

# **ETHICAL CONSIDERATIONS AND RECOMMENDATIONS FOR RESEARCH INVOLVING CHILDREN IN FOSTER CARE**

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## **Abstract**

The importance of ethics in research design and practice cannot be overstated. Ethical standards exist to protect participants from harm, coercion, or exploitation. Vulnerable populations require special considerations to protect them from unethical research practices, lack of informed consent, or coercion whether intentional or not. Youth placed in foster care represent a unique population of children who require additional protections. This paper details the unique vulnerabilities of foster youth, the reasons these vulnerabilities exist, and what researchers, reviewers, editors, and IRB personnel can do to mitigate the risks to foster youth within the standards of ethical research.

## **Introduction**

Children in foster care present some unique challenges to medical, legal, educational, and research professionals. They are difficult to identify and even more difficult to ascertain who, or which agency, is responsible for determining their best interests. In research settings, the challenges can be even greater as the considerations are broader and, in many cases, much less defined than in other settings. This paper lays out a rationale for why foster youth should be treated as a vulnerable participant class, some of the possible exemptions, and how researchers and Institutional Review Boards (IRB) can, or should, handle studies involving foster youth. Additionally, this paper seeks to give those planning to conduct research into foster youth an understanding of why this particular population is vulnerable and how to navigate topics such as informed consent, assent of the minor children, and potential issues related to coercion. This paper is directed at those who work under the umbrella of ethical inquiry, those who review the dissemination of those research studies (i.e. journal editors and reviewers, grant review panels, etc.), and those serving on IRB committees.

In 1974, the National Research Act was passed in response to concern about violations of ethics in research. Events such as the Stanford Prison Experiment, Tuskegee Syphilis Study, the Milgram experiments on obedience to authority, and other unethical research

studies continued even in the face of the Nuremberg Code – put in place after the Nuremberg trials uncovered the atrocities committed by the Nazis in the name of research (Moon, 2009). Out of this act, the Belmont Report was commissioned and led to three foundational principles under which all ethical research should be conducted: respect for persons, beneficence, and justice (HHS, 1979). In addition, Title 45, part 46 of the Code of Federal regulations (45 CFR § 46) specifies that prisoners (subpart C) and children (subpart D) have special considerations that apply to them as a result of vulnerabilities unique to these sub-populations. Further, the American Psychological Association (APA) code of ethics provides guidance regarding the rights and welfare of research participants. The publication manual of the APA, on which many scientific publications rely for proper formatting, also describes ethical principles and compliance in accordance with the APA code of ethics (APA, 2020). It is these documents which were primarily used to frame the justification for foster youth being considered uniquely vulnerable and in need of additional consideration when participating in human subject research studies.

## **Aren't They Just Children?**

The short answer is, obviously, yes. However, there are several important distinctions and vulnerabilities which are unique to foster youth. These include a tangible comparison to prisoners, extreme trauma, and a lack of parental involvement or knowledge of the child.

### *Pre-existing Protections for Children*

It is acknowledged that IRB and federal regulations already protect children as a broad category; however, this makes several assumptions not borne out in reality. First, 45 CFR § 46 clearly states that “Adequate provisions are made for soliciting the assent of the children and permission of their parents or guardians, as set forth in §46.408.” This statement assumes that the parents or guardians know the child well enough to give informed consent and that they are fully aware of factors that may cause the research to be detrimental to the child. Foster parents are provided fairly limited information related to the child’s history and, often, that history is still being investigated and gathered by law enforcement and child protective services.

Second, the “guardian” can have several different meanings and vary from case to case and by the location of the child in question. The assumption is often that the foster parent(s) have the best interests of the children in their care in mind when consenting on their behalf. Although not the majority, there are foster homes that exist solely for the monthly stipend received for fostering children (Donald, 1999).

Additionally, group homes are staffed with individuals tasked only with the safety and well-being of children with little more than a superficial knowledge of the child in question and the ability to give consent may rest with an organization administrator without any knowledge of, or interaction with, the child (Storer, Barkan, Stenhouse, Eichenlaub, Mallillin, & Haggerty, 2014). The existence of these possible scenarios and the potential lack of knowledge of even a caring and involved foster parent present reasons for extra caution to be taken in the planning and execution of research involving foster youth.

Additional considerations may involve changes in placement of foster youth during the research itself. Foster children move frequently. One study which examined 144 children in care reported the average number of placements was 8.02 with at least one child having 38 separate placements (Stott, 2012). The likelihood of moving during a research project is high and would potentially nullify the informed consent agreement.

