



## Exploring Topics Related to PBS Across Waiver Services Using Mixed Methods Research



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## Presenter Background

- Practitioners , Instructors, & Researchers
- Combined 36 Years working on various Kansas Waivers



## Today's Objectives

- Overview of Study Purposes
- Discuss Mixed Method Study Design
- Discuss Major Study Activities
- Share Study Findings and Recommendations
- Lessons Learned
- Implications and Future Work



3

## What is CMS?

The Centers for Medicare & Medicaid Services (CMS) is a branch of the U.S. Department of Health and Human Services. CMS is the federal agency which administers Medicare, Medicaid, and the Children's Health Insurance Program. Provides information for health professionals, regional governments, and consumers. Additional information regarding CMS and its programs is available at <http://www.cms.hhs.gov/>.

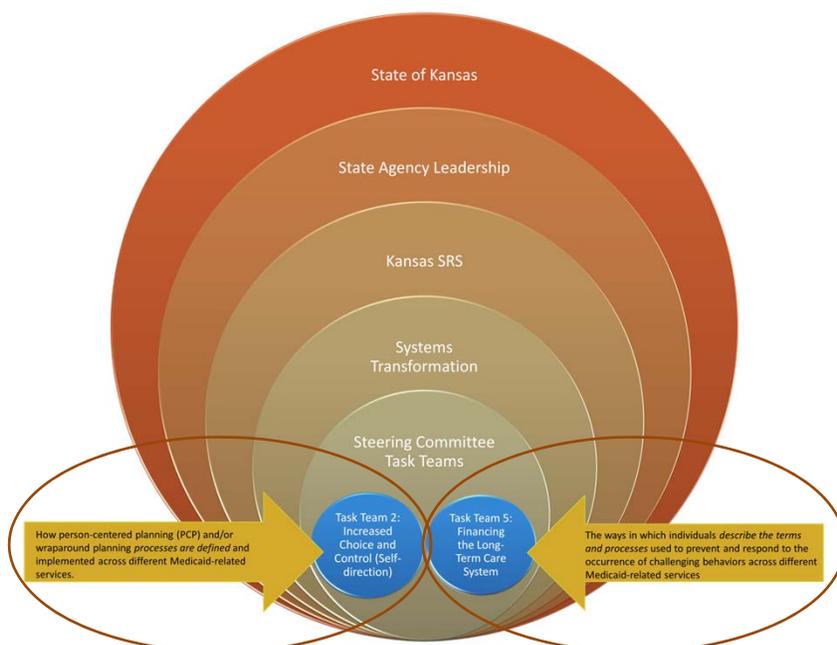
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## Kansas HCBS Waiver Services

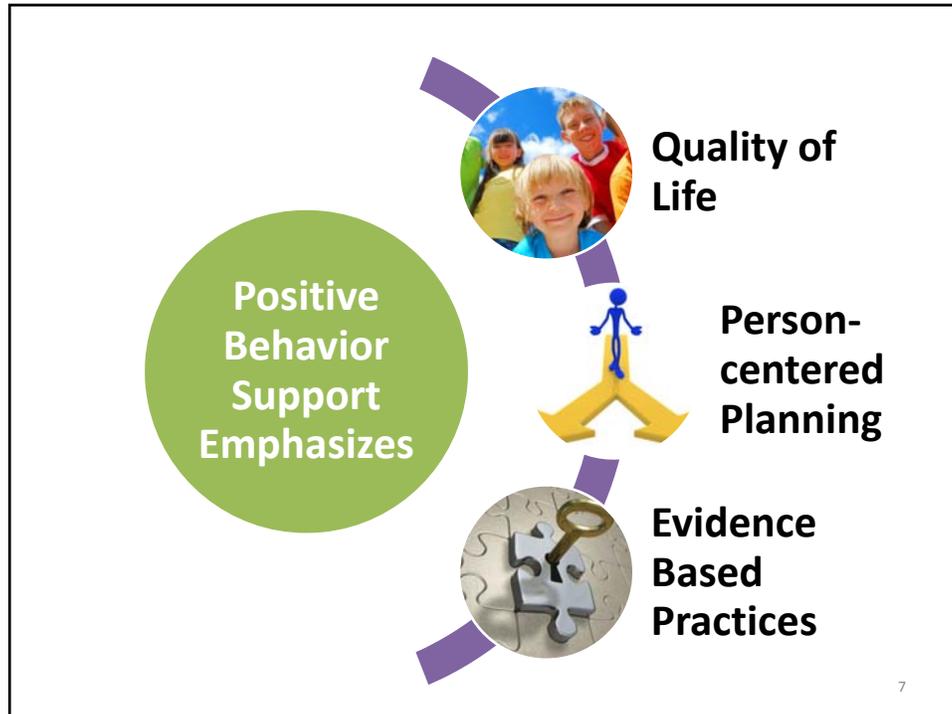
- Autism
- Developmental Disabilities
- Frail and Elderly
- Mental Health
- Physical Disabilities
- Technology Assistance
- Seriously Emotionally Disturbed
- Traumatic Brain Injury

5

## Real Choice Systems Change: Systems Transformation Grants



6



## Initiation of Studies

Kansas professionals in the Social and Rehabilitation Services (SRS) requested **two mixed methods studies evaluating person-centered planning and challenging behavior across seven Kansas waivers** from the Kansas Institute for Positive Behavior Support (KIPBS).

## Research Questions

- What are the ways in which individuals describe the terms and processes used to prevent and respond to the occurrence of challenging behaviors across different Medicaid-related services?
- How are person-centered planning (PCP) and/or wraparound planning processes defined and implemented across different Medicaid-related services?

