



Name of person submitting form: _____

Kansas Institute for Positive Behavior Support Consent Form for Parent or Guardians for Case Study during Training Program

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. If you do withdraw from this study, it will not affect your relationship with the Life Span Institute, the services it may provide to you, or the University of Kansas.

PURPOSE OF THE STUDY

The purpose of this project is to teach the people that work with your child or ward in developmental disability, mental health, child welfare, and education settings. These professionals are learning 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 working with you and your child is learning how to help a group of people like teachers, staff members, parents, and others to work together as a team. You will work with the person taking the KIPBS training program as a team 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 in this training project, 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 ward, 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.

The professional working with your child or ward will be taking the course for one year. During this training program, you may need to find a behavior specialist to help you if your child or ward begins engaging in severe problem behavior. The professional completing the course is facilitating the PBS plan with support from KIPBS experts. However, your child or ward may need more immediate and intensive support from a behavior specialist if he or she is engaging in problem behavior that is resulting in injury to self or others since the professional taking the course is still learning about positive behavior support.

The professional working with you will be asked to gather videotape footage of your child/ward over time and to videotape him or herself implementing simple PBS interventions with the child or adult. For instance, the professional may prompt your child or adult to communicate what s/he needs and deliver positive feedback for good behavior as part of a PBS plan you and the team decide to implement. Videotaping will occur for 20 minutes to an hour each time for up to six sessions that will be scheduled during the year the professional is working with you. This tape will be viewed in a small class of no more than eight professionals who are also taping themselves working with other children. The other professionals taking the course are working in jobs that involve supporting children and are also learning about PBS planning. A Kansas Institute for Positive Behavior Support Instructor will be using the videotape to help the professional learn more about PBS planning and to learn how to work with you to support your child better. This videotape footage will be destroyed after the course is complete and will not be seen by anyone else besides the instructors and a small number of other professional classmates during one class.

Each person taking the class is observed by someone from the Kansas Institute for Positive Behavior Support (KIPBS) while he or she is working on specific parts of the PBS plan process. For example, the professionals will be observed by KIPBS staff working with you during meetings, collecting information about your child or ward, and helping you and others implement interventions. The observations will help the instructors teach professionals to improve how they teach.

The professional will ask you and other people supporting your child or ward for any positive behavior support and person-centered plans that were completed in the past. This older positive behavior support plan will be compared to the new positive behavior support plan that the professional creates with you. Both positive behavior support plans 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 the professional's instructor and by three KIPBS staff. The instructor and KIPBS will keep all of your child or wards' information confidential. Communications between instructors and KIPBS staff will be kept in a locked cabinet and the KIPBS offices are kept

locked when no one is present. Only KIPBS staff members that work directly with instructors to train you will have access to your name and confidential information.

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 sign, you cannot participate in this study.

You or child or ward may experience feelings of discomfort participating in the meetings when KIPBS staff members are observing or when videotaping is occurring. 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. However, all observations and videotaping are focused on how well the professional is using positive behavior support, not on you or your child or ward. The videotape is used in one class and destroyed after the class is complete. You are free to choose not to be in a videotape or to cancel or reschedule meetings on days when KIPBS staff are coming to observe the professional. The three surveys you are asked to complete will be anonymous and the professional will be asking all of the people who support your child 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 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 again or reschedule for another day.

A potential risk is that your child's 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 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 discussed in class confidential and to destroy videotape information as soon as the course is completed. 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 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. 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 professional working with your child or ward will learn more about how to guide the positive behavior support process. The positive behavior support process is meant to be a team-based approach and you will have help guide the positive behavior support plan for your child or ward. In addition, the purpose of the positive behavior support plan is to improve your child or ward’s life and to prevent problem behavior.

You may withdraw your consent to participate in this study at any time. You also have the right to cancel your permission to use and disclose information collected about you, in writing, at any time, by sending your written request to: Rachel Freeman, 1052 Dole Human Development Center, 1000 Sunnyside Ave., Lawrence, Kansas 66045. If you cancel permission to use your information, the researchers will stop collecting additional information about you. However, the research team may use and disclose information that was gathered before they received your cancellation, as described above.

QUESTIONS ABOUT PARTICIPATION

Questions about procedures should be directed to the researcher(s) listed at the end of this consent form.

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my rights as a research participant, I may call (785) 864-7429 or (785) 864-7385 or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email mdenning@ku.edu.

Consent for Participation

I agree to take let my child or ward take part in this study as a research participant. By my signature I affirm that I am at least 18 years old and that I have received a copy of this Consent and Authorization form.

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|-----------------------------------|-------|------------------------|
| Type/Print Parent/Guardian’s Name | Date | Name of Child or Adult |
| Parent/Guardian’s Signature | Adult | Signature |

Content to Participate in Videotaping Activity

I understand that part of the course that the professional is taking involves videotaping my child/ward for 20 minutes to an hour each time for six videotaping sessions that will be completed during the year the professional is working with my child/ward. Videotape footage will be taken of my child in natural activities, and while the professional is showing me how to implement simple PBS interventions. My signature indicates that I agree to having my child videotaped and I understand that this tape will be viewed with the professional’s instructor and discussed in a small class of no more than eight professionals who are also taping themselves working with children as part of the course requirements. I understand that the tape will not be seen by anyone else besides the instructor and his or her classmates and will be destroyed after the course is completed.

| | | |
|-----------------------------------|-------|------------------------|
| _____ | _____ | _____ |
| Type/Print Parent/Guardian’s Name | Date | Name of Child or Adult |
| _____ | _____ | _____ |
| Parent/Guardian’s Signature | Adult | Signature |

Researcher Contact Information

Rachel Freeman
 Principal Investigator
 Dole Human Development Cntr.
 Life Span Institute
 1000 Sunnyside Ave
 University of Kansas
 Lawrence, KS 66045
 785 864-4057

Approved by the Human Subjects Committee University of Kansas, Lawrence Campus (HSCL). Approval expires one year from 1/12/2012. HSCL #15600

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. If you are a Professional in Training, please have both *Assent to Participate in the Positive Behavior Support Plan* and *Assent to Participate in Videotaping* signed. Graduates only need to complete the *Assent to Participate in the Positive Behavior Support Plan*.

“The purpose of this project is to help me do a better job at work by learning about positive behavior support. Positive behavior support helps change the things around you so you do not get upset or angry. I am learning to teach you things that will make it easier to get what you need to be happy. Do you want to help me learn to do 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 me learn about positive behavior support.”

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

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| <p>Approved by the Human Subjects Committee University of Kansas, Lawrence Campus (HSCL). Approval expires one year from 1/12/2012. HSCL #15600</p> |
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Assent to Participate in Videotaping

“Part of my class includes making a videotape of you so that my instructor can help me to learn more about positive behavior support. I will videotape myself working with you or I will videotape you and your parent (guardian, or staff person) so that my instructor can tell me how I can do a better job doing positive behavior support. If you agree you will be in the videotape with me, we will videotape six times this year for up to an hour each time. I will take the videotape to my classes where my instructor and classmates will tell me how to do a better job doing positive behavior support and I will destroy the tape by then end of the course so that no one else can see it. Is it okay to make a videotape with you in it?”

Do you continue to wish to participate in videotaping?

_____ 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

Forward this form to:

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Kansas Institute for Positive Behavior Support
1052 Dole
Lawrence, KS 66045
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