FACT SHEET

As states prepare to respond to the new priorities in the Community Mental Health Services Block Grant to implement evidence based practices for the early treatment of serious mental illness, it is important to be attentive to the needs of individuals living and working in rural communities.

# Implementation of Coordinated Specialty Services for First Episode Psychosis in Rural and Frontier Communities[1]

Coordinated Specialty Care (CSC) is an evidence based approach to providing early intervention for psychosis, and it has been found to improve outcomes.[2-3] This team based set of services can be particularly challenging to implement in rural communities, resulting in potential disparities in service availability for individuals living in rural and frontier areas.[1] Although best practices have been developed to support identification and treatment of psychosis, very few guidelines exist for providing this treatment in rural and frontier settings.

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## How is rural defined?

All U.S. states have regions that can be defined as rural when using one of the three main federal definitions of rurality:

- **The U.S. Census Bureau** uses census blocks to define urban areas (50,000 or more people) and urban clusters (at least 2,500 and less than 50,000 people). Areas outside these regions are defined as rural.[4]

- **The Office of Management of Budget** defines Metropolitan, Micropolitan, and Nonmetropolitan statistical areas based on population per county.[5] A metropolitan area contains a core urban area of 50,000 or more people, and a micropolitan area contains an urban core of at least 10,000 (but less than 50,000) people. Each metro or micro area consists of one or more counties and includes the counties containing the core urban area, as well as any adjacent counties that have a high degree of social and economic integration (as measured by commuting to work) with the urban core. When using this classification, it is important to define whether rural is being defined as communities of less than 10,000 (i.e., non-micropolitan and non-metro), or whether non-micropolitan areas are included within the designation of rural.

- **The U.S. Department of Agriculture Economic Research Services** classifies U.S. census tracts using measures of population density, urbanization and daily commuting to create Rural-Urban Commuting Area (RUCAs) Codes. [6] The most recent RUCA codes are based on data from the 2010 decennial census and the 2006-10 American Community Survey. RUCA Codes do not provide a specific definition of rurality; instead they use 33 categories that can be aggregated depending on the level of specification required.

Many states also include frontier regions which are especially remote and sparsely populated and can be defined at the level of zip code, county or census tract. According to the Affordable Care Act, frontier communities are defined as areas with a "population density of less than 6 persons per square mile within a service area and with respect to which the distance or time for the population to access care is excessive".[7] Frontier communities have particular challenges in providing access to health care due to long distances from population centers, availability of paved roads, seasonal changes in access to services due to inclement weather and road closures, and lengthy travel times to services, in addition to workforce shortages both in primary and specialty care.

## Key characteristics of Coordinated Specialty Care:

Coordinated Specialty Care (CSC) for First Episode Psychosis (FEP) emphasizes a collaborative, recovery-oriented approach between individuals who receive services (i.e., consumers), treatment team members, and when appropriate, family members and others who can provide support. Treatment planning is collaborative, involving shared decision making and addressing the following key areas: psychotherapy, pharmacotherapy, case management, supported education and employment, coordination with primary care, and family education and support. To maintain fidelity to the CSC model, a team leader must coordinate regular communication and meetings between all participants, and staffing configurations must ensure that consumers and families are receiving a sufficient intensity of services. Core functions of CSC include:[8]

1. **Specialized Training in FEP Care:** Access to clinical providers with specialized training in FEP care.

2. **Community Outreach:** Easy entrée to the FEP specialty program through active outreach and engagement. This includes community education events, consultations, and social marketing strategies to help families, teachers, and healthcare and social services providers recognize the signs and symptoms for FEP, as well as other community resources.

3. **Client and Family Engagement:** Provision of recovery oriented services in home, community, and clinic settings, as needed, with a strong emphasis on hopefulness and pursuit of life goals.

4. **Mobile Outreach and Crisis Intervention Services:** Acute care during or following a psychiatric crisis.