## Complex Stakeholders and Systems



## Large Geographic Area



11

## Why a Mixed Methods Design?

- Address complexity of stakeholders and systems
- Provide a more complete picture utilizing rich and diverse data
- Opportunity to develop broader and deeper understanding of issues related to research questions
- Enhances approach to gathering and analyzing data to the research questions

12

## Mixed Method Approach

The mixed methods approaches used in this research design included

- **qualitative analysis** of focus group and interview transcripts, an analysis of qualitative online survey data
- **quantitative descriptive analysis** of written behavioral plans and analysis of online survey data

13

## Purpose of the Challenging Behavior Study

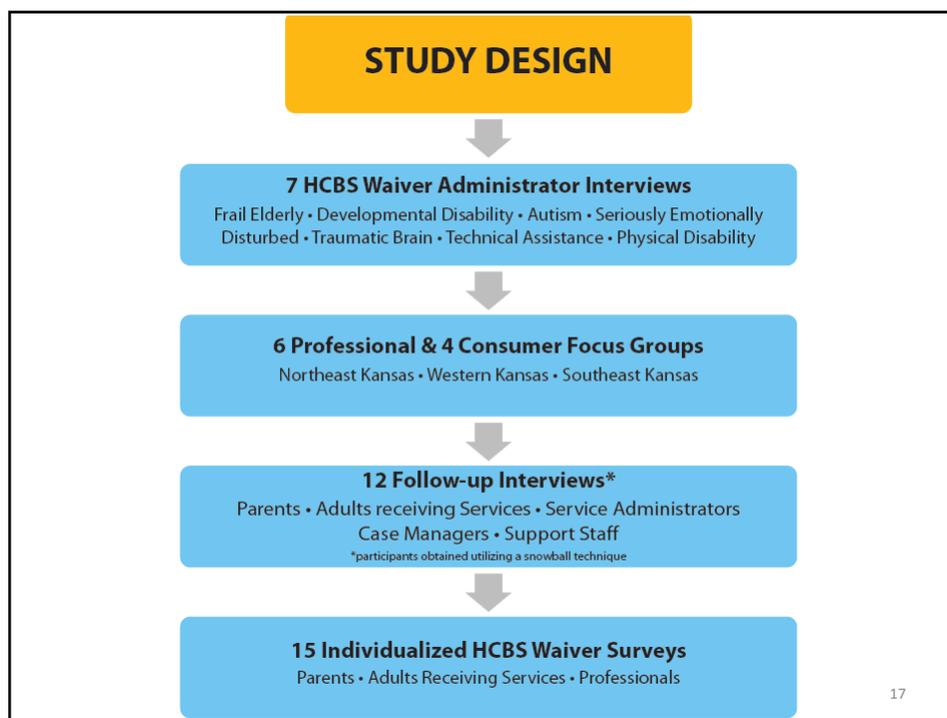
- Learn more about how Kansas addresses problem behavior from different perspectives
  - Families
  - Consumers
  - SRS staff members
  - Practitioners
  - Directors
- Assess the types of behavioral support plans that are implemented in Kansas
  - Strengths
  - Weaknesses
- What types of interventions are the most common?
- What agencies do to prevent problem behavior?

## Purpose of the Person Centered Planning Study

- Learn more about what Individualized Planning strategies, terminology and tools being used in Kansas
- Facilitate focus group events that will gather information about what
  - types of Individualized Planning and/or wraparound strategies are used in Kansas
  - the perspectives are about how Individualized Plan is implemented from different stakeholder perspectives
- Conduct a qualitative analysis to identify common organizational strategies and unique characteristics used in Kansas

## Major Elements of the Study

- Online survey
- Interviews
- Focus Groups
  - Garden City, Kansas (Southwest)
  - Pittsburg, Kansas (Southeast)
  - Topeka, Kansas (Northeast)
- Assessment of Individualized Plans



## Professional Interview Questions

- Based on your experience, what is the purpose of planning process? How would you describe your type of planning?
- Tell me about the planning process...think about one person you know and walk me through the planning process?
  - How are the individualized plans developed and implemented?
  - Who participates in the planning process? What are their roles in the development and implementation of a plan for the individual?
  - What are the outcomes of the planning process?
- Think back on how you described the process...what are the defining features or most important characteristics?
  - What are the top 5-6 defining characteristics of a planning process?
  - Of the planning process what needs to be changed to achieve more person centered outcomes which are the most important? Why?
  - What would you like to see changed?
- What do you think of when you hear the term PCP?

## Focus Group Discussion Guide Example Challenging Behavior/Professionals

### Script for Moderators

**Opening Introductions and Ice Breaker**  
Hi I'm \_\_\_\_\_ and I'll be the Moderator for this focus group. This is \_\_\_\_\_ and she will be the co-moderator. We are part of a team conducting research. (tell a little about yourself) First of all we want to thank you for your participation!

We'll be asking you some questions today. There are no right or wrong answers. The state of Kansas is doing an evaluation and we are helping by conducting these focus groups. Your answers are confidential and your names will remain anonymous. You are all free to interact with each other to discuss the questions but we'll want to make sure to give everyone a chance to share information. From time to time I may check in with the co-moderator to make sure everything is getting covered.

