

CHILD WELFARE PROFESSIONALS' PERCEPTIONS OF REFERRING FOSTER
CHILDREN TO THE GENETICS CLINIC

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Abstract

Background: Literature shows that foster children experience a high level of medical complexity, including mental, physical, and behavioral health challenges. Many foster children experience medical issues similar to those commonly evaluated in a pediatric genetics clinic. To date, no published research has explored foster care professionals' perceptions of the utility of pediatric genetic medicine for the children in their care. This qualitative research study investigates the thoughts and experiences of 12 foster care professionals with regard to referring foster children to be seen in a genetics clinic.

Methods: This study utilized a semi-structured interview to explore the research topic. The interview questions cover 12 central topics within the umbrella of 3 broader research questions. Twelve individuals, from 10 foster care agencies or Departments of Social Services (DSS) in New York State, participated in the study. Interviews were transcribed and coded for central themes, using Dedoose software. Themes were then analyzed through memo writing, and constructed into the final manuscript.

Results: This study establishes that many foster care professionals have limited knowledge of when and how a genetics consult could benefit a foster child. Yet these professionals showed willingness and readiness to learn more about genetic medicine and refer foster children for genetic evaluation more frequently. Those with prior experience making genetics referrals provided insight as to how genetics professionals could best serve the foster community. These recommendations included: getting to know the family dynamics before the appointment, involving the biological family in education and consent, and informing the children's multiple caregivers about the implications of genetic findings.

Conclusion: This study explored the current relationship between the foster care community and pediatric genetic medicine. It outlines the perceptions of child welfare professionals with and without experience collaborating with pediatric genetics in the management of foster cases. This project lays the groundwork for many future research opportunities, including exploring these same principles outside of New York State, or experimenting with new approaches to outreach to the foster community. Genetic counselors have the opportunity to learn about the foster care system and foster children's unique needs in the genetics clinic– to join the “village” of individuals supporting foster children through one of the most challenging phases of their lives.

1 | Introduction

At any given time in the United States, hundreds of thousands of children live in foster care, removed from the care of their biological parents and placed with a substitute caregiver. Foster care placements occur for a variety of reasons— most commonly neglect, parental substance abuse, parental unavailability, and physical or sexual abuse (Takayama 1998). Social workers employed by county-level Departments of Social Services (DSS) generally make the determination to remove children from their natural parents because of evidence that harm to a child has occurred or may imminently occur (Roberts 2001).

Contrary to popular belief, not all children in foster care have experienced direct physical harm from their natural parents. However, social workers often share the anecdote that “every child in foster care has trauma.” Indeed, literature on the topic indicates that at least 90% of children in foster care have experienced at least one identifiable traumatic event. Fifty-percent of foster children have experienced multiple distinct traumatic events over the course of their lifetimes. Many foster children have experienced or witnessed violence prior to placement— not exclusively domestic abuse, but also community-based violence such as robberies, assaults, and gun violence (Fratto 2016).

The event of entering foster care itself is traumatic. Children’s development and health deteriorate when they experience removal from their home and placement in substitute care (Hodges 2016). Past literature shows that children as young as early infancy experience developmental disruption if exposed to toxic stress or traumatic events. Children who experience trauma show an increased likelihood of developmental delay, intellectual disability, and mental illness (Dawson 1994). Foster parents frequently report that their foster children experience behavioral challenges, inadequate coping skills, and psychosomatic aches and pains (Ogg 2015).

Behavioral complaints are often top-of-mind for foster parents, but children in foster care show increased physical health needs over the general pediatric population, in addition to mental and behavioral health needs. A 1987 sentinel study first identified statistically significant differences in body condition and mental/behavioral health in foster children (Hochstadt 1987). Modern studies continue to affirm that foster children experience global developmental delay and intellectual disability at a much higher rate than their peers (Hodges 2016). Recent studies have also further stratified the physical and mental health risks affecting foster children, including a greater likelihood of overall poor health, asthma, obesity, speech problems, attention

deficit and learning disorders, vision and/or hearing loss, short stature, failure to thrive, infectious diseases, and mental illness (Jee 2008, Turney 2016, Wang 2011). Overall, 34% of foster children have some form of disability, with 11% having multiple disabilities (Seltzer 2017). Many foster agencies and DSS have recognized the health risks to foster children and implemented mandatory health and mental/developmental screenings for children entering foster care (Jee 2011, Hodges 2016).

Medical management in foster care often focuses on resolving urgent and immediate medical needs. A 2011 meta-analysis of foster care medical management indicated that priorities include: treating ongoing medical problems, documenting and treating abuse and neglect-related medical issues, providing medication and medical supplies, and referring children to specialists for urgent needs (Wang 2011). Interestingly, identifying causes of the children's medical concerns is not typically emphasized unless it relates to their reason for placement in foster care, i.e. if abuse or neglect is the suspected cause.

The same analysis also identified unique challenges of providing medical care to this community, including: lack of family history, lack of pregnancy and birth history, unavailable health records, and inadequate previous preventative care. A later study interviewing foster parents also identified similar challenges and additionally noted that caregivers often experience frustration and red tape when trying to obtain complete and accurate information about their foster child's medical history (Greiner 2015). Information may be intentionally hidden out of privacy or fears of stigmatizing the child. Medical histories may be provided only in a written paragraph from the foster agency, or given orally at the time of placement. These incomplete histories can lead to frustration from the child's healthcare providers, which further prevents receipt of adequate care.

Foster children often require healthcare management from a team of caseworkers, medical providers, and mental healthcare providers, all seeking to address their broad and complex needs with limited background information. A 2020 study in *Clinical Pediatrics* offered some care management recommendations for medically-complex foster children including: the involvement of a multidisciplinary care team, provision of remote care options, careful and centralized medical record-keeping, and provision of services to the entire biological family rather than just the children (Espeleta 2020). Pediatric genetic counselors and geneticists often work in a multidisciplinary team and play a role in care centralization and coordination. Yet the

role of genetics consults and genetic counseling services in the foster community has not yet been established.

2 | Theoretical Background

With many urgent needs to address— and given the challenges of providing care for this population— care managers for foster children may not regularly think about making referrals to genetics. Many of these care providers may not know much about genetic medicine or may not feel it has utility for meeting the urgent medical needs of foster children. Yet the literature demonstrates that many children in foster care have medical indications similar to those frequently seen in a pediatric genetics clinic such as: developmental delay, intellectual disability, failure to thrive, overgrowth or undergrowth, frequent infections, and known or suspected prenatal exposures (Jee 2011, Hodges 2016).

Given that nearly 1% of children in the United States are in foster care in any given year (USDHHS 2019), it stands to reason that most genetic counselors in the pediatric setting already see some foster children in their clinic, though that topic has never been studied directly. Genetic counseling literature has only recently included any exploration of genetic counseling in the context of a non-biological family. For example, a 2016 study in *The Journal of Genetic Counseling* established a high level of interest in genetics from adoptive parents— as a means of “filling the gaps” in their child’s history and allowing them to be proactive about their child’s health (Crouch 2016). These benefits of genetics could also assist in the care of children who are not yet adopted. Considering the high level of medical complexity in foster care, there are likely many foster children who could benefit from genetic evaluation and the inclusion of genetic healthcare professionals in their care team.

Much of the medical complexity of foster children can be attributed to traumatic events prior to, and related to, their familial separation. However, some of these health challenges could also be due to genetic or multifactorial disease, or to prenatal substance exposures. A genetics consultation could determine some of the biological, teratogenic, or multifactorial causes of these children’s medical complexity, allowing foster families and biological families to provide tailored care.

2.1 | Historical Studies

Historical literature on the subject of foster care and genetics is slim. In 1990, Dr. Julia Rauch wrote a review of utilization of genetic services in the foster community. Dr. Rauch's review identified that genetic services are underutilized in this community. The review notes that referrals to genetic services occur more frequently when foster children use a hospital with a medical geneticist on staff. Genetic diagnoses among foster children are identified twice as often when a medical geneticist is involved in a child's care team. Dr. Rauch identified that foster agencies lack adequate procedures for: identifying children who might benefit from genetic services, consulting with the child's pediatrician about the advisability of a genetics referral, ensuring that the caseworker and caregivers understand the implications of a genetic diagnosis, and ensuring appropriate documentation and follow-up (Rauch 1990). Dr. Rauch's review, published over 30 years ago, clearly outlines several shortcomings of the integration of foster care and genetic services. Yet no recent literature has attempted to find approaches to improve awareness and connectivity between the genetics community and the foster community.

Some lack of literature on the subject may be attributed to genetics and social work professionals feeling ethically uneasy about mixing genetic testing and foster care. In 1998, child welfare researcher Madelyn Freundlich wrote an ethical analysis of pre-adoption genetic testing and deemed the practice non-beneficial to children in foster care. She specifically shared concerns regarding foster parents requesting genetic testing on a potential adoptive child. She identified reasons that genetic testing may not offer the type of future-predicting that these prospective adoptive parents may seek. She noted that genetic testing provides inadequate predictive value for a child's future health, cannot rule out many serious diseases, and may detect susceptibility to a disease that will never affect the child. Additionally she noted concerns about children's privacy and the risk of genetic discrimination in adoption (Freundlich 1998).

Freundlich shares valid concerns about the use of genetic testing as a pre-adoptive screening. Performing genetic testing to cater to foster parents goes against genetic counselors' desires to serve the best interests of the proband. However, given the progression of child welfare policy since 1998, this topic is worth revisiting. In the 1990s and early 2000s, the United States government touted foster care as a pipeline to adoption. With a growing number of children in foster care, especially children of color, prompt adoption was considered the ideal resolution for these children. Foster care acted as a punitive measure for families that could not meet certain standards set by the DSS. Family preservation and reunification efforts were deemphasized.

