

The Confluence of Medical and Legal Advocacy: Selena's Story

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*“Alone, we can do so little;
together we can do so much.”*

- Helen Keller

Baby Selena cried as the blades of the medivac helicopter turned. Selena was being transferred from Philadelphia to Pittsburgh for a liver, pancreas, intestine, and possibly stomach transplant; sitting next to her, her attorney hoped for the best.

The medical needs of children in foster care are often delayed or unmet, and the reasons are many. Selena was born with “short gut syndrome.” Selena’s mother was unable to manage Selena’s medical needs, had little family support, and was dealing with her own legal issues. These concerns caused Philadelphia’s children and youth agency to investigate, and become involved with the family.

A children and youth agency’s intervention can begin with a report from virtually anybody. Once a report is made, the agency is required to investigate (The Pennsylvania Child Protective Services Law, 1990). If the investigation determines court involvement is necessary, the agency files a dependency petition triggering a court hearing. There, it is determined if a legal basis exists to adjudicate a child dependent, and exercise jurisdiction over the family.

In Pennsylvania, a child is adjudicated dependent if the court finds the child meets at least one of ten grounds that define a dependent child. If the child is found dependent, the court then addresses if it is safer

for the child to remain home, or be placed in kinship, or general, foster care (The Pennsylvania Juvenile Act, 1976).

Selena was adjudicated dependent because her mother couldn’t safely provide for her needs; Selena’s father’s whereabouts were unknown. Selena was removed from her mother’s legal and physical custody. However, as Selena’s medical needs were many, she remained hospitalized, and the agency began working towards reunifying Selena with her mother.

To provide reasonable efforts towards reunification, the agency establishes objectives for the child and parents. Selena’s mother’s objectives included hospital visits, medical trainings, consenting to Selena’s treatments, obtaining suitable housing, and resolving her own legal issues. Selena’s father’s sole objective was to make himself known; he never did. The court conducted permanency review hearings every 3 months, and assessed Selena’s parents’ compliance with those objectives.

As Selena’s parents were non-compliant with their objectives, there was no one to sign for Selena’s medical needs. In Pennsylvania, as in most states, the agency can sign for routine treatment, but consent for non-routine or invasive treatment must be obtained by a biological parent, or court order (55 Pa. Code § 3130.91, 1987). Pennsylvania law does not yet provide for the appointment of a medical decision maker for children in foster care. However, temporary legal custodian’s rights, such as a county agency for children in foster care, can be broadened to include consenting for non-routine procedures (*In re J.A.*, 2015). Nevertheless, Pennsylvania

courts are reluctant to broaden agency signing rights when biological parents' rights are still intact. Accordingly, every time Selena needed extraordinary medical treatment, the team had to obtain a court order.

After a year of parents' non-compliance, the court determined it was in Selena's best interest to change Selena's permanency goal from reunification to adoption and terminated her parents' rights (The Pennsylvania Adoption Act, 1980). Selena's legal path toward permanency was now clear, but her medical future was cloudy; her liver was failing. Running out of options, the team looked to an FDA-approved clinical trial conducted in Boston. However, there was approval for only 12 children participants; Selena would be the 13th. The team convinced the FDA to allow Selena to participate, but court approval was again needed. At an expedited hearing, the team convinced the court it was in Selena's best interest to participate in the clinical trial. The trial was deemed successful, but the recommendation was still to move forward with the organ transplants.

A hospital in Pittsburgh was the best transplant option for Selena. However, the hospital was reluctant to perform complex and aftercare-intensive procedures unless Selena was in a permanent post-op environment; this meant adoption. While the agency identified a pre-adoptive home, the hospital required the adoption to be finalized. Foster care agencies recommend a foster child be in the pre-adoptive home for at least six months prior to adoption petitions being filed, but Selena did not have that time. The team negotiated a waiver of the waiting period and convinced the hospital to withdraw its finalization requirement. Selena was now on the organ donor list!

The court approved two airlifts to Pittsburgh for the pre-op evaluations and surgeries. Unexpectedly, the pre-op evaluation revealed the clinical trial had worked better than anticipated, and Selena's liver function had returned to normal, so she no longer needed a liver transplant. What happened next was more than the team could have ever hoped for: Rather than first attempting the intestinal transplant, doctors performed an intestinal lengthening procedure, and it worked! Miraculously, Selena needed no organ transplants.

Looking back, Selena's attorney recognized how crucial this multidisciplinary team collaboration was for Selena. The team established the legal path, including adoption, to secure the best medical treatment possible for Selena. Team collaboration for Selena's young life paved the way - changed her story, if you will - from a tragic one to one where Selena gets to live a happy and healthy life with her forever family.

About the Authors

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References

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