



BROWN UNIVERSITY  
CONSENT FOR RESEARCH PARTICIPATION –  
ONLINE/REMOTE ASSESSMENT

Reducing the Duration of Untreated Illness Among Youth in the Juvenile Justice System  
Version #1; March 13, 2020

You and your teen are invited to take part in a Brown University and Miriam Hospital research study. Participation is voluntary.

- **RESEARCHERS:** Anthony Spirito, PhD, Jennifer Wolff, PhD, and Kathleen Kemp, PhD
- **PURPOSE:** We are trying to figure out ways to better help court-involved teenagers who report having upsetting thoughts and feelings and what types of services help the most. This is not a treatment study.
- **PROCEDURES:** This study involves online questionnaires and interviews over the phone or using Zoom software. For the online part of the study, you and your teen will be asked to complete a few personal questionnaires relating to your and their thoughts, emotions, and behaviors. Over the phone or using Zoom software, we will fully explain what that part of the study involves, and you will have the option to ask questions and agree to the remainder of the study if you would like to. If you agree, you and your teen will complete questionnaires and interviews about thoughts, feelings, behaviors, and attitudes. You can decide to decline any part of the study you wish.
- **TIME INVOLVED:** The online surveys and phone interviews will each take between 30-60 minutes. In total, the entire assessment may take 1.5-2.5 hours. There is a possibility of a follow-up visit in three months. This visit may be either in-person or remote like this one, and will be shorter, between 1-1.5 hours.
- **COMPENSATION:** You and your teen will each receive compensation (\$60 each) for completing this assessment. If your teen chooses to complete the interviews and not the surveys, they will be compensated \$40. Payment for participating in this study will be made using ClinCard, a pre-paid Mastercard that works like a debit card. This payment will be mailed to you.
- **RISKS:** Some of the questions may make you or your teen feel uncomfortable. You both may skip any questions you prefer not to answer or do not feel comfortable answering. This will not impact participation in the study. All participants will receive a list of contacts if they want to speak to someone about any health concerns or abuse- this list will be mailed to you with your payment. There is a risk of loss of privacy in this study including sensitive information on your teen's emotional state.
- **BENEFITS:** You/your teen may not directly benefit from being in this research study.
- **ALTERNATIVES TO PARTICIPATION:** If you or your teen do not want to participate in this study, your teen can still receive any care juvenile court staff believes is useful.
- **CONFIDENTIALITY:** To maintain confidentiality, we will assign all of you and your teen's data a numerical code. You and your teen's responses will not be connected to your or their identity. We will not share your teen's responses with court staff or anyone outside of this research project. However, your family's juvenile intake worker may know if you agreed to participate in the study. Please note that complete confidentiality can never be guaranteed when information is transmitted over the internet. Brown University and Lifespan staff sometimes review studies like this one to make sure they are being done safely and correctly. If a review of this study takes place, your records may be examined. Reviewers will protect your confidentiality. A description of this clinical trial will be

available on <http://www.ClinicalTrials.gov>, as required by U.S. law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

Payment for participating in this study will be made using a pre-paid card that works like a bank debit card. We will give you the debit card. You will be issued one card for the duration of your participation and this card may be used to pay you in any future Brown University studies you choose to participate in. You will also receive information about how to use this card and whom to call if you have any questions. Be sure to read this information, including the cardholder agreement. Money will be added to your card according to the study's payment schedule. You may use this card at any store that accepts Mastercard. You may also use an ATM with the Mastercard logo to withdraw cash. If you use the card to withdraw cash, or if the card is not used within any six (6) month period, you will be charged a fee that will reduce the total amount of money left on the card. Please read the FAQ information sheet for details about fees.

This card is administered by an outside company called Greenphire. Greenphire will be given your name, address, and date of birth. They will use this information only as part of the payment system and it will not be given or sold to any other company. Greenphire will not receive any information about your health status or the study in which you are participating. If your card is lost or stolen, please call 401-863-6688 or ask the study coordinator for a replacement card. You may be charged a fee if you request a replacement card from Greenphire directly.

To help us protect your privacy, we have a Certificate of Confidentiality. We can use this to:

- Refuse to disclose information that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings (e.g., a court subpoena).
- Resist any demands for information that would identify you, except as explained below.

The Certificate WILL NOT be used to:

- Resist a demand for information from personnel of the U.S. government agency sponsoring the project and that will be used for auditing or program evaluation of agency funded projects.
- Withhold information from an insurer, medical care provider, or other person who obtains your written consent to receive research information.
- Prevent disclosure to authorities of child abuse and neglect, or harm to self or others.

NOTE: The Certificate DOES NOT prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research.

- VOLUNTARY: You and your teen do not have to be in this study if you or they do not want to be. Even if you decide to be in this study, you can change their mind and stop at any time. You and your teen's decision to participate in this study will not affect their case or any court proceedings.
- CONTACT INFORMATION: If you have any questions about your teen's participation in this study, you can ask at any time by calling Drs. Spirito, Wolff, or Kemp at (401) 559-9626. You may also contact Dr. Spirito by calling (401) 444-1929 or emailing [anthony\\_spirito@brown.edu](mailto:anthony_spirito@brown.edu).
- YOUR RIGHTS: If you have questions about your rights as a research participant, you can contact Brown University's Human Research Protection Program at 401-863-3050 or email them at [IRB@Brown.edu](mailto:IRB@Brown.edu).
- CONSENT: Clicking the link below confirms that you have read and understood the information in this document and that you agree to participate in this study. You can print a copy of this form.



BROWN

BROWN UNIVERSITY  
CONSENT FOR RESEARCH PARTICIPATION

Reducing the Duration of Untreated Illness Among Youth in the Juvenile Justice System  
Version #1; January 31, 2019

You and your teen are invited to take part in a Brown University and Miriam Hospital research study. Participation is voluntary.

- **RESEARCHERS:** Anthony Spirito, Ph.D., Jennifer Wolff, PhD, and Kathleen Kemp, PhD
- **PURPOSE:** We are trying to figure out ways to better help court-involved teenagers who report having upsetting thoughts and feelings and what types of services help the most. This is not a treatment study.
- **PROCEDURES:** This study involves online questionnaires and at least one in-person assessment. For the online part of the study, your teen will be asked to complete a few personal questionnaires relating to their thoughts, emotions, and behaviors. At the in-person visit, we will fully explain what that part of the study involves, and you will have the option to ask questions and agree to the remainder of the study if you would like to. If you agree, you and your teen will complete questionnaires and interviews about thoughts, feelings, behaviors, and attitudes. You can decide to decline any part of the study you wish.
- **TIME INVOLVED:** The online surveys will take up to 20 minutes. The in-person visit will take 2-2.5hrs.
- **COMPENSATION:** Your teen will receive \$10 for completing these surveys at the time of the in-person assessment you have already scheduled with study staff. You and your teen will receive additional compensation (\$40-\$60 each) for each in-person visit completed. Payment for participating in this study will be made using ClinCard, a pre-paid Mastercard that works like a debit card. NOTE: Your teen will not receive compensation for these surveys (\$10) if you do not attend the in-person assessment. If you do not attend an in-person assessment within 30 days of completing this survey, we will destroy your responses.
- **RISKS:** Some of the questions may make your teen feel uncomfortable. They may skip any questions they prefer not to answer or do not feel comfortable answering. This will not impact their participation in the study. These assessments will not be reviewed immediately. All participants will receive a list of contacts if they want to speak to someone about any health concerns or abuse- this list will be given to you and your teen at the in-person visit. There is a risk of loss of privacy in this study including sensitive information on your teen's emotional state.
- **BENEFITS:** You/your teen may not directly benefit from being in this research study.
- **ALTERNATIVES TO PARTICIPATION:** If you or your teen do not want to participate in this study, your teen can still receive any care juvenile court staff believes is useful.
- **CONFIDENTIALITY:** To maintain confidentiality, we will assign all of your teen's data a numerical code. Your teen's responses will not be connected to their identity. Their online responses will be linked to responses obtained during the in-person assessment. We will not share your teen's responses with court staff or anyone outside of this research project. However, your family's juvenile intake worker may know if you agreed to participate in the study. Please note that complete confidentiality can never be guaranteed when information is transmitted over the internet. Brown University and Lifespan staff sometimes review studies like this one to make sure they are being done safely and correctly. If a review of this study takes place, your records may be examined. Reviewers will protect your confidentiality. A description of this clinical trial will be available on <http://www.ClinicalTrials.gov>, as required by U.S. law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

To help us protect your privacy, we have a Certificate of Confidentiality. We can use this to:

- Refuse to disclose information that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings (e.g., a court subpoena).
- Resist any demands for information that would identify you, except as explained below.

The Certificate WILL NOT be used to:

- Resist a demand for information from personnel of the U.S. government agency sponsoring the project and that will be used for auditing or program evaluation of agency funded projects.
- Withhold information from an insurer, medical care provider, or other person who obtains your written consent to receive research information.
- Prevent disclosure to authorities of child abuse and neglect, or harm to self or others.

