Health and Health Care are Essential to the Quality of Life of People with Intellectual Disability

Author List:

Alice Bacherini PhD

University of Perugia, Department of Philosophy, Social Sciences and Education, Piazza G. Ermini 1, 06123, Perugia, Italy

alice.bacherini@unipg.it

http://orcid.org/0000-0002-5544-0316

Laura E. Gómez PhD

Universidad de Oviedo, Department of Psychology, Plaza de Feijoo, s/n, 33003, Oviedo, Spain

gomezlaura@uniovi.es

https://orcid.org/0000-0002-0776-1836

Giulia Balboni PhD

University of Perugia, Department of Philosophy, Social Sciences and Education, Piazza G. Ermini 1, 06123, Perugia, Italy

giulia.balboni@unipg.it

https://orcid.org/0000-0002-3596-9255

Susan M. Havercamp PhD

The Ohio State University, Nisonger Center, 1581 Dodd Drive, Columbus, Ohio 43210, United States

susan.havercamp@osumc.edu

https://orcid.org/0000-0002-8764-7987

Author Contribution:

AB: Conceptualization; Investigation; Project Administration; Writing – Original Draft Preparation; Writing – Review & Editing. **LEG:** Conceptualization; Supervision; Writing – Review & Editing. **GB:** Conceptualization; Funding Acquisition; Supervision; Writing – Review & Editing. **SMH:** Conceptualization; Supervision; Writing – Original Draft Preparation; Writing – Review & Editing.

Corresponding Author:

Alice Bacherini, University of Perugia, Department of Philosophy, Social Sciences and Education, Piazza G. Ermini, 1, 06123, Perugia, Italy alice.bacherini@unipg.it

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Abstract

Health represents the dynamic balance of physical, mental, social, and existential well-being in adapting to conditions of life and the environment. Health is essential for the quality of life (QoL) of all individuals, including those with intellectual disability (ID). People with ID experience health inequities and barriers to quality health care that must be addressed to foster the QoL of this population. This paper illustrates how poor health negatively impacts each of the eight domains of the QoL model proposed by Shalock and Verdugo (2002) (e.g., health conditions limit work performance, decreasing opportunities for *personal development* and *self-determination*). Suggestions for healthcare practices and behaviors that would improve the quality of health care provided to people with ID, and thus their health and QoL, are offered (e.g., engaging people with ID in the medical conversation, talking to them in plain language and without jargon enhances the *personal development*, *self-determination, interpersonal relationships*, and *social inclusion* domains of QoL). Finally, we suggest actions that people with ID and their families might implement to maximize their health and wellness (e.g., maintaining a healthy lifestyle, using the health promotion resources provided by disability organizations).

Keywords: intellectual disability, health, health care, quality of life, health promotion, recommendations.

The Relationship Between Health, Healthcare and Quality of Life

Health. Health is essential to quality of life (QoL) of all individuals, including those with intellectual disability (ID) as being and feeling unwell compromises one's ability to experience good health and live fully. Health is a continuous and multidimensional state defined as the "dynamic balance of physical, mental, social, and existential well-being in adapting to conditions of life and the environment" (Krahn et al., 2021). Adaptation is influenced by internal and external resources, environmental factors, and supports. For example, a woman in crisis may rely on close friends and her spiritual faith to cope. A man with ID facing a health crisis may rely on family members to help him understand and make healthcare decisions and may draw emotional support from family members and friends. Although individuals with ID are not necessarily compromised in their ability to adapt (Krahn et al., 2021), they might face challenges due to the specific characteristics of their disability. For instance, a person with autism spectrum disorder and co-occurring ID, with high levels of supports needs, might be very reluctant to make the needed changes in their daily routines to adapt to extreme weather conditions. Consequently, accessing appropriate resources and supports to foster wellbeing and QoL is especially important for people with ID.