Who has the ability to provide consent is also unclear. At a minimum, who the legally authorized representative (LAR) is varies by state, locality, and even depends on that to which may be consented. For example, in Texas, a foster parent can consent to medical and educational needs but is not permitted or allow to give consent for the child to change their hair style if the parental rights have not been severed (TXDFPS, 2020). Consent for this still resides with the birth parents. Even medical treatments require differing levels of consent and who is able to provide such consent varies by procedure or issue. Again, in Texas, birth parents must give consent for vaccines or contraceptive services, foster parents—if named medical consenters (typical)—can consent to medications and treatments for injuries, and only the conservatorship caseworker can consent to inpatient psychiatric treatment (TXDFPS, 2020). This presents an ethical issue around informed consent that is unique to foster youth.

Wards of the state are specifically called out in 45 CFR § 46.409. However, to apply this to foster youth, an assumption must be made that all children in foster care are wards of the state or court. This is not the case in all states and in many circumstances the child will never become a ward. The distinction is nuanced but critical. For example, the Code of Federal Regulations defines a ward of the state as a foster child (34 CFR § 303.37) but provides a specific exception if the child has a foster parent who meets the definition of a parent as defined in 34 CFR § 303.27. That section includes, as a definition of a parent, a foster parent (unless state laws or regulations expressly prohibit a foster parent from acting as a parent), a guardian, a relative

(considered foster care under kinship care), or a surrogate parent so long as there is a court order that identifies a specific person as long as that person is not acting on behalf of the state. In other words, unless the child is in the physical custody of the state and has no specific appointed foster parent, surrogate parent, or relative (or non-state agency acting as such), the child is not a ward of the state.

This very narrow definition of a ward places most children outside the definition and those children are therefore not afforded protections under 45 CFR § 46.409. Further complicating this is the fact that parental rights are not terminated until very late in the process and until that point the state is only granted temporary conservatorship and even that is not granted upon removal of the child(ren) but is only ordered after an additional court hearing or series of hearings.

### *Foster Youth vs. Prisoners*

Foster youth are not inmates or prisoners; however, they are children in the custody, and under the protection, of the state. This fact, when viewed within the context and perception of a child being remanded into the custody of the state, is little different than being detained as a result of criminal activity. The terms “protective custody,” “wards of the state,” and “remanded to custody” are all terms used in both criminal justice and foster care to characterize the individuals who are in one system or another through a court order and who have no or limited say in whether they are in the system or where they will be sent (Greiner et al., 2018; Lipscombe, 2007; Paris, 2008).

From the child’s perspective, there may be little difference between foster care and jail—especially those sent to group homes—since they may not be capable of understanding the nuanced differences and the simple fact that they are not allowed to leave. The only recourse for a foster parent or group home administrator if a child is to abscond, is to involve law enforcement which may result in actual criminal charges or involvement of the court system (such as juvenile probation). Regardless of the legal outcome, the runaway child will most likely be physically detained by law enforcement and returned to the home or facility. Running away can also be used as justification for a higher level of foster care up to and including a secure detention facility.

Even prisoners can be placed in residential settings and still receive the protections of inmates in a correctional institution. The language in 45 CFR § 46.303(c) is clear that the applicable definition of prisoner is not limited to prison or jail inmates but also includes “individuals detained in other facilities by virtue of statutes or commitment

procedures.” This regulatory definition includes residential drug-treatment facilities, in-patient and residential psychiatric facilities, parolees in a halfway house or other facility, and, potentially, individuals on house arrest. The key component to determining whether an individual is considered a prisoner and considered a protected class is whether they were ordered there by a court or other body with authority. At issue here is that foster youth are remanded into the custody of the state by a court to be placed in a residential or institutional setting without their consent at the discretion of the state department with authority and prisoners are remanded into the custody of the state by a court to be placed in a residential or institutional setting without their consent at the discretion of the state department with authority. This is a distinction without a difference especially to the children who are not able to parse the nuanced language and legal jargon to know they are not, in fact, prisoners.

The argument is that both literally and in perception there is no difference between foster youth and prisoners in how the process is applied and their ability to control the outcome. Additionally, most children in foster care blame themselves and their own actions for either the abuse or neglect that lead to their removal, the removal itself, or both (Baker, Creegan, Quinones, & Rozelle, 2016). This reinforces that they are being punished and have been remanded to state custody as a result. This perception is not distinct from the experiences of an adult accused of a crime.

