

## **Obstacles to Attaining the Vision of Equal Opportunity for People with Intellectual Disability/Autism**

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### **Abstract**

This paper addresses the obstacles that impede efforts to enable people with intellectual disability and/or autism to experience equal life opportunities. Specifically addressed are chronic underfunding, workforce challenges, over-regulation, and a failure to focus on meaningful life outcomes.

### **Introduction**

People with intellectual disabilities or autism (ID/A) and direct support professionals (DSP) deserve better. People with ID/A should have every opportunity at life that others have. This includes the opportunity to live their life according to their own informed choice, given the restraints we all have (time, ability and resources). DSPs often need to work overtime and/or multiple jobs, just to pay their bills. DSPs should be recognized and paid at a level that reflects their work as highly trained professionals. There are many obstacles to realizing this vision. This opinion will address only a few – chronic underfunding of service, lack of a focus on outcomes, and over-regulation.

Providers have a critical role in assuring the health and welfare of people receiving Medicaid funded ID/A services. The link is undeniable between provider funding - DSP wages - DSP recruitment and retention - access to services - quality of service. Yet, ID/A providers have been funded below their cost and with no annual adjustment for inflation over decades. This lack of sufficient funding results in serious challenges with staffing levels, quality and access to services. It has created a service environment that makes it challenging to be creative and to support people with ID/A in making informed choices.

The ID/A system is focused on process, more than quality outcomes. Providers are regulated for documentation rather than to the impact their services have on people's lives. For example, providers are held accountable to documenting that they brushed a person's teeth three times a day, and are not incentivized for the person to have a clean dental exam. DSPs are in this profession because of their compassion for people with ID/A, not because of their passion for administrative tasks. With a focus on incentivizing outcomes, DSPs could help enhance the lives of people with ID/A while increasing their own pay.

Over-regulation is costly to both people with ID/A and providers. It diverts resources away from quality care and to administration. Regulations should be eliminated if they do not clearly improve the quality of life for people with ID/A or are not critical for accountability for the use of public funds. People with ID/A, family members, providers, local and state government may benefit from an honest conversation about regulations. This work is a grind and takes an ability to listen that is taxing for the best listeners. We need to come out of our silos and see the world through each other's experience. The reallocation of the ID/A system's precious and scarce resources from administrative compliance activities to improving the lives of people with ID/A and DSPs will reap rewards. It may allow all of us to see what the level of regulation and funding needs to be in order to bring about a brighter day. Then, people with ID/A and DSPs will be able to live a life of their choosing, within the typical restraints that we all have.

This is the opinion of the author, not to be construed as an opinion of any organization or affiliated person.