NOTE: The Certificate DOES NOT prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research.

- VOLUNTARY: Your teen does not have to be in this study if they do not want to be. Even if they decide to be in this study, they can change their mind and stop at any time. You and your teen's decision to participate in this study will not affect their case or any court proceedings.
- CONTACT INFORMATION: If you have any questions about your teen's participation in this study, you can ask at any time by calling Drs. Spirito, Wolff, or Kemp at (401) 559-9626. You may also contact Dr. Spirito by calling (401) 444-1929 or emailing [anthony\\_spirito@brown.edu](mailto:anthony_spirito@brown.edu).
- YOUR RIGHTS: If you have questions about your rights as a research participant, you can contact Brown University's Human Research Protection Program at 401-863-3050 or email them at [IRB@Brown.edu](mailto:IRB@Brown.edu).
- CONSENT: Clicking the link below confirms that you: 1) have read and understood the information in this document, 2) are the legal guardian of the participant (your teen) and 3) agree to allow them to volunteer to participate in this study. You can print a copy of this form.

**I Want to Participate [unique link to RedCap surveys]**

You are invited to take part in a Brown University and Miriam Hospital research study. Your participation is voluntary.

- **RESEARCHERS:** Anthony Spirito, Ph.D., Jennifer Wolff, PhD, and Kathleen Kemp, PhD.
- **PURPOSE:** We are trying to figure out ways to better help court-involved teenagers who report having upsetting thoughts and feelings and what types of services help the most. This is not a treatment study.
- **PROCEDURES:** This study involves online questionnaires and at least one in-person assessment. For the online part of the study, you will be asked to complete a few surveys relating to your thoughts, feelings, and behaviors. At the in-person visit, we will fully explain what that part of the study involves, and you will have the option to ask questions and agree to the remainder of the study if you would like to. If you agree, you will complete questionnaires and interviews about thoughts, feelings, behaviors, and attitudes. You can decide to decline any part of the study you wish.
- **TIME INVOLVED:** The online surveys will take up to 20 minutes. The in-person visit will take 2-2.5 hrs.
- **COMPENSATION:** You will receive \$10 for completing these surveys at the time of your in-person assessment. You will also receive payment for the in-person interviews and surveys completed. PLEASE NOTE: You will not receive payment for these surveys (\$10) if you do not attend the in-person assessment. If you do not attend an in-person assessment within 30 days of completing this survey, we will destroy your responses. Payment will be made using ClinCard, a pre-paid Mastercard that works like a debitcard.
- **RISKS:** Some of the questions may make you feel uncomfortable. You may skip any questions you prefer not to answer or do not feel comfortable answering. This will not impact your participation in the study.

**These assessments will not be reviewed immediately.** Everyone participating in this research study will receive a list of contacts if they want to speak to someone about any health concerns or abuse- this list will be given to you at the time of your in-person visit. There is a risk of loss of privacy in this study including sensitive information on your emotional state.

- **BENEFITS:** You may not directly benefit from being in this research study.
- **ALTERNATIVES TO PARTICIPATION:** If you do not want to participate in this study, you can still receive any care juvenile court staff believes is useful.
- **CONFIDENTIALITY:** To maintain confidentiality, we will assign all of your data a numerical code. Your responses will not be connected to your identity. Your online responses will be linked to the responses you provide during the in-person assessment. We will not share your responses with court staff or anyone outside of this research project. However, your juvenile intake worker may know if you agreed to participate in the study. Please note that complete confidentiality can never be guaranteed when information is transmitted over the internet. Brown University and Lifespan staff sometimes review studies like this one to make sure they are being done safely and correctly. If a review of this study takes place, your records may be examined. The reviewers will protect your confidentiality. A description of this clinical trial will be available on <http://www.ClinicalTrials.gov>, as required by U.S. law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

To help us protect your privacy, we have a Certificate of Confidentiality. This can be used by us to refuse to disclose information about you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings (e.g., a court subpoena) and to resist any demands for information that would identify you, except as explained below.

This certificate WILL NOT be used to resist a demand for information from personnel of the U.S. government agency sponsoring this project, who will use the information to audit or evaluate this project. This certificate does not prevent you or your guardian from voluntarily releasing information about you or your involvement in this research. We will not withhold information from an insurer, medical care provider, or other person who obtains your guardian's written consent to receive research information. This certificate DOES NOT prevent disclosure to authorities of child abuse and neglect, or harm to self or others.

- **VOLUNTARY:** You do not have to be in this study if you do not want to be. Even if you decide to be in this study, you can change your mind and stop at any time. Your decision to participate in this study will not affect your case or any court proceedings.
- **CONTACT INFORMATION:** If you have any questions about your participation in this study, you can ask at any time by calling Drs. Spirito, Wolff, or Kemp at (401) 559-9626. You may also contact Dr. Spirito by calling (401) 444-1929 or emailing [anthony\\_spirito@brown.edu](mailto:anthony_spirito@brown.edu).
- **YOUR RIGHTS:** If you have questions about your rights as a research participant, you can contact Brown University's Human Research Protection Program at 401-863-3050 or email them at [IRB@brown.edu](mailto:IRB@brown.edu).
- **CONSENT:** Clicking the link below confirms that you have read and understood the information in this document and that you agree to participate in this study. You can print a copy of this form.

**I Want to Participate**

**BROWN UNIVERSITY**  
**CONSENT FOR RESEARCH PARTICIPATION**  
Parent Consent Form for Self and Teen

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Name of Study Volunteer

Reducing the Duration of Untreated Illness Among Youth in the Juvenile Justice System  
Version 5; 4-12-19

**KEY INFORMATION**

You and your teen are invited to take part in a Brown University and Miriam Hospital research study. Your participation is voluntary.

- **PURPOSE:** We are trying to figure out ways to better help court-involved teenagers who report having upsetting thoughts and feelings and what types of services help the most. **This is not a treatment study.**
- **PROCEDURES:** You and your teen will be asked to complete interviews and questionnaires about your teen's thoughts, feelings, and behaviors. We will also ask about interest in your teen receiving counseling services. Three months from now you and your teen may be asked to complete a similar follow-up visit, including a few questionnaires about any counseling they received and if these services were helpful.
- **TIME INVOLVED:** This study begins with today's session which may take up to 2.5 hours. You may be contacted to participate in a follow-up session in three months. If you and your teen choose to participate, the follow-up session may take up to 2 hours.
- **COMPENSATION:** In total, your teen can receive between \$40 and \$140, and you can receive between \$60 and \$120. Payment for participating in this study will be made using ClinCard, a pre-paid Mastercard that works like a debit card.
- **RISKS:** You and/or your teen may feel uncomfortable about sensitive topics discussed, and there is a risk of loss of privacy in this study including sensitive information on your teen's emotional state.
- **BENEFITS:** You/your teen may not directly benefit from being in this research study. However, you and your teen may learn more about their thoughts and feelings.
- **ALTERNATIVES TO PARTICIPATION:** If you or your teen do not want to participate in this study, your teen can still receive any care juvenile court staff believes is useful, and you can still receive a list of resources and services in the community.

1. Researchers: This research is being conducted by Anthony Spirito, PhD. He may be contacted at [anthony\\_spirito@brown.edu](mailto:anthony_spirito@brown.edu) or 401-444-1929. Other researchers include Jennifer Wolff, PhD, who can be contacted at [jennifer\\_wolff@brown.edu](mailto:jennifer_wolff@brown.edu) or 401-444-3790, and Kathleen Kemp, PhD, who can be contacted at [kkemp@lifespan.org](mailto:kkemp@lifespan.org) or 401-444-8269. You can contact the study research assistant at 401-559-9626.

2. What is the study about? We are trying to figure out ways to improve services for court-involved teenagers when they report in their court appointment that they are having upsetting thoughts and feelings.

3. What will you and your teen be asked to do? You and your teen will each complete interviews and questionnaires about your teen's thoughts, feelings, and behaviors. You will also be asked to answer some questions about yourself and your family. We will also ask about how you and your teen feel about them receiving counseling services. This may take up to 2.5 hours.

About three months from now, as part of the research study, you and your teen may be asked to complete a follow-up visit including most but not all of the same interviews and questionnaires from the first session. Additionally, you and your teen will be asked questions about any counseling they have received and if these services have been helpful. This may take up to 2 hours. If your teen did receive any counseling, we will ask you to sign a release of information form so we can contact your teen's mental health counselor to obtain information about the frequency and type of services received.

We will use digital audio recorders during the interviews at both time points. The purpose of recording audio is to double check the answers you give our interviewer. We will keep this information confidential and available only to approved research staff. We will store these recordings on a secured computer drive for the duration of the study. At the conclusion of the study, we will destroy them.

We will also collect information from your teen's court file, including: information about your teen's involvement with the Rhode Island Family Court, such as number of charges, types of past charges, and whether your teen receives any new charges during the course of the study (3 months after the first session). We will also collect information, if available, from your teen's court file on any mental health screening at the Rhode Island Family Court and previous mental health treatment.