In more recent years, the landscape of foster care has changed significantly. Foster agencies and DSS have slowly transitioned to a family reunification and preservation model of foster care. Most foster care professionals now recognize that permanent familial separation damages children, even if their foster or adoptive home is physically “safer” than their original home. Most agencies now place increased emphasis on support for biological families, co-parenting between foster parents and biological parents, and teaching foster parents to hope for familial reunification rather than termination of biological parental rights– the legal prerequisite for foster parent adoption (Vaquero 2020).

Additionally, the new generation of foster care professionals have a deeper and broader educational background than their predecessors, which has been associated with openness to the involvement of new technologies like genetic testing (Taylor 2010). In essence, there has been a shift from the foster care system as an adoption agency, to the foster care system as a temporary landing place for children, while their families work to resolve any issues endangering the children. Meanwhile, foster care professionals have become more open to varied means of serving the children and their families, including the use of genetic technology.

While the foster system has many flaws and results in many permanent family separations, the shift to a reunification-focus changes the role that genetics could play in foster care. Rather than catering to foster parents wanting to pick out the most genetically-sound foster child for adoption, perhaps genetics professionals could offer explanations for a foster child’s medical complexity. A genetics consult could simply a child’s many symptoms to one overarching diagnosis, allowing better management of their care. Genetics professionals may be able to offer information and support that aids reunification, rather than discourages it. This study is the first step to exploring the possibility of a positive, biological-family-centered role for geneticists and genetic counselors serving the foster community.

2.2 | Study Purpose and Intent

The intent of this study is to seek an up-to-date understanding of foster care professionals’ thoughts, opinions, and experiences regarding the involvement of genetic medicine in the medical management of foster children. Prior research notes high medical complexity in foster children, which qualifies many of these children for a referral to genetic services. Literature also notes that contact with biological families can unfortunately be lost

during the foster care and adoption process— meaning that referral of a foster child to genetic counseling at foster intake may be the child’s last chance to be evaluated in the context of their family history. The literature clearly establishes that foster children do need genetic services, and that attributing all their medical complexities to trauma results in missed genetic diagnoses.

This research follows up on the issues that Dr. Rauch presents but does not resolve in her meta-analysis. For at least the past thirty years, both genetics professionals and child welfare professionals have recognized their less-than-ideal relationship. It seems that doctors and caseworkers still under-refer foster children to genetic counseling. This research will seek to explore foster care professionals’ willingness to refer foster children to genetic counseling— including determining whether the ethical concerns posed by Madelyn Freundlich still permeate in the minds of referring providers. This research can lay the groundwork for addressing these issues by educating the decision-makers of foster care case planning. It can help genetics professionals determine how to encourage physicians to refer children to genetics when they qualify, regardless of their trauma and neglect history. This research can ultimately assist genetics professionals with addressing the health disparities and disadvantages faced by children in foster care.

2.3 | Research Questions

This research focuses on three central research questions, which will provide an updated look into the relationship between foster care professionals and genetic medicine.

- How do foster agency staff members determine which foster children would be a good fit for a referral to genetics?
- What hesitations restrain healthcare providers and caseworkers from recommending foster children for genetic services?
- What benefits and challenges do agency staff identify regarding use of genetic services for foster children?

I further stratified these research questions into qualitative interview questions and prompts, outlined in detail in Appendix A. By posing these questions to foster care professionals, I explored the current state of familiarity with genetics within the foster community, and investigated how our relationship can improve. I sought to investigate whether foster care

professionals show greater comfort with genetics now compared to earlier studies, what ethical and privacy concerns remain (if any), and what utility they feel a genetics consult could provide for a foster child.

3 | Methods

3.1 | Study Design: A Qualitative Approach

This study utilized a qualitative approach to explore the research questions. A qualitative approach fits because there is deficient genetic counseling literature on the topic of providing care for foster children in the genetics clinic. Qualitative research allows broad exploration of a topic that has not been previously studied enough to ascertain highly specific research questions for investigation.

The project required an approach that allowed social connection between two professional groups— genetics professionals and foster care professionals. These two groups have not been previously connected for interprofessional discourse in a research study. Given that nearly 1% of children in the United States are in foster care in any given year, it stands to reason that most genetic counselors in the pediatric setting will at some point interact with foster children in the genetics clinic. Additionally, with the high level of medical complexity noted in foster children, it seems likely that many of these children could benefit from a genetic evaluation. Yet, a review of the literature from both the genetic medicine/counseling perspective and the foster care/social work perspective showed a lack of published exploration of the relationship between these two professional groups. Although some older literature postulates a working relationship between foster care and genetic testing, no prior research has involved a genetic counselor. Thus, foster care professionals' perceptions of the utility of genetic counseling has not yet been investigated. This qualitative study allowed a representative of genetic counseling and a representative of child welfare work to meet and discuss the benefits, challenges, and uncertainties of the relationship between these fields.

3.2 | Instrumentation: The Semi-Structured Interview

This study uses a semi-structured interview to explore participants' thoughts, opinions, and experiences regarding the topic. The semi-structured interview format allows the use of prompts to guide the discussion without restricting further exploration of ideas shared by

participants. Participants had varied roles within their organizations, and varied background knowledge of medicine and genetics. The semi-structured interview allowed contributions from a variety of child welfare professionals, because participants could focus on the topics to which they felt they could adequately contribute. It additionally allowed a balance between responsiveness to participants' shared ideas, while still exploring each research question in each interview (MacFarlane 2014).

The interview prompts are listed in full in Appendix A. The interview questions cover 12 central topics, with suggested follow-up prompts nested within those 12 domains. The questions received review and feedback from the study advisor Lindsey Alico Ecker and the Sarah Lawrence Institutional Review Board. I, Laura Cooper-Hastings, conducted the interviews. Lindsey Alico Ecker is a genetic counselor and educator with personal knowledge of the foster system. Laura Cooper-Hastings is a genetic counseling student who previously received foster care training through the Arizona Department of Social Services, and additional child welfare education through the Einstein College of Medicine Leadership in Neurodevelopmental and Related Disabilities (LEND) Fellowship. We, the research team, called on knowledge of both the intricacies of the foster system and our professional training as genetic counselors in the development of the semi-structured interview tool and in the process of conducting interviews. Our professional training as genetic counselors tends to bias us in favor of the use of genetic services, but our personal and professional experiences with the foster care system assisted us in presenting fair and balanced interview questions that explored all sides of the issue.

3.3 | Recruitment & Participants

I conducted recruitment by phone and email to New York State Foster Agencies. Contacts included private agencies and Departments of Social Services (DSS) in counties throughout New York State, as listed on The New York State Adoption and Foster Family Coalition website. Upon reaching each organization, I requested contact information for individuals within that organization who may be interested in speaking on the topic of genetic medicine in foster care medical management. I subsequently connected with those specific individuals and inquired with them about potential participation in the research study.

Enrollment Processes

1. When contacts agreed to participate in the study, I sent consent forms via email, which included consent to participate and consent to anonymized interview recording. I requested that participants read and sign the consent prior to the interview. All participants had their questions adequately addressed and returned the consent prior to their interviews.
2. I arranged 1-on-1 interview times and logistics with participants. Participants selected either a telephone or Zoom video conference interview.
 - Of note, one organization provided two participants who elected to participate together in a 2-on-1 Zoom video conference interview.
3. Participants joined the call at the established time, and completed an approximately 30-45 minute semi-structured interview, using the prompts listed in Appendix A. At the beginning of the meetings, I reviewed the consent forms and I received additional verbal consent before beginning the recording. I personally conducted each interview. I recorded through Rev Call Recorder (for phone interviews) or Zoom (for video conference interviews). For video conference interviews, I changed the participant's screen name to their anonymous participant ID.
4. At the completion of the semi-structured interview, all participants were offered compensation in the form of a \$15 gift certificate.
5. I continued recruitment and interviewing until after I had reached thematic saturation. Major themes were established after 8 interviews, and I continued to 12 interviews to ensure saturation.
6. After completing the interviews, I transcribed the recordings into text documents, and annotated with nonverbal cues from the video recordings, if applicable. I stored these text documents in a secure personal drive.
7. I coded these transcripts using Dedoose coding software. Coding methods included "in-vivo coding" and concurrent "structural coding". Using these methods, I extracted participants' own words to serve as codes, while at the same time applying thematic descriptors of concepts as codes. I identified themes that occurred frequently, and participants' experiences that stood out as unique, outlying, or exemplary.
8. After carrying out in-vivo and structural coding, I categorized and visually mapped the codes through Dedoose analysis tools. I synthesized and analyzed this qualitative data

through the manuscript writing process. I began the synthesis process by conducting analytic memo writing about the data. I ultimately condensed and amalgamated these memos, along with thematic analysis of the codes, into the Results and Discussion sections of this manuscript.

Participant Demographics

| | |
|-------------------------------------|----|
| Total Agencies Contacted | 90 |
| Total Agencies Participating | 10 |
| Total Participants | 12 |

Response Rate: 10/90 contacted agencies elected to participate, for an 11.1% response rate.

