Intellectual and Developmental Disabilities

Shared Citizenship, Context, and the Next Generation of Self-Determination Research --Manuscript Draft--

Manuscript Number:	IDD-D-23-00083R1
Article Type:	Perspectives
Keywords:	Self-determination; context; shared citizenship; intellectual and developmental disabilities
Corresponding Author:	Karrie A Shogren University of Kansas LAWRENCE, Kansas UNITED STATES
First Author:	Karrie A Shogren
Order of Authors:	Karrie A Shogren
	Ruth Luckasson
	Robert Schalock
Manuscript Region of Origin:	UNITED STATES
Abstract:	Self-determination is recognized as a key outcome in the disability field. However, the alignment of self-determination research with the shared citizenship paradigm and growing research on the role of context and contextual variables in shaping personal and collective self-determination outcomes has not yet been fully explored. In the article we: (a) describe the shared citizenship paradigm and self-determination; (b) summarize the current understanding of context; (c) identify contextual variables influencing self-determination; and (d) recommend research approaches, policies, and practices to guide the next generation of self-determination research. We highlight how adopting the shared citizenship paradigm and recognizing that context matters is essential to advancing self-determination, providing direction for future self-determination research, policy, and practice.

1

Self-Determination, Shared Citizenship, and Context

Abstract

Self-determination is recognized as a key outcome in the disability field. However, the alignment of self-determination research with the shared citizenship paradigm and growing research on the role of context and contextual variables in shaping personal and collective self-determination outcomes has not yet been fully explored. In this article we: (a) describe the shared citizenship paradigm and self-determination; (b) summarize the current understanding of context; (c) identify contextual variables influencing self-determination; and (d) recommend research approaches, policies, and practices to guide the next generation of self-determination research. We highlight how adopting the shared citizenship paradigm and recognizing that context matters is essential to advancing self-determination, providing direction for future self-determination research, policy, and practice.

Shared Citizenship, Context, and the Next Generation of Self-Determination Research

As researchers have begun to explore the concept of shared citizenship and its global applications, it is important to also consider the rich potential of both shared citizenship and context for advancing self-determination. A first step is to understand the shared citizenship paradigm (SCP) and understand how it can advance systemic change and self-determination. The SCP has been defined as "the collective and unifying set of values, assumptions, and perceptions that envisions, supports, and requires the engagement and full participation of people with disabilities as equal, respected, valued, participating, and contributing members of all aspects of society" (Schalock et al., 2022, p. 427). A next step is to explore the role of context in the lives of individuals with intellectual and developmental disabilities (IDD), and to explore how different contextual variables associated with enhanced shared citizenship can shape self-determination's operationalization and development. This exploration is an important step in advancing and shaping the next generation of self-determination research.

In 2013, Shogren presented a social-ecological analysis of the self-determination literature, highlighting research that has examined how student, family, school, disability service system, community, and societal factors impact the development and expression of selfdetermination in people with IDD across the life course. This analysis highlighted the longstanding focus in disability advocacy (Ward, 1988, 1996) and research (Abery & Stancliffe, 2003; Abery & Stancliffe, 1996) on advancing a multi-faceted understanding of selfdetermination and how it is influenced by contextual factors. In the 10 years since this analysis of the self-determination literature was published, two important areas of IDD-related research and application have emerged that have the potential to significantly impact the next generation of self-determination research. The first is the formulation and application of the SCP (Luckasson et al., 2023; Schalock et al., 2022); the second is the operationalization and better understanding of contextual factors that shape outcomes and impact both individual and collective self-determination (Shogren, 2013; Shogren, Luckasson, & Schalock, 2021). Collectively, these developments provide the framework for "moving from our traditional approaches of studying self-determination and its development in isolation and consider situating it within the larger context" (Shogren, 2013, p. 51). In subsequent sections of the article we: (a) describe the SCP and self-determination; (b) summarize the current understanding of context; (c) identify contextual variables influencing self-determination; and (d) recommend research approaches, policies, and practices to guide the next generation of self-determination research.

The Shared Citizenship Paradigm and Advancing Systemic Change and Self-Determination

Throughout history, the intellectual and developmental disability (IDD) field has embraced different value and belief systems (i.e., paradigms) that have guided how disability has been understood and how services and supports have been organized and delivered (Schalock et al., 2022). While the social-ecological model of disability has gained increasing acceptance throughout the world, deficit-based models still drive many aspects of supports and services and shape the focus on self-determination around the world (Shogren, 2013; Walker et al., 2011). While the goal of a social-ecological model is to understand the person, their environment, and the interaction between the two as a driver of needed supports (Thompson et al., 2009; Thompson et al., 2017), there is also a growing recognition of the need to understand the broader context within which people with IDD operate (Abery & Stancliffe, 2003; Abery & Stancliffe, 1996; Shogren et al., 2014).