**Standard Court Procedures.** As part of standard court procedures, parents and teens will be referred to community for follow-up mental health care or for an immediate evaluation if your intake worker feels that is what is needed now. Intake workers may also review material with you about mental health and contact you about whether you attended your appointment in the community after you leave today. (Note: this portion is not part of the research study)

4. Will you and your teen be paid? You and your teen will each receive \$60 for the time it takes to complete the questionnaires and interviews today. If your teen completes the interviews but not the questionnaires, they will receive \$40. If you are contacted for a follow-up in three months and choose to participate, you and your teen will also each receive \$60 for completing the surveys and questionnaires at that time. Your teen will receive \$40 if they only complete the interview but not the questionnaires at the follow-up visit. If your teen completes the online questionnaires in advance of this visit and/or the follow-up visit, they will receive \$10 per online session in addition to the \$60 for each in-person session. In total, your teen can receive between \$40 and \$140. You can receive between \$60 and \$120, in total.

Payment for participating in this study will be made using ClinCard, a pre-paid Mastercard that works like a debit card. We will give you the card at the conclusion of today's session. You will be given one card for the entire time of your study participation and this card may be used to

pay you in any future Brown University studies that uses ClinCard. You will also get information about how to use this card and whom to call if you have any questions. Be sure to read this information, including the cardholder agreement from Greenphire.

Funds will be added to your card based on the study's payment schedule. You may use this card online or at any store that accepts Mastercard. Please read the FAQ information sheet given to you by study staff for details about the ways you can use the card, some of which may involve fees that will reduce the amount of money on the card.

If you earn \$600 or more from Brown University in a single calendar year (either in a one study or across multiple studies), Brown will request your social security number to correctly identify you in the payment system and issue you an IRS 1099 Form. You may also be asked to complete a Form W9. This may affect your taxes. Only payments for being in research studies will be used to decide if you should receive the IRS form. Money for study-related parking, transportation, and other expenses are not included in this IRS disclosure.

This card is administered by an outside company called Greenphire. Greenphire will be given your name, address, and date of birth. They will use this information only as part of the payment system, and it will not be given or sold to any other company. Greenphire will not receive any information about your health status or the study in which you are participating.

If your card is lost or stolen, please call the study coordinator for a free replacement card. If you request a replacement card from Greenphire directly, you may be charged a fee.

Research Procedures	All parents	All teens
<b>Baseline Assessment</b> <i>[Parent &amp; teen each earn \$60, teen earns additional \$10 if surveys completed online ahead of time]</i>	<p><u>Parent assessment</u> (about 1 ½ to 2 hours)</p> <ul style="list-style-type: none"> <li>• Demographic information</li> <li>• Parent interview on teen mood and behavior and teen's treatment history</li> <li>• Parent questionnaires on motivation for and barriers to receiving counseling</li> <li>• Parent questionnaires on parent's own mood and behavior, and family functioning</li> </ul>	<p><u>Teenager assessment</u> (about 2 to 2 ½ hours)</p> <ul style="list-style-type: none"> <li>• Demographic information</li> <li>• Adolescent interview on thoughts, mood and behavior</li> <li>• Adolescent questionnaires on thoughts, mood, behavior, motivation for receiving treatment, and treatment history</li> </ul>
<b>3 Month Assessments</b> <i>[Parent &amp; teen each earn \$60, teen earns additional \$10 if surveys completed online ahead of time]</i>	<p>You and your teen complete assessments similar to the baseline session, including most of the same questionnaires and shorter interviews on the teen's mood, behavior, and treatment (about 1.5 – 2 hours total). You and your teen will also be asked about what services your teen received in the community and how satisfied you both were with those services. Your teen's court records will also be checked for any new charges.</p>	

5. What are the risks? You and your teen will be asked questions of a sensitive nature about mental health experiences. Answering the questions may sometimes make you or your teen feel upset or experience emotional distress. You and/or your teen can refuse to answer any questions you do not like. You and/or your teen can also stop participation in at anytime.

There is a risk of loss of privacy in this study including sensitive information on your or your teen's emotional state. The information you and your teen share with us could affect your or your teen's reputation and employability and could lead to negative legal consequences if it were disclosed with people outside of the study. We take this risk very seriously, and we will take steps to protect your family's information. For example, your or your teen's name will not be on any of the study questionnaires or materials. All of your and your teen's information will be identified only by a code number, not by names. Any information you and your teen share with us will be stored in locked cabinets or on a secure server or a password protected external hard drive in locked offices at Brown University.

6. What are the benefits? This study may not benefit you or your teen personally. However, by answering these questions and taking part in the assessment, parents and teenagers may have the opportunity to learn more about themselves and each other.

There is a possibility that participating in this research study may positively affect your teen's relationship with Rhode Island Family Court by satisfying the intake worker's concerns your teen should receive further mental health evaluation. However, this cannot be guaranteed, and the same positive effect may occur by arranging for further mental health evaluation outside of being in this study.

7. How will my and my teen's information be protected? All records from this study will be treated as private records. The records will be protected according to the rules of Brown University. To maintain confidentiality, we will assign all of your and your teen's data a numerical code. Your and your teen's name will not be on the questionnaires or interview forms. Your teen's online responses will be linked to responses obtained during the in-person assessment. Please note that complete confidentiality can never be guaranteed when information is transmitted over the internet. Information collected during the assessment is treated as confidential and will not be shared in ways other than what is outlined in this document. Paper records will be kept in a locked filing cabinet in a locked office at Brown University. All laptop computer data as well as any paper data that is entered into a computer database will be accessible only to research staff members and will be password protected. Only researchers working on this study will have access to the information provided by you and your teen.

Brown University and Lifespan staff sometimes review studies like this one to make sure they are being done safely and correctly. If a review of this study takes place, your records may be examined. The reviewers will protect your confidentiality.

In this study we will be audio recording your interviews. We will keep this recording confidential. We will store it only for the duration of the study and destroy it at the conclusion of the study.

We will not disclose details regarding your answers to the court. However, your family's juvenile intake worker may know if you agreed to participate in the study. To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health.



Study Volunteer Initials: \_\_\_\_\_

The researchers can use this Certificate to legally refuse to disclose information that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings, for example, if there is a court subpoena. The researchers will use the Certificate to resist any demands for information that would identify you, *except as explained below*.

The Certificate cannot be used to resist a demand for information from personnel of the United States federal or state government agency sponsoring the project and that will be used for auditing or program evaluation of agency funded projects. You should understand that a Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself, your teen, or your and/or your teen's involvement in this research. If an insurer, medical care provider, or other person obtains your written consent to receive research information, then the researchers will not use the Certificate to withhold that information.

The Certificate of Confidentiality will not be used to prevent disclosure to state or local authorities of *such as child abuse and neglect, or harm to self or others*. If you report you are actively suicidal, or plan to hurt someone else, we will get you help by telling appropriate authorities and taking appropriate medical action. In a situation that we are worried about your safety, the research team may have to tell someone that you were a research participant in this study. Also, if your teen reports that they have been sexually abused, physically abused, or neglected by a parent/guardian or caretaker, we may have to report this information to the Department of Children, Youth, and Families (DCYF).

A description of this clinical trial will be available on <http://www.Clinicaltrials.gov>, as required by U.S. Law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

**8. Are there any alternatives to this study?**

If you or your teen do not want to participate in this study, your teen can still receive any care juvenile court staff believes is useful. If you or your teen choose not to participate in this study, it will not affect your teen's case or any of your teen's court proceedings. If you are interested, you can still receive a list of resources and services in the community.

**9. What if I want to stop, or my teen wants to stop?** You and your teen can stop being in the study any time either of you want; your and your teen's decision to participate in this study will not affect their case or any court proceedings. Your and your teen's decision to participate in this study will not affect current or future relationships with Brown University and/or Lifespan.

**10. Who can I talk to if I have questions about this study?** If you have any questions about this study, you can ask at any time by calling Drs. Spirito, Wolff, or Kemp at (401) 559-9626. You may also contact Dr. Anthony Spirito at (401) 444-1929 or [Anthony\\_Spirito@Brown.edu](mailto:Anthony_Spirito@Brown.edu).

**11. Who can I talk to if I have questions about my or my teen's rights as participants?** If you or your teen have any complaints or questions about this project, you can call the Brown University Human Research Protection Program (HRPP) at (401) 863-3050 or toll-free at (866) 309-2095. You can contact the Brown University HRPP via email at [irb@brown.edu](mailto:irb@brown.edu).

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National Institute of Mental Health Data Archive (NDA)

Data from this study, including information about your teen, may be submitted to the NDA, a data repository run by the National Institute of Mental Health (NIMH) that allows researchers



studying mental illness to collect and share deidentified information with each other. A data repository is a large database where information from many studies is stored. Deidentified information means that all personal information about research participants such as name, address, and phone number is removed and replaced with a code. With an easier way to share, researchers hope to learn new and important things about mental illnesses.

