PERSON CENTERED PLANNING & QUALITY OF LIFE: KANSAS STUDIES

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OBJECTIVES

- Describe PBS and how Quality of Life (QOL) and Person Centered Planning (PCP) relate to PBS
- Share purpose of Quality of Life and Person Centered Planning studies
- Share findings/themes from QOL and PCP studies
- Discuss lessons learned and next steps
POSITIVE BEHAVIOR SUPPORT

PBS is a set of tools and processes for organizing the physical, social, educational, biomedical, and logistical supports needed to achieve basic lifestyle goals for individuals while reducing problem behaviors that pose barriers to these goals.

PBS emphasizes the importance of helping individuals (and their advocates) achieve a high quality of life using technology with four core defining features or components:

- The application of research-validated applied behavioral science;
- Integration of multiple intervention elements to provide ecologically valid, practical support;
- Commitment to socially important and durable lifestyle outcomes; and
- Implementation of support within family and organizational systems to ensure sustainable change over time.

Dunlap, Sailor, Horner, Sugai, Handbook of PBS, (2009 p3-5)
VALUES OF PBS

- A focus on increasing a person’s quality of life
- A long-term process of vision-setting and person-centered planning
- A focus on understanding the behavior’s message
- Consider the focus person’s point of view
- Give consideration to underlying neurological and medical conditions
- Contributes to personal growth and empowerment for team members
- Carries over into varied environments
- Enhances the person’s social status and self-esteem
- Presumes the person is competent
“Our chief concern is not with problem behavior and certainly not with problem people, but rather with problem contexts.”

-Edward G. Carr, JPBI Winter 2007
Utilizing Positive Behavior Support to Improve Quality of Life

Supporting Staff Behavior

Supporting Individual Behavior

Supporting Decision Making

OUTCOMES

SYSTEMS

DATA

PRACTICES
WHAT IS QUALITY OF LIFE?

“the dependent variable that best exemplifies the field of positive behavior support is QOL…”

– Edward G. Carr

- Main purpose of Positive Behavior Support is to increase quality of life
- Meeting a person’s needs and having equal opportunities as others without disabilities
- QOL includes more than just living conditions
- Optimal health and wellness

(Freeman, 2010)
Positive Behavior Support

Schools

Mental Health

Supported Employment

Individuals

Juvenile Justice

Transition

Early Childhood

I/DD Settings

Family Homes

Elder Care
WHAT’S IN A NAME?

PBS=Positive Behavior Support

KIPBS=Kansas Institute for Positive Behavior Support

APBS=Association of Positive Behavior Support

SWPBS=School-wide Positive Behavior Support

PBIS=Positive Behavior Interventions and Support

EBS=Effective Behavior Support

PBES=Positive Behavior and Employment Support

Pyramid Model=Early Childhood Positive Behavior Support

PBSS=Positive Behavior Sexuality Support
EXPANDING THE TRIANGLE TO COMMUNITY-BASED ORGANIZATIONS

Community-wide Behavior Support Systems

Intensive, Individual Interventions
* Individuals with intense needs
* Assessment-based
* High Intensity

Targeted Group Interventions
* Some individuals (at risk)
* High efficiency

System-wide Interventions
* All individuals
* Preventive, proactive
* Broad community focus

School-wide Behavior Systems

Adapted from Sugai, 2002
QUALITY OF LIFE STUDY: FINDINGS AND POSSIBLE NEXT STEPS
ENHANCING QUALITY OF LIFE THROUGH PERSON-CENTERED PLANNING
ARTICLE 63 – DEVELOPMENTAL DISABILITIES – LICENSING PROVIDERS OF COMMUNITY SERVICES

30-63-21. Person-centered support planning; implementation.
PERSON-CENTERED PLANNING

- Creates a vision for the team
- Process for identifying ideal lifestyle
- Focus on the positive
- Gathers important information for the PBS plan
- Decreases the need for more intensive interventions
- Priority and control is given to the individual
PCP GOALS SHOULD INCREASE/ENHANCE QOL

Quality of Life

- Self-Determination
- Dignity and Personal Development
- Interpersonal Relationships
- Natural Supports and Social Inclusion
- Rights
- Home
- Physical & Emotional Well-being/Health
- Finance/Material Well-being

Quality of Life (QOL) should increase/enhance in these areas.
8 DOMAINS OF QUALITY OF LIFE

- Emotional Wellbeing (positive feedback from others, stable and predictable environments, sense of safety),
- Interpersonal Relations (friendships and opportunities for intimacy and affection, affiliations and interactions with others),
- Material Well-being (ownership of possessions, meaningful employment),
- Personal Development (opportunities for education and habilitation),
- Physical Well-being (optimal health care and nutrition, mobility and general wellness),
- Self-determination (opportunities to set personal goals, make decisions and important life choices),
- Social Inclusion (natural support networks allow for participation in inclusive and integrated environments), and
- Rights (experience of ownership of key items and property, allowed due process, privacy and barrier free environments are the norm).

