Parent Support and Training
“A Calm Voice in A Storm of Uncertainty.”

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This Continuing Education Hour will:
1. Provide an overview of PST Services.
2. Describe the Family Driven Paradigm.
Research and Development for PST Services is supported by a collaborative contract with the Kansas Department for Aging and Disability Services.
Overview of PST and the Role of the PST Provider

In this section you will learn:

• What is PST?
• What is the Family Driven Paradigm?
What is PST?

PST is:

• A unique waiver service under the Home and Community Based Services Serious Emotional Disturbance (HCBS/SED) Medicaid Waiver.

• Honors caregivers as valuable and necessary members of their children’s treatment.

PST:

• Focuses on family/caregiver empowerment.

• Supports, educates, and trains caregivers.
What is PST?

ETHICS

Many PST providers are parents of children with special-needs or have experiences receiving and navigating child serving systems.

Research shows that the shared experiences PST providers and caregivers have create unique and strong working alliances.

Knowledge of ethics and ethical practices are especially important for PST Providers with shared experiences.
Acknowledging the importance of ethical practice and the need for specialized support, veteran PST providers in Kansas have developed “The PST Code of Ethics” to help guide effective working alliances with caregivers.
The Family Driven Paradigm?

Families having a primary decision-making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory, and nation.

PST services are a way to operationalize the family driven paradigm within services systems.

For more information please go to the National Federation of Families for Children’s Mental Health’s website. www.ffcmh.org
What is the Family Driven Paradigm?

The 10 guiding principles:

1. Shared decision-making and responsibility for outcomes are essential.
2. Families have accurate, understandable, and complete information.
3. Family voice is assured.
4. Peer support activities are necessary to reduce isolation and build connection.
5. Provide direction for funding decisions.
6. Providers take steps to promote Family Driven Care.
7. Administrators support with resources, staff, and time.
8. Barriers and discrimination created by stigma is removed.
9. Celebrate diverse cultures to eliminate mental health disparities.
10. Advance self-responsiveness to changing cultural and linguistic needs.
Research and Development

2007-2014

The 34 PST Best Practices (BPs) are defined.

Training developed and tested in the practice setting.

PST Best Practices were evaluated with families who receive HCBS SED Waiver Services.

Multi-site evaluation showed that when the PST BPs were carried out, youth spend less time in residential placement and time away from their families.
The PST Best Practices Model was adapted and tested for families with children with a developmental or intellectual disability.

Randomized Controlled Trial with Families Waiting for HCBS Medicaid Intellectual Disability or Developmental Disability Services Waiver.

All outcomes were trending in the right direction with the intervention group.

Increase Family Empowerment
Increase Family Quality of Life
Increase Social Support
Decrease Caregiver Strain
Family Driven Engagement Strategies & Tools to Support Family Driven Practices.

In this section you will learn:

• About the Research-Based PST Best Practice (BP) Implementation Tools:
  o Needs Assessment
  o PST Best Practices Guide
  o PST Toolkit for the Empowered Parent

• Ongoing support PST Providers Need
  o Sensitive Supervision
  o Access to Peers/Knowledge/Technical Assistance
The Needs Assessment

Research on the PST Best Practices model implementation showed that when referring providers, PST providers, and families used the

“Needs Assessment for Referral to Parent Support and Training Services,” all team members (including families) were more informed about the PST Provider’s role.

The Needs Assessment was modeled after the Medicaid Definition of the PST Service and is a detailed checklist of the possible interventions PST providers could provide. The intent of this implementation tool is to educate about the service and document everyone is in agreement with what the PST Provider is there to do.
The PST Best Practices Guide

The 34 PST Best Practices were designed to be flexible for fit in a variety of agency contexts.

Research has shown that when The PST Best Practices were provided, youth spent less time in residential placements and less time away from their families.
When Using the Needs Assessment.

By simply using the [Needs Assessment](#), in the referral process you and your team are carrying out 7 of the 34 PST Best Practices!!

