Improving Access to Care Through Family Involvement and Engagement in Coordinated Specialty Care: Innovations and Best Practices

> Nev Jones, PhD Department of Psychiatry, Morsani College of Medicine, University of South Florida Donna Fagan, CFP Certified Family Partner Lynda Gargan, PhD, Moderator National Federation of Families





June 9, 2020

Disclaimer

 This webinar was developed [in part] under contract number HHSS2832012000211/HHS28342003T from the Substance Abuse and Mental Health Services Administration (SAMHSA), U.S. Department of Health and Human Services (HHS). The views, policies and opinions expressed are those of the authors and do not necessarily reflect those of SAMHSA or HHS.



Family Engagement and Involvement in Coordinated Specialty Care

Nev Jones PhD, Assistant Professor Department of Psychiatry, Morsani College of Medicine University of South Florida



Objectives

- To describe different strategies used within CSC to support family involvement
- To explain the REORDER approach as operationalized within OnTrackNY
- To list potential cultural and socioeconomic barriers to family participation



Involve Families: Why?

Initial detection Assistance finding treatment Legal system School and work Attending appointments Financial support Instrumental support (housing) Emotional support (as friends/peer withdraw)

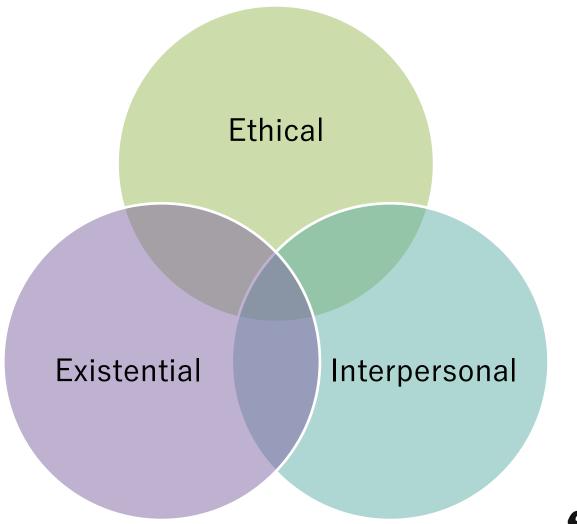
Getting back to goals: returning to school, work Longer-term costs of care

Maintaining hope and optimism

For some: Long-term intensive support Representative payee

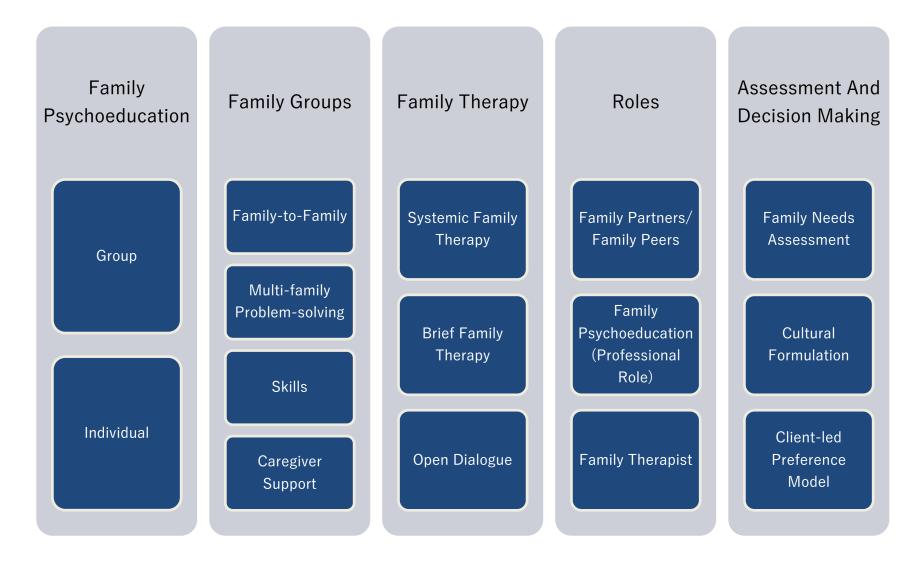


Fundamental Challenges





Involve Families in CSC : How?





Next steps for the field?

