
Assessing the Risks versus Benefits of Conducting Research with Adolescents in Foster Care

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Abstract

For researchers and designers to produce better design solutions for promoting adolescent online safety, we need access to study adolescent populations. While HCI research has moved in the direction of engaging directly with teens, this progress does not come without costs. Further, it also does not take into account the needs of particularly vulnerable teen populations. For instance, teens in foster care face higher levels of risk in general and, thus, have a greater need for protection beyond typical teens. Yet, when studying this population, many ethical challenges arise concerning a teen's privacy and eligibility to participate in research when they are part of the foster system. These challenges include: 1) Consent and Assent, 2) Confidentiality and Privacy, and 3) Sensitive Data. The goal of this paper is to present situations in which a researcher must evaluate the tradeoffs between privacy and advancing knowledge to benefit vulnerable populations, such as youth in foster care.

Author Keywords

Adolescents; Foster Care; Foster Parents; Informed Consent; Confidentiality; Privacy; Ethics.

ACM Classification Keywords

K.4.1 Computers and Society: Public Policy Issues

Introduction

Poole and Peyton [5] outlined the challenges and best practices for conducting interaction design research within adolescent populations. For instance, they emphasized the importance of involving teens directly in research and design, as opposed to using adults (e.g., parents) as proxies who act on their behalf. We draw upon this existing research as we embark on our own. While adolescents and their use of technology has been a specific topic of interest for the CSCW community [1,7], there has been little focus on teens in foster care. Thus, conducting research with this vulnerable population to design better technology solutions represents an important and novel area of inquiry.

However, our research presents unique challenges that make it increasingly difficult to engage with the population we are attempting to study. While we have been able to gain access to foster parents of teens within the state of Florida (where the research is being conducted), we have encountered a number of barriers gaining direct access to foster youth. Our goal is to outline the ethical and legal considerations for research with youth in foster care to help researchers and designers navigate some of these challenges and identify the trade-offs between privacy protection and conducting research to benefit such highly vulnerable populations. The following contributions are made within this paper:

- Highlight the importance of investigating foster youth's online behaviors and technology use.
- Provide an overview of the ethical and legal challenges encountered when conducting research with teens in foster care.

- Present questions to generate discussion on potential strategies for mitigating obstacles encountered during data collection with foster youth.

Background

As of September 30, 2014, over 400,000 youth were in the foster care system in the United States, and approximately 30% of these youth were between the ages of 13 and 20 [8]. While research has shown these adolescents demonstrate significantly greater involvement in different high-risk behaviors [4], we remain uncertain "how [technology influences] a teen's potential for engaging in high-risk behaviors" [2] (p.18). To address this uncertainty, the first author plans to deeply study youth within the foster system, including their online behaviors, risks they encounter online, and ways to potentially mitigate these risks. The following section will address three ethical challenges we have encountered in attempting to conduct this research.

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. According to FDA regulation 21 CFR 50.3(q), a ward, by definition, is "a child who is placed in the legal custody of the State or other agency, institution, or entity, consistent with applicable Federal, State, or local law." To our knowledge, in the state of Florida, 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 [3]. Unfortunately, obtaining consent from a teen's biological parent can prove difficult, if not impossible. Many of these teens are not in contact with their biological parents due to a variety of situations (e.g., parental incarceration). These types of situations create our first challenge: *Who provides legal consent for teens within the foster care system?*

Additionally, according to HHS regulation 45 CFR 46.409(b), researchers must appoint an independent advocate to each teen involved in a research project for the advocate to complete a risk/benefit analysis. This analysis evaluates the state of the child and his/her capabilities to participate in the research. While guidelines exist for choosing advocates, no regulations elucidate how the advocate shall complete the required analysis. Varma and Wendler [6] suggest that an advocate be familiar with the research being conducted, the teen's day-to-day caregivers, biological parents (if possible), the teen, and the teen's medical history (including situational factors such as relocations or socioeconomic status). Realistically, including an advocate in the research process is very difficult. Involving an additional person in the "care" of the teen is unfeasible, as building trust and understanding the life situation of a teen takes time. Thus, a second challenge is: *Does such regulation make research with teens within the foster care system prohibitive?*

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).

Ironically, foster youth may be too forthcoming with researchers, which could cause unanticipated consequences for the teens. 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 from a caregiver) to a researcher without understanding the ramifications of their actions. Although respect for confidentiality and privacy is a major principle of research ethics, in a case similar to the one mentioned, a researcher must break confidentiality with a participant to report the incident. Researchers must be fully aware of their responsibilities and the protocols for reporting a situation. Clearly disclosing these mandates to participants in the informed consent documents can support transparency between the researcher and participant. However, this introduces our next challenge: *How can we simultaneously build trust with foster youth while being transparent as to our role as mandated reporters?*

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 content violates the teen's rights or the analyst's personal values. For example, researchers must be

conscious of disseminating research results in a manner in which the participant's confidentiality and privacy are protected. We often try to accomplish this by removing all personally identifiable information and ensuring any publicly available comments, if retrieved from online platforms, are non-searchable. Unfortunately, with large social media data sets that contain photographs, there is limited flexibility for removing all identifiable information. Therefore, a researcher must make a tradeoff between the risks of exposing a teen's identity and conducting research to benefit this specific population of teens. Additionally, a researcher studying the sexting behaviors of a vulnerable teen may collect photos that affront their religious values and principles. This leads to the final challenge: *Even with consent, should the sensitive data collected from foster youth be considered accessible for research?*

Conclusion

We have not found a clear solution to these ethical and privacy challenges. Instead, 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, acknowledging the limitations of our approach. 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 to best understand how to address these problems.

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