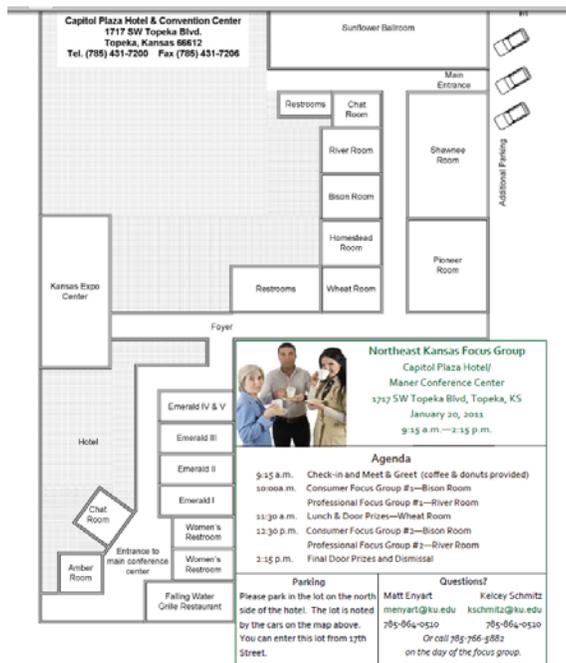
**Go over Ground Rules & confidentiality - ask for any other suggestions**  
Because we are taping and taking notes, I may remind you occasionally to speak up and to talk one at a time so that we can hear you clearly. Each time I ask a question, there is no need for everyone around the table to respond. However, it is important that a wide range of ideas is expressed. If you would like to add to an idea, or if you have an opinion that contrasts with those that have been aired, that is the time to add to the conversation. You don't have to go in a circle. There is no such thing as "your turn" - it is always your turn. Are there any questions?

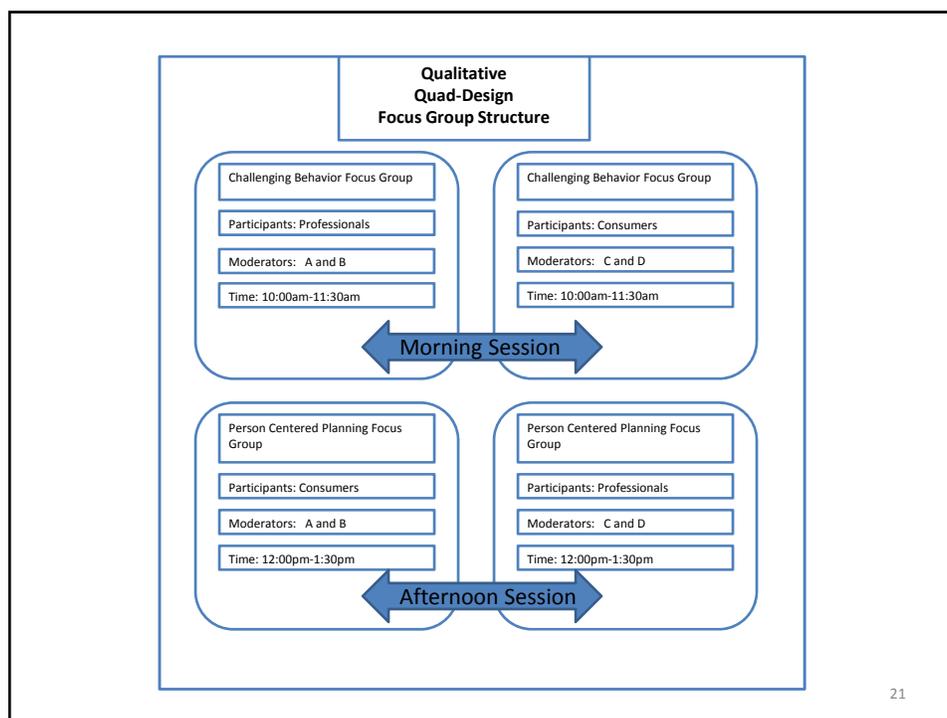
**Participant introductions**  
Let's start by asking each of you to introduce yourself. Please tell us your name and a little bit about what you are looking most forward to with the warmer weather.

**Say this:** Challenging behavior affects us all differently. Challenging behavior is something that has a negative social impact or consequence for someone. In more extreme cases, challenging behavior can cause damage to property or can cause injury to self or others.

### Focus Group Questions

1. **Introduction** Tell us about two problem behaviors you have encountered? What was the purpose of these behaviors?
1. **Transition** Think back to your experience with challenging behaviors and behavior supports and describe your experiences.
1. **Key** What types of behavior interventions have you implemented? Were they successful? Why or why not? What type of behavior interventions training have you received?
1. **Key** How do challenging behaviors impact the quality of life of the individual receiving services? How is your organization impacted by serving individuals with challenging behaviors? For example does this impact staff turnover?
1. **Key** What barriers make it difficult to provide effective behavior supports?
1. **Key** Describe what you believe would be the ideal effective behavior support system for the population you serve?
1. **Ending** Kansas is trying to determine what behavior supports are needed in Kansas across the Waiver systems. What advice would you give regarding the waiver(s) services you provide?





## Parent/Guardian/Consumer Interview Questions

- What do you call these types of planning meetings?
- How satisfied are you with your quality of life?
- What are the things you are working on in your person-centered meeting?
- Who is involved in person-centered planning?
- Tell me how you are involved in preparing for person-centered meetings?
- How does a person-centered plan help you have the life that you want?
- What would make your planning meetings better?
- What kinds of activities and communication occur in between your meeting?
- What could our state do to help improve person-centered planning?

