

BRIEF REPORT

Self-determination and quality of life of people with intellectual and developmental disabilities: Past, present, and future of close research paths

Cristina Mumbardó-Adam¹  | Eva Vicente²  | Giulia Balboni³ 

¹Department of Cognition, Development and Educational Psychology, University of Barcelona, Faculty of Psychology, Barcelona, Spain

²Department of Psychology and Sociology, University of Zaragoza, Faculty of Education, Zaragoza, Spain

³Department of Philosophy, Social Sciences and Education, University of Perugia, Perugia, Umbria, Italy

Correspondence

Cristina Mumbardó-Adam, University of Barcelona, Faculty of Psychology, Department of Cognition, Development and Learning, Passeig de la Vall d'Hebron, 171, 08035, Barcelona, Spain.
Email: cmumbardo@ub.edu

Abstract

In recent decades, research in the field of intellectual and developmental disabilities has targeted self-determination and quality of life constructs. Quality of life has been extensively studied within various theoretical frameworks. It has been used to guide the provision of appropriate support in daily life. In addition, a vast body of scientific literature has focused on the theoretical and practical underpinnings of self-determination as a construct in itself. To understand how self-determination is an essential supporting concept in the quality of life paradigm, this brief report unravels the complementary but unique role that each construct (quality of life and self-determination) embodies. Furthermore, we discuss the role of self-determination in the scientific literature and in the quality of life of people with intellectual and developmental disabilities, reflecting on how both lines of research can converge and be aligned from a common approach. The aim is to drive attention to areas of future research development that strengthen understanding of quality of life and the self-determination construct.

KEYWORDS

intellectual and developmental disabilities, self-determination, quality of life

Self-determination and quality of life (QoL) are both constructs that have lately drawn the attention of researchers and practitioners in the intellectual and developmental disabilities (IDD) field. Both constructs are epistemologically and practically related, as we will argue below. The main aim of this brief report is to unravel the role of self-determination in the QoL of people with IDD to report on how self-determination expression and promotion can

enhance QoL of people with IDD. This importance of self-determination in the past, present, and future research on the quality of life paradigm is exposed below, as self-determination has evolved from being a dimension in the QoL model, to become an intrinsic ally. As we will argue throughout the text, more attention needs to be paid thus on the alignment of both lines of research in the future.

Abbreviations: IDD, Intellectual and developmental disabilities; QoL, Quality of Life; QoLSM, Quality of Life Supports Model.

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SELF-DETERMINATION CONSTRUCT

Self-determination for people with IDD has its historical roots in the normalization, independent living and disability rights movements of the 1960s and 1970s (Nirje, 1969). The Functional Theory of Self-Determination (Wehmeyer, 1999) is the reference framework that has been most widely used to date. Recently, this conceptual framework has been reconceptualized under the name of Causal Agency Theory (Shogren, Wehmeyer, Palmer, Rifenshank, & Little, 2015), which is a theoretical approach based on the recent advances of positive psychology and the conceptualization of disability from a strengths-based lens. Within Causal Agency Theory, self-determination is defined as “a dispositional characteristic manifested as acting as the causal agent in one’s life” (Shogren, Wehmeyer, Palmer, Rifenshank, & Little, 2015, p. 258). Self-determined actions are characterized by volitional actions, agentic actions and action-control beliefs (Shogren, Wehmeyer, Palmer, Rifenshank, & Little, 2015). Acting volitionally implies driving autonomous actions toward freely chosen goals, while acting agentially ushers the person to attain those goals by regulating actions and navigating challenges and obstacles while they occur. These autonomous and self-regulated actions nurture action control beliefs, a sense of self-knowledge and empowerment to complete goals and thus improve QoL. Importantly, self-determination expression necessitates the person to act in a self-determined manner, but also that the context where people with IDD live and develop provides them with opportunities to exercise self-determination (Mumbardó-Adam et al., 2020; Shogren, Wehmeyer, Palmer, Rifenshank, & Little, 2015).