(Schalock et al., 2002)
Person Centered Planning Goals

- Improve Quality of Life
- Identify Supports & Services
- Important to vs. Important for
- What will the person do?

Improve Quality of Life

Important to vs. Important for

What will the person do?
UNIFYING QUALITY OF LIFE EVALUATION

- Each area within SRS evaluates services to define how customer outcomes and measures will be used.
- The goal is to begin linking evaluation that already occurs in SRS to the new quality of life definition.
- Each year, services report progress on each element of the quality of life definition.
- Summary provides SRS with unified way to evaluate quality of life.
<table>
<thead>
<tr>
<th>TARGET POPULATION</th>
<th>INPUTS</th>
<th>STRATEGIES</th>
<th>SHORT TERM OUTCOMES*</th>
<th>MEDIUM TERM OUTCOMES*</th>
<th>LONG TERM OUTCOMES*</th>
</tr>
</thead>
<tbody>
<tr>
<td>SRS Customers</td>
<td>Develop list of all programs and institutions.</td>
<td>Communicate Quality of Life Framework, philosophy, vision, and team progress throughout the agency. Provide Quality of Life resources to programs and institutions. Provide education about Quality of Life to programs and institutions.</td>
<td>Initial changes in condition, knowledge, attitudes, beliefs, skills, awareness. All programs and institutions have a clear understanding of Quality of Life. Programs and institutions gather data related to Quality of Life Outcomes.</td>
<td>Resulting behavior change (behavior, practice, decision-making, policies, etc.) All programs and institutions are measuring outcomes specifically related to quality of life for their population by July 1, 2009.</td>
<td>Quality of life improves for individuals served by SRS and our partners.</td>
</tr>
<tr>
<td>SRS Employees</td>
<td>Identify outcomes for the QOL Team. Obtain schedule of routine administrative meetings.</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>SRS Partners</td>
<td></td>
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</tr>
</tbody>
</table>

Who will benefit directly from the team’s efforts?
- SRS Customers
- SRS Employees
- SRS Partners

What we do – identified work effort(s) or project(s)
- Communicate Quality of Life Framework, philosophy, vision, and team progress throughout the agency.
- Provide Quality of Life resources to programs and institutions.
- Provide education about Quality of Life to programs and institutions.

Initial changes in condition, knowledge, attitudes, beliefs, skills, awareness.
All programs and institutions have a clear understanding of Quality of Life.
Programs and institutions gather data related to Quality of Life Outcomes.

Resulting behavior change (behavior, practice, decision-making, policies, etc.)
All programs and institutions are measuring outcomes specifically related to quality of life for their population by July 1, 2009.

We expect the following impacts/trends (social, economic, community, civic, environmental, systems):
- Quality of life improves for individuals served by SRS and our partners.
# SRS Program Areas

- **DBHS – Mental Health Services**
- **DBHS – Community Supports and Services**
- **DBHS – Addiction and Prevention Services**
- **ISD – Children & Family Services**
- **ISD – Child Support Enforcement**
- **ISD – Economic & Employment Supports**
- **ISD – Rehabilitation Services**
- **DBHS – Kansas Neurological Institute**
- **DBHS – Larned State Hospital**
- **DBHS – Osawatomie State Hospital**
- **DBHS – Parsons State Hospital**
- **DBHS – Rainbow Mental Health Facility**