Optimizing engagement

- Understanding why families who choose not to engage make these choices, how to meet their needs
 - Racial/ethnic/cultural and structural barriers and vulnerabilities
 - Transition to legal adulthood
 - Expanded array of involvement options/opportunities
 - Family partners/peers
 - Comparative effectiveness /family centered outcomes research

Direct support for family members

- Interventions focused on family member needs
- Non-parent family members: children, siblings, romantic partners

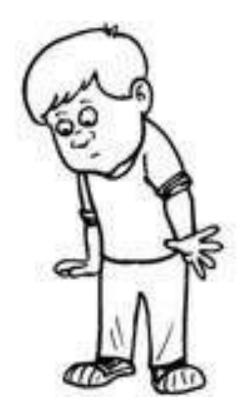
Family involvement after CSC

Exploring diverse approaches/philosophies

- Psychoeducation, Open Dialogue/Needs Adapted Treatment



What's Happening on the Ground





Rates of Family Involvement/Engagement

- Most common metrics = family involvement in psychoeducation session(s) or family contact
 - RAISE Navigate: monthly family participation in psychoeducation
 -> 22.5 48.4%
 - Washington State Journeys = 82% of families participated in at least one family psyched session over the course of one year¹
 - Arizona EPICENTER: 22% participation in individual family psyched, 44% in group psychoed²
 - OnTrackNY: Contact in each quarter over initial 12 months = 42.4%; mixed pattern = 21.2%; no contact = 2.9%; discharge before 12 months = 33.5%³

- 2. Breitborde NJ, Bell EK, Dawley D, et al. The Early Psychosis Intervention Center (EPICENTER): development and six-month outcomes of an American firstepisode psychosis clinical service. BMC Psychiatry. 2015; 15:266-71.
- 3. Jones et al (under review). Clients' Preferences for Family Involvement and Subsequent Family Contact Patterns in Coordinated Specialty Care for Early Psychosis in New York State.



^{1.} Oluwoye O, Reneau H, Stokes B, et al. Preliminary Evaluation of Washington State's Early Intervention Program for First-Episode Psychosis. Psychiatry Serv. 2019; 18: appi-ps.

- Foundation = REORDER¹
- Context : promote greater family involvement among adult clients through client-led shared decision making
 - Integration of semi-structured patient and family-centered assessment and shared decision-making tools

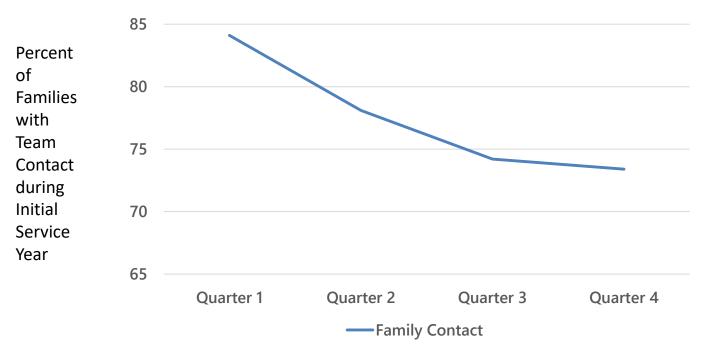




Client's Preferences and Family Contact at OnTrackNY

Baseline client preferences

- 59% unconditional family involvement
- 35% involvement with conditions
- 5.9% no involvement



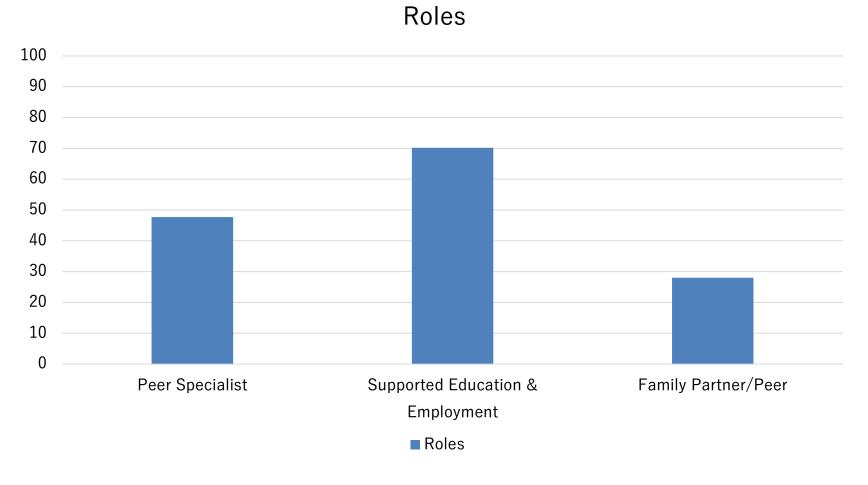


Open Dialogue/Needs Adapted Treatment

- Described as both "family therapy" and "system of care"
- Primary modality = network meetings
 - Include all individuals important to the individual
 - "Open" meetings stress reflective dialogue and processing
 - Clinicians share observations within the meeting, not private case conferences
 - Focus on exploring/healing tensions and conflict arising between network members
- Implemented in US, UK ODDESSI trial¹