5. **Transition of Care:** Transition to step-down services with the CSC team or discharge to regular care after 2-3 years, depending on an individual's level of symptomatic and functional recovery.

6. **Fidelity:** Assurance of program quality through continuous monitoring of treatment fidelity.

All of these functions can be challenging in rural and frontier communities. Challenges specific to these six areas, and strategies to address these challenges, are discussed below.

# 1. Specialized Training in FEP Care

There are workforce limitations in rural areas with a limited number of clinicians covering a wide range of services and programs. More than half of the counties in the United States have no behavioral health workers. [9] According to the U.S Department of Health and Human Services, as of October 5, 2012, there were 3,712 Mental Health Professional Shortage Areas across the U.S. with 87.7 million people living in these areas. It would take 5,834 practitioners to fill this mental health provider gap (a population to practitioner ratio of 10,000:1). [10] The lack of accessible health services is particularly acute for underserved populations, including racial and ethnic minorities and people of low income living in shortages areas. [11] These shortages become even more severe when considering the specialty knowledge required for FEP. As CSC programs are developed in rural regions with underserved communities, it will be essential to develop provider networks represented by the human service agencies that exist in the rural areas and to develop a telehealth infrastructure to provide access to clinicians with specialized training in FEP.



Clinical assessments conducted via telehealth can provide reliable diagnostic and treatment planning information and are generally acceptable to consumers and families. [12-13] Telehealth programs which facilitate direct clinical assessments via videoconferencing require several key infrastructure elements, including:

- Information sharing agreements between agencies;

- Secure technology systems to ensure privacy of clinical encounters;

- Protocols for documenting clinical encounters;

- Systems for sharing information across agencies and providers, such as standardized releases of information, up to date contact lists, and accessible fax machines to ensure that any confidential information is shared securely; and

- Appropriately trained staff to coordinate communication across sites.

Importantly, telehealth provides a secure venue for rural providers to consult with colleagues with expertise and more experience in providing FEP care. Telehealth consultation requires secure technology systems and protocols for sharing clinical information that are relatively easy to establish quickly. The American Telemedicine Association is a helpful resource which includes guidelines, manuals for best practice, and resources when making purchasing decisions. [14] Telehealth consultation is associated with improved clinical care by better supporting rural providers in delivering these specialty services, and/or problem solving about how they can best be delivered in the local context. Telehealth also has an additional benefit of improving the expertise of rural clinicians. [15]

One of the key components of CSC FEP care is to ensure fully coordinated care across healthcare services. As a result of workforce shortages in rural communities, care co-ordination can be especially challenging. Access to primary care, emergency health services and substance use treatment, for instance, are important services in the treatment of FEP that are limited in rural and frontier communities.[16-17] Epidemiological studies have indicated that there appears to be higher rates of untreated co-occurring mental health and substance use disorders in rural communities than in urban areas.[18] Since co-occurring substance use is common in FEP clients and contributes to poor outcomes, it is especially important for rural FEP programs to identify and partner with substance use treatment resources to ensure seamless coordination of care.[19] Similarly, recent work indicates that individuals with FEP are at elevated risk of premature mortality.[20] With these risks in mind, it is critical for CSC teams to actively seek out local health and primary care services and make efforts to strengthen these partnerships to facilitate good coordination and communication across services and agencies.

In order to deliver the core functions of CSC FEP care, it is essential to have a team of providers who include, at a minimum: a team leader, and a prescriber, as well as key staff who have expertise in supported employment, supported education, outreach, family support and care co-ordination.[8] Implementation of healthcare teams in rural areas often requires team members to fill multiple roles and to work across other programs. Therefore, it can be helpful to identify an experienced behavioral health clinician as the team leader who can give guidance and support to other staff members as they implement the core functions of the CSC FEP model. For example, case managers may have a good understanding of how to help consumers and families navigate systems of care. They can learn how to work closely with school systems and other vocational rehabilitation programs to develop solid supported employment and supported education opportunities.