For example, the Convention on the Rights of Persons with Disabilities (United Nations,

2006) has advanced a focus on the human rights of people with disabilities throughout the world, highlighting the rights of all persons, inclusive of those with disabilities, to equity, inclusion, and self-determination. These rights are key values and rights encompassed in the SCP. It further highlights the need for supports at the individual level that advance these outcomes. Significant work has been done to align individualized supports planning with the values of CRPD (Gómez et al., 2020; Lombardi et al., 2019). However, to further actualize the rallying cry of the disability advocacy community, "Nothing about us without us" (Charlton, 2000), there is also a need for broader, paradigmatic changes throughout society (e.g., changes in policies, changes in funding). Such changes must challenge systemic barriers and biases (e.g., ableism, racism, classism, nationalism) that thwart inclusive opportunities and self-determination. CRPD specifically highlights the need for paradigmatic changes to break down systemic barriers across the world to advance the shared citizenship and self-determination of people with disabilities:

[The CRPD] takes to a new height the movement from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society (United Nations, 2006).

Recently, the SCP was introduced as an approach to integrating the transformation of the field of IDD. The goal is to advance a shared vision for actualizing internationally the goals of social-ecological and human rights approaches to disability (Schalock et al., 2022) and the CRPD. The SCP focuses on the "engagement and full participation of people with IDD as equal, respected, valued, participating, and contributing members of every aspect of the society" (Schalock et al., 2022, p. 65). Both individual and collective self-determination is essential to

the SCP. From this perspective, a holistic approach to building systems of supports that promote equity and inclusion is needed that is rooted in an understanding of contextual factors that act as barriers and facilitators to this outcome. Such an approach can provide direction for advancing systemic change to enhance individual and collective outcomes, including self-determination and quality of life. The SCP and emerging work in this area also highlights the importance of engaging people with lived experiences of IDD throughout all aspects of defining and implementing the paradigm and research to support it (McDonald et al., 2023; Shogren, 2023).

In a recent survey of IDD leaders from across the world (Australia, Zimbabwe, Spain, Belgium, Argentina, Canada, South Korea, Portugal, Italy, Singapore, China, Netherlands), the cross-cultural relevance of the SCP was supported (Luckasson et al., 2023). Survey findings suggested one or more paradigm components (i.e., holistic approach, contextual model of human functioning, disability rights principles, and person-centered implementation strategies) were evident to a moderate degree in all represented countries. However, while approaches derived from the SCP were noted as being used to define and advance services and supports aligned with the values of self-determination and inclusion, the international expert respondents also emphasized that although there was emphasis on policy and professional activities in their respective countries, there were also ongoing difficulties with fully implementing the paradigm and changing beliefs, values, and practices throughout society. Overall, this work reflects the deeply rooted paradigmatic shifts that are occurring with the disability supports and services led by leaders in the disability community and the broader systemic barriers (e.g., societal attitudes, policies and practices rooted in old paradigms) that are creating challenges to full implementation and research on the impacts and outcomes of advancing shared citizenship across the world. The work also suggests the importance of remaining unified around these

values and the human rights advanced by CRPD.

The Current Understanding of Context

As reflected in the SCP, and in research in the IDD field, a better understanding of context and its influences on policy, practice, and outcomes is essential (Shogren, Luckasson, & Schalock, 2021). To increase our understanding of context, researchers have engaged in work over the past decade to further operationalize context (Shogren et al., 2014), define methods such as contextual analysis to assess contextual factors (Shogren, Schalock, & Luckasson, 2018) and drive systemic change (Shogren, Luckasson, & Schalock, 2018), and recognize the multidimensionality of context (Shogren et al., 2020). Context has been defined as "a concept that integrates the totality of circumstances that comprise the milieu of human life and human functioning" (Shogren et al., 2014, p. 110). Context can be viewed as:

(a) an independent variable that includes personal and environmental characteristics that are not usually manipulated such as age, language, culture and ethnicity, and family; (b) an intervening variable that includes organizations, systems, and societal policies and practices that can be manipulated to enhance human functioning and personal outcomes; or (c) an integrative concept that provides a framework for describing and analyzing aspects of human functioning, planning systems of supports, developing disability policy, and delineating the factors that affect both positively and negatively human functioning and personal outcomes (Schalock et al., 2021, p. 119-120).

As reflected in this definition, the ultimate goal of understanding context is enhancing individual outcomes, such as self-determination and shared citizenship. This has long been emphasized in the disability field, using different terminology. But, advancing this work within a shared citizenship context necessitates: (a) determining the broad contextual factors that hinder change and the forces for change that will increase momentum and receptivity for change, (b) ways to promote adoption and application, particularly of systemic changes (Luckasson, Schalock, & Bradley, in press); and (c) ways to increase partner participation in making change (Shogren, Schalock, & Luckasson, 2018). This approach highlights how contextual analysis can drive changes in supports and outcomes that will enhance valued outcomes at the level of the microsystem (e.g., individual), mesosystem (e.g., community and disability service systems) and macrosystem (e.g., policy and societal attitudes and biases) levels. It also brings increased focus to the role of the exosystem (e.g., external environmental factors that can indirectly influence an individual's self-determination, such as community resources) and the chronosystem (e.g., changes over time that influence individuals and all other levels of the ecological system). Unfreezing the status quo across contexts and advancing systemic changes are necessary to enhance personal outcomes and this is influenced by changes across all ecological systems. Increasingly, it is recognized that these systemic changes must embrace an anti-ableist approach to seek to remove societal biases, addressing biases about ability (Bogart & Dunn, 2019), gender identity (Hughes, 2022), race/ethnicity (Scott & Shogren, in press). Essentially, issues of intersectionality (Crenshaw, 1989, 2017), and the -isms (e.g., racism, sexism, classism) that create additional, systemic barriers for people with IDD who experience multiple marginalized social identities is necessary to fully address the facilitators and barriers to self-determination and shared citizenship.