## Online Survey

- Survey Gizmo
- Customized surveys for each waiver
- Two topics in each waiver to increase responses (PCP and CB)
- Hard copy/mail-in option

23

## Online Survey

- Gather information across stakeholders
  - Consumers
  - Family Members
  - Practitioners/Providers
  - Directors
  - SRS Staff Members
- Dissemination
  - Main Office
  - Regional Providers
  - Website
- Send to the Following
  - Community Developmental Disability Organizations
  - Community Service Providers
  - Community Independent Living
  - Home Health Agencies

### 30 Online Surveys

#### **Developmental Disabilities**

- Consumers, Parents, Professionals

#### **Physical Disabilities**

- Consumers, Professionals

#### **Seriously Emotionally Disturbed**

- Parents, Professionals

#### **Technical Assistance**

- Parents, Professionals

#### **Autism**

- Parents, Professionals

#### **Traumatic Brain Injury**

- Parents, Professionals

#### **Frail Elderly**

- Consumers/Family Members, Professionals

25

## Evaluation of Person-centered and Individualized Behavior Plans

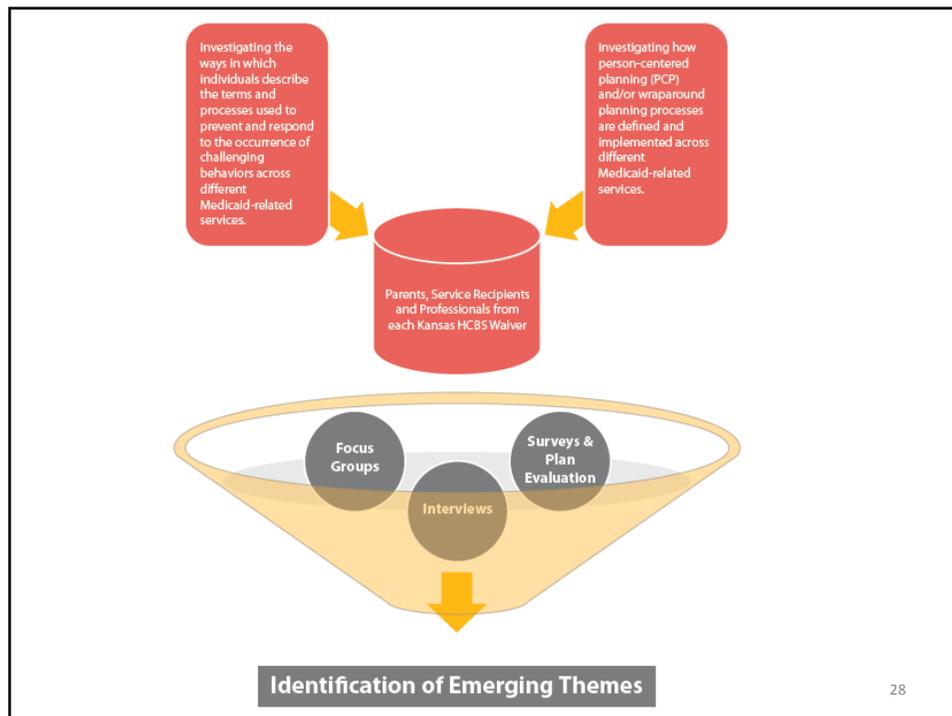
- Sample person-centered and individualized behavior plans submitted to the Kansas Institute for Positive Behavior Support by training participants
- Autism Waiver, Seriously Emotionally Disturbed, and Developmental Disability Waiver represented
- Three years sampled
- Organizations not duplicated

26

## HCBS Waiver Tools/Documents Reviewed

- Waiver manuals
- Waiver quality oversight tools
- Waiver regulations
- CMS website
- HCBS waiver definition
- Definitions related to person-centered planning and challenging behavior
- SRS website and related HCBS websites
- System maps
- Wichita State University Community Resource Teams study
- System Transformation Definition and all related ST documents
- Organization charts related to structure of waivers
- Advocacy organization documents related to PCP and CB

27



28



<b>Number of Participants in Focus Groups and Interviews by Waiver</b>	<b>Professionals</b>	<b>Consumers, Family Members, and Guardians</b>
<b>Autism</b>	1	1
<b>Developmental Disability</b>	5	6
<b>Frail Elderly</b>	5	1
<b>Physical Disability</b>	6	2
<b>Seriously Emotionally Disturbed</b>	7	1
<b>Technology Assisted</b>	3	0
<b>Traumatic Brain Injury</b>	7	2

## 492 Online Survey Participants

<b>Number of Individuals Participating in the Online Survey</b>	<b>Professionals</b>	<b>Consumers, Family Members, and/or Guardians</b>
<b>Autism</b>	39	15 (Parents)
<b>Developmental Disability</b>	217	51 (Consumers) 50 (Parents)
<b>Frail Elderly</b>	36	5 (Consumers)
<b>Physical Disability</b>	22	16 (Consumers)
<b>Seriously Emotionally Disturbed</b>	4	5
<b>Technology Assisted</b>	12	0 (Parents)
<b>Traumatic Brain Injury</b>	20	0 (Consumers)

## Data Analysis, Interpretations, and Findings

- Each study activity contributed different types of information that addressed the different research questions
- Qualitative Data
  - Codes were identified that represented major themes
  - Regular analysis meetings to update codebook
  - Themes were combined across waivers and captured in ongoing thematic table
- Quantitative Data
  - Survey data
  - Individual Plan data

33

## PCP Primary Themes

- Types of PCP and wraparound models including individualized planning processes
- Processes, systems, tools, or strategies utilized to support the waiver's individualized planning process
- Effectiveness of processes, systems, tools, and strategies related to the creation and implementation of individualized plans
- Impact of individualized planning on waiver recipient's quality of life
- Significant risks if individualized planning is not adequately addressed
- Comparison to other waiver services/strategies related to individualized planning
- Suggestions to improve processes, systems, tools, or strategies related to individualized planning

