



GUIDANCE MANUAL

# Peer Involvement and Leadership in Early Intervention in Psychosis Services: From Planning to Peer Support and Evaluation

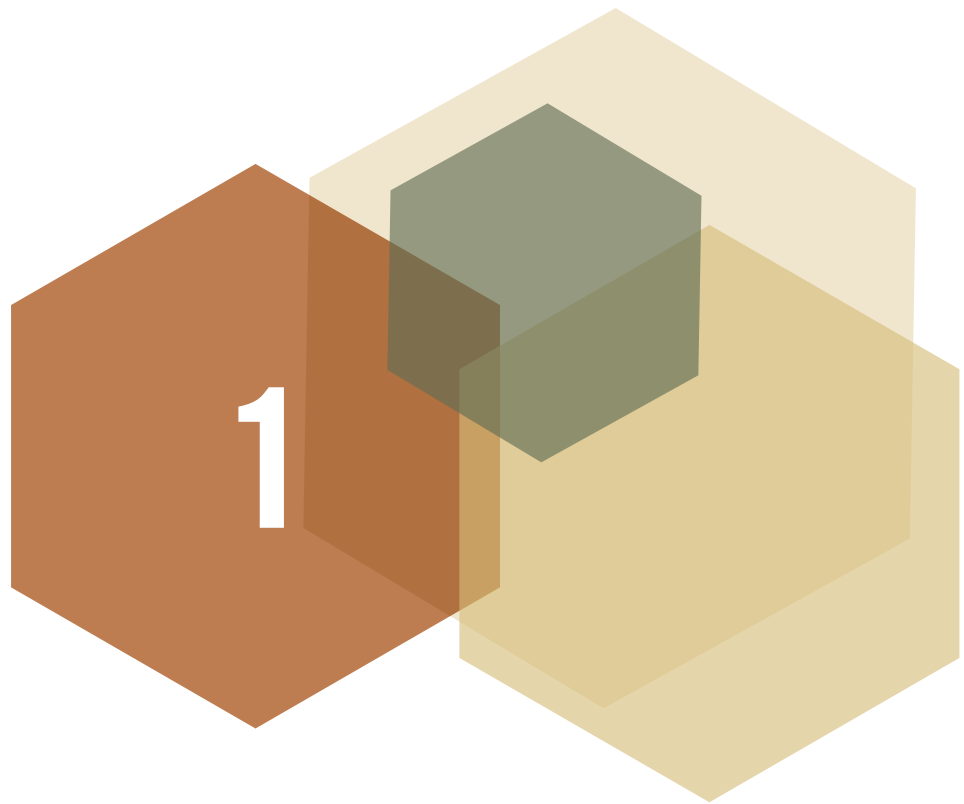
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# Introduction

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The goal of this guide is to provide a range of different stakeholders with information and best practices for peer support and leadership in early intervention for psychosis (EIP) services. Audiences that may find this manual to be useful include state-level administrators, clinical directors, peer and family advocates, young people, and early intervention planning committee members, as well as researchers and others with an interest in youth and peer involvement. This document includes many concrete examples of exemplary or innovative services, projects and individuals (see “spotlights”), and a comprehensive appendix of resources is offered at the end of the guide. Unlike many other U.S. peer support manuals, the aim of this guide is to provide coverage of a broad range of domains in which peers might assume leadership or advisory roles. These include program development and planning, direct service delivery (including peer support), public outreach and engagement, clinician education, and quality improvement and evaluation.

With respect to language, there are currently a number of synonymous or overlapping terms for both (first episode) early intervention services and ‘peers’ in popular use. Alternatives to EIP include “coordinated specialty care” (CSC), multidisciplinary teams (MDTs), first episode psychosis services, and multiple acronyms for specific models or programs (for instance, Australia’s Early Psychosis Prevention and Intervention Centre (EPPIC) model). Still further terms describe programs that focus on prevention or early intervention in prodromal psychosis or what has been referred to as the “at risk state”—programs that fall outside the scope of this guide. Similarly, “peers” are also commonly referred to as consumers, clients, service users (particularly in the UK and Europe), survivors and/or patients. Some early intervention programs prefer the generic terms “youth” or “young people” without further qualifications. In both cases, this guide consistently uses the terms “EIP” and “peer,” except in cases where an alternative term is more appropriate and/or when quoting publications or describing specific programs in which one of these alternate terms is used or preferred.



## **Background:** brief history of peer participation and the consumer movement

Following in the footsteps of very early advocates such as Clifford Beers, the U.S. consumer movement took off in earnest in the early-to-mid 1970’s. Since then, peers have successfully organized and advocated for: improved mental health services; peer-operated alternatives; and much greater inclusion in national and local mental health policy and planning initiatives, governance, and administration. Joining their colleagues in the cross-disability movement, a common rallying cry for peer advocates is the slogan, “Nothing about us without us.”

Today, most state-level divisions of mental health, as well as the Substance Abuse and Mental Health Administration (SAMHSA), include dedicated consumer affairs units or branches. SAMHSA currently funds national peer-run technical assistance centers that provide guidance and support to state-based consumer groups throughout the United States. The Agency does not require, but strongly encourages, consumer and family participation in the design, development and implementation of the various projects they fund.<sup>1</sup> Through its Bringing Recovery Supports to Scale Technical Assistance Strategy (BRSS TACS), SAMHSA also directly funds innovative consumer-directed projects and initiatives and supports projects that emphasize different forms of peer involvement.



In the non-profit sector, there are now hundreds of independent peer-led groups and organizations providing an array of different services including peer support, policy advocacy, community outreach and innovative programming.<sup>2</sup> Specific anti-stigma and peer support programs are now widespread and include the National Alliance on Mental Illness' (NAMI) peer-to-peer experiential learning program<sup>3</sup>, the Copeland Center's Wellness Recovery Action Plan (WRAP) groups<sup>4</sup>, Intentional Peer Support (IPS), the Hearing Voices Network, and Emotional CPR (eCPR).<sup>5</sup> Over the past several decades, these and other peer-developed programs have strongly influenced community mental health services and are increasingly recognized as evidence-based practices. WRAP is one prominent example of a peer-developed intervention that is now recognized as an evidence-based practice and has been implemented state-wide in many regions with state and/or county funding and support.<sup>6</sup> In addition, SAMHSA has created a toolkit on consumer-operated services grounded in evidence-based approaches and strategies.<sup>7</sup>

The past decade has also seen tremendous growth in state-level certified peer specialist training and licensing programs. Georgia is credited as the first state to have developed a Medicaid reimbursable peer specialist program, and in 2007, the Centers for Medicare and Medicaid Services (CMS) issued a formal director's letter clarifying Medicaid's capacity to reimburse peer specialists so long as they are supervised and meet core competency criteria determined by each state.<sup>8</sup> The U.S.-based International Association of Peer Specialists was founded in 2003 and in 2013 released an in-depth set of national practice guidelines.<sup>9</sup> Peer specialists employed in mental health service settings are increasingly common, and many states devote significant resources to peer specialist certification and continuing education.

While peer involvement and leadership in youth mental health remain less developed than in others areas, the last decade has seen significant growth in young adult and/or college-focused organizations and initiatives, including YouthMOVE National<sup>10</sup>, Youth Power!<sup>11</sup>, Active Minds<sup>12</sup>, and the Jed Foundation.<sup>13</sup> While few states have dedicated youth peer specialist training programs, many transition aged youth (TAY) and young adult service organizations directly train and employ young adults as support workers. Several national groups have developed youth-specific interventions including YouthMOVE's "youth peer to peer" support program and the Copeland Center's youth-adapted version of WRAP. In addition, several federally funded research and training centers—the Pathways Research and Training Center (RTC) at Portland State and the Transitions RTC at the University of Massachusetts—have dedicated ongoing resources to evaluating youth involvement in mental health settings and have pioneered many forms of youth participatory research and program development.<sup>14</sup>

Internationally, initiatives oriented toward strengthening peer involvement have also extended to participation—and even leadership—in program evaluation and research. In addition, a growing number of universities in the United Kingdom (U.K.) and Australia have implemented initiatives to employ permanent consumer teaching staff who are directly involved in the formal education and training of future clinicians and mental health workers and/or who carry out dedicated outreach and psychoeducation in the community.<sup>15</sup> In the U.K., the National Health Service (NHS) and associated research funding bodies now *require* some form of consumer involvement in all nationally-funded research.<sup>16</sup> Dedicated carer (family) and service user (peer) researchers (with a range of formal training backgrounds) are consequently increasingly common in British Universities. Several research institutes with a focus on service user-led research have been developed, including the Service User Research Enterprise within the Institute of Psychiatry in London and the Centre for Citizen Participation at Brunel University.<sup>17</sup> Private foundations and charities such as the McPin Foundation have emerged with the explicit goal of “transform[ing] mental health research by putting the lived experience of people affected by mental health problems at the heart of research methods and the research agenda.”<sup>18</sup>




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“It bothers me when I hear people talk about hiring peers for only certain types of jobs, whether they be entry-level clerical support or peer-specific direct service positions that are considered to be “treatment extenders” – low-cost supplements to “real” services. I think peers have a great deal to contribute as members of the mental health workforce and I hope that employers are looking at persons with lived experience for the whole range of “regular” staff positions, so ‘peers’ can bring to those positions the valuable perspective of lived experience, as well as the other talents they have that qualify them for any position. At our agency, all our posted job openings explicitly state, “people with experience of mental health recovery are encouraged to apply,” and peers fill the whole range of positions, from program directors to team leaders to outreach workers to employment specialists. Some work in our specifically peer-run program (which has a value all its own), but many others work at all levels, in administrative and clinical jobs, throughout the agency.”

—Sheila O’Neill, LCSW  
Thresholds Inc.

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Finally, peer involvement in clinician education—and in some cases initial selection and assessment—has become increasingly popular, though mostly outside the U.S. A recent survey of nursing programs in Australia found that over 60% utilized “lived experience educators,” for example.<sup>19</sup> In the U.K., some form of peer involvement is now required for all clinical training programs, both prior to and following formal qualification (or licensure).<sup>20</sup> In these countries, exciting and innovative strategies for peer inclusion are emerging.

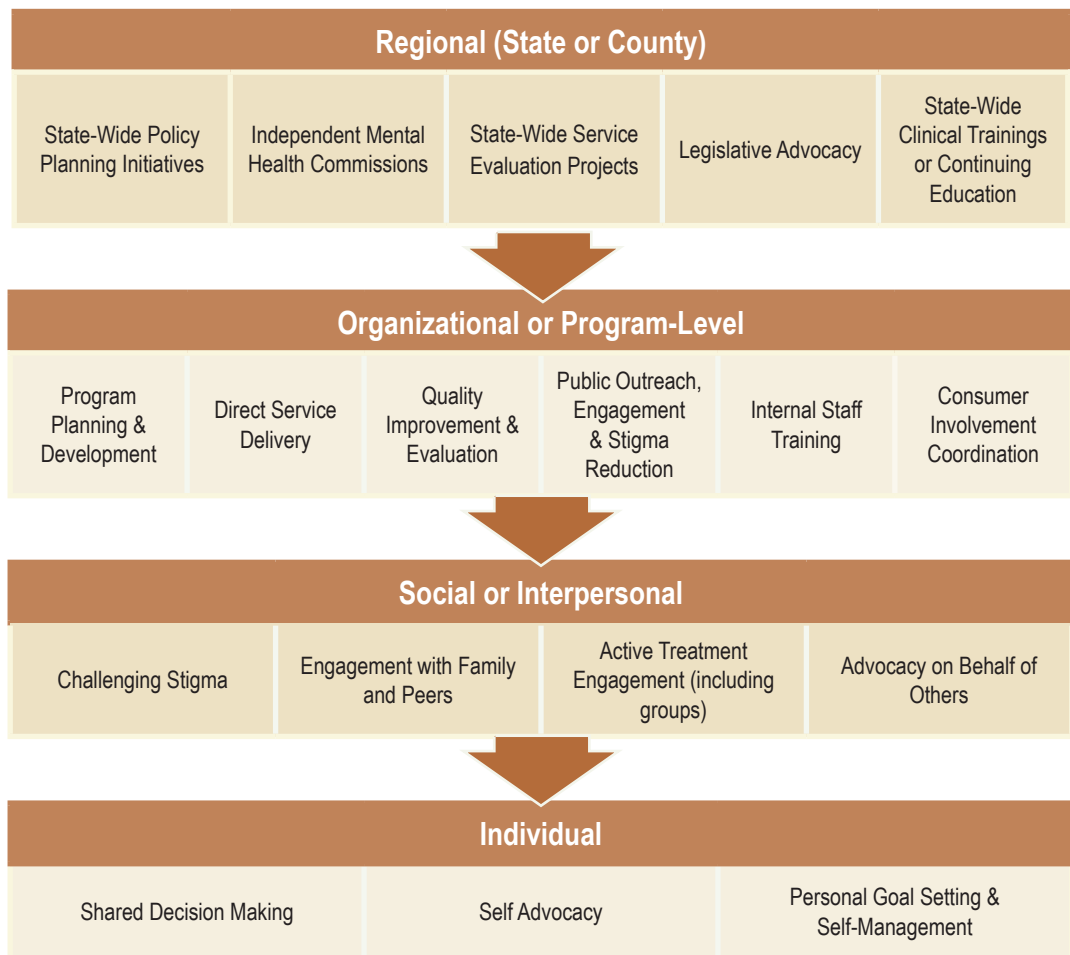
## **Background:** the goals of early intervention for psychosis services

In the most general terms, the goal of early intervention for psychosis (EIP) services is to intervene as soon as possible following an initial psychotic break in order to promote rapid recovery and minimize detrimental impacts on young people’s lives. Importantly, EIP services aim not only to reduce or alleviate symptoms but—perhaps more importantly—to help young people remain active and engaged in their communities and equipped with the best possible supports to pursue their life goals.<sup>21</sup> EIP is consequently not “just” about medical (or clinical) intervention, but a more holistic approach to youth and young adult recovery and wellbeing. In addition to providing and promoting more traditional clinical services (such as individual therapy and medication), high quality EIP programs feature supports for social and interpersonal engagement (including romantic relationships), vocational and educational achievement, civic participation, and physical wellbeing.<sup>22</sup>



## What is peer involvement in early intervention for psychosis services?

Peer involvement and leadership in early intervention settings can take many forms and can occur at multiple levels, including the individual, social or interpersonal, organizational, and regional levels. *Figure 1* provides a general overview of what peer involvement at these different levels might include.



**FIGURE 1.** Multiple Levels of Peer Involvement



This guide focuses primarily on involvement at the organizational and regional levels. However, it also includes discussion of how involvement at these levels can promote and strengthen social and individual involvement (and wellbeing), as well. The goal in each section of the guide is to describe and discuss a range of ways in which peers can influence, improve and inform EIP services. Dedicated sections of this manual will cover program development, policy and planning, direct service delivery, public outreach and stigma reduction, clinician education, and quality improvement/evaluation. *Figure 2* provides a further breakdown of these domains and examples of roles and activities that might fall under each.



**Figure 2.** *Involvement Domains with Examples of Activities & Roles*

### WHY INVOLVE PEERS IN EARLY INTERVENTION?

Potential benefits to peer involvement and leadership can be broken down by the same levels described above: the individual, interpersonal, organizational and regional (see Figure 3). As individuals, peers stand to benefit from greater participation (across domains) through a heightened sense of personal empowerment and self-efficacy and the development of concrete skills and work or volunteer experience. Research on peer support has also documented statistically significant improvements in symptoms, subjective well-being, and treatment self-advocacy.<sup>23</sup> Peer support (and other forms of normalization through peer interaction) have also been shown to decrease internalized stigma and lowered self-expectations<sup>24</sup>

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“Studies indicate that “normalizing” psychotic experiences is a crucially important step in helping distressed individuals gain a sense of hope and self-efficacy. One of the more powerful ways to normalize and convey this hope and empowerment is to embed Peer Supporters in FEP programs.”

— *Wayne Munchel, LCSW*  
*TAY Services Director*  
*Stars Behavioral Health*

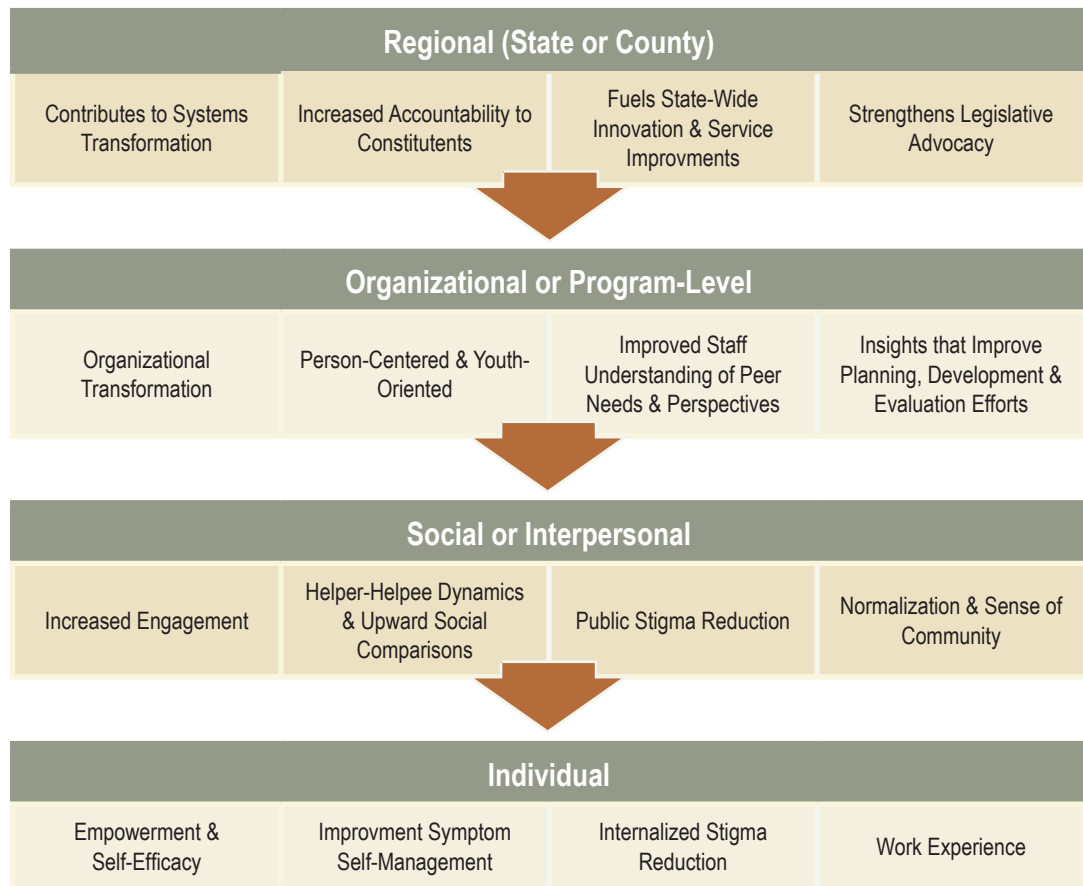
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From a more interpersonal perspective, the peer-to-peer relationships have been widely understood to exemplify the so-called helper-helpee principle, which holds that both helpers and helpees (roles which often alternate over time) reciprocally benefit from the helping interactions.<sup>25</sup> Clients likely also benefit from access to peer mentors—i.e., individuals with similar struggles but who are further along the path to recovery who can serve as guides or models of what might be possible in the future (a process known as “upward social comparisons”).<sup>26</sup> Importantly, the benefits of peer “mentors” hold not just for direct clinical services, but for peers occupying any number of different roles with whom newer clients might come in contact. Strong peer involvement in general (and, specifically, in outreach efforts) is also likely to increase the engagement of both current and prospective clients.<sup>27</sup> Peer-led groups or programs may provide additional incentive to attend appointments, for instance, or help prospective clients feel more comfortable about seeking services.<sup>28</sup>

“I never had the sense that the clinicians I was working with really understood what it was like, what I was up against. I kept trying to describe things I was experiencing and at some point it occurred to me that they just didn’t understand and never would and so I gave up. It was like a miracle the first time I met someone “just like me.” I didn’t have to have the right language, because they understood what I was trying to describe without me having to say it.”

—EIP Alumna



**Figure 3.** Benefits of Peer Involvement at Multiple Levels

While far less research has attempted to document the impact of peer involvement on organizations, a few studies have suggested that involvement positively impacts organizational culture, with specific benefits often depending on the form that involvement takes.<sup>29</sup> For instance, strong youth participation can increase the degree to which programs are youth-sensitive and youth-friendly (or, in other words, feel “cool” and non-threatening). Peer leadership may also help soften more pronounced power hierarchies in which providers are seen as “authorities” and clients largely or only as “passive recipients.” Peer staff can

also increase clinical staff members' awareness and sensitivity to the issues clients face.<sup>30</sup> Finally, peer participation in program planning, development and evaluation has enormous potential to draw attention to variables or factors that would otherwise be overlooked, to bring “patient-centered outcomes” to the foreground and help generate creative and innovative ideas and service improvement strategies.

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“For over a decade, I have been studying the outcomes of peer support initiatives. This involves close collaboration with those who have lived experiences of depression, psychosis, and other psychiatric difficulties. Together, we have studied models such as Wellness Recovery Action Plan (WRAP), and Building Recovery of Individual Dreams and Goals through Education and Support (BRIDGES). These peer-led interventions were developed by people in recovery to help them self-manage their wellness and self-direct the services they choose to receive. WRAP is now an evidenced based practice that is being used worldwide. BRIDGES has spread to 12 states and provinces in the U.S. and Canada. Unfortunately, research on peer-led recovery models is under-funded. Yet we need these types of collaborative research endeavors in order to document the outcomes of peer-developed and delivered programs.”

—Judith Cook, PhD  
University of Illinois at Chicago

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In one of the few existing empirical investigations of the impact of four consumer-run self-help organizations (CRO's) on the broader community (and government offices and initiatives), a group of Toronto researchers documented impacts both on the perception of those with whom the CROs interacted (e.g., government officials) and concrete changes.<sup>31</sup> For instance, policy makers and mental health program directors who came in contact with CRO advocates were more likely to see the value of consumer participation, and value consumer opinions. Concretely, the researchers observed positive (consumer friendly and recovery-oriented) changes in local clinical practices, service planning and specific funding allocations. In the United States, peers may also serve on commissions that play a “watchdog” role—i.e., helping ensure the accountability of state and federally-funded projects to both taxpayers and consumer stakeholders. Peers may also play a significant role in legislative advocacy through testimonials, protests and other forms of civic participation.

While these different levels of impact may be divided up for the purposes of discussion, ultimately they are all both bidirectional and mutually reinforcing. Strong regional involvement and associated impacts helps reinforce individual participation and benefits, for instance, and vice versa.



## Distinctions of Specific Relevance to EIP

### PEERS AND YOUTH PEERS

Most early intervention programs define their populations in part through age-based cut-offs. While these vary considerably around the world (ranging from the early 20's in some U.S. programs to 35 in most British National Health Service (NHS) EIP services), the focus population is generally youth and/or emerging adults. Youth involvement, in a narrow sense, is certainly key to meeting the particular needs of this population. At the same time, however, youth *age*. A peer specialist hired when he or she is 25 will not stay a “youth” forever; in practice, this raises important pragmatic questions about both the longer-term prospects for youth hired as (youth) peer specialists or advocates, and the role of peers who—perhaps having earlier received EIP services—are now in their late 20's, early 30's or older. At

present, no empirical research exists to help guide program planners and administrators in weighing the possible tradeoffs between hiring and employing peers of different ages (e.g., a peer specialist under 25, versus a 33-year-old). A further consideration is the potential value of additional experience or training that may accrue for “older” EIP peers, potentially including clinical licenses, lengthier experience running or developing peer-led programs, and research or evaluation training.