The framework for understanding context also involves describing the utility of understanding context as multifactorial, multilevel, and interactive. (Shogren et al., 2020). *Multifactorial* refers to the array of personal and environmental factors that influence the lives of people across contexts. These factors shape one's personal culture and outcomes. They also

reflect overarching factors that can facilitate outcomes (e.g., adoption of social-ecological, strengths-based understandings of disability in policies, organizations, and practice), and those that hinder valued outcomes (e.g., structural racism and ableism reflected in policies and practices that limit access and opportunities). Multilevel refers to the layers of influence within which contextual factors shape how people live, learn, work, and enjoy life. An ecological framework (Bronfenbrenner, 1979) is used to define these layers and includes the: micro or the immediate social setting including the person, family, close friends, and advocates; *meso* that includes the neighborhood, community, and any organizations providing supports; macro that includes the larger policy context and supports delivery system, and the overarching pattern of culture, society, country, or sociopolitical influences; exo that includes environment factors such as resources and supports for individuals wellbeing; and chrono or the changes over time that occur and influence outcomes. Finally, context *is interactive* as factors operate across the layers of influence, creating a complex web of influence amplifying various levels and factors for each person. Recognition of this interactivity necessitates efforts to build systems of supports that assess and address the fact that addressing only one contextual level or factor will not authentically address the totality of experiences that define each person's context, their cultural and social identities, and the supports they need for self-determination outcomes.

By adopting a comprehensive, multidimensional approach to contextual analysis the SCP can be advanced, ensuring the consideration of interactions across factors and systems that limit shared citizenship and other valued outcomes such as enhanced self-determination. This also pushes the field beyond simplistic understanding of person-environment interactions by acknowledging the complexity of the interactions that occur across levels and factors. It allows further acknowledgment of the systemic issues (e.g., disability, race/ethnicity, and gender bias)

that researchers have found impact opportunities and outcomes (Friedman, 2020; Friedman & VanPuymbrouck, 2019).

Contextual Variables Influencing Self-Determination

Self-determination has long been acknowledged as a key outcome in the disability field (Shogren & Ward, 2018). A large body of research has focused on advancing self-determination as a personal outcome, seeking to support people with IDD to have access to supports and opportunities that enable them to make choices and decisions about their lives and becoming causal agents (Shogren & Raley, 2022). This work has led to robust, cross-cultural demonstrations of the impacts of promoting and enhancing personal self-determination across the life course (Lachapelle et al., 2005; Nota et al., 2007; Verdugo et al., 2009). However, the multilevel, multifactorial, and interactive aspects of the contexts within which personal self-determination develops have not been fully and systemically explored. Although existing research has typically focused on a small subset of factors and analyzing their impacts on self-determination and its development, self-determination can also be understood as a collective outcome, reflecting an actualization of the collective rights of people with disabilities to determine their lives and supports (Charlton, 2000).

Contextual analysis and a social-ecological approach to understanding the development of self-determination can advance both personal and collective self-determination by changing contexts that may limit shared citizenship, including opportunities for self-determination. For example, research leveraging contextual analysis to understand self-determination outcomes is emerging and highlights the complexities of identifying and integrating contextual factors into analyses. It has long been acknowledged there is not "one way" or a "right way" to build supports for self-determination. Instead, understanding each person's capabilities and identities, the demands and characteristics of the complex environments they participate in, and the support needs created by the interaction is necessary to advance outcomes (Shogren, 2011). However, the degree to which this is integrated into the actual delivery of supports for self-determination is more limited. CRPD and the shared citizenship paradigm can provide unification across context and cultures. For example, Hispanic mothers in the United States shared stories of how schools did not respect or value their perspectives on self-determination, specifically family values for group decision making rather than individual decision making (Shogren, 2012). Black youth shared how their views of self-determination were not respected by schools when they were planning for their transition to adulthood (Scott et al., 2021). Other research has suggested that teachers perceive goal outcomes differently than students, and that these differences are greater when teachers and students have different social identities, that is when students have disabilities and/or are Black or Hispanic and teachers do not have disabilities and are White (Shogren, Hicks, et al., 2021).

Gaps in our understandings of what contributes to inequities in outcomes highlight the importance of addressing contextual variables that either enhance or limit shared citizenship and self-determination and identifying the changes needed to remove barriers to self-determination. As another example of the importance of assessing contextual factors, researchers analyzed the outcomes of a self-determination intervention implemented with high school students with and without disabilities in inclusive classrooms in the United States, the Self-Determination Learning Model of Instruction (Shogren, Raley, et al., 2018). When looking at outcomes for students with and without disabilities, one pattern of results was found (Raley et al., 2021). However, breaking down the data and analyzing outcomes separately for students with and without disabilities from varying racial and ethnic backgrounds, including racial and ethnic identities marginalized in

Self-Determination, Shared Citizenship, and Context

policy and practice in the United States, different patterns were seen (Shogren, Scott, et al., 2021). Specifically, multiply marginalized youth (i.e., those who experienced disability and identified as being from non-White racial backgrounds) experienced a drop in their self-determination levels after instruction started. While this rebounded to baseline levels or greater by the end of the year, the initial drop was not seen for White students, raising questions about why. While the study was not designed to understand these factors, it raises important questions that need to be addressed through further contextual analysis. For example, did the instruction not address specific needs and identities of students, but instead focus on dominant values in schools lead to an environmental mismatch? Why do schools struggle to address the diverse needs of all students in the school? What were students' and families' experiences of the instruction and how did it align with their family and community supports?

