

Discussion and Research Agenda

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Pathways' State-of-the-Science Conference concluded with a discussion and debriefing session during which discussants and Pathways staff met to distill important themes from the Conference, and to outline a research agenda in several key areas. Summaries of discussions and key elements of research agendas in each of these areas are presented below.

Three general principles that cut across the themes emerged during the discussion. These principles are important to consider as future research is developed, regardless of the specific topic area. These principles include:

- The imperative to meaningfully include the **voices and perspectives of young people** at all levels of systems of care—service, organizational, program and system—and in research aimed at changing and improving activity at each of those levels.
- The need to broaden our understanding of the **diversity of experiences of young people** with serious mental health conditions and to incorporate this understanding into the development and testing of policies, programs and interventions that are intended to benefit them. This includes attention to learning more about what helps—and what hinders—among young people who are homeless or unstably housed; young people who experience poverty; and young people who are LGBTQ and/or who are members of diverse racial, ethnic or cultural groups.
- The central importance of taking a **positive developmental approach** when working with youth and young adults and of focusing on outcomes that reflect this kind of approach. These outcomes include self-determination, community participation, supportive social networks, resilience, well-being and quality of life.

Peer Support

The limited research on peer support for youth and young adults with serious mental health conditions—as well as the larger, broader literature on peer support for adults—has provided tantalizing evidence regarding the ways in which peer support can be effective as a means of increasing engagement and supporting recovery. However, the literature is unequivocal in noting that, in order for the potential



of peer support to be realized, several essential steps must first be accomplished. Perhaps the most important of these is to more clearly define peer support roles, since without this clarity, it is not possible to create assessments of practice quality or fidelity, or to effectively evaluate peer support interventions or programs. A second priority is to build clearer theory that shows how specific elements of peer support roles are linked to desired outcomes, and that describes the unique contributions of “peerness” to outcomes. Clarifying roles and theory will, in turn, assist in building a clearer understanding of the spectrum of peer support roles—e.g., from informal to formal, from prevention to treatment, or from working with general populations of young people to working with very specific populations.

Clarification of peer support roles and theory in turn will make it easier for agencies and organizations to understand more about how the role should be implemented and supported, including: how peer support is best integrated with other services and supports; what kinds of training and supervision are required so that peer support providers are building general skills for working with young people in an effective and engaging manner, as well as specific skills related to “peerness;” and how best to recruit and retain peer support providers so as to ensure both their wellness and their productivity. Clarification of roles and theory will also make it possible to undertake high-quality research that tests propositions about the specific contributions that peer support can make to young people’s engagement and retention in services and supports, and to their recovery.

Priorities for research thus include

- **Learning more about the current implementation of peer support**, including role expectations, who is eligible to be a peer support provider; how the

role is integrated with other roles within systems of care, how other staff are trained to work with peer support providers and how peer support providers are recruited, trained, supervised and retained.

- **Laying the groundwork for and evaluating the impact of peer support**: Describing specific peer support role/s, describing what makes peer support for youth and young adults developmentally appropriate and how it is different from peer support for older adults; providing clear theoretical linkage between the activities of the role and outcomes of peer support, and testing these assumptions in high-quality research studies.
- **Evaluating program- or system-level initiatives to improve the implementation of peer support roles** through changes to, for example, hiring practices; training, coaching and supervision; education of agency staff and leadership, and the broader community, about peer roles; and approaches for ensuring that peer support providers can be productive and stay well, given their mental health challenges and the fact that many of the young people in these roles have not had successful employment experiences in the past.

Youth Voice

The meaningful inclusion of youth voice and leadership in youth-serving programs, agencies, and systems is an organic strategy to enhance positive youth development, promote engagement in programming, and continuously improve services. Within youth-serving organizations, more and more young people are being engaged in advisory work at an introductory level. Further, an increasing number of youth-run organizations are in a position to transform youth-serving systems by ensuring that youth voice and leadership inform decision-making within



and across organizations in ways that ultimately guide direct practice with young people (for example, by enhancing peer-delivered services).