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<td>1.</td>
<td>Identify family needs before making referral</td>
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<td>2.</td>
<td>Considers how PST services can help meet needs</td>
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<tr>
<td>3.</td>
<td>Describe PST services before referral is made</td>
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<td>4.</td>
<td>Family agrees to be referred</td>
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<td>5.</td>
<td>Provider refers family to PST service</td>
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<td>10.</td>
<td>Inquire about needs of family</td>
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<td>11.</td>
<td>How can PST services help family</td>
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Support & Training for The Empowered Parent

"I wouldn't change her for the world, but I would change the world for her."

Your PST Provider / April Patton 785-555-5555
APatton@KU.ed
Purpose of the Tool Kit

Your situation is unique but not abnormal. Parent Support and Training (PST) providers are here to walk alongside you as you navigate the various systems, services, and situations that face your child. We know that you have never loved anyone like you love your child. We know this because most of us parents as well. We also know that sometimes things are lot more difficult than anticipated, and sometimes it just helps to have someone work with you. You are the expert in your child’s care, you are the expert in knowing your child, and we are here to support you.

This tool kit is designed to be an interactive tool for you to use while working with your PST provider. In collaboration with Kansas Department of Aging and Disability Services – Behavioral Health and the University of Kansas, we collected insight from parents just like you on what would be helpful in a toolkit. The most important thing for parents was to have a real live person help them sort out resources and understand the best ways to advocate for their child – that’s your PST provider, the walking toolkit. However, this booklet is a box to store what you learn. Inside we have included sections to store resource information and contacts, manage your daily routines, conversations related to raising a child with extra needs, and a space to keep your aha moments and plans.

Welcome to the family!

1. Conversations
   The latest information on raising a child with extra needs, including insight from parents just like you.

2. Our Routine
   Schedules, lists, routines and other places to visually manage your child’s care.

3. Resources
   Store resource information related to your child’s services, support groups and online resource guides.

4. AHA!
   A place to keep AHA notes from your PST provider. Also, use the envelope in the back for safe tracking of your child’s plans, service contracts, etc.
Ongoing Support

Sensitive Supervision – Manage the Tension

Barbara Huff (Family Leader) explains that applying the family driven paradigm can create a natural tension between PST providers and other community based providers. In a previous study one supervisor says,

“You have to understand that you become an advocate, but you also have to learn that it’s a very fine line that you’re walking on. It’s like a little tightrope because you are representing the agency, but you’re also advocating for your client. At times you can be seen as adversarial within your own agencies. It’s a very tricky balance and the person has to be able to take supervision, to take direction so that she understands this tightrope that she’s walking on, because I don’t want her to fall. They have to understand that it’s a balancing act that you have to do. You’re needing to appease two different audiences at times. They have to be able to have the ability to understand that and not feel like I’m going to be an advocate for my client no matter what. Well, that’s not the world that we live in. You’re still employed through a mental health center and you still have expectations that the employer’s going to have, that the agency’s going to have, and you can do both. She’s learned how to do both. But it takes awhile to be able to do that. “
Ongoing Support

• Technical Assistance- Research on PST Services also suggests PST Providers need:
  – Access to PST peers who are doing the same work
  – Access to knowledge to meet the individualized needs families identify
  – Support to implement the Family Driven Paradigm
Ongoing Support

• The PST Research and Training Children and Families will offer quarterly technical assistance
  
  – Collaborating with the Center for Online Distance Learning
    • Design interactive webinars
  
  – Collaborating with the Department of Special Education
    • Support families who have youth with special needs attending a new certification program
    • Developing materials for online training for PST Providers
Increasing Access & Outreach

Collaborating Community Engagement Specialist – Sarah Goodwin Thiel

1. Making PST materials available to Scholars/Clinicians as well as Families

   Lib Guides  http://guides.lib.ku.edu/socialjustice/home
   Scholar Works  https://kuscholarworks.ku.edu/

2. Coordinating access to PST resources by linking in with naturally existing library resources across Kansas
Questions?
Thank you!