Two Pilot Areas
<table>
<thead>
<tr>
<th>Quality of Life Category</th>
<th>Program/Process Outcome</th>
<th>Quality of Life Outcome Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Relationships—Customers have meaningful personal relationships.</td>
<td>Percent of children in out-of-home placement who are placed in a location that promotes continuity of family relationships and community connections.</td>
<td>Percent of children who report services have strengthened their relationships with families.</td>
</tr>
<tr>
<td>Personal Health (physical, emotional, psychological)—Customers are physically, emotionally, and psychologically healthy.</td>
<td>Percent of Medicaid applications processed timely.</td>
<td>Percent of customers reporting feeling well 90% of the time.</td>
</tr>
<tr>
<td>Home—Customers have opportunities to live in safe and affordable homes.</td>
<td>Percent of participants in Rehabilitation Center for the Blind and Visually Impaired, Kan-SAIL, and Rehabilitation Teaching who demonstrate an improved ability to live independently at case closure</td>
<td>Percent of customers living where they want to live.</td>
</tr>
<tr>
<td>Finance—Customers have consistent economic resources to meet basic needs.</td>
<td>Percent of Kansas Early Head Start parents employed (part time and/or full time) or enrolled in education/training.</td>
<td>Percent of customers who report ability to meet basic needs.</td>
</tr>
<tr>
<td>Purpose—Customers feel their life is meaningful and have opportunities for personal growth through employment/education/activities.</td>
<td>Percent of TANF recipients entering employment.</td>
<td>Percent of customers who report working where they want to work.</td>
</tr>
<tr>
<td>Personal Choice—customers make choices about all aspects of life including the opportunity to pursue personal goals and interests and maintain control of his/her environment.</td>
<td>Percent of youth with Serious Emotional Disturbance (SED) that receive community based services and are not in custody, who live with parent(s), or live independently.</td>
<td>Percent of customers who report services have assisted in the pursuit of personal goals.</td>
</tr>
<tr>
<td>Personal Dignity—Customers are treated with dignity, respect and fairness regardless of ability, age, beliefs, and/or ethnicity.</td>
<td>Percent of adults and youth over age 14 respond that services were provided using family-centered principles.</td>
<td>Percent of customers receiving services from ISTs report being treated with dignity, respect, and fairness.</td>
</tr>
<tr>
<td>Natural support systems—Customers have connections beyond paid supports.</td>
<td>Percent of children with orders for medical support</td>
<td>Percent of customers reporting adequate natural support systems.</td>
</tr>
</tbody>
</table>
TYPES OF ASSISTANCE PROVIDED BY KU STAFF MEMBERS

- Attended Development Meetings
  - Management meetings
  - CSE and Mental Health planning meetings
  - Conference calls
- Conference Calls & Management Meetings
- Online Survey Development with CSE
  - Assisted with content and design
  - Offered to use survey system to send first survey out
- Focus Group Event with Mental Health
  - Purpose: gather information from state professionals using the Lancashire Quality of Life Tool
  - Five interviewers, 25 consumers
  - Provided transcript back to Nancy Rapp
STRATEGIES USED BY MENTAL HEALTH & CSE

- Completed tool that linked evaluation to quality of life
- Identified areas that could be improved
  - Created an action plan
  - Reports progress on regular basis
- Met as a team on a regular basis to brainstorm
WHAT WE LEARNED FROM SERVICES INVOLVED AS PILOTS

- Questions naturally arise about funding for this effort
  - There is a natural response by each evaluation unit to the lack of resources to add additional evaluation tasks
  - However, sometimes funding is available in other parts of the system
  - One important issue will be to encourage people to “work smarter not harder” and the other will be to be sure to communicate what is happening across different teams
WHAT WE LEARNED FROM SERVICES INVOLVED AS PILOTS (CONTINUED)

In early meetings we discussed changing evaluation processes to evaluate impact—this is not something we worked on in this group but probably should do so in the future

► This is something that appeared in the documents we reviewed initially

► A detailed focus on evaluation would help us learn about data gathered within services and understand how impact is being assessed currently

► This may also help SRS identify training needs for services related to this issue
  ► Provide examples from other parts of SRS that are doing a nice job
  ► This provides a way to celebrate and provide positive feedback
WHAT WE LEARNED FROM SERVICES INVOLVED AS PILOTS (CONTINUED)

The process works better with direct involvement of all staff members

- It is important for all staff members to know why they are asked to complete the task (not just the few people attending the planning meetings)

**Example:** initial resistance from KIPBS evaluation leader

- Kelcey and Rachel provided only a general overview
- KIPBS evaluation leader felt we were asking him to do “extra work” and said he didn’t see the purpose of this task
- Later, once the process was completed, this person had a better understanding and was proud of our efforts
WHAT WE LEARNED FROM SERVICES INVOLVED AS PILOTS (CONTINUED)

Awareness presentations and training opportunities are needed
- It will be important to systematically introduce this process to each service area/contract
- Training materials are needed
  - Purpose of process
  - Effective evaluation
  - Quality of life
- Trainer system may be needed to begin expansion of process
Identified all evaluation tools related to quality of life in KIPBS
- Completed the worksheet by linking every item of every tool to the elements of quality of life
  - KIPBS PC-PBS Checklist (fidelity of implementation)
  - KIPBS Impact Assessment (Impact summary form for empirical data and anecdotal data)
  - Global Risk Assessment
  - Three surveys completed during plan including
    - Quality of life
    - Contextual fit (How well does the plan fit the values, skills, and resources of the team)
    - Person-centered Plan satisfaction
- Created database to reorganize data already gathered
- Each element of quality of life construct will be summarized for this contract in the final report
- Evaluation report for 2009-2010 will include summary of quality of life by elements
WHAT WE ARE LEARNING FROM THE TWO CONTRACT EXAMPLES (CONTINUED)

