



Name of person submitting form: _____

Kansas Institute for Positive Behavior Support Consent Form for Parent or Guardians Receiving KIPBS Services from Graduates

INTRODUCTION

The Life Span Institute at the University of Kansas includes a training program that supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you want your child to participate in a Kansas Institute for Positive Behavior Support training program. You are free to decide not to sign this form and not participate in this study. Even if you agree to participate, you are free to withdraw at any time. By signing this form, you also are permitting the Kansas Institute for Positive Behavior Support (KIPBS) to collaborate with and share any necessary information with the State of Kansas systems and Managed Care Organizations (MCOs) related to eligibility determination and service fidelity.

PURPOSE OF THE STUDY

The purpose of this project is to evaluate how well the people that work with your child or ward in developmental disability, mental health, child welfare, and education settings work with you to implement positive behavior support. These professionals will help you build a positive behavior support (PBS). PBS is a set of strategies and tools that can help stop problem behavior from happening. The first step in PBS is to gather information about a child or adult's strengths and dreams and create goals that will help the child become happier. This first step is called a person-centered plan. The person-centered planning process is a way to start positive behavior support plan with a clear vision of what will improve a child or adult's quality of life. The next step is to assess why a child or adult engages in problem behavior. The assessment information is used to change routines and activities to decrease problem behavior. For instance, a child may engage in problem behavior because s/he does not like to get up and get ready for school or working the morning. A PBS plan might include reviewing the morning schedule with the child or adult, asking the child or adult to choose morning activities that s/he likes a lot, and rehearsing with him how s/he will get up and get dressed the next morning night before the routine. In the morning, the child is told that it is time to get up in five minutes, the curtains are opened up to increase light, a favorite show or song is turned on in the other room to encourage getting out of bed, and the morning schedule from the night before is presented to the child or adult. The PBS plan includes teaching the child or adult new communication skills that she can use instead of engaging in problem behavior. For instance, a PBS plan can include teaching a child or adult to ask for a favorite activity instead of crying and screaming. The person will help a group of people including you, your child or ward, teachers, staff members, and others to work together as a team. You will work with the KIPBS Facilitator to find out why your child or ward engages in problem behavior and to create a positive behavior support plan.



PROCEDURES

If your child or ward participates a positive behavior support plan, the professional will work with you, your child or ward, and other people who support your child or ward. Regular meetings will be set up with you, the child or adult, and other people who support your child or ward. The professional will lead you, your child and others through an assessment of your child's or ward's strengths. The group will talk about what kinds of things would make your child or ward and you happier and together you will create a person centered plan for helping to improve the quality of your child or ward's life. The next step will be to find out why your child or ward engages in problem behavior during routines and activities like going out to dinner, or doing household chores.

All professionals must submit positive behavior support plans to the KIPBS main staff for evaluation purposes. Your child or ward's positive behavior support plan may be selected to be reviewed to help the Kansas Institute make sure that the professional working with your child or ward is supporting him or her in the most effective way possible. The positive behavior support plan will be graded using a checklist that measures how well the professional did helping you and the people supporting your child or ward. For instance, the checklist helps the instructor grade how well the plan describes your child or ward's strengths, what information was collected to understand why problem behavior occurs, and if the plan had a positive impact on your child or ward's life. You will be invited to complete three short surveys that take a few minutes each to complete. These surveys are used to see if you are satisfied with the positive behavior support plan and if your child or ward's quality of life improved.

All of the information that is collected about your child or ward and his or her positive behavior support plan will be seen by KIPBS staff during the evaluation. KIPBS staff members will keep all of your child or ward's information confidential. Communications between KIPBS staff members will be kept in a locked cabinet and the KIPBS offices are kept locked when no one is present.

To maintain high levels of quality assurance, a group of KIPBS professionals meet on a regular basis (every two months) as the KIPBS Facilitator Board. KIPBS Facilitators and KIPBS staff members discuss issues, share ideas, and problem solve together. You can choose to allow information about your child to be shared during these meetings or you can ask that information about your child be shared just with KIPBS staff members. KIPBS Professionals and KIPBS staff members will keep all of your child or ward's information confidential. Communications between KIPBS staff members will be kept in a locked cabinet and the KIPBS offices are kept locked when no one is present. By signing this form, you also are permitting the Kansas Institute for Positive Behavior Support (KIPBS) to collaborate with and share any necessary information with the State of Kansas systems and Managed Care Organizations (MCOs) related to eligibility determination and service fidelity.

