

Aging Well With a Lifelong Disability: A Scoping Review

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Decision Editor: Patricia C. Heyn, PhD, FGSA, FACRM

Abstract

Background and Objectives: Existing literature highlights notable health and social inequalities for people aging with a lifelong disability and the need for research to better understand how we can support this group to age well. This scoping review mapped existing literature related to “aging well” in people with lifelong disabilities.

Research Design and Methods: Five scientific databases and gray literature sources were searched for studies related to “aging well” and “lifelong disability” (defined as a disability that a person had lived with since birth or early childhood).

Results: We identified 81 studies that discussed aging well with a lifelong disability, with most (70%) focusing on intellectual disabilities. Two themes captured existing research on aging well with a lifelong disability: (1) framing aging well with a lifelong disability, which included the ways that people with lifelong disability, their supporters, and existing research frame aging well for this group and (2) supporting people to age well with a lifelong disability, which involves the micro-, meso-, and macro-level factors where research suggests interventions to facilitate aging well could be situated.

Discussion and Implications: This synthesis highlights how aging well is currently framed in the literature and where interventions to improve aging well in this group could be situated. Literature highlights the importance of considering multilevel interventions to improve aging well. Evidence gaps include the lack of research conducted with groups other than those with intellectual disabilities and the need for more research examining aging well interventions.

Keywords: Aging well, Healthy aging, Lifelong disability, Successful aging

Ensuring that all older adults have opportunities to age well is a worldwide priority as the number of older adults continues to increase (United Nations, 2021). A number of holistic theories have attempted to capture what we mean by aging well such as the WHO theory of healthy aging (WHO, 2005), Rowe and Kahn’s theory of successful aging (Rowe & Kahn, 1987, 1997, 1998), the theory of selective optimization and compensation (Baltes & Baltes, 1990; Baltes & Cartensen, 1996), and Flood’s theory of successful aging (Flood & Scharer, 2006). While these theories differ in focus, there are some overlapping facets such as (1) emphasizing the gains associated with aging (e.g., wisdom and mastery); (2) the ways in which people can adapt to possible changes associated with aging; (3) reprioritizing different goals or activities due to age-related changes; and (4) maintenance of health, roles, participation functioning, and/or well-being.

However, there is the question of whether all-encompassing theories of aging well capture the experiences of our increasingly diverse aging population. This question is particularly pertinent for so-called “new” aging populations whose aging needs may differ from the general population. One such diverse population is people with lifelong disabilities, such as people aging with cerebral palsy, spina bifida, intellectual disability (ID), and autism spectrum disorder. It is particularly important that we develop our understanding of how to support people aging with a lifelong disability as there is evidence that life-course inequalities affect this group’s ability to age well, something Bigby (2004, p. 73) termed a “disadvantageous starting point for ageing.” Any research that seeks to understand aging well in people with a lifelong disability will need to frame this within the broader context of these life-course inequalities.

Received: July 5 2023; Editorial Decision Date: May 28 2024.

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The inequalities that influence aging well are diverse and wide-ranging affecting people from an individual (e.g., increased genetic and biological vulnerability to illness, psychological factors), through to societal level (e.g., cultural attitudes toward disability, disability policy). While there are many potential inequalities, existing research into aging and lifelong disabilities has focused mostly on health, social, and specific/unique inequalities.

Health inequalities include poorer lifestyle (Bigby et al., 2007; Heller et al., 2004; Heller & van Heumen, 2021; WHO, 2001) and issues accessing appropriate healthcare due to bidirectional communication difficulties between provider and service user (Bigby, 2004; Heller et al., 2004; Heller & van Heumen, 2021; Roll & Bowers, 2017), a lack of screening and health monitoring (Heller et al., 2004; Heller & Sorensen, 2013; Ng et al., 2015), and a lack of awareness among healthcare professionals of the specific impact of aging with a lifelong disability (Bigby, 2004; Heller et al., 2004; Heller & Sorensen, 2013; WHO, 2001). Healthcare inequalities could lead to health issues being undiagnosed, symptoms ignored, diagnostic overshadowing, and treatments not being adapted appropriately.

Social inequalities include lifelong difficulties in participation (e.g., education, employment, citizenship, volunteering, community inclusion), smaller and less diverse social networks, accessibility issues, stigma, ableism, and discrimination (Bigby, 2004; Harrison et al., 2021; Heller & Sorensen, 2013; Llewellyn et al., 2004; McCarron et al., 2019; Reppermund & Trollor, 2016; Walsh, 2002; Walsh et al., 2007). Social inequalities can lead to people with lifelong disabilities becoming devalued, marginalized, and having fewer opportunities for participation, which exacerbate social, health, and financial inequalities in older age (Heller & Van Heuman, 2021; Hogg et al., 2000; Van Heuman & Heller, 2017).

Finally, there can be specific and unique aging-related challenges for people aging with a lifelong disability such as the challenges linked to dual-aging families (where older parents are caring for older children with lifelong disability; Bigby et al., 2007; Heller et al., 2004; Hogg et al., 2000), a variable understanding of aging (Burke et al., 2014), and the lack of availability of specialized housing suitable for older people with a lifelong disability (Heller et al., 2004).

These inequalities all lead to a broader context where people aging with different lifelong disabilities experience a range of difficulties such as an increased risk of morbidity and mortality (Bigby et al., 2007; Heller & Van Heuman, 2021) and a greater risk of developing age-related health issues at earlier ages than the general population (Janicki, 1994; McCallion & Nickle, 2008). This diverse group may have unique needs associated with growing older and understanding what aging well looks like for this population will help us determine how to support aging well. Scoping review methodology allows us to map the existing evidence base and identify gaps. This scoping review will map existing research that has examined aging well in people with lifelong disabilities.

Method

Search Strategy

Initial database searches were undertaken in September 2021, and May 2022 for gray literature searches. An update search was undertaken in June 2023. Search terms related to “lifelong disability” and “aging well” were developed through mapping

exercises (i.e., examination of existing reviews, healthcare websites, and books) and consensus between the team (see [Supplementary Index 1](#)). We searched five scientific databases: PubMed/MEDLINE, ProQuest, EBSCOHost, Scopus, and ISI Web of Science. Gray area searches included screening the first 20 pages of Google, plus searching Bielefeld Academic Search Engine. We also hand-searched the citation lists of included papers. No restrictions were imposed on the search, and any non-English study was translated into English using Google Translate. The protocol was published on the Open Science Framework (<https://osf.io/y42md>). Amendments were made to the protocol: (1) exclusion of post-polio syndrome as a lifelong disability (as post-polio syndrome onset is typically 15–20 years after polio) and (2) exclusion of conference papers and posters (not possible to get the depth of data required for our synthesis).

The initial screening and full-text review were completed by K. J. Smith and S. Gupta, any disagreements were resolved through consensus or consulting with another member of the team. Covidence was used to support screening and data extraction.

Study Selection

We used Population Concept Context criteria to identify suitable studies:

Participants

Adults (aged 18 years and older) who have a lifelong disability. Lifelong disability was defined by the authors as any disability that a person had lived with since birth or early childhood.

Concept

“Aging well” (or a related term such as healthy aging, active aging, successful aging—for a full list, see [Supplementary File 1](#)).

Context

Studies could be from any setting.