34

## PCP Secondary Themes

- Emphasis on paperwork and productivity and oversight instead of a focus on effective service delivery
- The perceived importance of input from stakeholders into planning process;
- Issues related to a perceived lack of resources
- Disconnect between waiver philosophy and current waiver services, strategies, and system
- Collaboration challenges related to fragmentation between waivers or other community systems
- Systemic barriers negatively impact PCP services and supports (high case loads)
- Issues related to choices of waiver recipient
- Issues related to the skill level or training of waiver professionals and other support providers (including natural supports, parents)

35

## CB Primary Themes

- Types of challenging behavior
- The services, systems, or strategies utilized by the waiver to address behaviors
- Effectiveness of services, strategies, and systems to address challenging behaviors
- Impact of challenging behavior on waiver recipient's quality of life
- Significant risks if challenging behavior is not adequately addressed
- Comparison to other waiver services/strategies related to challenging behaviors
- Suggestions to improve services, strategies, and systems related to challenging behavior

36

## CB Secondary Themes

- Use of “regulation speak” or political jargon, including politically correct language
- Emphasis on paperwork and oversight instead of a focus on effective service delivery
- The perceived importance of input from stakeholders into planning process
- Issues related to a perceived lack of resources
- Emphasis on productivity versus effective service delivery
- Disconnect between waiver philosophy and current waiver services, strategies, and system
- Collaboration challenges related to fragmentation between waivers or other community systems
- Systemic barriers negatively impact challenging behavior services and supports
- Issues related to choices of waiver recipient
- Issues related to the skill level or training of waiver professionals and other support providers (including natural supports, parents).

37

## Themes Across Waivers and Studies

- Planning processes and service philosophy differ across waivers
  - Disconnect between philosophy and implementation
- Problem behaviors occur across all waivers
  - Intervention strategies vary from evidenced based practices to generic mixture of “what works”
- Systemic Barriers
  - Training (Professionals with limited skills writing/implementing behavior plans)
  - Paperwork emphasis
  - Lack of resources (esp. in rural areas)
  - Collaboration challenges (fragmentation)
- Law enforcement poorly trained to respond to problem behaviors
- Reactive strategies prevail across waivers, however there are many areas implementing preventative/evidenced-based strategies

38

## Evaluation of Person-centered and Individualized Behavior Plans

- KIPBS PC-PBS Checklist utilized to score plans
- Fourteen application plans -Cohorts 6-9 (2008-2011)
- 8 PBS plans
- 6 PCP plans
- No organizations were duplicated in this sample
- The majority (12/14 or nearly 86%) of the application plans in the sample represented the Developmental Disability Waiver.
- The Autism Waiver and the Seriously Emotionally Disturbed (SED) Waiver were also represented in the sample.

39

## Person-centered Plans

- **Areas of relative strength**
  - The consumer's preferred method of communication is described
  - Current health and physiology issues are described
  - Mobility (motor and transportation) issues are described
  - Planning and assessment participants are listed
  - Activities needed to assist the consumer to achieve goals are listed
- **Areas of relative weakness**
  - Plan outlines how changes in the consumer's Preferred Future Lifestyle will be evaluated.
  - Evaluation of achievement of goals or skills includes (at least one): (a) number of goals or skills achieved (b) other measures of achievement of goals or skills.
  - Evaluation of changes in the consumer's Preferred Future Lifestyle includes a statement regarding the status of each of the following: (a) type of preferred living setting (b) with whom the consumer wants to live (c) with whom the consumer wants to socialize (d) what work or other valued activity the consumer wants to do (e) what social, leisure, religious or other activities the consumer wants to participate in.
  - If there is evidence of changes in Preferred Future Lifestyle, achievement of goals, or that a service provided is unresponsive, there is a plan for revisions to reflect these changes.

40

## Individualized Behavior Plans

- **Areas of relative strength**
  - Environmental interventions address at least 3 of the following: (a) opportunities for choice (b) instructional/interaction approaches (c) school or day program curriculum (d) schedule predictability (e) prompts for appropriate behavior.
- **Areas of relative weakness**
  - Data from 3-5 student-conducted observations are described.
  - Baseline data are clearly graphed (including labels, axis values, titles, and legend).
  - Data to support each hypothesis statement about the function of problem behavior are presented.
  - Possible function of problem is addressed.
  - Replacement behaviors are operationally defined.
  - Minimizing positive and/or negative reinforcement for problem behavior is included.
  - Safety/emergency procedures for what to do if/when a crisis occurs are addressed.
  - Training needs are addressed.
  - Training needs are identified and/or a system of [training] support is established.
  - Baseline and intervention data for each target behavior are graphed.
  - Graphs are clear (including labels, axis values, titles and legend).
  - Indirect or direct measures of replacement behavior are provided.
  - A statement regarding the effectiveness of interventions is made
  - Data provided support statement(s) regarding the effectiveness of interventions

