## The U.S. Healthcare System: How it Restricts and can Better Serve Children with Disabilities

The United States healthcare system is notorious for its <u>expensive programs</u> that work to provide more <u>affordable healthcare</u> options regardless of one's socioeconomic status. These statements are entirely counterintuitive, given that the system was built with an inherent bias of <u>favoring the upper and middle class</u> more. However, it is not just those of different economic backgrounds that are impacted by the country's healthcare, it is also those with intellectual and developmental disabilities.

The history of those with disabilities stems from the beginning of time, but it was not recorded until the 1700s and 1800s (during the Antebellum Era). What people with disabilities went through in a time with little medical advancement compared to today is incredibly disheartening. While there are a multitude of local, national organizations, and encouragement to embrace all abilities and inclusion today, the idea of suppressing differences was emphasized then. For example, the rise of the eugenics misconception led to doctors believing they could control genetics by doing forced sterilization and lobotomies on people. Thankfully, <u>inclusion</u> has been more embraced today and allows everyone to celebrate each other and their strengths. Additionally, this has opened the door for increasing healthcare opportunities specific to those with disabilities. These have become more apparent after the passage of the Americans with Disabilities Act in 1990, which has worked to promote a more inclusive America by increasing access to resources such as parking, service animals, mobility devices, and even equal access to child care. Moreover, there are few healthcare programs that are specifically designed to help children with intellectual and developmental disabilities: The Medicaid Family Support Waiver and others based on one's state.

The Family Support Waiver is funded by Medicaid and provides more access to specific resources for people who are under 18 and have a disability. This includes forms of therapy (such as Speech and Occupational Therapy), home modifications or ramps, or personal care. It is a "waiver" since it waives the income requirement people with Medicaid usually must meet. This is a step in the right direction given that the Family Support Waiver has the opportunity to better support families and children with disabilities. However, the program falls short in its wait time. While getting regular Medicaid takes up to 90 days to determine eligibility in Indiana, one must wait <u>five years</u> to get a Family Support Waiver in the same state. This trend on long wait times can be found throughout the United States. It takes seven years in Florida, nine to 17 years in North Carolina, to name a few. The US healthcare system is maintained through cooperative federalism, where the state governments have responsibilities to provide healthcare programs to citizens in addition to the national government. 10 states have taken advantage of this by developing disability health programs under a Centers for Disease Control and Prevention (CDC) cooperative agreement, CDC-RFA-DD21-2103. This agreement aims to improve the health of people with disabilities through programs and organizations that serve citizens in a specific state. While these are steps in the right direction, there are various policy options to ensure there is affordable healthcare that can be provided in a timely manner across the United States.

First, to remedy the issue of the time consuming process of getting a Family Support
Waiver, Medicaid can increase access to one to two services <u>such as support services or types of</u>
therapy that are already included in the Family Support Waiver during the wait time for a lower
cost. This ensures the types of service a child with disabilities needs are at least accessible and
affordable for a family. Additionally, since one must be <u>under 18 and have a disability</u> to qualify,
families could fill out a form on their state's Medicaid website to show that they are eligible for a

waiver in addition to filling out a contact information and financial situation form so that they are reachable during the process. The funding for this policy would already be embedded into a state's Medicaid budget, but could slightly rise since families would get access to this affordable care earlier. However, the financial situation form will evaluate how much the family makes. Since these families do not initially qualify for Medicaid (that is for the Children's Health Insurance Program, or CHIP to accomplish), families can also offset the costs by paying no more than half to three quarters of the price for a healthcare service. This would ensure that Medicaid can cover the costs of those applying and on a Family Support Waiver in addition to their other programs and services they provide.

While 10 states have programs specifically for people with disabilities outside of Medicaid's Family Support Waiver, they are not available in all states and thus do not provide more resources for families with a child with intellectual or developmental disabilities to consider while waiting for a Family Support Waiver, for example. To solve this, Congress can pass a resolution to reinforce and prioritize the CDC-RFA-DD21-2103 throughout all 50 states. This would not only expand resources to support children with disabilities, but it would ensure families are aware of their options. As of 2021, 20% of Americans say they are aware of disability healthcare. With more programs not just across the United States, but within each state, families with a child with disabilities can seek more accessible care quicker rather than waiting years.

Once these programs and organizations are established, Medicaid (since it already has healthcare programs for children with disabilities) can work with the CDC to create a federal database to promote various health services and programs in each state while checking a child's eligibility requirements in real time. Specifically, families fill out their information on a "filter"

section to find programs in their state. Moreover, to maintain privacy, history will be wiped each time a person fills out their information for the database to filter unless a parent or guardian creates an account to access the database.

We as a nation have come a long way in the fight for inclusion and healthcare for children with disabilities, but if these policy proposals are implemented, we can get even closer to the finish line of fully promoting an inclusive society through healthcare programs and overall building support.

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