Inclusion

Primary research studies of quantitative, qualitative, and mixed methods designs, literature reviews and syntheses, commentaries, and gray literature such as unpublished research and dissertations.

Exclusion

Conditions and impairments considered to be “difficulties” rather than “disabilities” such as dyslexia (MENCAP, 2023). In addition, mental illnesses (e.g., depression, anxiety) were excluded due to typical onset in adolescence. We also excluded conference papers and proceedings.

Data Extraction

Data were extracted using a standardized data extraction form that included study-specific information (authors and date of publication, countries of authors, type of publication, and aim of the study), lifelong disabilities, participant characteristics (number of participants, age, % female, and living arrangements), model of “aging well” used, findings of the study relevant to aging well, and how aging well was framed within the study. Data extraction was carried out by K. J. Smith and 25% was verified by S. Gupta.

Synthesis of Results

Codes were mapped across the different studies by K. J. Smith and collapsed into broad themes that captured different aspects of aging well covered by the included studies. Due to the different levels at which aging well could be implemented, we grouped results using micro- (individual and relationships), meso- (systems and community), and macro-level (governments) categories.

Results

Search Strategy Results

After removing duplicates, the titles and abstracts of 3,261 papers from databases were screened. After title and abstract screening, 2,945 records were removed due to the age of the population studied, not being in a population with a lifelong disability or study not related to aging. Alongside database searches, gray area searches identified a total of 1,367 studies of which 28 were put forward for full-text screening. Full-text screening was conducted with 334 papers, with 255 subsequently excluded (reasons for exclusion are listed in Figure 1) and two papers identified during an update search leaving 81 studies.

Summary of Findings

Included studies examined ID ($n = 57$), developmental disabilities ($n = 5$), ID and developmental disabilities ($n = 7$), cerebral palsy ($n = 2$), autism spectrum disorder ($n = 1$), cystic fibrosis ($n = 1$), thalidomide survivors ($n = 1$), or a range of different lifelong disabilities ($n = 7$). Studies were framed

using a range of aging well-explanatory frameworks primarily healthy aging ($n = 29$), successful aging ($n = 19$), active aging ($n = 10$), aging well ($n = 5$), mixed theories ($n = 15$), or other ($n = 3$).

Most included studies were from authors based in Western countries most frequently the United States ($n = 22$), Australia ($n = 13$), mixed ($n = 14$), Ireland ($n = 7$), Canada ($n = 4$), United Kingdom ($n = 4$), Spain ($n = 4$), Netherlands ($n = 3$), Korea ($n = 2$), and Sweden ($n = 2$). Germany, Taiwan, and Belgium each had one study. The included studies utilized a range of methodologies with the most common being narrative review ($n = 37$), mixed methods ($n = 12$), and qualitative studies ($n = 15$). For more information about individual studies, see [Supplementary Index 2](#) for full data extraction table.

Two major themes were generated that captured existing literature around aging well with a lifelong disability (see [Table 1](#) for summary): framing aging well with a lifelong disability and supporting people to age well with a lifelong disability.

Framing Aging Well With a Lifelong Disability

This theme captures how aging well is currently framed within extant literature. This is split into subthemes of how aging well is framed by people with lifelong disabilities, how aging well is framed by the supporters and carers of people with lifelong disabilities, theories of aging well with a lifelong disability, and the components of aging well (see [Table 1](#)).

How aging well is framed by people with a lifelong disability

When asked to reflect on what is good about aging people spoke about the development of their personal characteristics

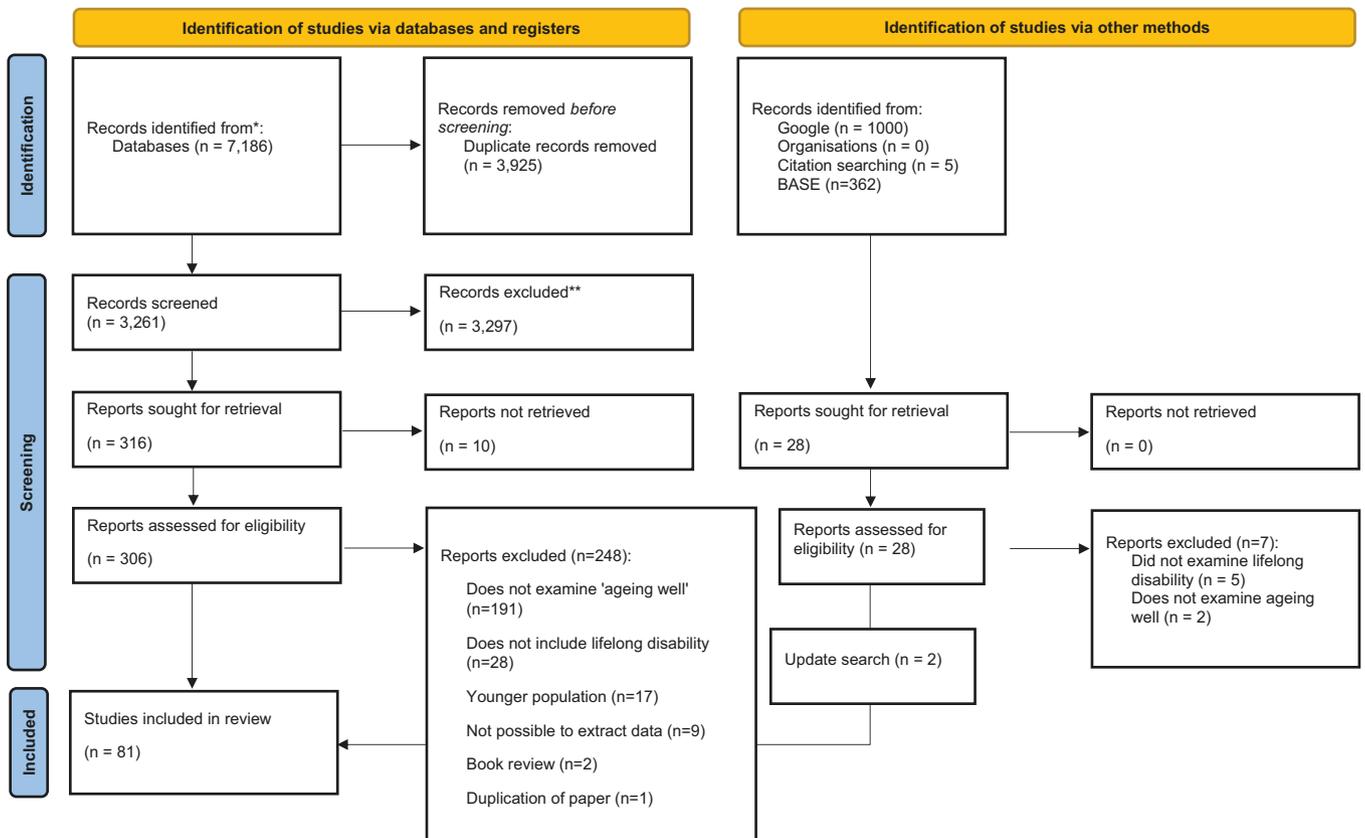


Figure 1. PRISMA flow diagram. BASE = Bielefeld Academic Search Engine; PRISMA = Preferred Reporting Items for Systematic reviews and Meta-Analyses.