# 2. Community Outreach

The process of facilitating entrance to an FEP specialty program differs between rural and urban communities. Access to behavioral health can be particularly challenging in rural and frontier communities owing to low population density and poor or non-existent public transportation systems. Lack of transportation, especially common among impoverished rural populations with a variety of economic and social challenges, is a common barrier to mental health service access and use.[21-22] Transportation barriers lead to missed appointments and delayed care, and eventually poorer health outcomes.[23] In a systematic review of 61 studies on barriers to receiving healthcare, transportation barriers were identified in 67% of the populations studied.[23] Transportation problems were particularly problematic for individuals with lower incomes or the under/uninsured--a common characteristic among people residing in rural areas, and for racially and ethnically diverse populations. Results from the Mexican American Prevalence and Services Survey, for instance, show that lack of transportation is one of the most commonly reported barriers to receipt of mental health care among Latinos.[24] Similarly, in a recent national study on access to mental health services at Indian Health Services and tribal facilities, 53% of the facilities reported that transportation was a major barrier to care among Native Americans.[25] In a systematic review of studies on barriers to mental health help-seeking among young people, transportation was a prominent barrier, particularly in studies of rural populations.[26] Studies on pathways to care among individuals with first episode psychosis have also found lack of transportation to be a common barrier. [27] Thus, attention to transportation is critical to outreach and often requires that services be delivered where consumers live and work rather than at clinic locations.

Another outreach strategy to address workforce (as well as transportation) challenges in rural and frontier communities capitalizes on existing informal networks between clinicians, schools, correctional systems, faith based organizations, other agencies and natural supports. These partnerships can sometimes be easy to develop in rural communities and are essential for active outreach and engagement related to identification of FEP. Rural areas also have advantages when building social marketing campaigns, as there is considerable knowledge of what works in local communities. Additionally, in many rural states, there is a centralization of public services such as the Department of Health or Department of Corrections. These centralized structures can make it easier to roll out statewide trainings or early identification social marketing campaigns on FEP. For example, North Dakota has developed a comprehensive social marketing campaign to address prescription drug abuse.[28] These strategies can be adapted to disseminate public health information on FEP.

# 3. Client and Family Engagement

There are also multiple challenges to engagement and retention in behavioral health services among rural residents. These challenges include lack of health insurance, low health literacy (especially related to psychosis), and differential cultural beliefs about symptom attribution among culturally diverse populations.[29-33] Embarrassment related to accessing behavioral health services can also be a problem among rural communities, where confidentiality and anonymity is a major concern.[34-36] Access for culturally diverse populations is complicated by: the lack of linguistically and culturally relevant services; lack of understanding alternative culturally based views and perceptions of illness; and the stigma associated with seeking treatment and consequent delay or avoidance of help-seeking.[37]



*The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care* (the *National CLAS Standards*) are intended to advance health equity, improve quality, and help eliminate health care disparities by providing a blueprint for individuals and health care organizations to implement culturally and linguistically appropriate services.[38] The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care: A Blueprint for Advancing and Sustaining CLAS Policy and Practice (The Blueprint) is an implementation guide to help organizations build and sustain culturally and linguistically appropriate services. The Blueprint dedicates one chapter to each of the 15 Standards, with a review of the Standard's purpose, components, and strategies for implementation. In addition, each chapter provides a list of resources that offer guidance on that Standard. This Blueprint can be used by organizations to increase cultural competency of outreach, engagement, screening, assessment, and service delivery. Additionally, modifications to the FEP-related evidence based practices (EBPs) can be guided by the Toolkit for Modifying Evidence-Based Practices to Increase Cultural Competence.[39] The purpose of the Toolkit is to provide mental health service organizations a structured method for modifying EBPs to better meet the needs of the cultural groups they serve, including rural and frontier communities.