RISKS

There are not many potential risks to your child or ward. However, it is possible that you or your child may feel pressure from the professional who works with you to allow your child to participate in a positive behavior support plan. We have taken a number of precautions to avoid the possibility that you will feel pressured to participate in the project. Professionals participating in the KIPBS project are taught that when asking your permission they must assure that they are not pressuring you to participate in any way. You and your child are the only ones who can agree to participate in the course and you or your child can withdraw your participation at any time. You are not required to sign this Consent and



Authorization form and you may decline to do so without affecting your right to any services you are receiving or may receive from the University of Kansas or to participate in any programs or events of the University of Kansas. However, if you do not to sign, you cannot participate in this study.

You or child or ward may experience feelings of discomfort while learning new ways how to change how you support your child or ward. It may also feel uncomfortable to complete a survey to tell professionals how satisfied you are with the positive behavior support plan by completing three surveys. The three surveys you are asked to complete are anonymous and the professional will be asking all of the people who support your child or ward to complete them as well. In addition, you are free to decide not to complete these surveys.

The professional will help you do interventions that you and the other team members have chosen as part of the positive behavior support plan. One risk may be that the child or ward will engage in problem behavior while you are learning to do an intervention. You can ask to stop these sessions at any time. In addition, the professional will stop a session if your child or ward begins engaging in serious problem behavior. When problem behaviors decrease or become less difficult, the professional will ask you if you would like to begin the session or reschedule for another day.

Even though all personal and identifying information is held confidential by instructors and KIPBS staff, a potential risk is that your child or ward's name or personal information will be accidentally shared or stolen from KIPBS offices. To prevent the accidental release of confidential information, instructors and main KIPBS office staff are the only people with access to names and identifying information. All confidential information will be stored in the KIPBS office which is locked and the master list of students and case studies documentation will be in a locked cabinet that only KIPBS staff can open.

Professionals are taught to keep all information confidential. Names and information that would identify your child or ward will be removed. Your child's or ward's name will not be associated in any way with the information collected for evaluation and research findings from this study. The KIPBS staff will use a number or a pseudonym instead of your name for evaluation research purposes. The researchers will not share information about you or your child unless required by law or unless you give written permission. KIPBS staff will destroy all confidential documents within 5 years but will keep evaluation data with no names or identifying information.

By signing this form you give permission for the use your information using a number or pseudonym for evaluation research purposes at any time in the future. By signing this form, you also are permitting the Kansas Institute for Positive Behavior Support (KIPBS) to collaborate with and share any necessary information with the State of Kansas systems and Managed Care Organizations (MCOs) related to eligibility determination and service fidelity. The Kansas Tort Claims Act provides for compensation if it can be demonstrated that the injury was caused by the negligent or wrongful act or omission of a state employee acting within the scope of his/her employment.

BENEFITS

The benefit of participating in this training program is that the positive behavior support plan is intended to improve your child or ward's life and to prevent problem behavior. The positive behavior support process is meant to be a team process and you will help guide the positive behavior support plan for your child.



Participant Assent to Participate
Child or Adult

Instructions: Please read the following to each child or adult participant in a Kansas Institute for Positive Behavior Support case study one time prior to starting any activities that involve the child or adult in the case. If the child or adult wishes to continue, please note this on the “Assent” portion below. If the child or adult does not wish to continue, please note this on the form. If the child or adult does not seem to understand what you read to them below, please note that as well. All Assent Forms should be forwarded to the Principal Investigator listed below. Graduates of the KIPBS training who send in a prior authorization request need to complete the *Assent to Participate in the Positive Behavior Support Plan* and the *Kansas Institute for Positive Behavior Support Consent Form for Parent or Guardians Receiving KIPBS Services from Graduates*.

“The purpose of this project is to help the people that work and live with you learn about positive behavior support. Positive behavior support helps change the things around you so you do not get upset or angry. I will be meeting with you and the people who live and work with you to learn more about the things that will make it easier for you to get what you need to be happy. Do you want to help the people who work and live with you learn more about positive behavior support? You can say that you do not want to do this any more at any time you want. Thank you very much for helping us teach positive behavior support to other people.”

I. Assent to Participate in a Positive Behavior Support Plan

Do you continue to wish to participate in the positive behavior support study?

_____ Yes

_____ No

_____ Does not seem to understand what was read to them (but parental consent/guardian support has been obtained)

Name of Child or Adult

Rachel Freeman
Kansas Institute for Positive Behavior Support
1052 Dole
Lawrence, KS 66045
Phone: 785-864-4057
Fax: 785-864-1284