During and after the study, the researchers will send deidentified information about your teen's health and behavior to NDA. Other researchers nationwide can then apply to the NIMH to obtain access to your teen's deidentified study data for research purposes.

Although only your teen's deidentified data will be shared with other researchers requesting access through the NDA, specific identifying information is required by the NDA in order to assign a Global Unique Identifier (GUID) to your teen. This information includes your teen's full name, biological sex, date of birth, and city/state of birth. We will collect this information from you by having you complete an NDA Information Form, if you agree to share your teen's data with the NDA. This information will be submitted to the NIMH via the NDA, and your teen will have a GUID assigned to them and linked only to their identity. NIMH is the only entity that will have access to your teen's identifying information, which will be stored in the NDA GUID database. Once your teen has a GUID within the NDA system, any data collected from your teen in future studies that use the NDA can be linked to the data that we share from this study.

Experts at the NIMH who know how to protect health and science information will look at every request carefully to minimize risks to privacy, and they will not share your teen's identity. The NDA also has a Certificate of Confidentiality to protect your teen's privacy, and that document will not waive any of the protections of the Certificate of Confidentiality granted for this study.

You and your teen may not benefit directly from allowing your teen's information to be shared with NDA. The information provided to NDA may help researchers around the world treat future children and adults with mental illnesses so that they have better outcomes. NIMH will also report to Congress and on its web site about the different studies that researchers are conducting using NDA data. However, you will not be contacted directly about data your teen contributed to NDA.

You may decide now or later that you do not want to share your teen's information using NDA. If you decide in the future that you do not want your teen's information included in the NDA, contact the researchers who conducted this study, and they will tell NDA, which can stop sharing the research information. However, NDA cannot take back information that was shared before you changed your mind. NDA information is available on-line at <https://data-archive.nimh.nih.gov>.

       Please initial here to choose to submit your information in the NDA

Please initial below if you would like to be contacted by our research team for future studies should you/your teen be eligible. This will allow us to contact you if other research opportunities become available, and you can make a decision at that time if you would like to participate.

       I would like to be contacted for future research studies



Your signature below shows that you have read and understood the information in this document, and that you agree for your teen to volunteer as a research participant for this study.

You will be given a copy of this form.

Study Volunteer Initials: \_\_\_\_\_

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Parent participant's Signature and Date

/

PRINTED NAME

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Research Staff Signature and Date

/

PRINTED NAME



Study Volunteer Initials: \_\_\_\_\_

## **Adolescent Assent to Participate in a Research Study**

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Name of Study Volunteer

Reducing the Duration of Untreated Illness Among Youth in the Juvenile Justice System  
Version 5; 4-12-19

### **KEY INFORMATION**

You are invited to take part in a Brown University and Miriam Hospital research study. Your participation is voluntary.

- PURPOSE: We are trying to figure out ways to better help court-involved teenagers who report having upsetting thoughts and feelings. **This is not a treatment study.**
- PROCEDURES: Today you will be asked to complete an interview and questionnaires about your thoughts, feelings, and behaviors. We will also ask you about whether you are interested in receiving counseling services. In three months, you may be asked to complete a follow-up visit including interviews and questionnaires about your feelings and behaviors, as well as any counseling services you received and if these services were helpful.
- TIME INVOLVED: This study begins with today's session which may take up to 2.5 hours. You may be contacted to participate in a follow-up session in three months. If you choose to participate, the follow-up session may take up to 2 hours.
- COMPENSATION: In total, you can receive between \$40 and \$140. Payment for participating in this study will be made using ClinCard, a pre-paid Mastercard that works like a debit card.
- RISKS: You may feel uncomfortable about the sensitive topics discussed and there is a chance of loss of privacy and confidentiality affecting your reputation.
- BENEFITS: You may learn some more about yourself and your thoughts and feelings. You may not directly benefit from being in this research study.
- ALTERNATIVES TO PARTICIPATION: If you do not want to participate in this study, you can still receive any care juvenile court staff believes is useful.

What is the study about? We are trying to figure out ways to improve services for court-involved teenagers who report having upsetting thoughts and feelings.

What will I be asked to do? You will be asked to complete an interview and questionnaires about your thoughts, feelings, and behaviors. We will also ask you about whether you are interested in receiving counseling services. This may take up to 2.5 hours. About three months from now you may be asked to participate in a follow-up study in which you will complete an interview and questionnaires about any counseling you received and if these services were helpful. We will audio record the interviews at both visits so we can double check the answers you give our interviewer.

We will also collect information from your court file, including: information about your involvement with the Rhode Island Family Court, such as number of charges, types of past charges, and whether you receive any new charges during the course of the study. We will also collect information from your mental health screening you received at the Rhode Island Family Court and in previous mental health evaluations, if they are in your court record.

Will I be paid? You will receive \$60 for the time it takes to complete the questionnaires and interviews today. If you complete the interviews but not the questionnaires, you will receive \$40. If you are contacted for a follow-up in three months and choose to participate, you will also receive \$60 for completing the surveys and questionnaires, and \$40 if you only complete the interview but not the questionnaires. If you completed the questionnaires online in advance of today's visit and/or the follow-up visit, you will receive \$10 for each online session in addition to the \$60 for each in-person session. In total, you can receive between \$40 and \$140.

Payment for participating in this study will be made using ClinCard, a pre-paid Mastercard that works like a debit card. You may use this card online or at any store that accepts Mastercard. We will give you the card at the conclusion of today's session. You will be given one card for the entire time of your participation and this card may be used to pay you in any future Brown University study that uses ClinCard. Money will be added to your card based on the study's payment schedule. You will also get information about how to use this card and whom to call if you have any questions. Be sure to read this information from ClinCard company called Greenphire for details about the ways you can use the card, some of which may involve fees that will reduce the amount of money on the card. Greenphire will be given your name, address, and date of birth. They will use this information only as part of the payment system, and it will not be given or sold to any other company. Greenphire will not receive any information about your health status or the study in which you are participating. If your card is lost or stolen, please call the study coordinator for a free replacement. If you request a replacement card from Greenphire, you may be charged a fee.

Research Procedures	All parents	All teens
<b>Baseline Assessment</b> <i>[Parent &amp; teen each earn \$60]            [If teen has completed online survey beforehand, they will receive \$10 bonus]</i>	<u>Parent assessment</u> (about 1 ½ to 2 hours) <ul style="list-style-type: none"> <li>Demographics</li> <li>Parent interview on teen mood and behavior</li> <li>Parent questionnaires on motivations for and barriers to receiving counseling</li> <li>Parent questionnaires on parent's own mood and behavior, and family functioning</li> </ul>	<u>Teenager assessment</u> (about 2 to 2 ½ hours) <ul style="list-style-type: none"> <li>Demographics</li> <li>Interview on thoughts, mood and behavior</li> <li>Questionnaires on thoughts, feelings, behaviors, and motivations for receiving treatment</li> </ul>
<b>3 Month Assessments</b> <i>[Parent &amp; teen each earn \$60. If teen has completed online surveys beforehand, they will receive \$10 bonus]</i>	Parents and teens complete assessments similar to the baseline session, including most of the same questionnaires and shorter interviews on the teen's mood, behavior, and treatment (about 1.5 – 2 hours total). You will also be asked about what services you received in the community and how satisfied you were with those services. Your court records will also be checked for any new charges.	

What are the risks? You will be asked questions of a sensitive nature about your mental health. When you are answering the questions, you may sometimes feel upset or experience emotional distress. You can refuse to answer any questions that you prefer not to answer. You can also stop your participation in the study at any time. There is a risk of loss of privacy in this study including sensitive information on your emotional state. The information you share with us could affect your reputation and employability and could lead to negative legal consequences if it were disclosed with people outside of the study. We take this risk very seriously and we take steps to protect your information. For example, your name will not be on any of the study questionnaires or materials. All of your information will be identified only by a participant number, not by names. Any information you share with us will be stored in locked cabinets or on a secure server or password protected external hard drive in locked offices at Brown University.

How will my information be protected? All of your records from this study will be treated as private records. The records will be protected according to the rules of Brown University. To maintain confidentiality, we will assign all of your data a numerical code. Your name will not be on the questionnaires or interviews. Your online responses will be linked to the responses you give during the in-person assessment. Please note that complete confidentiality can never be guaranteed when information is transmitted over the internet. Information collected during the assessment is treated as confidential and will not be shared in ways other than what is outlined in this document. Paper records will be kept in a locked file cabinet in a locked office at Brown University. All laptop computer data as well as any paper data that is entered into a computer database will be accessible only to research staff members and will be password protected. Only researchers working on this study will have access to the information provided by you.

Brown University and Lifespan staff sometimes review studies like this one to make sure they are being done safely and correctly. If a review of this study takes place, your records may be examined. The reviewers will protect your confidentiality.

In this study we will be audio recording your interviews. We will keep this recording confidential. We will store it only for the duration of the study and destroy it at the conclusion of the study.

We will not disclose details regarding your answers to the court. However, your family's juvenile intake worker may know if you agreed to participate in the study. To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health. The researchers can use this Certificate to legally refuse to disclose information that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings, for example, if there is a court subpoena. The researchers will use the Certificate to resist any demands for information that would identify you, *except as explained below*.

