will help new members understand the role of the board and their individual role on the board.
- Provide “Welcoming Training” to board members. “Welcoming Training” addresses issues such as jargon and how to make those who are not familiar with the culture feel comfortable participating on a board. Additionally, this training can provide background information to familiarize board members with the jargon. This training prepares boards for including all members who are not familiar with the language used in the behavioral health field.
- Compensate consumers and all board members equally. Do not compensate consumers with gift cards or money if other board members do not receive compensation in the same way. Only compensating consumers may make consumers feel tokenized.

PCPN recommendations for State PATH Contacts:

- Develop a State Advisory Committee of consumers.
- Require PATH Provider Agencies to reserve at least two seats on the board for current or former consumers.
- Review the program administration procedures of PATH Provider Agencies to ensure that they follow the above guidelines.
- Ensure that new PATH Provider Agencies adhere to the above recommendations regarding program administration, governance, and policy determination.

Program Evaluation

Program Evaluation—Applicants must demonstrate how consumers, family members, and youth will be integrally involved in designing and carrying out all research and program evaluation activities and participate in the development, delivery, and analysis of satisfaction assessments. These activities include: determining research questions, adapting/selecting data collection instruments and methodologies, conducting surveys, analyzing data, and writing/submitting journal articles.

PCPN recommendations for PATH Provider Agencies:

- Have current or former consumers meaningfully and actively participate in all phases (development, implementation, analysis, and write-up) of the evaluation. Consumers may have additional insight that non-consumers do not possess.
- Ask peer providers or current consumers to hand out the survey. Ensure that there are ways that consumers who cannot write or are not literate can participate in the evaluation.
- Be mindful of confidentiality. If possible, have consumers complete the survey in a private room, put the survey in an envelope when it is complete, and put the envelope into a locked box.
- Make sure that questions, written and verbal, do not lead the consumer to provide a particular answer.
- Share the evaluation results with consumers and ensure that there is follow-up. It is frustrating to participate in an evaluation but not see results or change.

PCPN recommendations for State PATH Contacts:

- Ensure that consumers have meaningful involvement in the development, implementation, analysis, and write-up of any statewide evaluations of the PATH program.
- Review the program evaluation procedures of PATH Provider Agencies to ensure that they follow the above guidelines.
- Ensure that new PATH Provider Agencies adhere to the above recommendations regarding program evaluation.

Appendices

- A. **PCPN Program Descriptions:** Brief program descriptions from PCPN member programs
- B. **Informed Consent:** Informed Consent for Participation in PATH Site Visit Conversations (*Advocates for Human Potential, Inc.*)
- C. **Informed Consent:** Authorization to Release Information (*Salvation Army Open Door Program, Marysville, CA*)
- D. **Rights Protection:** Grievance Policy and Procedure (*West Virginia Mental Health Consumer Association, Charlestown, WV*)

Appendix A: PCPN Program Descriptions

These descriptions were provided by the programs.

West Virginia Mental Health Consumers Association (WVMHCA) Peer Transitions (Charleston, WV) is peer operated and rests within the design of WVMHCA peer run services infrastructure. WVMHCA assists persons who have been institutionalized to recover the skills needed to transition back into the community. The project utilizes consumer run service/resource centers, transitional and permanent housing, peer support groups, and other programs that serve to enhance, expand, and create housing, outreach, and further peer services and supports.

Housing for New Hope (Durham, NC) involves consumers from the start, whether it is during our assertive street outreach efforts or by answering an inquisitive phone call from a consumer or interested family member. At first contact, staff gather and ask what the person would like help with; consumers are involved in deciding their own process from the start. If and/or when a person goes through our transitional housing program, they are required to participate in the housing program, do daily chores, and the house motto is “Freedom through responsibility.” They are encouraged and assisted in looking for and finding meaningful work, and start savings accounts for a “nest egg” when they graduate from the program. They have weekly classes in life skills, cook once a month for the local soup kitchen, and participate in local events. They are assisted in becoming productive members of society again, with a better perspective on life itself. Residents have a weekly house members only (no staff allowed) meeting to discuss how the house is functioning and to plan future efforts individually and as a group. There is staff on site, but the house is actually run by the residents. When someone graduates, they have the option to transition into independent living or one of Housing for New Hope’s affordable, supportive, housing developments and are given an award check to use with their “nest egg” to help with expenses.