Note: Two agencies provided two participants, resulting in 10 unique agencies participating, but 12 unique participants.

| Demographic | Participant Count | Participant Count |
|--------------------------------------|--------------------------|--------------------------|
| Employed by: Private / Public Agency | 5 private | 7 public |
| Geographic Location | 9 rural | 3 urban / suburban |
| Job Title | 3 medical staff | 9 social workers |

| Experience with Genetics | Participant Cnt. | Participant Cnt. |
|--|-------------------------|-------------------------|
| Cared for Child with Known / Suspected Genetic Dx | 7 yes | 5 no |
| Made a Genetics Referral | 4 yes | 8 no |
| Personal Experience with Genetics (Self, Family, etc.) | 2 yes | 10 no |

3.5 | Ethics

This study was approved under the Sarah Lawrence College Institutional Review Board:
Proposal SU_2021_4

4 | Results

4.1 | Foster Care Medical Management

Interviews began with a discussion of the medical needs and management of foster children. Participants in this study each described the process and challenges of medical management for foster children. As established in previous literature, children in foster care show greater physical and mental health needs than the general pediatric population. Specifically in this study, several participants endorsed that all or nearly all children entering foster care require mental and behavioral health services. Some participants shared that older children and teenagers in foster care automatically receive a referral for mental health counseling.

Similarly, some participants shared that many of the children experience some form of developmental delay or intellectual disability— often undiagnosed prior to the child’s entry into foster care. One caseworker cited her personal experience as a foster parent, noting that every one of her own foster children experienced some form of developmental delay, autism, attention-deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), or oppositional defiant disorder (ODD). Even though not all children in foster care fit a specific diagnosis of a learning disability or mental health disorder, participants generally endorsed a high level of mental and intellectual needs among the child in the care of their respective agencies.

“They may not be born with the— whatever the needs are [that] they have. But because of the trauma they’ve experienced and because of what they’ve gone through, I believe that most of our children are delayed in some way. Their overall well-being is delayed somehow. So whether that be educational, spiritual, moral, you know? ...They all have some sort of hill to climb, I’d say.” –

Participant 10

Many participants also made the explicit connection between the high level of mental health needs they see in foster care and the trauma that the children have experienced—

essentially stating that, since every foster child has a trauma history, every foster child will show some mental effects of trauma.

“There’s just, like, a lot of trauma and things that occurred there that they need assistance with as well. And I’d say that’s almost every kid.” –Participant 4

One psychiatric nurse practitioner in the study stated that he experiences many challenges with the psychiatric treatment of foster children. He shared that this group of children tend to be refractory to treatment for a variety of reasons including: limited psychiatric medications approved for use in children, difficulty connecting with their psychiatrist and/or therapist, and lack of treatment continuity due to moving foster homes or aging out of care. Every participant in the study endorsed the high mental and behavioral health needs of children in foster care.

Participants generally identified that a smaller proportion of foster children show increased physical health needs, with several participants sharing that approximately 25% of the children in their care require ongoing specialized medical care for physical health issues. There did not appear to be a clear pattern of specific physical health conditions that are more common in foster care. However, a few participants made reference to seeing several children with failure to thrive (FTT) and/or difficulty with eating. Interestingly, one participant mentioned overseeing a child with FTT– originally misattributed to difficulty adjusting to the foster home. She described that the team later determined that the child had a medical condition that impaired his ability to eat. She mentioned that her prior experience as a pre-medical student informed her ability to recognize a possible physical contribution to FTT, and that caseworkers with less medical background may have attributed the child’s FTT solely to poor mental health.

Despite a clear pattern of medical complexity in foster care, the most frequently cited medical challenge in this study isn’t a specific mental health or physical health condition. It is a lack of medical and family history available for the children. Participants shared a host of reasons that agencies lack history for the foster children in their care. Biological parents may feel intense fear about sharing that history, and may provide incorrect or incomplete information. They may feel that the agency will question or investigate anything they share. Additionally, placements sometimes occur on an emergency basis, resulting in a lack of time to obtain a history before proceeding with medical care for the child. Participants also spoke about the risk

that medical and family history becomes even more difficult to obtain and disseminate to caregivers the longer the child remains in foster care.

“It’s like you don’t know what you don’t know and then you lose it. Cuz you don’t know what they had then– and you don’t know where they are, there to now. You have nothing, you have no record of it.” –Participant 12, in reference to lost medical history

As the child remains in care, biological parents’ relationships with the agency and foster parents may change. Sometimes that relationship improves and they can provide more history for their child. However, participants noted that if the foster placement starts to move towards termination of parental rights and adoption, the biological parent may withdraw further. A lack of medical and family history makes it even more difficult for clinicians to assess the child’s condition and create a care plan.

4.2 | Dynamic of a Foster Child’s Care Team

The interview continued with a discussion of the structure of foster childrens’ care teams and the policies that direct their actions. Every participant described at least three central care team entities: the biological parent, the foster parent, and representatives from the foster agency: often called caseworkers or case managers. Most of the participants who worked for private agencies also mentioned internal medical staff who provide intake and ongoing healthcare for the children within that agency. By contrast, staff members from public Departments of Social Services (DSS) generally shared that they involve community physicians in their care of foster children. Each member of this care team provides some level of decision-making with regards to the medical care of foster children.

All participants indicated that they welcome and encourage biological parents to participate in medical decision-making for their children. For the majority of children in foster care, the biological parent(s) retain legal parental rights– meaning that they sign consent forms for medical treatment and testing. Therefore, their participation in medical appointments is paramount. Many participants shared that medical providers should focus their attention, interviewing, and teaching towards the biological parent.

Participants discussed the mental state these parents experience when their children are in foster care. Essentially, participants expressed that biological parents experience their own trauma related to the removal of their children. That trauma can present with varied emotions.

“I don’t know what it’s like to have your children taken away from you and have someone else to make decisions and stuff. So that always goes [with] a lot of anger, and anxiety, and frustration for them.” –Participant 7

Many of the agency workers echoed similar sentiments– that biological parent(s) face a mix of shame, guilt, and animosity towards authority figures. Additionally, they may be working through substance abuse or severe mental health diagnoses, leading to clouded memory and difficulty making decisions. These barriers can result in difficulty engaging with parents in a medical setting.

I can ask those questions to some of the parents, but unfortunately the parents aren’t always in the know or always so truthful I guess... so you don’t know what’s actually occurring.
–Participant 4

Yet, every participant who spoke about these challenges emphasized that the law backs the rights of biological parents to participate in, even lead, their children’s care plans while the children are under the guardianship of the state. To the degree that circumstances allow, biological parents can be expected to attend medical appointments, provide informed consent, and receive education about their child’s care plan, with the hope of eventual family reunification.

However, some participants shared that they have had experiences in which the biological parent was unable or unwilling to participate in appointments, or would not consent to provider-recommended plans-of-care. In these cases, participants described a means of legal override to allow the recommended care to proceed with the foster care agency or DSS spearheading the decision-making process, rather than the biological parent. That process generally involves the agency representatives presenting the case to a Family Court judge, who considers the perspectives of medical professionals, caseworkers, the biological family, and other

caregivers. The participants who spoke on this process generally noted that it often takes a lengthy amount of time, and that judges regularly make the determination to uphold parental rights, even if that decision goes against medical advice.

A few participants noted that their agencies ask biological parents for general medical decision-making consent at the time of their child's entry to foster care— a consent form that allows the agency to make routine medical decisions such as vaccinations or treating acute illness. However, even in cases when that form of consent is in place, the agencies continue to seek biological parent consent for higher-level visits such as pediatric subspecialty and genetics visits.

Although laws and policies tend to place the biological families and agencies at the head of the care team, the foster parents often provide valued input in the medical decision-making process for the children in their home. The foster parents receive training and supervision from their agency or DSS. That training includes rules and regulations regarding their involvement in their foster children's medical care. When discussing the role of foster parents, participants often mentioned that foster parents provide scheduling and transportation for appointments, inform medical staff of the child's recent health and behavior, and receive education regarding the child's management.

“I think it's very important to include them [foster parents] in those conversations. Because they're the ones who have to deal with the day-to-day fallout of whatever, good or bad, of whatever these things say.” –Participant 2

Participants also shared that a number of foster children share strong emotional bonds with both their biological parent(s) and their foster caregiver(s). Although the agency and biological parents may not always invite input from the foster parents in a decision, these foster parents play an important role in attending medical appointments. One participant, who is both a caseworker and a foster parent, shared the benefits of foster parent involvement in medical care.

Participant 4: I think it's just being there to help navigate any kind of questions that they have or, you know, make them feel a little bit more comfortable.

Me: Yeah, like the emotional support of having their day-to-day caregiver there.

Participant 4: Yep, and well and like if, if they're scared– just give the physical touch or the holding of the hand. Or, you know– if they're small enough– on their lap. Just make sure they're physically comfortable as well, you know?

Beyond emotional support for the child, a few participants mentioned that foster parents can provide an important buffer between the agency staff and the biological parents. One participant stated– regarding the relationship between these three groups– “The animosity is on us.” (Participant 11)– meaning the biological parent(s) feel greater resentment towards agency staff compared to foster caregivers. This participant and others explained that– in the minds of biological parents– agency staff often represent the system that hurt them, that took their children away. A few caseworkers shared that foster parents receive training regarding how to support the biological parent(s). This training enables skilled foster parents to provide a positive co-parenting relationship with the biological family. As a result, foster parents can mediate tension between the agency and the biological parent(s).

Every case will involve different dynamics between foster parents, biological parents, and agency representatives. Some participants shared an alternate view– that the presence of foster parents can upset the biological parents, rather than provide an emotional buffer.

“I have some bio parents that just can't get past that the kids were removed and placed with somebody else. So they have a very adversarial situation with the foster parent.”