Gaining access to the resources and supports needed to achieve balance may be limited by public policy and social determinants of health. These contexts reflect systems of oppression, including racism and ableism, that contribute to health inequities for people with ID. Even with the best healthcare system, people can experience poor health and QoL if they do not have the opportunities to access care. Indeed, social determinants of health (e.g., education, neighborhood, economic stability) explain approximately 70% of the variance in health outcomes (Schroeder, 2007). Similarly, environmental contexts, available supports, and social determinants can moderate or mediate an individual's QoL (Balboni et al., 2020;

Gómez et al., 2020; Schalock et al., 2016). For example, both social supports and quality health care could mediate the relationship between an illness or disease and well-being. In this paper, we describe the important relationship between health and QoL and illustrate how healthcare and other support systems can improve the health of people with ID.

Health Care. The healthcare system, comprised of healthcare professionals and public health entities, functions in three ways to improve population health: (a) diagnosing and managing illness; (b) engaging in primary and secondary prevention of illness and injury; and (c) promoting positive health habits (e.g., physical activity, healthy diet, social engagement) while discouraging negative habits (e.g., addiction, stress, risky behaviors). In clinical encounters with patients, healthcare professionals are responsible for diagnosing and managing acute and chronic health conditions, as well as engaging in primary (e.g., vaccination administrations) and secondary prevention of health conditions (e.g., screening). Healthcare professionals also provide health education and encourage their patients to engage in healthy behaviors. On a higher level, the public health agencies support the prevention of medical conditions (e.g., vaccination campaigns) and the promotion of healthy behaviors (e.g., smoking cessation campaigns). All people, including those with ID, rely on supports to adapt to life circumstances and to be healthy. We recommend supports to improve health, health care, and QoL of people with ID.

Quality of Life. As explained in more detail in another paper in this special issue by Verdugo et al. (2023), the Quality of Life Supports Model (QOLSM) is influencing how service professionals approach support provision (Gómez et al., 2021a, 2021b; Morán et al., 2023; Verdugo et al., 2021). The system of support indicates a broad range of resources and strategies that prevent or mitigate an ID or its effects, promote the development, education, interests and welfare of the person with ID and their family, and enhance their well-being. Elements of support are, for example, the promotion of independent or interdependent choices (e.g., through a supported decision-making approach) and autonomy, an inclusive and accessible healthcare environment, the use of specific devices, accommodations, and interventions adequate for the specific needs of each individual. The false assumption that ID confers poor QoL reflects pervasive negative biases and inaccurate assumptions about the QoL of people with ID (Bacherini et al., 2023; National Council on Disability, 2022).

Several models of QoL have been proposed, centered either on individual QoL (e.g., Gómez et al., 2010) or family QoL (e.g., Brown et al., 2006). Among individual QoL models, the most cited in the field of ID are those proposed by Cummins (2005), Felce (1997), and Schalock and Verdugo (2002). The Schalock and Verdugo's (2002) model emerged from international research on QoL and has abundant cross-cultural empirical evidence related to its validity (Conner, 2016; Gómez et al., 2011, 2015; Jenaro et al., 2005; Schalock et al., 2005, 2016; Wang et al., 2010). The Schalock and Verdugo model is broadly used in organizations for evidence-based practices in ID (e.g., Gómez et al., 2020; Morán et al., 2022; Schalock et al., 2011, 2017) and in non-ID populations (Fernández et al., 2019; Swerts et al., 2023; van Hecke et al., 2018).

According to this model, individual QoL is understood as a desired state of personal well-being that is made up of eight domains (e.g., personal development, interpersonal relationships, social inclusion, self-determination, rights, emotional well-being, physical well-being, material well-being), has both universal and culturally-dependent properties, has objective and subjective aspects, and is influenced by individual and environmental factors (Schalock et al., 2011). In this sense, contextual factors (e.g., available supports, ID-competent healthcare professionals) influence the successful provision of supports and thus the QoL of people with ID and their families.

Health impacts each of the eight QoL domains. Although the Convention on the Rights of Persons with Disabilities (United Nations, 2006) declared high quality health care a human right, people with ID experience significant barriers in accessing quality health care and poorer health compared to people without ID (Ali et al., 2013; Gómez et al., 2023; Havercamp & Scott, 2015; Williamson et al., 2017). Social, personal, and contextual factors contribute to these health disparities, and these health disparities must be addressed to improve the QoL of people with ID.

