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YOUNG ADULTS WITH SERIOUS MENTAL HEALTH CONDITIONS

Transition-age youth (ages 16-30) are at particularly high risk for the development of serious mental health conditions (SMHCs). (We use the term “serious mental health condition” purposefully here because of the lack of a single term that captures both “serious emotional disturbance” and “severe mental illness” for a population that spans child and adult systems.) Seventy-five percent of serious mental health conditions, such as schizophrenia, develop by the age of 24. Each year, roughly 20% of 18-25 year olds meet criteria for a current mental health diagnosis.ⁱ In addition, SMHCs are commonly accompanied by co-morbid health conditions, such as attention-deficit/hyperactivity disorder (ADHD) and substance use disorders.

Historically, young people who have utilized public mental health services as adolescents travel an onerous path into the adult world. Young people diagnosed with a serious mental health condition who age out of the child welfare system are subject to an abrupt end to their mental health services. There is a clear divide between child and adult service systems, each of which has different eligibility criteria and treatment coverage, with the adult systems usually providing less comprehensive coverage and services. Thus, youth who are aging out are likely to lose providers with whom they’ve developed trusting relationships, and need to find new ones in the adult system. For those who are not in the child welfare system, but are public health insurance recipients (e.g., Medicaid), mental health treatment continuity is often disrupted upon turning 18. In addition, at age 18 young adults can choose whether or not to engage in treatment, and if so whether or not to include their family, which may help or hinder their personal recovery journey.

Many young adults exiting child systems have experienced lengthy stays in residential treatment. Their transition to adulthood is complicated by strained or non-existent relationships with family members and a lack of role models exhibiting maturity and personal responsibility. Many of these young people struggle to maintain an emotionally and instrumentally supportive social network and are at times ostracized from others of their age group. These young adults are at a significant risk for homelessness and criminal justice involvement. Research shows having serious mental health challenges during the transition to adulthood is a strong predictor of health and psychosocial problems in later adulthood.ⁱⁱ

Transition-age youth diagnosed with SMHC usually experience a significant disruption in their vocational development, including delayed high school completion, not enrolling in post-secondary education programs, and not completing such programs when enrolled. While some employment as an adolescent is a significant predictor of employment as a young adult, many adolescents with mental health problems have not worked. One study showed that four years after completing high school only 42% of young people diagnosed with a SMHC were employed, with

only 50% employed 8 years after high school.ⁱⁱⁱ

Adult community mental health services have historically not been effective for, or appealing to, young adults. In addition, adult service providers are often not trained in adolescent development and are thus unprepared for the relatively immature psychosocial development of the transition-age youth (TAY) population. Adult services were designed to rehabilitate functioning rather than teach skills for the first time. Adult-oriented programs typically do not provide preparation for the job search process (e.g., resume development, interview practice), career planning, or post-secondary education, all of which are desired by young adults generally.

Additionally, transition-age youth perceive their needs and circumstances as different from those of older adults, and typically do not want to be in programs with middle-aged and older adults. In comparison to other adults, young adults generally:

- Do not see “recovery” as a process, but instead as a short-term goal, with an emphasis on returning to school or work directly;
- Take much bigger “risks” toward their search to define their identity, in part because the part of the brain that manages impulse control (e.g., the frontal lobe) is still developing;
- Have not developed or are at an early stage of developing resilience and confidence;
- Experience a heightened level of shame, stigma, and the concern that friends will learn about their diagnosis and avoid them.^{iv}

The stigma of being identified as a “mental patient” is another reason young adults do not engage in treatment or ask for other available supports. For example, young adults diagnosed with SMHCs are less likely to inform their post-secondary education program or their employer of their disability and need for accommodations when compared to young adults with other types of disabilities.^v

NEWER SERVICES DESIGNED TO MEET THE NEEDS OF YOUNG ADULTS

Starting in the 1990s, various stakeholders became acutely aware of the service gaps facing young adults diagnosed with SMHC. Early research efforts, led by Rusty Clark and Maryann Davis, developed and evaluated service models designed to address the expressed needs of young people diagnosed with SMHC. In 2001, Consumer Quality Initiatives (CQI), a peer-run research and evaluation organization in Massachusetts, conducted a participatory action research project co- led by young adults diagnosed with SMHC to identify young adult mental health service needs and gaps. They found that no service system for TAY existed in Massachusetts, and made broad-based recommendations, including the integration of peer mentors in service delivery and an infusion of young adult voice in policy and practice development. In 2008, the United States Government Accountability Office (GAO) followed up with a [report](#) on the progress of state and federal governments to address these gaps, finding that young adults continued to have great difficulty finding mental health services appropriate to their age group. With a greater public awareness of these service gaps, parent and transition-age youth-led policy and advocacy organizations (including [National Federation of Families for Children’s Mental Health](#) and [Youth](#)

[M.O.V.E.](#)) began to advocate more widely for the funding of services that meet the specific needs of TAY diagnosed with a SMHC.