The Certificate cannot be used to resist a demand for information from personnel of the United States federal or state government agency sponsoring the project and that will be used for auditing or program evaluation of agency funded projects. You should understand that a Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, medical care provider, or other person obtains your written consent to receive research information, then the researchers will not use the Certificate to withhold that information.

The Certificate of Confidentiality will not be used to prevent disclosure to state or local authorities of *such as child abuse and neglect, or harm to self or others*. If you report you are

Study Volunteer Initials

actively suicidal, or plan to hurt someone else, we will get you help by telling appropriate authorities and taking appropriate medical action. In a situation that we are worried about your safety, the research team may have to tell someone that you were a research participant in this study. Also, if you report that you have been sexually abused, physically abused, or neglected by a parent/guardian or caretaker, we may have to report this information to the Department of Children, Youth, and Families (DCYF).

A description of this clinical trial will be available on <http://www.Clinicaltrials.gov> as required by U.S. Law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

Are there any alternatives to this study? If you do not want to participate in this study, you can receive any care juvenile court staff believes is useful. If you choose not to participate in this study, it will not affect your case or any of your court proceedings. If you are interested, you can still receive a list of resources and services in the community.

What if I want to stop? If you do not want to be in the study, it is OK to say no. You can stop being in the study any time you want to, and nobody will be upset with you. Your decision to participate in this study will not affect your case or any court proceedings or any current or future relationships with Brown University or Lifespan.

Who can I talk to if I have questions about this study? If you have any questions about this study, you can ask at any time by calling Drs. Spirito, Wolff, or Kemp at (401) 559-9626. You may also contact Dr. Anthony Spirito at (401) 444-1929 or [Anthony\\_Spirito@Brown.edu](mailto:Anthony_Spirito@Brown.edu) .

Who can I talk to if I have questions about my rights as a participant? If you have any complaints or questions about being in the project, you can call the Brown University Human Research Protection Program at (401) 863-3050 or toll-free at (866) 309-2095. You may also email [IRB@brown.edu](mailto:IRB@brown.edu).

Your mom, dad, and/or guardian knows about this study, and they think it is OK for you to participate. Even if your mom, dad, and/or guardian says “yes”, you can still say “no”. If you want to be in this study, you can tell the research staff member and sign the form your parents signed.

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National Institute of Mental Health Data Archive (NDA)

Data from this study, including your information, may be submitted to the NDA, a database that allows researchers studying mental illness to collect and share deidentified information with each other. A data repository is a large database where information from many studies is stored. Deidentified information means that all personal information about research participants such as name, address, and phone number is removed and replaced with a code. With an easier way to share, researchers hope to learn new and important things about mental illnesses.

During and after the study, the researchers will send deidentified information about your health and behavior to NDA. Other researchers nationwide can then apply to obtain access to your deidentified study data for research purposes.

Although only your deidentified data will be shared with other researchers requesting access through the NDA, specific identifying information is required by the NDA in order to assign your information a Global Unique Identifier (GUID). This information includes your full name,



BROWN

Study Volunteer Initials

biological sex, date of birth, and city/state of birth. We will collect this information from you by having you complete an NDA Information Form, if you agree to share your data with the NDA. This information will be submitted to the NDA, a GUID will link your identity, and your identifying information, which will be stored in the NDA GUID database.

Experts at working on the NDA who know how to protect health and science information will minimize risks to your privacy and they will not share your identity. The NDA also has a Certificate of Confidentiality to protect your privacy, and that document will not waive any of the protections of the Certificate of Confidentiality granted for this study.

You may not benefit directly from allowing your information to be shared with NDA. The information provided to NDA may help researchers around the world treat future children and adults with mental illnesses so that they have better outcomes.

You may decide now or later that you do not want to share your information using NDA. If you decide in the future that you do not want your information included in the NDA, contact the researchers who conducted this study, and they will tell NDA, which can stop sharing the research information. However, NDA cannot take back information that was shared before you changed your mind. NDA information is available on-line at <https://data-archive.nimh.nih.gov>.

       Please initial here to choose to submit your information in the NDA

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Teen participant's Signature and Date / PRINTED NAME

I have reviewed this form with the minor participant:

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Research Staff Signature and Date / PRINTED NAME

**BROWN UNIVERSITY**  
**CONSENT FOR RESEARCH PARTICIPATION**  
Teen Consent Form for Self

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Name of Study Volunteer

Reducing the Duration of Untreated Illness among Youth in the Juvenile Justice System  
Version 1; 9-13-19

#### **KEY INFORMATION**

You and your caregiver are invited to take part in a Brown University and Miriam Hospital research study. Your participation is voluntary.

- PURPOSE: We are trying to figure out ways to better help court-involved teens who report having upsetting thoughts and feelings and what types of services help the most. **This is not a treatment study.**
- PROCEDURES: You and your caregiver will be asked to complete interviews and questionnaires about your thoughts, feelings, and behaviors. We will also ask about your interest in receiving counseling services. Three months from now you and your caregiver may be asked to complete a similar follow-up visit, including a few questionnaires about any counseling you received and if these services were helpful.
- TIME INVOLVED: This study begins with today's session which may take up to 2.5 hours. You may be contacted to participate in a follow-up session in three months. If you and your caregiver choose to participate, the follow-up session may take up to 2 hours.
- COMPENSATION: In total, you can receive between \$40 and \$140, and your caregiver can receive between \$60 and \$120. Payment for participating in this study will be made using ClinCard, a pre-paid Mastercard that works like a debit card.
- RISKS: You and/or your caregiver may feel uncomfortable about sensitive topics discussed, and there is a risk of loss of privacy in this study including sensitive information on your emotional state.
- BENEFITS: You/your caregiver may not directly benefit from being in this research study. However, you and your caregiver may learn more about your thoughts and feelings.
- ALTERNATIVES TO PARTICIPATION: If you or your caregiver do not want to participate in this study, you can still receive any care juvenile court staff believes is useful, and you can still receive a list of resources and services in the community.

1. Researchers: This research is being conducted by Anthony Spirito, PhD. He may be contacted at [anthony\\_spirito@brown.edu](mailto:anthony_spirito@brown.edu) or 401-444-1929. Other researchers include Jennifer Wolff, PhD, who can be contacted at [jennifer\\_wolff@brown.edu](mailto:jennifer_wolff@brown.edu) or 401-444-3790, and Kathleen Kemp, PhD, who can be contacted at [kkemp@lifespan.org](mailto:kkemp@lifespan.org) or 401-444-8269. You can contact the study research assistant at 401-559-9626.



2. What is the study about? We are trying to figure out ways to improve services for court-involved teens when they report in their court appointment that they are having upsetting thoughts and feelings.

3. What will you and your caregiver be asked to do? You and your caregiver will each complete interviews and questionnaires about your thoughts, feelings, and behaviors. Your caregiver will also be asked to answer some questions about themselves and your family. We will also ask about how you and your caregiver feel about you receiving counseling services. This may take up to 2.5 hours.

About three months from now, as part of the research study, you and your caregiver may be asked to complete a follow-up visit including most but not all of the same interviews and questionnaires from the first session. Additionally, you and your caregiver will be asked questions about any counseling you have received and if these services have been helpful. This may take up to 2 hours. If you did receive any counseling, we will ask you to sign a release of information form so we can contact your mental health counselor to obtain information about the frequency and type of services received.

We will use digital audio recorders during the interviews at both time points. The purpose of recording audio is to double check the answers you and your caregiver give our interviewer. We will keep this information confidential and available only to approved research staff. We will store these recordings on a secured computer drive for the duration of the study. At the conclusion of the study, we will destroy them.

We will also collect information from your court file, including: information about your involvement with the Rhode Island Family Court, such as number of charges, types of past charges, and whether you received any new charges during the course of the study (3 months after the first session). We will also collect information, if available, from your court file on any mental health screening at the Rhode Island Family Court and previous mental health treatment.

**Standard Court Procedures.** As part of standard court procedures, teens and caregivers will be referred to community for follow-up mental health care or for an immediate evaluation if your intake worker feels that is what is needed now. Intake workers may also review material with you about mental health and contact you about whether you attended your appointment in the community after you leave today. (Note: this portion is not part of the research study)

4. Will you and your caregiver be paid? You and your caregiver will each receive \$60 for the time it takes to complete the questionnaires and interviews today. If you complete the interviews but not the questionnaires, you will receive \$40. If you are contacted for a follow-up in three months and choose to participate, you and your caregiver will also each receive \$60 for completing the surveys and questionnaires at that time. You will receive \$40 if you only complete the interview but not the questionnaires at the follow-up visit. If you complete the online questionnaires in advance of this visit and/or the follow-up visit, you will receive \$10 per online session in addition to the \$60 for each in-person session. In total, you can receive between \$40 and \$140. Your caregiver can receive between \$60 and \$120, in total.

