Introduction to the Special Issue: Community Living and Participation

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Background. In July 2012 the Research and Training Center on Community Living at the University of Minnesota hosted a State-of-the-Science Conference on Community Living Outcomes and Quality of Life (SOSC). The purpose of this conference was to bring together researchers and other stakeholders to provide a summary of what is known, identify points of debate and gaps, and establish recommendations for future research related to community living outcomes and quality of life in for people with intellectual and developmental disabilities (IDD). The conference had a number of focus areas, including: social inclusion; self-determination; family experiences, support and siblings; employment; health and wellness; methodological issues in research; quality of life indicators; outcome predictors; and using outcome data to inform policy. The State of the Science Conference was a vehicle through which these key topics related to community living and participation could be discussed and future research goals identified. This special issue of Intellectual and Developmental Disabilities (IDD) includes papers written by the presenters and participants of the SOSC on key topics associated with community living outcomes.

Nature of the special issue papers. Instead of systematic reviews, this special issue presents a series of expert commentaries and narrative reviews that focus on important policy-related and conceptual issues that were examined at the State-of-the-Science Conference. As Lakin (2012) noted, "In policy research it is often necessary to accept the preponderance of good evidence through comprehensive reviews of all the available credible evidence". Ideally, such reviews select the best available evidence and analyze and interpret it in a manner underpinned by a detailed understanding of the circumstances in which the evidence was obtained, and of the IDD policy and service-delivery context in which the conclusions are to be applied. We hope readers will find that the commentaries, reviews and analyses presented in this special issue display these characteristics.

US focus drawing on US data. One feature of a number of the special-issue papers is a strong focus on outcomes, services, policy and research involving people with IDD in the US. A related characteristic is that many of these papers draw on data from one or more US national surveys, such as the Administration on Intellectual and Developmental Disabilities (AIDD) Projects of National Significance. These projects include the National Core Indicators project (Human Services Research Institute and the National Association of State Directors of Developmental Disability Services), Residential Information Systems Project (University of Minnesota), State of the States in Developmental Disabilities Project (University of Colorado, Boulder) and Access to Integrated Employment: National Data Collection on Day and Employment Services for Citizens with Developmental Disabilities (University of Massachusetts, Boston).

However, the spotlight on the US is not all encompassing. For example, Amado, Stancliffe, McCarron and McCallion (2013, this issue) draw on national findings from Ireland arising from the Intellectual Disability Supplement to The Irish Longitudinal...
and practice, then set out various unanswered questions and focus areas for future research.

Self-Determination. Self-determination is also critical to quality of life, community living and participation. The ability to make one’s own decisions and exercise control over resources allows people with IDD to influence the course of their life and how they participate and live in their communities. Being self-determined is associated with more positive outcomes for people with IDD in school and community life (Wehmeyer, Abery, Mithaug, & Stancliffe, 2003). System expectations and policy have begun to promote choice and self-determination for youth and adults with IDD. As these efforts have grown, so too has the self-advocacy movement and the expectations of individuals with disabilities and their families. In their article, Wehmeyer and Abery (2103 this issue) discuss self-determination and understanding effective strategies to teach self-determination skills to people with IDD are fundamental. They suggest it is important to ensure that individuals who provide paid and unpaid support to people with IDD understand how to support self-determination. Furthermore Wehmeyer and Abery (2103 this issue) suggest that given self-determination is usually being exercised within the context of relationships, it must also take into consideration how context (e.g. home, community, school, work etc.) influences relationships and opportunities for and the exercise of self-determination.

Employment. Recent decisions made by the U.S. Department of Justice (2012, 2013) have indicated that people with IDD, including transition-age youth, should be provided the opportunity to work. Most people with IDD want economic independence and employment through real jobs that pay real wages (Migliore, Mank, Grossi, & Rogan, 2007). As pointed out by Nord, Lueking, Mank, Kiernan and Wray (2103, this issue), despite policy and significant investments, employment systems face serious challenges in successfully supporting adults with IDD to obtain work integrated in the community. Nord et al. (2013, this issue) support the practice of participation in employment beginning early and providing youth in transition with work experiences in school and ensuring that they are employed immediately following education. By doing so, young people with IDD are more likely to be employed later in life and to earn more.