Yet sustainability continues to be a challenge when systems do not build capacity and structure to facilitate the recruitment of new voices and support the ongoing engagement of young people. For smaller youth-serving and youth-run groups at the initial stages of implementation, the field needs to do more to provide **data-informed technical assistance** around installing best practices for the inclusion of youth voice in advising and decision-making, especially in the absence of dedicated budgets and experienced staff. Similarly, larger organizations and systems need **empirically-supported frameworks and fidelity tools to better understand and implement the range of best practices** that enable and support the meaningful and consistent inclusion of youth voice and leadership over time. Lastly, to demonstrate the value of youth voice in policy and practice, **research needs to evaluate the impact when best practices that include young people in organizational advising, decision-making, and leadership are fully implemented.**

The field also needs to build knowledge and capacity for the advancement of young people from introductory involvement to higher levels of advising and leadership within organizations and systems. For example, given efforts to include youth and young adult voice in services and programming over the last decade, we now have a growing workforce that is “aging out” of more common advisory and peer support roles and is now in a position to manage youth voice programming and supervise peer support services from a place of both lived and professional experience. Yet the field has not yet identified or studied career pathways for this skilled workforce that allow them to move along a continuum towards administrative and leadership roles within systems.

Similarly, there is specifically a need for new institutional pathways that advance diverse groups of young people with lived experience into professional research and policy roles. One potential strategy is for researchers to take advantage of supplemental research funding for co-investigators with disabilities, including mental health conditions. However, there are few such institutional mechanisms in place to promote the intentional inclusion and career advancement of those with lived experience who want to pursue research and policy careers. This calls for improved efforts to both include young people’s voices in policy development and research initiatives as standard practice (for example, requiring the involvement of young people as a condition of funding), as well as the development of new mechanisms for young people to move from such advisory roles into existing educational and career pathways designed to train the next generation of researchers and policy-makers.

Training

By consistently incorporating youth and young adults as collaborators in our projects, Pathways RTC has developed and tested technology-supported training and coaching initiatives designed to increase transition service providers’ skills in providing developmentally appropriate, culturally responsive, and evidence-based supports. Accumulating research shows that combining training with practice exercises and ongoing coaching makes it more likely that providers will demonstrate increased knowledge of content and that they will apply new skills in their day-to-day practice with young people. In a recent national survey, service providers expressed high levels of need for further competence and skill development, particularly in areas such as trauma-informed care, incorporating youth culture



in interventions, working with the complex needs of youth, and culturally responsive practice with specific groups of young people.

Research on best practices in training to improve service provider intervention skills supports the design of training activities based on principles of adult learning, with self-directed learning relevant to individual learning needs and goals. Effective training builds on individuals' prior learning and existing skills, learning modality preferences (auditory, visual, sensory, experiential), and learning styles. For optimal knowledge translation to occur, training initiatives incorporate youth and family voice to increase understanding of service users and their contexts, and are based in supportive organizational environments. Additionally, continuously available on-the-job coaching, consultation, supervision, and provision of practice-focused feedback by supervisors, consultants, or peers enhances knowledge translation. With increasing availability of online and web-based training and technical assistance resources, increased comfort with using technology is also relevant for positive training outcomes.

Implications of our own work and a review of other studies suggest the following as priority areas for future research:

- What system-level changes and training initiatives will prepare service providers to meet the complex needs of youth living in poverty and with co-occurring conditions and multi-system involvement?
- What are cost-effective ways to support accessible web based TA, training, and coaching that includes youth voice?
- How can training content, delivery, desired outcomes, and measures be specified well enough to replicate and achieve fidelity to the intervention models being disseminated?

- What are the most effective strategies to incorporate youth and family voice in training initiatives, including training for political and organizational leaders, and how can the identified strategies be disseminated?
- How do we partner with public, private, and non-profit organizations in dissemination?

Social Networks/ Community Participation

It is widely accepted that community participation, social development, and social support network capacity are critically important to the developmental progression and ongoing well-being of young people with mental health challenges. While managing mental health symptoms, young people may experience perceived and real stigma, and an inhibited sense of belonging or personal agency, in ways that prevent typical social engagement and community integration. Additionally, mental health diagnoses may lead to social network disruption and periods of relative social isolation as young people receive treatment and navigate new interpersonal stressors. Yet, the current state of the science lacks acceptable and accessible interventions to build on young people's relational strengths and natural supports, overcome negative perceptions, and introduce self-determination skills around increasing social engagement and community participation.