Table 1. Themes and Subthemes of Aging Well With a Lifelong Disability

Major theme	Subtheme	N of studies and references
Framing aging well with a lifelong disability	How aging well is framed by people with lifelong disabilities	N = 12 <i>Burke et al. (2014); Dew et al. (2006); Greenwood (2010); Hwang et al. (2017); Kim et al. (2022); Mee Kim et al. (2020); Miskimmin (2014); Miskimmin et al. (2019); Newberry (2013); Pointu (2016); Strndova and Evans (2015); Steff (2009)</i> <i>Illustrative quotes</i> “experience and brain power is what is important to me; I’m the oldest here and X is 19, I can help him talking to him and telling him about things...” (<i>Burke et al., 2014, p. 213, ID</i>). “When I was younger, my mother) did everything for me. I never learned to do laundry til I came here. I did my own showers in XX (state institutional school). I learned there. And I put fitted sheets on and stuff. I learned a little there but I didn’t learn as much. I learned more here ... Now it’s pretty easy. I’m pretty used to it. I do my own laundry, my own shower, pick up my room, do what I need to do I love it. I like being able, doing my own things” (<i>Greenwood, 2010, p. 115, ID</i>).
	How aging well is framed by supporters and carers	N = 6 <i>Buys et al. (2012a, 2012b); Johansson et al. (2017); Northway et al. (2017); Spassiani et al. (2019); Steff (2009)</i> <i>Illustrative quotes</i> “She loves her independence, her independence is really important, she grasps it, any bits that she has—loves and just likes being out amongst it” (<i>Buys et al., 2012b, p. 1140, ID</i>). “even for us, it is not always easy (e.g., to persevere in physical 101 activity). I think that for them, it would be a need to have someone to support them” (<i>Steff, 2009, p. 101, ID</i>).
	Theories of aging well with a lifelong disability	N = 7 <i>Bigby et al. (2007); Haveman et al. (2009); Heller et al. (2004); Heller and Van Heuman (2021); Janicki (1994); McCarron et al. (2019); Reppermund and Troller (2016)</i>
	Components of aging well with a lifelong disability	Health: N = 45 <i>Bigby (2004); Bigby et al. (2007); Chion et al. (2016); De Leeuw et al. (2022); Esbensen et al. (2013); Fesko et al. (2012); Gonzalez-Alonso et al. (2017); Hahn (2012); Heller et al. (2004); Heller and Sorensen (2013); Henderson (2004); Hilgenkamp et al. (2011); Hussain et al. (2021); Hwang et al. (2017); Janicki (1994); Janicki (2009); Kim et al. (2022); Krinsky-McHale et al. (2008); Kwon (2014); LaPlante (2014); Lin and Lin (2021); Llewellyn et al. (2004); Mago et al. (2021); McCallion et al. (2017); McCallion and McCarron (2007); McCallion and Nickle (2008); Mendoza Canosa (2019); Milhalia et al. (2020); Miskimmin (2014); Ng et al. (2015); Overeynder et al. (1994); Ortega-Camero et al. (2021); Phadraig (2017); Reilly (2020); Reppermund and Troller (2016); Roth (2011); Santos et al. (2022); Scheppens (2019); Schoufour et al. (2014); Steff (2009); Spassiani et al. (2019); Walsh (2002); Walsh et al. (2001); WHO (2000, 2001)</i> Maintenance and development: N = 6 <i>Janicki (1994); Buys et al. (2012a, 2012b); MacTavish and Mahon (2005); McCallion and McCarron (2007); McCallion and Nickle (2008)</i> Productivity: N = 3 <i>LaPlante (2014); Llewellyn et al. (2004); McCallion and Nickle (2008)</i> Personal characteristics linked to disability rights: N = 27 <i>Bigby (2004); Buys et al. (2008, 2012a, 2012b); Dew et al. (2006); Fick (2019); Gonzalez-Alonso et al. (2017); Hahn (2012); Haveman et al. (2009); Heller et al. (2004); Heller and Van Heuman (2021); Hogg et al. (2000); Hussain et al. (2021); Hwang et al. (2017); Janicki (1994); Johansson et al. (2017); Kim et al. (2022); LaPlante (2014); Llewellyn et al. (2004); MacTavish and Mahon (2005); Mendoza Canosa (2019); Overeynder et al. (1994); Pointu (2016); Newberry (2013); Scheppens (2019); Spassiani et al. (2019); Strnadova and Evans (2015)</i> Quality of life, life satisfaction and well-being: N = 17 <i>Bigby (2004); Dell Barrio et al. (2018); Fesko et al. (2012); Heller et al. (2004); Heller and Van Heuman (2021); Hussain et al. (2021); LaPlante (2014); Llewellyn et al. (2004); McCallion and McCarron (2007); McCallion and Nickle (2008); McCarron and McCallion (2007); Mendoza Canosa (2019); Milhalia et al. (2020); Reppermund and Troller (2016); Thorpe et al. (2001); Van Puyenbroeck (2006); Wark et al. (2022)</i>