This paper highlights how poor health outcomes negatively impact each of the QoL domains. Finally, we offer specific suggestions for healthcare professionals, family members and other supports, for people with ID themselves to improve the health and QoL of people with ID.

Health Impacts the Eight QoL Domains

Poor health might directly or indirectly limit *personal development*. For example, acute and chronic health conditions (either physical or mental) could negatively impact one's energy level or mood, limiting one's ability to engage in activities of daily living (e.g., self-care) or work performance and might increase support needs and decrease opportunities for *self-determination*.

Poor health is also associated with social isolation, a negative indicator of *social inclusion*, closely related to *interpersonal relationships*. For example, fatigue, depressed mood, and anxiety often lead people to limit contact with peers, friends, and family. Similarly, poor health limits community participation (i.e., cultural, political, religious activities and relationships). Lack of engagement with other people and in the activities of the community negatively impacts a person's cultural and social capital (Menardo et al., 2022).

The QoL domains of *physical* and *emotional well-being* are perhaps most closely related to self-perceived health. Indeed, when rating their own health, people consider their physical health status (health problems) but also broader QoL wellness indicators such as fitness, social engagement, mood, stress, and a sense of self-worth.

People with ID might have difficulty finding cognitively accessible resources on healthy eating and physical activity as well as healthcare professionals who are able and willing to provide them care. These barriers directly impact the *rights* domain.

Finally, poor health negatively impacts *material well-being*. In addition to the high costs of health care, poor health might require multiple healthcare visits and affect concentration and stamina, negatively impacting one's work productivity. Reduced productivity might lead to job loss and/or inadequate income to support one's self and family. When additional help is needed to complete activities of daily living, the person might incur the added expense of paid supports.

Improving the Health of People With ID: Recommendations for Healthcare Professionals

By providing high quality health care, professionals can improve the health and QoL of their patients. For example, healthcare professionals should speak directly to the patient with ID, including them in conversations about their health and health care. Patients will be more engaged in their health care if professionals check that medical information is understood, ask patients about their preferences, respect their right to choose and refuse treatment, and adopt a supported decision-making approach if the patients experience limitations in making independent decisions. To properly do this, healthcare professionals should identify the most appropriate ways to communicate with each patient with ID, including the use of accommodations or augmented communication devices. Additionally, healthcare professionals promote *personal development* and *self-determination* when they ask questions and offer explanations using clear language and avoiding technical jargon. For example, explaining what a medication is for, how and when to take it, and what side effects to anticipate, empowers the patient with ID to assume some responsibility for their own care. Similarly, talking with patients in clear language about choices that impact their health (e.g., tobacco use, sleep, drinking water, physical activity, sexuality) allows them to make informed health choices. Public health information should be shared in multiple formats, including plain language, to reach people with ID. These practices directly enhance *self-determination, physical* and *emotional wellbeing.* Recognizing that people with ID are vulnerable to behavioral health conditions and considering that some of these may indicate the presence of untreated trauma (e.g., manifesting aggressive behavior when feeling unsafe), healthcare professionals should be vigilant for expressions of anxiety or distress and make appropriate referrals to behavioral health professionals (e.g., ID psychologists experts in trauma-informed care) to improve the *emotional well-being* of the person with ID. Offering health education classes or interventions in groups provide opportunities for patients to establish and strengthen *social inclusion*. Similarly, recommending team-based physical activity also promotes *interpersonal relationships* and *physical well-being*.

Furthermore, care should be provided in a private room with enough space to give the patient the opportunity to move freely (e.g., if using a wheelchair or other mobility device) and have their personal belongings with them. This environmental adjustment, in addition to enhancing *emotional well-being*, will have a direct impact on *material well-being* as well. Concerning this latter QoL domain, healthcare professionals should be aware of the financial barriers to healthy lifestyle choices and to health care including transportation costs, out of pocket costs of health care and medication, and the cost of missing work for healthcare appointments.

Healthcare professionals performing all these exemplary behaviors respect and enhance the *rights* domain of people with ID, who have the right to fulfill their potential in a healthy and supportive environment (United Nations, 2006) made of professionals who have been adequately trained and able to communicate in a respectful way.