–Participant 12

Caseworkers encouraged any medical care provider to take the time to understand these relationships. Every foster situation involves many parties with complex relationships to one another. To create the best environment for medical care and counseling, genetic counselors should ensure that the child and their parent(s) feel comfortable with the representation of other parties in the room. They can encourage both foster parent and biological parent involvement when that involvement is conducive to positive co-parenting. Otherwise, they should give favor to the biological family.

The role of foster parents in medical decision-making can increase if case goal shifts from reunification with the biological family, to adoption. Participants sometimes made this

distinction with a shift in language from “foster parent/home” to “pre-adoptive parent/home”. They encouraged greater involvement of a pre-adoptive parent in medical decision-making, compared to a more temporary foster parent. Of course, the case plan can fluctuate as biological parents progress or regress in their reunification goals. For that reason, participants shared that they prefer to involve the foster parents in medical appointments whenever possible, in case those foster parents become adoptive parents to the child in the future.

The foster child care team expands beyond the core group of biological parents, caseworkers, and foster parents. Participants mentioned therapists, pediatricians, teachers, and the child’s extended family– all of whom may contribute ideas and recommendations for the foster child’s care. As the child ages, they increasingly engage in their own care plan, including providing assent for testing and procedures. In short, foster children have many adults in their lives who can provide input for a care plan. Anyone providing medical care for a foster child should seek to understand the caregiver dynamics prior to the appointment, whenever possible.

4.3 | Participants’ Prior Knowledge of Genetic Medicine and Counseling

As discussed in Section 3.3, about half of the participants had prior experience with genetics in foster care to some degree– either caring for a child with a genetic diagnosis or making a genetics referral themselves. This section explores the preconceptions of those participants who had not interacted with pediatric genetic medicine prior to this study.

For participants who had not worked with pediatric genetics within the foster system, most of them still had some conceptualization of genetic medicine and genetic counseling. A few of these participants mentioned that they knew of genetics in a prenatal or cancer setting– in fact, one participant had seen a cancer genetic counselor herself. One nurse mentioned that he had encountered pharmacogenomic testing in his practice, and another participant mentioned that she knew about direct-to-consumer genetic testing for ancestry. Some participants also mentioned that they’d been hearing about genetics in the media in recent years. None of these participants had heard of pediatric genetics before, but all of them expressed that this topic sparked their interest, and that they felt open to learning about how genetics could apply to the children in their care.

For participants who lacked any background regarding the process of a pediatric genetics session, I typically provided a case example and walked them through the structure of a session. I

used the example of evaluating a young child with autism and developmental delay– collecting a family and medical history, a geneticist performing a physical exam, and then a genetic counselor educating and consenting the family for genetic testing. Participants tended to gravitate towards two points of this case example– the autism diagnosis and the process of genetic testing.

Some participants expressed surprise at the existence of a genetic test for the evaluation of mental / behavioral conditions like autism. As mentioned, these participants tended to have an awareness of genetics in some context, but were largely unfamiliar with the pediatric setting or using genetics within behavioral health. As many of the participants had already mentioned the high level of mental and behavioral complexity in foster care, everyone seemed intrigued in a discussion of using genetics to find a potential cause for behavioral issues.

“I wasn’t aware... it makes sense to me why there would be, but I wasn’t aware that there are potential gene markers for... that could indicate if something is going on that could affect behavior or autism spectrum disorder. Or learning disabilities and stuff.” –Participant 3

The process of genetic testing also caught participants’ attention, but more so out of concern. It seemed that most of the participants presumed that genetic testing would be a painful or complex process for the child, and a potential cause of further trauma. They shared that some children attend many medical appointments during their time in foster care. Like all children, they experience fear of strange adults like doctors, and fear of being poked and prodded. Some of the participants questioned whether genetic testing would involve an invasive procedure such as a spinal tap. However, these same participants also seemed reassured when they heard that a genetics appointment involves mostly talking, and that genetic testing can be performed on a non-invasive or minimally-invasive sample type such as saliva or blood.

Overall, this group of participants reacted in a positive-neutral manner to the idea of using genetics in foster care. They expressed curiosity to know more about genetic medicine and genetic counseling. Of course, these participants elected to participate in an interview about genetic medicine, which likely skewed the sample towards individuals who already felt open to that idea.

4.4 | Participants' Genetics Case Experiences

For the participants who had worked with genetics in foster care previously, the interview focused less on their preconceived notions about genetics. Instead, participants shared their prior case experiences. Collectively, these participants shared a variety of incidences in which they involved genetics in a foster case.

Several participants mentioned knowing about Fetal Alcohol Spectrum Disorder (FASD) and its connection to genetic medicine. Some participants had experience with referring to a geneticist for ruling out FASD, and others had heard about it as something to watch out for in children in their care. Two participants specifically mentioned that they'd received training to recognize the dysmorphic features associated with FASD. With a focus on this specific diagnosis, some participants saw it as a starting point— something to rule in or rule out to gain some direction for the foster child's case plan.

“Children who may have come, you know, parents who have been abusing drugs or alcohol the whole pregnancy. Those kids would be initially scheduled for genetics so that I could just rule out anything. And just have a place to start, as far as the treatment and development.”

—Participant 7

A few participants mentioned that in some cases, the desire for a diagnosis of FASD for a foster child results in further teratogenic and genetic workup. Participants 1 and 2 (who work for the same agency and were interviewed together) spoke about an adolescent who they'd referred for genetic counseling for suspected FASD.

“I had a kid that we were working with, so this recently just came up for me. Where it basically— something was going on that we couldn't figure out. And as the team started looking at different things— I'm not even, I don't even know who brought it to the surface. It was you know, ‘Maybe we should get some genetic counseling. Cuz is this something like Fetal Alcohol Syndrome?’”

—Participant 1

“I think so many avenues have been addressed with this one particular child that it was almost like, “There’s something going on. We can’t quite figure it out.” –Participant 2, in reference to the same foster child.

“It kind of blew my mind to know the layers to this, getting into it. What we could find, what we would– what else we would be uncovering. I thought it was way more simple. ‘Oh we’re just gonna get a diagnosis, and then we’re gonna have a treatment.’” –Participant 1

These caseworkers recalled that the genetics evaluation resulted in ruling out FASD, which led to the pursuit of genetic testing for other conditions. Further testing meant more appointments and involvement of the child’s biological father. The caseworkers also encountered challenges because the child’s biological mother was deceased. Foster care professionals may come to genetics for a highly specific reason, such as a suspicion of FASD, and discover that the consult raises more questions than answers.

In the same vein of highly-specific referrals, one participant shared that her agency had sent several children for evaluation of frequent fractures, with the differential diagnosis of non-accidental trauma versus “brittle bone disease”. In one such instance, seeking a genetics consult changed the outcome of the case.

“I remember specifically one case where the mother– the child was brought into care because they had been a prior [foster child] and their legs had been broken. But the mother, the family... weren’t necessarily educated as to what could have caused it. So, easily attributed to abuse and neglect. After [the] child entered care then it happened [again], I believe with the foster parent. And the mother’s like “Yeah, you know, it’s happened with me.” So you start to listen to them. And say, “Wait, I need to hear what they have to say because they have the history; I don’t.” And eventually someone does listen. And eventually our nurses do the right thing and they make those referrals. They will make the referral. They have the assessment done. And then at least I can have the science to back up the claim and get the courts to listen. And then, you know, whole different outcome, right?” –Participant 8

A different participant also shared an example of genetics changing the outcome of a case. As a caseworker and homefinder, she cared for a sibling group who all shared a genetic diagnosis. In this case, the children had been diagnosed with a rare microdeletion syndrome during their time in foster care. Eventually, their parental rights were terminated and this caseworker took on the task of finding a permanent adoptive home for the sibling group. She shared how she placed the children's photos and story on an adoption website. Although she could not post their specific diagnosis for privacy purposes, she could share that they had special needs. This caseworker recalled how a mother inquired about the children after she recognized their distinctive facial features in the photos. Upon learning that they had a microdeletion syndrome, this mother shared that she had previously adopted a child with a microdeletion syndrome and felt confident managing those needs. This mother eventually adopted the sibling group. Ultimately, knowing the children's specific diagnoses helped this caseworker find the ideal adoptive match for them.

Another caseworker spoke about two cases involving genetics— one case of suspected muscular dystrophy, and another of a baby experiencing developmental delay and failure to thrive.

“We’ve had one who was at the primary care doctor, who was wonderful, and thought that he might have muscular dystrophy. So, we went to the geneticist...he did end up being diagnosed—very early on, thankfully—with Duchenne Muscular Dystrophy. So that helped. Where if it didn’t get caught until way later, now he has a chance. He’s on drugs that were recently approved by the FDA that he can try that might extend his life.” –Participant 5

Participant 5: *We did have another one who was a baby— malnourished baby— when the child came into care. Going through the gastroenterologist, other regular appointments, that child did get referred [to genetics]. Because of developmental delays... becoming so severe. You know, you can’t tell at first when they get here, but as he was getting older he did have to go. Because they were— you could just tell they were so severe. So you get all the services and providers involved. But if it’s still that much, then we did end up sending him.*

Interviewer: *Interesting. But they weren’t able to find anything that you know of?*

Participant 5: *They did. And I actually just forgot cuz I had that other case in mind. Um, I just can't remember what the different diagnoses were. Cuz it was a few years ago. But they did. They found things and we ended up getting extra services involved.*

Even when the caseworker didn't recall the exact diagnosis made by genetics, she remembered that the genetic diagnosis resulted in greater access to services. In one case, a child received a diagnosis that resulted in access to a lifesaving medication, and in another case, the child gained access to support services. Other participants echoed this benefit, or identified it as a possible benefit, even if they'd never experienced it. They noted that documentation of a highly-specific diagnosis can increase services and benefits for a child, including provision of early intervention, a home health nurse, or greater financial support from the government. Most of the participants' ventures into genetic medicine stemmed from a desire to provide more services for the children in their care. Foster families and caseworkers may not just be coming to genetics to end a diagnostic odyssey. They may be hoping for a genetic diagnosis to access much-needed services for the child.