41

## Sample Qualitative Data

42

Common Individual planning processes	
Autism Waiver	The Autism Specialist meets with family members and takes the lead writing the individual behavior plan. The Autism Specialist trains the family and other In Intensive In-home Support Staff (IIS) on the individual behavior plan. The plan is reviewed regularly at meetings and updates are shared with the staff implementing the plan.
Developmental Disability	Case managers facilitate an individualized planning meeting based on person-centered planning philosophy. Names of the planning process vary from agency to agency but typically agency's require all case managers within the agency to use the same format. Examples of the names used to describe the process include: person-centered plans, individual service plans, and group action planning. The plan must be updated annually with some agencies requiring six month reviews.
Frail Elderly	The Universal Assessment Instrument (UAI) is completed by the case manager with each waiver participant. Once the assessment is completed a plan of care is created that identifies goals related to the waiver services that each person receives. The plan must be updated annually.
Physical Disability	The Universal Assessment Instrument (UAI) is completed by the case manager with each waiver participant. Once the assessment is completed a plan of care is created that identifies goals related to the Physical Disability Waiver services that each person is receiving. The plan is updated annually.
Technology Assisted	The MATLOC is utilized by case manager to determine the medical needs of each child receiving services. A plan of care is created by the case manager and a Notice of Actions is sent to the medical providers. The Technology Assisted Waiver provides temporary services with eligibility re-assessed every six months.
Traumatic Brain Injury	The Universal Assessment Instrument (UAI) is completed with an addendum page specifically related to the TBI waiver by the case manager with each waiver participant. Once the assessment is completed a plan of care is created which identifies goals related to waiver services for each person. The plan must be updated annually.
Seriously Emotionally Disturbed	A wraparound plan is facilitated and written by a facilitator with the family, child, and waiver service professionals actively involved in the planning process. Schools and other community providers may also be included in the planning process. Plans are updated as needed but must be updated annually.

## Individual Planning Processes Across Waivers

- Perceptions, knowledge, and experience varied across the waiver participants with respect to both PCP and wraparound planning.
- Participants from the Developmental Disability Waiver were most familiar with specific PCP processes while professionals from the Seriously Emotionally Disturbed Waiver were more familiar with wraparound planning and systems of care.
- Many of the participants in the Autism and Traumatic Brain Injury waiver appeared to have closer ties to the PCP processes.
- However, many of these participants across Developmental Disability, Autism, Traumatic Brain Injury, and Seriously Emotionally Disturbed indicated that instead of specific PCP and wraparound models involving specific training hours and certification requirements, most of the implementation efforts in Kansas tended to be a more generic, blended mixture of PCP or wraparound models.

- Participants described PCP and wraparound differently across the waivers.
- For some of the participants, the planning processes were more direct and used the traditional models used in the Developmental Disability and Mental Health Wraparound Systems of Care fields (Also including Traumatic Brain Injury Waiver).
- Some waiver areas included individualized planning processes that did not use traditional PCP or Wraparound, however, the processes contained many of the key features of these models or used a generic mixture of “what works” (Developmental Disability, Seriously Emotionally Disturbed, Traumatic Brain Injury, Autism Waiver).
- Other waiver services include planning processes that are established accomplish important smaller elements of the PCP or wraparound process related to health and safety, independence in the community and specific consumer needs (Frail Elderly, Physical Disability, and Technology Assisted). These waiver areas tended to incorporate some of the terminology and philosophical and values-based statements that align with waiver planning processes.

45

## Findings Related to Terms/Processes Associated with PCP

- Case managers facilitate an individualized planning meeting based on person-centered planning philosophy.
- Names of the planning process vary from agency to agency but typically agency’s require all case managers within the agency to use the same format.
- Examples of the names used to describe the process include: person-centered plans, individual service plans, and group action planning.
- The plan must be updated annually with some agencies requiring six month reviews.

46

**One mother described the effectiveness of the Autism waiver services that, in part, addressed challenging behavior in the following manner:**

*“Although problem behaviors still occur, the number of events has decreased....My quality of life has improved and my house is not more intact [less damaged due to property destruction], even the dog is happier [decrease in aggression towards the dog], [my son] is better at helping around the house and is more affectionate...and has made a lot of improvement socially, he will come get you when he has problems and will look you in the eye and talk to you”*

## Training

- A veteran professional familiar with the traditional PCP process unsure whether PCP training was ever delivered to organizations.
  - She said that she was unsure how PCP was actually introduced, saying *“I think it was an underlying assumption that that this is how people are operating.”*
- Veteran professionals described comprehensive training and supports that included both philosophy and information about service provision.
- Faded training opportunities; not as familiar with the underlying values, philosophy and vision for PCP.
- Great need for **renewed energy placed in training and technical assistance** if PCP and wraparound is to continue to grow and thrive in Kansas.

## More on Training

- Effective case management has become a lost art and new case managers are not getting the training they need.
- Online trainings not sufficient.
  - To really learn new skills, hands-on training and ongoing follow-up training supports were necessary to effectively learn both case management and the PCP process.
- Some case managers reported that they often felt unprepared to meet the needs of waiver recipients due to lack of training.
- A participant emphasized the importance of systems change and training in PCP and wraparound by saying that *“What was really needed was quality, hands-on training with a plan for implementation and sustainability”*.
- Unfortunately, a number of the participants indicated that many organizations have had to reduce or eliminate training budgets due to funding cuts.

49

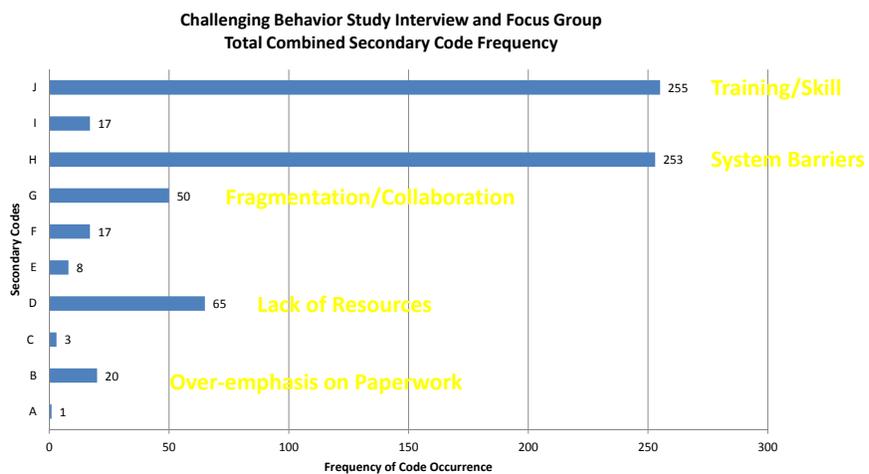
**Some of the professionals in the study reported they were required by regulations to create behavior intervention plans but did not have adequate behavior training.**