SELF-DETERMINATION IN THE QOL LITERATURE

Besides being a construct that has been given sufficient attention to form a study field, self-determination is closely aligned with QoL models and even infused in their roots. Research suggests that the QoL construct can be considered a driving concept toward improving professional practices and policies in the field of IDD. One of the theoretical frameworks of QoL that has been transculturally validated and is most widely used in this field is the one developed by Schalock and Verdugo (2002). This conceptual model of individual QoL is comprised of eight domains, one of which is self-determination. QoL is in turn influenced by moderator and mediator variables and enhancement strategies (Schalock et al., 2016). One of these variables and strategies is self-determination. As a

mediating factor, self-determination represents a personal status that propels the attainment of QoL-related outcomes (Powers et al., 2012). Similarly, QoL enhancement strategies include developing personal talents and maximizing personal involvement by providing individualized support, and facilitating personal growth opportunities (Schalock et al., 2016). Examples of QoL enhancement strategies are decision making, choice making, risk taking, goal setting, self-advocacy, and self-management skills (Schalock et al., 2016), all of which are aligned with self-determination expression and development. In fact, self-determination embodies a characteristic of the person that involves being the causal agent of his or her life (Shogren et al., 2015) implying the use of several skills such as decision making, goal setting and attainment, self-regulation and self-management, among others. In people with IDD, the expression of these skills is highly influenced by contextual opportunities that can either hinder or support the person’s expression of agency (Mumbardó-Adam et al., 2020; Shogren et al., 2015), as previously stated.

Indeed, to respond to the needs of people with IDD and enhance their QoL, they must be supported in their agency and their expression of self-determination. Tailored opportunities and support provisions are required to achieve this (Claes et al., 2012). For this reason and considering the importance of individualized support in QoL enhancement, Schalock and Verdugo’s QoL model has been recently reconceptualized to be integrated with the support model (Thompson et al., 2009). In the Quality of Life Supports Model (QoLSM; Gómez et al., 2021a; Verdugo et al., 2021), the QoL model (Schalock & Verdugo, 2002) embodies WHAT is important in the life of people with IDD, while the Supports model (Thompson et al., 2009) depicts HOW we should partner with the person with IDD to improve their QoL (Verdugo et al., 2021).

Besides the QoL domains formerly defined by Schalock and Verdugo’s model, the QoLSM incorporates some core values, one of those being the emphasis on self-determination and decision-making supports (Gómez et al., 2021). Other core concepts include: the human and legal rights of people with a disability; the capacities approach to human development and disability; and the cross-cultural emphasis on inclusion and equity for individuals with a disability and their families. Accordingly, and derived from these core concepts, the individual (and his/her family) is placed at the center of the model with an emphasis on inclusion, equality, personal development and self-determination (Schalock et al., 2014). Besides these core values and the QoL domains, the QoLSM also defines systems of supports and facilitating conditions to enhance QoL (Gómez et al., 2021b). For instance, personal choice and autonomy stand out as

main elements of the supports system (Gómez et al., 2021b), with both skills closely related to self-determination. Further, facilitating conditions to improve QoL include building responsive and supportive environments that are crucial to scaffold self-determination development, as previously presented.

SELF-DETERMINATION PROMOTION ENHANCES QOL

Self-determination promotion has extensively been associated with the achievement of personal outcomes. Predictively, and given the close relationship this construct has with the QoL model (Schalock & Verdugo, 2002) and the QoLSM (2021a), QoL could be enhanced with strategies. For example, developing personal talents or maximizing personal involvement are both related to essential components of self-determination, such as volition, agentic action or action-control beliefs. Facilitating personal growth opportunities and providing individualized support also enhance QoL (Schalock et al., 2016). The development of personal talents necessarily entails supporting the person by exploring their preferences, interests, strengths, and weaknesses to decide which talents, attitudes, and personal characteristics need to be supported to serve their personal outcomes. Similarly, personal involvement is maximized when the person learns to self-advocate and is empowered enough to understand that his or her actions might lead to personal outcomes, as long as the context provides opportunities to do so. For example, students with IDD showed more self-determination-related skills in inclusive settings (Hughes et al., 2013). Also, home and families of people with IDD definitely stands as a crucial context to build responsive opportunities to self-determination development, although research has been scarce to date (Dean, Kirby, et al., 2021). This is in line with the need to provide individuals with disabilities with inclusive settings and opportunities. Following this rationale, one might hypothesize that improving one's self-determination would necessarily lead to a better QoL (Wehmeyer & Schalock, 2001).