Instead of conflating peers and youth-peers, we suggest considering the particular goals of different positions, roles and partnerships and weighing the relative pros and cons of both peers and youth-peers. For example, a youth-peer might be the best fit for an outreach position involving anti-stigma programming in high schools, whereas a more involved program development position (with lead responsibility for designing, implementing and evaluating new clinical initiatives) might be more appropriate for a more experienced peer with graduate training and/or lengthier experience.

### CURRENT CLIENTS, ALUMNI, AND NON-CLIENT/ALUMNI PEERS

A related set of distinctions might be drawn between current clients of an EIP service, service alumni, and peers who may or may not have experience of specialty EIP intervention (or have received treatment under a different EIP model), as illustrated in the following table. It is probably most helpful to think of each of these “peer” categories as capable of contributing valuable (but in some cases likely different) perspectives and insights. Current clients are likely the “closest to the ground” in terms of active programming, whereas alumni can contribute insights grounded both in their EIP experiences, and the experience of navigating the other side (i.e., the transition to regular adult services and/or school, work and community living). “Locals” (whether current clients or program alumni) may also have stronger existing ties with surrounding communities and an easier time reaching and engaging area youth. Conversely, “external” peers may be better positioned to take stock of an existing program in light of comparative experiences in other settings or with different models.



Category	Description	Considerations
Current Clients	Individuals who are currently clients of a particular EIP program	Close familiarity with services currently being offered, but no experience of discharge or post-discharge services. Client status may create ambiguities or issues around interacting with staff and/or clinicians in a non-clinical context while also being a client.
Non-Client/ Non-Alumni Peers	Individuals who received services in a particular early intervention program in the past	Less familiarity with current services (especially if they have changed since their discharge) but nevertheless personal understanding of, and ties to, the program. Alumni also have experience of discharge and post-discharge and potentially also additional experiences and expertise (e.g., may have trained as a social worker after discharge).
Former Clients (Alumni)	Peers who may have received early intervention services elsewhere and/or experienced services through a different treatment model	Less familiarity with, no personal experience of, and fewer direct ties to the program, but able to bring more of a comparative perspective. Like program alumni, have likely had a chance to develop additional skills or expertise.

### PEERS WITH AND WITHOUT PERSONAL EXPERIENCE OF PSYCHOSIS

Finally, most programs will likely confront the issue of potentially hiring peer staff both with and without specific personal experience of psychosis. Rationale for hiring peers without psychosis may include legal considerations and/or a need or desire to hire the most qualified applicant (regardless of diagnosis or particular treatment experiences). There appears to be little or no empirical evidence that diagnostically-matched peers are more effective or more likely to engage clients. The popularity of symptom- or diagnostically-specific peer groups (such as those organized by the Hearing Voices Network, Alcoholics Anonymous, and suicide attempt survivor organizations) might nevertheless be seen as indirect evidence of the potential value of such matches, at least under some circumstances.

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“I’m probably biased, as I have lived experience with psychosis, but I believe strongly that in a first episode, it is more helpful to have a peer who is truly a peer [experiencing the same] mental health condition, as they can better understand what the client is going through. It is my experience that I am more helpful to those persons who have had similar experiences to my own, although I am able to relate to a larger population.”

—Cheryl Farney, CRSS  
Peer Specialist, Psychosis Program  
University of Illinois at Chicago

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## Cross Cutting Considerations: Making Involvement Meaningful

Before moving into the specific sections covered by this guide, please consider a series of cross-cutting considerations (or best practices) of relevance to any project or program.

### 7 Peer Involvement Self-Assessment Questions

1. Have attempts been made to include peers *as early as possible* in planning a new initiative or program? (*Timing*)
2. Do peers have the *power to make decisions and shape programs*, or are they limited to “advisory” roles? (*Power*)
3. Are peers *financially compensated* in a manner equal to non-peers? (*Compensation*)
4. Is there a *critical mass* (or sufficient number) of peers involved to make a difference? (*Numbers*)
5. Have steps been taken to ensure that *peer wellness* is prioritized? (*Wellness*)
6. Has the program or organization *invested in peer capacity building*—e.g., paying peers to attend conferences and workshops and to learn new skills? (*Investment*)
7. Have program leaders or administrators taken explicit steps to ensure that peer perspectives are valued, and that resistance to peer involvement is systematically addressed? (*Organizational Culture*)

### TIMING

Ideally, peers will be ‘invited to the table’ as early as possible in the process of planning a new program or initiative. Early involvement helps to ensure that peer input is not an after-thought but rather a meaningful component of planning and development. Since key decisions are often at the beginning of a project’s lifecycle, early involvement also helps to maximize the impact of peer perspectives. For projects involving grants or funding applications, this means participation in the application process.

### POWER SHARING

In many settings, peer involvement remains limited to “advisory” positions in which peers have no actual control over decisions or policy. While advisors certainly play an important role (whether peers, clinicians or researchers), exclusively advisory roles are not a substitute for other forms of direct involvement. Ideally, at least some peers will occupy positions in which they have the power to make (or directly influence) decisions about

policy, program development and so on. This might include positions on governance and planning committees or a staff position with the authority to make more substantive changes to existing programs.

### FINANCIAL COMPENSATION

For better or for worse, financial compensation often (directly or indirectly) reflects the perceived value of employees or consultants (and the assumed value of their expertise, skills or level of responsibility). Compensation should, therefore, always be carefully thought through. In cases in which peers are involved in a voluntary capacity (e.g., as interns or unpaid support group facilitators or co-facilitators), administrators should do as much as they can to make these experiences skill-building and enriching. In addition, wherever possible, non-financial alternatives (such as academic credit, or credit for a “service learning” component of a class) should also be investigated.

### THE “CRITICAL MASS”

Beyond the fact that a single individual (or two) cannot possibly “represent” the interests of a diverse group of peers, it is easy for any solitary peer representative to feel uncomfortable speaking up in a project that otherwise includes only non-peers (at least some of whom are typically more senior).<sup>32</sup> Discomfort and reticence is likely to be even greater if there are also strong age differences (e.g., a youth or young person in a group that otherwise includes only “older” adults). A “critical mass” of peers, conversely, is likely to bolster peer confidence and involvement because any individual member can (in most circumstances) count on “back up” from other peer members. In addition, “critical mass” facilitates projects in which peers are able to check in with someone they feel will understand if they are feeling disempowered or “unheard,” or, for example, if a peer felt that a comment during a committee meeting was offensive but is not sure if they are “being over-sensitive” or “over-reacting.” Sometimes the ability to exchange a nonverbal wink or “knowing look” with a peer across the room during a meeting can make a world of difference.

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“It’s essential to have more than one peer (at least two, ideally more) on any board or committee in order to have meaningful peer input. More than once (as an ‘experienced’ committee member with some longevity and status), I’ve been in a position to ensure that a younger peer’s valuable contribution – something I would not have thought of, and didn’t initially agree with - was heard rather than “shot down” by the rest of the committee in question; the point she made actually was a key element of our final decision. Perhaps more basically and importantly, even the most experienced peer participants, advocates, and professionals need the support of at least one other peer to feel truly empowered to say what we really think, knowing that someone with some shared perspective is there to provide (often not necessarily stated) support.”

—Shirley Helm, MA  
Training Department, Thresholds

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### PRIORITIZING PEER WELLNESS

There are now a number of case studies and ethnographic research projects that warn against situations in which peer workers end up relapsing or feeling overwhelmed by work in clinical settings in which there is inadequate attention to wellbeing and/or poor planning around accommodations and/or medical leaves of absence.

It is therefore essential that efforts are made to work collaboratively with each peer staff member to figure out what supports are or might be needed (if any), including accommodations and an advance crisis plan (as relevant to the individual). In addition, employers should work to develop thoughtful and proactive accommodation and leave policies that take into account such factors as the often episodic nature of psychosis. Finally, it's important to call attention to the difference between prioritizing peer wellness and supports and "lowered expectations." Needing specific accommodations (usually only some of the time and under some circumstances) in no way means a given staff member is incapable of higher level work or would be an "unreliable" addition to a more intensive or ambitious project.



### INVESTING IN CAPACITY BUILDING

Active and intentional investment in peers' skills and capacities is critical. Peer specialists should not be seen as cheap labor but rather, as Jessica Wolf explains, positions with mobility (see Wolf expert Q & A, p. 55). The same is true of other types of entry level peer positions including evaluation assistants, outreach workers or assistants, and so on. In addition, wherever possible, programs should try to invest in high quality skill-building opportunities including sponsored travel to conferences, and participation in relevant trainings and workshops. Supervisors should encourage leadership in new projects and initiatives peer staff are interested in pursuing. Ideally, EIP administrators would view peers (and young adult clients) as future leaders in peer-led project development, clinical work, policy advocacy, and research.

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“Good human resource practice suggests the importance of clear job descriptions and specific position requirements, consistent supervision and regular interactive employee performance assessment, together with awareness of and attention to building competencies and career paths for behavioral and integrated healthcare workers and direct service workers in general. This is especially important for young entry-level workers, as their initial learning about career development can help shape their attitudes and performance.”

—Jessica Wolf, PhD  
Decision Solutions & Yale University

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## ADDRESSING ORGANIZATIONAL CULTURE

Finally, areas of resistance to peer involvement (or even outright stigma or disparaging attitudes) should be proactively addressed as quickly and efficiently as possible. In some cases this might involve private dialogue with particular staff members; in others, group discussion or a peer-involvement or diversity “in-service.” If necessary, external consultants can be brought in to facilitate such an in-service as is common with respect to other areas of diversity (e.g., consultant-led in-service days on racial or LGBT diversity



and inclusion). While in-services and consulting fees can be (relatively) expensive, in the long run these costs can be easily justified in situations in which there are significant impacts on organizational culture, support for peer involvement and improved working relationships between peers and non-peer staff. Organizational leaders should also “model” respectful and collaborative attitudes. For example, by making a point of asking peers for their opinions (and taking these seriously), crediting peers with important ideas and feedback during higher-level governance meetings, and so on. Thoughtful integration of peers within an EIP service can also help call attention to less obvious aspects of organizational culture such as language used during team meetings.

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“[Another] area of great impact a peer can have on a team is on other team members’ thoughts and language when discussing clients and diagnoses. A peer often can help keep pejorative language out of our conversations, and thus our thoughts/approaches as well. With a peer on board, our team’s use of words like “crazy,” “sick,” “noncompliant,” “self-destructive,” and other similar terms decreased. In their place, we used more recovery oriented terms, such as “symptomatic,” “ambivalent,” “struggling,” “coping,” “seeking comfort,” etc. This led to us seeking more client input and feedback, which in turn helped empower the clients, and helped them feel more heard and understood.”

—Neil Falk, MD  
Psychiatrist, EASA Multnomah County

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## Diversity, Intersectionality & Peer Involvement

Attention to racial, ethnic and cultural diversity, as well as other (intersecting) minority identities, is of enormous importance to early intervention services in general as well as peer involvement efforts more specifically. Even today, most ethnic/racial minority groups remain significantly under-represented in mental health services, across the professions.<sup>33</sup> The same is true for members of many other sociopolitical minority groups, including individuals from disadvantaged socioeconomic backgrounds, persons with physical or learning disabilities, and members of the LGBT community.<sup>34</sup> Under-representation has been less well-documented among peers (and within the broader peer movement), but remains a serious issue



The importance of attending to diversity is arguably even greater within early intervention services due to the often complex intersections between psychosis (and symptoms), mainstream Western treatment models, and culture/race/ethnicity.<sup>35</sup> A study of the EIP experiences of young adults and community carers from ethnic/racial minority backgrounds in the U.K., for instance, found that clients frequently sought help from spiritual/faith healers and viewed religious and cultural practices and philosophies as deeply entangled with the experience of psychosis.<sup>36</sup> The researchers also found that EIP practitioners were frequently unfamiliar with minority clients' cultural and religious needs and uncertain how to distinguish between culturally normative unusual experiences (such as speaking in tongues) and psychosis. Broader research on cultural variation in psychosis has identified significant differences in the content of voices, the form symptoms take and the impact they have on the affected individual.<sup>37</sup> Significant differences have also been identified in “pathways to care” across minority groups (i.e., the typical “paths” young adults follow in seeking initial treatment following a first break).<sup>3</sup>

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“We had . . . a Baptismal Service, and, quite a number of the staff came, and one of the service users suddenly spoke in tongues, . . . The result of that was a bit of a shock wave, and his psychiatrist was thinking of upping his medication . . . So of course I was then able to speak to that particular consultant psychiatrist . . . I acquainted him to the fact that according to, the Christian Scriptures, this was something that was happening in the early Christian days, with all the early Christian leaders in the beginning, and from time to time it happens. So this chap said, this psychiatrist said, “Oh, so I don’t need to up his medication?” I said, “No, . . . this happens.”

—*Minority spiritual care representative*  
Quoted in Islam et al. (2015)

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“Well, I think this is where it’s important that the health care professionals and the psychiatrists or consultants and the nurses, work with the Imams and try and understand Islamic perspective on mental health . . . these are the things that one needs to look at, . . .which would differentiate from, someone, suddenly going into this transit of speaking in tongues [or becoming mentally unwell].”

—*Minority spiritual care representative*  
*Quoted in Islam et al. (2015)*

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Virtually all the arguments made in support of general peer inclusion apply equally to the question of minority group inclusion. For some young people, racial/ethnic (or other minority) identities may be more important than experiences of psychosis when it comes to engagement or feeling understood. For young people who are learning English as a second language or who have only recently emigrated from other parts of the world, cultural identity and preferences for engaging with peers who speak their native language may be even stronger.

For all these reasons, minority and racial/ethnic diversity—ideally reflecting the local communities served as closely as possible—should be a driving consideration in all inclusion initiatives. When minority diversity, for whatever reason, is not reflected in a given project or initiative, this should always be made clear. For instance, an engagement guide created by an all-white group of youth should acknowledge potentially significant cultural or other group differences up-front. Disparities in engagement or participation should always be treated as red flags that potentially point to broader organizational problems (with diversity or cultural sensitivity) that likely need to be addressed regardless.

Finally, as with all other EIP service staff and volunteers, peers of all races and backgrounds should receive training in cultural sensitivity (or humility) and culturally-informed care.<sup>39</sup> Ideally such training would be psychosis-specific and include discussion of possible differences in the form and content of symptoms, in explanatory frameworks, and in treatment preferences and context.

On the pages that follow are Question and Answer (Q & A) segments with two peer experts that highlight some of the points made in this introduction section of the guide.

## Ethnic/Racial Minority Issues in Early Intervention

### EXPERT Q & A: JAYASREE KALATHIL, PHD

Jayasree Kalathil is a peer researcher in the U.K. and an internationally recognized expert on racial/ethnic considerations in the context of mental health services and research. She leads [Survivor Research](#), a virtual collective of user/survivor researchers and trainers interested in promoting critical perspectives in mental health, especially around issues of marginalization and minoritization. Her publications include: *Dancing to Our Own Tunes*, exploring black mental health service user involvement; a report on black women's recovery narratives entitled *Recovery and Resilience*; and the children's book *The Sackcloth Man*.

**Q:** *Why is it essential to think critically about race and diversity (and move beyond tokenism & rhetoric) in any/all early intervention peer involvement efforts?*

**A:** I have to start by saying that I do not know of any early intervention service that centrally employs peer involvement and addresses issues of racial and cultural diversity. So I am going to talk about black and minority ethnic peer involvement in crisis care more generally.



There is decades of evidence, at least in the U.K., about the fact that mental health services are failing to meet the needs of people from black and minority ethnic (BME) communities. People from many of the BME communities are more likely to be diagnosed with schizophrenia, involuntarily committed, sectioned under the Mental Health Act, put in seclusion, over-medicated, and given a Community Treatment Order, when compared to white British communities.<sup>1</sup> Meanwhile, they are also less likely to be referred for psychological therapies<sup>2</sup>, including the Improving Access to Psychological Therapies (IAPT) service rolled out by the NHS<sup>3</sup>.

The evidence on access to and experience of EI services, by contrast, is not as well documented, as there is limited research in this area. There is some evidence to show that BME communities are more likely to access statutory services, brought to them under the powers of the MHA, when in severe crisis rather than early on. Many reasons have been posited for this: some of it places the onus within communities, such as the existence of stigma about mental health issues within communities and lack of awareness about mental health, while others point to more structural issues. An important piece of work in 2002 found that negative views about black people (the 'big, black and

<sup>1</sup> See, for example, Care Quality Commission (2014) *Monitoring the Mental Health Act in 2012-13*. London: CQC; Karlsen, S., et al (2005) 'Racism, psychosis and common mental disorder among ethnic minority groups in England'. *Psychological Medicine*, 35, 1795–803; NIMHE (2003) *Inside Outside: Improving Mental Health Services for Black and Minority Ethnic Communities in England*. London: Department of Health.

<sup>2</sup> Mind. *We Still Need to Talk: A Report on Accessing Talking Therapies*. London: Mind.

<sup>3</sup> Glover, G and F Evison (2009) *Use of New Mental Health Services by Ethnic Minorities in England*. North East Public Health Observatory.



dangerous' stereotype, for example), racism and cultural ignorance undermined the way in which mental health services responded to their needs and caused heavy reliance on medication and coercion. Meanwhile, the existence of high rates of coercion within services and lack of personally and culturally appropriate care choices left service users and families reluctant to approach services for help, thereby increasing the likelihood of crisis. This provoked even more coercive responses "resulting in a downward spiral, which we call 'circles of fear', in which staff see service users as potentially dangerous and service users perceive services as harmful."<sup>4</sup>

The continuing existence of this situation was pointed to in a recent study which looked at ethnic variations in pathways into EI services, and suggested that "reducing coercive routes to services that may well contribute to subsequent high rates of disengagement from services and compulsory treatment" is a key challenge for EI services.<sup>5</sup>

The situation described above points to the need for a much more critical look at issues of 'race' and culture within services. Current discussions do not, in my opinion and experience, go beyond a generic argument for increasing diversity. The focus on issues of 'race'/culture within services and ensuring race equality within services has pretty much disappeared from public policy. Views on peer involvement (or user involvement as it is known in the U.K.) have long argued that, for any meaningful involvement to take place, there needs to be a fundamental shift in hierarchies of power, decision making, leadership and, crucially, in the structures of forums where involvement takes place. Policy frameworks for involvement seem to assume that collaborative work between those with personal experiences of using services and those who provide them will take place without challenges. For example, the Department of Health in its statement about patient and public involvement posits an ideal situation where participants in involvement forums will rarely need to be adversarial and will be able to work in a positive and collaborative manner. But if your experience of service is negative – because of compulsion, coercion, or racism – you are not going to be able to work collaboratively unless involvement forums allow safe spaces for discussing difficult emotional journeys through services.<sup>6</sup> I am yet to see good examples where such important initial preparatory work takes place.

A second issue is about who gets involved (as peer staff, advisors, ambassadors and so on). User involvement forums continue to be marginalising and inaccessible to many BME service users – we are still considered 'hard to reach'.<sup>7</sup> Lack of involvement has implications not only for changing the nature of services delivered but also for how knowledge about racially and culturally appropriate services is developed and produced.

<sup>4</sup> Keating, F, Robertson, D, McCollough, A and Francis, E (2002) *Breaking the Circles of Fear: A review of the relationship between mental health services and African and Caribbean communities*. London: Sainsbury Centre for Mental Health

<sup>5</sup> Ghali, S., et. al. (2013). 'Ethnic variations in pathways into early intervention services for psychosis'. *The British Journal of Psychiatry*, 202.4: 277-283.

<sup>6</sup> Blakey, H (2006) 'Participation: Why bother?' *Mental Health Today*, May, 23-26.

<sup>7</sup> For further on this see Kalathil, J (2013) "'Hard to reach"? Racialised groups and mental health service user involvement'. In *Mental health service users in research: Critical sociological perspectives*, ed. P Staddon. Bristol: The Policy Press.



There are many examples where peer involvement works well for people from BME communities in other types of services. However, it has also been argued that there needs to be an expansion of the meaning of the term 'peer' to include a focus on other shared identities beyond those of service use or experience of a mental health problem. For example, in a study that explored the values and principles of peer support, 75% of the participants said that "a peer needed to have more than a shared personal experience of mental distress in common with them;" and 66% of participants from BME backgrounds said that "a shared ethnic and cultural background would be important in a peer."<sup>8</sup> "Being black people together", where racialised and cultural experiences both within society and in mental health services and their implications for mental health/distress can be discussed and shared without fear, was a key aspect of how the projects studied for this work defined peer support.

There is some evidence to show that community and faith based crisis resolution has some positive impact in meeting the needs of people from BME communities, but this is often dismissed as unhelpful as it prolongs the journey into psychopharmacology. Perhaps what is required is to explore the possibility of more community based services that are equipped to deal with the crisis of psychosis rather than thinking about EI as only possible within the structures of statutory services.

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<sup>8</sup> Faulkner, A and Kalathil, J (2012) *The freedom to be, the chance to dream: Preserving the values and principles of peer support*. London: Together.

## International EIP Advocacy

### EXPERT Q & A: STEPHANIE WEBSTER

Stephanie Webster is an Australian consumer educator and advocate, with a graduate diploma in adult education, and she is currently completing a Master's in public health. Stephanie has been involved in multiple lived-experience educational initiatives over the past decade and began EIP-specific advocacy in 2011. She is a member of the International Physical Health in Youth Stream (iphYs) of the International Early Psychosis Association (IEPA) and was the sole consumer member of the core writing team for the iphYs' Healthy Active Lives (HeAL) 2013 Consensus Statement. HeAL focuses on physical health outcomes in youth with psychosis and has been endorsed by numerous international health organizations. Stephanie has spoken locally and internationally on the life expectancy gaps for persons with psychosis related issues at the intersections of drug prescribing, physical health effects and medication-related decision-making.

***Q:** As one of the only peer advocates involved in international early intervention physical health advocacy, how would you describe the current level of peer involvement and leadership?*

**A:** I was fortunate that when I reached out to the leaders of the emerging iphYs collaboration (Dr. Jackie Curtis, Dr. David Shiers, and the late Professor Helen Lester) in 2011, they welcomed the inclusion of a peer educator in an early conference. None of us had actually met before that date. I have had many experiences in advocacy over the years where reaching out to professionals has not resulted in meaningful engagement. Sometimes emails go unanswered and thoughtful questions about involving peers in current or future activities are met with a 'we have to think more about that' kind of response with no further action. This reliance on being 'invited in' by specific people with an openness to hearing more doesn't constitute structural involvement.

***Q:** What needs to change?*

**A:** People with lived experience need to be embedded in the education of health professionals at the university level so that emerging workers see that centering lived experience is at the heart of mental health practice. I would also like to see training delivered on rights, ethics and social perspectives of health in psychiatry.