*“For the most part the agencies give you the bare minimum training and turn you loose.”*

*-Direct Support Professional on the MR/DD Waiver*

Challenging Behaviors Identified	
<b>Autism Waiver</b>	A broad range of behaviors were included such as aggression (hitting, kicking and scratching), difficulties communicating, refusing to eat or only eating certain types of foods. Behaviors that occurred in community settings were of concern to these participants.
<b>Developmental Disability</b>	A broad range of behaviors were identified including physical aggression, elopement, self-injurious behavior, property destruction, and verbal aggression.
<b>Frail Elderly</b>	Behaviors identified include victimization, refusal of support, refusal to take medications, self-neglect, hoarding and a variety of dementia and Alzheimer related behaviors.
<b>Physical Disability</b>	Behaviors identified include hoarding, substance abuse, and victimization.
<b>Technology Assisted</b>	Behaviors identified include pica, pulling out g-tubes, physical aggression, and defiance.
<b>Traumatic Brain Injury</b>	Behaviors identified include public masturbation, sexual aggression, victimization, physical aggression, substance abuse and delusional behavior. Behaviors that result in losing one's job or place in the community.
<b>Seriously Emotionally Disturbed</b>	Specific behaviors identified included defiance, impulsivity, high anxiety, and behaviors related to significant mental illnesses. It was noted that behaviors could be intense and severe in nature including suicide attempts and physical aggression.

## CB Waiver Study Findings



## General PCP Comments from Parents/Guardians

- “Would be interested in more goals set which encourage more community support and participation in interactive programs for persons of smaller stature. Was delighted when area community center had a music therapy class which was interactive.”
- “I understand why the PCP is necessary, but feel it is not part of a normal lifestyle. They are completed to meet the requirements of the law, the focus is not to serve the person. There is not enough professionals to properly assess them. “

53

## Professional Survey Data

Do you want to share anything else about challenging behavior in Kansas?

Sample Responses
I feel this is caused or made worse by the support staff due to lack of training.
A standardized PBS in-service should be a training requirement for ANYONE in this field. The old KUAP material was great, but long and not as effective of a format.
There are not enough supports out there or pay for supports for those who are required to serve these individuals. This requirement puts staff, clients, and agencies at risk in many ways.
We spend so much time collected data geared towards the BASIS that it is too time consuming and confusing to add separate data collection specific to individual plans. We have so much other paperwork that we don't have time to properly train our staff.
Generally Case Managers are responsible for developing behavior plans without any formal education or training.
I am a TCM. I work with many agencies that do not have their own behavior support professionals. Conducting functional assessments, writing and facilitating implementation of plans is extremely time consuming. With an average of 5 hours of TCM time per month, per person-this is not enough time for a TCM to be responsible for these tasks as well as the rest of the TCM tasks.
As an agency we do a very poor job of recognizing behavior challenges. For some reason the standard is that we wait until it becomes a crisis situation or some major damage / destruction has taken place before we act on the behaviors. The other thing is again that we do not implement the behavior plans as written- I am not sure if it is a lack of understanding or if they just don't think it will work. One agency staff I work with said on the day of the meeting to develop the behavior support plan- said it is not going to work- without even trying it.

54

## Recommendations Based on Findings of Challenging Behavior and Person Centered Planning Studies In Kansas

### Goal Measurement

- Measurement and goal setting are particular areas of focus that many individuals would benefit from learning more about in PCP and wraparound.
- Placing online examples, resources and tools on the SRS website would be very valuable for professionals interested in learning more about implementation processes. This site could be organized for leaders at the organizational level as well.

## Define Evidence-based Practices for PCP and Wraparound and for Challenging Behavior

A state-level definition would assist Kansans as they seek to promote effective implementation of person centered planning and wraparound processes interventions that prevent and/or reduce challenging behavior.

57

## Create Standards and Expectations to Improve the Consistency and Implementation Efforts Across the State.

- Create standards for behavioral support practices to improve the consistency and implementation efforts across the state.
- A clear set of expectations from the state sets the stage for organizations to work towards a higher level of fidelity as it relates to the prevention of challenging behavior.
- Standards for implementation of PCP would be valuable for organizations. [Self-assessment tools and processes would allow organizations to create their own action plans for improvement.](#)
- Incentives from the state could be established with a review process set up for awards given to organizations that show not only high self-assessment, but also have high scores from outside, objective reviews.

58

## Create a Layered Training System

The state might consider a model similar the Missouri system that include four levels:

- 1) awareness level trainings for consumers and professionals to be introduced to the basics related to preventing problem behavior;
- 2) professional development modules and training opportunities for individuals to begin learning specific skills related to Applied Behavior Analysis and PBS;
- 3) training and technical assistance systems to mentor facilitators who can guide team-based problem solving for an individual child or adult who engages in challenging behavior; and finally,
- 4) expert-level trainers are being recruited across the state who can assist in guiding these activities in their own regions across the state.

59

## Embed Training Related to Behavior in Existing Systems

- The state could consider the current pre-service and in-service systems and create an action plan for increasing the types of training opportunities across waivers related to challenging behavior.
- If limited funds are available, training should be allocated for case managers first, and then expanded to a broader group of stakeholders.