- Contractual work provided with state funds should also be expected to align evaluation to quality of life definition
- Expectations for contractors to address quality of life and report evaluation data
  - Consider a policy for all contractors
  - Create guidelines and examples to follow
  - Make available online
NEXT STEPS
WHAT WE ARE LEARNING…. OBSERVATIONS FROM MANAGEMENT TEAM PROCESS

Services aligning already existing evaluation processes to the new quality of life definition will need:

- An easy to follow process for assessing current evaluation process for each service/contract
- Examples of how other services have completed the task
- Guidelines to follow that are easy and provide opportunities to generalize information to each service and setting
- A way to evaluate quality of life annually (ongoing reporting process)
- Training materials to prepare staff members within the services
  - Awareness
  - Processes
  - Tools
- Access to quality of life training materials
POTENTIAL OUTCOME OF DATA-BASED DECISION MAKING

Expanding evaluation of quality of life across services

- In some services there are limited opportunities to gather information from stakeholders
- However, the same stakeholders receive services from other areas of SRS
- Evaluation could take place at key points for multiple services
  - More efficient evaluation
  - Linking communication across service systems
- Possible Outcome: Decrease fragmentation and improve services for consumers
WHAT WE ARE LEARNING….
OBSERVATIONS FROM TEAM PROCESS

A data-based decision making process within SRS is needed with summaries of quality of life data shared at different levels of the system:

- KIPBS contract summarizes data
- Reports progress to Community Supports and Services (CSS)
- CSS reports progress to a group of SRS professionals monitoring overall progress on quality of life across services
DESIGN A QUALITY OF LIFE WEBSITE TO GUIDE
EXPANSION & PROVIDE HOME FOR TRAINING MATERIALS

- Purpose: Main site for services to start learning about how to align evaluation to quality of life
- Major Elements of Site:
  - Process for reporting quality of life outlined in easy to understand format
  - Examples of how this task has been completed by other services and contracts
  - Examples of how data-based decision making is occurring within SRS
  - Online instruction and training materials for SRS staff members on effective evaluation
    - Provide examples of best practice in evaluation
    - Teach how to evaluate impact more effectively
  - Online instruction and training materials SRS staff on quality of life
DISCUSSION

- How is Quality of Life measured in your organization?
- What are some ways, if you aren’t already measuring QOL, you could start?
- What information, tools, and resources would you find helpful?
Volunteer Opportunity = Free Registration

Greeter
Information/Credit Table
Poster Session
Registration Desk
Session Hosting

Deadline to Volunteer: January 17, 2012

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System-wide Interventions
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* Preventive, proactive
* Broad community focus

School-wide Behavior Systems

1-5%
5-10%
80-90%

Adapted from Sugai, 2002
RESEARCH OBJECTIVE

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

- The Medicaid-related waiver services in Kansas that are of interest in these studies include: Autism, Developmental Disabilities, Frail and Elderly, Mental Health, Physical Disabilities, Technology Assistance, Seriously Emotionally Disturbed, and Traumatic Brain Injury.
How person-centered planning (PCP) and/or wraparound planning processes are defined and implemented across different Medicaid-related services.

Task Team 2: Increased Choice and Control (Self-direction)

Task Team 5: Financing the Long-Term Care System

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.
THE CENTERS FOR MEDICARE AND MEDICAID DEFINITION DEFINE PCP IN THE FOLLOWING MANNER:

“Person-centered planning is a process, directed by the family or the individual with long-term care needs, intended to identify the strengths, capacities, preferences, needs and desired outcomes of the individual. The family or individual directs the family or person-centered planning process. The process includes participants freely chosen by the family or individual who are able to serve as important contributors. The family or participants in the person-centered planning process enables and assists the individual to identify and access a personalized mix of paid and non-paid services and supports that will assist him/her to achieve personally-defined outcomes in the most inclusive community setting. The individual identifies planning goals to achieve these personal outcomes in collaboration with those that the individual has identified, including medical and professional staff. The identified personally-defined outcomes and the training supports, therapies, treatments, and or other services the individual is to receive to achieve those outcomes becomes part of the plan of care.”