Research has consistently shown that adults with IDD and a higher level of self-determination also had a better quality of life (e.g., Lachapelle et al., 2005; Wehmeyer & Schwartz, 1998). In an international study, Lachapelle et al. (2005) found a moderate positive relationship between QoL and self-determination. Furthermore, the essential characteristics of self-determined behavior could predict the membership of a group with a higher or lower quality of life. McDougall et al. (2010) found that participants' level of self-

determination predicted the QoL dimensions of personal development and satisfaction. Further, self-determination has been found to predict QoL in adolescents and young adults with IDD (Mumbardó-Adam et al., *in press*), or to mediate this relationship (Powers et al., 2012). Other studies have demonstrated that interventions intended to improve self-determination in people with IDD (including people with generalized support needs), positively affected their QoL (Álvarez et al., 2022; Pascual-García et al., 2014). Finally, and consistent with the latest advances in QoL and self-determination theoretical frameworks, the field of positive psychology has expanded research in areas pertaining to well-being and life satisfaction that are related to QoL and self-determination in people with IDD (Wehmeyer, 2020). For example, Shogren et al. (2006) found that hope and optimism predicted life satisfaction with the mediation of self-determination and locus of control in people with IDD.

ALIGNING BOTH CONSTRUCTS

The emphasis that QoL paradigms place on self-determination, specifically the latest QoLSM, nurtures a new approach that researchers in the field must consider. Figure 1 presents an attempt to align both models, consistently with current research. In alignment with the QoLSM, self-determination stands as a core value that guides research and practice putting the right for people with IDD to self-determination first, according to current research targeting the promotion of rights in people with IDD (Gómez et al., 2022). Under this umbrella, self-determination embodies a QoL dimension that contributes to QoL enhancement when correctly assessed, supported, and promoted. Consistently, self-determination, as a QoL enhancement strategy, must thus be improved in two complementary ways, by supporting the development of personal talents and skills related to self-determination and causal agency (e.g. decision making, problem solving...) and by building personal growth opportunities, that facilitates contextual opportunities to empower the personal agency. As previously stated, self-determination development and QoL enhancement necessitate that the person could learn to act in a self-determined manner and that his or her context creates opportunities for the person with IDD to train these abilities.

Unraveling the role that self-determination plays in the QoL of people with IDD thus implies understanding the new advances in the theoretical framing of QoL paradigms and the self-determination construct. Derived from the former explanation of QoLSM and self-determination

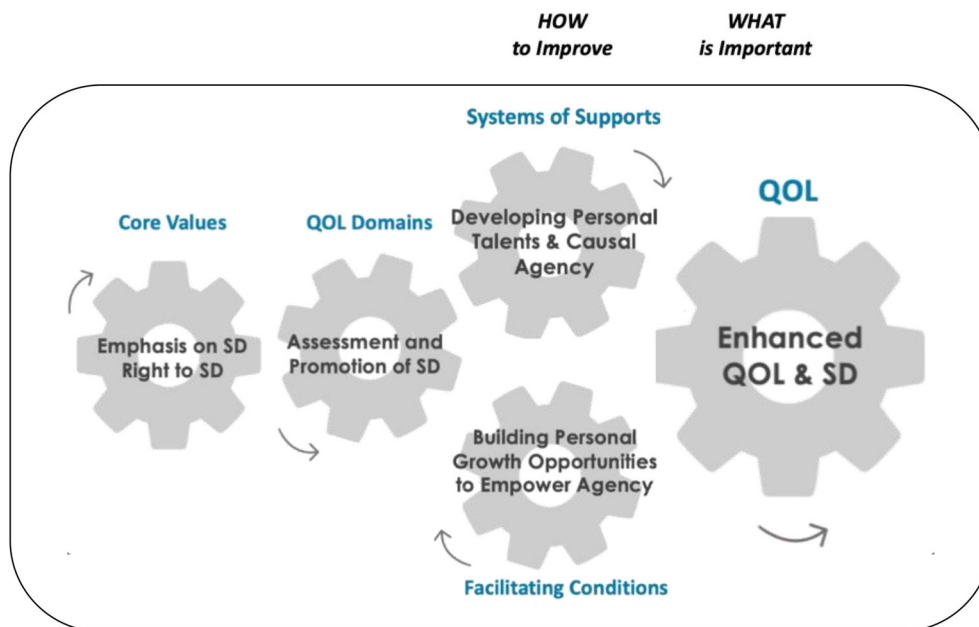


FIGURE 1 Alignment between self-determination research and QoLSM model.

research alignment, to our understanding, future research should examine how self-determination can support QoL enhancement in four ways.

