
Using Participatory Design to Give Foster Teens a Voice in Designs for Their Own Online Safety

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Abstract

Compared to typical teens, **teens in foster care** face higher levels of offline risks, but little research has determined if this is also true regarding their online risk experiences. Yet, studying this underserved population poses many ethical challenges, including: 1) consent and assent, 2) confidentiality and privacy, and 3) sensitive data. We propose using **participatory design** as a method to help ensure that the ethical concerns around balancing privacy and disclosure, trade-offs between privacy and beneficial outcomes, and collecting and analyzing foster youth data, are calibrated to the specific needs of our user population.

Author Keywords

Adolescents; Foster Care; Ethics; Participatory Design.

ACM Classification Keywords

K.4.1 Computers and Society: Public Policy Issues

Introduction

In the U.S. alone, approximately 400,000 children are removed from their homes and placed into foster care each year, and approximately 30% of these youth are between the ages of 13 and 20 [3]. While research has shown these adolescents demonstrate significantly greater involvement in different high-risk behaviors [8], we remain uncertain how technology may play a part in foster teens' risk behaviors [4]. To address this research question, we plan to study youth within the foster system, including their online behaviors, risks they encounter online, and ways to potentially mitigate these risks. In this position paper, we outline some of the key ethical challenges we have faced as we embark on this research and propose using participatory design to address some of these challenges.

Formative Work

While adolescents' use of technology has been a specific topic of interest for the CSCW community [2,12], there has been little focus on teens in foster care. We have begun to investigate the problem space of online safety for teens in foster care by conducting semi-structured interviews with a convenience sample

of eight foster parents of teens [1]. Our initial findings have shown a great need for future research in this area as foster parents have confirmed that youth are using technologies to facilitate high-risk behaviors that have led to severe consequences, such as involvement in sex trafficking, rape, and emotional dysregulation through abusive online relationships.

Yet, our end goal is to engage with foster youth directly, as opposed to relying on reports from foster parents. While we have been able to gain access to foster youth in group homes within the state of Florida (where the research is being conducted), we have encountered a number of barriers for moving forward. We discuss the context of our research, the ethical challenges we have encountered, and participatory design as a potential strategy for mitigating these obstacles. Our goal is to balance the trade-offs between privacy protection and conducting research that would benefit underserved populations of teens in foster care.

Ethical Challenges

Consent and Assent

Because foster youth are often considered wards of the state after they are removed from the homes of their biological parents, the IRB consent and assent process becomes complex. Federal, state, and local laws govern the participation of wards in research. No clear guidelines exist regarding consent and assent for youth in out-of-home placement to participate in behavioral research. There are informal regulations in place that require parental (i.e., biological parent) consent for the adolescent to participate [5]. Unfortunately, obtaining consent from a teen's biological parent can prove difficult, if not impossible. According to HHS regulation 45 CFR 46.409(b), researchers must appoint an

independent advocate for each foster teen involved in a research project so that they can complete a risk/benefit analysis. Advocates should be familiar with the research being conducted, the teen's day-to-day caregivers, biological parents, the teen, and the teen's biographical and medical history [11]. Yet, no regulations specify how the advocate should complete the required analysis. Further, including an advocate in the research process does not address the problem making sure that the teens are involved in decisions related to their own risks and benefits.

Confidentiality and Privacy

While researchers often ensure confidentiality and privacy as a right reserved for research participants, the laws protecting foster youth may actually prohibit us from making such ethical guarantees. For instance, Florida law requires all individuals who suspect or become aware of child abuse, abandonment, or neglect to report the incident to the Florida Abuse Hotline as mandated child abuse reporters. Yet, many of the online risks teens in the foster care system face fall on a thin line between abuse and illegal activity (e.g., sexual solicitations). Foster youth are accustomed to repeating their life stories to multiple individuals (e.g., case managers, guardians, local authorities). Therefore, they may be open in expressing harmful situations (e.g., abuse) to a researcher without understanding the ramifications of their actions. Clearly disclosing these mandates to participants in the informed consent documents can support transparency between the researcher and participant but may not be enough.

Sensitive Data

Working with highly vulnerable populations may involve collecting extremely sensitive data (e.g., sexually

explicit material, drug use, criminal behavior). Handling these data can be difficult, especially if the information could be harmful to the teen. For example, researchers must be conscious of disseminating research results in a manner in which the participant's confidentiality and privacy are protected and must make tradeoffs between the risks of exposing a teen and conducting research to benefit this specific population of teens.

Participatory Design with Foster Youth

We propose using participatory design as a potential way to address some of the ethical challenges presented above. Although discussions around participatory design are often orthogonal to that of ethics in research, previous work in participatory design has identified a series of steps [6] that actually help address many of the ethical concerns that arise in conducting research with underserved populations. For example, participatory design researchers have discussed with their participants the ethics of the participant-designed solutions without publishing reflections on the ethics of the research project itself [17]. It can be argued that participatory design is inherently more ethical because researchers are placing value on the knowledge of the participants [10].

In our work to design an informative and ethical participatory research project to investigate sensitive topics with young participants, we have built on existing principles and practices of participatory design [7,9] and laid out principles guiding our study that have helped us to identify and adhere to ethical standards and protect the privacy of the youth in our study:

- **Transparency:** Being open to participants about our intent to better understand their social behavior

- **Autonomy:** Giving participants control over what is shared and how it is shared (anonymously or not)
- **Literacy:** Providing participants with comprehensive information about both technological and social aspects of the issue at hand.

Conclusion

In conclusion, we plan to engage youth in foster care as participatory designers for mitigating their own online risk behaviors. Our participatory design process will ensure that ethical concerns around collecting and analyzing foster youth data, balancing privacy and disclosure, and trade-offs between privacy and beneficial outcomes are calibrated to the specific needs of our population. Our end goal is to engage with foster youth to best understand how to address these problems, ethically.

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