

## **Support Coordinators as a Marginalized Population: The Need for Inclusive Research**

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### **Abstract**

Through the lens of the inclusive research framework, this paper illuminates the marginalization of support coordinators (SC) who work specifically with people who experience intellectual and developmental distinctions (IDD) and are enrolled in the Medicaid home and community-based service system (HCBS). This marginalization exists within both academic literature and the operational frameworks of home and community-based services. Despite their integral role in supporting the needs of the IDD population in all states where the Medicaid HCBS system is operated, support coordinators are conspicuously absent as both participants and researchers in the existing body of scholarly work. This paper explores the lack of representation and voice of the SC, advancing the argument that as scholar practitioners, not only are SC's positionally best suited to explore the impact of the HCBS system, their exclusion not only undermines the holistic understanding of case management as an intervention but also perpetuates a gap in the effective implementation of home and community-based services. The research underscores the necessity of inclusive practices that incorporate the perspectives and expertise of support coordinators, thereby enabling a more comprehensive and equitable discourse within the academic and service delivery spheres.

### **Plain Language Summary**

This research highlights the lack of recognition and involvement of support coordinators (SC) who work with people with Intellectual and Developmental Disabilities (IDD) in the academic literature. Although they are the primary resource for coordinating care and support services, they are frequently missing from academic studies and discussions. This exclusion makes it harder to fully understand and improve Medicaid-funded home and community-based services provided to people with IDD. The paper suggests that including the voices and expertise of SCs is needed for better IDD research and service delivery.

### **Article**

Support Coordination is a social service intervention within the Medicaid Home and Community-Based Services (HCBS) system. The term is often used interchangeably with case management. However, support coordination is a separate and distinct intervention used almost exclusively to support people who experience intellectual and developmental distinctions and/or Autism (IDD/A) and are enrolled in the HCBS system. Support Coordination is the linchpin that connects HCBS program participants and their families to the services provided through the Home and Community-Based Service System

(Bogenschutz et al., 2019; Brent, 2018; Cooper et al., 2018). In addition, support coordination is the mechanism through which services funded by the HCBS system are monitored for utilization, cost containment, and oversight of service recipients' health and safety (Brent, 2018; Bogenschutz et al., 2019; Spitz, 1987).

The State of the States in Intellectual and Developmental Disability Services (SOTS) is considered a project of national significance by the Administration on Community Living. For over forty years, the researchers associated with the SOTS project have been producing a bi-annual report that illuminates the priority services within the HCBS system specific to IDD support structures. Priority services are determined by spending trends in each state. In fiscal year 2021, over \$8 billion was spent nationwide on HCBS for people with IDD/A. The data collected on the service priorities throughout the country, as indicated through trends in expenditures, include technology, supported living, personal assistance, family support, and supported employment. What the SOTS review does not include in its report is expenditures for or on support coordination. Despite the significant role that support coordination plays within the HCBS system nationwide, there has been little discussion over the 40 years of the SOTS reports on expenditures for support coordination/case management/targeted case management services within the HCBS structure as it pertains to IDD services.

Support coordination is not represented in the SOTS reporting structure and receives very little attention in academic literature. Within the body of scholarly literature on IDD supports and services, as well as the research covering the vast service sectors where case management is a common intervention, few studies evaluate or explore the nature of support coordination as a specific intervention and critical component of the IDD service system. Fewer still are studies that give voice to support coordinators (SC) as both study participants and researchers. This represents a significant gap in understanding the HCBS system's efficacy, some 40 years after its implementation following the deinstitutionalization movement. Medicaid Long-term care HCBS Waiver programs across the country provide support to a wide range of vulnerable and underserved populations, including people with physical disabilities, mental health conditions, and older adults (Maniates, 2024; Dodson et al., 2024). In this discussion, references to the HCBS system refer specifically to the component of the waiver program intended to support people with IDD/A.

The SC's voice, as both researcher and participant, is a critical gap in a comprehensive understanding of the HCBS system. Within the academic literature on case management, there is a robust discussion of the populations served, models and structures, and reactions to and with case management (Chouinard et al., 2021; Rapp et al., 2014; Tuten et al., 2008). Similarly, in the narrow body of literature that addresses support coordination as an intervention within the IDD service system, conversations are being held about support coordinators/case managers from the service recipients' perspective (Joo & Liu, 2018; NCI). Few studies in either body of literature, however, are exploring the experiences of the support coordinators themselves.