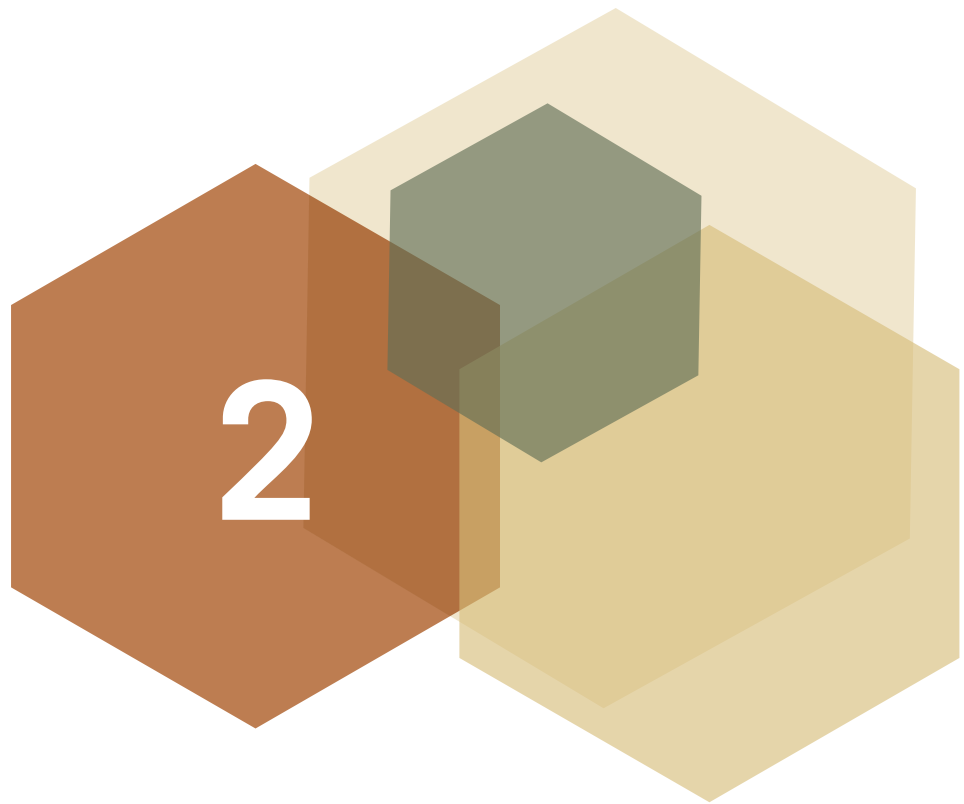
*Q: How do you think exposure to peer perspectives affects clinicians and researchers?*

**A:** It raises questions they have never asked themselves before. For example, hearing what it is like to sit through a three day conference on psychosis as a consumer (when not one consumer spoke) really moved the leaders in the HeAL initiative to become advocates locally and within IEPA.

*Q: What advice do you have for U.S. policy makers, clinicians and researchers contemplating greater peer involvement in early psychosis programs and initiatives?*

**A:** Researchers can play a central role in advocating for peers in the education of health professionals and can contribute to peer capacity building. Policy makers can embed expectations of peer positions in programs they fund and ensure that there is a critical mass of peers in all major decision making forums. Clinicians can advocate within their own settings and educate themselves on issues of importance to the peer movement.

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## Program Planning, Policy & Development

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While it is much harder to study or document the impact of peer involvement in program planning, policy and development (particularly at the national or state-level), common sense tells us that the implications of broader policy decisions are often profound. Involvement is therefore not just important because of the effects it has, but for social justice reasons—i.e., the “right” of those with psychosis to help shape policies that directly affect them.

Most readers are likely familiar with the concept of “tokenism.” The Oxford English dictionary defines tokenism as “the practice or policy of making merely a token effort or granting only minimal concessions, especially to minority or suppressed groups.” For example, one or two members of an under-represented group might be asked to join a committee or advisory board of 20 or 30 and with little real support or investment in making sure that their voices are heard and perspectives centered. Similarly, peers might be invited on to a project as “advisors” (thus allowing planners to “tick a box”) but without having any actual influence over decisions. Because of the importance of moving past

tokenism—which remains pervasive—and instead supporting meaningful involvement, much of this section focuses on what this means and how to make it a reality.<sup>40</sup> Arguably, meaningful participation involves not only the individuals included as community “representatives” on particular boards or committees, but also the extent to which project or policy leaders engage (and ideally partner) with the broader community, including existing peer organizations and advocacy networks. This section thus begins with a brief overview of strategies derived from strengths-based community planning models.

### A STRENGTHS-BASED, COMMUNITY-ENGAGED APPROACH TO PLANNING

One option to consider is a strengths-based and community-engaged approach to planning, such as asset-based community development (ABCD).<sup>41</sup> Like other

empowerment oriented models, ABCD seeks to identify and build on local and regional strengths and de-emphasize community limitations, problems or pathology. For instance, planners might acknowledge the negative consequences of recent state-level cuts to mental health services, but at the same time take stock of (and build on) the strengths of a coalition of service and advocacy organizations that joined forces to contest these cuts (and learned to work together in the process). These strengths (or assets) at the level of grassroots organizing and inter-organizational collaboration could then be explicitly incorporated into planning and development projects.

ABCD also emphasizes stakeholder engagement, participation and leadership. Planners are directed to engage with community members as leaders and participants in policy and service development rather than passive recipients. Solutions are thought to lie in the community, even though time and resources

may be needed to uncover these solutions and transform them into policy or action. ABCD also emphasizes community building (whether within a small planning committee or across five counties): social change happens when stakeholders feel connected to each other, and invested in working toward common rather than competing goals. The Asset-Based Community Development Institute at Northwestern University provides a range of free tools and resources, including asset mapping instruments and a detailed toolkit developed at Monash University (see links in the Appendix). The importance of some form of asset mapping, or the systematic identification of community assets, cannot be overstated. All too often, policy makers, planning committee chairs, or contractors in fact have little knowledge of the breadth of peer expertise available in a given region.



Principle	Description	Considerations
<b>Focus on community assets</b>	Community strengths and assets emphasized	Existing peer & professional advocacy coalition formed in response to funding cuts
<b>Stakeholder leadership</b>	Community stakeholders as project leaders rather than service recipients	Peers and family members lead or co-lead new EIP service planning and development efforts
<b>Community building</b>	Focus on strengthening a sense of connection and shared purpose among stakeholders	Activities are developed that bring together professionals, peers and family members in order to increase a sense of solidarity and shared purpose
<b>Asset mapping</b>	Systematically map a community's existing assets	Identification of all existing peer-run organizations and groups, as well as peer consultants or trainers whose programs, skills and expertise might be tapped in the context of EIP implementation
<b>Partner with existing peer-run organizations</b>	Where appropriate, partner with existing peer-run organizations and tap their strengths	An external peer-run organization provides an EIP service with trained facilitators
<b>Transparency &amp; open process</b>	Selection and involvement of stakeholders should be transparent and, if possible, an open process	Open application process for advisory board members and transparent selection criteria
<b>Project-member match</b>	Stakeholder representatives or committee members should have experience, backgrounds, skills and abilities that "match" the project or committee	A state planning committee chooses an EIP alumni who moved to the area from another state, and a local doctoral student with evaluation skills and experience of psychosis

*Table 1. Overview of Best Practices in Program Planning & Development*



### Partnership with existing peer-run organizations and initiatives

From a practical perspective, one of the cornerstones of a strengths-based approach in the area of early intervention planning is the identification of existing peer-run organizations and initiatives. For instance, high schools, colleges and universities may have existing campus-based mental health organizations such as Active Minds. Local communities may host a variety of mental health mutual support groups, peer-run advocacy or support organizations, or youth mental health initiatives. There may also be state-wide consumer networks or coalitions or peer-run programs embedded within community mental health centers. Many cities are also home to peer evaluation and/or research consultants, as well as peer clinicians.



Existing peer-run organizations (PROs) and groups are important for both state-level and program-level planning and development efforts. At the state-level, for instance, PROs can help ensure program stability through lobbying and direct advocacy around (continued) funding. At the program level, it may be easier and more cost-effective to partner with a PRO that provides certain services (such as support groups) than to offer them directly. Collaboration with external PROs may also help ensure continuity of engagement during and following EIP discharge and/or be able to provide additional services that a particular EIP service does not have or cannot fund.

### Transparency and open process

Ideally, decisions about who is (or has been) invited to participate in a particular planning group or initiative should be as transparent as possible, particularly when public funds are involved. Wherever possible, there should be a public application process for advisory or steering committee members. “Behind the scenes” appointments can easily lead other groups or individuals to feel excluded or devalued, and negatively impact a sense of broader (shared) investment in a particular project by many different groups.

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“I heard about this working group that [my program] put together, and another peer was invited, and I didn’t know why [she was but not me]. I didn’t say anything about it, but it made me question my own value, and after that I stopped trying to get more involved.”

—*Early Intervention Alumnus*

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### Stakeholder-project “match”

While it is never possible to perfectly match a given development project with stakeholders, it is nevertheless important to at least consider the extent to which the community members who are invited to join have knowledge of early intervention services or models, youth mental health, and psychosis or (at a minimum) are invested in learning about these issues. Some community-based research methodologists have gone even further in recommending systematic analysis of any potential board or committee member including assessment of their skills and ability to contribute, their reputation in the community and potential conflicts of interest. A more targeted board or group (for instance focused on evaluation) might want to consider potential member’s evaluation or research background, understanding of basic methods, and familiarity with human subject protections and associated research ethics.




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“Peer involvement in policy and planning requires that there be a reasonably “deep bench” of peer contributors who have a certain level of expertise and savvy, who have had the opportunity to develop subject-matter knowledge, as well as the confidence to contribute and be taken seriously. This is not to say that the life experience of other peers is not important and should not be solicited and valued, but it can be all too easy to discount the perspective of someone who doesn’t have some knowledge of a broad range of relevant issues.”

—Shirley Helm, MA  
Training Department, Thresholds

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Unfortunately, “real world” advisory board and committee slots often include individuals selected primarily for reasons of convenience rather than project fit. One potential consequence is that, on the surface, a particular key stakeholder group (such as “consumers” or “peers”) appears to be represented, but the representative in question is in fact unable to meaningfully weigh in on or contribute to the project in question (or is not especially interested or invested).

### STATE-LEVEL INVOLVEMENT

**Boards and Committees.** Involvement or representation on boards and/or committees is one of the most common, and in some ways easiest, ways of involving peers and other stakeholders in a new policy or planning initiative. The best practices discussed in the introduction and above apply: participation ideally needs to begin as early in the planning process as possible and to include decision-making authority, not just advisory responsibilities. A critical mass of peers should be involved, and participation should also be premised on a broader membership (and project leaders) who genuinely value peer perspectives. For youth in particular (or any member lacking experience on a state-level board), an orientation of some kind should ideally be provided.

**Lobbying and Legislative Activity.** In addition to serving on state-level development, planning or oversight boards, committees and working groups, peers might assume leadership roles in lobbying efforts and policy advocacy, or testify at state (or federal) house and senate hearings.

As for many other issues and constituencies, those most affected by policy changes are often their own best advocates if provided with appropriate tools and encouragement. NAMI National's planned early intervention policy toolkit (see spotlight on p.32) is a powerful example of the sorts of supports and investment that can help grassroots peers and family members to influence local policy makers.

**Ensuring peer involvement in contracted activities.** State-level advisors and administrators can also help ensure greater peer voice by mandating a peer involvement plan as part of any Requests for Proposals (RFPs), using peer involvement as a selection criterion, and requiring that contractors, once selected, document peer involvement. In some cases it might also make sense to independently administer satisfaction and/or involvement surveys to stakeholders with whom a contractor works. Failure to do so can reinforce the often implicit message that contractors need only propose peer involvement without having to follow through on it or take the time and effort to make sure that such involvement is meaningful and sustained over the course of the project.

## PROGRAM-LEVEL INVOLVEMENT

Virtually all the discussion points covered above apply equally to program level planning and policy. There are a few additional involvement areas also worth mentioning, however. These include involvement in hiring committees, research approval committees, and in decision-making concerning relationships or collaborations with external organizations.

- **Hiring Committees.** Stakeholder or service recipient inclusion on hiring committees is increasingly common (for instance, even some high schools include students on hiring committees for new teachers). A large part of the rationale is that those who will be (or have experienced being) on the receiving end of the services a new staff member is being hired for are often able to ask important questions that others might not think of and/or detect potential problems or tensions with a prospective employee.
- **Research Approval Committees.** Research directly affects clients and can also help set the tone for services in a particular clinic. Programs that already operate a research approval committee should therefore strongly consider including clients and/or peer staff and carefully weighing their opinions regarding the impact of proposed projects.
- **External Collaboration.** Finally, external collaborations can significantly impact clients and the services they receive. Beyond a general right to be involved, clients and/or peer staff may have access to information about potential external organizations that other staff do not, or otherwise be able to weigh in on impacts due to their unique perspective.

## Concluding Remarks

While the general motto “the more involvement, the better” certainly holds in planning and policy, it is important to reiterate the importance of ensuring that such involvement is meaningful. Honesty, reflexivity, and attention to underlying power dynamics can all go a long way in this sense. Sometimes this may be as simple as stopping and taking the time to imagine whether or not one would feel comfortable voicing an opinion if one were in the shoes of a particular peer involve in a given committee or working group.

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## Spotlight

### State Early Intervention Planning: Vermont

In order to facilitate the planning and implementation of early intervention services under the Community Mental Health Services Block Grant 5% set-aside to address first episodes of serious mental disorders, the state of Vermont has partnered with the Vermont Cooperative for Practice Improvement (VCPI). Because Vermont is a small, rural state with a very low mental health block grant allotment, the set-aside steering committee faces a number of unique challenges and have devoted the first year of the set-aside to planning, training, and infrastructure development.

During this planning phase, the VCPI has taken multiple steps to ensure robust peer, family and stakeholder inclusion in all aspects of project development and decision-making. The projects' steering committee (SC) includes representatives from a diverse array of different Vermont-based projects and organizations, including peer-led or peer-informed initiatives such as Soteria Vermont and those piloting innovative practices such as Open Dialogue. VCPI has also actively sought out external peer consultants who, along with steering committee members, will be directly involved in a planned statewide needs assessment and environmental scan. The needs assessment itself also seeks to center the perspectives of peers and family members through interviews and/or focus groups aimed at better understanding local needs and priorities.



Asked to comment on the importance of meaningful peer inclusion in planning, research and implementation, VCPI Executive Director, Sarah Squirrell, reports, “Everything we do, at every level, should be about the needs, hopes, goals and dreams of people and families seeking help and wellness. It is our responsibility and in our best interest as a system of care to ensure that the personal and familial experiences of peers inform the identification and adoption of appropriate practices and treatment approaches.”



## Policy Spotlight

### NAMI National's Early Intervention Policy Toolkit

NAMI National is currently developing a dedicated policy toolkit for NAMI grassroots leaders, representing peers and families, to work at the state and local levels on early intervention program dissemination. The toolkit will provide materials to help educate state legislators, policy makers and other community leaders regarding the importance of early intervention and the broader implementation of early and first episode psychosis programs.

The toolkit will also address the following key issues:

- Building political will and steps toward incremental change.
- Current sites, growing momentum and sustainability.
- Research outcomes and promising data to make the case.
- Funding early and first episode psychosis treatment.
- Building workforce capacity.
- States achieving success in dissemination.

**In addition to the toolkit, NAMI is also planning the following direct policy activity:**

Meeting with major health insurance companies and the Center for Medicare and Medicaid Services (CMS) to ensure that the full array of coordinated specialty care components provided for early and first episode psychosis treatment (including educational and vocational supports) is covered by both private insurance and Medicaid plans.

Working on targeted outreach and technical assistance with two to four states in 2016 to secure commitment and advances on statewide expansion of early and first episode psychosis programs.

Developing strategic partnerships with other national organizations involved in early intervention programs to work collaboratively on the broader dissemination of these programs.

Asked about the importance of advocacy geared toward funding and financial sustainability, Darcy Gruttadaro, Director of NAMI's Child and Adolescent Action Center reports that, "NAMI represents individuals experiencing early and first episode psychosis and their families, and we see the tremendous role we can play in working to ensure that these programs are more broadly disseminated around the country."





## Advocacy Spotlight:

### NAMI National's Early and First Episode Psychosis Learning Community

In early 2015, NAMI National formed an early psychosis learning community (LC) with the goal of educating and engaging grassroots leaders (mostly family members and peers) about research and program development in early intervention. Currently, 40 different NAMI state and/or affiliate leaders are involved. The LC meets monthly by teleconference with an annual meeting planned in conjunction with NAMI's annual convention. NAMI has also developed a dedicated early psychosis web-section ([www.nami.org/feplearningcommunity](http://www.nami.org/feplearningcommunity)) that links to the research and program initiatives around the country and will include fact sheets and high impact resources designed to facilitate and strengthen local advocacy efforts.

#### **Additional projects the LC is currently planning include:**

- Opportunities for NAMI affiliate leaders to meet and exchange information with leading early intervention researchers and program directors, as well as lateral contact between NAMI leaders in different states.
- Targeted work on effective dissemination of best practices and the development of strategies to work with local policymakers.
- Adapting existing NAMI educational programs, including Ending the Silence (a 50-minute health or psychology class for middle and high school students) and Parents and Teachers as Allies (a 2-hour in-service program for school personnel on mental health conditions) in order to better cover early warning signs and early intervention.
- Strengthening collaboration between NAMI's policy, communications and education teams in order to create broader visibility on the importance and benefits of early identification. These efforts will be primarily focused on outreach to communities and child-serving systems.

Darcy Gruttadaro, Director of NAMI's Child and Adolescent Action Center, underscores the importance of both national and local peer and family advocacy around early intervention: "There is tremendous promise in the early and first episode work because it provides young adults the services and supports they need to keep their lives on track and the key role that families play in their recovery."

## Program Spotlight:

### EASA Young Adult Leadership Council

The Oregon Early Assessment and Support Alliance (EASA) statewide Young Adult Leadership Council was established in April 2013 to help shape the direction of EASA and broader system development, emphasizing participatory decision-making and peer support. The Leadership Council's vision is **“to unite the voices and strengths of young adults and their allies to create a thriving community and a revolution of hope!”**

Their mission is to guide the direction of the EASA program by providing an experience of healing and growth, creating an outlet for expression, educating and supporting EASA participants and graduates, responding to, gathering and using feedback, and advocating for change.

Leadership Council members have participated in a wide range of activities including speaking at EASA graduations and workshops, developing and implementing staff training, reviewing and analyzing outcome data, developing methods of supporting people new to the program, reaching out to policy makers and the community, and identifying long-term needs for support. The Leadership Council has developed a set of recommendations regarding housing supports and works with Oregon Health Authority on policy development. They played a significant role in designing and implementing a statewide conference in 2013, titled “Truth Spoken, Silence Broken” focused on EASA clinicians, participants, family members and the mental health community. They are currently building an EASA participant survey, designed to solicit feedback and improve services, reviewing the Introduction Training for EASA clinicians to provide feedback, and will soon embark on reviewing and recommending changes to the EASA Practice Guidelines which provide the framework for EASA's structure and activities.



**Christina Wall, the Council's current coordinator, also responded to a few more practical questions, as well:**

**Q:** *Who are the members and how many are there?*

**A:** Participants are both current and former EASA clients. Currently we have 9 members, but that can fluctuate--the group has decided at this time not to cap how many can be on the council.

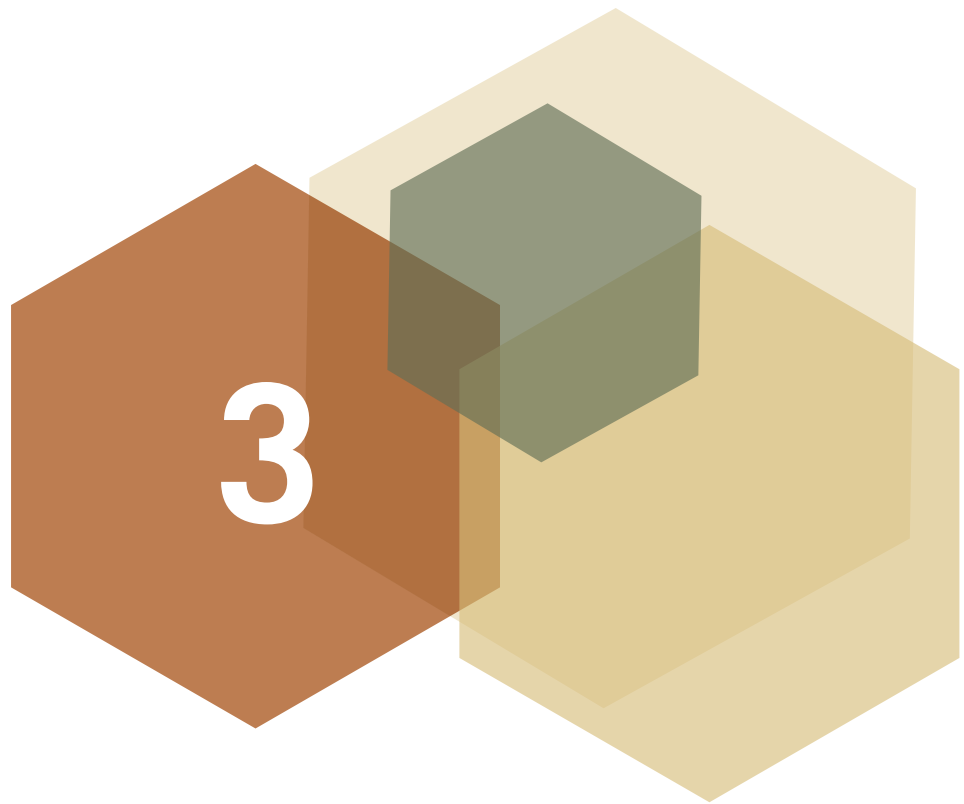
**Q:** *How often does the council meet and how are the members compensated?*

**A:** The council currently meets once a month on the second Saturday from 10am-2pm. They are paid an hourly stipend and can be reimbursed for travel. They can also get paid for doing outside committee work, such as speaking at a multifamily group, manning a table at a health fair or other community event, or other various things we might do outside the monthly meetings. Most of the council members are also going to school and/or working another job.

**Q:** *How are new members recruited and how do they officially join the Council?*

**A:** Recruiting started with reaching out to the counties that had an EASA program and speaking with the clinicians, occupational therapists, peer supports and others. They were encouraged to refer clients that they felt would be interested. Those interested fill out an application. We provided both paper applications and it is also online at [easacommunity.org](http://easacommunity.org). Recruiting continues this way, as well as the council members talking about it at various meetings, conferences and by word of mouth. All council members read each application, meet with potential members, and then make the decision as to whether or not invite the applicant to join the council.

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## Direct Services: Peer Specialists & Peer Support

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Peer-led services and supports have a long history in the U.S., and different models or programs are increasingly recognized as evidence-based and/or emerging best practices.<sup>42</sup> Across the nation, trained or certified peer specialists can now bill Medicaid for their services, and programs and/or state agencies are also often able to tap additional funding for a broader range of peer support activities. A growing number of early intervention programs have at least some peer support component in place. This section of the guide has three major aims: (1) to review the evidence and thinking behind peer support; (2) to discuss the different forms that peer services can take and their relevance to early intervention settings (e.g., peer groups, embedded peer specialists); and (3) to provide practical guidance on issues such as peer specialist recruitment, training and support within early intervention settings.

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“Peer support services are an evidence-based mental health model of care that consists of a qualified peer support provider who assists individuals with their recovery from mental illness and substance use disorders. CMS recognizes that the experiences of peer support providers, as consumers of mental health and substance use services, can be an important component in a State’s delivery of effective treatment.”

—Center for Medicare and Medicaid Services,  
Letter to State Medicaid Directors, 2007

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## EVIDENCE AND MECHANISMS

In an influential early article, Phyllis Solomon describes key processes underlying peer support: social support; experiential knowledge; social learning; social comparisons; and the helper-therapy (or helper-helpee) principle.<sup>43</sup> Each of these components is discussed below:

- **Social support.** Social support can be broken down into dimensions that include: emotional support (empathy, sense of being understood); informational support (referrals to external advocacy groups or legal aid, advice on negotiating accommodations); and instrumental support (e.g., offering to give another peer a ride to an event of shared interest). Overall, social support helps individuals feel: like they are part of a community; that they matter to others; and that others are invested in their wellbeing (and not because they are paid to do so).
- **Experiential knowledge.** Experiential knowledge refers to the knowledge one acquires through doing things (for example the “active work” of recovery), as well as undergoing experiences outside of one’s control (a first break, hearing voices). Just as a surgeon masters the art and science of surgery not just by reading a textbook but through real-world practice, direct experience of psychosis and recovery often imparts knowledge, understanding and insight that is unavailable to persons without these experiences.
- **Social learning.** Social learning theory stresses the importance of learning that takes place in social contexts through the observation of (and interaction with) others. While a client might be “taught” how to manage distressing thoughts in therapy, for example, participation in a support group can provide direct exposure to others who are actively “enacting” a variety of coping strategies or self-management techniques. Consequently, these individuals may be seen as more “credible” sources of knowledge about coping or recovery.
- **Social comparisons.** So called “upward social comparisons” describe a function of social situations in which an individual is exposed to a peer who is successfully managing her life and symptoms, and serves as a kind of living proof that it is possible to weather the challenges of psychosis (including societal prejudice) and/or flourish in spite of them. Upward social comparisons may help kindle hope and positive group identity and counteract internalized group stigma.