Payment for participating in this study will be made using ClinCard, a pre-paid Mastercard that works like a debit card. We will give you the card at the conclusion of today's session. You will be given one card for the entire time of your study participation and this card may be used to

pay you in any future Brown University studies that uses ClinCard. You will also get information about how to use this card and whom to call if you have any questions. Be sure to read this information, including the cardholder agreement from Greenphire.

Funds will be added to your card based on the study's payment schedule. You may use this card online or at any store that accepts Mastercard. Please read the FAQ information sheet given to you by study staff for details about the ways you can use the card, some of which may involve fees that will reduce the amount of money on the card.

If you earn \$600 or more from Brown University in a single calendar year (either in a one study or across multiple studies), Brown will request your social security number to correctly identify you in the payment system and issue you an IRS 1099 Form. You may also be asked to complete a Form W9. This may affect your taxes. Only payments for being in research studies will be used to decide if you should receive the IRS form. Money for study-related parking, transportation, and other expenses are not included in this IRS disclosure.

This card is administered by an outside company called Greenphire. Greenphire will be given your name, address, and date of birth. They will use this information only as part of the payment system, and it will not be given or sold to any other company. Greenphire will not receive any information about your health status or the study in which you are participating.

If your card is lost or stolen, please call the study coordinator for a free replacement card. If you request a replacement card from Greenphire directly, you may be charged a fee.

<b>Research Procedures</b>	<b>All parents</b>	<b>All teens</b>
<b>Baseline Assessment</b> <i>[Parent &amp; teen each earn \$60, teen earns additional \$10 if surveys completed online ahead of time]</i>	<p>Parent assessment (about 1 ½ to 2 hours)</p> <ul style="list-style-type: none"> <li>Demographic information</li> <li>Parent interview on teen mood and behavior and teen's treatment history</li> <li>Parent questionnaires on motivation for and barriers to receiving counseling</li> <li>Parent questionnaires on parent's own mood, behavior, and family functioning</li> </ul>	<p>Teen assessment (about 2 to 2 ½ hours)</p> <ul style="list-style-type: none"> <li>Demographic information</li> <li>Adolescent interview on thoughts, mood and behavior</li> <li>Adolescent questionnaires on thoughts, mood, behavior, motivation for receiving treatment, and treatment history</li> </ul>
<b>3 Month Assessments</b> <i>[Parent &amp; teen each earn \$60, teen earns additional \$10 if surveys completed online ahead of time]</i>	<p>You and your caregiver complete assessments similar to the baseline session, including most of the same questionnaires and shorter interviews on the teen's mood, behavior, and treatment (about 1.5 – 2 hours total). You and your caregiver will also be asked about what services your teen received in the community and how satisfied you both were with those services. Your teen's court records will also be checked for any new charges.</p>	

5. What are the risks? You and your caregiver will be asked questions of a sensitive nature about mental health experiences. Answering the questions may sometimes make you or your caregiver feel upset or experience emotional distress. You and/or your caregiver can refuse to answer any questions you do not like. You and/or your caregiver can also stop participation in at any time.

There is a risk of loss of privacy in this study including sensitive information on your or your caregiver's emotional state. The information you and your caregiver share with us could affect your or your caregiver's reputation and employability and could lead to negative legal consequences if it were disclosed with people outside of the study. We take this risk very seriously, and we will take steps to protect your family's information. For example, your or your caregiver's name will not be on any of the study questionnaires or materials. All of your and your caregiver's information will be identified only by a code number, not by names. Any information you and your caregiver share with us will be stored in locked cabinets or on a secure server or a password protected external hard drive in locked offices at Brown University.

6. What are the benefits? This study may not benefit you or your caregiver personally. However, by answering these questions and taking part in the assessment, parents and teens may have the opportunity to learn more about themselves and each other.

There is a possibility that participating in this research study may positively affect your relationship with Rhode Island Family Court by satisfying the intake worker's concerns you should receive further mental health evaluation. However, this cannot be guaranteed, and the same positive effect may occur by arranging for further mental health evaluation outside of being in this study.

7. How will my and my caregiver's information be protected? All records from this study will be treated as private records. The records will be protected according to the rules of Brown University. To maintain confidentiality, we will assign all of your and your caregiver's data a numerical code. Your and your caregiver's name will not be on the questionnaires or interview forms. Your online responses will be linked to responses obtained during the in-person assessment. Please note that complete confidentiality can never be guaranteed when information is transmitted over the internet. Information collected during the assessment is treated as confidential and will not be shared in ways other than what is outlined in this document. Paper records will be kept in a locked filing cabinet in a locked office at Brown University. All laptop computer data as well as any paper data that is entered into a computer database will be accessible only to research staff members and will be password protected. Only researchers working on this study will have access to the information provided by you and your caregiver.

Brown University and Lifespan staff sometimes review studies like this one to make sure they are being done safely and correctly. If a review of this study takes place, your records may be examined. The reviewers will protect your confidentiality.

In this study we will be audio recording your interviews. We will keep this recording confidential. We will store it only for the duration of the study and destroy it at the conclusion of the study.

We will not disclose details regarding your answers to the court. However, your family's juvenile



intake worker may know if you agreed to participate in the study. To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health. The researchers can use this Certificate to legally refuse to disclose information that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings, for example, if there is a court subpoena. The researchers will use the Certificate to resist any demands for information that would identify you, *except as explained below:*

The Certificate cannot be used to resist a demand for information from personnel of the United States federal or state government agency sponsoring the project and that will be used for auditing or program evaluation of agency funded projects. You should understand that a Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself, your caregiver, or your and/or your caregiver's involvement in this research. If an insurer, medical care provider, or other person obtains your written consent to receive research information, then the researchers will not use the Certificate to withhold that information.

The Certificate of Confidentiality will not be used to prevent disclosure to state or local authorities of *such as child abuse and neglect, or harm to self or others*. If you report you are actively suicidal, or plan to hurt someone else, we will get you help by telling appropriate authorities and taking appropriate medical action. In a situation that we are worried about your safety, the research team may have to tell someone that you were a research participant in this study. Also, if you report that you have been sexually abused, physically abused, or neglected by a parent/guardian or caretaker, we may have to report this information to the Department of Children, Youth, and Families (DCYF).

A description of this clinical trial will be available on <http://www.Clinicaltrials.gov>, as required by U.S. Law. This website will not include information that can identify you. At most, the website will include a summary of the results. You can search this website at any time.

**8. Are there any alternatives to this study?**

If you or your caregiver do not want to participate in this study, you can still receive any care juvenile court staff believes is useful. If you or your caregiver choose not to participate in this study, it will not affect your case or any of your court proceedings. If you are interested, you can still receive a list of resources and services in the community.

**9. What if I want to stop, or my caregiver wants to stop?** You and your caregiver can stop being in the study any time either of you want; your and your caregiver's decision to participate in this study will not affect your case or any court proceedings. Your and your caregiver's decision to participate in this study will not affect current or future relationships with Brown University and/or Lifespan.

**10. Who can I talk to if I have questions about this study?** If you have any questions about this study, you can ask at any time by calling Drs. Spirito, Wolff, or Kemp at (401) 559-9626. You may also contact Dr. Anthony Spirito at (401) 444-1929 or [Anthony\\_Spirito@Brown.edu](mailto:Anthony_Spirito@Brown.edu).

**11. Who can I talk to if I have questions about my or my caregiver's rights as participants?** If you or your caregiver have any complaints or questions about this project, you can call the Brown University Human Research Protection Program (HRPP) at (401) 863-3050 or toll-free at (866) 309-2095. You can contact the Brown University HRPP via email at [irb@brown.edu](mailto:irb@brown.edu).



Data from this study, including information about yourself and/or your caregiver, may be submitted to the NDA, a data repository run by the National Institute of Mental Health (NIMH) that allows researchers studying mental illness to collect and share deidentified information with each other. A data repository is a large database where information from many studies is stored. Deidentified information means that all personal information about research participants such as name, address, and phone number is removed and replaced with a code. With an easier way to share, researchers hope to learn new and important things about mental illnesses.

During and after the study, the researchers will send deidentified information about your health and behavior to NDA. Other researchers nationwide can then apply to the NIMH to obtain access to your deidentified study data for research purposes.

Although only your deidentified data will be shared with other researchers requesting access through the NDA, specific identifying information is required by the NDA in order to assign a Global Unique Identifier (GUID) to you. This information includes your full name, biological sex, date of birth, and city/state of birth. We will collect this information from you by having you complete an NDA Information Form, if you agree to share your data with the NDA. This information will be submitted to the NIMH via the NDA, and you will have a GUID assigned to you and linked only to your identity. NIMH is the only entity that will have access to your identifying information, which will be stored in the NDA GUID database. Once you have a GUID within the NDA system, any data collected from you in future studies that use the NDA can be linked to the data that we share from this study.

Experts at the NIMH who know how to protect health and science information will look at every request carefully to minimize risks to privacy, and they will not share your identity. The NDA also has a Certificate of Confidentiality to protect your privacy, and that document will not waive any of the protections of the Certificate of Confidentiality granted for this study.