Besides the admittedly dark comparison between foster care and prison, there is the rationale for prisoners to be a protected class in the first place. Prisoners have diminished autonomy as do children in foster care and as a result are far more susceptible to coercion and manipulation than other children and, as referenced above, do not necessarily have the protections parents or other guardians might provide through the informed consent process. Additional protections should be in place for an equally vulnerable population who, in addition to these concerns, lack the emotional, developmental, and cognitive maturity of their adult counterparts.

### *Extreme Trauma*

All children experience trauma at some point in their lives. The difference for children in foster care is the severity and nature of that trauma. There is also a sequence to that trauma that is compounded at each step in the system as new traumas are added and previous trauma is exacerbated. No child enters the foster care system without an initiating trauma. This is the abuse, neglect, abandonment, or total loss of family that lead a court to place them in the care of the state.

This is often not a one-time event, but a lifetime of traumatic experiences that has finally garnered the attention of a concerned party or has reached a point of severity which leaves law enforcement and the courts to intervene (Greeson et al., 2011).

After the initial trauma comes the trauma of removal. This frequently involves law enforcement or child protection services (CPS) officers taking physical custody of the children and, against their will, placing them in an emergency shelter, the home of a relative, foster home, or in the CPS offices themselves. At this point, they are unable to see or speak with their parents and are likely in an environment of which they are completely unfamiliar. They may not know where the bathroom is, lack comforts like their own toiletries, familiar foods, or even their own clothing. They sleep in a bed unfamiliar to them and they cannot communicate with the people who they trust to take care of them – their parents. They also likely blame themselves and view their environment as a punishment for their actions or behaviors (Baker et al., 2016).

These events lead them to reach out for attention, affection, and safety. This may be manifested in exhibited negative behaviors in which the child is testing the placement to determine whether it is temporary or not, over-compensated displays of affection or promiscuity to attract or garner attention or affection, or withdrawal from socialization as to avoid creating connections they fear will be lost. They may also display more than one of these depending on the environment or people involved.

These traumas and resulting fear are continually compounded and reinforced as they move through the system. They also create a situation in which the children can be easily manipulated or coerced—even from well-meaning adults—and presents a risk not present for children outside of care. The trauma caused by events leading up to and from entering the system, loss of control and personal autonomy, and reliance on strangers for protection combined with a lack of cognitive, emotional, and developmental maturity leaves children in foster care more vulnerable than their non-fostered peers and in need of additional protections.

## **Coercion**

The ability to be easily manipulated or coerced as a result of limited autonomy and severe personal trauma is evident in two key statistics, 80% of prison inmates have spent time in the foster care system (Juvenile Law Center, 2018) and 60% of sex trafficking victims recovered through FBI raids in 2013 were foster youth (Saar, 2014). These children are more vulnerable to exploitation than non-fostered

youth yet lack the protections non-fostered youth are more likely to enjoy.

Prisoners, the homeless, and the infirm are afforded additional protections and deeper review throughout the research process. The risk that foster youth are more easily coerced and share many of the same conditions as prisoners clearly differentiates them from other children and most adults. It is no coincidence that felons and sex-trafficking victims are most likely to have been in foster care. These children and the adults they become are more easily manipulated than their peers. They can be talked into actions more easily as a result of the traumas experienced and the need for attention and affection. This creates the possibility for them to consent/assent to research not in their best interest or simply for a tangible reward or feeling of acceptance. They may also lack adults who are able to look out for their best interest through the consent and research processes. For the same reason as prisoners and other groups who may have greater susceptibility to coercion, foster youth should be afforded similar protections.

## **Role of Researchers, Reviewers, and IRB**

Much of the rationale for protection of special populations in research comes either out of nefarious research practices or research so poorly designed that it was unethical. In discussions and in teaching about ethical research, we use Tuskegee, MKUltra, and the Nazis as examples of abhorrent research practices. We teach that the Stanford Prison Experiment and Milgram's infamous obedience study are examples of well-meaning research that crossed ethical lines in either its design or lack of consideration of the long-term negative consequences of the studies. These are extreme examples of unethical research and not common breaches of ethics that are seen by review boards, dissertation committees, and the researchers themselves. Often, ethical violations are small and unintentional. Most are corrected through the review process or when discovered through the course of research. Those researchers who willfully violate ethical norms and pay little attention to potential risks are not the audience of this paper and do not represent the vast majority of researchers in the field.