Additionally, peer navigators have proliferated in the past decade and often times can provide culturally relevant help. They are especially helpful in linking people with serious mental illnesses to health services.[40] Peers are an integral component in behavioral health programming in many states and an innovative way to address workforce shortages in rural communities. In many states peer support services are reimbursable under Medicaid, and there is an increasing acceptance among providers regarding the value of peers as members of health care teams.[41] A peer navigator may be especially

helpful for those with early psychosis, because connecting with an individual in recovery who shares a similar lived experience is thought to lead to increased hope, developing insight and communication skills regarding their symptoms and experiences, a change in beliefs about the efficacy of treatment, and decreases in embarrassment and fear related to treatment.[42-43] Research shows that peers can be effective in helping reluctant individuals with mental illnesses engage in treatment, which leads to improved outcomes. A randomized controlled trial showed that contacts with providers increased significantly when individuals worked with a case management team that included a peer compared to a team that did not. Contacts with providers actually decreased over the same period among those who did not work with a peer.[44] Thus, peer navigators can increase engagement and retention in CSC and may be especially important in communities with workforce challenges and limited access to licensed clinicians.

# 4. Mobile Outreach and Crisis Intervention Services

Mobile crisis services are community-based programs designed to provide on-site assessment, stabilization, and referrals for individuals in crisis; with the goal of reducing barriers to mental health care, providing crisis intervention in natural settings, avoiding unnecessary hospitalizations, and linking individuals with on-going community-based services.[45] While mobile outreach and crisis intervention services have many benefits, there remain implementation challenges, especially in rural and frontier communities. One challenge is insurance-related since commercial insurance and Medicare will not reimburse for mobile crisis services.[46] Additionally, funding may be difficult to obtain to purchase vehicles and compensate personnel.[46] This is especially true in rural and frontier areas, whose population cannot support 24/7 crisis services, and whose geographic isolation limits the possibility of sharing services across counties. Mobile crisis outreach may be less expensive than police intervention, especially costs resulting from psychiatric hospitalization.[47] Although dated, in a comparison of effectiveness and efficiency, Scott showed that mobile crisis programs resulted in a 23% lower average cost per case compared to regular police intervention.[48] However, workforce shortages in rural and frontier communities often limit the possibility of hiring trained behavioral health providers in these traditionally underserved communities. Therefore the use of telehealth can cut down costs when crises arise, as 24/7 services can be accessible from a distance, for those instances that do not require immediate medical intervention for stabilization (e.g., emergency room, inpatient hospitalization). Crisis Intervention Teams (CIT) are intended to improve the way law enforcement and the community respond to people experiencing mental health crises. While there are unique challenges to implementing CIT in rural communities (e.g., homes, law enforcement and emergency responders being spread over great distances), CIT programs have been successfully implemented in rural communities with strong community support.[49]

# 5. Transition of Care

While 2-3 years or service with the CSC team are recommended for transition to step-down services or discharge to regular care, this decision should be guided through appropriate level-of-care planning and awareness of an individual's degree of symptomatic and functional recovery.

Regular care for people with psychosis includes a range of medical and psychosocial interventions which may include programs such as psychosocial rehabilitation, supported employment, and medication monitoring.[50-52] Some of these formalized psychosocial interventions may be difficult to access in rural communities where there is not sufficient population density to develop large programs through the healthcare system. Therefore, when making transition plans for clients, it is important to identify local resources that provide social support and opportunities to engage in meaningful activities such as work, volunteering, and education. In smaller communities, it will be important for the CSC team to reach out to informal groups and programs such as faith based organizations and community centers which may provide these important functions.



Since many rural communities do not have access to general psychiatrists, it is also key to ensure that transitioning clients have regular access to physicians who are comfortable with prescribing antipsychotic medications. Primary care providers can play an important role in maintaining regular medical review and medication monitoring, but they may benefit from support in identifying access to psychiatric consultation when needed.

