Innovative Practices Supporting Individuals with Developmental and Intellectual Disabilities and Their Families Throughout the Lifespan

Stephen Davis and Sara Molina-Robinson 23 March 2017

Introduction:

There are approximately seven million individuals with intellectual and developmental disabilities (I/DD) in the United States but only about 25% receive services through publicly-funded programs such as Medicaid and Medicare. The rest are supported by the family and private services. However, as the system moved from institutional care to home and community-based services, families are seeking public funded services. Additionally, as the caregivers age they need more support taking care of the person they support.

The disabilities rights movement and efforts to create awareness about the rights of people with disabilities have a long history. Parents and self-advocates have been at the forefront of the movement, mobilizing, educating, and influencing policy and service systems so that individuals with intellectual and developmental disabilities have the services and supports to live, work and participate in their communities. In 1973, the Rehabilitation Act was passed to protect the civil rights of people with disabilities. Section 504 of the Act provides equal opportunity for employment within the federal government and in federally funded programs, prohibiting discrimination on the basis of physical or mental disability and equal access to public services.[1] In 1975, the passage of the Education for All Handicapped Children Act ensured equal access to public education in more inclusive settings for children with disabilities. The Education for All Handicapped Children Act was renamed in 1990 to the Individuals with Disabilities Education Act (IDEA), which provided additional guidance on inclusion and parents' rights. The Americans with Disabilities Act (ADA) was also passed in 1990 and ensured equal treatment and access to people with disabilities to public services and employment opportunities, and the Olmstead Supreme Court ruling in 1999 encouraged the national trend toward deinstitutionalization for people with disabilities.[2]

System Transformation and Best Practices

Full participation and inclusion do not happen overnight. We need to consider how we promote and support people with disabilities and their families through the different phases in their lives—school years, adulthood, and aging. Each phase presents a different set of opportunities to support choice, involvement, and self-determination. Each phase prepares the person and their family for the next.

The school years, as we say, are the formative years. Schools in partnership with families and supports coordinators have an explicit role to prepare students for the next phase of their lives. Special education should be, for each student, an individualized process that considers the student's strengths and supports their learning. Schools have an important role during the transition out of school process. The transition process, which typically begins at age 16, should incorporate standardized assessments that help the student, family and their support staff match their interests and skills with options of training, education and employment after graduation.[3]

The goal is to ensure that a person with a disability is not sitting home after graduation not engaged in any activity, not because they want to, but because the transition process did not work like it should.

Transition for most of us from school to adulthood means employment. The ability to earn money to support our needs and do the things we enjoy doing like going to the movies, out to dinner or on vacation is fundamental to an everyday life and valued role in one's community. For many, employment gives us a sense of purpose and pride.[4] So how do we create the opportunity for people with disabilities to share the same experience? How do we support them to explore and decide what job he or she wants to seek out instead of fitting them into workshops and settings not necessarily of their choice? We need to promote social capital so everyone understands the benefit of any person, including persons with a disability, contributing to our society. We need to create more opportunities for people with disabilities to become part of the workforce in competitive employment.

Participating in competitive employment for individuals with intellectual and developmental disabilities can be achieved through partnerships that create employment models that are responsive to the person’s interest and abilities. For example, Repsol, an energy company based in Spain, facilitates employment of persons with disabilities at petroleum stations. Repsol’s commitment to support the integration of all able people into the workforce resulted in a well-thought-out program implemented with guidance from disabilities experts. There are several components of the program, including analysis of what skills are needed for each position to make the best match with the person, job training and workforce training to prepare employee, employer and co-workers and set clear expectations, and vocational training. The Repsol Foundation and ONCE Foundation, whose mission is to ensure social inclusion of people with disabilities, have implemented Framework Cooperation Agreements to further define their commitment and partnership toward the integration of differently abled people into the workforce.[5]

Adults with disabilities should have the option of where they live. The resources and direct service providers are not always available to support a person in their desired living situation. In Pennsylvania, supportive living, life sharing, and community group homes are all options that may come with long waiting periods. As persons with disabilities and their caregivers grow older they are faced with a different set of situations and challenges that impact their living situation and needs for additional or enhanced supports. There may be a need for additional supports in the home for daily living activities, to address health and safety and quality of life. These needs present an opportunity for the ID and Long Term Living systems to collaborate in support of the person and their aging caregiver. Supports Coordinators need to navigate the system to obtain a package of comprehensive services that support the person and their family member.

The supports needed across the lifespan for people with disabilities and their families, like for many, are often complex because of the nature of their diagnosis, and difficult to coordinate at times because of the complexity of the public system. We need continued partnership with families who, in the caregiving role, understand the needs of the family member. There is a realization that families need services that support their caregiver role. Families have, at times, an overwhelming set of responsibilities.

Understanding and addressing their needs improves their ability to provide care.

Supporting Families National Community of Practice, a project through the Institute for Human Development University Center on Excellence in Developmental Disabilities, focuses on supporting families by addressing recommendations from the Wingspread Family Support Summit in 2011.[6] The goal of this five-year project is to help states develop principles, policies and practices to support families across the lifespan and to establish indicators to measure progress towards achieving the goals. Pennsylvania is a participating state in this project that has the potential to reshape how we view and fund services to families.

Conclusion

As the service delivery system transitions from Intermediate Care Facilities for Persons with Intellectual Disabilities (ICF/ID) to Home and Community-Based Services, resources are being allocated to both models, which results in a financial hardship to the system. In 1991, New Hampshire became the first state to close all its public institutions. Several states have since followed, including Vermont, Rhode Island, New Mexico, Alaska, Hawaii, Maine, West Virginia, and Michigan, as well as the District of Columbia. Pennsylvania is moving in that direction. We need to get there so funding can be allocated to creating a comprehensive sustainable inclusion model. Furthermore, we need to reevaluate how we are making decisions about levels of services and looking to implement the right standardized assessment process that will result in a more effective allocation of resources.

While we have come a long way, there is still much work to be done to fully support and include people with intellectual and developmental disabilities in our society and to support their families in their caregiver roles. We need to understand how to facilitate and support choice and self-determination. Furthermore, we need to feel comfortable with the choices of the people we support, share their vision and be innovative in fulfilling it. While biases prevent the full implementation of ADA, civil rights and inclusion laws, funding streams create roadblocks with rules about what is covered for payment under the waivers programs. To support people with disabilities to lead everyday lives, it’s going to require partnerships with public officials, nonprofit organizations, business, schools, supports coordination organizations, service providers, self-advocates and families to create models of support and services rooted in the values of choice and self-determination creating valued social roles. This will require training, technical assistance, and incentives to schools, employers and landlords to promote and reward integration of differently abled persons into the communities of their choice. As a society, we will see the long-term benefits in years to come.

References

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