- **Helper-therapy principle.** Finally, the helper-therapy principle holds that individuals often derive an array of personal benefits from helping others. In settings such as a support group in which “help” is reciprocal (i.e., everyone is both a helper, at times, and helpee at others), all members collectively benefit from an increased sense of personal efficacy, group efficacy, and empowerment. Instead of having to turn to outside “experts” for help and solutions, peer group members are able to uncover their own “in-group” expertise, authority and capacity for learning and growth.

Unfortunately—at least from the perspective of evidence-based mental health—empirical documentation of the impact of peer supports (particularly participation in naturalistic, open-ended peer support groups) is difficult. Available experimental and observational methodologies often struggle to map out the many ways in which peer support may impact individuals.<sup>44</sup> As is true of peer supports in substance use and addiction, the multi-methods evidence base for peer support continues to grow.<sup>45</sup> For instance, a recent systematic review and meta-analysis of randomized controlled trials (RCTs) of peer-led interventions identifying three high quality studies in which peer interventions increased quality of life and hope.<sup>46</sup> In a recent study focusing specifically on individuals with psychosis from ethnic/racial minority backgrounds, Larry Davidson and colleagues (2012) found that the addition of a peer-facilitated person-centered planning component significantly increased engagement and sense of control over treatment, while a peer-led community connector component increased quality of life, positive self-regard, and sense of community belonging.<sup>47</sup> Similarly, Judith Cook and colleagues’ rigorous studies of WRAP have demonstrated impacts not only on symptoms, hope and quality of life, but also patient self-advocacy with providers.<sup>48</sup>




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“I have been a researcher evaluating integrated peer service delivery models for more than 20 years. Whether the projects are about mental health, people with HIV/AIDS, or other chronic health conditions, we have consistently seen the influence of peer supports on promoting wellness and recovery. There is perhaps nothing more powerful than lived experience and the ways in which people can support others with their contributions as services providers and advocates.”

—Lisa Razzano, PhD, CPRP  
University of Illinois at Chicago

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### Developmental context

While peer support, and certainly social support more broadly, is important for persons of all ages and backgrounds, it may play a particularly important role in the lives of youth and young adults. Adolescence and young adulthood typically encompass multiple major life transitions, intense personal growth and change, and the consolidation of personal and



social identity, sense of self, and personal goals and values.<sup>49</sup> Young people tend to be much more strongly invested in same-age peer relationships than older adults, and also more negatively affected by social exclusion and isolation.<sup>50</sup> Finally, the social skills learned and negotiated during early adulthood (including dating and socio-sexual development) may impact young people for the rest of their lives.<sup>51</sup> The developmental importance of mentors and ‘role models’ for youth is also well-documented.<sup>52</sup> For instance, longitudinal data on foster care youth who were mentored has demonstrated long-term adult impacts on both psychological well-being and physical health.<sup>53</sup>

### Peer navigators

Peer navigators are typically distinguished from other types of peer specialists in that their focus is typically on helping patients “navigate” treatments and health systems. For example, a peer navigator in the context of cancer might help a patient figure out regular transportation to chemotherapy sessions, coordinate care between different specialists and troubleshoot diet options at home. In mental health settings, peer navigator programs have mostly been implemented in the context of integrated psychiatric and physical care.<sup>54</sup>

Researchers at Orygen Youth Health’s EIP program in Melbourne, Australia, proposed a peer support intervention somewhat similar to U.S. peer navigators for clients during and following discharge from EIP.<sup>55</sup> While the trial was never undertaken for feasibility reasons, the idea is a solid one: in a U.S. setting, for example, peer navigators might help clients troubleshoot in the transition from EIP to standard mental health and associated support services (an area of tremendous unmet need). Peer navigators might also be used to help current clients succeed in specific non-healthcare domains. For instance, a peer navigator might help a client who is a prospective student register for classes, meet with student disability services staff, fill out a financial aid application and negotiate specific accommodations with faculty.

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“The impact of a peer support staff member on the team often is related to the peer not having a “professional presence,” and the transference issues that go along with such a presence. Many times, for example, a client will be reluctant to acknowledge symptoms or behaviors to professional team members for fear of consequences. I have been involved in many cases in which a client did not want to divulge an addictions relapse, for fear of being shamed by the provider. In other cases, a client felt suicidal, and feared being hospitalized involuntarily if s/he divulged these feelings. However, in these cases clients felt more comfortable discussing these issues with a peer. Perhaps the clients were more open to talking with a peer as they felt the peer would be able to empathize as a person instead of seeing things in a clinical vein. Perhaps the lack of the power differential often present between client and provider led the clients to be more open with a peer. Perhaps the subtle verbal and nonverbal cues professionals pick up in their training are absent in peers, leading to more open/less guarded communication with a peer. As one of our clients said, she trusted the peer more than me on some issues, for as I “worked with people like her,” the peer had “been her, and felt like her.”

—Neil Falk, MD  
Psychiatrist, EASA Multnomah County

### Embedded peer specialists

Unlike peer navigators, who are often most focused on establishing linkages and working through barriers to particular services, peer specialists “embedded” within a coordinated mental health team typically run groups, are available to meet with clients 1:1, share information with other clinical team members and attend clinical case conferences and/or team meetings.<sup>56</sup> In some cases, peer specialists might also take on case management responsibilities including assessment, service coordination and reviews of clients’ needs and progress.<sup>57</sup>

In an EIP setting, peer specialists might also take on a variety of other specific roles and responsibilities including co-facilitating multi-family groups (MFGs), and organizing EIP service orientations and graduations (or other client and family-oriented events). A peer specialist might also help manage or oversee community engagement efforts (such as presentations at local schools or civic organizations), coordinate an internal speaker’s bureau, coordinate a program newsletter or operate social media accounts.

Additionally, peer specialists can play a valuable role on governance committees, hiring committees and clinical case conferences (or clinical team meetings). One of their more significant contributions in such settings may be to contribute to organizational change. Georgia’s pioneering peer specialist program, for instance, explicitly charges peer staff to “act as change agents in the mental health system by providing professional, clinical, and administrative colleagues with their unique insight into mental illness and what makes recovery possible”.<sup>58</sup> Along these lines, in the quote above, Neil Falk of EASA Multnomah County draws attention to situations in which peer specialists have been able to learn critical treatment-related information (such as a client’s substance use) that might otherwise go undisclosed.

### Vocational/Educational Peer Specialists

Vocational peer specialists (or peer staff whose responsibilities largely revolve around clients’ vocational and/or educational goals) are increasingly common in the broader community mental health system.<sup>59</sup> While this manual is not intended to serve as a “guide” to supported education or vocational rehabilitation, it is important to note that education may be a central goal for EIP clients and the foundation of greater peer involvement and leadership (both within and outside EIP services), as well as a core element of support for peer staff.

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“Severe psychiatric symptoms first become apparent for many people during the late high-school and early college years. When symptoms first manifest many people have their educational goals permanently interrupted. This educational disruption can begin a lifetime of failed attempts at education and relegate people to poverty, unemployment, homelessness, and low paying jobs. The poverty associated with low education may even contribute to shortened life spans. The earlier a successful supported education intervention is provided the longer an individual has to benefit from having achieved a higher education and potentially higher level income. There is encouraging research that links increased education of people with psychiatric disabilities with increases in higher paying jobs, longer-term employment, and upper management positions.”

—Trevor Manthey, PhD  
University of Kansas

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As mentioned above, a vocationally-focused peer specialist might take on a “navigator” role and help clients access services, and establish relationships with key administrators and offices on campus, or provide more holistic “wraparound” supports including facilitating study groups, organizing or arranging extra tutoring, and directly liaising with school- campus-based staff, and local employers or internship program administrators. An education-focused peer specialist might also help establish on-campus (or school-based) groups and/or services. For additional ideas as to the potential role(s) peer staff might play in this area see the table below, as well as the education and peer-focused Q & A segments with Trevor Manthey (p. 56), Steven Adelsheim (p. 58) and Jessica Wolf (p. 55).

Education-Focused Peer Support	Examples
Liaison for individual clients	Works with student and school officials to develop individualized accommodations & support plan; attends initial meetings & provides ongoing coordination
Program liaison	Works with EIP service and school to develop ongoing communication about particular clients and collaboration vis-à-vis educational support for clients
Organize on- and off-campus educational support and/or study groups	Organizes or helps initiate peer support or study groups at local schools & colleges; connects clients with school and campus based supports
Collaborate on school- and campus-based policy reform	Works directly with school and university administrators to better coordinate services for students with psychosis and to address institutional barriers stemming from policy and/or protocol (e.g., leaves of absence, medical withdrawals)
Collaborate on school- and campus-based projects and initiatives	Collaborates with school or university based staff to develop evidence-based anti-stigma & awareness initiatives targeting faculty and staff (or other key stakeholders); works with the student disabilities office to develop accommodation strategies that are specifically tailored to students with psychosis

### Peer support groups

Peer support groups are perhaps the best known form of peer intervention and can adopt a variety of underlying philosophies or procedures. Some groups are highly structured (like Alcoholics Anonymous), others last for only a set number of weeks (such as WRAP), while others are open-ended and unstructured but nevertheless endorse a core set of beliefs (such as Hearing Voices Network groups). Described below are a selection of support group models or approaches that are currently being used in early intervention settings:

- **Intentional Peer Support.** Intentional peer support (IPS) is one of the more widely implemented peer support approaches and is currently the primary model used with Parachute NYC (see feature on p. 52). IPS is a generalist approach that emphasizes: (1) mutual learning instead of one person “helping” another; (2) relationship building rather than what is happening to ‘an individual’; and (3) an orientation toward possibility (and the future) rather than what is currently “wrong”.<sup>60</sup> IPS sharply distinguishes between clinical work and peer support and cautions against conflating one with the other (for instance by pushing peer specialists to assume a more strongly hierarchical “helper” role).
- **Wellness Recovery Action Planning (WRAP).** WRAP is currently the only specific peer-led intervention listed within SAMHSA’s evidence-based practices registry.<sup>61</sup> A semi-structured intervention, WRAP facilitators (i.e., group leaders) all undergo a standardized training and certification process, and closed sessions spanning approximately eight weeks.<sup>62</sup> The program revolves around the development of an overarching recovery plan that spans everyday wellness practices, the identification of personal triggers and coping strategies, advance crisis planning, and post-crisis recovery.
- **Trauma-Focused.** A substantial body of research links childhood trauma and adversity (including sexual and physical abuse) to psychosis.<sup>63</sup> Additional work has focused on the potential for the onset of psychosis itself (or the societal reaction to first onset) to be experienced as traumatic.<sup>64</sup> As research on mutual support among abuse survivors has demonstrated, it is often much easier for affected individuals to open up to others with similar experiences.<sup>65</sup> Whether oriented toward childhood or adolescent trauma specifically or the trauma of onset, a trauma-focused and -informed group takes as its starting point the premise that trauma plays a central role in many clients’ experiences and seeks to create a space in which the meanings and consequences of trauma can be safely explored.<sup>66</sup> See the Q & A segment with Leah Harris on page 51 for further discussion.
- **Hearing Voices Network (HVN).** In general, there has been less development of groups specifically focused on experiences of psychosis and that adopt a non-generalist practice framework. The HVN is a significant exception in that it focuses strongly on voice hearing (and psychosis more broadly) with a philosophical foundation grounded in both research and clinical work on voices.<sup>67</sup> Hearing voices groups (HVGs) often include a focus on trauma (and the connection between voices and trauma) and hold that voice hearing (and other psychosis-related experiences) are meaningful, and connected to the individual’s identity, sense of self, culture and history in important ways.<sup>68</sup>

- **“Clinical” Peer Support Groups.** Support groups—both those that are peer facilitated and professionally facilitated—may also adopt a more traditionally clinical approach. A CBTp framework, for example, has been adapted for a support group context, and more clinically oriented workbooks or homework might be incorporated into a group framework.<sup>69</sup>
- **Work or School-Focused Support Groups.** Alternately, support groups can focus on critical aspects of community inclusion such as work or school. A school-focused group, for example, might include discussion of issues such as accommodations, disclosure in educational settings, and experiences of campus-based stigma or discrimination. Vocational groups might also explore members’ future career goals, and work-related fears, hopes and dreams. Occasional guest speakers (for instance, a successful young professional in the local community with past experience of psychosis) might be brought in to share their own experiences negotiating symptoms or a diagnosis in the context of school and work.
- **Activities Groups.** Finally, instead of revolving around discussion, peer-led groups can instead focus on a particular activity (or combination of activities). For example, an EIP program might host a “band” or facilitate jam sessions. Clients might organize field trips or outings, or instead organize a group around a particular sport (basketball, soccer) or physical activity (such as hiking).

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“For me for sure the [peer] social groups have probably been the most helpful thing [about early intervention]. We do stuff together, and get to know each other and no one is judgy. Before that I’d basically lost all my friends, I was isolating and that was making things worse... So yeah, the groups have been so important. “

—Early Intervention Client

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### Mentoring

The value of both “natural” mentoring (i.e., mentoring that develops outside the context of an intervention or dedicated program) and formal mentoring programs is well documented in the literature on youth development.<sup>70</sup> Mentoring programs can focus on one-to-one relationships or involve a group of mentees with a single mentor. Overarchingly, what sets mentoring apart from other types of peer (or non-peer) interventions, is that a mentor is understood from the outset as a more experienced “guide” whose goal is to help his or her mentee(s) develop to their fullest potential (often, but not always, with an eye to vocational or career goals and identity) and to facilitate mentees’ original visions of or for the future.<sup>71</sup> Unlike a clinical relationship, the mentor (although in some sense a dedicated “helper”) is not there to intervene because of his or her mastery of coping-focused techniques, but rather to inspire, to encourage, and to weigh in with advice grounded in personal experience.



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“I guess, okay, I really just want to know: are there people like me, doing what I want to do, and can I talk to them?”

--Early Intervention Client

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In large part due to the stigma of psychosis (and disclosing a schizophrenia spectrum diagnosis), a full-fledged mentoring program might not be feasible in a newly implemented EIP program, but over time an internal database of alumni might make such programs possible down the road. In the meantime, more feasible “components” of evidence-based mentoring programs might be incorporated. For example, a program could Skype in successful (publicly disclosed) peers living elsewhere in the country for one or two sessions of discussion or Q & A with clients.



## Project Spotlight:

### STANFORD “WORK & SCHOOL STORIES” PROJECT

The Stanford University based project “Work & School Stories” is currently collecting accounts of school and work from individuals with psychosis working in an array of different careers and areas. These accounts will eventually be turned into a publicly accessible database, searchable by career area, targeting youth and young adults with recent onset psychosis. Check the website for updates: [www.voicesoutside.org](http://www.voicesoutside.org)

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## Peer Staff Pragmatics

### Recruiting peer staff.

New programs often wonder how to go about recruiting new peer staff. Some concrete suggestions include:

- Asking local consumer leaders (e.g., state or county office of consumer affairs staff or heads of local peer-run organizations) for suggestions and/or to post on their listservs;
- Posting job announcements in local community mental health centers, as well as youth organizations and service agencies;
- Advertising nationally, particularly for full-time or non-entry-level positions; and
- Recruiting through local universities and community colleges (including job fairs, & campus career center listservs or databases).

Job descriptions should be as clear and up-front as possible about the position’s roles and responsibilities, and clarify how the program views “lived experience” and sensitivity to developmental concerns as assets. Job descriptions will ideally lay out not only traditional “benefits” (such as health care and compensation) but also a program’s investment in staff



capacity building, and commitment to career mobility. Finally, when other avenues fail or a program is uncertain how to proceed, consultants can be brought in to assist with recruitment and hiring. Both nationally and at the state-level there are a growing number of peer consultants with expertise in the recruitment and hiring of peer specialist and related issues.

***Peer wellness planning, work accommodations and leave policy.***

As mentioned in the introduction, peer wellness planning is an essential component of the hiring and orientation process. Human resources staff should be well versed in the Americans with Disabilities Act (ADA), and in the types of accommodations a peer staff worker might need. Policies regarding medical leaves of absence (paid or unpaid) should be established ahead of time, with thought given to the implications of particular leave policies for staff with psychosis.

Some programs that work with peers also utilize dedicated planning tools or forms, in some cases including advance crisis planning.<sup>72</sup> While potentially very helpful, employees' preferences need to be respected. Legally, neither advance crisis or wellness planning, nor work accommodations can be *imposed* on a new employee.<sup>73</sup> Below are some do's and don'ts to consider:

Do's	Dont's
Ask about potential accommodation or support needs and reassure new staff that they will not be discriminated against for requesting accommodations.	Impose accommodations or imply that peer staff categorically "need" accommodations.
Provide locally tailored lists of possible accommodations—i.e., accommodations of relevance to the position and setting of the particular EIP service.	Suggest that any list of accommodations is exhaustive or express unwillingness to help think through alternative or novel accommodation solutions.
Suggest that if the peer employee wants, Human Resources (or other staff) will work through a wellness or advance crisis plan with them.	Force new peer staff to complete a wellness or advance crisis plan.
Clearly explain policy around medical leaves of absence, including financial and practical considerations (e.g., necessary documentation and criteria) if a peer employee ends up having to take time off.	Hand out a policy manual without further explanation or clarification.
Clearly explain grievance policies, including reports of discrimination and/or harassment.	Limit policy to a very general non-discrimination statement and provide no further explanation of employees' options if they feel they have experienced disability-related discrimination or hostile attitudes from particular staff.

### Organizational culture & preparation.

While anti-discrimination and harassment policy and associated grievance procedures are one way of safe-guarding employee rights, ideally an EIP service will take many additional steps to ensure that organizational culture and climate are supportive of peer staff involvement and respect the unique and important perspectives peers can offer. If regular staff have never worked with a peer specialist before, some form of preliminary training should be provided that:

1. Clarifies the role of the peer specialist(s) in the local setting, as well as the role of peer support more generally (including the often unique challenges of peer support work in an otherwise traditional clinical setting);
2. Provides an overview of the evidence and conceptual underpinnings of peer support and peer involvement; and
3. Covers the basic forms that prejudice or discrimination (intentional or unintentional) can take in a mental health service setting, including micro-aggressions against peer staff.

### Microaggressions

*Definition:* Sue (2010) defines microaggressions as “brief and commonplace daily verbal, behavioral, and environmental indignities that communicate hostile, derogatory or negative...slights and insults to the target group.” Microaggressions are typically unintentional and the perpetrator may not be aware that he or she has said or done anything offensive.

#### Examples of microaggressions in psychosis service settings include:

- Staff ‘cliques’ that exclude peer support workers.
- Continued use of reductionistic clinical language only when peer staff are not present (but that peer staff are aware of).
- Assumptions that peer staff (or individuals with psychosis more generally) do not have formal academic backgrounds, have not graduated from college, don’t understand more technical language, etc.
- Inviting a peer to join a committee (ostensibly as a token peer) but never, during committee meetings, actually asking the peer to share his/her perspective or weigh in on decisions.
- “Jokes” that are not meant to be offensive but clearly resonate differently with persons with lived experience such as “did you forget to take your meds this morning?”

As noted in the introduction, there is now ample evidence from ethnographic and qualitative studies, as well as first person accounts, that peer specialists not infrequently encounter prejudicial attitudes among other staff and/or feel that they are operating in unfriendly or unsupportive organizational climates.<sup>74</sup> It is therefore critical that administrators and other staff make all possible efforts to ensure that more isolated pockets of prejudice or resistance to peer involvement are swiftly addressed, and broader efforts made to develop (and sustain) a climate of respect and support.

## Training

Like other clinical staff, certified peer specialists are likely to begin employment with at least some degree of background training and/or coursework, as well as new and ongoing training needs. Beyond any certification process and associated training, peer staff may have a variety of other experiences, in some cases including non-peer-specific mental

health training (e.g., an undergraduate degree in psychology or social work or a certificate in psychiatric rehabilitation).

States also vary significantly in terms of specific peer specialist certification requirements and provision of ongoing peer specialist training opportunities.<sup>75</sup> Only a few states have dedicated youth-focused peer specialist trainings or tracks.<sup>76</sup>



There are now many resources on peer specialist training and competencies (see Appendix). In addition, some programs may opt to filter new staff (including peers) through a general (usually brief) training and orientation program. Because the majority of these resources do not include specific consideration of either psychosis or youth development, it is suggested that additional attention be given in the following areas (again, further resources are available in the Appendix):

- **Structural and cultural competence.** In many ways an extension of cultural competence, structural competence refers to familiarity with the complex and often intersecting ways in which structural and institutional factors (including racism, socioeconomic marginalization, welfare policies, and contemporary forms of segregation) affect risk for particular conditions (i.e., psychosis), pathways to care, attitudes toward treatment, available social support, and ultimately outcomes.<sup>77</sup> Structural competence helps de-emphasize individual problems and re-center social, environmental and cultural influences on health.
- **Variability of symptoms.** Peer specialists (and front-line clinicians in general) are often given a very simplified picture of psychotic symptoms. In fact, decades of clinical research underscore the variability not only of the range of symptoms any given individual might experience, but also the variability within symptom domains. For example, “voices” may be literally auditory, soundless or thought-like, or even communicated primarily through mental images or feelings instead of words.<sup>78</sup> Awareness of such variability can help peer specialists and others to validate clients’ experiences, even when they differ from their own.
- **Variability of course and recovery trajectories.** Similarly, the long-term literature on “course” (or the particular trajectory of an individual’s symptoms and recovery) foregrounds the number of different paths psychosis can follow. Some individuals may recover completely (i.e., never again experience symptoms or functional impacts following an initial period of psychosis), some may experience symptoms episodically (with varying intervals), and others may experience continuous symptoms. Again, basic awareness of these differences can help validate clients’ experiences and sensitize staff to the many possible outcomes a young person might face in the future.

- **Variability of treatment effects.** Similarly, clients' responses and needs with respect to treatments (including medications, therapy, and supportive psychosocial interventions) are highly variable. For example, some individuals respond well to medications whereas for others the impact on symptoms is minimal and may be overshadowed by serious side effects.<sup>79</sup>
- **Negotiating boundaries with youth and family members.** Negotiating boundaries may be particularly challenging for peer staff who are themselves young adults. An evaluation of an innovative youth-peer-led project called the Tay INN in San Jose, CA, for example, found that peer mentoring staff themselves perceived considerable difficulties negotiating boundaries with other youth<sup>80</sup>, and this may be particularly challenging in the context of more informal or leisure activities. Heightened family involvement may also create relatively unusual boundary challenges, for instance if a parent orients toward a particular peer specialist (who is also working with the parent's adolescent).
- **Strategic disclosure.** Strategic uses of disclosure (including disclosure of diagnosis but also of different symptoms or experiences) is challenging regardless of the circumstances. Youth peer staff who have only relatively recently developed psychosis (and have less—or even no—experience with peer support) will likely need additional guidance and support. While disclosure can be very helpful (for both parties) it can also leave peer staff feeling vulnerable or exposed in a detrimental or distressing way.<sup>81</sup> Quality supervision is also critical to the ongoing negotiation of disclosure (see below).
- **Basic youth development theory/principles.** Finally, it is important to provide a basic foundation in youth development for peer staff (and any other clinicians) who are hired without previous youth-focused training or coursework. At a minimum, youth development training should cover the life-long impacts of young adult experiences (including education and community integration), identity formation, and developmentally specific (and normative) risk behaviors. A foundation in positive youth development (PYD) theory and practice would also be beneficial. While largely in line with recovery-oriented mental health work, PYD is an explicitly youth-focused and developmentally-informed approach to intervention that seeks to build on both individual and community assets and help lay a foundation for success as a mature adult. PYD praxis includes a targeted focus on some areas that are typically addressed in quality community mental health programs, but also important areas that are often not, such as the development of moral competencies (sense of right and wrong, orientation to social justice), positive sociocultural identity, and the exploration of spiritual identity, meaning or practices.<sup>82</sup> Additional resources on PYD are provided in the Appendix.