# 6. Fidelity

When providing FEP services in rural communities, it is also important to be attentive to maintaining fidelity to the CSC team model and recommended staffing ratios. Implementing EBPs in rural areas can be challenging due to limitations in personnel, vast geographic areas, and other resource shortages.[1, 53] If adaptations to the model need to be made, it will be important to document the specific nature of these adaptations and to track health outcomes to understand the implications of any adjustments to the model. When monitoring fidelity, it is important to track a range of outcomes, including reduction in symptoms, quality of life, health care utilization and retention in treatment. A variety of outcomes will enable programs to better understand how their services impact various dimensions in a person's life and where there are opportunities for improvement. Also, it is helpful to use a standardized method for making these adaptations, such as the aforementioned Cultural Adaptation Toolkit.

## A Phased Strategy to Address the Challenges Inherent In Delivering CSC in Rural Communities

FEP CSC programs should strive to implement a continuum of services and strategies that can be integrated into the existing medical, behavioral, and community infrastructure. Strategies can be implemented in the following phases in order to address the various obstacles to the development of a strong FEP program.

**PHASE 1**: Establish an FEP coalition or working group that consists of medical, behavioral health, and community stakeholders. The role of this coalition is to identify community needs and available resources as they apply to FEP and to create an action plan that will work for the community. Key roles of the coalition include: developing community readiness and leadership in the area of FEP; identifying and facilitating the creation of sustainable partnerships; and mobilizing financial and community resources.

**PHASE 2**: Helping potential community "gatekeepers" to assist with identification of psychosis and connecting individuals to services as soon as possible is critically important. Multiple individuals in the community should receive training, including Community Health Workers, first responders and public safety officials, justice workers (e.g., judges and court officials if available), public health officials, teachers, library staff, bus drivers, religious/spiritual leaders, medical personnel, behavioral health workers, and other natural helpers in the community. Telehealth can be used to

train providers in rural primary care sites, emergency rooms, and schools in appropriate screening for FEP, as well as to provide support and training for rural and frontier sites in the implementation of specific EBPs (e.g., assertive community treatment, psychotropic medications, cognitive behavioral therapy, psycho-education, supported employment/ education, multi-family groups, etc.). Collective learning via webinars and other distance learning via telehealth or teleconference can be utilized to connect rural providers and community members with experts in the area of FEP that may reside outside the community.

**PHASE 3**: Outreach to the community needs to be regular and ongoing in order to continue to educate and maintain visibility of the screening, referral and early intervention efforts. The goals of outreach are to strengthen bonds with potential referral sources in addition to conducting social marketing, education, and awareness campaigns. National efforts increasingly call for a movement toward a "public health" approach to behavioral health care.[54] A public health-based, early intervention approach to FEP includes the development of public awareness and outreach to educate individuals, families, and the greater community about the importance of early recognition and intervention for psychosis, as well as the provision of responsive and acceptable services. The goal of ongoing community outreach efforts is to shorten the time between the appearance of symptoms and the receipt of help – shorten the duration of untreated psychosis. Mental Health First Aid has been promoted as one community-wide education effort to ensure that gatekeepers are able to identify psychosis and other mental health issues, and refer to services.

Social media can also be utilized to disseminate a public health message and increase awareness related to FEP, thus enhancing early identification efforts. For example, there is the SAMHSA "What a Difference a Friend Makes" campaign to help young adults learn tools to help support a friend who is living with mental illness and in the recovery process. Another effort is to meet community members where they "work, pray, and play," as promoted by the Advisory Panel on Outreach and Education.[55] The panel recommends use of multiple channels to share messages about psychosis and treatment options such as: radio, local newspaper, flyers, bill statements (e.g., cable, electricity bill), town hall meetings, community dinners, state and county fairs, community health enrollment fairs, faith based organizations, and work with civic groups such as Chambers of Commerce and Rotary Clubs. These efforts are especially powerful in rural and frontier communities.