Of note, two participants learned about genetic medicine while caring for an adolescent foster child who gave birth to an infant with congenital defects. These two participants work for the same agency, so they are likely referring to the same case. Even outside of this case, it seemed that some participants had a greater knowledge of perinatal genetics, and had not considered genetics for an older child.

Participant 9: *We had a mom. A teenage mom. She had several...what is that, hydrocephaly? Babies and you know they, they usually don't live more than a year.*

Interviewer: *Yeah, like water on the brain, the brain kinda swells up, the head gets big.*

Participant 9: *Yeah, but it was more than that. It was like some genetic thing. Because she had two babies. She, I don't remember if the other one was lost or what happened, but she had it twice. And she was a juvenile herself. So I know there was that situation because I believe the child was put in hospice.*

"We've had a teen mom that we recommended [genetics] evaluation... because she had one baby that died, that was born with a pretty significant... I don't know what it was called. But part of

her brain was not, not there. But, baby died early on. And then she had– she got pregnant again.

–Participant 10

These participants' example demonstrates a point raised by several other participants– that they referred a child for genetics evaluation when they knew the child's medical issues had been present since birth. The birth of a medically-complex infant into foster care resulted in these participants gaining exposure to genetic medicine for the first time.

Caseworkers and medical providers may not know that an older child's medical issues began at birth, unless the child was already in foster care at the time. By sharing their first exposures to genetics, these participants highlighted a key issue that may cause a lack of genetics referrals from foster care. If decision-makers do not know how long a child has been affected with a medical issue, they may not identify genetics as a potential cause.

4.5 | Perceived Utility of Genetics in Foster Cases

The aforementioned case examples illustrate some of the perceptions of child welfare professionals regarding genetics. There is an alternative perspective to consider– the thoughts and experiences of those who have not involved genetics in foster care previously. Collectively, these two groups can identify the known and potential benefits and limitations of genetics in foster cases.

One agency nurse shared an example of a case of medical complexity, in which the agency is still seeking a definitive diagnosis. This nurse had not yet considered referring the child for a genetics consultation.

“Our medically-fragile little guy, I don't know why he has some of these problems. I don't have the history to go off of.” –Participant 6, speaking of a child with cerebral palsy in the care of her agency.

When asked about her thoughts on involving genetics in such a case, this participant stated that she views it as a good idea. She mentioned the lack of medical history, but also the lack of a predictable future for this child. She, like several other participants, supposed that the involvement of genetics could assist the agency with reaching a more concrete understanding of

a child's medical issues. These caregivers want to know what they can expect from the child's life course. They predict that a genetic diagnosis could offer some prediction of outcomes for medically-complex children. As the interviewer, I tried to make clear that genetics cannot replace a lost medical history or always find a diagnosis. Yet, participants still felt that genetics could assist in filling in at least some of the gaps. Those participants who had used genetic services before seemed satisfied with the provision of genetics expertise. They appreciated the attempts to collect and retain history and the progress made towards a definitive diagnosis for the child.

Most participants at some point referenced a desire to tap into genetics expertise and gain information that could inform the case plan. Any specialized medical care could provide some helpful information and anticipatory guidance. Yet the genetic piece stood out to many of the participants— tied to their desire to find out “what is going on” within a foster child's biological family.

“I see so many families that I continuously get reports on, or continuously are working with. And I think this genetics would be interesting to find out if they— what might be going on with the family over what we're seeing, that they're getting so many multiple reports.” –Participant 11

“I do have a lot of generational families that I deal with. So beneficially that helps us to understand some of the past family history of issues, concerns, problems that I can look at for the kids who come into care, if they come in through that family.” –Participant 12

Thinking about genetics brought up this concept of families who become involved with the foster care system several times, even over multiple generations. Certainly, many social and environmental factors contribute to cyclic foster care involvement. However, these participants wondered if a hereditary issue could also contribute. Participants hoped that a genetics consult could provide insight into these generational foster cases— whether through a genetic diagnosis or evaluation and preservation of the family history. A few participants mentioned that the biological parents they work with often show similar intellectual and learning difficulties to their children. These participants noted that genetics consults may provide a unique opportunity to understand the biological or teratogenic causes for these similarities, rather than attributing it all to social factors or poor parenting.

“I think that if there is something non-invasive that can be done to help this child, who was dealt a terrible hand, have the best chances at proceeding and having a more quote-unquote normal life, then... I can't see an argument... that would supersede that.” –Participant 3

As discussed in Section 4.3, some participants initially feared that gaining this type of information would require invasive testing. Once they learned that genetic testing can be performed on a blood or saliva sample, these participants identified the non-invasiveness of genetic testing as a positive. Many of the caseworkers had experienced the challenges of getting a child or teenager onboard with a lengthy or invasive medical test. They noted that these are children with a trauma history and heightened sensitivity to pain and fear. These participants seemed pleased with the risk-benefit ratio of a genetic test– the potential to receive significant valuable information, with little to no risk of physical harm.

Many participants took this benefit a step further. Genetics can provide substantial information with little physical risk, but then what is the benefit of information? These participants noted that information like a diagnosis (or even the knowledge that some diagnoses have been ruled out) can result in increased provision of important services. This concept came up in a few of the aforementioned case experiences– for example, the child whose diagnosis of Duchenne Muscular Dystrophy resulted in eligibility for a life-extending medication. Yet participants recognized that most genetic diseases will not result in this type of highly-specialized therapy. Even so, they felt strongly that genetic diagnoses could help tailor treatment and intervention for the children in their care.

“Particularly with children, early intervention is best. So, the earlier you can figure out something and save time from kind of guessing like ‘Maybe it's this, let's treat it for this, and then if it responds then, you know, well then I know we're right. If not, then I go back to square one. Like back and forth, back and forth, back and forth. If you can kind of hone in on even a couple different things. Not even necessarily a specific one. But you can tailor treatment towards guiding treatment choice. Kind of one realm versus, the global spectrum. Then I think the earlier that's able to be accomplished, the better the prognosis is for the child.” –Participant 3

This point ties to the whole purpose of foster care. As a few participants stated, foster care exists to provide parents and children with support services, to hopefully preserve the family unit. Several participants identified that a genetic diagnosis could help biological families know their child's potential medical and behavioral challenges, so that they could access services in a timely manner.

“They get to ask questions. They get to understand what’s going on with their child. And when there’s something genetic that was passed down, they get information about what they need to do... It is really important for them to be there... To figure out ‘What’s going on? How’s my child gonna look? What do I expect? What services can I get to help support him, support me?’”

–Participant 8

The genetics consultation provides an opportunity for each stakeholder in the foster case to learn how to better care for the child. That care includes referrals to external services like physical therapy or special education, and learning how to care for the child at home. Participants in this study generally felt involving a teaching and counseling figure in this process makes sense. One participant in particular stated that she feels the counseling aspect of a genetics consult could supersede even the medical benefit. Participants generally wanted the appointment to allow family members and caregivers to communicate with one another, emotionally heal, and work collectively towards the best interests of the child.

“I get most of our kids right into counseling...get the parents right into counseling. I never look into any kind of genetics... [mental health issues] are the most pressing problems I see. I’m thinking genetics, like the person could have something that could be explored, but it would probably be more so in the counseling/mental health level.” –Participant 11

After identifying these benefits, some participants expressed a sense of urgency that more foster care professionals be made aware of genetic services. Several participants commented that either they or their colleagues did not have enough knowledge of genetics. These participants believed that with further education for the foster community about genetics, it could be used as a new outlet to support the children in their care. One participant mentioned that a genetic

diagnosis may provide information that supports familial reunification, and that the speed of that reunification matters.

Participant 8: *You can't give parents back six months, a year, two years of their child's life while they were away from them.*

Interviewer: *It sounds like the referral to genetics for something like that is often coming too late.*

Participant 8: *Yeah.*

Interviewer: *Like it's an end-of-the-line, everything else has been ruled out.*

Participant 8: *I'll tell you what—you don't hear about it. That's the sad part.*

4.6 | Constraints and Ethical Concerns of Genetics in Foster Cases

During the interviews, participants identified some of the barriers that prevent them from involving genetics more often (or at all) in the care of foster children. Most participants in this study at some point mentioned not knowing much about genetic medicine or its benefits. One participant felt she did know a lot about genetics, but noticed that her colleagues did not. One nurse practitioner, specializing in psychiatry, mentioned that he was previously unaware that genetic testing could be useful within his patient population.

“If I had more understanding of what genes—I guess what sort of behavior patterns or diagnosable diseases that affect children or foster children—are available through genetic counseling or through genetic testing, then I think I'd be a lot more likely to use it.” –Participant 3

Beyond educating the foster care agencies, genetics professionals must also assist with educating the biological families about the utility of genetics. Many participants stated that biological parent consent is one of the most substantial issues they face when pursuing a medical care plan for a foster child. Participants generally assigned a high importance to preserving trust with the biological family by seeking their input and consent in medical decisions.