Improving the Health of People with ID: Recommendations for Family Members and Other Support Providers

Because health is largely determined by our healthy (and unhealthy) choices, family members and (paid and unpaid) support providers can play an important role in improving the health of people with ID. Being physically active, drinking water, spending time with friends are ways of improving one's health. Like people without ID, who rely on others for practical, social, emotional, or spiritual support, so too do people with ID. For example, we ought to choose—and our loved ones ought to vigorously support us—to make healthier lifestyle choices (e.g., physical activity, social engagement, eating fruits and vegetables, drinking more water and less sugary drinks, avoiding smoking). For people with ID, family members and support providers should help explain the relationship between these lifestyle behaviors and health. They ought to make the healthy choices more easily available and more attractive (e.g., floating pieces of fruit in a pitcher of water on the counter, using a step counter to set goals and compete). Additionally, support providers should provide transportation and otherwise promote the engagement in social and community activities, encourage independence, and support personal life goals such as working or living independently, possibly with technology or remote support assistance.

Family members and other support providers should take advantage of existing plain language health information products, educational resources, and supports for people with ID (e.g., from American Public Health Association, Leadership Education in Neurodevelopmental Disabilities, Ohio Disability and Health Program, The Sibling Leadership Network, Plena Inclusion). People with ID and their families should take advantage of these resources to improve their QoL. Through these tools, people with ID and their families ought to develop the awareness, resources, and advocacy skills to gain better access to health supports and high quality healthcare on par with their peers without ID (Grenwelge & Zhang, 2013; Ryan & Griffiths, 2015).

Implications and Discussion

There are two important points that emerge from this discussion. First, good health has the same positive implications on the QoL of people with and without ID. Most of the supports, accommodations, and good practices recommended for people with ID are equally beneficial for people without ID. This promotes equity by, for example, sharing information in a way that can be understood clearly, valuing individual choice and self-determination, and providing the supports needed to maximize health and QoL.

The second important consideration that emerges from this paper concerns the organization of the healthcare practice and system, which may not offer patient-centered or accessible health care to patients with ID. Changes are needed at the systems level as well as at the professional level. At the systems level, for example, healthcare professionals often have no power to determine the number of patients scheduled per day or the number of minutes allocated to each appointment. They might not have the authority to purchase accessible diagnostic equipment or to make reasonable modifications to the facility to make it more welcoming and accessible to patients with disabilities. Some patients require more time for health visits and cannot use inaccessible weight scales, exam rooms, exam tables, diagnostic equipment, and rest rooms. Hence, there is a need to change the health system to provide equitable care to patients with ID and to embrace the psychoeducational, sociocultural, and justice perspectives in health care (Gómez et al., 2023; Schalock et al., 2018, 2021b).

To achieve this goal, improvement of ID awareness and knowledge, and about how to provide quality healthcare to patients with ID should be prioritized in health education in preservice, graduate/residency, and professional development contexts (Ankam et al., 2019;

Havercamp et al., 2021; National Council on Disability, 2022). ID training will prepare the healthcare workforce to provide a better quality of care to their patients with ID who will then face fewer barriers, better health and higher QoL (Bacherini et al., 2022; Bacherini et al., 2023). Likewise, people with ID and their families, by maintaining a healthy lifestyle and using resources and tools made available by several programs and associations, can maximize their health outcomes and improve their QoL. For this purpose, factors that impact health and QoL at the individual, organizational, and societal level (e.g., social determinants of health, inclusion) should be considered in healthcare training and in planning QoL enhancement strategies (e.g., individualized supports, growth opportunities) for people with ID.

Contributions to the QoL Framework

This paper contributes to the QoL framework by:

- Clarifying how poor health negatively impacts each of the QoL domains and not only those related to physical and emotional wellbeing;
- Suggesting the healthcare workforce adopt specific practices and behaviors to improve the quality of care and thus the QoL of people with ID;
- Suggesting actions that people with ID and their support providers might take to maximize their health and wellness;
- Facilitating the development or improvement of training programs, interventions, and curricula to foster the ID competencies of healthcare professionals, as well as opportunities for people with ID and their families to learn about health supports and prevention service resources.

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