**PHASE 4:** An open referral policy with referrals coming from both formal (e.g., doctors, etc.) and informal networks (e.g., family, friends, teachers, etc.) is also integral. This referral and screening phase may start simultaneously with training and outreach activities. As individuals are screened, systems need to be in place to link all individuals needing supports for FEP to appropriate interventions. Telehealth can be used to link the individual to a qualified provider for further assessment and treatment recommendations. This individual may be a social worker or community health worker who conducts the screening

and, as appropriate, connects the individual to psychiatric services in the community or to help via telehealth. Regardless of the strategy it is important that a local point of contact be established to provide in person support as needed. The point of contact could be a provider from the established coalition (Phase 1), or it may be a particular program or individual identified by the coalition as the point of contact for all referrals. The referral process should be carefully and thoroughly discussed in the training (Phase 2) and should be developed through ongoing outreach efforts (Phase 3).

Another possible triage approach uses primary care clinics and involves having an identified behavioral health provider onsite (e.g., Social worker) to further assess and make treatment recommendations. A third possible triage approach is the development of a community hotline program (staffed by a behavioral health provider either in the community or in an urban setting where more staff is available) through which additional screening and connection to resources can occur. Thus, increasing referral networks is critical in rural and frontier settings.

**Phase 5:** Once an individual has been referred, key components of an FEP program include: psychiatric consultation and medication management; case management or comprehensive community support services (e.g., housing, education, employment, income support, etc.); family psycho-education; recovery-based individual therapy; and relapse prevention planning. Many clinicians have experience and familiarity with cognitive behavioral therapy which can be an effective approach in supporting recovery and relapse prevention. Ensuring linkages to these services is critical.

## Conclusions

There are several important strategies for diminishing the obstacles to successful FEP program implementation in rural and frontier areas. For instance, it is important to ensure a network of informal and formal services and supports that can be navigated by individuals, along with a support system that wraps around individuals. Additionally, telehealth can connect rural and frontier providers to program specific expertise. This may involve a primary care doctor consulting with a psychiatric provider via telehealth to manage the prescription of psychiatric medications, or it may involve connecting an individual directly with an experienced provider in another location who can conduct a psychiatric assessment, prescribe medications, and perform ongoing medication management via telehealth services. Many state Medicaid plans have now included telehealth benefits as a reimbursable service and the Centers for Medicare & Medicaid Services specifies Current Procedure Terminology (CPT) codes that can be used when billing third parties.[56] Additionally, some managed care organizations will reimburse for telehealth consultation between providers.

Currently, the reimbursement status for telehealth is widely variable between communities, states and funders. The American Telemedicine Association website has a State policy resource center that can help programs identify their local reimbursement opportunities.[57] Cognitive behavioral therapy, family psychoeducation, and relapse prevention planning for FEP may also be provided by a therapist, counselor, or psychologist via telehealth services. These clinical services are generally reimbursable through existing service definitions and billing codes. It continues to be challenging to identify sustainable methods of covering costs of other core components of CSC FEP care, such as supported employment and supported education. Programs may find it helpful to work closely with their local Medicaid authority to advocate for sustainable reimbursement policies to support the delivery of evidence based care in rural and underserved communities.

Additionally, utilizing existing supports is key. In many rural and frontier areas, primary care physicians are a key element of the behavioral health service workforce. A medical or clinical home model with integrated care allows for a social worker or other behavioral health staff to be embedded or co-located in a medical practice. Also, because of the enormous lack of transportation in rural and frontier communities, attention to transportation is critical to outreach and engagement. Other strategies critical to outreach and engagement include increasing health literacy and capitalizing on opportunities to build on existing informal networks between clinicians, schools, correctional systems, faith based organizations and other agencies and natural supports. Finally, the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (the National CLAS Standards) can be used to guide organizations to implement culturally and linguistically appropriate services, and the Toolkit for Modifying Evidence-Based Practices to Increase Cultural Competence can be used to assist providers in modifying EBPs to better meet the needs of the cultural groups they serve, including rural and frontier communities. Peer navigators can assist with increasing engagement and retention in CSC, especially in communities with workforce shortages and limited access to licensed clinicians. Although FEP program implementation can be challenging in rural and frontier communities, there are many resources and strategies for overcoming these challenges.

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