Interviewer: *[Are] there reasons that you can think of that you might decide against involving genetics, even if you were suspicious of a genetic condition? Kind of like family dynamic situations, ethical situations, that kind of stuff?*

Participant 12: *Yeah I mean obviously we wouldn't be going for anything like that if it was a foster child that the goal is return to parent, and the parent was adamantly against it. Unless we could really prove that it was... beneficial to the child. Or that there was a significant concern by a physician. Which again, we would always consult physicians on these things, and what they felt. We don't arbitrarily make those decisions.*

Different agencies shared different policies about the consent process when addressing urgent medical needs versus undergoing more specialized diagnostics. Essentially, in emergency situations foster parents can provide consent to treatment, though different agencies had different definitions of an emergency. Additionally, the agency often has a blanket consent to routine medical care. However, these types of consent don't apply to genetic evaluation or testing. This consent issue ties back to the critical importance of receiving specific approval from the biological family before involving genetics in a foster case. Some participants recognized that certain biological families would not consent to this type of specialized care, no matter how much education they receive about it. Some participants stated that, although many biological parents want their children to receive all recommended care, receiving consent for genetics will always remain a barrier for certain families.

The family court system and / or the commissioner of social services can provide a legal override if biological parents refuse to consent to medically-necessary care, but participants generally stated that they only use this avenue as a last resort. A few participants specifically stated that family court judges hesitate to override a parent's wishes, even if medical-necessity has been proven. This point applies to all medical decisions, but seems especially important in the consideration of genetic testing. Genetic testing results can carry lifelong implications for the child and their family members, and participants generally recognized that biological families deserve a say in obtaining that type of information. Participant 9– who herself has a genetic disease– noted that she would not choose to pursue a legal override if a biological family chose not to pursue genetic testing. She shared how some of her own at-risk family members have chosen not to receive genetic testing, and how that experience strengthened her resolve to align with biological parents' wishes in foster cases.

“I wouldn’t wanna overrule a parent because once you have that information, you can’t take it [back]... you can’t no longer not have [it].” –Participant 9

One participant mentioned that genetic counselors should be upfront with the biological parents, and the agency, regarding the potential family impacts of genetic testing. This experience came from the participant who referred an adolescent to genetics only for ruling out FASD, but then further genetic evaluation was recommended. The caseworker described her surprise at learning that they may need to involve the biological family, even uncover genetic information with relevance for those family members.

“I think that’s one of the things that happened with us, that I didn’t realize would be a part of what we would be doing when we were exploring this... that the genetic counselor was talking with us about...that the next step to this is possibly uncovering things that could be needing to be told to other family members. And would you tell the family members or would you not? And we were like ‘What, that’s a lot, like that’s a lot. And I don’t think we’re there yet.’” –Participant 1

This caseworker shared that the biological family agreed to participate in genetic testing, but that the agency would not have pushed them if they did not want to participate. The other caseworker from this agency added that they would not want to harm their relationship with the biological family by pushing them towards potentially discovering unexpected genetic results.

“I do a lot of family-finding– looking for relatives that can help and be supportive. What if we do uncover; with this further genetic testing, things that... might be life-changing or be perceived as negative. What do we do with that information?” –Participant 2

Another participant stated that she also could foresee unexpected findings as a potential drawback, and that she would like to know how to support the families through those types of findings. Genetic counselors could assist with preparing families and agencies to work through these ethical challenges of genetics in foster care.

“I would say for the kids in foster care, that, you know, we would definitely work with the birth parents and explain why we felt it was necessary. And what that could, the implications that it could have. But also how we could assist if there was something that came about that they couldn’t handle on their own.” –Participant 12

Beyond ethical concerns, some participants mentioned more logistical concerns regarding genetics in foster cases. For example, foster children receive their medical coverage through Medicaid, and some participants mentioned that Medicaid coverage for genetic testing could present a challenge.

“It would be forever to get this one approved, that one approved, or whatever. So I can’t imagine. But I think that in cases whereby if it was... to determine some medical treatment... like we’ll get the override. It’s for the testing. I don’t think it [would be], “Oh no we can’t.” Like I think they would do it, but there would be a lot of red tape.” –Participant 8

In the event that Medicaid does not offer coverage for genetic evaluation or testing, there likely would not be anyone available to pay an out-of-pocket cost on behalf of the child. However, many foster children have several adults in their lives— their parents, foster parents, caseworkers, and others— with a willingness to advocate for the child’s needs. Medical care providers like genetic counselors could also join in that advocacy, to ensure that cost does not prevent a child receiving the genetic evaluation they need.

Participants also spoke about timing as a logistical concern. Returning to the case of the adolescent referred to rule out FASD, the caseworkers shared how they hoped genetics would provide them a quick diagnosis to explain the child’s complex medical and behavioral history. They expected to attend a single appointment and then use the new diagnosis to access additional services for that child. However, the process took longer than expected, and went in an unexpected direction. They didn’t necessarily see it as a drawback that they didn’t receive the diagnosis they expected, but they did experience frustration with the time-consuming nature of the genetics evaluation. Reaching a diagnosis may require multiple appointments, multiple lines of testing, and months of waiting. It’s a different timeline than many other doctor’s appointments.

Participants generally expressed that they'd like to know the proposed timeline in advance, so that they can consider whether genetics is a good route to take in a particular case.

In the same vein, some participants stated that a longer-term diagnostic exploration may not serve foster children as well as their non-fostered peers. Foster care medical management often must focus on urgent needs such as tending to injuries from abuse or neglect and catching up on basic medical and dental care. While discovering a hereditary condition in the family may be beneficial, it's not going to be the first thing that comes to providers' minds when working with a foster child. One nurse described her means of prioritizing the children's medical needs when they come to her for an intake evaluation— demonstrating that she often must address pressing needs that present an immediate risk for the foster child.

Interviewer: How do you prioritize their varying needs, their varying medical needs, for these foster kids? If they have a lot going on mental health, a lot going on physical health, dental care is way behind, how do you prioritize for them?

Participant 6: It's like— let's use dental care for an example. Like this tooth was in pretty rough shape and needed to [be] removed. Risk of an infection. Like that's really like right up at the top of the list as something that I need to take care of. Where if someone had a cavity— 'Ok I need to get a filling in the next month.'

Interviewer: Yeah. So something that's at a risk of getting worse.

Participant 6: Right.

Me: Pretty urgently.

Participant 6: And then you end up look[ing] if they have any other health issues. Where if, ok you get an infection in your tooth— and you have this health issue— that puts you at even more risk. We really need to take and get this taken care of cuz now this other disease or other health issue is going to cause you even more problems.

Me: So it's also considering the way that their complexities play in with each other.

Participant 6: Yeah.

As this nurse explains, children often come into foster care with several medical concerns that pose additional risk if not addressed immediately. Finding an overarching cause for the

child's medical complexity is important– but it may fall to the bottom of the priority list in favor of addressing more urgent needs.

4.7 | Care Considerations for Genetic Counselors

Lastly, participants identified anything that genetics professionals should consider when working with the foster community. Participants generally noted that foster children do require special care considerations because of their unique family situation and their trauma history.

“I mean, sadly enough... we want our kids to be treated just like every other kid. But there's so many reasons why they can't be.” –Participant 8

Some participants who had already worked with genetics in foster care had feedback regarding their experience. For example, one participant mentioned that the genetics team focused too much on interacting with the foster parents, rather than the agency and biological family. She identified that the team assumed the foster parent, the present caregiver, would provide the history of the child– when in reality the other parties could have provided much more information.

“When they initially did the conversation, they talked to the resource parent who had– it was in March that they initially met [with genetics], April? Somewhere around there. And they had only been with that resource relative since August. But there's years of history before. And they never even talked to the caseworker.” –Participant 2

This participant did note that the genetic counselor in this appointment responded to the caseworker's feedback, and began to involve the caseworker and biological parent more fully. This participant highlighted the need for genetic counselors to appreciate the unique family structures seen within foster care, seek to understand that dynamic prior to the session, and involve all parties in the process. She suggested that when genetic counselors prepare for a case with a foster child, they should know who will attend the session and how each party would like to participate.

Other participants echoed that emphasis on understanding the unique family structures, as well as the background of the case. Within that umbrella of “understanding the family structure”, there was a huge focus on connecting with the biological family. They emphasized that genetic counselors should understand that biological parents will have the most history on the child, and will likely influence decision-making more than any other party. Failure to engage with the biological family can result in appointments falling through, incomplete histories, or inability to gain consent for genetic testing.

“You gotta know the background of the child, and the history, you know, and sit down and talk with the bio parent, and get them onboard. Cuz like I said, we can’t do no, I meant we don’t take kids anywhere without the bio parents being onboard.” –Participant 11

Participants also shared their thoughts on how to tailor the genetic counseling session with attentiveness to the unique considerations of a foster care situation. On the educational side of the session, they emphasized teaching with a low level of complexity. Foster children and their biological parents often come from disadvantaged backgrounds, and experience chronic stress. They may not have the bandwidth to understand complex information, so genetic counselors should prepare to break information down to the key takeaways. Genetic counselors should keep in mind that the foster parents understanding the information is not sufficient. Foster placements can change. Even the child’s relationship with their biological parents, unfortunately, can end. In foster cases, there is an increased importance to convey at least the basic medical information to the child if they are old enough. A few participants also shared the importance of a clear written record of the discussion, which can move with the child if their placement changes.

Some participants emphasized that genetics counselors should connect information about the diagnosis directly to resources that can help the family.

