

**Title of Research Study:**

Testing the impact of the PROACTIVE parent program with the caregivers of youth in the child welfare system

IRB Number: STU00214486

**Principal Investigator:**

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**Supported By:**

This research is supported by an internal grant awarded by Northwestern's Department of Psychiatry and Behavioral Sciences. This internal grant was funded by the Ken and Ruth Davee Foundation.

**Key Information about this research study:**

The following is a short summary of this study to help you decide whether you want to participate. This research study aims to test the impact of a new program called "PROACTIVE Parent." This program is designed to help foster parents better understand their youth's mental health needs, gain skills that can help them support their youth's mental wellbeing, and, if necessary, locate mental health services. In other words, this program is designed to help foster parents improve their skills to more effectively manage their youth in care's behavior and social and emotional needs.

If you agree to participate, you will be asked to meet with a parent coach for 30-60 minutes for up to 10 sessions over the course of up to 12 weeks. In these meetings, you will learn about your youth's mental health needs while also learning skills to promote mental wellness. You will also be asked to complete a series of surveys before your first session and after your last session.

We expect that you will be in the research project for up to 12 weeks.

The primary risk of participation for you is feeling uncomfortable talking about mental health with the research team.

The main benefit of participation is that you will learn skills that will help you improve your and your youth's mental wellbeing.

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.

We expect about 50 parents will be in this research study.

You can ask all the questions you want before you decide.

**Why am I being asked to take part in this research study?**

We are asking you to take part in this research study because you are a foster parent to a child with mental health needs residing in Illinois.

**How many people will be in this study?**

We expect about 50 foster parents will be in this research study.

**What should I know about participating in a research study?**

- Someone will explain the research study to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide.
- You do not have to answer any question you do not want to answer.

**What happens if I say, “Yes, I want to be in this research”?**

If you agree to participate, you will receive the PROACTIVE Parenting intervention via Zoom over the course of up to 12 weeks. Before beginning and after finishing the program, you will complete a survey consisting of questionnaires that will look at how empowered you feel in navigating your youth's care, your skills, knowledge, and ability to manage their mental health care services, your child's levels of depression and anxiety, and your ability to regulate your emotions. You will also answer demographic questions related to you, your youth in care, and the services your youth in care/family receives. During the intervention, you will meet with a parent coach, an internal member of the Northwestern research team, once a week for 30-60 minutes. During these sessions, you will be asked to have your video on. If you choose not to have your video on, the parent coach choose to cancel/reschedule the session. If you and your parent coach feel you need additional time to talk about the skills you learn or to find mental health services in your area for your youth in care, there is the possibility that additional sessions can be scheduled.

We would like to record (e.g. both audio and visual recordings) the sessions in order to promote training and program development. You have the option to opt out of recordings in this consent form.

**Will being in this study help me in any way?**

We cannot promise any benefits to you or others from your taking part in this research. However, possible benefits include improved knowledge of your youth in care's mental health needs, learning skills that will best support your youth's social, emotional, and behavioral needs, and increased knowledge about how to find evidence-based mental health services in your community.

**Is there any way being in this study could be bad for me?**

Although there will not be any direct risks, one possible risk of participation is feelings of anxiety or discomfort from sharing personal and potentially sensitive information regarding yourself and your

child with research study staff. However, it's voluntary for you to participate in the study or to share any information. You do not have to answer question that makes you uncomfortable, and if you wish, you can stop participating in the study at any time.

A possible risk for any research is that confidentiality could be compromised – that is, that people outside the study might get hold of confidential study information. We will do everything we can to minimize this risk, as described in more detail later in this form. All information will be stored on Northwestern University's secure server. In addition, this information will only be accessible to authorized personnel (e.g. the research staff, Northwestern IRB).

### **What happens if I do not want to be in this research, or I change my mind later?**

Participation in research is voluntary. You can decide to participate or not to participate. If you do not want to be in this study or withdraw from the study at any point, your decision will not affect your relationship including access to services and support with Northwestern University/Northwestern Memorial Healthcare, the Department of Children and Family Services, or the agency with whom you work regarding the specialized foster care program.