(http://www.cu.edu/partnership/cdservices/resources/PCP-CMSdefinition04-04.pdf)
MAIN RESEARCH QUESTION

How is person-centered planning (PCP) and/or wraparound planning processes are defined and implemented across different Medicaid-related services?
NARROWING IN

- How are PCP processes described by individuals who receive and/or provide services in the state of Kansas?
- What are the most common person-centered (and wraparound) planning processes that are used in the state of Kansas?
- How effective are the PCP and wraparound strategies?
- Are there major differences in the ways in which individuals receiving Medicaid-related services experience PCP or wraparound planning?
- What are the major strengths and weaknesses of PCP (and wraparound) processes used in Kansas to improve quality of life and coordinate services?
- How could the state of Kansas improve supports for individuals receiving PCP (or wraparound planning?)
STUDY PARTICIPANTS

1) individuals receiving waiver services,
2) parents and guardians of individuals receiving waiver services,
3) providers who work with individuals receiving waiver services,
4) state professionals within Social and Rehabilitation Services (SRS),
5) other professionals and community members who may be involved in working, living, providing services, and communicating with individuals receiving waiver services.
MAJOR ELEMENTS OF THE STUDY

- Online survey
- Interviews
- Focus Groups
  - Garden City
  - Pittsburg
  - Topeka
- Assessment of Individualized Plans
19 Interviews
10 Regional Focus Groups
STUDY DESIGN

7 HCBS Waiver Administrator Interviews
Frail Elderly • Developmental Disability • Autism • Seriously Emotionally Disturbed • Traumatic Brain • Technical Assistance • Physical Disability

6 Professional & 4 Consumer Focus Groups
Northeast Kansas • Western Kansas • Southeast Kansas

12 Follow-up Interviews*
Parents • Adults receiving Services • Service Administrators • Case Managers • Support Staff
*participants obtained utilizing a snowball technique

15 Individualized HCBS Waiver Surveys
Parents • Adults Receiving Services • Professionals
Investigating 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.

Investigating how person-centered planning (PCP) and/or wraparound planning processes are defined and implemented across different Medicaid-related services.

Parents, Service Recipients and Professionals from each Kansas HCBS Waiver

Identification of Emerging Themes

Focus Groups

Surveys & Plan Evaluation

Interviews
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
Individual Plan Evaluation

Two types of written behavioral plans to review include person-centered plans and positive behavior support plans. These plans are already available within the KIPBS project to review. The purpose of the review will be to evaluate the extent to which plans reflect the key features of PCP, wraparound, applied behavior analysis and/or positive behavior support using a tool called the Person-centered Positive Behavior Support Checklist (PC-PBS Checklist). The impact of the plans will also be evaluated using the KIPBS Impact Assessment.

Further Thematic Analysis & Recommendations

Findings and recommendations will be shared with the two Systems Transformation teams and other SRS leaders.
Map of Study Participants
FOCUS GROUP QUESTIONS

- What is the individual's planning process called in your waiver system?
- Think back to your most recent experience with your planning process. Tell us about it. Who was involved? Describe the individual receiving waiver services? How is progress monitored related to planning goals?
- What makes the planning process effective? What are elements of an effective plan?
- In what ways does the planning process impact the service recipient’s quality of life? Give some examples of goals that the service recipient has had that are related to quality of life.
- What training is needed for the service recipient, staff, and families to effectively participate in or facilitate the planning process? Do you feel this training has been provided?
- What challenges impact providing and implementing effective plans? How do you address them?
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?
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?
FINDINGS: 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 стратегии related to individualized planning
• Suggestions to improve processes, systems, tools, or strategies related to individualized planning
FINDINGS: 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).
ONLINE SURVEY

