SYSTEM OF CARE-COMMUNITY FOR EARLY SIGNS AND SYMPTOMS (SOC-CESS)

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May 31, 2019

Presentation Objectives

- Rationale for DMH pursuit of supports for children and youth at CHR for psychosis
- Impart the history and current trends in early intervention in psychosis
- Introduce the goals of the SOC-CESS grant
- Review data from the implementation of SOC-CESS to date
- Provide outcomes regarding Family Engagement and Voice
- Provide outcomes regarding Youth Engagement and Voice
- Action in the Community

DMH Rationale for pursing SOC-CESS

- Mental Health Block Grant Set Aside
- Included in the 21st Century Cures Act
  - Block Grant 10% set aside funds for early serious mental illness. Below is the language included in the statute as well as the initial guidance SAMHSA provided regarding the definition of the ESMI population.
  - Statutory Language
    - a State shall expend not less than 10 percent of the amount the State receives for carrying out this section for each fiscal year to support evidence-based programs that address the needs of individuals with early serious mental illness, including psychotic disorders, regardless of the age of the individual at onset.

What is Prodromal?

"period of altered functioning or symptomatology before the frank or threshold psychosis"

- Most psychotic disorders begin with prodromal phase
- There is a presence of sub-threshold psychotic features (less in intensity and duration)
- Disorders of thought content (delusions), perceptual abnormalities, poor concentration and attention, emotion and affect changes, impaired stress tolerance, and impaired energy.

Why the Focus on the Prodromal?

- Earlier detection and care may ↓ the rate of developing psychosis
- Reduction in the duration of untreated symptoms could minimize harm
- Possibly even prevent transition to psychosis

Ultra High Risk (UHR)

- One or more of the following characteristics:
  - **Attenuated Positive Symptom Syndrome (APS)**
    - Positive symptoms present at least 1x weekly
    - Unusual thought/delusional ideas; conceptual disorganization; paranoia; grandiosity
  - **Brief Limited Intermittent Psychotic Symptoms (BLIPS)**
    - Experienced episodes of frank psychotic symptoms for less than 7 days and have spontaneously subsided
  - **Generic Risk and Deterioration Prodromal Syndrome (GRDPS)**
    - Also known as Train and State Risk Factor (Trait)
    - Family hx of psychotic d/o in any 1st degree relative
    - Decline in role functioning and either a dx of schizotypal personality d/o

Loewy RL, Pearson R, Vinogradov S, Bearden C, Cannon TD. Psychosis Risk Screening with the Prodromal Questionnaire Brief version (PQ-B). *Schizophr Res.* 2011; 129(1): 42-46

Nelson B, Yuen K, Yung AR. UHR for psychosis criteria: Are there different levels of risk for transition to psychosis? *Schizophr Res.* 2011; 125 62-68

Building a DBH Continuum of Services

DLA 20 Eligibility

Eligibility for services for adults and youth based not only on strict diagnosis, but on functional needs. TAY can potentially remain in youth services up to age 25 and are then eligible for adult services when transition is appropriate.

Age Range Initiative

Allows TAY to be dually enrolled in the youth and adult systems, giving providers the flexibility to access both youth and adult funding based on the individual's needs.

SOCCESS

In partnership with CCBHCs, DBH intends to provide early surveillance and detection of prodromal risk factors for children ages 9-17, provide psychosocial interventions, identify and treat early mental health symptoms and psychosis.

Coordinated Specialty Care/ ACT TAY

Team based treatment approach designed to provide individuals ages 16-25. Individuals and families receive early intervention services from a team of specialists sensitive to the unique needs of transitional age youth.

Children ⟷ **Adult**

SOC-CESS

- SAMSHA grant initiated in April, 2016
- Three sites: Burrell Behavioral Health, Compass Health Network, and Ozark Center
- Goals
  - Expand the clinical services available by establishing evidence-informed practices a available to the children and youth identified through surveillance and referral to be at chronic high risk for psychosis
  - Establish and sustain both Family and Youth engagement to foster voice, education and advocacy
  - Establish and sustain Systems of Care to include SOC-CESS goals and values.

Why early signs and symptoms?

- Severe mental illness (which includes psychosis) negatively affects the life trajectory and costs billions of dollars in mental health and other services
- Through research, it has been determined that early intervention can change the life trajectory for children and youth who are at high risk for experiencing psychosis
- Expanding services and supports, including clinical services, family and youth peer supports, and community education are vital to changing life trajectories.