Overall, this work highlights the importance of contextual analysis with the goal of challenging inequities and marginalization of groups based on various social identities, including disability, race/ethnicity and gender identity. Without considering the broader systemic, contextual factors that lead to supports (including instruction) not being responsive to the multiple identities experienced by each of us, there will be an ongoing focus on changing the person rather than changing the context and aligning supports with what a person wants and needs.

That cultural differences must be celebrated and elevated has been noted in cross-cultural research on self-determination assessment that can also inform contextual analysis of crosscultural considerations in supporting self-determination and shared citizenship. Assessments of self-determination have been validated across groups, cultures, and languages suggesting universal aspects of self-determination and shared citizenship, and the need to have a unified focus on advancing disability and human rights across the world, such as through the CRPD. However, even with these universal elements, nuances in the operationalization of the selfdetermination construct have been noted across languages and cultures which has important implications for cross-cultural research, policy, and practice. For example, a new selfdetermination assessment was developed in the late 2010s, the Self-Determination Inventory (Shogren & Wehmeyer, 2017). In a U.S sample of over 4,000 youth with and without disabilities with a range of racial and ethnic identities, differences in their self-determination levels were found. In this sample, students who identified as White/European American and without disabilities consistently scored higher on self-determination assessments than other groups. Black/African American and Hispanic/Latinx students as well as students from other racially and ethnically marginalized groups (Native American or Alaskan Native, Asian American, and Native Hawaiian or Pacific Islander) scored lower than White/European American students with and without disabilities (Shogren, Shaw, et al., 2018). Socioeconomic status also explained some of the variability. This highlights the need to contextually analyze the multiple factors across systems and ecological levels that lead to these inequities as well as the degree to which the assessment is aligned with the cultural identities of various students and groups of students. This critical need to understand cross-cultural differences in selfdetermination has led to multiple translation and cross-cultural validation activities.

The *Self-Determination Inventory (SDI)* has been translated into multiple languages, including Spanish, French, Chinese, and American Sign Language, providing additional insights into cross-cultural factors related to nationality, language, and other identities. And, while universal elements of the self-determination construct and its measurement have been identified across countries and cultures, differences in the expression of self-determined actions have also been identified. For example, validation studies of the SDI: Student Report Spanish Translation have shown that the assessment has reliability with Spanish youth (Mumbardó-Adam et al., 2017) showing a unidimensional structure consistent with the theoretical framework that guided the development of the Self-Determination Inventory (Shogren et al., 2019). There were similar findings with the SDI:SR French Translation (Shogren, Gerasimova, et al., 2021). Although, one item (*I choose what my room looks like*) was problematic and did not seem to relate to selfdetermination across the Spanish, French, and Chinese Translation. It may be in other contexts that choosing what one's room looks like is not as important as other areas, like setting goals for the future or for engaging with friends. Similarly in the SDI: SR Chinese Translation the same item, as well as a second ("*I know my strengths*") were perceived differently by youth, potentially reflecting the fact that in a society like China, where family and communal values are highly regarded, a focus on individual strengths may be de-emphasized and not discussed as frequently at school or home (Xu et al., 2022).

The research described above provides additional insight into the importance of the next generation of self-determination research integrating a cross-cultural framework rooted in the shared citizenship paradigm that does not privilege one approach (e.g., U.S. values) and instead considers all contextual factors, including time (chronosystem) and opportunities and resources (exosystem). For example, in Chinese, the term "self-determination" did not appear in the Chinese disability literature until 2005 (Bao & Zhang, 2005; Xu et al., 2020) meaning there has not been as much focus on defining or supporting self-determination and that there is ongoing discussion and debate about what self-determination means and how to integrate it into a shared citizenship paradigm. In France, self-determination has long been a focus across French-speaking countries, with efforts to enhance self-determination in school settings (Lachapelle &

Lussier-Desrochers, 2009). In Spain, differences were also identified in responses to items by youth with and without disabilities. For example, items about making plans for the future and feeling confident in one's abilities both showed different functioning across youth with and without intellectual disability. This may be due to different experiences of adolescents with IDD as in the Spanish sample they experienced segregated settings and perhaps fewer opportunities to plan for a future and build confidence in their abilities (Mumbardó-Adam et al., 2017; Shogren et al., 2019). This is supported by research that suggests that students with IDD in Spain have fewer opportunities to engage in self-determined actions at home compared to their peers without disabilities (Mumbardó-Adam et al., 2018).