318 Total Survey Participants

- 50 Parents
- 51 Consumers
- 217 Professionals
  - 80% Professional providing services
  - 20% Professional who provides training direct staff
  - 6% State professional
PARENTS/GUARDIANS
<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>The team meets regularly to review the person-centered plan.</td>
<td>0.0%</td>
<td>3.2%</td>
<td>58.1%</td>
<td>38.7%</td>
<td>0.0%</td>
</tr>
<tr>
<td>I am familiar with the term person-centered planning.</td>
<td>0.0%</td>
<td>9.7%</td>
<td>32.3%</td>
<td>58.1%</td>
<td>0.0%</td>
</tr>
<tr>
<td>I am directly involved in inviting people to attend person-</td>
<td>6.5%</td>
<td>25.8%</td>
<td>41.9%</td>
<td>35.5%</td>
<td>9.7%</td>
</tr>
<tr>
<td>centered planning meetings for my child.</td>
<td>2</td>
<td>8</td>
<td>13</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>I am directly involved in leading the person-centered planning</td>
<td>6.5%</td>
<td>25.8%</td>
<td>35.5%</td>
<td>19.4%</td>
<td>12.9%</td>
</tr>
<tr>
<td>meeting.</td>
<td>2</td>
<td>8</td>
<td>11</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>The team has access to the person-centered plan.</td>
<td>3.2%</td>
<td>0.0%</td>
<td>54.8%</td>
<td>38.7%</td>
<td>3.2%</td>
</tr>
<tr>
<td>My child's person-centered plan my child is involved with is</td>
<td>0.0%</td>
<td>9.7%</td>
<td>45.2%</td>
<td>35.5%</td>
<td>9.7%</td>
</tr>
<tr>
<td>effective.</td>
<td>0</td>
<td>3</td>
<td>14</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>I believe the team includes all of the people that need to be</td>
<td>0.0%</td>
<td>6.5%</td>
<td>38.7%</td>
<td>48.4%</td>
<td>6.5%</td>
</tr>
<tr>
<td>present for an effective person-centered planning process.</td>
<td>0</td>
<td>2</td>
<td>12</td>
<td>15</td>
<td>2</td>
</tr>
<tr>
<td>My child's services are being coordinated effectively through</td>
<td>0.0%</td>
<td>6.5%</td>
<td>48.4%</td>
<td>38.7%</td>
<td>6.5%</td>
</tr>
<tr>
<td>the person-centered planning process.</td>
<td>0</td>
<td>2</td>
<td>15</td>
<td>12</td>
<td>2</td>
</tr>
<tr>
<td>The goals identified in the person-centered planning process</td>
<td>0.0%</td>
<td>16.1%</td>
<td>54.8%</td>
<td>22.6%</td>
<td>6.5%</td>
</tr>
<tr>
<td>are almost always achieved.</td>
<td>0</td>
<td>5</td>
<td>17</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>The individual facilitating the person-centered plan is a good</td>
<td>0.0%</td>
<td>3.2%</td>
<td>45.2%</td>
<td>48.4%</td>
<td>3.2%</td>
</tr>
<tr>
<td>facilitator.</td>
<td>0</td>
<td>1</td>
<td>14</td>
<td>15</td>
<td>1</td>
</tr>
<tr>
<td>The person facilitating the person-centered planning process</td>
<td>12.9%</td>
<td>35.5%</td>
<td>25.8%</td>
<td>19.4%</td>
<td>6.5%</td>
</tr>
<tr>
<td>would benefit from additional training and support.</td>
<td>4</td>
<td>11</td>
<td>8</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Overall, the person-centered planning process has increased my</td>
<td>0.0%</td>
<td>9.7%</td>
<td>48.4%</td>
<td>35.5%</td>
<td>6.5%</td>
</tr>
<tr>
<td>child's quality of life.</td>
<td>0</td>
<td>3</td>
<td>15</td>
<td>11</td>
<td>2</td>
</tr>
</tbody>
</table>
GENERAL PCP COMMENTS FROM PARENTS/GUARDIANS

▶ “After the age of 21 the case managers should be more involved than just seeing the person two times a year! Often, it is left to the parent(s)/guardian(s) to carry out the person-centered plan.”