The theories and practices that best inform this discussion, centered on the missing voice of the support coordinator, are those of inclusive research methodologies (Webb et al, 2023; Whitley et al., 2023). Support coordinators, their experiences, and their voices are invisible in the body of research on HCBS systems related to IDD, as well as in the literature on case management as an intervention in the human and social services. Kat Holmes (2017) asserts

that “One important way to change invisibility is to seek out the perspectives of people who are, or risk being, the most excluded by a solution”. As a result of the direct support worker crisis, budgetary challenges, and the implementation of the CMS Finale Rule, changes in the service delivery system are inevitable (Maniates, 2024; Anderson, 2024). The research also indicates that those most excluded from policy, practice, and implementation discussions tend to have the most significant insight into the problems (Holmes, 2017). Given the role's positionality, any change or shift in the structure, design, or function of the HCBS system must be made with significant consideration of and input from SCs.

Inclusive research is not a new paradigm or methodology and has a long and deep history in the landscape of research modalities (Whitely et al., 2023; Hewitt et al., 2022). Moreover, owing its roots to people with IDD and the disability rights movements (Warmesley et al., 2018), inclusive research has broad application across various marginalized groups and sectors and is rooted in a universal principle: “Nothing about us without us”. Given the methodology, which includes diverse perspectives with specific emphasis on marginalized groups, I would argue that SCs represent a marginalized group within the network of IDD supports and services because there are few studies conducted by, with, or about support coordinators and their experiences within the HCBS system, despite their critical role within that system.

The need for in-depth studies of the SC's role, the presence of the SC's voice as a co-researcher, and the SC's role as an initiator and driver of research is also supported by theories such as social role valorization and emancipatory research traditions. Social role valorization, as articulated by Wolfensberger (1980), speaks to the concept of the researcher as a valued social role, engaged in a valued activity, and developing valuable skills. The role of the SC, by virtue of its positionality within the IDD HCBS system and in collaboration with the participant and their family, is clearly a valued role. Despite its demonstrated value, the role of SC is not given a seat at the decision-making table beyond SCO agency leadership, nor does it receive financial compensation typically associated with a valued role within a given system. As a result, the SC fits the definition of a marginalized person/group. A marginalized group or person experiences social, economic, and/or political exclusion or discrimination based on characteristics such as race, ethnicity, gender, sexual orientation, socioeconomic status, and disability or religion. There is little to suggest, nor am I making the argument that the exclusion of the voice of the SC from the academic research is caused by discrimination. However, it is abundantly clear that this group of people is excluded from decision-making rooms and research because there is a perception that SCs' work and roles are entry-level (Bogenschutz et al., 2019). This perception has resulted in an unequal power relationship that lies at the root of the SC's exclusion from the decision-making table. From that perspective, the methodologies and paradigms of inclusive and emancipatory research have direct application to the field of IDD Support Coordination.

Fortunately, the voice of the IDD SC is not entirely silent. Four recent studies examine the perspectives and experiences of SC's within the specific context of the IDD system. Shank (2006) examined the experiences of DD service coordinators in Nebraska's IDD system. Rachel Tindal and her colleagues (2019) address the missing voice of case managers in early intervention programs. Davis (2018) completed a phenomenological study of the experiences of IDD support coordinators in Southeastern Pennsylvania, and Bogenschutz, Dinora, and Johnson (2019) conducted semi-structured interviews and focus groups with SC's, SC

supervisors, and SCO leadership. Each of these studies identified the IDD SC as the fundamental lynchpin in the HCBS system. Each study also supports the fact that SC's are either intentionally or inadvertently excluded from policy making and have a minimal presence in the research that is heavy with studies and evaluations of the impact and the effectiveness of the HCBS system on the lives of people who experience IDD.

As one of the primary leverage points in the HCBS system (Meadows, 2008), the SC's voice is crucial to fostering a comprehensive understanding of the HCBS system. The absence of the SC perspective in the body of scholarly work surrounding the IDD service system is conspicuous and undermines efforts to improve the effectiveness of the HCBS system. Because of the dearth of research on IDD Support coordination as an intervention and on the experiences and reflections of IDD SCs, there is significant room for a wide array of study approaches and areas of inquiry. Recommendations for future research include, but are not limited to, replicating existing study methodologies within the IDD SC population, regionally and nationally, and exploratory phenomenological research that seeks to understand the needs, status, and perspectives of the IDD SC and how they view the HCBS system. Lastly, as a workforce in crisis, there is ample opportunity to involve SCs as principal researchers and participants in designing the research methodology to understand how to stabilize and improve the overall competency and professional stature of the workforce, based on the needs identified by those for whom the changes would impact.

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