Quality of life. Experiencing a good quality of life is a desired outcome of the services and supports
provided to people with IDD and their families. This construct has been measured in many ways and is most often identified through various life domains. Brown, Hatton and Emerson (2013, this issue) discuss the importance of using both subjective and objective methods in measuring quality of life and make an important distinction between indicators that are common to all people and those that are unique to individuals. They identify a series of challenges in using aggregated data from quality of life indicators to inform policy and practice. In a notable conceptual contribution, they propose that the capabilities framework (Nussbaum, 2011) may offer a complementary approach and a potentially more suitable way of understanding and evaluating IDD policies and practices.

Interestingly, Moseley et al. (2013, this issue) discuss the importance of using outcome indicators to inform IDD policy and practice. They offer a specific example from Kentucky where significant changes have been made to specific IDD policies, services and funding based on outcome data from the National Core Indicators program. Specifically, these data identified comparatively poorer outcomes for people with IDD in Kentucky in relation to integrated community employment, health and exercise, psychotropic medication use, and loneliness and friendships.

Readers may care to consider the extent to which the ideas set out by Brown et al. (2013, this issue) are compatible with the approach described by Moseley et al. (2013, this issue).

Families. Families play critical roles in the lives of people with IDD. The majority of care provided to individuals with IDD receive throughout their lives is provided by families. In one recent study family caregivers report spending more than 40 hours per week providing support to the person with IDD (Anderson, Larson, & Wuorio, 2011). Therefore, it is critical to assist families to ensure they can effectively support their family member with a disability. Hewitt et al. (2013, this issue) present a narrative review focusing on the status of research on families that provide support at home to individuals with IDD. Hewitt et al. examine the funding, policy and service-delivery situation in the US and identify a number of areas of debate that will inform future research and policy. These include (a) the current absence of a consensus definition of family support, which makes it difficult to compare like with like when examining family support research, policies and services, and (b) the absence of single, unified, and comprehensive US database on family support meaning that key questions about family support recipients cannot currently be answered conclusively.

Health and wellness. Good health is a fundamental component of community participation. People with IDD experience health disparities (Institute of Medicine, 2007; U.S. Public Health Service, 2005). There are numerous reasons for this, many which are true for all people such as gender, race, poverty and access to health and specialty care. Other reasons include the availability of healthcare professionals that fully understand the nature and needs of people with IDD and outreach to people with IDD in community health programs. Irrespective of the reason for such disparities, they do exist and people with IDD also are more likely to have co-occurring disorders and conditions (e.g. epilepsy, mobility, mental health disorders, high blood pressure and high cholesterol) that complicate general health and well-being (Traci, Seekins, Szalda-Petrie & Ravesloot, 2002). Increased attention through research, policy initiatives and program development has evolved to address these health disparities, yet they still exist. Anderson, McDermott, Marks, Humphries, and Larson (2013, this issue) examine these critical issues and propose a number of important future research foci to reduce disparity for people with IDD including: improved practices for monitoring and treatment for chronic conditions; an enhanced understanding of how to promote health among those in the IDD population who are aging; addressing the health needs of people with IDD who are not part of the disability service system; developing a better understanding of how to include people with IDD in community-focused health and wellness programs; and improving access to general medical care or specialized programs.

Summary. This special issue of IDD provides articles on each of these important areas related to community living and participation. In addition, an article is included that presents information on important methodological challenges in the use of self-reported and population-based data in IDD research (Emerson et al., 2013, this issue). As noted earlier, Moseley et al. (2013, this issue) discuss the critical intersection between research and policy and the need to make evidence-based policy decisions. Together we believe that the special-issue articles provide a timely insight into what we know, what points of debate exist and what we do.
not know about community living and participation for individuals with IDD. Our hope is that together these articles help shape the future direction of research and in turn policy and practice in the US and more broadly.

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References


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