Who Consents? Medical Decision-Making for Children in Foster Care

Mary V. Greiner, MD, MS,[a,b] Grace Muntz, MSW, LSW[c]

abstract

Children in foster care have complexity around medical decision-making because of their unique custody status. When medical decision-making is necessary for a child in foster care, what perspectives are important? What if opinions are not aligned? Who makes the final decision for consent? This Ethics Rounds focuses on a young child in foster care who has had repeated ear infections. Foster caregivers and family of origin are not in agreement on the treatment plan. Two experts, a foster care pediatrician and a child welfare professional, comment on the important considerations for the case, including involvement of legal representation and best interest representation in medical decision-making as well as the variability in child welfare response by state.

There are more than 390 000 children in foster care (ie, in the custody of a county or state child welfare agency and placed with temporary caregivers, including licensed foster caregivers, approved kinship caregivers, or in congregate or independent living situations) in the United States.[1] Children in foster care have higher rates of medical problems compared with children in the general population.[2] Higher rates of medical complexity result in the necessity for increased medical decision-making. Medical decision-making, including the medical consent process, can be challenging when a child is in foster care, particularly when involved parties are not in agreement.

THE CASE

You are an otolaryngologist who is seeing a new patient, M.J., for evaluation of recurrent otitis media. M.J. is a 2-year-old female in the protective custody of child welfare. She was placed into a nonrelative foster home 11 months ago. She has visits with her biological parents every week for 2 hours at a visitation center, supervised by her child welfare caseworker.

M.J.'s medical history is significant for facial bruising, a broken arm, and 4 rib fractures diagnosed 11 months ago, attributed to physical abuse. Over the past 6 months, she has experienced 4 ear infections, including 1 episode of a perforated tympanic membrane. During your visit, you identify mild conductive hearing loss and recommend tympanostomy tubes bilaterally.

The foster parents, who have missed multiple days of work caring for a fussy and uncomfortable child with ear infections, are eager to proceed with tympanostomy tubes. The child welfare caseworker notifies the biological parents, and M.J.'s mother recalls she had a retained ear tube as a child and is reluctant to proceed.

Who should you ask to consent for tympanostomy tube surgery for this young child in foster care?

GRACE MUNTZ, MSW, LSW, CHILD WELFARE PROFESSIONAL COMMENTS

From a child welfare perspective, one must consider the geographic location of the agency. Child welfare agencies all over the United States operate differently

[a]*Cincinnati Children's Hospital, Cincinnati, Ohio;* [b]*University of Cincinnati, Cincinnati, Ohio; and* [c]*Hamilton County Job and Family Services, Cincinnati, Ohio*

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Address correspondence to Mary V. Greiner, MD, MS, Department of Pediatrics, Cincinnati Children's Hospital Medical Center, 3333 Burnet Ave, ML 3008, Cincinnati, OH 45229. E-mail: mary.greiner@cchmc.org

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once you get below federal regulations and laws. The child welfare agency must then follow additional interpretations, laws, codes, and regulations of the state they are located in. Additionally, depending on the state, a child welfare agency may be county administered, meaning the individual counties each have "local rules" to consider as well. It is important that you have an understanding of the different types of custody, commonly used child welfare terminology, and what they mean in the area in which you practice:

- Jurisdiction: This is who has the power to make decisions, typically used in context regarding the court or government agency
- Temporary custody versus permanent custody: This difference varies dependent on the child welfare system; in Ohio, when an individual or child welfare agency has temporary custody, it is short-term custody, typically giving parents an opportunity to work toward getting their child(ren) back in their custody/care. Permanent custody is long-term custody, typically referred to when a child welfare agency has terminated all rights of the child's parents to that child. The child welfare agency now has permanent custody and that child is available for adoption.
- Termination of parental rights: This is done through an order of a court, ending all legal, financial, medical, and social responsibility between a parent (or both) and their child.
- Family of origin: This term is used to represent the "family" or the parent/child relationship. This often refers to one's biological family; however, it also represents adoptive parents, or any "family" that has provided significant caretaking responsibilities for the child.

Medical personnel must also have an understanding of how their child welfare agency operates as far as parental consent. For instance, in Ohio, once M.J.'s procedure is scheduled, we (child welfare agency who holds temporary custody) would seek parental consent as it appears they have done. M.J.'s parent is "reluctant" to proceed, but she has not denied consent. Often when this happens, parents want more information or to speak to a medical provider about their concerns. Connecting the parent with the medical provider, either by phone or at an appointment, is valuable so that the parent can express their concerns and/or have their questions answered.