“Like we do get bad news. I feel like sometimes, not all doctors, but like some doctors [are] like ‘well this is your news’ but there’s no ‘well this is what we can do for you’, or ‘this is how we can help you’, or ‘here’s a support that we can put in place for you.’” –Participant 6

As mentioned with regards to benefits of genetics, participants saw genetics as an excellent opportunity to provide families with early intervention and other services. Additionally, genetic counselors can provide biological parents with attentiveness and emotional support that benefits the well-being of the entire family unit.

The counseling piece is I think very important because you're sometimes dealing with a population that doesn't have the educational level, and what they don't know scares them. –

Participant 12

Presenting clear information, providing support, and reducing fear for the biological family can result in increased willingness to participate in the genetic testing process. Many participants felt positively about the involvement of a genetic counselor in the genetics evaluation process. It seemed that many participants had experienced the rushed feeling of meeting with busy specialist physicians. Sometimes they had felt that the family received too much medical information too quickly or with too much complexity. Yet those who had previously worked with genetic counselors recalled the slower speed of that process. While genetics may not always provide an immediate answer or a quick fix, genetic counselors can take advantage of the opportunity to provide greater attention to each case. Especially in foster cases, every stakeholder benefits from additional counseling, education, and opportunities to ask questions.

5 | Discussion

5.1 | Addressing the Research Questions

This study qualitatively investigated the current relationship between foster care and genetic services. It explores how foster care professionals in New York State have used genetics, and what they understand about its utility. It also touches on the ethical nuances of performing genetic consults and testing when a child is separated from their biological family. This exploration centered around three core research questions:

- How do foster agency staff members determine which foster children would be a good fit for a referral to genetics?

- What hesitations restrain healthcare providers and caseworkers from recommending foster children for genetic services?
- What benefits and challenges do agency staff identify regarding use of genetic services for foster children?

5.11 | Referral Process

Regarding the first research question— participants’ level of education about genetic services seemed to have the greatest effect on how often foster agencies refer to genetics. Participants who had never referred to genetics often expressed that they were not aware of some of the indications that would make appropriate genetics referrals. Even in the case of participants who had referred to genetics at least once, they did not state that they used any form of checklist or algorithm to determine which children to refer to genetics. Most of the participants had simply heard about genetic services at one point in their careers, generally through word-of-mouth from other providers or agency workers. It did not seem that any of the agencies had strict guidelines for when to refer to genetics— they simply had a case that required a genetic work-up for a specific reason (such as suspicion of Fetal Alcohol Syndrome or Osteogenesis Imperfecta). Those cases caused the agency to be more aware of genetics in the future.

Interestingly, one participant concluded her interview by expressing how excited she felt to learn about genetic medicine for the first time and how she would be telling the commissioner (her boss) about our discussion. In fact, in a few interviews participants seemed enthusiastic about learning a new means of helping the children in their care. These reactions demonstrated that many foster care professionals would likely be receptive to training about how to involve genetic professionals in more of their cases. Ethical concerns about using genetic services seemed overall minimal, especially if the biological parent shows willingness to consent. These reactions demonstrate that increased community outreach between geneticists, genetic counselors, and Departments of Family / Social Services would likely lead to an increase in genetics referrals from the foster system.

The risk of such education is the potential for an overwhelming amount of referrals, many of which will not result in the identification of genetic disorders. The literature shows that severe mental and behavioral health issues, along with poor growth and development occur at

extremely high rates in foster children. Unfortunately, most of these disparities can be attributed to abuse, neglect, and lack of stability. However, as is true in any randomly selected group of children, some children in foster care do have genetic disorders. There is a well-documented high level of medical complexity in foster care. This study adds the knowledge that foster care professionals want to involve genetics as often as families will allow. However, plentiful research also demonstrates that there is a shortage of geneticists and genetic counselors, resulting in long waitlists for genetic consults— especially in the pediatric setting. Although genetics professionals would like to assist as many children as possible, there are limits to how many referrals they can accept while still reaching urgent cases efficiently. If more genetics professionals engage in outreach to the foster community, there will be a need for a means of paring down to the most appropriate referrals. I propose some ideas for managing this influx of referrals in Sections 5.3 and 5.4.

5.12 | Benefits of Genetics in Foster Care

The second major research question centered on participant's perceptions of the benefits of genetics in foster cases. Every participant with prior experience consulting genetics identified it as beneficial to the management of foster cases. Those without prior experience making genetics referrals often started the interview feeling unsure, neutral, or warm towards the idea. By the end of the interview, they typically seemed more energized towards the idea, and could identify some potential benefits of genetics in foster cases. The most frequent benefits participants identified were: genetics for evaluation of generational foster families, genetics as “early intervention”, and genetics as a therapeutic process.

Many participants brought up this concept of generational foster families— children in foster care whose siblings, parents, and other family members also spent time in foster care. Of course, “predisposition to be in foster care” is not a genetic condition. On the contrary, one might assume that this cycle occurs solely because of social and psychological factors. Children without modeling of good parenting may go on to struggle with parenting themselves. Families face generational poverty, resulting in generations of family members being unable to provide the necessary care for their children. Based on a review of foster care literature, these principles are true.

However, the participants in this study questioned if there might be identifiable biological factors that also contribute to generational poverty, neglect, and foster care involvement. Many

dominant genetic conditions affect learning and executive functioning. A family may seem like generations of individuals who just can't seem to stop the cycle of abuse or neglect. In reality, that could be a family affected by a neurodevelopmental disorder. Regarding teratogenicity, an individual born with FASD may suffer intellectual impairment, putting her at risk to make poor choices herself— for example, drinking during her own pregnancy. It is unknown how often biological factors may contribute to cyclic foster care involvement, as this topic has not yet been studied. Nevertheless, the participants in this study identified that genetics professionals can help the foster care community consider the biological factors affecting the families in their care. Genetics professionals could play a role in shifting blame away from these families, and working towards solutions for them.

Within the same vein of providing solutions, several participants expressed enthusiasm for genetics as a starting point for identifying services that could benefit a foster child. Sometimes in the general population, a family may pursue a genetics evaluation for a child when other specialists have been unable to identify the underlying cause of the child's medical issues. Some participants in this study mentioned that they presently use genetics in that manner— as a last stop. Yet several of these participants stated that they wished to involve genetics sooner— to be able to identify appropriate referrals and have their suspicions of a possible genetic disorder either confirmed or ruled out promptly.

Of course, every family wants to end the diagnostic odyssey and obtain the best care for their child. It seemed, however, that this promptness is especially important in foster care. One participant described foster care as hopefully a brief stop— an opportunity for a child to gain access to additional services and evaluations. She described it as the chance for parents to get on their feet while the children have their needs addressed in a safe and stable environment. The sometimes quickly shifting nature of foster care was cited as a reason that some participants have never involved genetics in a case. Genetics can be a long process, and that timeline may not fit with many foster cases. Yet, several participants shared that— through the study interview— they learned about the wealth of information genetics can offer. They generally followed this comment by sharing a desire to involve genetics in cases more often and sooner.

However, within this enthusiasm lies some probable misconceptions about what genetics can offer. For example, several participants shared that they'd love to have "the genetic test" right away, as a starting point to know how to manage a case. Genetics professionals know that

there is not one “genetic test” that can explain everything about a child’s medical history. Genetics often does not provide the definitive answers families seek. Often the explanation of a child’s medical complexity is multi-faceted, not a single genetic diagnosis.

In reality, if genetics were a starting point for an evaluation of features like failure to thrive in foster children, clinics would be inundated with referrals for children that are simply experiencing the symptoms of neglect. As physicians often learn– “when you hear hoofbeats, think horses, not zebras”, or in other words, assume the most likely cause of the symptoms. Genetics consults for foster children would essentially be looking for the proverbial zebras among many horses. Yet, finding those zebras makes a difference– and the participants in this study could recognize that principle. As one participant stated, “You can’t give parents back six months, a year, two years of their child’s life while they were away from them” (Participant 8). Genetic counselors must consider how to work with foster agencies to help them find those zebras– to help them identify the children who would most benefit from genetics. This research demonstrates that the foster agencies are willing and ready to work with genetics. They see the benefits of seeking genetic diagnoses for foster children, and they want guidance through that process.

5.13 | Challenges of Genetics in Foster Care

Beyond the need for education surrounding genetic medicine, only one other major challenge of genetics in foster cases came up during the interviews. Many participants stated that working with the children’s biological parents presents a unique challenge in foster care. Working with parents is a challenge of pediatrics in general. However, in the general pediatric population most parents will have made the appointment themselves, and typically want to attend it. In the case of a court-ordered appointment, or an appointment made by the state or the foster parents– biological parent(s) interest may vary. Unfortunately, the people making those appointments may not always get the biological parents on the same page before proceeding. Especially in the case of genetics, biological parent(s) may feel uneasy or confused about the appointment, and ultimately refuse to participate.

Every study participant at some point referenced the importance of biological parent consent in medical appointments. Most agencies and counties have specific rules in place stating that foster parents cannot consent to care, and the agency can only consent to routine visits and

emergency care. Depending on the policies of different agencies, a child may or may not be allowed to attend a genetics appointment without their biological parent(s). Yet, even when they can attend the visit, the management options will be very limited without biological parent consent. Only the biological parent(s) can consent to genetic testing— unless the agency feels so strongly about it that they are willing to seek a legal override. Outside of the legal and ethical issues— pediatric genetic testing often requires parental samples. Even if caseworkers, foster parents, the child’s pediatrician, and the family court system all believe that genetic testing will benefit a child— there’s only so much genetics can offer without the biological parents’ support.