Clinical Supports

- Group Family-CBT
- SPARCS
- Neurofeedback
- Biofeedback
- Virtual Reality
- Prolonged Exposure
- Metabolic Screening
- Pharmacogenetic Testing

- ↓ Use of psychotropic medications
- ↑ Engagement of youth and families
- ↑ In protective factors and resilience

YOUTH ENGAGEMENT

First, let's play a small game! How much do you know about youth culture? *Don't worry – these are all family-friendly ☺

- What does "tbh" mean?
- Who was at Coachella this year?
- Do you know of anyone who's recently been "cancelled"?
- Do you know how to floss? (Not your teeth)
- What's your favorite meme?
- What social media accounts do you have? What about your agency?
- When is the last time you or someone at your agency asked a young person for input (NOT technical support ☺) on something that concerns them?

How did we get here?

- Peer support was being utilized as early as the 1950s but was formalized in the 1990s
- Consumer Survivor Movement (1970s) started with people with lived experience coming together to advocate for patient rights
  - However, this largely left out younger people and families
- The Family Movement (1980s)
- Youth Movement (2000s)
- Multiple culture changes poised us for where we are now!

What is youth voice?

- Starting with the premise that *EVERYONE should have a seat at the table*
- Continuing to recognize that youth is a culture and youth input is *unique and valuable*
- Advocating for the place of those with lived experience on treatment teams
- Reflecting a commitment to receiving youth and young adult input through hiring practices, policies and administrative access

What would a youth/young adult position look like?

- Youth Peer Support Specialists (training now available!)
- Youth Coordinators
- Youth Advocates
- Start with champions in your own agency and work from there!

What else can we do?

- Draft a formal policy statement
- Start a youth/young adult advisory council
- Hold trainings/add training on youth voice to your new employee orientation
- Regularly evaluate how young people perceive their place in your agency, and what they would change given the chance
- Take a look at best practices from other states – Youth MOVE National and Youth ERA are great examples!
- Reference the Y-VAL for a validated tool and more concrete steps

SOC-CESS's Lessons Learned

- Recruitment is hard. Incentives and compensation are a must!
- Young adult staff with lived experience bring more than one would think!
- Overall, people agree with youth voice – moving toward concrete conversations about implementation comes next!
- Breaking down language barriers between youth/young adults and professionals overall increases quality of communication and care.
- Lived experience and education/licensure should both be equally represented – both are needed and valid.
- Dedication to any sort of engagement must permeate the system, top to bottom – it should be an agency-wide effort!

FAMILY SUPPORT PROFESSIONALS

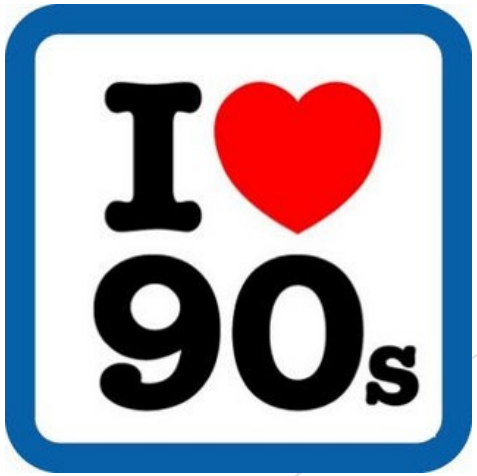
A Little History: FSP in Missouri

Why Was Family Support Readily Accepted?

- The President's New Freedom Commission on Mental Health, along with SAMHSA and the Centers for Medicaid and Medicare realized people were very capable of navigating the child care systems.
- They realized they could harness this energy and knowledge to assist other families. Many times a Family Support Provider will be able to form bonds of trust and safety with a family where previous efforts to engage went unanswered.
- Knowing someone else has "been there and done that" can engender trust quickly.
- Peer to peer, parent to parent, and now youth to youth models remove "clinical" barriers that may be present.