Table 1. Continued

Major theme	Subtheme	N of studies and references
		Social participation, activities and relationships: N = 28 Balandin (2002); Bigby (2004); Bigby et al. (2007); Boulton-Lewis et al. (2008); Burke et al. (2014); Buys et al. (2012a); Fesko et al. (2012); Fick (2019); Greenwood (2010); Hahn (2012); Heller and Van Heuman (2021); Hogg et al. (2000); Hwang et al. (2017); Kim et al. (2022); Llewellyn et al. (2004); McCallion and McCarron (2007); McCarron et al. (2019); Milhalia et al. (2020); Miskimmin (2014); Pointu (2016); Newberry (2013); Ortega-Camero et al. (2021); Reppermund and Troller (2016); Schepens (2019); Spassiani et al. (2019); Walsh (2002); WHO (2001); Wilson et al. (2010)
		Financial assets: N = 3 LaPlante (2014); MacTavish and Mabon (2005); Mee Kim et al. (2020)
		Access to health and social care: N = 6 Chion et al. (2016); Mago et al. (2021); Overeynder et al. (1994); Reppermund and Troller (2016); Roth (2011); WHO (2001)
		Access to community services: N = 13 Bigby (2004); Fick (2019); Hogg et al. (2000); Hussain et al. (2021); Janicki (1994); Janicki (2009); LaPlante (2014); McCallion and Nickle (2008); Newbronner et al. (2017); Mee Kim et al. (2020); Miskimmin (2014); Ortega-Camero et al. (2021); Schepens (2019)
Supporting people to age well with a lifelong disability	Life-course approach to reduce inequalities	N = 14 Bigby (2004); Bigby et al. (2007); Evenhuis et al. (2001); Fick (2019); Gonzalez-Alonso et al. (2017); Heller and Van Heuman (2021); Janicki (2009); Mago et al. (2021); Miskimmin (2014); Van Heuman and Heller (2017); Walsh et al. (2001, 2007); WHO (2000, 2001)
	Micro-level interventions to support aging well	Future planning: N = 13 Bigby (2004); Del Barrio et al. (2018); Heller et al. (2004); Heller and Van Heuman (2021); Hogg et al. (2000); LaPlante (2014); Llewellyn et al. (2004); McCallion and Nickle (2008); McCarron and McCallion (2007); Ortega-Camareno et al. (2021); Schepens (2019); Van Heuman and Heller (2017); Walsh (2003)
		Person-centered care: N = 13 Bigby (2004); Dukes (2018); Fick (2019); Haveman et al. (2009); Heller et al. (2004); Heller and Van Heuman (2021); Hogg et al. (2000); MacTavish and Mabon (2005); Overeynder et al. (1994); Reppermund and Troller (2016); Roll and Bowers (2017); Roth (2011); Schepens (2019)
		Promoting choice: N = 14 Greenwood (2010); Hogg et al. (2000); Hussain et al. (2021); Janicki (1994); MacTavish and Mabon (2005); Mee Kim et al. (2020); Ortega-Camareno et al. (2021); Overeynder et al. (1994); Pointu (2016); Roll and Bowers (2017); Reppermund and Troller (2016); Schepens (2019); Strnadova and Evans (2015); Van Heuman and Heller (2017)
		Formal and informal support: N = 14 Gonzalez-Alonso et al. (2017); Heller et al. (2004); Hogg et al. (2000); Janicki (1994); Johansson et al. (2017); Kim et al. (2022); Miskimmin (2014); Newbronner et al. (2017); Ortega-Camareno et al. (2021); Schepens (2019); Spassiani et al. (2019); Van Heuman and Heller (2017); Walsh (2002); WHO (2001)
		Supporting carers: N = 13 Buys et al. (2008); Dew et al. (2006); Esbensen et al. (2013); Hogg et al. (2000); Hwang et al. (2017); McCallion and McCarron (2004, 2007); Miskimmin (2014); Miskimmin et al. (2019); Overeynder et al. (1994); Pointu (2016); Walsh (2002, 2003)
		Healthy lifestyle: N = 15 Bigby (2004); Buys et al. (2008); Gonzalez-Alonso et al. (2017); Haveman et al. (2009); Heller et al. (2004); Hwang et al. (2017); Kim et al. (2022); Kwon (2014); LaPlante (2014); Overeynder et al. (1994); Phadraig (2017); Reppermund and Troller (2016); Schepens (2019); Steff (2009); Van Heuman and Heller (2017)
		Education on the impact of aging: N = 5 Bigby (2004); Haveman et al. (2009); Mee Kim et al. (2020); Ortega-Camareno et al. (2021); Walsh et al. (2001)
		Technology and assistive devices: N = 5 Bigby (2004); Fick (2019); Heller et al. (2004); McCarron et al. (2019); Overeynder et al. (1994)

Table 1. Continued

Major theme	Subtheme	N of studies and references
		Lifelong learning and social participation: N = 16 <i>Buyts et al. (2008); Fesko et al. (2012); Heller et al. (2004); Heller and Van Heuman (2021); Hussain et al. (2021); Hwang et al. (2017); Kim et al. (2022); Llewellyn et al. (2004); MacTavish and Mabon (2005); Mee Kim et al. (2020); Miskimmin (2014); Miskimmin et al. (2019); Schepens (2019); Strnadova and Evans (2015); Van Heuman and Heller (2017); Wilson et al. (2010)</i>
		Developing and maintaining social networks: N = 7 <i>Heller and Van Heuman (2021); Hussain et al. (2021); Janicki (1994); Mee Kim et al. (2020); Reppermund and Troller (2016); Van Heuman and Heller (2017); WHO (2001)</i>
	Meso-level interventions to support aging well	Access to quality specialized healthcare: N = 28 <i>Bigby (2004); Chiron et al. (2016); Evenhuis et al. (2001); Hahn (2012); Hahn and Aronow (2005); Heller et al. (2004); Hogg (2000); Hussain et al. (2021); Janicki (1994, 2009); Johansson et al. (2017); LaPlante (2014); Lin and Lin (2021); Mago et al. (2021); McCarron and McCallion (2007); Miskimmin (2014); McCarron et al. (2019); Ortega-Camareno et al. (2021); Overeynder et al. (1994); Reilly (2020); Reppermund and Troller (2016); Roth (2011); Thorpe et al. (2001); Van Heuman and Heller (2017); Walsh (2002, 2003); WHO (2000, 2001)</i>
		Well-educated health and social care workforce: N = 15 <i>Bigby (2004); Corrado (2013); Evenhuis et al. (2001); Fick (2019); Heller et al. (2004); Hogg (2000); Johansson et al. (2017); McCallion and McCarron (2004); McCallion et al. (2017); Northway et al. (2017); Reilly (2020); Spassiani et al. (2019); Walsh (2002, 2003); WHO (2001)</i>
		Health promotion: N = 12 <i>Evenhuis et al. (2001); Haveman et al. (2009); Heller et al. (2004); Heller and Sorensen (2013); Heller and Van Heuman (2021); Hogg (2000); LaPlante (2014); McCallion and McCarron (2004); Ng et al. (2015); Reppermund and Troller (2016); Santos et al. (2022); Walsh et al. (2001)</i>
		Inclusive communities and environments: N = 6 <i>Bigby (2004); Haveman et al. (2009); Heller et al. (2004); Hogg (2000); Miskimmin (2014); Steff (2009)</i>
		Services and support: N = 10 <i>Bigby (2010); Heller and Van Heuman (2021); Hogg (2000); Janicki (1994); LaPlante (2014); McCarron and McCallion (2007); Miskimmin (2014); Newberry (2013); Roll and Bowers (2017); Thorpe et al. (2001)</i>
		Good quality and appropriate housing: N = 12 <i>Bigby (2004); Corrado (2013); Fick (2019); Hogg (2000); Janicki (1994, 2009); McCallion and Nickle (2008); Mee Kim et al. (2020); Miskimmin (2014); Schepens (2019); Spassiani et al. (2019); WHO (2000)</i>
		Day programmes and activities: N = 7 <i>Bigby (2004); Bigby et al. (2007); Corrado (2013); Hogg (2000); McCarron et al. (2019); MacTavish and Mabon (2005); Newberry (2013)</i>
		Reducing stigma and discrimination: N = 3 <i>Fick (2019); Llewellyn et al. (2004); WHO (2001)</i>
		Research: N = 11 <i>Evenhuis et al. (2001); Fesko et al. (2012); Gonzalez-Alonso et al. (2017); Henderson (2004); Hogg (2000); Llewellyn et al. (2004); McCallion and McCarron (2004); McCallion and Nickle (2008); Newbronner et al. (2017); Overeynder et al. (1994); Phadraig (2017)</i>
	Macro-level interventions to support aging well	Policies for aging well with a lifelong disability: N = 11 <i>Bigby (2010); Fesko et al. (2012); Hussain et al. (2021); Janicki (1994); Miskimmin (2014); Overeynder et al. (1994); Phadraig (2017); Reilly (2020); Schepens (2019); WHO (2000, 2001)</i>
		Promotion of disability rights: N = 5 <i>Bigby (2004); Heller and Van Heuman (2021); Hogg (2000); Janicki (1994); Miskimmin (2014)</i>
		Worldwide agenda for aging well with a lifelong disability: N = 4 <i>Evenhuis et al. (2001); Hogg (2000); Hussain et al. (2021); WHO (2001)</i>

Notes: Those studies highlighted in bold italics are those that were focused on populations with intellectual disabilities and/or intellectual and developmental disabilities. This is because 70% of included studies focused on people with intellectual disabilities and highlighting these studies allows visualization of how these groups were influential in generated themes. Illustrative quotes are provided for those themes that comprised mostly of qualitative research.

and values such as independence, self-determination, resilience, and a strong sense of self and self-advocacy (Burke et al., 2014; Dew et al., 2006; Greenwood, 2010; Hwang et al., 2017; Kim et al., 2022; Pointu, 2016; Strndova, 2015). They also spoke about positive psychological outcomes of aging such as wisdom, being more fulfilled, self-esteem, and feeling more competent in day-to-day life (Burke et al., 2014; Greenwood, 2010; Pointu, 2016). Social factors were also identified as being important for aging well, including social participation and inclusion, supportive friends and family, inclusive communities, congenial living arrangements, and partaking in enjoyable social and leisure activities (Burke et al., 2014; Dew et al., 2006; Hwang et al., 2017; Kim et al., 2022; Mee Kim et al., 2020; Miskimmin 2014; Miskimmin et al., 2019; Newberry, 2013; Pointu, 2016). See Table 1 for illustrative quotes.