In the early 2000s, policy and funding bodies began to encourage mental health service providers to develop programming that was person-centered for adults and family-centered for youth, a movement away from a service structure that provided treatments primarily based on diagnosis and not personal preferences. With the release of the [President's New Freedom Commission report](#) in 2003 states began to leverage federal funding to develop policies aimed at transforming the deficit based adult community mental health systems to one that is recovery oriented (i.e., strengths-based, trauma-informed, and responsive to consumer values and preferences). Federal funding also supported states to use Systems of Care principles and Wraparound methods to develop strengths-based youth services tailored to the specific needs of youth and family (“family driven” and “youth guided”).^{vi}

In addition, the U.S. National Institute on Mental Health, through the Recovery After an Initial Schizophrenia (RAISE) initiative, and the Robert Wood Johnson Foundation funded large-scale research projects to develop and test service models aimed at improving the outcomes of youth and young adults experiencing a recent onset of psychosis. The results from these research initiatives led to SAMHSA setting-aside 5% in 2015 and 10% in 2016 of each state’s annual Mental Health Block Grant to be used for state integration of recently identified evidence-based services for first-episode psychosis such as “coordinated specialty care” (CSC). SAMHSA also funded the Healthy Transitions grant program for states and counties to develop a continuum of service strategies for TAY.

As a result of these efforts, new clinical and community based approaches are emerging to meet the needs of young adults diagnosed with SMHC. Core elements across all of such programs are that they:

- Are strengths-based and “optimistic” in approach;
- Focus on a young person’s recovery (psychological, social, vocational), not just on mental health symptom control, stability, and functioning;
- Actively involve the clients, and if desired family members, in treatment decision making.

For example, the [Transition to Independence Process \(TIP\) Model](#) is a widely adopted approach that empowers young people to be involved in treatment and goal planning and to choose who he or she wants to be involved in this process.^{vii} TIP focuses on making progress across five transition domains, including employment and career, education, living situation, personal effectiveness and wellbeing, and community-life functioning. States such as Massachusetts are using SAMHSA funding to develop a Wraparound enhancement grant to develop youth and family services that are appealing to TAY.

[Components of Coordinated Specialty Care \(CSC\)](#) approach has emerged as a best-practice for treating individuals with first episode psychosis (FEP). Major CSC components include collaboration with key stakeholders (e.g., teachers), cognitive and behavioral skills training, low-dosage medications, supported employment/education, case management, family education, and outreach. A recent study found that CSC clients experienced significant improvements in

symptoms and quality of life compared to those receiving regular care. The peer and vocational elements of these models are in the very early stages of development.

SAMHSA has also worked with the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) to fund two young adult oriented research and training centers (RTCs):

- The [Transitions RTC](#) aims to improve supports for TAY ages 14-30 who are diagnosed with SMHC and trying to successfully complete their schooling and training and move into personally rewarding work lives. TAY involvement in all stages of research and development is a cornerstone of the center. (University of Massachusetts Medical School, Worcester, MA, Department of Psychiatry, Systems and Psychosocial Advances Research Center).
- The [Pathways RTC](#) aims to improve the lives of TAY diagnosed with SMHC through the research and development of interventions focused on building young people's assets in four areas: 1) self-determination and positive identity, 2) youth- and young adult-directed decision making, 3) skills needed for adult roles, and 4) supportive relationships with peers and adults. (Portland State University, School of Social Work)

PEER SUPPORT PROVIDERS

Peer support providers, or “peers,” are individuals in recovery from mental health and/or substance use issues who strategically share their lived experience with clients to inspire hope, provide emotional support, and aid in developing a recovery plan. Peers also encourage and prepare clients to become more involved in their own health and treatment decisions. The validation and bonding over shared-lived experiences between a peer and client is critical in mitigating the power differential that typically exists between professional practitioners and clients.

Peers exemplify that recovery is possible, which is a new notion for many clients who have been led to believe that “stability” and symptom control is their best future. Peers also can share practical skills for navigating the health care system and developing wellness tools. The peer role is often integrated into adult community mental health treatment services.

Unique Characteristics & Value of the Peer Role

Peers are unique in relation to other mental health professionals in four primary ways.

They:

- **Use their personal recovery story with clients strategically.** For example, if a client is having difficulty overcoming a barrier towards recovery, a peer may use an example of how she or he has struggled in similar circumstances but persisted and found resources to overcome such a barrier. A peer may also share community resources they learned about in their recovery journey, such as specific peer groups, websites and communities, and particular providers.
- **Are role models/exemplars.** Peers are “living proof” that recovery and meaningful employment are possible for people diagnosed with SMHC. In the face of negative stereotypes, peers are concrete examples of recovery, instilling hope in people who may have lost hope.
- **Advocate on behalf of the client.** Peers advocate for their client’s perspective and for greater client involvement in treatment decision making. This includes presenting the client’s preferences in staff meetings and case discussions, focusing attention on client interests and strengths, and challenging stereotypes. Peer support staff break down barriers between clients’ and providers’ perspectives and open channels of communication.
- **Engage in Mutuality.** When people diagnosed with SMHC talk of mutuality, they speak of a relationship based on respect, compassion, unconditional positive regard, and reciprocity. Establishing mutuality in a paid helping relationship can be a challenge due the inherent power imbalance introduced through professional certification and pay. Thus, peers must focus on their relationship to the client, and not just on client needs. Both parties must recognize that each of them can learn from and be impacted by that relationship, regardless of their specific roles.