### Supervision

As for other clinicians and mental health workers, quality supervision is critical to peer staff members' professional development and growth as peer support workers. Ideally, supervisors would either themselves have experience of peer support, or substantive training and/or experience supervising peer staff. Supervisors who do not understand

what peer specialists do (or the distinction between peer support and traditional clinical work) are, among other things, unlikely to be able to guide peer staff in the strategic use of disclosure, or negotiation of boundaries in the context of relationships that aim (by design) to be much more explicitly reciprocal than therapist-client relationships.<sup>83</sup>



For many reasons, in real-world clinical settings, supervisors who are themselves peers are not always available. In such cases, whenever possible, supplemental supervisory opportunities should be made available. These might include peer in-services or workshops with national or regional peer trainers, occasional consultation with experienced peer support consultants, and/or participation in regional and/or national peer specialist organizations (such as the international association of peer specialists or iNAPS).

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“A peer supporter is someone who is empathetic and is a role model for positive recovery, whereas clinical interventions and group therapy use clinical language and theory to support recovery behaviors. A peer supporter is someone who can listen and share experience with a client without telling the client what is best for them and without prescribing how a client can achieve recovery, whereas clinical interventions and group therapy are more rigid and prescriptive of what is best and how a client should pursue recovery.”

—Cheryl Farney, CRSS  
Peer Specialist, University of Illinois at Chicago

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**Peer staff support & capacity building**

As has been emphasized throughout this guide, support for peer staff members' career development and investment in building their skillsets are essential components of high quality peer inclusion efforts. There are many different ways in which programs can support peer staff (and volunteer) development. See the accompanying table for a few examples.

Capacity Building Activity	Examples
Conferences	Paid time off/reimbursement for regional and/or national conferences on mental health (e.g., Alternatives)
Workshops & Continuing Education	Paid time off/reimbursement for mental health workshops, trainings & continuing education
"Cross-Modal" Training	Providing training or professional development opportunities outside staff members' current specializations. For instance, training in basic evaluation or quality improvement strategies for peer staff whose primary duties are service-oriented (e.g., peer support)
"Protected" Project Time	Encouraging staff to pursue innovative self-initiated projects and providing "protected" time for work on them
Participation in Internal & External Committees	Peer staff participation in internal committees, as well as "paid time" to serve on external advisory boards, committees and national policy or practice development projects
University-Provider Collaborations	Collaborating with local universities or colleges to create credit bearing internships or service learning projects, course credit opportunities, and/or hybrid "work & study" programs that allow peer staff to simultaneously accrue work experience and credit towards a psychiatric rehabilitation (or related) degree



## Trauma-Informed Care

### EXPERT Q & A: LEAH HARRIS

Leah Harris has spoken and written widely on the topics of mental health, suicide prevention, and trauma-informed care. She is a trainer and consultant with the National Center for Trauma Informed Care, and a trauma informed care specialist/coordinator of consumer affairs at the National Association of State Mental Health Program Directors.

***Q:** In your trauma-focused work you draw on both personal experience and decades of work as a peer advocate and leader. In general, what do you think is so critical about trauma-informed care?*

**A:** Trauma informed care is based on a significant body of research demonstrating that the majority of people in all of our “systems” – behavioral health, juvenile justice, criminal justice, foster care, child welfare, etc. have likely experienced one or more traumatic events in their lives. (See the Adverse Childhood Experiences (ACE) Study to learn about the wide variety of mental/physical health and social consequences of unaddressed trauma.) Trauma informed care promotes values such as voice and choice, collaboration, mutuality, and peer-to-peer support, which help to increase the empowerment of persons receiving services, promote meaningful engagement with treatment, and lead to greater resilience and whole health over the long term.

***Q:** Extending these thoughts to early intervention in psychosis (EIP) services, how do you think such services would ideally incorporate trauma-informed principles and what role do you think peers might play?*

**A:** All aspects of EIP services should be trauma-informed. The physical environment should be soothing and welcoming; all staff, persons receiving services, and their family members should receive training and information about trauma and trauma informed care. Collaborative and person-centered approaches should be built into all aspects of service delivery; services should avoid coercive methods, which devalue voice and choice; and persons with histories of trauma should be offered a range of trauma-specific interventions and therapies. Peer-to-peer and family-to-family support should be incorporated in all aspects of EIP services, from assessment, to participating on the treatment team, to program design and evaluation. Peer and family support groups should be available during and after formal involvement with the EIP program.

***Q:** Do you also see a unique role for peers in educating EIP clinicians about the contexts and effects of trauma? What might this look like?*

**A:** Absolutely. Peers can concretely illustrate the effects of trauma and re-traumatization in ways that theoretical discussions cannot. They should be a central part of any trauma-informed trainings provided to new and existing staff and service users. They can also provide ongoing consultation as part of treatment teams, sharing examples of how traumatic experience manifests in the lives of individuals and their families, and the specific factors, approaches, and practices that help and hinder the process of trauma healing.

## Peer Involvement in Parachute NYC

### EXPERT Q & A: KIM HOPPER PHD & THE PARACHUTE PROCESS EVALUATION TEAM

Parachute NYC is an innovative crisis intervention program (with dedicated first episode teams) that has garnered significant media and clinical attention since it debuted in 2013. Kim Hopper (who supervises the field team doing the qualitative part of the implementation analysis) and members of the evaluation team (Lauren Cubellis, Judy Sugarman, and Jen van Tiem) offered input on Parachute's experiences engaging and including peers to date. Note: all peers involved in Parachute went through training in both intentional peer support (IPS) and the needs-adapted treatment model (NATM). See the Appendix for further information and resources on IPS and NATM.

*Q: What can you tell me about what your team sees as the benefits of peer involvement/peer leadership in Parachute so far?*

**A: Benefits:** This is disruptive innovative work. Benefits often become clear and can be tracked over time, through a co-evolutionary, developmental process, as the team works out original, synthetic, even hybridized ways of practice: experimenting, bringing different approaches together, and so on.

From what we've seen so far, peers definitely seem to help disrupt status quo routines. For instance:

- **Broadening treatment options:** Peers help draw attention to the problems and risks of coercion and hospitalization. Instead of referring clients to other services (or hospitals), peers in some cases intervene or suggest different options.
- **Pace of deliberation:** With peers on board, both assessment and decision-making are slowed down, less rushed and more careful.
- **Language:** Clinicians report being much more self-conscious about resorting to diagnostic or objectifying language with peers as part of their teams – pulled back to the here-and-now, ferreting out untold stories, taking the broader view, and easing up on pathology.
- **Positioning/deploying self-disclosure:** determining when it is helpful (and/or appropriate) to utilize self-disclosure as a tool, and how to navigate the boundaries of the disclosed space (peers in the workplace versus peers in private lives).
- **Disrupting routine elsewhere in MH system:** Peers help create new relationships/new ways of interacting with hospitals: e.g., creative negotiating and establishing trust, convincing hospitals that the respites (and peers) have the necessary resources to handle certain crises.

**Peers also help buffer transitions.** For example:

- An unexpected benefit of the team’s commitment to “continuity of care” involves both follow-through and “smoothing” when transitions to non-Parachute parts of the public mental health system prove necessary. This has been especially obvious in a few recent instances of potentially traumatic hospitalization – with peers/team effectively taking the lead away from law enforcement and reducing their role to stand-by security, not coercive force.

**Finally, peers help embody hope (securing and a sense of solidarity around finding a job):**

- Peers are evidence embodied: The recovery message is personified, not simply espoused – when a peer member of a crisis team self-identifies as once-in-terrible-trouble herself. Our experience is that this is of huge value to both the person in crisis *and* the family (itself also in uncharted waters).
- Peers help connect clients to a network of peers through alumni days at respites, and the dissemination of information about other peer-run organizations and training programs beyond Parachute.
- Finally, clients in many cases have become peer specialists in Parachute and other programs. Clients see what peer staff are doing and how it’s possible to transform a stigmatized identity into a marketable asset (Parachute has created 64 FTE’s for peers).

***Q: How about what your team perceives as the ongoing challenges of peer involvement?***

**A: Integrating peers seamlessly remains challenging:**

- There are still holdovers from classical clinical training among both the peer and non-peer staff, including ingrained language/larger culture, assumptions regarding fear and risk, and stubbornly individualistic notions of recovery.
- Peers’ role ambiguity on the teams (even though role-played in trainings) remains an issue and is still largely a matter that is worked-through with practice and time.
- The presence of peers also raises questions and ambiguities regarding “disclosure” on the part of non-peers (who may nevertheless have a variety of potentially relevant personal experiences that could be shared with clients).
- Different agencies have also taken on peers in different ways and there is uneven agency commitment to issues such as accommodating peers’ schedules, ensuring ongoing training/supervision, and hiring procedures and criteria.
- There is lingering uncertainty regarding roles on crisis teams: peers are often too easily deployed to handle “case management” tasks instead of more therapeutic work and diverted to housekeeping tasks in respites.

**Peers may need some distinctive supports, and Parachute still needs to figure these out:**

- Preferably experienced peers, seasoned in working within systems, yet located outside, would be able to offer EAP or team-specific supervision. For example: some counseling on managing “boundaries” in ways that are distinct from guidelines typically instilled as part of professional training (i.e., less concerned about maintaining rigid neutrality and distance), yet still consistent with agency requirements.
- It is often assumed that peers already know how to embody recovery, but this takes time. Peers need support to deploy peer narratives selectively and effectively as well.

**Effects of job strain on peer workers include:**

- Managing the sheer demand of the “emotional labor” that both crisis teams and respite work requires;
- Effective management of work hours so as to preserve peers’ SSI and health benefits; and
- Alienation/commodification of once-shared, circulating gift of common ordeal and the struggle to come back:
  - The transformation of peer work from an informal/moral economy of shared experience to an exchange compensated by a third party payer converts something previously given as a gift into a wage labor product.
  - Tension between giving of oneself to support someone through shared and resonant experience and selling oneself in the service of an institutional apparatus.
  - Peer staff experience burnout as a result of self-alienation. Being paid for this work seems to change the incentive, especially when promise of progressive change diminishes and the institutional structure remains.
  - What does it take to make sense of the difference between offering oneself as a friend or supportive caregiver, and as a paid consultant working with others to make a living? How do peers navigate this boundary – which shapes up differently on different teams, and when comparing respite vs. mobile team work?

## Peer Workforce Development

### EXPERT Q & A: JESSICA WOLF, PHD

Jessica Wolf, PhD, is the Principal of Decision Solutions behavioral health workforce consulting practice in Fairfield, CT; an Assistant Clinical Professor in the Yale Department of Psychiatry; and a Senior Consultant for the Annapolis Coalition on the Behavioral Health Workforce. Dr. Wolf founded and for 16 years coordinated the Housatonic Community College MERGE Mental Health Certificate Program in Bridgeport, CT for peers and non-peers. Recently, she has spearheaded Education Pays, a national initiative to advocate for increased peer access to degree programs and higher education along with the promotion of overall peer career development.

***Q:** Some commentators have referred to peer specialist positions as a “career ghetto”. How much mobility do you think there is for young people initially entering the workforce as peer specialists?*

**A:** We do not have good information as yet about career mobility for peer workers; it’s important to gather and evaluate data in this regard. However, we do know from research and reports by Baron and others that specific career ladders and career development initiatives are essential for direct service and similar workers such as peer workers not to become stuck in poorly-paying jobs with minimal opportunities for career advancement. The U.S. Veterans Administration has created peer specialist positions and career ladders that are potential models for other settings. We believe it’s essential to attend to career paths, ladders and career development now when the peer workforce is “young” rather than down the road when hiring and employment practices are entrenched and peer workers become disaffected and leave the field. Again, this is especially important for young adult peer workers beginning careers in the field.

***Q:** Thinking more broadly about the integration of peers (including young adults) into the clinical workforce, what policy or practice changes would you like to see?*

**A:** It’s essential that peer values and peer roles become integral elements in behavioral & integrated health workforce practice - not “second-class” or “token” or “make-work” roles and jobs. We understand concerns that peer support and peer work not be co-opted by the prevailing clinical model. This requires genuine dialogue and continuing self-assessment and conscious learning by all participants, including ongoing in-service training co-designed by peers and other staff, role-plays and activities that enable workforce participants to truly understand the strengths that all bring to the work, as well as barriers creating distrust and silos. Commitment by top level leaders that is articulated and translated into action at all levels is essential to inspire everyone to transform “clinical” and “peer” practice into a new recovery-oriented paradigm of partnership among staff and between staff and customers or clients based on self-determination and choice. This doesn’t happen overnight and requires continuing diligence, mindfulness and conscious attention together with co-leadership by peers, administrators and clinicians.

We humans are hard-wired with an intrinsic “conservative impulse” which leads us reflexively to resist change. Understanding this innate tendency can be very helpful as we move out of our comfort zones into more daring and rewarding practices. While change isn’t easy, in supportive partnerships we can rise to and meet the challenges of change.

## Supported Education

### EXPERT Q & A: TREVOR JAY MANTHEY, PH.D

Trevor is currently a research associate at the University of Kansas with a PhD in social welfare and research expertise in a variety of interventions aimed at promoting self-determination and consumer choice in the context of psychiatric care. Along with colleagues at the university's Center for Mental Health Research and Innovation, Trevor has led a number of projects related to supported education (SE), including the latest iteration of an SE toolkit and associated fidelity scale.

**Q:** *What distinguishes supported education from supported employment interventions such as Individual Placement and Support?*

**A:** One of the primary differences is, of course, the focus on education rather than employment. One of the goals of supported education is to help develop a long-term career, or increase the employability of, the person attempting educational pursuits. On the surface some might contend that supported employment models like IPS run counter to educational goals, however, I view them as complimentary. Just like in the broader population, an educational degree isn't for everyone. Some people are primarily interested in employment and don't want to pursue education, therefore enrolling in a supported employment program is a good option. Alternatively, for those who wish to postpone work in order to pursue their education, a supported education program may be a better choice. In addition, supported employment models like IPS can be adapted to include supported education elements and a few pilot programs have attempted to do so. An integrated model approach may be ideal for people who choose to pursue both work and education at once. The latest KU supported education fidelity scale and toolkit was developed in order to help facilitate just such an integrated program. Unfortunately there is still a lack of funding mechanisms and political support for researching, developing or implementing stand-alone and/or integrated supported education programs. Access to these beneficial supported education programs is limited for many people with psychiatric symptoms who both want and need it.





**Q:** *What role do you see for peer leadership and peer support in the development of supported education policy, programming and/or the delivery of services?*

**A:** Peer support and peer leadership have a large part to play in the future of supported education. Peers are in a unique position to be leaders in the supported education field. Lived experience with psychiatric symptoms and their relationship to the difficulties and triumphs associated with successful educational pursuits provide a powerful platform from which to guide the development of research, policy, and supported education program models. Peers who have experienced academic success are essential role models showing that academic achievement is possible. Peers help to facilitate hope, can help increase individuals' motivation for academic success, and can also assist with coping strategies to manage symptoms during times of high academic stress. Peers in the role of educational specialists can help with navigating the nuts-and-bolts of campus life, accommodations offices, and online technology. Peer support workers are in a unique position to bring their educational life experiences to the table when helping a fellow student walk through the pros and cons of deciding whether to disclose their disability to campus accommodations offices, teachers, or other students.



For example, I know of an excellent peer support worker here in Kansas who has become one of the most sought after members of her supported education team. She provides essential support for disclosure decisions, accessing educational resources, linking people to social support, ensuring access to tutoring, ensuring access to accommodations, advocating with academic personnel, registering for classes, navigating class schedules, in-the-moment symptom management coaching, and instilling a hope that education is possible. She has also successfully built long-term relationships with a variety of local educational institutions. One educational institution valued her so much they offered her some office space so she wouldn't need to constantly return to the community mental health center. Peers should be an important part of the future of supported education service development and delivery.

## Education & Peer Involvement Outside of the EIP Clinic

### EXPERT Q & A: STEVEN ADELSHEIM, MD

Steve is a clinical professor of psychiatry and the director of community engagement at Stanford University's Psychiatry Department. Prior to moving to Stanford, Steve directed Recovery After 1<sup>st</sup> Schizophrenia Episode (RA1SE) and Early Detection for Prevention of Psychosis Program (EDIPPP) sites at the University of New Mexico. At Stanford, Steve is one of the core faculty involved in setting up a new university-based early intervention clinic (INSPIRE). Steve has also led the development of the Prodrome and Early Psychosis Program Network (PEPPNET), a national early intervention program network, and he co-leads the National Council for Behavioral Health's early psychosis community of practice.

**Q:** *You've been a public advocate of a stronger developmental approach to early intervention. Can you say a little bit about what that means?*

**A:** Most of the program components utilized in early intervention come from treatment models with adults with long-term and persistent mental illness. These programs continue to be adjusted to try to help younger people, who are identified earlier, and with possibly less persistent symptoms. If we really want successful early intervention programs, it is time to consider program needs from the perspective of the emerging adolescent and building services forward from that age group's needs, rather than from the perspectives of older adults.

**Q:** *Specifically, you've stressed the importance of developing education-focused supports based not only within EIP clinics, but also in schools and on college campuses. What would this look like and why do you think it's so important?*

**A:** Currently our early intervention programs have a much larger focus on supported employment than supported education. As we get better at identifying young people with early intervention needs sooner, it becomes critical to develop appropriate accommodations to help young people stay in school and be successful. Most 504 and IDEA programs don't take into account the needs of young people experiencing early psychosis. We have much work to do to educate school personnel, students, and families about key strategies for remaining successful in secondary schools and colleges.

**Q:** *What are your thoughts on the possibilities for peer leadership and involvement in the context of school- and campus-based early intervention programming?*

**A:** As young people in early intervention programs learn to successfully navigate academic settings they (and their families) develop critical experience in learning strategies for academic success while dealing with early psychosis, as well as how to manage school stress. It is critical for those with lived experience to directly share their knowledge and skills with other students.

*Q: Do you think peers have a unique role to play in keeping EI services both youth-focused and developmentally-focused?*

**A:** Totally! As all programs work towards earlier identification of those with psychosis, the peer voice is critical in ensuring services and programs speak to the appropriate developmental needs of those most likely to use and benefit from the service. Without that connection, these programs will just not be used or valued.

## Peer Support and Identity in Early Psychosis

### EXPERT Q & A: TIMOTHY KELLY MA, PHD STUDENT

Timothy Kelly is a doctoral student in counselor education and supervision at the University of Iowa with extensive experience working with youth and young adults experiencing psychosis across a range of settings including TAY, transitional housing, a youth peer warm line, college counseling, and mobile crisis as both a peer and a (peer) professional. He completed his master's degree in mental health counseling at Lewis and Clark College in Portland Oregon. Timothy has lived experience of psychosis and first developed symptoms as an adolescent. His current research, in part stemming from his own experiences as a youth, includes research on identity development in early psychosis and the socio-cultural variables involved in recovery and resilience.

**Q:** *Your current work focuses strongly on identity development in psychosis. Can you say just a little about what “identity development” means?*

**A:** Identity encompasses the range of responses a person might offer to the question, “Who am I?” Identity can be organized into three dimensions. At the *individual* level the focus is on things like a person's abilities, goals, a sense of their future, and their experience of personal agency. The *relational* level focuses on the person's roles in relationships like son, mother, friend or employee. Finally, the *collective* level focuses on the social groups to which a person belongs, and the meanings attributed to those groups like Latino, Women, LGBTQ, or “persons with mental illness.” The questions that come up in relation to these dimensions are particularly central in the lives of adolescents and young adults. Young people are often developmentally focused on belonging in interpersonal relationships, exploring their aptitudes, vocational choices and future goals, developing their sense of agency and autonomy as emerging adults, and determining the “groups” to which they belong.

The process one goes through in engaging these questions is often conceptualized as a developmental process. That is, it is a process of change and growth and can be usefully organized into phases that occur with some regularity across persons. Race and gender identity are among the aspects of a person's experience that have been usefully conceptualized in developmental terms, and so has career development and mental health recovery. So, identity development describes processes in which a person engages the question of “who am I” across individual, relational and collective levels—and how this changes over time.



**Q: What's important to understand about youth identity development in the context of recent onset psychosis?**

**A:** Initial episodes of psychosis most often occur at a time in a young person's life when questions of identity are quite central. So it is important to understand that young people are already in a period when identity development is occurring across multiple life domains, and that the experience of psychosis complicates and may threaten those processes. Just imagine a young person who is new to college, engaging new interests and possible career paths, finding their peer groups, and exploring aspects of themselves along dimensions of sexuality, gender or cultural identity. Now imagine how an experience of psychosis interacts with these processes.

At the *individual* level, an experience of psychosis can be disruptive of one's sense of personal agency, leaving one wondering if one has any control over one's life or experience. A young person might also question whether the experience of psychosis will cause them to lose valued abilities, or foreclose future plans like a specific career path.

At the *relational* level, an experience of psychosis can be disruptive to relationships. A young person may face questions of how to repair relationships following a period of strange or frightening behavior. They may face questions of what to disclose depending on the role of the relationship (e.g., employee, friend). They might also feel that the experience of psychosis forecloses the possibility of current or future roles they might value, like being a parent or a romantic partner.

At the *collective* level, an experience of psychosis risks situating a young person in a social category (e.g., mental patient, psychotic, schizophrenic) that all too often carries strong negative associations. A young person—or those in their life—might begin to see the person in terms of this category. This can create a burden for the young person whose identity might begin to be narrowly centered around these negative associations, while losing access to more positive collective associations. So this collective level involves both the social categories the young person sees themselves belonging to, and the social categories through which they are perceived by others. It is important to recognize that the meaning that is attributed to psychosis—by the person themselves and those in their life—will shape the impact the experience has on the person's identity.

For instance, if one believes that psychosis is solely the result of a malfunctioning brain, then one might perceive oneself as having very limited agency over that experience. Others might perceive them as being blameless in strange behavior, but might also perceive them as being intrinsically flawed and to be avoided. If one believes it is not possible for a person who has experienced psychosis to succeed academically, or be a good romantic partner or parent, then one may avoid or foreclose the possibility of these relationships. If one believes that the social category of persons who experience psychosis is entirely negative, one's sense of belonging to this group can bring a sense of shame and diminished self-esteem.

**Q:** *What sort of role do you think peer support groups as well as naturalistic peer-to-peer friendships and mentoring relationships might play in light of the above?*

**A:** Both peer support groups/peer-to-peer friendships and mentoring relationships can create opportunities to buffer against the negative impacts an experience of psychosis can have on a young person's identity, as well as provide support in encouraging the healthy identity development processes that are normative for young people.