Overall, the body of work regarding the contextual variables influencing selfdetermination suggests that across and within cultures and countries, an overarching frame of shared citizenship holds, shaped by an array of contextual factors including disability, language, and other aspects of personal cultures, but that families, students, and community members may hold different perceptions of self-determination, how to support it, and how valued it is as an outcome. This suggests the importance of having shared understandings of core human rights, such as those defined by CRPD, for jurisdictions to strive for, while also recognizing the operationalization of the values through policies and practices may be nuanced when operating in a specific cultural context. For example, understandings about shared citizenship and contextual factors are linked to opportunities for self-determination, biases about disability, and access to inclusive supports in any culture. Each of these foundational elements may shape available opportunities and specific intervention strategies adopted to advance shared values. This highlights the importance of contextual analyses to further understand the factors that shape self-determination and supports for its development not only at the individual level, but also at the system and society level. Essential to this will be an understanding of the broader systemic factors, such as rate and extent of adoption of the shared citizenship paradigm that may influence broader system and societal attitudes about disability and self-determination.

Recommendations for Future Self-Determination Research, Policy, and Practice

Given research, theory, and practice advancements, there is little question that context matters in advancing self-determination, and the adoption of the SCP. However, as described in the previous sections, there are ongoing struggles with defining and actualizing an approach to assessing and intervening to change and advance contexts that fully integrates the values of shared citizenship, including the advancement of self-determination. Addressing the nuances of different cultural contexts as well as each person's social identities and the impacts of these identities on how systems support (or do not support them) remains a critical area that needs to be more robustly addressed, moving beyond developing approaches in one culture or targeting one group to identifying overarching factors that can be changed to allow for effective personalized supports across cultures and identities.

To overcome these challenges, there are multiple areas that can be addressed through research, policy, and practice. Table 1 summarizes recommendations for the next generation of self-determination research, policy, and practice. First, advancing understanding and adoption of the SCP is a critical step to change broad societal understandings of disability and to challenge systemic barriers that are deeply embedded in both disability systems as well as other systems throughout society that perpetuate ableist beliefs, policies, and practices. Second, we need to further develop and test approaches to engage in comprehensive contextual analyses at the individual, organization, and system levels to understand the personal and environmental factors that shape outcomes. Specifically, we need formalized processes for contextual analysis that can

Self-Determination, Shared Citizenship, and Context

be integrated with supports needs assessment and planning for individualized supports and broader, systemic supports that address key contextual factors across ecological systems. Such work must extend beyond analyzing "the environment" or just one contextual factor or a small number of factors in isolation, and instead consider the *totality of circumstances that comprise the milieu of human life and human functioning*. In doing so, we can further advance opportunities for people with disabilities, their families, and their supporters to identify and address key variables that advance or limit outcomes, and challenge these barriers through personalized supports or systemic change. This can be linked with other efforts to align supports provision with the values of the SCP and CRPD.

A key part of actualizing self-determination throughout all these efforts must be advancing inclusive research, policy development, and practice that fully engage people with IDD throughout all phases of research, policy, and practice. The right to science is recognized as a universal human right, but is often narrowly interpreted as equity in experiencing the benefits of science (Chapman & Wyndham, 2013; United Nations, 2012). A broader interpretation, however, can be considered that fully engages people with IDD and other partners in all aspects of the research process, including using research to inform policy and practice (Kover & Abbeduto, 2023; Shogren, 2023). Systemic barriers such as ableist assumptions about how people contribute to the scientific process remain major barriers in this process. Change is needed to create systems and supports that enable people with IDD to lead or co-lead all phases of the research process, including its development, implementation, and dissemination.

Celebration of the diverse identities, funds of knowledge, and resources of people with IDD must be elevated and used to create personalized approaches across cultures and identities to support universal values such as those articulated by CRPD and the SCP. Too often the

Self-Determination, Shared Citizenship, and Context

diverse social identities experienced by people with IDD are not fully understood, nor are the implications for supports, services and systemic barriers, and context fully analyzed (Johnson et al., 2021). Each person brings a range of identities and experiences to their lives, their goals, and their vision for how they will act as a causal agent over their lives. Too often notions of intersectionality of how our multiple social identities shape how the world treats us have not been fully embraced in self-determination, shared citizenship, and IDD research (Johnson et al., 2021). Change is needed to use this as the foundation of our research, policy, and practice to advance self-determination (Hughes, 2022; Shogren & Raley, 2022).

It is time to fully integrate efforts to advance self-determination and disability justice into the shared citizenship across the world. Doing so provides a means to make systemic change, leading to more effective, individualized supports that consider contextual variables and leverage them to advance personal and societal valued outcomes while recognizing universal human rights, including the right to shared citizenship. Considering this across cultural contexts will allow for context-specific variables to be leveraged to create universal supports for equity, inclusion, and self-determination and thereby advance the goals of the SCP that involves the engagement and full participation of people with IDD as equal, respected, valued, participating, and contributing members of every aspect of the society.

References

- Abery, B., & Stancliffe, R. (2003). An ecological theory of self-determination: Theoretical foundations. In M. L. Wehmeyer, B. Abery, D. Mithaug, & R. Stancliffe (Eds.), *Theory in self-determination: Foundations for educational practice* (pp. 25-42). Charles C. Thomas Publishing Company.
- Abery, B. H., & Stancliffe, R. (1996). The ecology of self-determination. In D. J. Sands & M. L.
 Wehmeyer (Eds.), *Self-determination across the life span: Independence and choice for people with disabilities* (pp. 111-145). Brookes.
- Bogart, K. R., & Dunn, D. S. (2019). Ableism special issue introduction. *Journal of Social Issues*, 75(3), 650-664. <u>https://doi.org/10.1111/josi.12354</u>
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.
- Chapman, A., & Wyndham, J. (2013). A human right to science. Science, 340(6138), 1291.
- Charlton, J. I. (2000). Nothing about us without us: Disability oppression and empowerment. University of California Press.
- Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A Black feminist critique of antidiscrimination doctrine, femist theory and antiracist politics. *University of Chicago Legal Forum*, *1989*(1), 139-168.