National Implementation of Family Peer/Partner Roles



111 unique locations/sites

SAMHSA Substance Abuse and Mental Health

Jones et al. (Under review). Addressing Trauma, Structural Disadvantage, and Cultural Differences in Early Intervention in Psychosis Services: International Landscape and Provider Miesekalministration

Ethnic/Racial/Cultural Intersections

٠

Reasons for Disengagement

umbrella	All Contractor Contractor Contractor	Frequency N + 215		
Category	Contributing Codes/Description	n.	3	
Client Rejects EIP Services	Regative response to cognitive behavioral therapy for psychosis (specifically), client claims only family pressure kept them angaged previously, rejects therapy, rejects medications, client believes EIP (specifically) is not helping them	42	363	
Client does not believe psychosis is the problem	Client does not believe that EP services are addressing their actual problems (e.g. need for a job), client does not believe that their problems are caused by 'poschess'/disagree with diagnesis	35	30.4%	
Sesting treatment strewhere	Prefer: service more focused on trauma, a lower intensity service, an external provider, a program, with greater cultural specificity/hon-English- speaking provider, program seer as more convenient geographically	30	26%	
ANT AWDS	Abruptly disengaged without a reason and refused to return calls/follow up	22	19.1%	
Family Sixengaged	Analy rejects or concerned about the loadions/medical theatment or therapy, family shots efficacy, family has opted to send client to a different program, family has opted to send client back to their home country for treatment, family angry because of the way treatment, decisions were handled, family desengated/refusing to return calls for unknown relation	30	17.0%	
Therapist/case manager left	Thersploty/case snamager left the DP service and this was ofted as the primary cause for disengagement	50	8.7%	
Symptoin or Substance Usa	Significant substance use driving disengagement, worsening symptoms driving disengagement, withdrawai from medications and associated relapse driving disengagement	<u>80</u>	18%	

Table 2: Baseline characteristics by Parnily Contact Pattern (n=761).

	Grouped by Family Contact Pattern			000	I				
	Always Op-32%		Mad		Seu				Different bits groups
Monaren		16.95 M (80)		Nort Mysilly		5. sr 36 (80)		No or M (NB)	proles
Desargraphics									
Age (grand)	123	26.2 (5-1)	181	21.9 (3.8)	23	10.1 (2.6)	234	21.2 (1.5)	6001
Gester									8.401
Female		25.8%	.01	12.9%		88.8%	114	213%	
Main	294	79.3%	284	\$5.8%	13	89.1%	1=1	56.5%	
2000	11	0.0%	11	1.2%		0.0%	1	1.04	1.162
Rect									8,004
When Our Departury	100						71	28.2%	
Black (Nos Bioparis)	92	28.3%	**	42.2%	12	14.9%	+1	11.2%	
Higania		29.1%	-08	25.8%	1	10.9%	43	2675	
	12	1016		2.7%	1	4.1%	: 29	11.0%	
Departure (Mahat									6.000
Concerned.	18	0.7%	- 32	5.2%	2	1176	24	1.0%	111.000
Public	147	41.7%	- 64	12.2%	12	\$4.3%	124	10.05	
Private	150	41.4%	- 86	17.0%	90	22.7%	65	11.96	
Other	18.		14	43%	160	10.4%	18	3.0%	

Marked differences in contact pattern by race



• 100% of families who unilaterally disengaged were from ethnic/racial minority groups



First Person Perspectives on Barriers to Family Engagement and Involvement



Intersections: African American Family Perspectives

Lack of trust/gaps in understanding	"How can some young white therapist with no kids know what it's like to raise a black son in America? "
Unacknowledged intersections between race and psychosis	"I gotta think that the police presence in the neighborhood, harassment, shootings, that that's part of this… But I never heard anyone [in the program] say it"
Lack of time and resources	Responsibilities for care of other minor children, disabled family members; working multiple jobs; no transportation; unstable housing; attribution of psychosis to drug or alcohol use; medication only programs simpler and easier to access