Family Support

- During the 80's and 90's, family voice began to be heard
- Isolation, lack of sufficient income, stigma, family problems
- Pioneer states: MO, MI, MN, NH, LA, AL, OR, WV, WA, NJ, PN
- 35 states gained funding from Medicaid in 2001, MO was one



Benefits of FSP program

- Two fold in nature
  - Advocate
  - Ease the burden on staff shortages
- Not clinical
- Still considered a valuable service and equal team member
- Helps families feel heard and supported
- Evidence based

Goals of FSP training

- Build family resiliency using strength based principles
- Support families in decision making tools
- Help families see hope in their situation
- Peer to peer support
- Help families find their way through daily struggles
- Advocacy

Resiliency

- Resilience helps people withstand stress and trauma. It does not mean going through life with no challenges, but does help a person cope effectively.
- We are not born with it, we have to develop it. People who have achieved a higher degree of resiliency can use their strongest asset to help others learn the same: Their Story

Factors in Acquiring and Sustaining Resilience

- Make realistic plans, ability to carry them out
- Positive sense of self and abilities
- Communication/problem solving skills
- Ability to manage strong impulses and feelings
- Protective factors to balance or out-weigh risk factors
- Connections to family and friends, community
- Ability to remain hopeful and optimistic

System of Care

- Expanding System of Care teams in Cole County/Holt Summit, Jasper County, and Green County
- Agencies serving children work together to identify children at CHR/UHR and the services needed to support them
- Agencies include

Children's Division	Juvenile Justice
School Districts	DMH
Advocacy groups	Boys/Girls Club
Big Brothers/Big Sisters	CASA
Department of Health	Faith Communities
Social Services agencies	Missouri Families 4 Families

DATA

NUMBERS SCREENED
NUMBER RECEIVING SERVICES
DEMOGRAPHICS AND DIAGNOSES

Number screened (as of 3/31/2019)	977
Total currently receiving services	223
Total currently participating in evaluation	158

Most common diagnoses	
Depression	41%
ADD/ADHD	34%
Anxiety	30%
Conduct/ Oppositional Defiant Disorder	28%

DEMOGRAPHICS

Demographics	
Gender	%
Male	39.50%
Female	55.50%
transgender	1.00%
other/unknown	4.00%
Race/Ethnicity**	
Black	11.60%
Asian	2.80%
White	69.20%
American Indian	12.00%
Hispanic/Latino	4.40%
Housing status	
Living with someone other than caregiver	1.00%
Education	
Elementary	21.08%
Junior High	44.86%
High School	34.05%
***This table includes only consumers participating in the evaluation.**	
****Note. Because participants may select multiple races, column totals do not sum to 100%.**	

ACTIVITY AT THE SYSTEM LEVEL

Indicator	Goal (all years)	To date	Progress toward goal
Policy Development	27	14	63%
Workforce development	1244	1041	84%
Family involved in service delivery	130	21	16%
Partnership collaboration	24	3	13%

IMPROVEMENT OBSERVED FROM BASELINE TO FOLLOW-UP MOST EVIDENT IN SCHOOL BEHAVIORS AND ABILITY TO COPE

NOMS responses	% change
Psychosocial Wellbeing	From baseline to follow-up (6 mos.)
Overall health, positive	4%
Handling daily life, positive	10%
Gets along with family, positive	-5%
Gets along with friends, positive	-1%
Doing well in school, positive*	15%
Able to cope, positive*	15%
Satisfied with family, positive	-3%
Nervous, most or all of the time	-8%
Nopeless, most or all of the time	-4%
Restless, most or all of the time	1%
Depressed, most or all of the time	-5%
Everything effortful, most or all of the time	-6%
Worthless, most or all of the time	-6%

THE NUMBER OF YOUTH REPORTING POSITIVE OUTCOMES INCREASED ACROSS SEVERAL DOMAINS. SIGNIFICANTLY FOR HAVING FUN.

Youth Responses			
Columbia Impairment Scale			Sig.
	Baseline	Follow-up	
Problem with…	%	%	p
Getting into trouble	73.70%	78.90%	0.562
Getting along with mother	68.40%	83.30%	0.285
Getting along with father	81.30%	71.40%	0.169
Feeling unhappy or sad	94.70%	78.90%	0.088
Behavior at school or job	68.40%	55.60%	0.175
Having fun	78.90%	52.60%	0.014
Getting along with adults	52.60%	47.40%	0.705
Feeling nervous	100.00%	89.50%	~1
Getting along with siblings	82.40%	94.10%	0.333
Getting along with kids his/her age	77.80%	89.50%	0.365
Getting involved in activities	78.90%	63.20%	0.169
With school work/doing his/her job	78.90%	55.60%	0.07
With behavior at home	78.90%	78.90%	1
Distracted easily	100.00%	100.00%	1