Crenshaw, K. (2017). On intersectionality: Essential writings. The New Press.

Friedman, C. (2020). The relationship between disability prejudice and disability employment rates. *Work*, *65*(3), 591-598. https://doi.org/10.3233/WOR-203113

- Friedman, C., & VanPuymbrouck, L. (2019). The relationship between disability prejudice and medicaid home and community-based services spending. *Disability and Health Journal*, *12*(3), 359-365. <u>https://doi.org/https://doi.org/10.1016/j.dhjo.2019.01.012</u>
- Gómez, L. E., Monsalve, A., Morán, M. L., Alcedo, M. Á., Lombardi, M., & Schalock, R. L.
 (2020). Measurable indicators of CRPD for people with intellectual and developmental disabilities within the quality of life framework. *International Journal of Environmental Research and Public Health*, *17*(14), 5123. <u>https://www.mdpi.com/1660-4601/17/14/5123</u>
- Hughes, O. E. (2022). Supporting Gender Self-Determination for People With Intellectual and Developmental Disabilities. *Inclusive Practices*, 1(2), 70-74. https://doi.org/10.1177/27324745211044452
- Johnson, K. R., Bogenschutz, M., & Peak, K. (2021). Propositions for race-based research in intellectual and developmental disabilities. *Inclusion*, 9(3), 156-169. <u>https://doi.org/10.1352/2326-6988-9.3.156</u>
- Kover, S. T., & Abbeduto, L. (2023). Toward Equity in Research on Intellectual and Developmental Disabilities. *American Journal on Intellectual and Developmental Disabilities*, 128(5), 350-370. <u>https://doi.org/10.1352/1944-7558-128.5.350</u>
- Lachapelle, Y., & Lussier-Desrochers, D. (2009). Sur le chemin de l'autodétermination : Un matériel pédagogique en soutien à l'autodétermination d'élèves présentant une déficience intellectuelle [On the road to self-determination: Educational materials to support the self-determination of students with intellectual disaiblities]. In D. V. Guerdan, G. Petitpierre, J. P. Moulin, & M. Haelewyck (Eds.), *Participation et responsabilités sociales : Un nouveau paradigme pour l'inclusion des personnes avec une déficience*

intellectuell [Participation and social responsibilities: A new paradigm for the inclusion of people with intellectual disabilities] (pp. 183-196). Peter Lang.

- Lachapelle, Y., Wehmeyer, M. L., Haelewyck, M. C., Courbois, Y., Keith, K. D., Schalock, R., Verdugo, M. A., & Walsh, P. N. (2005). The relationship between quality of life and selfdetermination: An international study. *Journal of Intellectual Disability Research*, 49(10), 740-744. https://doi.org/10.1111/j.1365-2788.2005.00743.x
- Lombardi, M., Vandenbussche, H., Claes, C., Schalock, R. L., De Maeyer, J., & Vandevelde, S. (2019). The concept of quality of life as a framework for implementing the UNCRPD.
 Journal of Policy and Practice in Intellectual Disabilities, *16*(3), 180-190.
 https://doi.org/https://doi.org/10.1111/jppi.12279
- Luckasson, R., Schalock, R. L., Tassé, M. J., & Shogren, K. A. (2023). The intellectual and developmental disability shared citizenship paradigm: its cross-cultural status, implementation and confirmation. *Journal of Intellectual Disability Research*, 67(1), 64-76. <u>https://doi.org/https://doi.org/10.1111/jir.12992</u>
- McDonald, K. E., Schwartz, A. E., Feldman, M. F., Nelis, T., & Raymaker, D. M. (2023). A
 Call-In for Allyship and Anti-Ableism in Intellectual Disability Research. American
 Journal on Intellectual and Developmental Disabilities, 128(6), 398-410.
 https://doi.org/10.1352/1944-7558-128.6.398
- Mumbardó-Adam, C., Guàrdia-Olmos, J., & Giné, C. (2018). Assessing self-determination in youth with and without disabilities: The Spanish version of the AIR self-determination scale. *Psicothema*, 30(2), 238-243. <u>https://doi.org/10.7334/psicothema2017.349</u>
- Mumbardó-Adam, C., Guàrdia-Olmos, J., Giné, C., Raley, S. K., & Shogren, K. A. (2017). The Spanish version of the Self-Determination Inventory Student Report: Application of item

response theory to self-determination measurement. *Journal of Intellectual Disability Research*, 62(4), 303-311. <u>https://doi.org/10.1111/jir.12466</u>

- Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. (2007). Self-determination, social abilities, and the quality of life of people with intellectual disabilities. *Journal of Intellectual Disability Research*, 51(11), 850-865. <u>https://doi.org/10.1111/j.1365-2788.2006.00939.x</u>
- Raley, S. K., Shogren, K. A., Rifenbark, G. G., Lane, K. L., & Pace, J. R. (2021). The impact of the self-determined learning model of instruction on student self-determination in inclusive, secondary classrooms. *Remedial and Special Education*, 42(6), 363-373. https://doi.org/10.1177/0741932520984842
- Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021). Intellectual disability: Definition, diagnosis, classification, and systems of supports (12th ed.). American Association on Intellectual and Developmental Disabilities.
- Schalock, R. L., Luckasson, R., Tassé, M. J., & Shogren, K. A. (2022). The IDD paradigm of shared citizenship: Its operationalization, application, evaluation, and shaping for the future. *Intellectual and Developmental Disabilities*, 60(5), 426-443.

https://doi.org/10.1352/1934-9556-60.5.426

- Scott, L. A., & Shogren, K. A. (in press). Advancing anti-racism and anti-ableism in transition: Equity-oriented indicators for research. *Career Development and Transition for Exceptional Individuals*.
- Scott, L. A., Thoma, C. A., Gokita, T., Bruno, L., Ruiz, A., Brendli, K., Taylor, J., & Vitullo, V. (2021). I'm trying to make myself happy: Black students with IDD and families on promoting self-determination during transition. *Inclusion*, 9(3), 170-188.
 https://doi.org/10.1352/2326-6988-9.3.170

- Shogren, K. A. (2011). Culture and self-determination: A synthesis of the literature and directions for future research and practice. *Career Development for Exceptional Individuals*, 34(2), 115-127. <u>https://doi.org/10.1177/0885728811398271</u>
- Shogren, K. A. (2012). Hispanic mothers' perceptions of self-determination. *Research and Practice for Persons with Severe Disabilities*, *37*(3), 170-184.

https://doi.org/10.2511/027494812804153561

- Shogren, K. A. (2013). A social-ecological analysis of the self-determination literature. Intellectual and Developmental Disabilities, 51(6), 496-511. https://doi.org/10.1352/1934-9556-51.6.496
- Shogren, K. A. (2023). The right to science: Centering people with intellectual disability in the process and outcomes of science. *Intellectual and Developmental Disabilities*, 61(2), 172-177. <u>https://doi.org/10.1352/1934-9556-61.2.172</u>
- Shogren, K. A., Gerasimova, D., Lachapelle, Y., Lussier-Desrochers, D., Hagiwara, M.,
 Petitpierre, G., Fontana-Lana, B., Piazza, F., Courbois, Y., Desbiens, A., Haelewyck, M.
 C., Geurts, H., Pace, J. R., & Hicks, T. A. (2021). Preliminary reliability and validity of
 the Self-Determination Inventory: Student Report French translation. *Manuscript submitted for publication*.
- Shogren, K. A., Hicks, T. A., Raley, S. K., Pace, J. R., Rifenbark, G. G., & Lane, K. L. (2021). Student and teacher perceptions of goal attainment during intervention with the selfdetermined learning model of instruction. *The Journal of Special Education*, 55(2), 101-112. https://doi.org/10.1177/0022466920950264

- Shogren, K. A., Luckasson, R., & Schalock, R. L. (2014). The definition of context and its application in the field of intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 11(2), 109-116. <u>https://doi.org/10.1111/jppi.12077</u>
- Shogren, K. A., Luckasson, R., & Schalock, R. L. (2018). The responsibility to build contexts that enhance human functioning and promote valued outcomes for people with intellectual disability: Strengthening system responsiveness. *Intellectual and Developmental Disabilities*, 56(4), 287-300. <u>https://doi.org/10.1352/1934-9556-56.5.287</u>
- Shogren, K. A., Luckasson, R., & Schalock, R. L. (2020). Using a multi-dimensional model to analyze context and enhance personal outcomes. *Intellectual and Developmental Disabilities*, 58(2), 95-110. <u>https://doi.org/10.1352/1934-9556-58.2.95</u>
- Shogren, K. A., Luckasson, R., & Schalock, R. L. (2021). Leveraging the power of context in disability policy development, implementation, and evaluation: Multiple applications to enhance personal outcomes. *Journal of Disability Policy Studies*, 31(4), 230-243. <u>https://doi.org/10.1177/1044207320923656</u>
- Shogren, K. A., & Raley, S. K. (2022). *Self-determination and causal agency theory: Integrating research into practice*. Springer. <u>https://doi.org/10.1007/978-3-031-04260-7</u>
- Shogren, K. A., Raley, S. K., Burke, K. M., & Wehmeyer, M. L. (2018). The Self-Determined Learning Model of Instruction: Teacher's guide. Kansas University Center on Developmental Disabilities.
- Shogren, K. A., Schalock, R. L., & Luckasson, R. (2018). The use of a context-based change model to unfreeze the status quo and drive valued outcomes. *Journal of Policy and Practice in Intellectual Disabilities*, 15(2), 101-109. <u>https://doi.org/10.1111/jppi.12233</u>