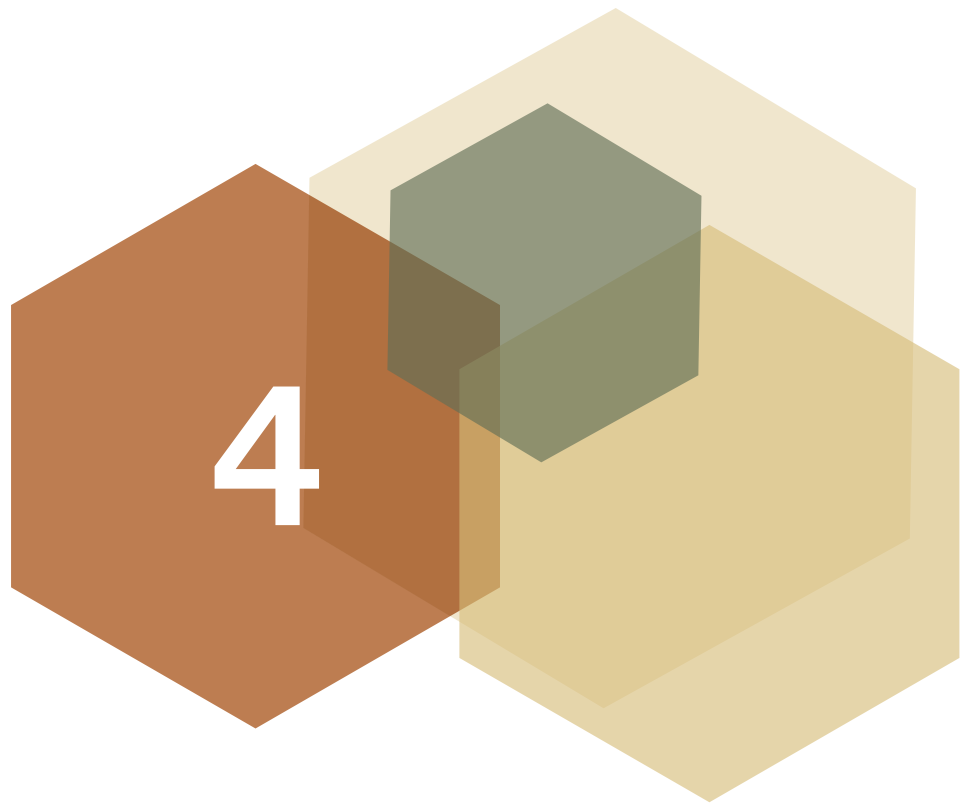


Peer support groups can provide opportunities for young people to explore what the experience of psychosis means to them, which can encourage a sense of agency that fosters resilience and active coping. Strategies for maintaining resilience and coping can be shared and practiced. The impact that the experience of psychosis has on other relationships can be shared with peers who may be uniquely able to relate. It is also possible to explore meanings for this experience which can buffer against negative group associations. To the extent that the group itself is attractive to the young person, it may itself inspire a more positive group association and mitigate a sense of isolation that all too often comes with this experience.

Mentoring relationships can provide role models which can foster a sense of hope and possibility, and buffer against negative identity impacts. To the extent that young people have access to role models that have experienced psychosis, but who have been successful in valued outcomes (e.g., career, family, relationships, hobbies), they may be encouraged in the belief that the outcomes they value are possible. In addition to serving as role models, mentors can draw on their own experience to provide guidance to young people on how to navigate issues that arise for persons who experience psychosis, like disclosure in different settings or coping with relapse in the context of work or school.

Peer support and mentoring have been successful in building positive identity and resilience across a variety of youth development programs including those for youth who have experienced foster care, LGBTQ youth, and others. I believe these should be integral components in all early psychosis programs.





## Public Outreach and Stigma Reduction

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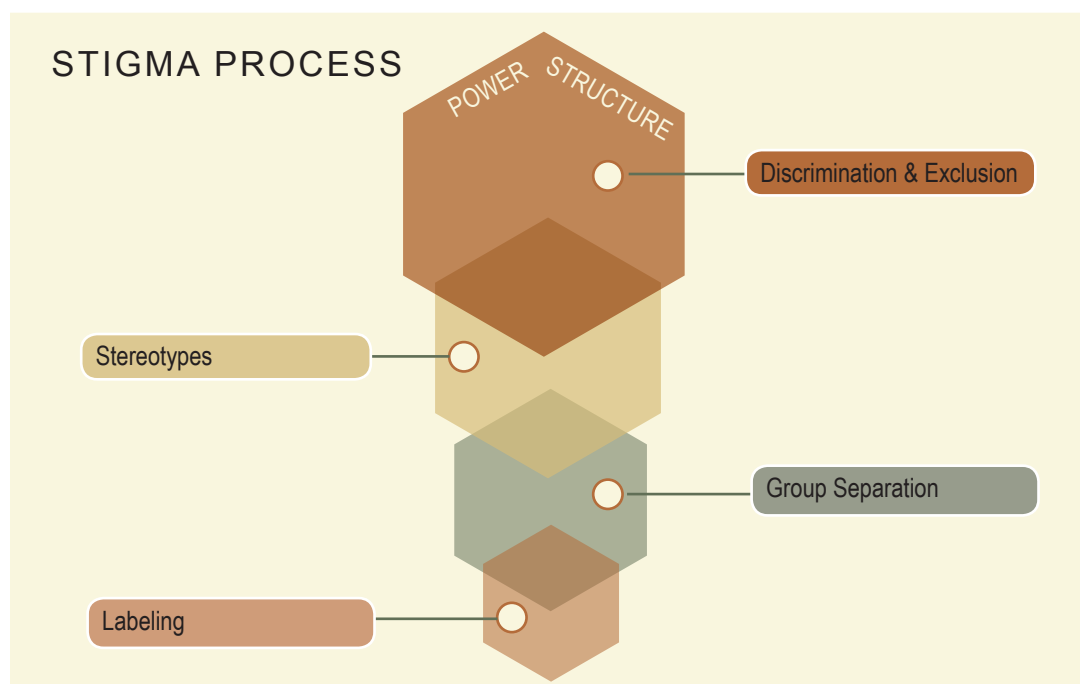
In large part because of the well-documented importance of connecting young people with treatment and supports as soon as possible after the initial onset of psychosis, dedicated public outreach and stigma reduction aimed at promoting help seeking, community awareness, and support have played a bigger role in EIP services than many other areas of mental health. A large body of research suggests that “contact” with persons with psychiatric disabilities (early psychosis for the purposes of this guide) is an essential component of both awareness and stigma reduction programs.<sup>84</sup> This section focuses specifically on awareness and stigma strategies in which peers play a central role.

### Basic Stigma Concepts

In a seminal paper on stigma<sup>65</sup>, Bruce Link and Jo Phelan lay out the following components of the stigma process:

1. **Labeling.** The labeling of specific human differences (such as “psychosis”).
2. **Stereotypes.** Cultural beliefs that link these differences to negative stereotypes. For example, the Western stereotype that “people with psychosis are dangerous.”
3. **Separating “Us” from “Them.”** Identifying individuals who have been labeled (e.g., with psychosis) as a distinct and different out-group (“they’re not like us”).
4. **Rejection and Discrimination.** Discriminating against, marginalizing and/or excluding members of the out-group (people with psychosis) both directly and indirectly. Discrimination might take structural forms (for instance, laws or policies that make it difficult for people with psychosis to get certain types of jobs or to adopt) or attitudinal ones (blaming gun violence on psychosis, avoiding colleagues who have psychosis, etc.). Stigma is often internalized by members of the stigmatized group, leading to lowered self-expectations, fear of disclosing, and social withdrawal.
5. **Enabling Power Structures.** Finally, the above components are framed as contingent on social, political, and economic power hierarchies. For instance, most people with psychosis live in poverty and therefore cannot influence policy through economic means; people with psychosis are often not provided sufficient supports to get through college and hence rarely obtain more powerful positions in clinical services or research.

From Link and Phelan’s perspective, a lot needs to change in order to significantly alter the stigma process. Instead of targeting stereotypes in isolation from power structures, it is advisable to simultaneously address the structures and norms that allow stigma to flourish.



### Ethnic/Racial Considerations & Intersectionality

Unfortunately, a large proportion of persons with psychosis are not only “stigmatized” because of their diagnosis, but also by virtue of other marginalized (e.g., racial/ethnic, sexual, socioeconomic or disability) identities. Poverty, racial discrimination and ethnic isolation, for example, are all risk factors for developing psychosis.<sup>86</sup> The majority of individuals with psychosis are also under-educated and unemployed or under-employed and therefore often end up living in poverty.<sup>87</sup> Comorbid substance abuse is common—in many cases in an attempt to cope with social exclusion and perceived failure as well as symptoms.<sup>88</sup> Intersectional theory holds that these intersecting sources of marginalization fundamentally change or intensify the forms discrimination takes. One can see this in some recent examples of extreme violence (brutal killings) of homeless persons who were also members of racial/ethnic minority groups and experiencing serious mental illness.<sup>89</sup> The price they paid for their identities was not just loss of a job, but their lives. Individuals with multiple marginalized identities (e.g., currently homeless, ethnic/racial minority and a serious psychiatric disorder) are significantly over-represented in the criminal justice system, often serve longer terms, and are more likely to be incarcerated on non-violent or misdemeanor charges.<sup>90</sup> Incarceration, in turn, puts individuals at increased risk of trauma and/or assault.<sup>91</sup>




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“As opposed to examining gender, race, class, and [disability] as separate systems of oppression, the construct of intersectionality references how these systems mutually construct one another. Intersectional paradigms suggest that certain ideas and/or practices surface repeatedly across multiple systems of oppression.”

—Patricia Hill Collins

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### Evidence-Based Stigma Reduction

There is now a substantial body of research concerning the most salient elements of mental illness stigma and stigma reduction. With respect to awareness and public education campaigns in early psychosis specifically, this literature cautions us against stigma and awareness materials grounded exclusively in strongly biological views of psychosis. Instead, social, cultural and environmental influences and factors should be emphasized alongside discussion of genetic and/or neurochemical factors. Second, stigma campaigns should emphasize contact with individuals with psychosis, target particular local audiences, and involve “credible” examples of distress and recovery.

**Avoid Strongly Biological Explanations of Psychosis.** While findings for other psychiatric disabilities (including depression and anxiety) are far more mixed, the empirical literature on psychosis and schizophrenia has converged on the finding that a strongly biological view of psychosis does not decrease stigma. A large, multi-national meta-analysis of population-based stigma studies, for example, found that as biomedical literacy (i.e., understanding of psychosis as a brain disorder) increased, stigma either remained unchanged or even worsened.<sup>92</sup> A second meta-analysis of cross-sectional stigma studies has found the biological explanations of schizophrenia decreases blame, but leads members of the public

to want greater social distance from persons with schizophrenia and to see them as more dangerous.<sup>93</sup> Researchers have hypothesized that a biological explanation may lead people to view those with schizophrenia as even more strongly “other,” and to reduce optimism about the effectiveness (and permanency) of treatment.<sup>94</sup> For instance, community members may think that a person with psychosis is safe on his or meds, but unsafe off them, since the medications are only suppressing rather than ‘curing’ underlying brain abnormalities. Recent studies have suggested that the same logic may hold for internalized stigma; and internalized beliefs in biological causality also correlate with less benefit from and engagement with psychological interventions such as CBTp.<sup>95</sup>

Placing less emphasis on “brain disorder” does not mean eliminating biology or genetics from the discussion, but instead focusing more strongly on: (a) empirically established social and environmental factors (including adverse childhood events, trauma, bullying/social exclusion, and poverty); (b) psychosocial treatments and their effectiveness; and (c) rates of recovery (or the possibility for recovery) among a subgroup of EIP clients and alumni not taking ongoing medications.<sup>96</sup>

Do's	Don'ts
When explaining causal or contributing factors, do emphasize known social, cultural and environmental influences.	Don't narrowly frame psychosis as a biological brain disorder and center medications over and above psychosocial interventions.
Involve EIP clients and alumni in public awareness and anti-stigma projects.	Don't provide professionally-led psychoeducation without a contact component.
Tailor presentations or other materials to particular audiences in particular settings and contexts.	Don't use a one-size-fits-all presentation format with exactly the same content regardless of the audience.

**Embrace TLC3.** Patrick Corrigan, one of the most influential anti-stigma researchers in the United States, summarizes evidence-based best practices in stigma reduction with what he terms TLC3 (**t**argeted, **l**ocal, **c**redible, **c**ontinuous **c**ontact).<sup>97</sup> Specifically:

- 1. Contact.** Contact with persons with psychiatric disabilities (here, psychosis) is fundamental to changing public and community attitudes. A recent meta-analysis of anti-stigma interventions, for example, has demonstrated that the effect sizes of interventions involving contact are nearly twice those of education-only interventions.<sup>98</sup>
- 2. Contact must be targeted.** Effective contact-based interventions focus on particular groups or stakeholders and tailor the intervention to these groups. For instance, a project intended to change attitudes within a largely Latino/a community should be culturally specific; a project geared to changing attitudes among middle school students should address the particular stereotypes or misconceptions that youth between the ages of 11 and 14 tend to hold.

3. **Contact programs should be local.** In addition to targeting particular groups (or audiences), programs should be local in the sense of adapting to differences across areas and sites. A program that works well in a wealthy, suburban private school may not work as well in an impoverished inner-city public school, for instance, even if the two schools are only 20 minutes apart.
4. **The featured contacts should be credible.** Whether the intervention involves web-based videos or a live presentation, the young adults who are featured should be as credible as possible to the target audience. For instance, a panel of Latino/a young adults who graduated from a rural (primarily Latino/a) high school several years ago and return to that school to lead an anti-stigma workshop are likely to be seen as much more credible “living proof” of recovery than a white Hollywood actress broadcast on an auditorium screen.
5. **Ideally, contact is continuous (ongoing).** So far, research suggests that a single (or even several) awareness, outreach or anti-stigma program is in no way sufficient to change attitudes and behaviors.

#### EIP Outreach Models & Projects.

To date, all public awareness and media campaign studies specific to EIP have been conducted outside the U.S. (though a trial is currently underway in Connecticut). A 2011 systematic review of these studies found mixed effects.<sup>99</sup> None of the studies directly examined the program’s effects on young people themselves or on non-health-professional members of the community. None of these projects measured stigma, and only a few involved contact of any time (for the most part in a minimal way, with a primary emphasis on education and awareness of the signs and symptoms of early psychosis). While these studies do not provide much guidance on peer-involved contact-based models, there are a range of possibilities from the broader world of public awareness and stigma reduction in mental illness. Here are a few:

- **Speaker’s Bureaus.** A speaker’s bureau generally consists of a list of individuals who are willing to speak to groups and organizations either individually or as part of a panel. The speakers are typically paid (usually by the host organization) and have received at least some coaching or support developing high impact presentations and narratives.
- **Hybrid Community Presentations.** Another common format is a live presentation that includes both contact (through a recovery narrative) and educational or informational material about symptoms and treatment. These presentations are most effective (as above) if tailored to a specific audience. For example, a presentation geared towards faith-based leaders should look different (and cover different material) than a presentation aimed at primary care providers or school nurses.
- **Web & Social Media.** The potential for internet, app and social-media based interventions is enormous, particularly among youth.<sup>100</sup> Recent studies have demonstrated that youth frequently search for information on mental health prior to seeking (and during) treatment for early psychosis.<sup>101</sup> Once materials have been developed, the costs of website or app maintenance are often minimal. Peers—particularly young adult peers—are not only likely to be more familiar with the latest trends and technologies, but are often enthusiastic about do-it-yourself tech development (which might include short documentaries, digital stories, or music videos).



### Internalized Peer (& Family) Stigma.

Finally, while public stigma (and lack of awareness) is almost certainly the greater problem, various forms of internalized stigma—often taking the form of lowered self-expectations—can also play out in extremely detrimental ways for young people and their families. Many factors undoubtedly influence the internalization process, including fear and uncertainty, societal expectations, social isolation or exclusion, and institutional barriers. Interventions that target internalized stigma are nevertheless important.

To date, the impacts of both contact-based and educational interventions for self-stigma have been disappointing. As a consequence, Pat Corrigan and colleagues have recently developed an innovative empowerment-oriented disclosure intervention called Coming Out Proud (see Spotlight). Pilot controlled data from a Coming Out Proud trial in Germany demonstrated significant decreases in stigma stress, disclosure related distress, secrecy and participant's perceptions of the benefits of disclosure.<sup>102</sup>



## Public Outreach & Social Media Spotlight

### COMING OUT PROUD ON COLLEGE CAMPUSES

Coming Out Proud (COPp) is an innovative three-session group program run by peer facilitators. The program is premised on the idea that secrecy about a psychiatric diagnosis has negative impacts both on the individual and his/her relationships with others (for instance degree of relational honesty).

The three COPp sessions cover: (1) consideration of the pros and cons of disclosing to different people and under different circumstances; (2) different ways of disclosing to others; and (3) meaningful ways of telling one's story and/or narrating one's experiences to others, either in the context of, or following, disclosure. COPp has been explicitly adapted for use with young adults in campus settings with a dedicated college campus manual and workbook (see Appendix).

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EIP community events, including family “orientations” in which current and past clients and their families help introduce new clients and families to early intervention and program “graduations” also help challenge stigma and promote a sense of hope in what it is possible for persons with psychosis to achieve. Additional family and community events (for instance a potluck, BBQ or holiday mixer hosted by the EIP provider agency), can serve similar purposes, exposing both youth and families to peers who are farther down the road to recovery. Stars' TAY UnConvention (see the spotlight segment at the end of this chapter) is an even more innovative example of an empowerment-oriented one-day event and could easily be adapted for an EIP only population.



Finally, efforts to reduce internalized stigma can also be as simple as providing a list of memoirs or first person accounts by individuals with psychosis who have succeeded in various arenas (for example the clinical psychologist Fred Frese or law professor Elyn Saks). As stressed in other sections of this guide, one of the most critical contributions peers can make—whether intentionally (through direct contact) or through writings or documentaries—is to serve as living reminders of what is possible and keep young people’s dreams—and ambitions—alive.



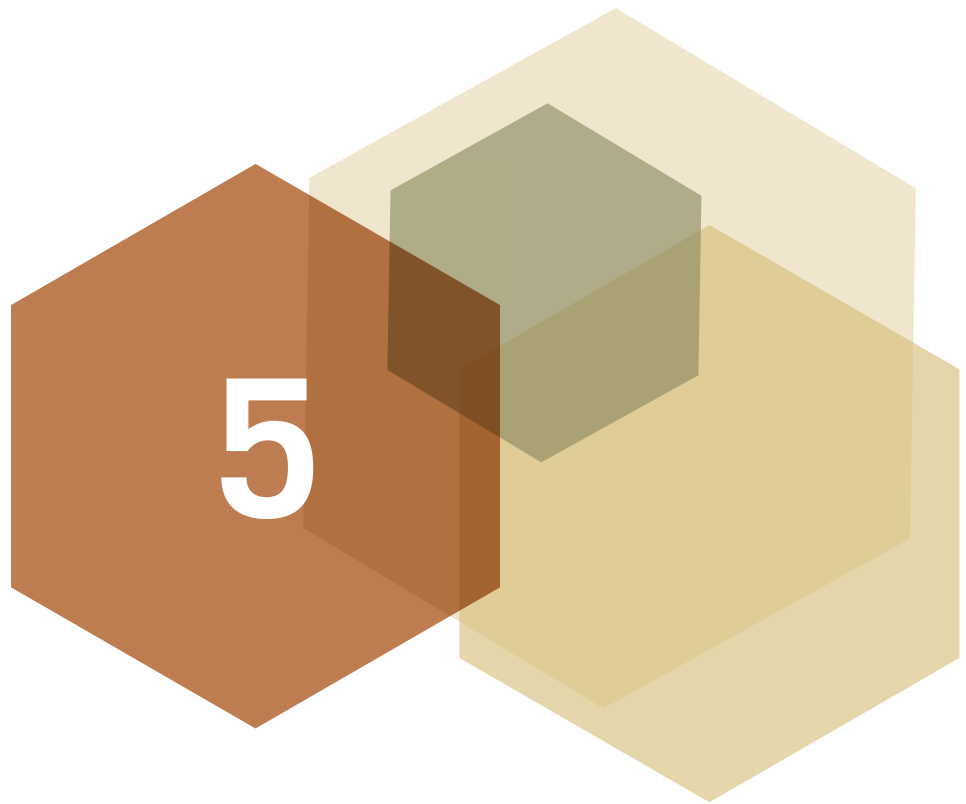
## Youth Involvement Spotlight

### STAR BEHAVIORAL HEALTH’S TAY UNCONVENTION

The Transition Aged Youth (TAY) “UnConvention” or “UnCon” is a semi-regular (recurring) all-day event that brings together youth with lived experience, peer advocates, and TAY providers. The event is open to everyone (i.e., youth and providers from a diverse array of agencies, organizations and settings), and the participation fee is kept as low as possible. The UnCon is organized through a partnership between Stars Behavioral Health and the Project Return Peer Support Network (PRPSN), and each (specific) UnCon is co-organized and designed by youth advocates. Surveys sent out to youth in advance help determine the focus of any particular UnCon.

Asked about the UnCon, Wayne Munchel, director of TAY services for Stars Behavioral Health, asks “rather than passively listening to various experts on youth services and the latest evidence based practice – what out-of-the-box things might we learn if we heard directly from youth themselves? In addition, what if TAY providers had an opportunity to exchange ideas on what’s working (and what’s not) with each other?” UnCon, he emphasizes, allows “teachers to become students, and students to become teachers.”

More broadly, Wayne explains “the TAY UnConvention seeks to be a community of learning that crosses the usual boundaries and silos. Crossing different regions, different programs, different service systems and different generations – it’s an opportunity to cross-pollinate and network. Brainstorm topics are chosen by attendees prior to gathering. This year’s discussions will include: how to effectively advocate for yourself and others; how to get/give help for supporting educational goals; and how to better connect with youth and mental health providers. TAY UnConventions are serious about fun, so there will be interactive art projects, live Twitter feeds and Open Mic performances. The “UnCon” attempts to live up to the oft-repeated adage; “nothing about us without us”.”



## Clinician Education

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As noted in the introduction, formal peer involvement in clinician training is increasingly common outside the U.S. and is now mandated by virtually all regulatory (licensing) clinical associations in the U.K. (see feature on the UK Mental Health in Higher Education project p 74). In these countries, peer educators are often seen as central to systems change.<sup>103</sup> While continuing clinical education and discrete workshops or in-services are likely of most relevant to EIP program administrators and planners, this chapter also briefly touches on the forms that peer involvement in the context of formal clinical education might take.

“Sometimes people who are completely unsuited to peer support work end up in such positions because that’s the only option they see for themselves or that others see for them.

(What happens when your only ‘recovery role model’ is a peer support worker?) Being a person in recovery shouldn’t be the only qualification for a peer-specific job, nor should it limit one to a peer-specific job. I have/have had a number of diagnoses of serious mental illnesses and varying experiences of treatment and services in my 45 years as a “consumer of mental health services” but have no talent for – or any desire to provide – direct services. I’m fortunate to work in the Workforce Development Department of a psychiatric services agency where I can use my personal perspective (as well as my academic and teaching background) to inform my work training agency staff.”

–Shirley Helm, MA  
Thresholds

### Continuing Education.

As in most other domains, involvement in clinician education can take many forms. At the most basic level, either internal or external peers (e.g., members of a local speaker’s bureau) might be invited to come and speak to a group of clinicians. In most cases in the U.S., the focus of such a presentation would be personal narratives of recovery, rather than presentations in other areas (e.g., peer views on CBTp or barriers to physical health care). Peers might also be incorporated into a training or workshop in a more passive way. For example, they might serve as a “case study” or help a clinical trainer demonstrate a particular technique.