▶ “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.”
CONSUMERS
<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know what a person-centered plan is.</td>
<td>3.0%</td>
<td>3.0%</td>
<td>75.8%</td>
<td>18.2%</td>
<td>0.0%</td>
</tr>
<tr>
<td>My meetings use person-centered planning.</td>
<td>0.0%</td>
<td>0.0%</td>
<td>84.8%</td>
<td>15.2%</td>
<td>0.0%</td>
</tr>
<tr>
<td>My person-centered plan helps me meet my goals.</td>
<td>0.0%</td>
<td>6.1%</td>
<td>57.6%</td>
<td>36.4%</td>
<td>0.0%</td>
</tr>
<tr>
<td>I invite people to come to my person centered planning meetings.</td>
<td>0.0%</td>
<td>3.0%</td>
<td>66.7%</td>
<td>30.3%</td>
<td>0.0%</td>
</tr>
<tr>
<td>I lead my person-centered planning meeting.</td>
<td>3.0%</td>
<td>12.1%</td>
<td>63.6%</td>
<td>21.2%</td>
<td>0.0%</td>
</tr>
<tr>
<td>My staff looks at my person-centered plan.</td>
<td>0.0%</td>
<td>0.0%</td>
<td>75.8%</td>
<td>24.2%</td>
<td>0.0%</td>
</tr>
<tr>
<td>My staff meets regularly to discuss at my person-centered plan.</td>
<td>0.0%</td>
<td>0.0%</td>
<td>75.8%</td>
<td>21.2%</td>
<td>3.0%</td>
</tr>
<tr>
<td>Everyone I need to help me comes to my person-centered planning meeting.</td>
<td>0.0%</td>
<td>3.0%</td>
<td>69.7%</td>
<td>24.2%</td>
<td>3.0%</td>
</tr>
<tr>
<td>My person-centered planning meetings help me get what I need to reach my goals.</td>
<td>0.0%</td>
<td>3.0%</td>
<td>63.6%</td>
<td>30.3%</td>
<td>3.0%</td>
</tr>
<tr>
<td>I reach most of my person-centered plan goals.</td>
<td>0.0%</td>
<td>9.1%</td>
<td>69.7%</td>
<td>18.2%</td>
<td>3.0%</td>
</tr>
<tr>
<td>My case manager helps me have good person-centered planning meetings.</td>
<td>0.0%</td>
<td>0.0%</td>
<td>63.6%</td>
<td>36.4%</td>
<td>0.0%</td>
</tr>
<tr>
<td>My case manager needs more training on how to help me have good person-centered planning meetings.</td>
<td>15.2%</td>
<td>33.3%</td>
<td>45.5%</td>
<td>3.0%</td>
<td>3.0%</td>
</tr>
<tr>
<td>My person-centered plan has made my life better.</td>
<td>0.0%</td>
<td>3.1%</td>
<td>68.8%</td>
<td>28.1%</td>
<td>0.0%</td>
</tr>
</tbody>
</table>
PROFESSIONALS
<table>
<thead>
<tr>
<th>PROFESSIONALS</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am familiar with the term person-centered planning.</td>
<td>0.0% 0</td>
<td>0.0% 0</td>
<td>5.1% 8</td>
<td>94.9% 148</td>
<td>0.0% 0</td>
</tr>
<tr>
<td>The meetings I am involved in use person-centered planning processes.</td>
<td>0.0% 0</td>
<td>2.6% 4</td>
<td>15.4% 24</td>
<td>79.5% 124</td>
<td>2.6% 4</td>
</tr>
<tr>
<td>The person-centered process meetings I facilitate are effective.</td>
<td>0.0% 0</td>
<td>1.9% 3</td>
<td>42.3% 66</td>
<td>37.2% 58</td>
<td>18.6% 29</td>
</tr>
<tr>
<td>The person-centered process meetings I participate in are effective.</td>
<td>0.6% 1</td>
<td>7.1% 11</td>
<td>51.9% 80</td>
<td>35.1% 54</td>
<td>5.2% 8</td>
</tr>
<tr>
<td>The person for whom the person-centered process is held is actively involved in choosing who will attend the meetings.</td>
<td>1.3% 2</td>
<td>9.7% 15</td>
<td>47.1% 73</td>
<td>38.1% 59</td>
<td>3.9% 6</td>
</tr>
<tr>
<td>The person for whom the person-centered process is held actively participates (child) or leads (adult) the meetings.</td>
<td>5.2% 8</td>
<td>18.1% 28</td>
<td>48.4% 75</td>
<td>25.2% 39</td>
<td>3.2% 5</td>
</tr>
<tr>
<td>The person-centered plan is referred to on a regular basis.</td>
<td>1.9% 3</td>
<td>5.8% 9</td>
<td>41.0% 64</td>
<td>49.4% 77</td>
<td>1.9% 3</td>
</tr>
<tr>
<td>The goals and objectives included in the person-centered process are measurable.</td>
<td>2.6% 4</td>
<td>11.5% 18</td>
<td>51.9% 81</td>
<td>32.1% 50</td>
<td>1.9% 3</td>
</tr>
<tr>
<td>Person-centered processes are scheduled regularly throughout the year.</td>
<td>1.9% 3</td>
<td>13.5% 21</td>
<td>32.7% 51</td>
<td>50.6% 79</td>
<td>1.3% 2</td>
</tr>
</tbody>
</table>
## What Percentage of the Person-Centered Plan Goals Are Directly Related to Helping the Individual Meet Their Preferred Lifestyles?

<table>
<thead>
<tr>
<th>Value</th>
<th>Count</th>
<th>Percent %</th>
</tr>
</thead>
<tbody>
<tr>
<td>0%-20% of the goals directly address preferred lifestyles</td>
<td>6</td>
<td>4%</td>
</tr>
<tr>
<td>21%-40% of the goals directly address preferred lifestyles</td>
<td>22</td>
<td>14.6%</td>
</tr>
<tr>
<td>41%-60% of the goals directly address preferred lifestyles</td>
<td>23</td>
<td>15.2%</td>
</tr>
<tr>
<td>61%-80% of the goals directly address preferred lifestyles</td>
<td>36</td>
<td>23.8%</td>
</tr>
<tr>
<td>81%-100% of the goals directly address preferred lifestyles</td>
<td>64</td>
<td>42.4%</td>
</tr>
</tbody>
</table>
EXAMPLES OF GOALS PROVIDED ON THE SURVEY

Self Care:
- I would like to become better at personal hygiene.

Household Chores:
- I will set the table Monday, Wednesday and Friday at supper.
- Encourage consumer to learn household chores to the best of their ability
- Jane will carry her laundry to the laundry room twice a week.
- Person Served will sort their laundry’s whites from darks weekly

Leisure Activities:
- Take a trip to Hawaii
- Plant a flower garden
- Learning to ride a bicycle through a program especially designed for individuals with special needs

Behavior:
- Getting an individual to take a shower every day without throwing a tantrum.