- Shogren, K. A., Scott, L. A., Hicks, T. A., Raley, S. K., Hagiwara, M., Pace, J. R., Gerasimova, D., Alsaeed, A., & Kiblen, J. C. (2021). Exploring self-determination outcomes of racially and ethnically marginalized students with disabilities in inclusive, general education classrooms. *Inclusion*, 9(3), 189-205. <u>https://doi.org/10.1352/2326-6988-9.3.189</u>
- Shogren, K. A., Shaw, L. A., & Mumbardó-Adam, C. (2019). The assessment of selfdetermination in Spanish and American Adolescents: The Self-Determination Inventory: Student Report. *Intellectual and Developmental Disabilities*, 57(4), 274-288. https://doi.org/10.1352/1934-9556-57.4.274
- Shogren, K. A., Shaw, L. A., Raley, S. K., & Wehmeyer, M. L. (2018). Exploring the effect of disability, race-ethnicity, and socioeconomic status on scores on the self-determination inventory: Student report. *Exceptional Children*, 85(1), 10-27. https://doi.org/10.1177/0014402918782150
- Shogren, K. A., & Ward, M. J. (2018). Promoting and enhancing self-determination to improve the post-school outcomes of people with disabilities. *Journal of Vocational Rehabilitation*, 48(2), 187-196. https://doi.org/10.3233/JVR-180935
- Shogren, K. A., & Wehmeyer, M. L. (2017). *Self-Determination Inventory*. Kansas University Center on Developmental Disabilities.

Thompson, J. R., Bradley, V., Buntinx, W. H. E., Schalock, R. L., Shogren, K. A., Snell, M. E.,
Wehmeyer, M. L., with, Borthwick-Duffy, S., Coulter, D. L., Craig, E. P. M., Gomez, S.
C., Lachapelle, Y., Luckasson, R. A., Reeve, A., Spreat, S., Tasse, M. J., Verdugo, M. A.,
& Yeager, M. H. (2009). Conceptualizing supports and the support needs of people with

intellectual disability. *Intellectual and Developmental Disabilities*, 47(2), 135-146. https://doi.org/10.1352/1934-9556-47.2.135

- Thompson, J. R., Shogren, K. A., & Wehmeyer, M. L. (2017). Supports and support needs in strengths-based models of intellectual disability. In M. L. Wehmeyer & K. A. Shogren (Eds.), *Handbook of research-based practices for educating students with intellectual disability* (pp. 31-49). Routledge.
- United Nations. (2006). *Convention on the rights of persons with disability*. <u>http://www.un.org/disabilities/default.asp?navid=14&pid=150</u>
- United Nations. (2012). The right to enjoy the benefits of scientific progress and its applications: Report of the Special Rapporteur in the field of cultural rights. <u>https://documents-dds-ny.un.org/doc/UNDOC/GEN/G12/134/91/PDF/G1213491.pdf?OpenElement</u>
- Verdugo, M. A., Martín-Ingelmo, R., de Urríes, F. B. J., Vicent, C., & Sánchez, M. C. (2009). Impact on quality of life and self-determination of a national program for increasing supported employment in Europe. *Journal of Vocational Rehabilitation*, 31(1), 55-64. <u>https://doi.org/10.3233/JVR-2009-0473</u>
- Walker, H. M., Calkins, C., Wehmeyer, M. L., Walker, L., Bacon, A., Palmer, S. B., Jesien, G. S., Nygren, M. A., Heller, T., Gotto, G. S., Abery, B. H., & Johnson, D. R. (2011). A social-ecological approach to promote self-determination. *Exceptionality*, *19*(1), 6-18. https://doi.org/10.1080/09362835.2011.537220
- Ward, M. J. (1988). The many facets of self-determination. NICHCY Transition Summary. *National Center for Children and Youth with Disabilities*, *5*, 2-3.

- Ward, M. J. (1996). Coming of age in the age of self-determination: A historical and personal perspective. In D. J. Sands & M. L. Wehmeyer (Eds.), *Self-determination across the life span: Independence and choice for people with disabilities*. Paul H. Brookes.
- Xu, T., Qian, X., Rifenbark, G., Shogren, K. A., & Hagiwara, M. (2022). Psychometric properties of Self-Determination Inventory: Student report among Chinese students with and without intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 60(1), 41-56. <u>https://doi.org/10.1352/1934-9556-60.1.41</u>

Table 1

Recommendations for the Next Generation of Self-Determination Research, Policy, And Practice

Summary of Recommendations

- Operationalize the relationship between the concept of self-determination and the shared citizenship paradigm.
- Advance the understanding and adoption of the shared citizenship paradigm as a framework and catalyst to enhance self-determination.
- Develop systematic approaches for comprehensive contextual analysis at the individual, organization, and systems levels to enhance self-determination outcomes.
- Integrate contextual analysis with support needs assessment and planning.
- Align the provision of specific supports to the core components of the shared citizenship paradigm and the moderators of self-determination.
- Involve people with IDD in identifying contextual factors that advance or limit personal and collective outcomes, including self-determination.
- Advance inclusive research, policy development, and practice.
- Maximize the diverse identities and funds of knowledge of people with IDD to enhance self-determination and shared citizenship.
- Identify context-specific variables that enhance equity, inclusion, and self-determination.
- Advance a greater focus on self-determination, disability justice and the shared citizenship paradigm across the world.
- Determine the impact of enhanced self-determination on shared citizenship indicators such as social inclusion, interpersonal relations, equity, participation, and community and societal contribution.