First, researchers should endeavor to expand research evidence to understand the predictive, mediating, and moderating relationship among these constructs, and to better comprehend the mechanisms that enhance QoL through self-determination promotion (e.g., Álvarez et al., 2022; Gómez et al., 2020). A more in-depth approach to both constructs' development must try to comprehend what other factors can contribute (as mediators or moderators) to the relationship between both concepts. Future research is needed to address the following questions, among others. Which supports aiming to improve personal self-determination are in turn favoring the QoL of people with IDD? Are those supports equally contributing to QoL enhancement?

Second, and closely related to the first point, an urgent challenge for the field is for future studies to consider both self-determination related skills and contextual opportunities' development when targeting self-determination and QoL enhancement. Empirical studies assessing and promoting self-determination to enhance QoL must remember that both evaluation and intervention should target enhancement of self-determination skills and the construction of opportunities to develop those skills (Mumbardó-Adam et al., 2020; Vicente et al., 2020). In this sense, further attention must be given to environment of people with IDD, such as the family context (Dean, Kirby, et al., 2021), to better understand how to support environmental based opportunities that target self-determination development. To date, research has

generally focused on assessing and promoting skills related to self-determination. However, based on the importance of opportunities and supports, future research will need to address the following questions: how should we integrate the assessment of self-determination development opportunities in current or future instruments? How should we gather self-determination skills enhancement and the construction of opportunities to develop those skills within interventions? And finally, how should we individualize those interventions to each environment (e.g., home, school, job) so as to support the building of effective opportunities for self-determination skills enhancement?

Third, the vast amount of research tackling these issues has targeted people with IDD, but there is scarce evidence about QoL and self-determination in people with other disabilities or with general support needs (Morán et al., 2019, 2022). With this aim, future research is needed to better understand: (a) how is self-determination expressed and developed in people with various disabilities and profiles of support needs? and (b) how should we individualize QoL enhancement strategies and supports based on individual differences in self-determination expression?

Fourth, QoL outcomes relate to different areas of a person's life, including the transition to adult life, employment, health, or education. Comprehending how self-determination can improve these QoL-related outcomes would help to determine which supports should be allocated to attain these outcomes. For example, the focus of educational practices could shift toward students' QoL (Wehmeyer & Schalock, 2001) and working on self-

determination-related abilities within the employment context could enhance personal outcomes in young adults with autism spectrum disorder (Dean, Hagiwara, et al., 2021). Further research should expand knowledge on the following questions: (a) is the promotion of self-determination related skills and the construction of opportunities to develop those skills effective to reach specific QoL related outcomes? And (b) which tailored self-determination enhancement strategies are better suited for each QoL related outcome? Finally, (c) which is the specific contribution of self-determination to educational, employment or health related outcomes?

In future decades, efforts should thus be focused on better understanding the intrinsic relationship between these two constructs, and on how self-determination can support QoL enhancement following the research approach above mentioned. By joining QoL and self-determination research paths, the focus is clearly placed on to what is relevant in the lives of people with IDD and, perhaps more importantly, in how partnering with them might achieve it.

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ETHICS STATEMENT

This material is the authors' own original work, which has not been previously published elsewhere. The paper reflects the authors' own research and analysis in a truthful and complete manner. The paper properly credits the meaningful contributions of co-authors and co-researchers.

ORCID

Cristina Mumbardó-Adam  <https://orcid.org/0000-0002-2295-9891>

Eva Vicente  <https://orcid.org/0000-0003-0394-5205>

Giulia Balboni  <https://orcid.org/0000-0002-3596-9255>

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