This paper began as a desire to have foster youth deemed a specific protected population for IRB purposes. While I still believe that should be a goal, there are concerns that would need to be addressed prior to their addition. After consultation with IRB and policy experts, I determined that raising awareness of the issues related to ethical research with this population was a first step and to let this

paper serve as a starting point for further discussion. To frame this discussion, the Belmont Report (HHS, 1979) serves as a guide.

### *Beneficence*

First, do no harm. A simple maxim reminding researchers to maximize the benefits of the research while minimizing the potential risks to the participants. For most research, this is a relatively simple task. It becomes more difficult when we are performing research that is invasive to a participant's body and intrusive to their mind. We know the psychological damage that can be inflicted from studies that do not take beneficence into account. Milgram and the Stanford experiments clearly demonstrate this. It is incumbent on us, as researchers and reviewers, to ensure we identify potential risks and take measures to reduce them. When working with children in foster care, the issues raised throughout this paper need to be considered when working with these children. This includes the questions asked in interviews and surveys and even in the consent process itself. Asking about parent involvement at home or asking a child to have their mom or dad sign the consent form may trigger a reaction in that child. If, in the course of the research, it is discovered that a child is in foster care, great pains should be taken to make sure that they are protected. However, as easy as it would be to just remove the child from the study, think of the harm isolation, lack of participation, or identification could do to that child.

### *Justice*

Foster youth should be treated fairly and equally with respect to their non-fostered peers. Care must be taken to protect their identity as foster youth. When deciding whether or not to use this paper as a justification for the addition of foster youth as a protected population there was the fear that it could create a barrier to interventions or research studies that would be beneficial to them. This would include exclusion from research in educational or medical settings where their status as foster youth is irrelevant. Researchers should ensure that if participants are identified during the course of research, that care is taken to protect them as described in this paper. Children in foster care represent an invisible population and their status is generally protected. Rarely will they self-identify and will attempt to blend in even referring to strangers with whom they live as mom and dad to keep up appearances, or they may enter care during the study. It would be potentially detrimental to attempt to identify children in foster care as a result of regulations put in place without considering justice as a core tenant of that policy.



### *Respect for Persons*

Generally, we consider people autonomous agents with the right and capacity to decide for themselves whether or not to participate in research. In some cases (prisoners and the infirm), we understand that there must be additional protections in place. Children are also protected, and although foster youth are children, the safeguards we assume children have in the informed consent process likely do not exist for this population. There is also a significant risk of coercion as detailed in this paper. Researchers should take care when working with these youth to ensure that incentives and other recruitment practices do not rise to this level even if they would not be considered coercive to non-fostered youth. Finally, ask yourself why you are conducting research that involves this population. Respect the fact that these children have no fault whatsoever in the reasons for placement and refrain from research on this population simply out of convenience or empathy. Avoid using these children as proxies for research into abuse or neglect or simply as at-risk students.

### *Normalcy*

In foster care, we operate in the context of normalcy. We recognize that the lives of these children have been turned upside-down and irreparable harm has been done as a result of the process. With that in mind, every effort is made to make their experience as “normal” as possible. Research should be no different. Ensure these children are treated as everyone else in the study. If informed consent is, or appears to be, problematic, ensure that the child has the same access to beneficial treatments or experiences regardless of whether you are able to collect and use the data or not. Be mindful that in educational settings, there is a high likelihood that there is a child in foster care in every class. Ensure you are using inclusive language when referring to parents and not assuming they have them at home.

## **Conclusion**

Adding foster youth as a protected class may be the best route to take. However, this needs more discussion and variety of opinion prior to developing a protocol for addressing research with this population. It is incumbent on researchers, editors, reviewers, and IRB panels to consider the issues raised in this paper when assessing studies and proposals which include foster youth. Researchers should investigate the state and local laws surrounding consent and include them as part of their methodology. Strong rationales should be given as to why this population should be specifically included and why other similar populations cannot be used. Recruitment should be scrutinized to ensure potential coercion is mitigated or eliminated

and the concept of normalcy is considered. Above all else, the principles of beneficence, justice, and respect for persons should be evident in the research and rationale for conducting it. These children are uniquely vulnerable and until such time as policy is able to be crafted for addressing these issues, great care must be taken to prevent any more harm being done to a group of children who have had enough trauma for several lifetimes.

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