Employment:
- Continue to be employed until reaches retirement age.
- Person will obtain a part-time job this year which meets their interests and skills.
GOAL EXAMPLES (CONTINUED)

Health
- The Vega System for seizures was discussed for my individual at her last Person Center Plan.
- maintaining weight loss

Budgeting
- Consumer will learn to budget his/her money

Living Situation
- To move away from home and select new service provider

Communication
- Developed a sign language objective to assist client in the goal of increase communication.

Relationships
- Person served wanted more contact with family; goal was developed to get more involved with family by sending cards, letters, pictures, etc. to family members on a regular basis.
PCP Goals Listed as Examples in Survey

- Relationships: 3
- Learn New Skills: 6
- Health: 3
- Communication: 2
- Living Situation: 7
- Budget: 7
- Health: 5
- Employment: 13
- Behaviors: 12
- Leisure Activities: 21
- Household Chores: 13
- Self Care: 13

Frequency
“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.”

“We are consistent with what we do to prepare for meetings and scheduling meetings. We always involve the person in the planning as much as they can be. The meetings are positive and usually fun for the person served.”

“Very person centered-add photos and pictures to the plan which results in more participation by those whom the plan is for. Update the individuals goals, highlights, strengths during the meeting and update supports during a separate basis meeting. This also makes it a more reinforcing process.”

“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.”
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.”
► “The licensing requirements that have been tacked on to the PCSP has snowballed this plan into more of a licensing/CYB document than a person driven goal plan.”
► “I would like more precise training and examples of good written goals to better benefit our individuals.”
► “I have read several PCSP from internal and external sources and I feel that the client’s wishes are sometimes lost. I feel it is more reflective of barriers versus tools to over come.”
► “More accountability for the document being a living breathing document and needs to have measurable goals.”
► “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.”
ADDITIONAL QUESTIONS

- What is the average length of written plans?
  - 48.4% answered 6-15 pages
  - 38% answered 16-25 pages

- What is the average meeting length for a person-centered planning process?
  - 53% answered one hour
  - 33.5% answered 2-3 hours
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.
FINDINGS RELATED TO 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.
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.

“I would like to see the outcomes that the person is hoping to get as being part of the process, how this will be measured how we will get there. One thing that drives me crazy is when a goal suddenly disappears from the plan. Did the goal get met, did it disappear? We need tracking systems that allow us to know how someone is doing overtime on a PCP. This is something we are working on…”
One case manager who works within a Developmental Disability organization emphasizing PCP processes stated that:

“Ours are truly person-driven. The individual has to provide input on what their plan is, but with that being said, we have a lot of non-verbal individuals so the team is trying to determine what that person wants through their actions and so forth, but anybody that’s verbal tells us what they want to work on, what they think they need to work on to get to what their preferred lifestyle is and the team helps identify that and identify what we need to do to help them get there.”
The term “evidence-based research” can be defined in a number of different ways.

- A state-level definition would assist Kansans as they seek to promote effective implementation of person centered planning and wraparound processes.
CREATE STANDARDS FOR PCP AND WRAPAROUND PRACTICES TO IMPROVE THE CONSISTENCY AND IMPLEMENTATION EFFORTS ACROSS THE STATE.

- A clear set of expectations from the state sets the stage for some organizations to fail to achieve even the minimum implementation fidelity as it related to the prevention of challenging behaviors.

- At the systems level, 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.
CLEAR SET OF EXPECTATIONS NEEDED

Failing to provide a clear set of expectations from the state sets the stage for some organizations to fail to achieve even the minimum implementation fidelity as it related to the PCP and Wraparound. As one person put it:

“They [the state] need to make very clear what pieces do they expect when the standards are being met. A care plan needs to be made for agencies just like we do for people. I don’t see that being done by the state…..So I do a really elaborate PCP plan and the person next door sits down for 5 minutes, and says check check check check…they [the state] should have expectations of exactly what it looks like and not let us on our own do it on our own like we usually do………..Some people do a great job and some people do a hideous job.”
CREATE A LAYERED TRAINING SYSTEM FOR PCP AND WRAPAROUND PLANNING SYSTEMS ACROSS THE LIFESPAN.

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.
CONSIDER LIMITING 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).
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.
CONSIDER PROVIDING PCP AND/OR WRAPAROUND TO WAIVER RECIPIENTS WHO CURRENTLY DO NOT RECEIVE THE MORE TRADITIONAL PLANNING PROCESS.

Some of the consumers 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.
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.
CONSIDER STRATEGIES THAT SUPPORT TRAINING IN RURAL AREAS.

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.
QUESTIONS/DISCUSSION
Volunteer Opportunity = Free Registration

Greeter
Information/Credit Table
Poster Session
Registration Desk
Session Hosting

Deadline to Volunteer: January 17, 2012

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