Moving up a level, there are a growing number of clinically-oriented peer trainers (even in the U.S.), some of whom are peer specialists, and others are peers with traditional clinical degrees in social work, counseling, clinical psychology and related fields. For example, many hearing voices network (HVN) groups and trainers organize dedicated workshops for clinicians that may include a simulated experience of voice hearing, and tools and strategies for exploring the meaning and impact of clients’ experience of voices.

“It was extremely refreshing to learn more about a different approach to working with voice hearers. I loved the idea of really diving into the voice hearer’s experience and walking that road with them to better understand the purpose of the voices, and how to engage in respectful dialogue and compromise. I firmly believe that [other] staff would greatly benefit from being trained in how to gather the voice hearer’s back story [and] profile the voices.”

—Anonymous clinician participant in a peer-led  
Hearing Voices training



In addition to clinician trainings focused on psychosis more broadly, discrete trainings or workshops provide an opportunity to explore more specific topics and intersections such as psychosis and sexuality, cultural and/or racial differences, and the relevance of spirituality in early intervention. Trainers from other countries may also be able to share valuable perspectives on approaches to psychosis (as well as clinical care) that have developed outside the U.S. See, for example, the profile of the series of trainings that the Bay Area PREP program organized with New Zealand hearing voices trainer Debra Lampshire in the next Spotlight segment.



### Program Spotlight:

#### **CLINICIAN WORKSHOPS WITH AN INTERNATIONAL HEARING VOICES TRAINER (BAY AREA PREP)**

Debra Lampshire is an internationally respected mental health educator and consumer advisor at the University of Auckland in New Zealand. Drawing on her own experience of voice hearing and recovery, Debra leads workshops at home and around the world on alternative ways of working with voices. Over the last year, the Felton Institute's Prevention and Recovery in Early Psychosis (PREP) programs have brought Debra Lampshire to northern California to lead hearing voices workshops at multiple PREP centers, including rural sites in the central valley and central coast. Adriana Furuzawa, PREP's Director, comments on the impact of Debra's trainings:

*“The initiative to bring Debra Lampshire to the communities served by PREP stemmed from a desire to expand the worldview of our consumers and their caregivers, clinical providers, and other community members. These events brought everyone together in lively discussions, where providers were eager to learn from a colleague with lived experience who could normalize and bridge the gaps in communication in an empathic way. Family members and their loved ones struggling with psychosis engaged in a powerful dialogue, taking away helpful tips to understand one other’s experiences. A conversation about psychosis quickly changed into a discussion about life, identity, roles, and the factors that need to be aligned for one to overcome life challenges and flourish. Back by popular demand, Debra Lampshire led a second series of workshops in three of the five counties served by PREP during the first half of 2015.”*

### University-based training.

In addition to the forms of clinician involvement mentioned above (all of which could also be used in formal academic training settings), peer educators at the university level might also assume substantive roles in curriculum development, course content, and student assessment. Beyond incorporating material on specific peer-developed or -informed approaches, there might also be scope for coverage of such topics as the history and politics of the consumer/peer movement, alternative conceptualizations of “madness,” or even representations of psychosis in art or poetry. See the Mental Health in Higher Education spotlight feature later in this chapter for a more detailed discussion of some of the forms peer involvement education is taking in the U.K. An additional example of non-clinically-focused peer-developed coursework is Ryerson University’s popular “Mad People’s History” course, described by its instructors as providing a historical overview “from the point of view of people who were, and are, deemed “mad.”<sup>104</sup>




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“As the adult psychiatry residency training director, it is essential that trainees understand the importance of the recovery model and have the opportunity to work with and learn from persons with lived experience. Having a certified recovery support specialist (CRSS) on staff has provided a rich learning experience whether it be collaborating on the inpatient unit during rounds or in our outpatient clinic groups. Residents are exposed first hand to the benefits of peer support in the recovery process.”

—Robert Marvin, MD  
University of Illinois at Chicago

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The Q & A segment with Cherise Rosen later in this chapter highlights some additional forms that clinician education might take in a medical school or medical training center setting. These include a seminar series featuring a rotating battery of speakers from around the U.S. and the world, many of whom (including researchers and doctoral-level clinicians) also have lived experience of psychosis. In addition, as Robert Marvin highlights in the quotation above, embedded peer specialists can operate not only as members of the clinical team but also as in vivo “instructors.”

## Program Spotlight and Q & A: Mental Health in Higher Education (mhhe)

Mental Health in Higher Education (mhhe) is an interdisciplinary project based in Lancaster, England and currently coordinated by Jill Anderson. mhhe was set up in 2003, as an initiative of the U.K. Higher Education Academy, and - now unfunded - has since grown to become a true “hub” for “learning and teaching about mental health across the disciplines.” Lived experience plays a major role in mhhe, both in the context of peer involvement in education (including both clinical and non-clinical university courses) and education “about” peers, peer advocacy and peer support. Jill agreed to provide further details about the mhhe hub and the project’s accomplishments.

***Q:** First off, mhhe provides an amazing array of different resources and has links to many associated projects. How would you summarize the overarching goals of mhhe, and can you say a little bit more about what you do?*

**A:** There has long been an acceptance that interprofessional working on the one hand, and consumer/survivor involvement on the other, are key to the effective provision of mental health support. It is a small step from there to recognize the need for interprofessional education and consumer/survivor involvement at pre- and post-qualifying levels - where students from diverse professions learn with, from and about each other – and from people on the receiving end of services - to improve collaboration and the quality of support. It takes only one step further to recognize that educators, based in universities, need opportunities to learn and network too, in relation to their teaching (both across disciplines and with people who have been on the receiving end of services). Yet research pressures can mean they have limited time for dialogue about teaching at all, let alone with those outside their discipline. That’s where mhhe - and its networking site, the mhhe hub - come in. In the early years we spent time travelling the length and breadth of the country, to introduce people to their colleagues on the adjoining corridor!

***Q:** Can you say a bit about work that mhhe has been involved in, in terms of educating clinicians and educators about peer advocacy/activism, and alternative ways of thinking about and working with “mental illness”?*

**A:** Mental health is a contested field. Intrinsic to our work has been a determination to see beyond vocabulary to meanings and intentions. That terms, such as ‘clinical’, have such different connotations - in different disciplinary, professional and experiential contexts - can impede communication. In our attempts at cross-fertilization we have attempted to bring ideas developed within the service user/survivor movements to the attention of educators who might not otherwise have come across them, and to promote debate – universities (still) provide some space for that - about how concepts such as recovery or peer advocacy are being put in to practice. It can be easy to get trapped in our own disciplinary and professional boxes – reading the same journals, attending the same conferences. mhhe’s work can be as simple as opening some windows onto what is going on elsewhere.



**Q:** *American audiences are often less familiar with British and Australian “service user [peer] educators.” What do they do? How do you think they impact services?*

**A:** In the U.K., it is a requirement of the professional regulatory bodies that service user and carer educators are involved in both pre- and post-qualifying education. They contribute directly to teaching sessions (drawing on their own experience of using, being coerced into and/or denied, services) and are increasingly involved too in other ways; for example, on program management committees, in interviewing prospective students and in the assessment of their work. At the University of Birmingham they have been involved in facilitating interprofessional learning groups – for social work, clinical psychology and nursing students and post-registration medics – on mental health theory and practice. We know a lot about how such initiatives are experienced by those involved (students, academic staff and service users); less about their impact on future services. In my view, a search for ‘evidence’ of ‘impact’ on services – though actively sought by many - is destined to frustration: firstly, because it is difficult to isolate this one aspect of what, at its best, is a holistic educational process; secondly because it is dependent on a ‘transfer’ view of learning. More fruitful, in my view, is to consider how students – who may of course themselves be consumers/survivors - are impacted in the here and now, and how that process (which is a kind of realignment) opens them up to further learning.

**Q:** *Can you give us an example of a model service user education project?*

**A:** There are many examples to choose from, ranging from very well resourced projects such as Comensus at the University of Central Lancashire, which employs three service user and carer education coordinators (McKeown et al, 2010) and organizes the regular Authenticity to Action conferences, to initiatives which are more modest in scale. Some projects have been time limited but have generated invaluable teaching resources. See for example the films produced by the Centre for Interdisciplinary Mental Health: <http://www.birmingham.ac.uk/research/activity/social-policy/ceimh/index.aspx>

**Q:** *What advice would you have for American educators or administrators who are just starting to think about these issues?*

**A:** (1). Involving service users and carers in education is one very valuable way of prioritizing the importance of knowledge gained from lived experience. It is not the only way of doing so. Both students and educators embody such experience too. (2). Service user and carer involvement in learning and teaching is not an add-on to existing approaches to learning and teaching. It needs to draw on service user and carer led-research and implies a fundamental challenge to the accepted knowledge base. (3). Open sharing, particularly when it comes to teaching, can feel counter-cultural in universities. Form alliances wherever you can: across disciplines, across institutions, with students, between stakeholder groups; and, of course, across the Atlantic!

McKeown, M., Malihi-Shoja, L. & Downe, S., supporting the Comensus Writing Collective (2010), *Service User and Carer Involvement in Education for Health and Social Care*, Chichester: Wiley-Blackwell.

## Peer Involvement in Clinician Education

### EXPERT Q & A: CHERISE ROSEN, PHD

Cherise Rosen is an Assistant Professor of Psychiatry and Public Health at the University of Illinois at Chicago (UIC), and the Director of Quality Improvement Services. Her research interests focus on the subjective experience of psychosis, and she is the former clinical director of a first episode psychosis specialty clinic. Over the past five years, Cherise has led or supported an array of peer training and involvement initiatives within UIC's psychosis clinic. These include multi-day hearing voices movement training led by peer leaders from the U.K. and a "social psychiatry and alternative approaches to psychosis intervention" seminar series for psychiatric residents and other trainees (featuring a different presenter every week, about half of whom have lived experience of psychosis).

**Q:** *You've spearheaded a number of peer involvement projects, and so I first just want to ask you more globally to say a few words about the impact of peer involvement in the context of clinician training and residency education.*

**A:** Peer involvement in training can best be described by sharing a peer-integrated clinical supervision discussion on "fixed delusions." In the discussion, the peer specialist shared with the clinical team her lived experience of a "fixed delusion" and how she came to understand this belief as related to unresolved issues, thus the need to maintain the belief. The peer's subjective experience added a dimension to the training that would have otherwise been missing. Peer involvement as "consumer educators" is essential.

**Q:** *Turning to your work introducing residents and trainees to peer-led and peer-developed psychosis alternatives, including those that are not currently "evidence-based," what sort of impact do you think this has?*

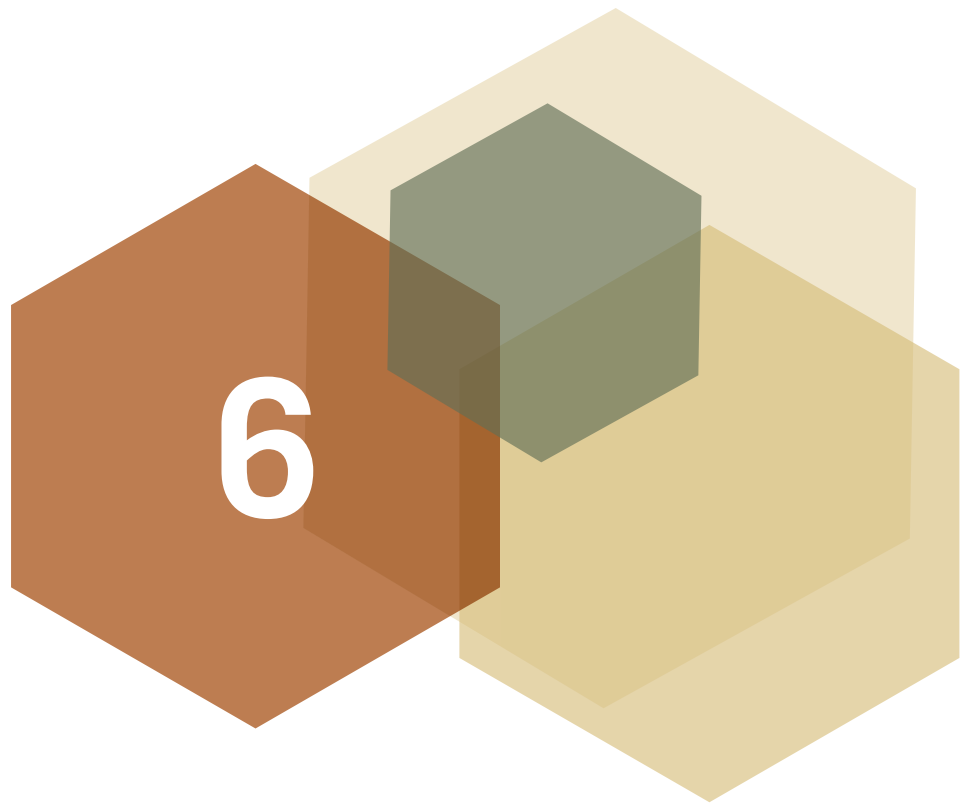
**A:** Evidenced-based training and practice are included in all clinical training programs, as they should be. However, part of the work in academia is teaching trainees to apply critical thinking about current and emerging models of care and to be aware of and consider alternatives. I would hope that trainees would bring this openness and critical thinking into their clinical practice.

**Q:** *What about the impact of an internal peer specialist on trainees?*

**A:** The peer at UIC is part of the clinical team; she attends rounds, leads groups, and works individually with people in developing a recovery plan. She is open and comfortable with sharing her lived experience with psychosis. It is in this context that trainees are introduced to and witness the power of peer-to-peer work.

**Q:** *Having directed an early psychosis program yourself, what advice would you offer new programs seeking to involve peers in (ongoing) clinician training?*

**A:** The most frequently asked question in the FEP clinic was "are there other people like me." Peer specialists in early psychosis programs should be the standard of care not the exception.



## Quality Improvement, Evaluation and Research

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Looking to broader mental health issues and populations, there are a wide range of different participatory and peer-led research models, including forms of community-based participatory research (CBPR), participatory action research (PAR), co-production, and peer-led research. Within and across these models, the extent of participation varies considerably. At one end, one might place forms of participatory “lite” research that look more or less like traditional (non-peer involved) models but with the addition of a community advisory board; at the opposite end is peer-led research in which the PI or co-PI of a project is him or herself a researcher with lived experience of psychosis leading a team of peer co-researchers. In different contexts and settings, peers might be involved as advisors, as research assistants, as co-interviewers in a qualitative or oral survey project, and/or as partners in data analysis and reporting. Peer involvement methods may also include components specifically oriented toward gathering broader community input (e.g., beginning with a community survey asking about study-related preferences or priorities) or ongoing stakeholder engagement (e.g., through periodic project “town hall meetings” or community feedback sessions). A selection of participation components are described in the first table below, followed by broader engagement components, which are highlighted in the second table.

Project Area	Forms of involvement
Project focus and goals	Determining the focus of the research project; what questions to ask; what the project's goals are; what design to follow
Research ethics	Developing research ethics protocol; how to protect the interests of the community; appropriate incentives or compensation
Recruitment	Making decisions about inclusion/exclusion criteria; what groups to recruit; recruitment strategies; direct involvement in recruitment activities
Interviews or focus groups	Conducting interviews, administering surveys and/or facilitating focus groups, either alone or alongside a non-peer researcher
Measures & surveys	Selecting existing measures; developing novel survey questions; creating and validating new measures or scales
Community engagement	Involvement in broader community engagement efforts; ensuring that the community is aware of what is happening; ongoing outreach to additional stakeholders
Analysis & writing	Direct involvement in coding and analysis (qualitative or quantitative); writing project reports and/or research manuscripts
Sustainability planning	Figuring out next steps; how to continue the work of the project; how to ensure that research is used and/or impacts policy or practice

Strategy	Description
Dissemination	Open-ended “needs assessment” type survey administered prior to beginning a project that is designed to better understand a broad cross-section of community members’ preferences and priorities
Public website	Public project website with accessible information on a research project, regular updates, contacts and information on how to get involved
Public meetings or town-halls	Meetings or town-halls geared toward involving a broader cross-section of stakeholders, building trust and promoting community dialogue about the project
Accessible report	Accessible (plain language) report(s) or updates, made available to the public via project website, community listservs, and local organizations
Policy briefs	Briefs that focus on the policy implications of research project findings and suggest pragmatic next steps for policy change

In the literature on peer research involvement there has been significant debate as to the extent to which different forms of participation or leadership in fact alter or merely mask existing power differentials.<sup>105</sup> Consequently, in the U.K. in particular, strong emphasis has been placed on full project leadership or co-leadership, typically by one or more (co-) primary investigator(s) or lead evaluator(s) with doctoral-level training.<sup>106</sup> Alternately, one might think about how much “power” or influence peers have across project components. The next table lays out select components of what is perhaps best conceptualized as a “spectrum” of peer influence broken down by advisory board and (individual) peer co-researchers directly involved in a particular project.

Component	Minimal Influence	Moderate Influence	Strong Influence
Advisory board or steering committee	Purely advisory role; no direct control over project decisions	Certain project decisions determined by the board through a group vote or consensus process	All major project decisions made by the board through a group vote or consensus process
Peer co-researchers	Assist with community engagement, recruitment and similar activities but have little or no direct control over the project; not involved in analysis or report writing	Directly involved in data collection, “assistant” role in analysis, some control over design and focus, minimally involved in report writing	Directly involved in all stages of the research process with authority/influence equal to lead non-peer researchers

Importantly, there is no single “best practice” approach to peer involved research. Instead, different methods are likely to be more or less feasible or appropriate depending on project-specific resources, local social capital, and funding mechanisms. For instance, if funding is not available to pay peers as co-interviewers, it would be ethically (as well as practically) problematic to expect them to do so without any compensation. The principles of meaningful involvement discussed in the introduction nevertheless apply—e.g., whether peers are involved as advisors, “assistants” or full research partners, they should be involved as early as possible in project planning, empowered to influence projects decisions, and provided with as many opportunities as possible for skill-building and professional growth.

### Peer collaborator backgrounds

As in other the other domains in this guide, it should not be assumed that all “peers” are untrained in research and evaluation. In the U.S., there are a growing number of Master’s and doctoral level researchers and consultants with lived experience of psychosis; in some cases an EIP program’s own young adult clients might simultaneously be studying research methods or working in research labs at school. While it may not always be possible to include peers with an established background in research methods, there are risks if a project team includes exclusively untrained peers without substantial investment in capacity building. Power hierarchies are difficult to address, for instance, when there are pronounced group differences not only in social identity (e.g., patients versus professionals) but also in age and background understanding of research decision-making. It is unrealistic to suppose that a group of young people with absolutely no training in statistics can meaningfully weigh in on decisions about what quantitative analyses to carry out, for example.



Some methods (or approaches to analysis) are nevertheless more accessible than others. For example, participatory researchers have developed a variety of protocols for direct stakeholder involvement in qualitative coding and analysis (Foster et al., 2012; Jackson, 2008) whereas full participation in quantitative analysis is rare. Researchers in the U.K. have also articulated specific strategies for peer-informed measure development (Rose et al., 2011) and peer-informed systematic reviews (Rose et al., 2006) that include both academically trained and untrained peers.

### Tools, Strategies and Suggestions

While a lengthy discussion of different participatory and peer-led research methodologies would be beyond the scope of this guide, presented below are a few manageable suggestions for greater peer involvement in quality improvement and evaluation even in settings in which there is little or no full-fledged “research” underway.

- **Peer staff-led QI Projects.** Even for peer staff who have no research training or background, the “logic” of administering pre-post (or even only post) surveys is straightforward. A peer specialist who runs a support group may enjoy and value undertaking his or her own ‘evaluation’ or an evaluation of a different group or project. Feedback can immediately be used to inform changes and/or tweaks that help address any common concerns.
- **Collecting & Analyzing Client & Family Feedback.** While it may not constitute research in a more formal sense, ongoing collection of client and family feedback is a critical component of quality monitoring and improvement. While regular program staff often do not have time to systematically review (much less code and analyze) anonymous feedback or complaints, peer volunteers and/or interns may find it both interesting and empowering to have the opportunity to do so.



- **Involvement in the Selection of Outcome Measures.** Many clients—especially in a research-intensive clinic—will likely have had more experience filling out questionnaires than many clinicians or evaluators. Thinking through the face validity and usefulness of a particular measure does not take specialized training and the value of tapping peer insights into what matters should not be underestimated. In addition, peers or clients may be able to (and interested in) generating novel items that, while not part of a validated battery, may nevertheless yield important insights, whether a given project is formal research or a more casual evaluation. Most often, clients are not asked for feedback or input of any kind during measure selection (or development).



- **Research Discussion & Advisory Group.** Finally, please note the spotlight on the British National Young People’s Advisory Group that follows below. On a more local scale, the Sussex Early Intervention in Psychosis service’s “service user research forum” (SURF) operates in a similar way. In both cases, “regular” (i.e., academically untrained) peers meet to discuss research and/or meet with and advise researchers in the early stages of project development. A common assumption in the U.S. often seems to be that clients “wouldn’t be interested,” an assumption that is contradicted by the existence of these groups in the U.K. Particularly at a national level, it should in fact be easy to put together a national advisory group with even a minimum of funding and institutional support.



## Participatory Research Spotlight:

### YOUNG PEOPLE'S MENTAL HEALTH ADVISORY GROUP (U.K.)

In the United Kingdom, a National Young People's Mental Health Advisory Group (YPMHAG) was first established in January of 2014. The YPMHAG currently consists of 14 members, all youth between the ages of 16 and 24 with lived experience of mental health challenges or of supporting others with them. These young people come from across England and meet in-person every six weeks in London.

Lisa Doughty, [facilitator] of the project, responded to some questions about how the advisory group is organized and examples of projects to date.

*Q: First, how is the YPMHAG funded? Do researchers who consult with the group pay anything?*

**A:** The YPMHAG is funded by the NIHR Clinical Research Network and in the future will become part of the Service User Research Enterprise (SURE) at the Institute of Psychiatry, Psychology and Neuroscience at King's College London. Our current model allows researchers one free visit and then to pay for future contacts with the group by incorporating it into their own research grants or from their own resources.

*Q: What generally happens at the group's London meetings?*

**A:** We deal with both researchers and group business. We have at least two researchers explain their studies and then they receive feedback. Then we discuss planning for training or ongoing projects. Researchers provide easy to read documents in advance and describe their research to the group who discuss the project in small groups or as a whole panel. Key points of advice are sent to the researcher after the meeting.

*Q: Can you give me one or two concrete examples of projects the YPMHAG has played a larger role in?*

**A:** The group advised the Chief Medical Officer on a national survey to investigate the national prevalence of mental health problems amongst young people. They have also played a large part in the development and evaluation of a new cognitive remediation program for people with schizophrenia. They gave initial feedback on the design, tested the final computer program, and provided advice on how to make it more interesting. They are now giving more advice on the presentation of the research study to individuals with schizophrenia and the information and consent forms they will receive.

*Q: Very briefly, why do you think groups like the YPMHAG are so important?*

**A:** Dame Sally Davies, Chief Medical Officer for England said she wants to see, "young people who understand mental disorders involved in the research looking into these areas. There's a big benefit to this." The group offers a unique insight for researchers, both due to their own experiences and ages. Researchers frequently comment on the valuable insight they provide, highlighting issues they had not even thought of. Such insight, only obtainable through lived experience, can only enhance mental health research amongst this specific age group.