60

## Reduce/Limit Caseload Sizes for Case Managers

- Limiting the number of cases that any one individual can support has implications for funding but also helps to ensure that consumers receive effective services.
- The state is encouraged to discuss this complicated issue with providers and to consider alternatives to the current approach in place in Kansas across some waivers (some waivers already have these limits in place).

61

## State and Regional Waiver Service Self-Assessment and Action Planning

- Establish regional work groups with professionals, representing the different waivers.
- The purpose of the regional work groups would be to begin brainstorming how waiver services might be reorganized to improve transitions across waivers, provide services to consumers in a manner that is more streamlined and less fragmented.
- Create evaluation and data-based decision making systems that follow consumers *across* waivers and evaluate the SRS services as a whole.

62

## Provide PCP/Wraparound Planning to All Individuals

- Some of the individuals who currently don't receive traditional PCP or Wraparound would benefit from these types of planning processes.
- The state might consider how these types of processes could be made available.

63

## Community-based Training

- Create a plan to systematically teach communities how to support individuals who are receiving waiver services.
- Examples of areas of focus include mentoring and supports for elderly individuals who need assistance shopping and engaging in everyday community activities and how to assist individuals who are engaged in self-direction.

64

## Training in Rural Areas of Kansas

The participants in the study discussed a number of challenges that professionals in rural areas experience that make effective team-based behavioral support more challenging.

- Professionals receive less training, have limited human/financial resources, and do not receive additional funds related to loss of productivity and expenses related to extensive travel.

65

## Sample Quotes

66

## Strengths of Organizations Planning Process

- “Flexible, inclusive, the person is involved in determining what services they want and what supports they would like to receive.”
- “The process is totally focused on the child's needs as related to his/her disabilities and the supports needed to meet those needs. We facilitate cross-systems meetings to include education, foster care, mental health, other waiver providers (TA/Autism), family preservation, etc.”
- “Always kept positive both in writing and at the meeting. Totally re-written each year, not just updated. Input asked for from all involved with the person. The plan is simple and useable, and reflects the person's CURRENT lifestyle. A new staff can read the plan and know how to work with the person - their likes/dislikes, routines, health, etc.”

67

## Opportunities for Improvement

- “My greatest concern is the lack of review by day and residential providers who do not refer to the PCSP and do not follow the plan's goals for the individual.”
- “I would like more precise training and examples of good written goals to better benefit our individuals.”
- “My observations have been that each year plan move farther away from the intent of identifying individual preferences and barriers more towards trying to meet sometimes arbitrary requirements from CDDO and SRS. It seems so much quality assurance has been put into place that plans are written more to meet oversight expectations than individual needs.”

68

## General PCP Comment from Parents/Guardian

“I understand why the PCP is necessary, but feel it is not part of a normal lifestyle. They are completed to meet the requirements of the law, the focus is not to serve the person. There is not enough professionals to properly assess them. “

69

## Focus Group Quotes

- “We went from congregate settings and institutions and to community life and individualized schedules and, with budget cuts, we tend to revert back to that institutionalized, congregate settings...so **when you get congregate settings...we’re seeing problem behaviors due to the lack of individualized schedule that fits that person’s individual needs.**”  
-DD TCM
- “I would love to be able to see **some type of training, education, for any family that is referred** in like our first degree type of programs. To educate them in the **early intervention of positive behavior supports.**”  
-DD TCM
- “We need **more training** on how to handle those situations and how to make **good positive behavior support plans.** And then the agencies need to have the **ability to train those staff on how to follow those plans.**”  
-DD TCM

70

## Interview Quotes & Findings

- *A parent reported that law enforcement had been called to her daughter's apartment by staff and when the parent followed up with staff to see if they had followed her daughter's behavior plan she reported **she had not read it and had not received any training related to her daughter's behaviors.** This parent said this had been the case with the majority of the staff her daughter has had. In this situation she believed the staff unintentionally caused the behavior which resulted in a very traumatic situation which could have been avoided.*

71

**Some of the professionals in the study reported they were required by regulations to create behavior intervention plans but did not have adequate behavior training.**

*"For the most part the agencies give you the bare minimum training and turn you loose."*

*-Direct Support Professional on the MR/DD Waiver*

**One mother described the effectiveness of the Autism waiver services that, in part, addressed challenging behavior in the following manner:**

*“Although problem behaviors still occur, the number of events has decreased....My quality of life has improved and my house is not more intact [less damaged due to property destruction], even the dog is happier [decrease in aggression towards the dog], [my son] is better at helping around the house and is more affectionate...and has made a lot of improvement socially, he will come get you when he has problems and will look you in the eye and talk to you”*

## Unexpected Surprises

- Professionals from different waivers interested in what is happening in other areas
- Sensitivity regarding individualization of study activities
- High amount of cuts to resources and training.
- Exemplary examples of effective practices despite resource reductions
- Significant risks identified to most vulnerable populations

## Lessons Learned

- Collaboration with Stakeholders & State Leaders
- Survey Validation Process and Feedback
- Considering Diversity of Focus Groups
- Awareness of Other State-wide Study Activities
- Consistency Critical for Interview Process
- Importance of Debriefing
- Ongoing Thematic Analysis
- Regional Issues (i.e. cultural, rural, urban)

75

## Ongoing Activities and Incorporating Results of Studies

- Challenging Behavior Group for Developmental Disabilities
- Statewide Quality Oversight Committee for Developmental Disabilities
- PBS Kansas Standards and Modules Training
- Mental Health and PBS in Kansas
- Publications
- Kansas Institute for Positive Behavior Support Training and Technical Assistance
- State-wide Planning

76

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77

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78

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79