The potential lack of biological parent support is the most unique and prominent challenge of genetic medicine within foster care. In the interviews, participants often discussed the emotions these parents feel when interacting with the foster parents, agency workers, and other authority figures like doctors. They often want the best for their children, and want to support anything they can do to help their child. Yet they face incredible stigma, shame, and fear as a result of losing their children to foster care. As a result, they may appear difficult to work with and unwilling to support the care plan.

However, several participants expressed their gratitude that a counseling figure, like a genetic counselor, could help the biological family through the process. When a genetics clinic receives a referral from a foster agency, a genetic counselor might consider taking a few minutes to contact the biological parent(s) and ascertain their willingness to participate in the process. Taking the time to keep the biological family in the loop and answer their questions may result in the ability to offer a full genetic workup to the child, rather than being limited by lack of parental consent. Many participants also emphasized that working with biological parents effectively takes time. Even if they don’t show willingness to participate in a first appointment, they may warm up to the idea over time. As trained counselors, GCs can explore the emotions that may hold the biological parent(s) back from participating, and build a relationship of trust that may result in willingness to participate in the future.

5.3 | Practice Indications

This study explores the relationship between foster care and genetic counseling for the first time. It shares foster care professionals’ experiences working with geneticists and genetic counselors, and explores any concerns or knowledge gaps that may impede that process. We

conclude with the following practice recommendations for pediatric genetic counselors when working with a foster care case in clinic.

- Policies and procedures of foster agencies vary by state and county. Genetic counselors should seek to understand the operating procedures of the foster agencies with which they work.
- Genetic counselors should prepare to involve multiple stakeholders in a genetic counseling session for a foster child– mainly biological parents, foster parents, and caseworkers.
- Genetic counselors should generally direct ascertainment of medical and family history toward the biological parent, or caseworker, rather than the foster parent. Foster parents may provide recent updates but often do not know the complete history.
- Genetics professionals should prioritize obtaining consent from the biological parents, even if it pushes back the timeline of genetic testing.
- Genetic counselors can consider making connections with local foster agencies and DSS, to ensure that foster care case planners know that genetic evaluation is an option for the children in their care.

Overall, this research demonstrates that foster agencies are willing and ready to work with genetic medicine. Pediatric geneticists and genetic counselors can consider whether they receive any referrals from local foster agencies, and if so, if any other agencies have never made such a referral. They may try to connect with the agencies that have never made those referrals, and introduce those agencies to the concept of genetic medicine. Caseworkers may know that a child would benefit from a neurology consultation due to a history of seizures, for example. Yet the same caseworkers may never think of making a genetics referral for that child– unless they are provided with education about it. As genetic counselors make efforts to connect with the foster community, they may find that they receive more referrals to see foster children in the genetics clinic, offering us greater opportunity to positively contribute to the case plans of these children in need. There is a risk of receiving too many referrals from foster agencies, resulting in long wait times and low genetic testing yield. This risk can again be addressed through education

and building a collaborative relationship with foster agencies, so that caseworkers recognize the most relevant cases to refer to genetics.

5.4 | Study Limitations and Research Recommendations

This qualitative study lays the groundwork for further exploration of how to tailor genetic counseling to work effectively with the foster care community. Qualitative research allows broad inquiry into topics that have not been studied before, but it does have its inherent limitations. This study in particular focused on the experiences of a small group of foster care professionals in New York State. Their stories capture their genuine, unrestricted reactions to the thought of genetic medicine for foster children. Those stories don't represent all possible opinions of foster care professionals, and they aren't intended to. Foster care policy varies by area, as does openness to genetic medicine in general. Conducting these interviews in a different geographic area or with different participants may have yielded different results.

This group of participants likely overrepresents individuals who are open to the idea of genetic testing within a foster context. Many agencies that were contacted declined participation in this project, which may demonstrate some hesitancy from those agencies to discuss genetic medicine. This project highlights a few stories of how genetics has impacted foster cases and how foster care professionals have chosen to involve it or not. It provides some practice recommendations for genetic counselors to consider, but there is likely more feedback which the foster community could provide, as genetic counselors continue to interact with them through research and clinical practice.

There are three major directions for future research in this area. First, a wider-scale study could quantify the current status of genetic medicine's relationship with foster care. Well-established literature shows that around 1% of children in the United States are in foster care at any given time. This study demonstrates some of the barriers that may prevent foster children from being evaluated in the genetics clinic, but no quantitative data currently demonstrates that foster children are underrepresented in genetics referrals.

Additionally, this study presents an opportunity for pediatric genetics clinics to improve upon their current practice procedures when working with foster children. Clinics can consider comparing their current workflow with some of the recommended practice guidelines, molded from the feedback shared by participants in this study. For example, if a clinic currently uses

administrative staff to schedule appointments and call out reminders, they may consider using a genetic counselor to make some of those calls when the case involves a foster child. A genetic counselor contacting the biological family provides the opportunity to offer a more in-depth explanation of the purpose of the appointment and the benefit to the child, which may increase biological parent willingness to participate in the session and/or consent for testing. There is an opportunity for genetics clinics to research how these practice changes may impact the outcome of cases involving foster children.

Finally, this project demonstrates the great need for genetics professionals to engage with foster care professionals— increasing awareness of genetic services and their proper use. For genetic counselors who may not see many foster children in their clinic, they may consider carrying out a research project similar to this one, within their own local area. These practitioners may discover concerns and hesitations held by decision-makers at their local foster agencies and DSS, which hold the agencies back from making more frequent genetics referrals. On the other side of that coin, genetic counselors in clinics who see many foster children may consider connecting with the referring agencies to help them determine the most appropriate referrals. For example, they might develop educational materials to help these caseworkers distinguish signs of genetic syndromes from signs of abuse or neglect. There are many varied opportunities for geneticists and genetic counselors to forge deeper relationships with the foster system in an effort to best serve the foster children in their communities.

6 | Conclusion

This study broadly explores the current relationship between the foster care community and pediatric genetic medicine. The study gathered the experiences of child welfare professionals with and without experience collaborating with pediatric genetics in the management of foster cases. The study shows that many foster care professionals have limited knowledge of when genetic evaluation could benefit a foster child. Yet these professionals showed willingness and readiness to learn more about genetic medicine, and refer foster children for genetic evaluation more frequently. Those with prior experience making those referrals provided insight as to how genetics professionals could best serve the foster community. These recommendations included: getting to know the family dynamics before the appointment, involving the biological family in education and consent, and informing the children's multiple caregivers about the implications of

genetic findings. This project lays the groundwork for many future research opportunities, including exploring these same principles outside of New York State, or experimenting with new approaches to outreach to the foster community. Genetic counselors have the opportunity to learn about the foster care system and foster children's unique needs in the genetics clinic– to join the “village” of individuals supporting foster children through one of the most challenging phases of their lives.

Author Contributions

This research project– including conceptualization, literature review, recruitment, transcription, coding, data analysis, and manuscript writing– was conducted by Laura Cooper-Hastings under the advisement of Lindsey Alico Ecker.

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Conflict of Interest

Laura Cooper-Hastings and Lindsey Alico Ecker declare no conflicts of interest.

Human Studies and Informed Consent

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

Animal Studies

No non-human animal studies were carried out by the authors of this article.

Data Sharing and Data Accessibility

The data that support the findings of this study may be available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Appendix

Appendix A | Interview Prompts

Part 1: Medical Care for Foster Children

- What is medical management like for foster children?
- Are there any unique challenges of medical care for foster children?
 - If so, describe.
- In your experience, what percent of foster children would be considered medically complex?
- For participants who are healthcare providers: what is your training like?
 - Do you have only general healthcare training, or any special training to work with foster children?
- How common are referrals to specialists for foster children?
 - What are the most common referrals provided?
 - Are there any challenges with achieving follow through on these referrals?
 - If so, describe.
- Who consults together to determine the best plan of care for a foster child?
 - How do you prioritize the various medical needs of a foster child?

Part 2: Understanding of Genetic Counseling and Genetic Medicine

- What do you know about genetic counseling?
 - What is your perception of the role of a pediatric medical geneticist?
 - What is your perception of the role of a pediatric genetic counselor?
- Do you feel it is appropriate to pursue genetic medicine for foster children?
 - Why or why not?
 - What are some of the reasons you might suggest a referral for a foster child to genetics?
 - What are some reasons you might decide against a referral for a foster child to genetics?
 - What do you feel is the utility of a genetics referral?
 - How do you determine which children might need further evaluation from genetics?
- What would you expect a genetics appointment to look like for a foster family?
 - What role would the foster parents play in a genetics appointment?
 - What role would the biological family play in a genetics appointment?
 - What role would the agency play in a genetics appointment?
- In your experience, are there any ethical or legal issues that can arise when involving genetics in the care of a foster child?
 - Do you have any concerns about genetic information about a foster child becoming available to prospective foster or adoptive parents?

- In your opinion, is there anything that genetics providers should do differently when working with foster children (compared to working with their non-fostered peers)?
 - What would you want genetics providers to know about foster care and the foster system?

Part 3: Personal Experiences with Referring

- Have you ever been involved in the referral of a foster child to genetics?
 - If yes, how often or how many times?
 - What have been the general outcomes of these children's visits to genetics?
 - How satisfied were you with the care that the genetics clinic provided for these children?
 - Have there been any genetics referrals that worked out especially well or were especially helpful?
 - Have there been any genetics referrals that have been ultimately unhelpful?
 - Have you had any genetics referral experiences that stand out to you positively or negatively?

Appendix B | Codebook

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