You can leave the research at any time and it will not be held against you. You just have to let your parent coach or another research team member know.

If you decide to withdraw from this study, the researchers will ask you if information already collected from you can be used.

### **How will the researchers protect my information?**

Efforts will be made to limit the use and disclosure of you and your child's personal information, including research study records, to people who have a need to review this information. We cannot promise complete secrecy. Organizations that may inspect and copy your information include the IRB and other representatives of this institution. The following conditions also apply:

If research staff and/or parent coaches identify a need for more comprehensive mental health services, we will direct participants to identify referrals to mental health care providers for you or your youth in care upon your agreement using DCFS' Service Provider Identification & Exploration Resource. This resource can be found at <https://spider.dcf.illinois.gov/Search/SearchAgency>. In addition, your case worker will be contacted to help identify mental health resources for you or for your child.

If your responses indicate that either you or your youth in care is experiencing suicidal ideations, we will contact the case worker that supports your youth in care. If we cannot contact your case worker, we will contact a representative at the agency at which your case worker works. If we are not able to contact your child's case worker or the agency, we are required to contact emergency services.

If we suspect potential risk for or perpetration of child abuse or neglect, we, the research staff and/or parent coaches are required and permitted by Illinois law and Northwestern University policy to immediately report relevant information to DCFS.

**Who will have access to the information collected during this research study?**

Efforts will be made to limit the use and disclosure of your personal information, including research study records, to people who have a need to review this information. We cannot promise complete secrecy.

There are reasons why information about you may be used or seen by other people beyond the research team during or after this study. Examples include:

- University officials, government officials, study funders, auditors, and the Institutional Review Board may need access to the study information to make sure the study is done in a safe and appropriate manner.
- The research team may give information to appropriate authorities for reasons of health and safety – for example, if you indicate that you plan to harm yourself or others, or for public health reasons.

We will not ask you about child abuse, but if you tell us about child abuse or neglect, we may be required or permitted by law or policy to report to authorities.

Most tests done in research studies are only for research and have no clear meaning for you or your youth's mental health needs. If the research results have meaning for your health, the researchers will contact you to let you know what they have found.

**How might the information collected in this study be shared in the future?**

We will keep the information we collect about you during this research study for study recordkeeping. Your name and other information that can directly identify you will be stored securely and separately from the rest of the research information we collect from you.

De-identified data from this study may be shared with the research community, with journals in which study results are published, and with databases and data repositories used for research. We will remove or code any personal information that could directly identify you before the study data are shared. Despite these measures, we cannot guarantee anonymity of your personal data.

**Will I be paid or given anything for taking part in this study?**

If you agree to take part in this research study, we will pay you \$20 for attending and completing the initial session. You will also be paid \$20 after completing the final assessment. This means, in total, you will be paid up to \$40 for your participation. You will either be paid via a physical or virtual gift card.

**Who can I talk to?**

If you have questions, concerns, or complaints, you can contact:

Research Project Manager, Ashley Murphy, at [ashley.murphy@northwestern.edu](mailto:ashley.murphy@northwestern.edu)

Principal Investigator, Heather Risser, at [heather.risser@northwestern.edu](mailto:heather.risser@northwestern.edu)

This research has been reviewed and approved by an Institutional Review Board ("IRB"). You may talk to them at (312) 503-9338 or [irb@northwestern.edu](mailto:irb@northwestern.edu) if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

**Optional Elements:**

The following research activities are optional, meaning that you do not have to agree to them in order to participate in the research study. Please indicate your willingness to participate in these optional activities by placing your initials next to each activity.

**Example Optional Elements**

I agree      I disagree

The researcher may video record me to aid with quality improvement and training. The researcher will not share these recordings with anyone outside of the immediate study team.

The researcher may keep my contact information in order to contact me in the future to see whether I am interested in participating in other research studies by the Principal Investigator.

**Electronic Consent**

By providing your name and date, this document indicates your permission to take part in this research.

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Name of Participant

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Date

If you are the research member, please click this link to access the form to place your e-signature conforming that consent was obtained:

<https://redcap.nubic.northwestern.edu/redcap/surveys/?s=4PFLPF3ETW>