ISSUE BRIEF

Social Inclusion of People with IDD

Social inclusion is the "next frontier" issue in intellectual and developmental (IDD) research, policy, and practice. Incorporating personal relationships and community membership, social inclusion permeates many parts of life, and should be understood in the context of community living setting, employment, education, self-determination, and other life domains.

▶ Introduction

Social inclusion goes far beyond one's simple presence in the community. It is about how we play, the roles we take in civic life, who we love, how we connect with faith, and how we build fulfilling relationships with others.

Despite challenges in creating a unified definition, there is growing consensus that social inclusion includes both personal relationships and community belonging (Simplican et al., 2014). We know that people with intellectual and developmental disabilities (IDD) view friendship (Matheson et al., 2007) and love (Morales et al., 2014) in the same ways that people without disabilities do. From small-scale studies, there is also evidence that planned interventions can assist people with IDD to achieve greater inclusion in faith communities, sports activities, their neighborhoods, and community organizations, and that such participation can help increase quality of life (Dahan-Oliel, et al., 2012).

▶ Need for Research

Research about social inclusion of people with IDD is in the early stages, and while it appears that improving inclusion can have positive effects, both for people with IDD and their communities, research is necessary to inform public policy and practice. Public policy controls funding, and funding shapes practices. We need to understand which practices are effective, which measures are appropriate for evaluation, and how to monitor the outcomes of policy changes.

▶ Metrics Research Goals

To ensure that the outcomes of interventions can be demonstrated, research is necessary to develop a collection of appropriate metrics to measure elements of social inclusion and their relationships to other valued outcomes. Being able to measure social inclusion outcomes will enable us to understand what works to promote social inclusion and what does not.

▶ Environmental Research Goals

Social inclusion is inherently tied to the interaction of personal variables (type of disability, race, gender, cultural orientation, etc.) with the social environment. Research to illuminate how these variables intersect is necessary to elicit effective practice and demonstrate that such practices can be successfully implemented in complex environments.

▶ Embedment Research Goals

People with IDD typically access supports in a number of domains (e.g., health, employment, housing, education) that may either facilitate or serve as barriers to social inclusion. To ensure that social inclusion outcomes are incorporated (or embedded) in measures of human services, research is necessary to identify evidence-based practices that support

IMPACT

Steve is a pretty typical guy. He lives in a group home with three housemates on a nice suburban street and works 20 hours a week bagging groceries at a local supermarket. His home and work are important parts of Steve's life, but they are not what give him the most fulfillment.

Like most of us, Steve's relationships and community belonging are what really make life fulfilling. Steve has a girlfriend who lives 10 miles away. They have long talks on the phone, but rarely see each other. He loves baseball, but can usually only watch his favorite team on TV since he cannot get to the games. Steve's faith is important to him, but he typically goes to services only once a month, on the weekends when he stays with his parents. He would like to be more active in all of these things, but transportation difficulties, thin staffing at his group home, and limited options to promote social inclusion all hold back his dreams to build his relationships, practice his faith, and cheer for his team in person (or maybe even play baseball in a local league).

Steve has benefitted from the community living movement in his lifetime, but social inclusion for Steve and people like him remains elusive.

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▶ Training Research Goals

To ensure that stakeholders are prepared to scale up social inclusion in diverse systems, research is crucial to identify effective training and preparation to build capacity for social inclusion among self-advocates, family members, practitioners, and policy makers.

▶ Community Research Goals

To ensure that communities are optimally prepared, research is necessary to identify the most effective strategies to

promote the social inclusion of people with IDD and to demonstrate that they can be successfully implemented in diverse communities.

▶ Lifespan Research Goals

The relative level of social inclusion a person experiences at any one time is precipitated by many decisions that occurred earlier in their life. Research to illuminate lifespan trajectories may help us develop strategies for early interventions to employ to optimize inclusion throughout the lifespan.

▶ Conclusion

Taken as a whole, the goals presented above represent a comprehensive set of research priorities which, if accomplished, would result in major advances in knowledge that would inform practice and policy.

▶ References

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