How aging well is framed by supporters and carers

Supporters and carers (e.g., family, support workers, housing providers) spoke about the centrality of support in helping people with a lifelong disability to age well, particularly in relation to facilitating independence, self-determination, and social participation (Buys et al., 2012a, 2012b; Johansson et al., 2017; Spassiani et al., 2019). Supporters and carers spoke about the importance of their knowledge of the people they cared for and their experience in working with populations with lifelong disabilities as being key in facilitating aging well (Buys et al., 2012a; Northway et al., 2017; Spassiani et al., 2019), and where family carers were no longer available, the central roles that support workers played in the lives of the older adults they supported (Buys et al., 2012b; Northway et al., 2017). The importance of social and leisure activities, exercise, and friends was also emphasized (Buys et al., 2012b; Johansson et al., 2017; Steff, 2009). See Table 1 for illustrative quotes.

Theories of aging well with a lifelong disability

Three studies proposed specific theories of aging well for people with lifelong disabilities. McCarron et al. (2019) suggested four pillars of positive aging for people with ID: participation, healthy aging, security, and cross-cutting (which includes positive attitudes to aging and use of technology). Janicki (1994) proposed that successful aging for people with a lifelong disability included retention of functional capacity, maintaining autonomy, remaining out of institutions, and engaging in activities that are important to them. Finally, Heller et al. (2004) and Heller and Van Heuman (2021) presented the supports outcomes model of aging well, which has key outcomes of independence, good quality of life, physical and emotional well-being, and community inclusion, which are facilitated by the underlying abilities, health, and functioning of the individual, the inclusiveness of their environment, and the opportunities given to exercise self-determination.

There were also critical considerations around how applicable existing theories of aging well are for people with lifelong disabilities. Issues were found with the successful aging theory of Rowe and Khan (1997), specifically the criterion that to successfully age people must avoid disease/disability, which cannot be achieved by people with a lifelong disability (Bigby et al., 2007; Haveman et al., 2009; Heller & Van Heuman, 2021; Reppermund & Troller, 2016).

Components of aging well with a lifelong disability

The meaning of aging well was seen as something that was specific to an individual (Burke et al., 2014; Dukes, 2018; Hwang et al., 2017). Furthermore, most studies emphasized the holistic components that contributed to aging well, rather than identifying a single component that was indicative of aging well (see Supplementary Table 2).

At a micro-level, the components of aging well identified across studies spanned health, support, maintenance and development, productivity, psychological factors, social relationships, and social participation. For health, 45 studies emphasized the importance of having increased longevity, good or maintained physical and cognitive functioning, mental health, physical health, oral health, and a healthy lifestyle alongside fewer behavioral issues, a reduced risk of secondary health conditions, and an absence of pain (see Table 1 for references).

Maintenance and development referred to the idea that aging well was indicated by maintaining capabilities and skills while also developing new interests and skills in six studies (see Table 1). Linked to this four studies suggested that productivity could be a key indicator of aging well, be that in terms of volunteering roles, social participation, or employment (see Table 1).

At a psychological level, personal characteristics linked to disability rights such as the promotion of independence, autonomy, empowerment, self-determination, self-efficacy, self-advocacy, and resilience were all emphasized as being important components of aging well in 27 studies (see Table 1). Alongside this achieving a good quality of life, life satisfaction, and good well-being were seen as central outcomes indicating aging well in 17 studies (see Table 1).

At a social level, 28 studies mentioned that enjoyable social and leisure activity, opportunities for social and community participation, security, community inclusion, meaningful social roles, and good social relationships with friends and family were all important components of aging well (see Table 1).

The accumulation of financial assets and planning financially for the future was also something that was mentioned as important for aging well so that people with lifelong disabilities had the assets needed to support them in older age (LaPlante, 2014; MacTavish & Mahon, 2005; Mee Kim et al., 2020).

At a meso-level, access to health and social care, housing, and services were all mentioned as key components of aging well. Having good access to health and social care was seen as important for aging well in six studies particularly in terms of improving physical, mental, and social health (see Table 1). Furthermore, being able to access services in the broader community that could support with aging well such as transportation, housing, and social services was highlighted by 13 studies (see Table 1).

Supporting People to Age Well With a Lifelong Disability

This theme encompasses the different micro-, meso-, and macro-level ways that studies suggest we can support people with a lifelong disability to age well. Authors emphasized the importance of taking a life-course approach to supporting aging well to reduce health and social inequalities for people with a lifelong disability (see Table 1). The different ways that

we can support people with lifelong disabilities to age well are discussed in more depth below.

Micro-level interventions

Micro-level ways to improve aging well included future planning, person-centered care, promoting choice, formal and informal support, supporting carers, healthy lifestyle, education on the impact of aging, technology and assistive devices, lifelong learning and social participation, and developing and maintaining social networks.

Future planning includes plans for family carers no longer being able to support the person with a lifelong disability (Bigby, 2004; Del Barrio et al., 2018; Heller et al., 2004; Hogg et al., 2000; McCarron & McCallion, 2007; Ortega-Camareno et al., 2021; Van Heuman & Heller, 2017; Walsh, 2003), ways to support people through bereavement (Bigby, 2004; McCallion & Nickle, 2008; McCarron & McCallion, 2007), ways to support people if their health and functioning declines (Bigby, 2004; McCallion & Nickle, 2008), long-term care (McCarron & McCallion, 2007), financial planning (LaPlante, 2014; Van Heuman & Heller, 2017), and preretirement planning (Heller & Van Heuman, 2021; Llewellyn et al., 2004; McCarron & McCallion, 2007; Schepens, 2019). To facilitate key outcomes of aging well in terms of self-determination, autonomy, and independence, it has been suggested that the person with a lifelong disability be actively involved in this planning (Van Heuman & Heller, 2017).

Person-centered care has been identified as an important way to promote aging well for people with a lifelong disability and consists of being mindful of what is important to the person with a lifelong disability and their family through individualized planning, monitoring, health screening, promoting autonomy, and regular reviews to maintain health and well-being (Bigby, 2004; Dukes, 2018; Fick, 2019; Haveman et al., 2009; Heller & van Heumen, 2021; Hogg et al., 2000; MacTavish & Mahon, 2005; Overeinder et al., 1994; Reppermund & Troller, 2016; Roll & Bowers, 2017; Roth et al., 2011; Schepens et al., 2019). It is recognized that aging well depends on an individual's capabilities, health, functioning, and support (Heller et al., 2004), and that people with a lifelong disability often have better outcomes when involved in care decision making (Heller & Van Heuman, 2021).