YOUTH RESPONSES. SYMPTOMS IMPROVEMENTS SIGNIFICANT IN HAVING FUN, UNDERSTANDING OTHERS, TAKING OTHER'S BELONGINGS

Pediatric Symptom Checklist			Sig.
	%	%	p
Fidgety	100.00%	94.70%	~1
Feels sad	100.00%	84.20%	~1
Daydreams too much	73.70%	89.50%	0.18
Refuses to share	78.90%	63.20%	0.169
Does not understand other people's feelings	84.20%	57.90%	0.052
Feels hopless	73.70%	68.40%	0.306
Trouble concentrating	100.00%	94.70%	~1
Fights with other children	68.40%	68.40%	1
Is down on himself/herself	78.90%	78.90%	1
Blames others for his or her trooubles	63.20%	42.10%	0.147
Seems to be having less fun	89.50%	63.20%	0.019
Does not listen to rules	73.70%	68.40%	0.561
Acts as if driven by motor	47.40%	47.40%	1
Teases others	52.60%	42.10%	0.138
Worries a lot	89.50%	89.50%	1
Takes things that do not belong to him/her	47.40%	21.10%	0.048

PARENTS REPORTED IMPROVEMENTS IN SOME YOUTH BEHAVIORS (LOWER % BETTER)

Parent responses			
Columbia Impairment Scale			
	Baseline	Follow-up	Sig.
Problem with…	%	%	p
Getting into trouble	71.00%	67.70%	0.793
Getting along with mother	83.90%	73.30%	0.285
Getting along with father	84.00%	75.00%	0.224
Feeling unhappy or sad	100.00%	90.30%	~1
Behavior at school or job	60.00%	77.40%	0.106
Having fun	74.20%	71.00%	0.739
Getting along with adults	64.50%	61.30%	0.764
Feeling nervous	93.50%	96.80%	0.57
Getting along with siblings	82.10%	88.50%	0.457
Getting along with kids his/her age	87.10%	77.40%	0.319
Getting involved in activities	83.90%	80.60%	0.739
With school work/doing his/her job	77.40%	76.70%	0.926
With behavior at home	90.30%	90.30%	1

PARENTS' RESPONSES INDICATE A NUMBER OF INCREASED SYMPTOMS INCLUDING REFUSING TO SHARE, DRIVEN BY MOTOR, AND TAKING OTHER'S BELONGINGS.

Patient Symptom Checklist			Sig.
	Baseline	Follow-up	p
Fidgety	87.10%	93.50%	0.321
Feels sad	100.00%	96.80%	~1
Daydreams too much	74.20%	74.20%	1
Refuses to share	61.30%	83.90%	0.031
Does not understand other people's feelings	83.90%	90.00%	0.35
Feels hopeless	90.30%	90.30%	1
Trouble concentrating	93.50%	90.30%	0.656
Fights with other children	61.30%	71.00%	0.313
Is down on himself/herself	93.50%	90.30%	0.313
Blames others for his or her troubles	83.90%	80.60%	0.739
Seems to be having less fun	87.10%	87.10%	1
Does not listen to rules	83.90%	90.30%	0.316
Acts as if driven by motor	54.80%	77.40%	0.004
Teases others	51.60%	67.70%	0.124
Worries a lot	96.80%	93.50%	0.32
Takes things that do not belong to him/her	38.70%	61.30%	0.028
Distracted easily	93.50%	96.80%	0.32

IMPROVEMENTS WERE OBSERVED BY CAREGIVERS ACROSS THE BOARD WITH REGARD TO CAREGIVER STRAIN. SIGNIFICANT IMPROVEMENTS HIGHLIGHTED

Caregiver Strain Questionnaire			Sig.
	Baseline	Follow-up	p
Interruption of personal time	93.10%	73.30%	0.044
Missing work or neglecting duties	75.90%	63.30%	0.24
Disruption of family routines	79.30%	53.30%	0.011
Having to do without things	31.00%	26.70%	0.69
Financial strain	48.30%	43.30%	0.586
Disruption of relationships	79.30%	63.30%	0.111
Unhappy about child	96.60%	76.70%	0.062
Embarrassed about child	55.20%	30.00%	0.002
Angry at child	51.70%	43.30%	0.437
Worried about child's future	100.00%	80.00%	~1
Worried about family's future	75.90%	40.00%	0.003
Guilty about child	79.30%	63.30%	0.003
Resentful towards child	24.10%	16.70%	0.152

Questions?