

ENHANCING YOUTH VOICE IN HEALTHCARE DECISIONS

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RECOMMENDATION SUMMARY

In order to help ensure timely, appropriate, and consistent access to healthcare tailored to foster youth, and empower them to advocate for their own needs, Congress should 1) establish national standards for personalized appropriate healthcare transition plans in consultation with the youth and their provider, 2) set national standards to designate a specific and consistent individual to act as the youth's medical decision maker, and 3) provide funding to support state-level creations of a centralized information-sharing platform that allow healthcare professionals, foster youth, and the child welfare system access and ability to modernize record-keeping and reduce misinformation.

EXECUTIVE SUMMARY

Over 85% of foster youth have significant physical, developmental, and mental health needs (Leslie et al., 2005). Despite a high need for healthcare services, youth do not presently receive access to high-quality healthcare responsive to their needs. To help ensure all youth receive timely, appropriate and consistent access to healthcare that is specific to their individual needs, Congress should pass legislation designed to increase youth voice and autonomy.

PERSONAL REFLECTION

Throughout my time in foster care, I encountered several negative experiences with the healthcare system due to a lack of transparency and failure to respond to my unique responsiveness to my needs. Like many other foster youth who experience significant trauma, I was ordered to attend court-mandated therapy. One therapist made decisions for me based on a report I had never seen. When I eventually learned about the report and requested to review it, I found that it significantly misrepresented my needs. Despite this, I was denied any input in my care or the opportunity to explore alternative strategies.

In addition, my social worker required documentation demonstrating that I went to the doctor annually. However, I personally never saw those records myself and had no way of knowing whether they accurately reflected my visits. After aging out of the foster care system, I finally had the opportunity to review some of my recorded healthcare information, which revealed considerable inaccuracies.

THE PROBLEM & CURRENT LAW

Numerous studies document a correlation between Adverse Childhood Experiences (ACEs), traumatic life events that occur before age 18, and poor physiological, psychosocial, and developmental health outcomes (Bryan, 2019). Boullier and Blair (2018) found that the more ACEs a child experiences, the higher their risk of early death and life-threatening conditions. Over half of all youth reported to the child welfare system experience four or more ACEs, compared to only 13% of the general population (Stambaugh et al., 2013).

Despite the clear need for healthcare services, systemic barriers still impact foster youth's access to care. Placement instability, defined as frequent placement disruptions, often results in missing or incomplete medical histories, leading to inadequate care (Deutsch & Fortin, 2015; Smith, 2005). Additionally, providers may avoid providing referrals for specialized services due to burdensome documentation requirements and poor information-sharing between child welfare agencies and healthcare providers (Deutsch & Fortin, 2015). These gaps can be detrimental to foster youth, who frequently need more intensive and specialized services, leaving many of their healthcare needs unmet.

Currently, legal authority over a foster youth's healthcare decisions is shared among multiple parties, including the child welfare system, birth parents, and foster parents. This often manifests in the youth themselves being excluded from powerful decision-making about their care (Chilton, 2022). Deutsch and Fortin (2015) found that being required to coordinate among several medical decision-makers results in poor record-keeping and misinformation. Policies exist to support autonomy for individuals unable to make medical decisions, such as judicial mandates to consider a person's preferences when appointing conservators for individuals with disabilities. These protections should be extended to foster youth (AL Code § 26-2A-104, 2024; Cal. Probate Code § 1810, 1990; § 72-5-410, MCA).

Foster youth often face coercive medical practices, exclusion from treatment decisions, and a lack of individualized care (Barnett et al., 2018). For example, approximately half of foster youth report feeling forced to take psychotropic medication (Moses, 2011). Many youth have also reported being overprescribed medications or denied alternative approaches. However, in order to receive responsive and appropriate care, foster youth require access to a diverse range of holistic treatment options (Cancel et al., 2020). Additionally, medical decisions for youth in congregate care settings often fail to consider youth's cultural, religious, or personal needs (Barden, 2021). This lack of autonomy contributes to increased rates of substance use, homelessness, and incarceration in adulthood (Chilton, 2022).

Minor consent laws vary significantly by state. Foster youth are often expected to make medical decisions at specific ages without previously having opportunities to advocate for themselves (Barnett et al., 2018; National Center for Youth Law, n.d.).

THE PROBLEM & CURRENT LAW (CONTINUED)

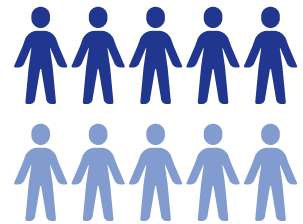
According to the American Academy of Pediatrics (AAP), best practices include consistently incorporating youth perspectives in their medical decisions (Katz et al., 2016). The AAP also recommends transition planning that consists of supporting independence and preparing adolescents for the shift from pediatric to adult care (White et al., 2018). Research shows that enhancing patient autonomy increases commitment to treatment, patient satisfaction, and overall well-being (Doyle et al., 2013; Rathert et al., 2012).

POLICY RECOMMENDATIONS

In order to help ensure timely, appropriate, and consistent access to healthcare tailored to foster youth, and empower them to advocate for their own needs, Congress should:

- **Establish national standards for personalized appropriate healthcare transition plans in consultation with the youth and their provider.** These plans should be updated annually and include developmentally appropriate goals that support youth autonomy. Courts should annually review the youth's progress and access to opportunities outlined in the plan.
- **Set national standards to designate a specific and consistent individual to act as the youth's medical advocate.** This individual should be selected based on the youth's preference and have documented ability to meet the youth's medical needs. They should be accountable for providing age-appropriate assistance so that each youth can understand, consent to, and acquire medical treatment. Youth should retain the right to change their designated medical advocate.
- **Provide funding to support state-level creations of a centralized information-sharing platform that allow healthcare professionals, foster youth, and the child welfare system access and ability to modernize record-keeping and reduce misinformation.** Several pilot programs already exist in California, Florida, Texas, and Massachusetts. These platforms use personalized interfaces and protect privacy by restricting access to information based on an individual's qualifications.

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