Promoting choice in care, community and leisure activities, relationships, and housing is important in allowing people with lifelong disabilities to exercise self-determination (Hogg et al., 2000; Hussain et al., 2021; Janicki, 1994; MacTavish & Mahon, 2005; Ortega-Camareno et al., 2021; Reppermund & Troller, 2016; Schepens, 2019; Van Heuman & Heller, 2017). Furthermore, developing ways to encourage people to self-advocate has been identified as important for aging well (Overeinder et al., 1994; Roll & Bowers, 2017) as illustrated by the finding that for people with a lifelong disability feeling empowered, self-sufficient, and able to self-advocate is important to them (Greenwood, 2010; Kim et al., 2022; Mee Kim et al., 2020; Pointu, 2016; Strnadová and Evans, 2015).

Maximizing the availability of formal and informal support for people with lifelong disabilities is suggested to be fundamentally important for them to age well (González-Alonso et al., 2017; Johansson et al., 2017; Newbronner et al., 2017; Ortega-Camareno et al., 2021; Walsh, 2002; WHO, 2001). Carers have a key role in maximizing autonomy, independence, health, well-being, personal development, and enjoyable activities (Heller et al., 2004; Hogg et al., 2000;

Janicki, 1994; Johansson et al., 2017; Miskimmin, 2014; Schepens, 2019; Spassiani et al., 2019; Van Heuman & Heller, 2017). In addition, people with lifelong disabilities acknowledged the importance of support from friends and family for their health, well-being, and participation (Buys et al., 2008; Dew et al., 2006; Hwang et al., 2017; Kim et al., 2022; Miskimmin, 2014; Miskimmin et al., 2019; Overeinder et al., 1994; Pointu, 2016).

Research indicates that the well-being of a person with a lifelong disability is closely linked to the well-being of their primary carer (Esbensen et al., 2013); therefore, it is important to support the health and well-being of carers by monitoring and alleviating caregiver burden and provide support to carers (Hogg et al., 2000; McCallion & McCarron, 2004, 2007; McCarron & McCallion, 2007; Walsh, 2002, 2003).

Promoting healthy lifestyles and intervening when lifestyle is less than optimal have been identified as key ways to prevent the development of secondary health conditions and health inequalities (Bigby, 2004; González-Alonso et al., 2017; Haveman et al., 2009; LaPlante, 2014; Overeinder et al., 1994; Reppermund & Troller, 2016; Schepens, 2019; Van Heuman & Heller, 2017). Having the involvement of carers and broader systems has also been identified as facilitating healthier lifestyles (Heller et al., 2004; Steff, 2009). Health promotion (in particular in terms of exercise and nutrition) was also something that people with a lifelong disability recognized could help improve their health (Buys et al., 2008; Hwang et al., 2017; Kim et al., 2022; Steff, 2009). Suggestions for improving lifestyle have included fitness programs (Kwon, 2014; Overeinder et al., 1994), exercise (Steff, 2009), and improving oral healthcare (Phadraig, 2017).

Improving understanding of aging for both people with a lifelong disability and those who care for them (Mee Kim et al., 2020; Ortega-Camareno et al., 2021) has been suggested as being important for promoting aging well and preparing for potential change (Haveman et al., 2009). Specific examples are given around the impact of menopause for females (Bigby, 2004; Walsh et al., 2001).

The use of technology (Fick, 2019; McCarron et al., 2019) and assistive devices (Bigby, 2004; Heller et al., 2004; Overeinder et al., 1994) can be important tools that help people to remain independent for longer. It has been suggested that training people how to use these tools could be important for facilitating aging well (Overeinder et al., 1994).

To promote autonomy, independence, self-determination, and other characteristics shown to be important for aging well, researchers suggest that engaging in lifelong learning, meaningful social roles, volunteering, or employment can give people a sense of purpose (Fesko et al., 2012; Hussain et al., 2021; Llewellyn et al., 2004; MacTavish & Mahon, 2005; Van Heuman & Heller, 2017; Wilson et al., 2010). Furthermore, personal development and learning new skills can be important in helping people to age actively (Heller et al., 2004; Heller & Van Heuman, 2021; MacTavish & Mahon, 2005; Schepens, 2019). Learning new skills, being employed, volunteer work, and feeling productive and involved were all mentioned as important for promoting well-being in interviews with older people with lifelong disabilities (Buys et al., 2008; Hwang et al., 2017; Kim et al., 2022; Mee Kim et al., 2020; Miskimmin, 2014; Miskimmin et al., 2019; Strnadová & Evans, 2015).

Identifying and developing ways to support people with a lifelong disability to increase their social networks and develop new relationships are also important for aging well (Heller & Van Heuman, 2021; Mee Kim et al., 2020; Reppermund & Troller, 2016; WHO, 2001). It has been suggested that fostering social skills could be an important way to increase or maintain involvement with others (Janicki, 1994). Allowing people to be meaningfully engaged in their communities is also important to aging well (Hussain et al., 2021; Janicki, 1994; Van Heuman & Heller, 2017).

Meso-level interventions

Meso-level interventions that could be undertaken to support people with a lifelong disability to age well spanned inclusive communities and environments, access to quality specialized healthcare, a well-educated workforce, services and support, housing, day programs and activities, health promotion, reducing stigma and discrimination, and undertaking research.

The most salient way to improve aging well at a meso-level was suggested to be by improving access to quality specialized healthcare. This is suggested to involve lifelong and joined up care where people with lifelong disabilities receive regular health checks, monitoring of existing health conditions, screening, and treatment from multidisciplinary teams to manage complexity (Bigby, 2004; Chiron et al., 2016; Evenhuis et al., 2001; Hahn, 2012; Hogg et al., 2000; Hussain et al., 2021; Janicki, 2009; Johansson et al., 2017; LaPlante, 2014; Lin & Lin, 2021; McCarron & McCallion, 2007; McCarron et al., 2019; Miskimmin, 2014; Ortega-Camarero et al., 2021; Reilly, 2020; Reppermund & Troller, 2016; Roth et al., 2011; Thorpe et al., 2001; Van Heuman & Heller, 2017; Walsh, 2002, 2003; WHO, 2000, 2001). Ensuring the accessibility of this healthcare and that care for older adults be targeted to their specific aging needs were additional factors emphasized by study authors (Bigby, 2004; Hogg et al., 2000; Janicki, 1994; Mago et al., 2021; McCarron & McCallion, 2007; Miskimmin, 2014; Overeynder et al., 1994; Roth, 2011; Walsh, 2002; WHO, 2001). It was also suggested that consulting people with lifelong disabilities and their carers in shaping and advocating for health interventions and services was an important way to improve their healthcare (Heller et al., 2004; Thorpe et al., 2001).