Provider Perspectives: Culture and Immigration

Cultural stigma	"a number of families have been quite private about their involvement with our program and staunchly refuse to participate in multi-family groups or willingness to disclose their situation to members of their community. I have observed this with families of various racial/ethnic groups, including Cambodian, Thai, Russian, Pakistani, Indian"
Cultural differences in how treatment is understood	"The cultural challenges have appeared most significantly in the intensive family work required in first episode programs. It has made family engagement and family support of interventions challenges. The concept of shared decision making has been particularly difficult for some families, particularly families from cultural backgrounds that place a high value on authority, particularly the authority of doctors"
Cultural explanations	"Sometimes different cultural beliefs can impact on engagement with traditional services, such as when families or individuals have different explanatory frameworks for difficulties"
Language	"not speaking English is a significant barrier, especially for families where older members may have less grasp on English"



Competing responsibilities	"when client's loved ones are financially strapped and have to work 6-7 days/week there is often little time to involve the loved ones in clients' care, which can often be a key component of engagement with FEP"
Structural barriers	"[poverty] impacts clients and families by making it harder to access services (literally get to services), to be contactable (changing phone numbers, numbers stop working, homes change). They are subject to higher levels of violence and stress"
Family members' direct struggles	"It is hard for people to act as caregivers when they are struggling [themselves] day to day"



Ways Forward? Validating and Addressing Underlying Determinants





Facilitating Meaningful Engagement Framework

Facilitating Meaningful Engagement of Young People and their Families in Early Intervention Programs:



Discuss and validate client and family member explanations, values and the meaning of their experiences

Acknowledge the intersections of psychosis and trauma and integrate trauma-informed practices

Work to defuse and de-escalate power struggles

Build pro-engagement program policies focused on a welcoming environment and sense of community

https://www.nasmhpd.org/content/online-tutorial-facilitating-meaningfulengagement-young-people-and-their-families-early



What Matters Most to Us: Audiovisual Narratives to Empower Culturally Diverse Youth

Project Aim: To develop, through a participatory process, audiovisual narrative tools aimed at empowering culturally diverse youth to express what matters to them in the context of their cultural identities and backgrounds, and in turn, enhance their engagement in early-intervention services.

Tools: Four short films to empower youth and families to talk about their culture, background, identities, and what matters to them in early care.

Funded by NAMI STAR Center

Inspiring youth to talk about what matters to them



Are you a current or past OnTrackNY participant and between the ages of 18 and 25?

Would you like to help us develop videos and other tools to inspire youth to talk about their culture, background, and views about care?

What would I do? Join a Youth Advisory Board and attend meetings to give my input about videos for other young people.

How often? Participation is completely voluntary, but we hope that those who volunteer will commit to coming to four meetings this 2015 summer/fall.

Will I receive a compensation? Yes, a \$50 stipend for participating in each advisory board meeting.

Interested?

Call Samantha Diaz at (646) 774-8060

Psychiatric Institute Center of Excellence for Cultural Competence

New York State

or Oscar Jimenez Solomon at (646) 774-8247







David https://youtu.be/EaqcatcraMo



Taina https://youtu.be/wHv74WXF3gg

Ronke (*) https://youtu.be/MOjoTpiLjX8



Mike (*) https://youtu.be/k-fYgXvuAIw

(*) Developed in partnership with STAR Center and SAMHSA funding

What Matters Most: Empowerment Videos for Young People in Early Care

What Matters Most (Trailer): https://youtu.be/6YB2LTb1bLo

What Matters Most: Ronke <u>https://youtu.be/MOjoTpiLjX8</u>

What Matters Most: Mike https://youtu.be/k-fYgXvuAlw

What Matters Most: David https://youtu.be/EaqcatcraMo

What Matters Most: Taina https://youtu.be/wHv74WXF3gg



Structural Competency - Core Tenets (Metzl and Hensen, 2014)

1. Recognizing the structures that shape clinical interaction

Including class, level of education (and access to educational institutions), structural racism

2. Developing an extra-clinical language of structure

e.g. 'structural vulnerability'
'Internal oppression' as reflected in the body and the psyche

Metzl JM, Hansen H. Structural competency: Theorizing a new medical engagement with stigma and inequality. Social science and medicine. 2014 Feb 1;103:126-33.