Further, there is a growing understanding of individual health and well-being as occurring in a broader, multi-level community context, such that research and practice should not lose sight of higher-level opportunities to strengthen institutional, system-level, and community-level capacity to support young peoples' participation. For example, this may



look like network-oriented initiatives to provide low-barrier opportunities for young people to engage (e.g., drop-in centers), to promote the availability of accessible natural support relationships (e.g., peer support models), and to install sustainable youth and young adult voice throughout organizations, services, and programming. Combined, such approaches encourage multiple welcoming opportunities for young people to connect to social contexts in ways that promote a sense of belonging, social development, and community integration.

Thus, next steps to advance the state of the science around enhancing the social networks and community integration of young people with mental health conditions include individual and community-level research approaches. First, we need to **develop and test stand-alone programs and/or add-on service enhancement models to demonstrate the effectiveness of individual-level interventions** to address support network deficits and participation challenges of young people with mental health conditions. Second, we need to **evaluate the impact of community-level strategies to increase the participation of young people on validated measures of social network enhancement and community integration**. Combined, such multi-level approaches can enhance young peoples' social development in the context of supportive community networks that recognize that mental health challenges can make such participation more difficult.

Family Involvement in the Transition Process

The transition into young adulthood has changed over the past 50 years for all young adults, regardless of whether or not they have disabilities. The typical age at which young people reach traditional markers

of adulthood—completion of education, financial independence, home leaving and family formation—is now well past 30. For young people with mental health disorders, the transition period may be even more extended and complicated. Family, broadly construed to include parents, siblings, grandparents and other extended family, as well as chosen family members, is a major source of resources to young people in the forms of financial and other tangible support, as well as emotional support. Although many young people want and need to develop independence from their families, there is a delicate balance between achieving independence and utilizing the resources and support available through the family.

Most treatment programs for young adults encourage self-sufficiency and building skills for independence. Often service providers exclude family members from involvement in planning for transition either intentionally or by default. Most of the existing evidence-based interventions provide no explicit role for family members, nor do they provide guidance on how to best identify and include family members in the transition process. Although there are some families who should not be included in a young person's life because of abuse or exploitation, generally, family members are an important resource that is a constant through the young adult's life and is often underutilized.

In contrast with other disabilities fields, little research has been conducted to examine the benefits and challenges of family involvement in the transition process for youth and young adults with serious mental health conditions. Limited research about the benefits and challenges of family participation has provided almost no guidance to service providers and has not resulted in recognition of best practices.



Research is needed in several areas. First, **studies that directly document family members' experiences regarding their involvement in the transition process**, including things that are helpful as well as policies and practices that create problems for them and their transition-age children, could produce useful information for current practice and future research. One example of an identified policy challenge is the abrupt shift that occurs when young people reach the age of majority (usually 18, but laws and regulations vary across states). When young people become legally responsible for their own health care decisions, HIPAA and other privacy requirements exclude family members from health care information, planning, and decisions without their children's consent.

Research is also needed to **explore and describe the needs and preferences of young people about the involvement of their family members during the transition period**. Young people who have transitioned should be asked to identify what worked and what didn't work for them. In particular, information

provided by family members and young adults about positive practices could be "bundled" and disseminated to service providers, family members, and youth and young adults. Alternative ways of discussing family resources with young people and alternative ways of setting boundaries that maintain the young person's privacy need to be identified or developed.

Finally, research needs to be conducted that will **document the impact of structured family involvement on outcomes for young adults with mental health disorders**. All currently recognized evidence-based interventions and those under development need to articulate the role played by families and test whether and how family involvement affects individual and program outcomes. Outcomes such as homelessness, richness of social networks, connection to community, employment opportunities, and quality of life may be affected by family resources, values, and culture. Finally, all research in this area must be informed by both family members and young people, either as advisors or as co-researchers.

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