A well-trained health and social care workforce is a tangible way studies suggest we can improve healthcare and health outcomes for people with a lifelong disability (Corrado, 2013; Hogg et al., 2000; Johansson et al., 2017; McCallion et al., 2017; Northway et al., 2017; Reilly, 2020; Spassiani et al., 2019; Walsh, 2002; Walsh et al., 2001; WHO, 2001). To achieve this it has been suggested to create educational materials on the impact of aging, the importance and differences of communication, how illnesses could present differently and increase awareness of primary and secondary conditions (Bigby, 2004; Evenhuis et al., 2001; Fick, 2019; Heller et al., 2004; Hogg et al., 2000; McCallion et al., 2017; Reilly, 2020; Walsh et al., 2001, 2003; WHO, 2001).

Several studies also mentioned the importance of creating and implementing health promotion activities to improve healthy lifestyle for people with a lifelong disability to reduce the risk of some secondary conditions (Evenhuis et al., 2001; Haveman et al., 2009; Heller et al., 2004; Heller & Van Heuman, 2021; Hogg et al., 2000; LaPlante, 2014; McCallion

& McCarron, 2004; Ng et al., 2015; Reppermund & Troller, 2016; Walsh et al., 2001). A recent systematic review from Santos et al. (2022) found four types of health promotion programs: physical activity and/or healthy nutrition (shown to improve physical health), health education/screening (shown to reduce health risks and change behaviors), social inclusion/community participation (shown to increase participation), and mixed approaches. Mixed approaches aimed at increasing health screening and health education were proposed to be the most promising health promotion activities (Santos et al., 2022).

Given the importance of social participation and social relationships for people with a lifelong disability (Bigby, 2004; McCarron et al., 2019), many studies emphasized the importance of ensuring that communities were inclusive for people with a lifelong disability. This could be in terms of a mixture of specialized and generic facilities where they would be able to interact with lots of different people and feel included in their broader community (Bigby, 2004; Heller et al., 2004; Hogg et al., 2000; Miskimmin, 2014). An inclusive community should be accessible for people with a range of impairments, allowing occupational opportunities, have accessible information, accessible transport, and include spaces suitable for health promotion activities such as physical exercise (Bigby, 2004; Haveman et al., 2009; Steff, 2009).

An additional suggestion relevant to social participation and lifelong learning for aging well is that there be a range of opportunities for day programs, retirement programs, and leisure activities for people with a lifelong disability (Bigby, 2004; Bigby et al., 2007; Corrado, 2013; Hogg et al., 2000; McCarron et al., 2019). For people aging with a lifelong disability, these programs and activities have been suggested to provide opportunities for social participation, building social relationships, maintaining or developing new skills, improving lifestyle, feeling productive, learning, and promoting a sense of self (Bigby et al., 2007; Hogg et al., 2000; MacTavish & Mahon, 2005; Newberry, 2013).

Others community-based resources suggested to facilitate aging well are accessible services and support workers to support people with a lifelong disability and their families (Janicki, 1994; McCarron & McCallion, 2007; Miskimmin, 2014). Specialist services and support should cover a range of resources such as welfare, financial planning, legal planning, advocacy, independence, employment or vocational opportunities, social resources, and activities (Heller & Van Heuman, 2021; Hogg et al., 2000; LaPlante, 2014; Newberry, 2013; Roll & Bowers, 2017; Thorpe et al., 2001). It was also suggested that disability services and aging services build better links to support people aging with a lifelong disability (Bigby, 2010).

Having good quality and appropriate housing is also suggested to be a key component of aging well (Janicki, 2009; Miskimmin, 2014; WHO, 2000). Some authors proposed that aging in place is optimal for aging well (Bigby, 2004; Fick, 2019; Mee Kim et al., 2020; Miskimmin, 2014) with it being important that people remain out of institutions (Janicki, 1994; McCallion & Nickle, 2008; Schepens, 2019). Housing with support should be well-funded, integrated into the community, appropriate for people with a range of impairments, have well-trained and supportive staff, clear protocols for how to support aging well, adaptable for age-related changes, and a culture that promotes building relationships and participation in activities and programs (Corrado, 2013; Hogg et al., 2000; Schepens, 2019; Spassiani et al., 2019).

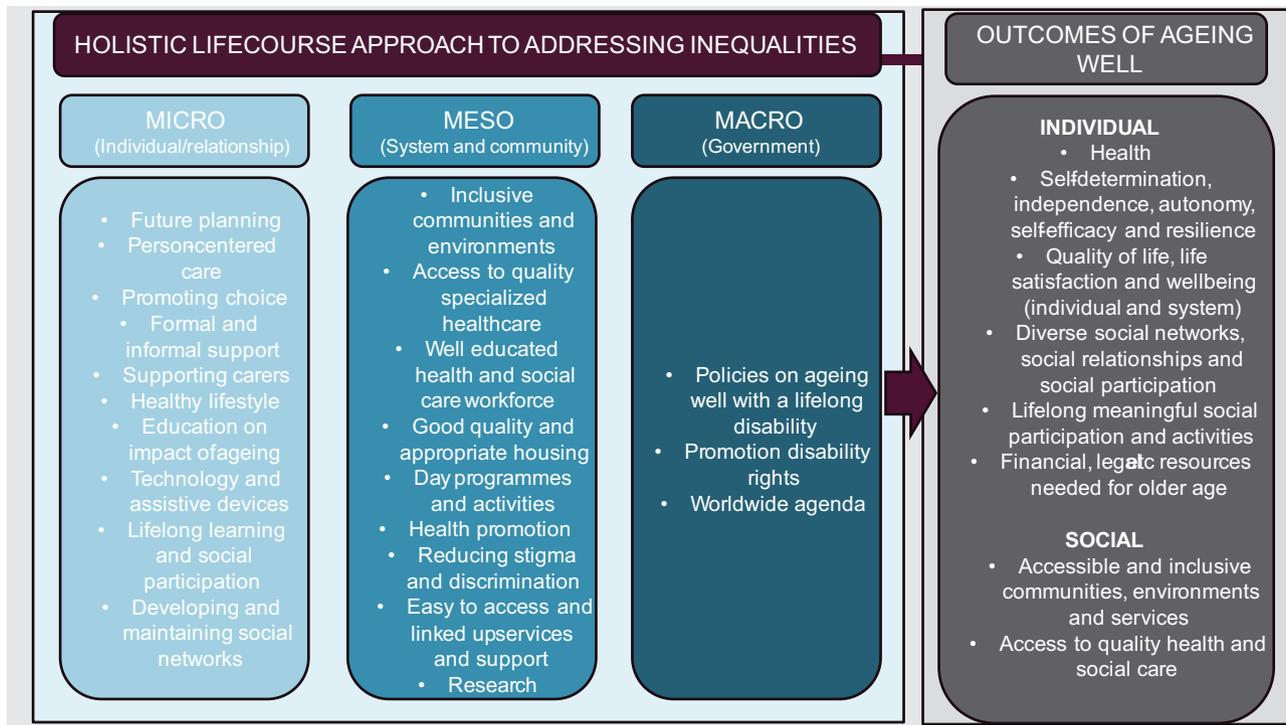


Figure 2. Promoting aging well for people aging with a lifelong disability.