Daybreak (Santa Monica, CA), a project of Ocean Park Community Center (OPCC, Santa Monica, CA) provides a comprehensive system of care for adult women recovering from homelessness and mental illness. From the minute Daybreak members walk through its doors, they are fully engaged in charting and evaluating the course of their recovery by setting goals which then become the benchmarks of their self-defined success. Whether still living on the streets and attending our day program, residing in our shelters, or participating in our Permanent Supportive Housing Programs, members are encouraged to utilize the many groups and activities Daybreak offers to help them reach their goals. Ranging from living skills to money management to art and equestrian therapy to housing options to entrepreneurial education, each group and activity offers concrete tools which empower members to rebuild their lives, facilitating their supported transition into and successful retention of permanent housing. In 2008, Daybreak was awarded the PATH Exemplary Practice Award in the area of Consumer Empowerment.

Appendix B: Informed Consent for Participation in Projects for Assistance in Transition from Homelessness (PATH) Site Visit Conversations

1. You have been invited to participate in a PATH Site Visit conducted by Advocates for Human Potential, Inc. and AFYA, Inc. on behalf of the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services. The information we gather will be used to help develop a Site Visit Report on this State's administration of the PATH program.
2. Your participation will involve sharing your thoughts and opinions on your experiences with homelessness, the PATH program, and the mental health system. The amount of time involved in your participation will take no more than two hours.
3. There are no known risks associated with this activity.
4. The possible benefit to you from this study is that you will assist us in evaluating the effectiveness of a program designed to transition people from homelessness, with the possible outcome of improving these services for people who are homeless.
5. Your participation is voluntary and you may choose not to participate in this activity or withdraw your consent at any time. You will NOT be penalized in any way if you choose not to participate.
6. We will do everything we can to protect your privacy. Information is presented as a group response to questions. We may refer to your community, but we will not use your name unless you give consent specifically for that.

I have read this consent form and have been given the opportunity to ask questions. I will also be given a copy of this consent form for my records. I hereby consent to my participation in the activity described above.

Participant's Signature

Date

Appendix C: Authorization to Release Information

I, _____ authorize: _____ To release information to:

Name: _____ Name _____

Address: _____ Address: _____

Phone #: _____ hone #: _____

The purpose or need for such disclosure is:

Specific Information is to consist of the following:

1. Yes/No Narrative account of case history, progress in recovery, and staff recommendations for continuum care.
2. Yes/No Communication for the purpose of assisting in my recovery.
3. Yes/No Communication concerning family/children.
4. Yes/No Communication concerning legal matters.
5. Yes/No Communication concerning financial agreement/payment agreement.
6. Yes/No Other information (Specify) _____

I understand I may revoke this consent at any time and that upon fulfillment of the above stated purpose, this consent will automatically expire without my expressed revocation. Unless sooner revoked or fulfilled, this consent will expire one year from the date signed.

I hereby acknowledge the above records are protected under Federal Regulations (CFR 42 part 2) and cannot be released without my specific consent.

Participant's Signature

Date

Staff Signature

Date

Appendix D: Grievance Policy and Procedure

Policy

It is a policy of WVMHCA that all of its consumers will be treated with respect, dignity, and equality. If you feel your rights as a consumer have been violated in any way, we ask that you send a written statement to the Executive Director.

Procedure

1. You may request a grievance form from any WVMHCA staff member.
2. Complete the form and return it to the receptionist.
3. The form will be routed to the Division Director for review. Whenever possible, the Division Director will attempt to resolve the issue through the service team process.
4. The Division Director will conduct an investigation. Findings from the investigation will be sent to the consumer within ten working days of initial receipt.
5. If the problem is not satisfactorily resolved, the consumer may consult the Executive Director, explain the conflict, and any resolution steps taken. The consumer may request a meeting of all involved parties. Findings from this review will be sent to the consumer within ten working days.
6. If the problem is not satisfactorily resolved, a committee of the Board of Directors will review the original complaint and the Director's findings. Findings from this review will be sent to the consumer within ten working days.
7. In any case, the plan for resolving the grievance will be documented and implemented.

It is important to conduct a professional, impartial, timely, and thorough investigation. In some cases, suggested resolution options will be provided and/or an Improvement Plan requested from the facility involved. A findings letter/report will be generated at the conclusion of all investigative activities. These findings will be forwarded to the complainant after the facility has been offered an opportunity to comment. The final findings report will be sent to the complainant accompanied by any comments provided by the facility. If the facility chooses to comment, the comments will be included in the findings report in the exact form and content received. If the facility is requested to submit an Improvement Plan, this activity may be ongoing as determined by circumstances of the case.

If you have any questions or need any assistance with this, please call a WVMHCA Division Director at xxx-xxx-xxxx.