Assuming child welfare only holds temporary custody, it means that this parent still has their residual rights, including medical decision-making. While on the surface it may seem simple, as child welfare does hold custody and will be the ultimate party to provide this consent, we do not want to eliminate the family of origin in these important decisions for their own children.

Ultimately, if there is a conflict with a planned procedure and M.J.'s parents do not consent to the procedure, the child welfare agency can seek legal intervention for the final decision-making in this process. This would entail the child welfare agency speaking with their attorneys and going to court where a magistrate or judge would hear both sides (why the medical team is recommending the procedure and whoever is opposed to the procedure) and then they would decide on the final medical decision. I understand that this is often seen as problematic because of the time it takes to get in front of a magistrate or judge, which may ultimately delay care. However, with strong communication between the medical personnel and child welfare, problem solving and proactive measures (advanced planning, clear communication, strong relationships) can be deployed to eliminate or minimize delay while still giving the family of origin a voice in their child's medical care. For example, medical and child welfare professionals must have open and transparent conversations that occur on an ongoing basis. These conversations should be in place before M.J.'s consent request or emergent situations. Points of contact should be developed and there should be ongoing meetings to develop and maintain a partnership approach, understanding of each other's systems, and ultimately how to ensure children in child welfare custody do not receive delayed medical care resulting from obtaining the necessary approvals for consent.

I hear the question from individuals outside the child welfare system in many different forms, but essentially "Why ethically do we care what the family of origin would want when they did something bad, unsafe, horrible, etc, to their child and that action resulted in them losing custody of their child?" or "Why should they have any say regarding anything for this child?" After practicing many years, I would pose this question in response: In the worst moment of your life, when you were stressed, overwhelmed, or in a crisis, and you disciplined your child or you yelled at your child, have you thought about the situation and regretted your actions or your words? Most say yes. And for most of the cases that I have worked, supervised, read, or somehow came across my desk, this is the situation for the parent(s) involved with child welfare. Parents have made a mistake or needed help for the behavior or action that led to their child to be removed. So, when child welfare takes legal intervention to ensure the child's safety, initially, it is temporary in nature. So again, I would pose a question to you: If your child was temporarily at a grandparent's home, or at a friend's home, while you went on a 2-week work trip, or you were indisposed, would you want someone to consent for your child to have ear tube

surgery, without your knowledge, input, and/or involvement? Would you want your child returned to you after surgery and you have no idea what happened? The answer typically is no. Therefore, although these parents are often judged, you should take the circumstances that occurred to the child out of your medical decision-making. Child welfare will handle the consequences and ensure that the child is safe. As medical professionals, think of these parents as yourself, or your sister, or a friend and honor their rights to be involved with their children, just as you would want someone to do for you or someone you love.

MARY V. GREINER, MD, MS, FOSTER CARE PEDIATRICIAN COMMENTS

The first thing that comes to my attention reviewing this case is that you know that M.J. is in the protective custody of child welfare and that the people accompanying her are nonrelative foster parents. This may seem like a small feat, but in fact it is quite common that health care providers are not aware of the legal and custody status of a child with child welfare involvement. It can be very confusing, particularly when the caregivers do not fully understand the arrangement either. Fortunately, in this case, it is clear to all involved that M.J. is in the custody of child welfare and is living in a nonrelative foster home. Additional legal details are missing that may be important for the ultimate decision on who is legally authorized to consent to treatment. Is she in temporary custody or permanent custody? Have M.J.'s parents' parental rights been terminated? It seems unlikely that they have been terminated as the caseworker has reached out to them. However, legal status is dynamic and M.J. could be in the middle of a permanent custody trial that may change her legal status during her health care course. All this will play into the decision on consent.

When making recommendations for health care, providers will typically focus on evidence-based care. In this case, you have considered the American Academy of Otolaryngology-Head and Neck Surgery's Clinical Indicators for Myringotomy and Tympanostomy. M.J. has had recurrent episodes of acute otitis media with more than 4 episodes in a 12-month period and is demonstrating hearing loss.[3] You are also trying to minimize the complications of repeat ear infections: avoiding risks of infection spread that can result in mastoiditis or rarely meningitis, decreasing risk of repeat eardrum rupture or disintegration of the mastoid, and eliminating hearing loss that could impact development of speech and language and/or social skills over time.[4] M.J. appears to meet criteria for tympanostomy tube surgery.

