ISSUE BRIEF

Supporting Families of People with IDD

Families form a core unit of our society, and people with intellectual and developmental disabilities (IDD) often receive the majority of their emotional, physical, and material support from their families throughout their lives. To better understand how families can maximize their capacity, strengths, and unique abilities to support their family members with IDD, more information on families, their needs, and what constitutes successful outcomes is necessary.

▶ Introduction

Families play a critical role in our overall system of long-term care for people with intellectual and developmental disabilities (IDD). It is estimated that families currently provide $335 billion worth of caregiving annually for their members with disabilities (Feinberg, et al., 2011). Nationally, only 25% of people with IDD receive formal support services, and it is estimated that more than half receive those supports in the family home (Braddock et al, 2015; Larson et al, 2014).

▶ Need for Research

While families are the primary source of long-term supports for most people with IDD, the role of families is not fully acknowledged in disability policy and practices (Hecht, et al, 2012). Research is needed to identify the most effective supports for families within complex systems, identify practices that promote their economic sustainability, and establish metrics to monitor and evaluate the success of public policies and practices regarding family support.

▶ Family Demographics Research Goals

Recent decades "have seen profound shifts in the demographic context of family life" (Sweeney, 2012, p. 667). US families are an increasingly complex web of culture, ethnicity, multi-generational structures, faiths, and economic units. As the typical US family is no longer a nuclear family or two-parent household, research is crucial to understand the needs of today's families and to identify the support practices that are most effective in achieving desired outcomes. In order to construct family supports that result in positive outcomes, policy makers must understand the complexity of family units and the barriers experienced by specific sub-groups of families. They must plan to improve access and utilization for all families.

▶ Economic Research Goals

For families that include a person with IDD, economic sustainability and community participation contribute to the overall quality of life for all family members. In order to inform public policy and practices, research is crucial to identify the formal and informal supports that would enable caregivers to earn meaningful wages in addition to providing long-term supports for their family member with IDD. The intent of family support should be to strengthen the lives of family members as well as to recognize their significant contribution to long-term care.

IMPACT

Javier is a 52-year-old man with intellectual disability who lives with his 84-year-old mother. His mother finds it increasingly hard to meet his day-to-day needs and for both of them to do things in the community that they enjoy.

Javier's younger sister, Maria, is concerned about the health of their mother and wonders who will support her brother in the future.

Maria, who is barely making ends meet with two teenagers of her own, is afraid of losing her job because she is spending more and more time coordinating supports for her mother and brother. She knows the family needs a long-term plan, but when she reaches out for help she is told she is not eligible for most services, and for those she is eligible for, there is waiting list. Three generations of one family are heading toward a crisis.

▶ Quality Research Goals

Within the United States, very few public resources are allocated to formal family support services (Braddock et al, 2015, Rizzolo et al., 2013), and even less for evaluating the impact of those supports. Research designed to identify effective models of family support, barriers to and facilitators of implementation, and metrics to assess quality and outcomes are crucial. The maintenance of robust data systems by states to monitor publicly funded service utilization and outcomes for people with IDD and their families could also be used for ongoing quality enhancement.

▶ Conclusion

There is a significant need to understand and address families' support needs. States and organizations that offer family support services do so with little consensus on the nature of the practices or on measures of success. Research is needed to

identify the most effective supports for families within complex systems, identify practices that promote their economic sustainability, and to establish metrics to monitor and evaluate the success of public policies and practices regarding family support.

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