In the last decade, the peer role in the U.S. has developed as a profession, accompanied by practice guidelines and codes of ethics. This development has been spearheaded by state and national consumer run organizations, which first introduced the role to providers and state and county governments in the 1980s. State mental health authorities and insurance companies began to take notice and fund such positions. In the late 1990s and 2000s, federal agencies such as SAMHSA, the Centers for Medicare & Medicaid Services (CMS), and the Veterans Administration (VA) developed policies and funding sources to encourage providers to incorporate the peer role into services. These developments have generated exponential growth in the peer position. Based on information provided by 31 states, the number of peer positions is estimated at 13,000 nationally. In the VA alone there are at least 1,000 peer positions.^{viii} Further growth has been fueled by the Affordable Care Act’s (ACA) behavioral health parity requirement, which, along with a shortage of traditional providers, has elevated the peer role as a federal and state funding priority. With regard to young adult peer positions specifically, federal and state agencies have begun to create [policies to support that role](#) in child/adolescent and adult mental health services.^{ix,x} For example, in 2015, CMS and SAMHSA issued an informational bulletin to states offering guidance on designing Medicaid

benefit packages that include peer support services for young adults experiencing a recent onset of psychosis.^{xi} Some states have used SAMHSA's systems of care enhancement grants to embed young adult peers in Medicaid funded wraparound services.

While lived experience of mental illness and recovery is necessary for the peer role, training and certification as a "Certified Peer Specialist" (CPS) is an important credential which many providers and state governments now require or favor for peer employment.^{xii}

The peer role provides TAY, particularly those with limited or no post-secondary education and/or employment experiences, with a new opportunity to enter the labor force, obtain a professional job, learn transferable skills, build resumes, and network towards a self-desired career path

Certification requires that peers be trained in the basic set of core competencies (see unique characteristics above and code of ethics below), and then pass an exam demonstrating those competencies. CPS trainings are offered in most states, though training requirements and certification standards vary by state and organization. The required number of training hours ranges from 30 to over 100, the required amount of work or volunteer experience ranges from none to approximately 500 hours, and the training curricula highly varies.^{xiii}

Peer Specialist Code of Ethics- Massachusetts

1. The primary responsibility of Certified Peer Specialists is to help people achieve what they want most in life, their own goals, needs and wants. Certified Peer Specialists will be guided by the principles of self-determination for all.
2. Certified Peer Specialists will maintain high standards of personal conduct. Certified Peer Specialists will also conduct themselves in a manner that fosters their own recovery and integrity.
3. Certified Peer Specialists will openly share their recovery stories, and will likewise be able to identify and describe the supports that promote their recovery.
4. Certified Peer Specialists will, at all times, respect the rights and dignity of the people with whom they work.
5. Certified Peer Specialists will never intimidate, threaten, harass, use undue influence, physical force, or verbal abuse, or make unwarranted promises of benefits to the individuals with whom they work.
6. Certified Peer Specialists recognize that everyone is different and we all have something to learn from one another. Therefore, Certified Peer Specialists will not practice, condone, facilitate or collaborate in any form of discrimination on the basis of ethnicity, race, sex, sexual orientation, age, religion, national origin, marital status, political belief, mental or physical disability, or any other preference or personal characteristic, condition or state.

7. Certified Peer Specialists will advocate as a partner with those they support that they may make their own decisions in all matters when dealing with other professionals.
8. Certified Peer Specialists will respect the privacy and confidentiality of those they support.
9. Certified Peer Specialists will advocate for the full integration of individuals into the communities of their choice and will promote the inherent value of these individuals to those communities. Certified Peer Specialists will be directed by the knowledge that all people have the right to live in the least restrictive and least intrusive environment of their choice.
10. Certified Peer Specialists will not enter into dual relationships or commitments that conflict with the interests of those they support.
11. Certified Peer Specialists will never engage in sexual/intimate activities with those to whom they are currently providing support, or have worked with in a professional role in the past year.
12. Certified Peer Specialists will keep current with emerging knowledge relevant to recovery, and openly share this knowledge with the people with whom they work.
13. Certified Peer Specialists will not engage in business, extend or receive loans, or accept gifts of significant value from those they support.
14. Certified Peer Specialists will not offer support to another when under the influence of alcohol or when impaired by any substance, whether or not it is prescribed.