Undertaking research was also suggested as a means to facilitate aging well (McCallion & McCarron, 2004). Some authors suggested that we needed to better understand the long-term impact of aging with a lifelong disability to know where appropriate interventions and policies could be situated (Evenhuis et al., 2001; Fesko et al., 2012; González-Alonso et al., 2017; Henderson, 2004; Newbronner et al., 2017; Overeynder et al., 1994). Some studies suggested that a broad research agenda was needed that could support the development of policies and practice around aging with a lifelong disability (Henserson, 2004; Overeynder et al., 1994). Other authors suggested that research was urgently needed to understand which interventions might be most effective in promoting healthy aging and where investigating these interventions should be situated (Hogg et al., 2000; Llewellyn et al., 2004; McCallion & Nickle, 2008; Overeynder et al., 1994; Phadraig, 2017).

Finally, tackling stigma and discrimination by avoiding the stereotyping of people with lifelong disabilities, challenging perceptions that people with lifelong disabilities are vulnerable and require care, and increasing awareness and education around stigma (Fick, 2019; Llewellyn et al., 2004; WHO, 2001) have also been suggested as important for aging well.

Macro-level interventions

At the government level, facilitating aging well could be achieved by the implementation of policies, promotion of disability rights, plus a worldwide agenda for how we could support people to age well with a lifelong disability.

Government policies designed to promote aging well for people with a lifelong disability were seen as a core way to facilitate healthy aging (Bigby, 2010; Miskimmin, 2014; WHO, 2000, 2001). Suggestions included policies focused on aging in place, health, life-course healthcare, health promotion, tackling stigma, inappropriate admission to care homes,

integration of services and support, workforce training and planning, joining up services, leisure, and day programs (Bigby, 2010; Hussain et al., 2021; Janicki, 1994, 2009; Overeynder et al., 1994; Phadraig, 2017; Reilly, 2020; Schepens, 2019). These policies also require that funding and infrastructure be levied to support their implementation (Schepens, 2019; Fesko et al., 2012; WHO, 2001).

The promotion of disability rights was seen as something that could not and should not be disentangled from aging rights (Bigby, 2004; Heller & Van Heuman, 2021; Hogg et al., 2000; Miskimmin, 2014). It is acknowledged that these rights should be promoted from a top-level down and include equity, choice, self-determination, participation, inclusion, and human rights (Bigby, 2004; Hogg et al., 2000).

The development of a consistent worldwide agenda to support aging well with a lifelong disability was also suggested to be something that could help governments focus policies and practices (Evenhuis et al., 2001; Hussain et al., 2021). However, it was noted that many theories of aging well with a lifelong disability are specific to developed countries and come from a place of financial privilege, which may not be appropriate for developing countries where limited resources mean the focus on aging will be moreso about survival than aging well (Evenhuis et al., 2001; Hogg et al., 2000; WHO, 2001). It is therefore suggested that each country should be aware of aging with a lifelong disability but respond to this in line with their own traditions, values, structures, and resources (Hogg et al., 2000).

Discussion

Across different studies, aging well with a lifelong disability was mostly conceptualized using a person-centered systemic approach that emphasized a range of individual (e.g., health, functioning, well-being, quality of life, independence,

autonomy, meaning), relational (e.g., support, relationships, participation, activities), and societal (e.g., health and social care, housing, services) components. This synthesis also brought together the different ways that research has suggested we could facilitate aging well for people with a lifelong disability. Proposed interventions suggest taking a life-course approach to addressing inequalities at a micro- (e.g., person-centered care, future planning, increasing social networks, improving health), meso- (e.g., quality specialized health and social care, quality, and appropriate housing), and macro-level (e.g., policies, promotion of disability rights). It should be noted that these facilitators will not work in isolation and multilevel interventions are necessitated to improve the outcomes identified as important in this review as people aging with a lifelong disability have multifaceted needs that need multidisciplinary support (Hussain et al., 2021; Janicki, 2009).

Many of the factors identified as important for aging well with a lifelong disability within this review resonate with broader factors that have been identified in worldwide strategies for aging well in the general population. This includes the importance of integrated care, access to long-term care, tackling age-related discrimination, and age-friendly communities (UN, 2021). However, there were nuances in factors that should be considered important for people aging with a lifelong disability such as future planning for aging family carers, the central importance of carers and supporters, and promotion of disability rights (e.g., Bigby, 2004). Furthermore, this synthesis has identified a range of ways that we could tackle the health and social inequalities seen in people aging with a lifelong disability (Bigby, 2004; Heller & Van Heuman, 2021; see Figure 2).

Research Gaps

Findings from this review highlight that most research into aging well with a lifelong disability is situated in people with ID and that there is marked need to investigate this in other groups such as those with cerebral palsy, autism spectrum disorder, spina bifida, and lifelong sensory impairments. Much research into many of these conditions is primarily biomedical and so less likely to explicitly address aging well. Other research gaps identified include the need for more research to understand what types of interventions might be most effective for people aging with different lifelong disabilities, particularly at the macro-level such as policy or political change.

Strengths and Limitations

The strengths of this review include the comprehensive search undertaken across databases and gray literature to meet the study aim. However, it should also be noted that to be eligible for inclusion in this review studies must have explicitly mentioned aging well. There is a much wider literature around topics relevant to aging well for people with different lifelong disabilities and literature was not included within this review unless they specifically mentioned a term related to aging well. There was a lack of information within this review on improving biological risk factors, which is an acknowledged risk factor for poor health in this population; however, this is likely due to the focus of this review on holistic models of aging well rather than biomedical models (as this literature does exist). Furthermore, the identification of lifelong disability as one that a person lived with since birth or early childhood could mean that we missed out some groups who

have been living with disability for most of their lives if onset was later than childhood. The evidence contained within this review also highlights that aging well is a concept applicable primarily to industrialized countries, and there is a need to better understand whether and how aging well could be facilitated in low- and middle-income countries. An additional limitation is that many of the factors that influence lifelong disability were looked at individually, whereas in reality it is likely a complex interplay of various micro-, meso-, and macro-level factors that will influence aging. Finally, lifelong disability is an umbrella term that captures a wide range of conditions and impairments that could affect individuals very differently. While there are commonalities in the experiences of people with lifelong disability, there needs to be an awareness that the aging needs of different groups will vary—highlighting the importance of a person-centered approach.

Conclusion

There are many commonalities between the aging needs of people aging with a lifelong disability and the general population. However, there are also nuances and differences that should be borne in mind by professionals working with this group. The aging needs of this group need to be formalized in policy and care recommendations and this review allows us to identify core areas where interventions should be targeted.

Supplementary Material

Supplementary data are available at *The Gerontologist* online.

Funding

This work was supported by a UK/Ireland networking grant from the Economic and Social Research Council and Irish Research Council (grant number ES/V007432/1). The funders had no input into this scoping review.

Conflict of Interest

None.

Data Availability

The search strategy is available as [Supplementary Material](#) and protocol was preregistered on the Open Science Framework (<https://osf.io/y42md>).

Acknowledgments

We would like to thank Professor Mary McCarron and Dr. Ann Leahy for their help with the initial stages of this project.

Author Contributions

Kimberley Smith (Conceptualization [lead], Data curation [lead], Formal analysis [lead], Funding acquisition [lead], Investigation [lead], Methodology [lead], Project administration [lead], Resources [lead], Supervision [equal], Writing—original draft [lead], Writing—review & editing [lead]), Saahil Gupta (Investigation [supporting], Project administration [supporting], Writing—review & editing [supporting]), Jennifer Fortune (Conceptualization [supporting], Funding acquisition

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