You and your caregiver may not benefit directly from allowing your information to be shared with NDA. The information provided to NDA may help researchers around the world treat future children and adults with mental illnesses so that they have better outcomes. NIMH will also report to Congress and on its website about the different studies that researchers are conducting using NDA data. However, you will not be contacted directly about data you contributed to NDA.

You may decide now or later that you do not want to share your information using NDA. If you decide in the future that you do not want your information included in the NDA, contact the researchers who conducted this study, and they will tell NDA, which can stop sharing the research information. However, NDA cannot take back information that was shared before you changed your mind. NDA information is available on-line at <https://data-archive.nimh.nih.gov>.

\_\_\_\_\_ Please initial here to choose to submit your information in the NDA.

Please initial below if you would like to be contacted by our research team for future studies should you/your caregiver be eligible. This will allow us to contact you if other research opportunities become available, and you can make a decision at that time if you would like to participate.

\_\_\_\_\_ I would like to be contacted for future research studies.

Your signature below shows that you have read and understood the information in this document, and that you agree to volunteer as a research participant for this study.



BROWN

Study Volunteer Initials: \_\_\_\_\_

You will be given a copy of this form.

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Teen participant's Signature and Date

/

PRINTED NAME

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Research Staff Signature and Date

/

PRINTED NAME

**BROWN UNIVERSITY**  
**ONLINE CONSENT FOR RESEARCH**  
**PARTICIPATION: TEEN FOR SELF**

Reducing the Duration of Untreated Illness Among Youth in the Juvenile Justice System  
Version #1; September 13, 2019

You and your caregiver are invited to take part in a Brown University and Miriam Hospital research study. Participation is voluntary.

- **RESEARCHERS:** Anthony Spirito, Ph.D., Jennifer Wolff, PhD, and Kathleen Kemp, PhD
- **PURPOSE:** We are trying to figure out ways to better help court-involved teenagers who report having upsetting thoughts and feelings and what types of services help the most. This is not a treatment study.
- **PROCEDURES:** This study involves online questionnaires and at least one in-person assessment. For the online part of the study, you and your caregiver will be asked to complete a few personal questionnaires relating to your thoughts, emotions, and behaviors. At the in-person visit, we will fully explain what that part of the study involves, and you will have the option to ask questions and agree to the remainder of the study if you would like to. If you agree, you and your caregiver will complete questionnaires and interviews about thoughts, feelings, behaviors, and attitudes. You can decide to decline any part of the study you wish.
- **TIME INVOLVED:** The online surveys will take up to 20 minutes. The in-person visit will take 2-2.5hrs.
- **COMPENSATION:** You will receive \$10 for completing these surveys at the time of the in-person assessment you have already scheduled with study staff. You and your caregiver will receive additional compensation (\$40-\$60 each) for each in-person visit completed. Payment for participating in this study will be made using ClinCard, a pre-paid Mastercard that works like a debit card. NOTE: Your teen will not receive compensation for these surveys (\$10) if you do not attend the in-person assessment. If you do not attend an in-person assessment within 30 days of completing this survey, we will destroy your responses.
- **RISKS:** Some of the questions may make you feel uncomfortable. You may skip any questions you prefer not to answer or do not feel comfortable answering. This will not impact your participation in the study. These assessments will not be reviewed immediately. All participants will receive a list of contacts if they want to speak to someone about any health concerns or abuse- this list will be given to you and your caregiver at the in-person visit. There is a risk of loss of privacy in this study including sensitive information on your emotional state.
- **BENEFITS:** You/your caregiver may not directly benefit from being in this research study.
- **ALTERNATIVES TO PARTICIPATION:** If you or your caregiver do not want to participate in this study, you can still receive any care juvenile court staff believes is useful.
- **CONFIDENTIALITY:** To maintain confidentiality, we will assign all of your data a numerical code. Your responses will not be connected to your identity. Your online responses will be linked to responses obtained during the in-person assessment. We will not share your responses with court staff or anyone outside of this research project. However, your family's juvenile intake worker may know if you agreed to participate in the study. Please note that complete confidentiality can never be guaranteed when information



is transmitted over the internet. Brown University and Lifespan staff sometimes review studies like this one to make sure they are being done safely and correctly. If a review of this study takes place, your records may be examined. Reviewers will protect your confidentiality. A description of this clinical trial will be available on <http://www.ClinicalTrials.gov>, as required by U.S. law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

To help us protect your privacy, we have a Certificate of Confidentiality. We can use this to:

- Refuse to disclose information that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings (e.g., a court subpoena).
- Resist any demands for information that would identify you, except as explained below.

The Certificate WILL NOT be used to:

- Resist a demand for information from personnel of the U.S. government agency sponsoring the project and that will be used for auditing or program evaluation of agency funded projects.
- Withhold information from an insurer, medical care provider, or other person who obtains your written consent to receive research information.
- Prevent disclosure to authorities of child abuse and neglect, or harm to self or others.

NOTE: The Certificate DOES NOT prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research.

- VOLUNTARY: You do not have to be in this study if you do not want to be. Even if you decide to be in this study, you can change your mind and stop at any time. You and your caregiver's decision to participate in this study will not affect your case or any court proceedings.
- CONTACT INFORMATION: If you have any questions about your participation in this study, you can ask at any time by calling Drs. Spirito, Wolff, or Kemp at (401) 559-9626. You may also contact Dr. Spirito by calling (401) 444-1929 or emailing [anthony\\_spirito@brown.edu](mailto:anthony_spirito@brown.edu).
- YOUR RIGHTS: If you have questions about your rights as a research participant, you can contact Brown University's Human Research Protection Program at 401-863-3050 or email them at [IRB@Brown.edu](mailto:IRB@Brown.edu).
- CONSENT: Clicking the link below confirms that you: 1) have read and understood the information in this document, 2) are 18 years of age or older and 3) volunteer to participate in this study. You can print a copy of this form.

**I Want to Participate [unique link to RedCap surveys]**



**Agreement to Participate in a Research Study:**  
Juvenile Intake Worker Consent Form

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Name of Study Volunteer

Reducing the Duration of Untreated Illness Among Youth in the Juvenile Justice System

Version 3; 10-29-18

**KEY INFORMATION**

You are being asked to take part in a Brown University and Miriam Hospital research study. Your participation is voluntary.

- **PURPOSE:** We are trying to figure out ways to better help court-involved teenagers who may have thought disturbances. You are being asked to participate in this study because you work with teens in the court system and participated in a Quality Improvement program designed to improve psychoeducation and appropriate mental health referrals for teens with thought disturbances who are seen in court-related proceedings.
- **PROCEDURES:** Today, you will complete an interview and some questionnaires about screening and referral of teens with thought disturbances. This will take about 30 minutes.
- **TIME INVOLVED:** Up to 30 minutes per interview.
- **COMPENSATION:** None
- **RISKS:** You may feel uncomfortable answering some questions and there is a chance of loss of privacy and confidentiality.
- **BENEFITS:** There are no benefits to you.

1. **Researcher:** This research is being conducted by Anthony Spirito, PhD. He may be contacted at [anthony.spirito@brown.edu](mailto:anthony.spirito@brown.edu) or 401-444-1929.

2. **What is the study about?** You are being asked to participate in this research project because you have been identified as someone who sees teens with mental health concerns in the juvenile court system and took part in the Quality Improvement program to enhance referral of these teens to treatment. The purpose of this research project is to understand how effective you believe the enhanced screening and referral program for teens with signs of a thought disturbance has been. This research is sponsored by the National Institutes of Health.
3. **What will I be asked to do?** If you decide to take part in this study, you will be asked to participate in an interview to find out your ideas about the enhanced screening and brief intervention for these teens in the court system. You will also be asked to identify the best ways to sustain the program into the court system in the future and to complete one questionnaire. The interviews will be held in a private room at the Family Court or affiliated Family Court offices in the community. This will take about 30 minutes. All of



your responses to the interview questions will be audio or video-recorded. You can request to stop audio recording at any time. These audiotapes will only be labeled with a study code and will not include labels with names. These audiotapes will be stored in a locked file cabinet and only study staff will have access to these tapes. These tapes will not be provided to the Court. We will destroy the digital audio files after the recordings have been transcribed, which will occur around the completion of the study. The transcriptions of the interviews will be de-identified.

4. Will I be paid? Court personnel, administrators, and intake workers are unable to receive compensation for participation in a research study. Therefore, a one-time donation of \$300 will be donated to your department to help support mental health and substance use screening efforts.
5. What are the risks? The questionnaire that you will complete are commonly used in research. It is possible that you may become upset or experience emotional distress when answering questions. You may choose not to answer any questions and you may stop your participation in the study at any time. There is a risk of loss of privacy or confidentiality of your answers. We take this risk very seriously, and we will take steps to protect your information. We describe the steps we will take below.
6. What are the benefits? This study will not benefit you personally.
7. Are there any alternatives to this study? There are no alternatives to participation in this study.
8. How will my information be protected? All of your records from this study will be treated as private records. The records will be protected according to the rules of Brown University. Your name will not be on the questionnaires. During audio or video assessments, you will be asked to use your first name only. All information will be identified only by a code number, not your name. Information collected during the assessment is treated as confidential and will not be shared. Records will be kept in a locked filing cabinet in a locked office at Brown University. All audio and video recordings will be stored on a secure server or a password protected, external hard drive stored in a locked cabinet. Only researchers working on this study will have access to the information provided by you.

