

System Change

Throughout the United States, we see more and more people with disabilities in our neighborhoods. We see them taking tickets at our local theater. They ask us if we want paper or plastic at the grocery store. We see parents of younger children with disabilities walking on our main streets or in our malls.

So many of us feel good about the fact that there are people with disabilities who are working a job or interacting within our community. The fact remains that what we are seeing, remains the tip of the iceberg.

When a parent realizes that their child has disabilities, the family physician usually (and should) recommends they go to a county-based agency operated by their state government to confirm the diagnosis. This is, for the most part, a protracted process.

Once the local authority and the school system, the child is eventually given an Individual Education Plan (IEP). If the parents ask the right questions, the individuals are placed on a “waiting list” within their state for “functional services.” It may seem premature to the parents of a person with disabilities to request getting on the wait list, especially when their child has not yet reached second grade. Please rest assured, this is extremely important.

Historically, parents will have an uphill battle for at least the next two decades. The battle is fought to deal with their offspring’s disabilities, but it is even more difficult for the families to navigate a system fraught with little guidance to accessing services.

The lack of the political will to address not only the complexity of service delivery, but also the provision of it in most states, is abysmal.

Throughout the United States, parents are placed on waiting lists for services for their offspring. In some states, parents are given preferential treatment if they have enough money or connections to move up the wait list.

In each state, there is an average of about 6,000 people with severe disabilities on waiting lists. In New Jersey, New York and Pennsylvania combined, we estimate that there are well over 25,000 families waiting for services. Parents who have passed retirement age likely have a son or daughter living with them who are in their 30s or even 40s.

The system is broken, but it can be fixed easily. Medicaid needs to be repurposed, rather than increased dramatically. Families on wait lists are not “waiting” for a nursing home or an expensive institution. They are waiting for in-home supports, small housing or even someone to help their son or daughter find a job (or at least meaningful activities they will enjoy) while they are in their teens.

Parents need to learn about options. They should find out from their school system or a local nonprofit about how to access services. There are thousands of nonprofit organizations committed to helping families expedite the process. However, the only way to reduce the waiting list is a multi-faceted effort to meet with policy makers and ask for repurposing Medicaid.

There are training programs that parents can attend to learn about this process. It is up to them if they want to learn and then apply this knowledge for system change.

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