Structural Competency - Core Tenets (Metzl and Hensen, 2014)

- 3. Rearticulating "cultural" formulations in structural terms
 - Moving beyond 'ethnic identity' to deeper formulations of the complex interactions between culture, class, choice and social-material capital
- 4. Observing and imagining structural interventions
 - Actively validating the ways structure shape experience
 - Intervening at the level of structures and institutions



Structural Competency - Core Tenets (Metzl and Hensen, 2014)

- 5. Developing structural humility
 - Structural Competence = Beginning of a discussion rather than an endpoint





Family Support In Coordinated Specialty Care

The Role of Certified Family Partners in Coordinated Specialty Care

Donna Fagan, CFP Certified Family Partner





Engaging Families in Coordinated Specialty Care

"When lived experience is counted as another source of expertise - and is combined with the provider's experience and training - the sum of what the partners have to offer leads to greater and more lasting change."



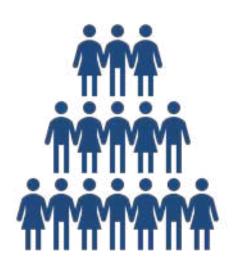
Texas Family Voice Network The Power of Partnering with Families



Family Partners and Coordinated Specialty Care

CSC Teams in Texas can include:

- Team Lead/Primary Clinician
- Supported Education Employment Specialist
- Psychiatrist or Prescriber and Nurse
- Therapist or LCDC
- Outreach Coordinator
- Mental Health Peer Specialist
- Certified Family Partner



https://hhs.texas.gov/sites/default/files/documents/doing-business-with-hhs/provider-portal/behavioral-health-provider/coordinated-specialty-care/initial-evaluation-first-episode-psychosis-early-intervention-programs.pdf



A Family Partner Is:

- A Family Partner has real life experience parenting a child with mental, emotional or behavioral health disorders and who can articulate the understanding of their real-life experiences with another parent or family member.
- A Certified Family Partner has real life experience parenting a child with mental, emotional or behavioral health disorders and who can articulate the understanding of their real-life experiences with another parent or family member...AND has successfully completed the certification process.





Family Involvement in Texas

Family Involvement in Texas System of Care "Why is This Important"





System of Care Values – Partnering with Families

- "Importance is placed on partnering and the leveling of power differences...Healing happens in relationships and in the meaningful sharing of power and decision-making."
- Partnering fosters trust building between the system provider and families.
- When lived experience is counted as another source of expertise and is combined with the provider's experience and training - the sum of what the partners have to offer leads to greater and more lasting change.



https://txfvn.files.wordpress.com/2020/01/txfvn-provider-tip-sheet-1-draft-2.pdf



The Value of Lived Experience

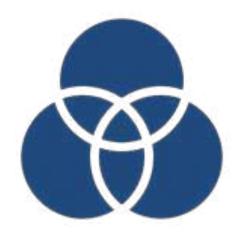
- A Family Partner's personal lived experience caring for a child or young adult with mental, emotional or behavioral health concerns is their primary tool used in supporting families. A family partner's lived experience is critical to engaging the family and in establishing a trusting relationship that is valued.
- For staff who are not family partners, their lived experience may inform their work with individuals they serve, but it is not the primary tool utilized to do their jobs.





Certified Family Partners in Community Mental Health

- Formal Members of the Recovery Team
- Mental Health Professionals
- Provide Continuity of Care and have strong links to the community
- Provide Evidenced-Based Practices examples include: Motivational Interviewing, Nurturing Parenting Program
- Supervise, train and mentor other family partners





Texas HHSC Approved Family Partner Services

Family Partner Services

- Share our personal stories
- Ensure confidentiality
- Peer Group facilitation
- Attend prescriber appointments
- Provide continuity of care
- Role model self-care, parenting, and advocacy
- Ensure a family's voice is heard in treatment
- Mentoring
- Emotional support
- Systems navigation
- Link to resources

Medicaid Reimbursable Family Partner Services

- Non-Clinical Skills Training
- Medication Training
- YES Waiver Wraparound Family Support





Family Partners in Wraparound Services

- Primary caregiver of a child with emotional or behavioral challenges
- Lived experience navigating systems of care with their child
- Uses lived experiences to provide hope and peer support to other families experiencing similar challenges
- Ensures other parents have a voice in their child's care and are active participants in the wraparound process
- Engage and collaborate with people from diverse backgrounds and be able to maintain a non-judgmental attitude towards both families and professionals