Brown University and Lifespan staff sometimes review studies like this one to make sure they are being done safely and correctly. If a review of this study takes place, your records may be examined. The reviewers will protect your confidentiality.

All laptop computer data as well as any paper data that is entered into a computer database will be accessible only to research staff members and will be password protected. All paper data will be stored in locked file cabinets behind locked doors and will only be accessible to research staff members. Only research staff who have direct contact with you will have access to your identity.

To further keep others from learning about your participation in this study, we have gotten a Certificate of Confidentiality from the federal agency giving us money for this study. With



this certificate, the research team cannot be forced to tell (even if the court orders us to do so) any information that would identify you.

A description of this study will be available on <http://www.Clinicaltrials.gov> as required by U.S. Law. This website will not include information that can identify you. At most, the website will include a summary of the results. You can search this website at any time.

9. What if I want to stop? Participation is voluntary. Also, if you decide now to participate, you will be able to change your mind later and withdraw from the study. There will be no penalty if you decide to withdraw from the study later.

10. Who can I talk to if I have questions about this study? If you have questions, you can email or call Anthony Spirito, PhD. He may be contacted at [anthony.spirito@brown.edu](mailto:anthony.spirito@brown.edu) or 401-444-1929.

11. Who can I talk to if I have questions about my rights as a participant? If you have any complaints about your participation in this study, or would like more information about the rules for research studies, or the rights of people who take part in those studies, you may contact the Brown University Human Research Protection Program anonymously, if you wish, at (401) 863- 3050 or toll-free at (866) 309-2095.

### **Consent to participate**

Your signature below shows that you have read and understood the information in this document, and that you agree to volunteer as a research participant for this study.

You will be offered a copy of this form.

*I* PRINTED NAME

Participant's Signature and Date

*I* PRINTED NAME

Research Staff Signature and Date



**Agreement to Participate in a Research Study:**  
Stakeholder Consent Form

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Name of Study Volunteer

Reducing the Duration of Untreated Illness Among Youth in the Juvenile Justice System

Version 3; 10-29-18

**KEY INFORMATION**

You are being asked to take part in a Brown University and Miriam Hospital research study. Your participation is voluntary.

- PURPOSE: We are trying to figure out ways to better help court-involved teenagers who may have thought disturbances. We want to find out what you think about ways to assist families in trying to get their teens to the appropriate mental health treatment.
- PROCEDURES: You will be asked to complete an interview and questionnaire about screening and referral programs for these teens.
- TIME INVOLVED: Up to 30 minutes per interview
- COMPENSATION: None
- RISKS: You may feel uncomfortable answering some questions and there is a chance of loss of privacy and confidentiality.
- BENEFITS: There are no benefits to you.

1. Researcher: This research is being conducted by Anthony Spirito, PhD. He may be contacted at [anthony.spirito@brown.edu](mailto:anthony.spirito@brown.edu) or 401-444-1929.

2. What is the study about?

You are being asked to participate in this research project because you have been identified as a key stakeholder from the juvenile court system interested in the treatment of teens with thought disturbances. The purpose of this research project is to understand how effective you believe a screening and referral program for teens with signs of a thought disturbance could be and how it might be sustained in the juvenile court system. This research is sponsored by the National Institutes of Health.

3. What will I be asked to do?

If you decide to take part in this study, you will be asked to participate in an interview conducted by a member of our research team. The goal of the interview will be to understand how the program for teens with signs of a thought disturbance being tested within the juvenile court system has been received by the court administration and staff. You will also be asked to identify the best ways to incorporate the program into the court system in the future. You will be asked to complete a questionnaire and an interview. This will last approximately 30 minutes and will be scheduled at your convenience. The interviews will be held in a private room at the Family Court or affiliated Family Court offices in the community.



All of your responses to the interview questions will be audio or video-recorded. You can request to stop audio recording at any time. These audiotapes will only be labeled with a study code and will not include labels with names. These audiotapes will be stored in a locked file cabinet and only study staff will have access to these tapes. These tapes will not be provided to the Court. We will destroy the digital audio files after the recordings have been transcribed, which will occur around the completion of the study. The transcriptions of the interviews will be de-identified.

**4. Will I be paid?**

Court personnel, administrators, and intake workers are unable to receive compensation for participation in a research study. Therefore, a one-time donation of \$300 will be donated to your department to help support mental health and substance use screening efforts.

**5. What are the risks?**

The questionnaires and interview that you will answer are commonly used in research. It is possible that you may become upset or experience emotional distress when answering questions. You may choose not to answer any questions and you may stop your participation in the study at any time. There is a risk of loss of privacy or confidentiality of your answers. We take this risk very seriously, and we will take steps to protect your information. We describe the steps we will take below.

**6. What are the benefits?**

This study will not benefit you personally.

**7. Are there any alternatives to this study?** There are no alternatives to participation in this study.

**8. How will my information be protected?**

All of your records from this study will be treated as private records. The records will be protected according to the rules of Brown University. Your name will not be on the questionnaires. During audio or video assessments, you will be asked to use your first names only. All information will be identified only by a code number, not your name. Information collected during the assessment are treated as confidential and will not be shared. Records will be kept in a locked filing cabinet in a locked office at Brown University. All audio and video recordings will be stored on a secure server or a password protected, external hard drive stored in a locked cabinet. Only researchers working on this study will have access to the information provided by you.

Brown University and Lifespan staff sometimes review studies like this one to make sure they are being done safely and correctly. If a review of this study takes place, your records may be examined. The reviewers will protect your confidentiality.

To further keep others from learning about your participation in this study, we have gotten a Certificate of Confidentiality from the federal agency giving us money for this study. With this certificate, the research team cannot be forced to tell (even if the court orders us to do so) any information that would identify you.



BROWN

Study Volunteer Initials

A description of this study will be available on <http://www.Clinicaltrials.gov> as required by U.S. Law. This website will not include information that can identify you. At most, the website will include a summary of the results. You can search this website at any time.

**Consent to participate**

Your signature below shows that you have read and understood the information in this document, and that you agree to volunteer as a research participant for this study.

You will be offered a copy of this form.

Participant's Signature and Date

*I*

PRINTED NAME

Research Staff Signature and Date

*I*

PRINTED NAME

# NDA E-consent

Please complete the survey below.

Thank you!

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- **WHAT IS A DATA REPOSITORY?**

A data repository holds research data and makes that data available for future use by the broader research community. Data repositories may have specific requirements about the research topic, data re-use and access, file format, and data structure that can be used. Many data repositories have restrictions on who can add and access data.

- **WHAT IS RESEARCH DATA?**

Research data is any information or biospecimens (identifiable or anonymous) you provide to the research team for the purposes of conducting this research study.

- **WHAT IS PERSONALLY IDENTIFIABLE INFORMATION (PII)?**

Personally Identifiable Information (PII) is the information that can be used to recognize or trace your identity, such as your name, social security number, finger prints, and DNA sequence.

- **WHAT WILL HAPPEN TO MY RESEARCH DATA?**

If you allow us to share your research data with an NIH data repository, we will need to collect your personal information as it appears on your birth certificate (first name, middle name [if applicable], last name, date of birth, sex, and town/city/municipality of birth). This PII will be used to create a Global Unique Identifier (GUID), so your research data can be properly catalogued in the data repository. Your PII will never be shared with the data repository.

Other researchers can apply to the data repository to receive a copy of your GUID and research data for their own research. Your PII will never be shared with these researchers.

- **WHAT ARE THE RISKS?**

Your research data could be accidentally shared with someone who may attempt to learn your identity.

- **WHAT ARE THE BENEFITS?**

You will likely not benefit directly from allowing your research data to be shared with the data repository.

- **DO I HAVE TO DECIDE NOW?**

You may decide to share or stop sharing your research data with the data repository at any time by contacting the research team (email and phone number) and asking them to start or stop sharing your research data with the data repository.

Creating a GUID and sharing your data with the data repository are optional and not required to participate in this study.

- **CAN INFORMATION ABOUT ME BE DESTROYED?**

Your GUID and your research data in the repository will be destroyed upon your request.

However, once shared with other researchers, the shared copy of your GUID and your research data cannot be destroyed.

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1)

- DECLINE TO SHARE DATA:** I do not want the research team to share my research data with an NIH data repository.
- PERMISSION TO SHARE DATA:** I give permission for the research team to use my personal information as it appears on my birth certificate (first name, middle name [if applicable], last name, date of birth, sex, and town/city/municipality of birth) to create a GUID and share my research data with an NIH data repository.

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2) Printed Name:

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3) Signature:

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4) Date:

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