## Peer Research Spotlight: Rory Byrne, PhD

Now a postdoctoral researcher at the University of Manchester/Manchester NHS Psychosis Research Unit, Dr. Byrne first interfaced with the mental health system through local primary care services, and then as a participant in a world-first early detection and intervention research trial in Manchester (EDIE; Morrison et al., 2004). He later worked as a user-researcher on major early psychosis projects including a larger, multi-site replication of the EDIE trial, before moving into a doctoral program. His dissertation, *“Understanding psychological treatment for psychosis from the perspective of those with lived experience: ‘What’s important to us?’* explored service users’ priorities and preferences for treatment of psychosis-spectrum difficulties, as well as their experiences of cognitive behavioral therapy. Five papers from the dissertation have now been published (see below), including a comprehensive review of service users’ priorities for treatment of psychosis (“patient-centered outcomes”) and a follow-up service user-led Delphi study on the same topic. This important work has helped re-center (and address) major gaps in the early detection and intervention literature on the perspectives of service users.

Asked about his views regarding the importance of service user involvement in research, Dr. Byrne reports: “Despite decades of professional-led research into psychosis, there remains a huge amount of uncertainty about what causes such experiences, and what works for those who need help. It makes complete sense therefore to widen our collective perspective to include service users as co-researchers. We can help to ensure research questions are relevant and meaningful, we can help in the design of research processes to improve the personal impact of study participation, and we can offer new insight into the analysis of research findings. On a personal level, user-researchers may also offer valuable examples of recovery and success to our peers.”

### Select Works by Dr. Byrne:

- **Byrne R & Morrison AP (2014).** Service Users’ Priorities and Preferences for Treatment of Psychosis: A User-Led Delphi Study. *Psychiatric Services*.
- **Byrne RE & Morrison AP. (2013).** Young people at risk of psychosis: Their subjective experiences of monitoring and cognitive behaviour therapy in the early detection and intervention evaluation 2 trial. *Psychology and Psychotherapy*.
- **Kilbride M, Byrne R, Price J, Wood L, Barratt S, Welford M & Morrison AP (2013).** Exploring service users’ perceptions of cognitive behavioural therapy for psychosis: a user led study. *Behavioural and Cognitive Psychotherapy*, 41(1):89-102.
- **Byrne R & Morrison AP (2010).** Young people at risk of psychosis: A user-led exploration of interpersonal relationships and communication of psychological difficulties. *Early Intervention in Psychiatry*, 4(2):162-8.
- **Byrne R, Davies L & Morrison AP (2010).** Priorities & Preferences for the Outcomes of Treatment of Psychosis: A Service User perspective. *Psychosis*, 2(3): 210-217.

## Peer Research Involvement in the United States

### EXPERT Q & A: SUE ESTROFF, PHD

Sue Estroff is a professor of social medicine at the University of North Carolina at Chapel Hill, and she is an internationally recognized medical and psychiatric anthropologist. Much of Sue's work has focused on the subjective experience and sociocultural determinants of psychosis, and she is a long-time advocate of greater research involvement and leadership by persons with psychiatric disabilities. Recently, Sue was a co-investigator on NIMH's Recovery after Initial Schizophrenia Episode (RAISE) initiative.

*Q: In your own work, you've consistently emphasized the risks of research that fails to take into account the subjective experiences of peers and the social contexts in which, for example, experiences of early intervention unfold. Can you say a bit more about this?*

**A:** The issue here is one of scholarly rigor and accuracy. When we fail to learn from the people who use services, we risk designing and implementing interventions that do not address their needs. For example, the research shows consistently that providers, family members, and users have some common ground in terms of identified needs and goals. Yet, there are more differences than commonalities. For example, a large body of research reveals that people who actually use services value the quality of relationships (e.g., respect, recognition, decisional partnership, and inclusion) as much if not more than the actual intervention model. We spend a lot of time looking at treatment models, and fidelity to the model when implemented. But we do not spend comparable time and energy critiquing the model itself with the assistance and from the view of users. To illustrate, our largely Medicaid and medically necessity based system of mental health service delivery and financing is toxic to therapeutic relationships. The number of units of service (defined by Medicaid bureaucrats and state politicians) provided will trump quality and amount of time spent recovering with a trusted provider. When we ask 'yes or no' satisfaction questions, we miss the point. When we measure the factors we consider to be important without including measures of what users want and need, we miss many points. The business of measuring outcomes should begin with the sometimes messy deliberative process of learning and understanding what people who use services need and want in their own terms. Service-user-developed measures and treatment quality indicators are in the works. Our recent comprehensive review of outcomes measures for person centered care in mental health (Green *et al*, 2014) documents these efforts and the need for more attention and resources to be devoted to their development and implementation. To the extent that received wisdom is tested and modified or even upended, we will be engaged in the kind of discovery the field needs.

*Q: What is your perspective on the value and potential impact of greater peer involvement in early intervention research?*

**A:** There is a great deal of momentum and excitement about early intervention at present. It is important to remember that ‘early’ is a relative term, and in clinical trials can vary widely. Early intervention is in its own ‘early’ period. We must learn from the experiences of people who are unfamiliar with changes in their thinking and feelings in order to offer assistance in a timely, useful, and enabling manner. Early intervention falls into a space between child-adolescent and adult divisions of mental health specialties. As such, there is considerable need for the wisdom and insights of people who use services and/or have lived experience in this space to inform our approaches. This goes beyond focus groups to the active involvement of people with lived experience in the development of services and in the ongoing assessment of their responsiveness to the people who use them.

*Q: Looking at the state of early intervention research in the U.S. right now, what is your assessment of the degree to which the research happening now is participatory and/or “patient-centered”?*

**A:** There are some promising foundations and possibilities. At least three teams of researchers, one in Canada and two in the U.S., have devoted considerable effort to eliciting and understanding the experiences of people who were in early intervention programs. The extent of peer involvement with the actual research design, implementation and analysis in these studies is not clear to me. However, with the roll out of substantial funding for states to implement early intervention programs, the opportunities and need for peer researchers is huge. While many states have offices of peer and user services in mental health divisions, their presence in the evaluation and outcomes offices is less apparent.

*Q: What do you think would need to happen for greater implementation of (and investment in) participatory approaches to EI?*

**A:** It will be important to identify people with lived experience who are interested in and have the background necessary to participate. A ‘workforce’ development approach of outreach and training is probably the best way forward. This will necessitate partnerships with peer researchers, user groups, researchers and providers to locate potential participants and enable them to have the tools, skills, and access needed. The current block grant does not to my knowledge contain funding identified for this purpose. Clearly, a state and/or federal initiative in partnership with universities and perhaps NIH would be ideal. Most importantly, the integration of peers into the process should be monitored and facilitated.

## Endnotes

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<sup>105</sup> Trivedi, P., & Wykes, T. (2002). From passive subjects to equal partners Qualitative review of user involvement in research. *The British Journal of Psychiatry*, 181(6), 468-472.

<sup>106</sup> Callard, F., & Rose, D. (2012). The mental health strategy for Europe: Why service user leadership in research is indispensable. *Journal of Mental Health*, 21(3), 219-226.

Russo, J. (2012). Survivor-controlled research: A new foundation for thinking about psychiatry and mental health. In *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, 13(1).

Sweeney, A., Beresford, P., Faulkner, A., Nettle, M., & Rose, D. (2009). *This is survivor research*. PCCS Books.

# Appendix A:

## Checklists and Samples

### 7 COMPONENTS OF MEANINGFUL PEER INVOLVEMENT SELF-ASSESSMENT QUESTIONS

#### 1. Timing:

**Have attempts been made to include peers as early as possible in planning a new initiative or program?**

- a. If not, how does the group plan to deal with potential power dynamics or tensions stemming from uneven or unequal involvement in early decisions that may have already significantly shaped a program or initiative?

#### 2. Power:

**Do peers have the power to make decisions and shape programs, or are they limited to “advisory” roles?**

- a. If some members have the power to actually make concrete decisions about policy or programs, and others can only “weigh in,” how will any resulting power dynamics be addressed? What steps can be taken to ensure that peers feel like they still have a meaningful say?
- b. In a project involving committees or working groups, are peers positioned similarly to non-peers? E.g., are there peer chairs or co-chairs, or are peers limited to non-leadership roles?

#### 3. Compensation:

**Are peers financially compensated in a manner equal to non-peers?**

- a. If some non-peers are compensated, but peer members are not, what steps can be taken to address the hierarchies that such a division might create?
- b. Have program leaders fully thought through the implications of compensating non-peers but not peers?

#### 4. Numbers:

**Is there a *critical mass* (or sufficient number) of peers involved to make a difference?**

- a. If there is only one (or very few) peers involved in a majority non-peer group, can steps be taken to make those peers involved feel more supported?
- b. Have all possible steps been taken to ensure that peers (often, though not always, with less seniority than other non-peer group or project members) feel comfortable speaking out when in a minority?

**5. Wellness:****Have steps been taken to ensure that *peer wellness* is prioritized?**

- a. In addition to more formal supports, has peer wellness been raised more informally (but explicitly) at the outset of a project or new position? Have staff or other group members acknowledged potential stressors (micro-aggressions, other staff or members who might not be supportive of peer involvement) and affirmed the toll this can take? Is there a plan for addressing burn-out or frustration on the part of (minority) peers?
- b. If peers are expected to “advocate” within the project or group (often, though not always, from a minority position, or with less seniority), are the potential impacts of advocacy recognized? Are there concrete support plans? For example, if a peer is put in a position in which she/he feels forced to “challenge” a more senior member or leader?

**6. Investment:****Has the program or organization *invested in peer capacity building*—e.g., paying peers to attend conferences and workshops and/or to learn new skills?**

- a. If peers are involved in a project or committee in which they lack equivalent expertise to other members (for instance a peer without evaluation experience on an evaluation committee), are efforts made to provide the individual with more background or additional training?

**7. Organizational or Project Culture:****Have program leaders or administrators taken explicit steps to ensure that peer perspectives are valued, and that resistance to peer involvement is systematically addressed?**

- a. If a peer comes to another program or project member or leader with concerns (about stigma, negative or dismissive attitudes or lack of investment), are these members or staff prepared to take steps to support the peer and/or challenge dismissive attitudes?
- b. Is there a process or protocol for expressing concerns or grievances? Have peers been assured that they will not be retaliated against or ‘punished’ for raising concerns about other members or staff?
- c. If feasible, have program or project-wide ‘diversity’ or ‘peer involvement’ trainings or in-houses been considered?

## Sample Job Announcement: Young Adult Peer Specialist (40 hours)

### SETTING

[Gateways Early Intervention] is a community-based specialty mental health program serving youth and young adults with a first episode of psychosis. Services are holistic and include medication management, individual and group therapy, family services, vocational counseling, peer support and community outreach. Gateways has consistently been ranked as one of the best small employers in [Metro County] and is dedicated to creating a supportive work environment for peer staff.

### POSITION DESCRIPTION

The Youth Peer Specialist is a core member of one of Gateways' multidisciplinary teams with primary responsibility for carrying out recovery support functions and helping with individual client's treatment and treatment planning. The Youth Peer Specialist meets regularly with the multidisciplinary team, sees clients one-on-one, oversees or facilitates one or more peer support groups and documents all encounters as per standard protocol. In addition, the Peer Specialist is available to meet with family members and visits prospective and/or current clients who are in the hospital.

### **Additional responsibilities may include:**

- Serving on ad hoc program and/or hiring committees
- Involvement in internal evaluation and/or quality improvement efforts
- Overseeing the development of new peer-led resources and supports

### **Minimum Qualifications**

- Personal experience of mental health services
- High school diploma or GED
- Valid driver's license
- Interest in working with youth and young adults with psychosis
- Some experience working in a peer support setting
- Peer certification within six months of hiring date

## Sample Job Announcement: Young Adult Involvement Coordinator (20 hours)

### SETTING

[Gateways Early Intervention] is a community-based specialty mental health program serving youth and young adults with a first episode of psychosis. Services are holistic and include medication management, individual and group therapy, family services, vocational counseling, peer support and community outreach. Gateways has consistently been ranked as one of the best small employers in [Metro County] and is dedicated to creating a supportive work environment for peer staff.

### POSITION DESCRIPTION

The Young Adult Involvement Coordinator has primary responsibility for developing and coordinating client and alumni involvement in the program. The Coordinator oversees Gateways' peer speaker's bureau, manages the program's youth-oriented social media and outreach efforts, and assists in organizing events such as new family orientations and client graduations. In addition, the Coordinator has the lead role in managing Gateway's young adult leadership council.

### **Additional responsibilities may include:**

- Meeting with community partners, including representatives from local schools and youth organizations
- Recruiting and supervising youth and young adult volunteers for specific projects
- Tracking and/or documenting overall involvement

### **Minimum Qualifications**

- Personal experience of mental health services
- High school diploma or GED
- Valid driver's license
- Interest in working with youth and young adults with psychosis
- Some experience (paid or unpaid) with community outreach

# Appendix B: Select Links & Resources

## 1. FEATURED PROJECTS & AREA EXPERTS

[EASA Young Adult Leadership Council](#)

Contact: *Christina Wall*

EASA Center for Excellence

Regional Research Institute

Portland State University

[503.725.9606](tel:503.725.9606)

[christina.wall@pdx.edu](mailto:christina.wall@pdx.edu)

[Education Pays!/Peer Workforce Development](#)

Principal, Decision Solutions

Assistant Clinical Professor

Yale Department of Psychiatry

[JWolfDS@gmail.com](mailto:JWolfDS@gmail.com)

[www.facebook.com/groups/educationpays](http://www.facebook.com/groups/educationpays)

[Mental Health In Higher Education \(mhhe\)](#)

Contact: *Jill Anderson PhD*

[j.anderson@lancaster.ac.uk](mailto:j.anderson@lancaster.ac.uk)

[NAMI National Early Intervention Projects](#)

Contact: Darcy Gruttadaro, J.D.

Director, NAMI Child & Adolescent Action Center

Phone: [703-516-7965](tel:703-516-7965)

Email: [darcy@nami.org](mailto:darcy@nami.org)

[University of Illinois at Chicago Psychiatry Clinician Education](#)

Contact: *Cherise Rosen PhD*

Assistant Professor of Psychiatry and Public Health

Director of Behavioral Health Quality Improvement & Services Research

Department of Psychiatry

University of Illinois Hospital & Health Sciences System

Phone: [312.355.5234](tel:312.355.5234)

Email: [crosen@psych.uic.edu](mailto:crosen@psych.uic.edu)



Young People's Mental Health Advisory Group (YPMHAG)

Contact: *Lisa Doughty*

King's College London

Email: [lisa.doughty@kcl.ac.uk](mailto:lisa.doughty@kcl.ac.uk)

PREP Alameda County

Contact: *Dina Tyler*

Coordinator of Peer and Family Support Services

PREP Alameda County

Phone: [510-697-7737](tel:510-697-7737)

Email: [dina@mhaac.org](mailto:dina@mhaac.org)

[www.askprep.org](http://www.askprep.org)

Vermont Young Adult Early Episode Psychosis Initiative/  
5% Set-Aside Steering Committee

Contact: *Sarah Squirrell*

Vermont Cooperative for Practice Improvement & Innovation

Email: [s.squirrell@snhu.edu](mailto:s.squirrell@snhu.edu)

Parachute NYC

Qualitative Implementation Contact:

Kim Hopper PhD

Nathan Kline Institute for Public Mental Health

New York State Office of Mental Health

Email: [hopper@nki.rfmh.org](mailto:hopper@nki.rfmh.org)

TAY UnConvention

Contact: Wayne Munchel LCSW

Stars Behavioral Health Services

Phone: (310) 221-6336

Fax: (310) 221-6351

Email: [wmunchel@starsinc.com](mailto:wmunchel@starsinc.com)

Timothy Kelly ABD PhD

School of Counseling Psychology

University of Iowa

Email: [timothy-kelly@uiowa.edu](mailto:timothy-kelly@uiowa.edu)

Phone: 503-258-7060

Trevor Manthey PhD

University of Kansas

Email: [trevormanthey@gmail.com](mailto:trevormanthey@gmail.com)

## 2. EARLY INTERVENTION PEER INVOLVEMENT GUIDES & PAPERS

Consumer Participation in a Youth Mental Health Service. Katherine Monson & Melissa Thurley. *Early Intervention in Psychiatry*, 5, 381-388.

Youth Participation in Early Psychosis. Orygen Youth Health.

## 3. PEER INVOLVEMENT IN CLINICIAN EDUCATION

Learning from Experience: Involving Service Users in Mental Health Education and Training. Jerry Tew, Colin Gell & Simon Foster, Mental Health in Higher Education (mhhe) & National Institute for Mental Health in England.

Mental Health In Higher Education Hub.

Service User and Carer Involvement in the Assessment of Student Learning: An Annotated Bibliography. Jill Anderson, Mental Health In Higher Education project.

Service User Involvement in the Design and Delivery of Education and Training Programmes

Leading to Registration with the Health Professions Council. Mary Chambers & Gary Hickey, University of London.

Service User Involvement in Mental Health Training, Education and Research in West Yorkshire. West Yorkshire Mental Health Research and Development Consortium.

## 4. PEER-LED AND/OR PARTICIPATORY RESEARCH

Open Access Resources

A Guide to User-Focused Monitoring: Setting Up and Running a Project. *Sainsbury Centre for Mental Health (UK)*.

Mental Health Service User Leadership in Research. *Service User Research Enterprise (UK) Institute of Psychiatry, King's College London*.

Sharing Experience Learned Firsthand (SELF). *Lived Experience Research Network*.

Transforming Services: Changing Lives (Working for User Involvement in Mental Health Services). *The Centre of Excellence in Interdisciplinary Mental Health (UK), The University of Birmingham and Suresearch*.

User Controlled Research: Its Meanings and Potential. Report Summary. *Shaping our Lives & the Centre for Citizen Participation, Brunel University*

User/Survivor Leadership & Capacity Building in Research: White Paper on Promoting Engagement Practices in Peer Evaluation/Research. Lived Experience Research Network.

## 5. UNIVERSITY CENTERS & INDEPENDENT RESEARCH ORGANIZATIONS THAT ACTIVELY PROMOTE PEER INVOLVEMENT IN RESEARCH

### United States:

[Lived Experience Research Network](#)

### Australia and New Zealand:

[Australian National University, Depression & Anxiety Consumer Research Unit](#)

[International Association of Service User Academia](#)

### United Kingdom:

[Brunel University, Centre for Citizen Participation](#)

[Durham University, Service User Led Research in Mental Health](#)

[INVOLVE User-Controlled Research](#)

[King's College London, Service User Research Enterprise](#)

[Making Waves](#)

[McPin Foundation](#)

[Recovery in Sight](#)

[RETHINK Research Program](#)

[Survivor Research](#)

[Service User Research Forum \(SURF\) Lancaster Early Intervention Service](#)

[Suresearch](#)

[National Service User Network, Survivor Researcher Network](#)

## 6. PEER SUPPORT & SUPPORT GROUP RESOURCES

[Hearing Voices Network/InterVoice](#)

Primary website of the international hearing voices movement.

[National Alliance on Mental Illness \(NAMI\)](#)

[Needs Adapted Treatment Model \(NATM\) for Psychosis](#)

[Intentional Peer Support](#)

[Peer Support for Consumers with Psychosis \(Peer-Led Group CBTp\)](#). Elizabeth Cook.

[Voice Collective \(UK\)](#)

Supports & resources for children and young people who hear voices.

[Youth Wellness Recovery Action Plan \(WRAP\)](#)

Guide to WRAP for Youth.

[YouthMOVE National Peer to Peer](#)

Youth focused peer support program.

[We HEAR WA \(Australia\)](#)

Online community for youth who hear voices.

## 7. PEER SUPPORT ASSOCIATIONS

International Association of Peer Supporters (iNAPS)

Peers for Progress: Peer Support Around the World.

## 8. PEER SPECIALIST HIRING, SUPERVISING & TRAINING

Building a Foundation for Recovery: A Community Education Guide on Establishing Medicaid-Funded Peer Support Services and a Trained Peer Workforce. SAMHSA.

DBSA List of Peer Specialist Continuing Education Resources. Depression and Bipolar Support Alliance.

O'Brien-Mazza, D., & Boyd, J. (2014) *Frontiers in Peer Support Supervision*. VA Psychology Leadership Conference. <http://www.avapl.org/conference/pubs/2014%20Conference%20Presentations/3%20-%20OBrien-%20Mazza%20-%20AVAPL%20Peer%20Supervision%20Final.pdf>

Peer Providers in Integrated Health. SAMHSA-HRSA Center for Integrated Health Solutions.

Peer Specialist Training and Certification Programs: A National Overview. International Association of Peer Supporters.

Peer Specialist Toolkit. Veteran's Administration.

Pillars of Peer Support Services Summit Six: Peer Specialist Supervision. Pillars of Peer Support.

Practices in Peer Specialist Supervision and Employment. *New Jersey Psychiatric Rehabilitation Association.* Peggy Swarbrick & Pat Nemec.

Recovery to Practice Continuing Education for Peer Support Providers. iNAPS & SAMHSA.

## 9. PEER WORKFORCE DEVELOPMENT ARTICLES & RESOURCES

Baron, R.C. (2007). A review of current information about the careers of the direct support professional workforce in the mental health, developmental disabilities, and substance abuse service delivery systems. A report from The Southeastern Pennsylvania Behavioral Health Industry. Philadelphia, PA: UPenn Collaborative on Community Integration. Available at [http://www.1199ctraining.org/pdfs/behavioral\\_health\\_report.pdf](http://www.1199ctraining.org/pdfs/behavioral_health_report.pdf)

Centers for Medicare and Medicaid Services (CMS) (2015). Roadmap of Core Competences for the Direct Services Workforce. <http://medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/workforce/workforce-initiative.html>

O'Brien-Mazza, D., & Zimmerman, J. (2012). The Power of Peer Support. VHA Mental Health Services. <http://www.mentalhealth.va.gov/docs/peersupport.pdf>

Wolf, J. (2014). Peer career implications of an academic credential: Report from the field. *American Journal of Psychiatric Rehabilitation*, 17(4), 329-347.

Wolf, J. Lawrence, L. H., Ryan, P. M., & Hoge, M. A. (2010). Emerging practices in employment of persons in recovery in the mental health workforce. *American Journal of Psychiatric Rehabilitation*, 13, (3), 189 –207.

## 10. YOUTH MENTAL HEALTH ORGANIZATIONS & RESOURCES

[Active Minds](#)

[JED Foundation](#)

[Mad Students Society \(Canada\)](#)

[YouthMOVE National](#)

## 11. YOUTH-FOCUSED ANTI-STIGMA PROJECTS

[Coming out Proud on College Campuses](#)

[Project Let's](#)

## 12. POSITIVE YOUTH DEVELOPMENT RESOURCES

[Best Practices: Positive Youth Development](#). Oregon Commission on Children & Families.

[Positive Youth Development](#). Youth.Gov

[Positive Youth Development](#). US Department of Health and Human Services Family and Youth Services Bureau.

[Positive Youth Development in the United States: Research Findings on Evaluations of Positive Youth Development Programs](#). Richard Catalano, Lisa Berglund, Jeanne Ryan, Heather Lonczak & David Hawkins, US Department of Health and Human Services & National Institute for Child Health and Human Development.

## 13. ASSET-BASED COMMUNITY DEVELOPMENT RESOURCES

[Asset-Based Community Development Institute](#). Northwestern University.

[Shifting Focus: Alternative Pathways for Communities and Economies](#). *Latrobe City Council and Monash University*.

[The Capacity Inventory \(Asset Mapping Tool\)](#). *John Kretzmann & John McKnight*.

#### **14. EARLY PSYCHOSIS/EARLY INTERVENTION DOCUMENTARY & VIDEO RESOURCES & FIRST PERSON ACCOUNTS**

[Simon Says: Psychosis](#)

Short documentary on early psychosis and early intervention in the UK.

[A Little Insight](#)

Animation created by young people who hear voices.

[Trips and Journeys: Personal Accounts of Early Psychosis](#). Orygen Youth Health.

[Work and School Stories: Collection of Accounts from Adults with Psychosis Working in a Variety of Careers](#). Stanford University Voices Outside Project.