<u>https://hhs.texas.gov/sites/default/files/documents/doing-business-with-hhs/provider-portal/behavioral-health-provider/yes/yes-policy-manual.pdf</u> https://nwi.pdx.edu/pdf/qualifications-for-family-partners.pdf



CMH Family Partner Services – Minimum Qualifications

Certified Family Partner or Family Partner Pursuing Certification:

- Family Partner Supports
- Family Training
- Parent Support Group

Certified Family Partner:

- Medication Training or Support
- Skills Training and Development

UM Guidelines Child and Adolescent Services, Appendix H: Provider Qualifications: Standard Requirements for Services <u>https://hhs.texas.gov/sites/default/files/documents/doing-business-with-hhs/provider-portal/behavioral-health-provider/um-guidelines/trr-utilization-management-guidelines-child.pdf</u>

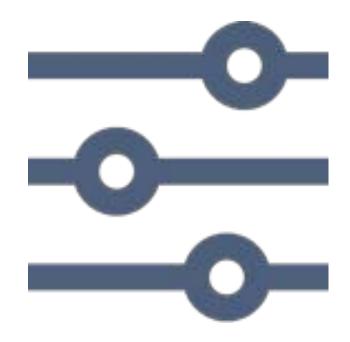


Family partners serve families of individuals in following transition age levels of care:

- LOC YES YES Waiver and Wraparound (Until 19th birthday)
- LOC TAY Transition Age Youth (Ages 16-25)

Family Partner Support Providers in CSC Services FEP Family Contact

 LOC EO – LOC CEO and LOC AEO (Ages 15 – 30)





Transition Age Youth – LOC TAY "The Warm Hand-off"

Without the "Warm Hand-off" During the Age of Self-Determination The Importance of Youth and Adult Peer Support

Age of Self-Determination Individuals with SED and SMI *"Falling Off The Planet"*

Dropping out of mental health and SUD Services Relying on peers (Friends vs MH Peer Specialists) Self determination reinforced by the community Community and youth serving systems of care Help from Adult and Youth Mental Health Peer Specialists

Wraparound Services

"The Importance of Community Buy In"

Why engage the family and community in mental health transition age services? Educating the family and community in wraparound services Formal and informal supports for young adults Importance of natural supports to adolescents with SED

Why Parents Need the "Warm Hand-off"

The Importance of Family Partner Services

Transitioning

Why is it so hard to "let go?" "You're only as well as your least well child"

> Understanding SED, SMI and MH Systems Formal and informal supports for caregivers Learning and Respecting Boundaries Practicing self-care Help from Certified Family Partners

Caregiver Buy-In

"Mama Bear"

Trusting your child to systems that have failed them. Self-determination and caregiver push back When you are no longer the "expert in your child's care" "Happy Birthday Letter"



Fast Facts about CSC in Texas

- There are 3000 new FEP cases in Texas each year. 1
- In 2018, LMHAs in Texas operated CSC programs in 10 of 39 Local Mental Health Authorities. 2
- In 2019, HHSC's Coordinated Specialty Care program added 13 new sites to increase access to care throughout the state, particularly in rural areas. 3
- Each CSC team serves a maximum of 30 people at an average cost of \$425,000. 4
- CSC's program serves adolescents and young adults from ages 15 to 30 who have had a psychotic disorder diagnosed within the last 24 months. 5

A Guide to Understanding Mental Health Systems and Services in Texas, 4th Edition -2018, Hogg Foundation for Mental Health, 1, 2, 4

News Release July 22, 2019, Texas Health and Human Services Commission, Dr. Courtney N. Phillips, HHS Executive Commissioner, HHSC Expands Treatment for Early-Onset Psychosis to Rural Texans, Contact Christine Mann 512-424-6951, 3, 5



Texas Resiliency and Recovery Utilization Management System

Special Considerations Regarding Peers and Recovery

SAMHSA recognizes peer services as a critical component to the recovery process. DSHS endeavors to facilitate processes that acknowledge this role. As such, the following recommendations highlight how peers and/or family partners might be best utilized within this level of service.

- Share individual experience related to recovery and act as a model of hope and resilience
- Provide education about the recovery process
- Promote social integration by educating about resources in the community that may support continued recovery, such as individual operated service providers, mutual aid groups, social organizations related to the individual's interests, health clubs, etc.