However, medical decision-making is more complicated than implementing evidence-based care to avoid complications. Medical decision-making must also respect the patient's autonomy. "The patient is treated as most intimately engaged with her own values, preferences, and priorities. As these could be drawn from any one of countless and incommensurable rankings, there is no 'right answer' and the patient decides what (if any) treatment is worthwhile."[5] This is further complicated in pediatrics because parents generally make decisions on behalf of their children. Surrogate decision-making by parents should "maximize the benefits for [the] child by balancing health care needs with social and emotional needs within the context of overall family goals, cultural beliefs, and values."[6] Parents have broad but not unlimited rights to make decisions on behalf of their children to protect and promote the health interests of their children while balancing constraints, obligations, and interests.[7] If parental decision-making places a child at significant risk of serious imminent harm or fails to meet the child's basic interests, and all other alternatives for resolution have failed, the health care system must seek state intervention.[7] However, this is an approach that everyone would avoid and a collaborative decision-making process is much preferred.[8] It is important to mention the importance of supporting the growing autonomy of children to be involved in decision-making when age, context, and development are appropriate.[9] In this case, M.J. is not of an age or level of development to contribute to decision-making about whether to have tympanostomy tube surgery.

The most unique challenge of this case is that M.J. is in the (temporary, we are assuming) custody of child welfare. Child welfare, acting as the custodian, assumes legal responsibility for M.J.'s care and supervision, including ensuring her wellbeing. Laws vary state to state so it is important to know your own state laws and policies regarding consent.[10–12] Generally, if parental rights have not been terminated, the parents maintain some residual parental rights, including reasonable visitation, determining the child's religious affiliation, and typically some medical decision-making. Child welfare has an "obligation to make 'reasonable efforts' to obtain consent from parents for any medical, nonemergent procedure."[13] The first goal of foster care is family preservation, so continuing parental involvement in medical decision-making is not only legally required, it is also imperative to support reunification. If and when this child is able to successfully return home, it will be the biological parents who will have to deal with the ramifications of the medical decisions while the child was in custody.

Legally, who has authority to consent can vary from jurisdiction to jurisdiction. Coauthors and I previously proposed that decisions about children in foster care's participation in research should involve both legal representation and best interest representation. A legal representative has authority to consent, and the best interest representative knows the child's personality and preferences and how they shape the determination of what is

in the child's best interest. The legal representative can be a child welfare professional or a juvenile court judge, often with a role for biological parents who have not had parental rights terminated. The best interest representative can be biological parent(s), foster caregiver(s), a child welfare worker, or a Guardian ad Litem/Court Appointed Special Advisor depending on the circumstances.[14] This approach can be applied to nonemergent medical procedure decision-making as well. Decisions about other types of health care, such as routine care, emergency care, and end-of-life care may have very different considerations.

The legal representative in this case would generally be the child welfare system; however, states vary on whether the child welfare professional or the biological parent will sign the consent form for the tympanostomy tube surgery. In this case, the best interest representatives are probably the biological parents and foster caregivers working together. The biological mother can express her values and preferences and share her previous experience. The foster caregivers can describe the effect of recurrent ear infections on M.J. Ideally, you would lead a meeting, which would likely require an additional office visit, including the child welfare professional, the biological parents, and the foster caregivers and you would collaborate, respecting differences in beliefs and values and discussing risks and benefits, to make an informed decision for M.J.

OUTCOME

After child welfare confirms that M.J. is in temporary custody and parental rights have not been terminated, you schedule a second presurgical clinic appointment for M.J., inviting her foster caregivers, her parents, and her caseworker. M.J.'s mother is able to share her concerns about her experience with a retained ear tube as a child and foster caregivers describe the impact of ear infections on M.J., including pain and difficulty sleeping. You explain M.J.'s medical and audiological findings as well as your recommendation for tympanostomy tube surgery, including risks and benefits. At the conclusion, M.J.'s parents and foster caregivers are in agreement to proceed and the child welfare agency signs consent for the surgery. M.J. undergoes a successful surgery with a united team supporting her.

ARMAND H. MATHENY ANTOMMARIA, SECTION EDITOR, COMMENTS

Children being in foster care may disrupt the usual ethical justifications for parental decision-making. For example, the foster caregiver(s) may better appreciate the illness' effect on the child and the child's preferences regarding treatment than the biological parent(s). It therefore is important for providers to collaborate with child welfare professionals to identify the legally authorized decision maker, frequently the biological parent(s), and support them to make the best decision for the child.

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