Texas Resiliency and Recovery Utilization Management System

Special Considerations Regarding Peers and Recovery

- Provide medication training and support as appropriate
- Provide education about the early onset program
- Provide engagement interventions to individuals to foster full participation in treatment
- Certified Peer Specialists and/or Certified Family Partners may serve as a member of the treatment team offering feedback to other providers regarding his or her observations of an individual's stage of recovery and/or efforts made towards fulfilling the individual's recovery goals.

https://hhs.texas.gov/sites/default/files/documents/doing-business-with-hhs/provider-portal/behavioral-health-provider/um-guidelines/trr-utilization-management-guidelines-child.pdf page 60



TRR UM Guidelines CSC Family Partner Services

The following are listed as Core Services that can be provided by family partners (not adjunct services) under LOC CEO (Early Onset):

- Family Partner Services
- Individual Family Training
- Group Family Training
- Parent Support Group
- Medication Training



Use of these services is dependent on staffing and is at the discretion of the Local Mental Health Authority, LMHA.

UM Guidelines Child and Adolescent Services – Appendix E: LOC Early Onset (LOC-EO) <u>https://hhs.texas.gov/sites/default/files/documents/doing-business-with-hhs/provider-portal/behavioral-health-provider/um-guidelines/trr-utilization-management-guidelines-child.pdf</u>



Family Partner Services in FEP Programming

- CFPs use our core competencies
- CFPs provide emotional support to families reducing caregiver stress
- CFPs engage the family and maintain engagement in the treatment process
- CFPs use our personal lived experience when appropriate to provide hope
- CFPs provide peer to peer mentoring
- CFPs provide information and link families to community resources
- CFPs facilitate family peer groups
- CFPs use motivational interviewing to identify strengths and needs
- When identified, CFPs provide non-clinical skills trainings
- CFPs provide coaching and psychoeducation to the family
- CFPs provide services to the family as identified in the person-centered recovery plan and within our scope of practice



Family Partners providing Family Training

Making the Case for Family Psychoeducation Provided by CFPs

Currently Provided by CFPs in Children's Mental Health Services

- Nurturing Parenting Program
- Barclays Defiant Child
- Barclays Defiant Teen

Currently Provided by CFPs in Coordinated Specialty Care

OnTrackNY Resources for Families

Currently Provided by CFPs in Community

• NAMI Family to Family





Family Education in CSC

Coordinated Specialty Care Family Education - Psychoeducation

The OnTrackNY Program - Resources for Working with Families

- Identifying Family Strengths and Needs
- Weekly or Monthly Sessions
- Can be used in group or individually
- Understanding Psychosis and SMI
- Understanding Difficult Behaviors
- Recognizing and Understanding Feelings
- Developing Empathy and Self-Care
- Understanding Self-Worth and Recovery
- Problem Solving
- Identify Natural Supports





OnTrack

My health. My choices. My future.

Family Education in HHSC – Comparison - CSC

Approved Non-clinical Skills for Caregivers or LAR in HHSC Services

Nurturing Parenting Program - Barclays Defiant Child - Defiant Teen

- Identifying Family Strengths and Needs
- Weekly or Monthly Sessions
- Can be used in group or individually
- Understanding Mental Health
- Brain Development
- Recognizing and Understanding Feelings
- Developing Empathy and Self-Care
- Improving Self-Worth and Resiliency
- Problem Solving
- Identify Natural Supports





Thinking Outside the CSC Box in Community Mental Health

Why Not Wraparound in CSC? LOC EO - LOC YES - LOC TAY



Special Considerations for Adolescents Are we missing a great opportunity for engaging families?

https://nwi.pdx.edu/pdf/wraparound-for-older-youth.pdf



A Family Partner's personal lived experience caring for a child or young adult with mental, emotional or behavioral health concerns is their primary tool used in supporting families. A family partner's *lived experience is critical to engaging the* family and in establishing a trusting relationship that is valued.

https://txfvn.files.wordpress.com/2020/01/txfvn-provider-tip-sheet-1-draft-2.pdf



Links to CSC resources can be accessed through Texas Family Voice Network webpage.

https://txfvn.org

https://txfvn.org/resources





SAMHSA's mission is to reduce the impact of substance abuse and mental illness on America's communities.

www.samhsa.gov

1-877-SAMHSA-7 (1-877-726-4727) • 1-800-487-4889 (TDD)