



Disability and Aging: A Literature Review on Advocacy and Activism for Sustainable and Resilient Community Living

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Abstract

The book chapter purports to provide insights, research gaps, and lessons using a narrative literature review approach. The discussion was centered on unveiling aging (aging with disability and disability with aging included) advocacy and activism for living arrangement-institutionalized, while taking inspiration from disability movement that is led by disabled people that adopted independent living as an example of community living. The discourse discovered that advo-

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cacy on aging began in the 1970s, while oriented toward feminism; however, the twenty-first century fosters social innovation as well as learning from independent living, thereby making the chapter to foster the idea of giving options for the aging population to choose preference on living arrangements that enhance freedom and dignity as essential human rights.

Keywords

Ageing and disability · Independent living · Sustainable and resilient community living · Empowerment · Sustainable socioeconomic participation and development · Advocacy and activism

Introduction

The purpose of this chapter is inspired by approaches from the activism and advocacy of disabled people to inform aging activism and advocacy for effective use of existing data to strengthen evidence-based policy and program development. The chapter provides the reader with a comprehensive background to understanding current knowledge while highlighting the significance of new dimensions that emerge from insights, gaps, and lessons for community living as informed by advocacy and activism in developing and developed countries. The chapter purports to be a literature review that establishes value, perspectives, and scientific documentation of narrative (activities), both historical and those mushrooming as progressive and contemporary-innovative activism and advocacy geared toward community living of (i) aging with disability, (ii) disability with aging, and (iii) aging while learning from independent living principles applied by disabled people. It is further inspired by a growing call from scholars to ensure that the requirements of this ever-increasing population segment are not ignored by promoting traditional solutions and historical assumptions while extracting value from the population group. Further inspiration of this chapter draws from the heart of the 2030 agenda for sustainable development and its pledge to leave no one behind, paying particular attention to the most vulnerable groups, thereby bringing attention to the need for an intersectional approach based on multiple individuals and environmental characteristics that can hinder effective participation of the aging society such as an older person who has an impairment further facing disablism, added to existing ageism already confronted by.

As background and rationale, literature shows the developed countries' family size as shrinking while exponentially increasing the aging population (Veress & Bagirova, 2018). The United Nations Department of Economic and Social Affairs (UNDESA) report (2017) shows that, globally, the number of persons aged above 80 years is projected to increase more than threefold between 2017 and 2050, resulting from a decline in fertility, improvement in survival, and medical excellence throughout the world. However, the effects of the COVID-19 pandemic brought a need to reconsider responses to aging through advocacy and activism in societies in the global village.

As illustrated in Table 1. While developed countries reveal an inevitable increase in the share of the aging demographics, African countries range from 53 to 75 years (Statistica, 2021).

Table 1 presents the average estimated life expectancy without considering COVID-19–induced death rate. Taylor and Smith (2017) had an increased concern about the sustainability of the welfare system and the supply of labor. On the one hand, labor unions and governments in developed countries have implemented reforms to encourage people to retire later and employers to hire older workers (Taylor & Smith, 2017). On the other hand, advocacy organizations have enthusiastically promoted the working-longer agenda (Taylor & Smith, 2017). Amid calls to work longer, the availability and quality of paid employees and how those not employed would build and maintain a sense of identity are critical issues that have received little consideration in policy and advocacy on aging and living arrangement. Just as highlighted in Table 1, Australian Treasury’s 2015 Intergenerational Report projects substantial change in the composition of its population by 2054–2055; a more considerable proportion of the people will be aged 65 and over, with the number in this age group more than doubling. Labor force participation among people aged over 15 is projected to decline.

The aspects mentioned above affect living arrangements, thereby positioning the chapter to contribute insights toward bringing interventions from an advocacy perspective, as there is a need for careful consideration when responding to the needs of the elderly while taking advantage of their unrealized and overshadowed value to societies (Sorensen & Black, 2001). This chapter focuses on advocacy and activism of disability and aging population groups toward sustainable and resilient community living of the aging population (including aging with disability and disability with aging). The said population groups experience similar challenges in institutionalized Living, requiring similar solutions (Altpeter et al., 2014). On the one hand, Pogach (2019) believes there is a need to give the aging population opportunities to choose between institutionalized and independent living arrangements inspired by the development of the present chapter. On the other hand, consider the global trends that reveal an inevitable increase in movements led by disabled people. At the same time, it has become evident that aging also causes an increase in the number of persons with disabilities, as many would acquire some form of impairment (Robertson, 1999, cited

Table 1 Old age by gender and life expectancy projections

Gender	Developed countries – average life expectancy		Developing countries – average life expectancy	
	present	post-2030	present	post-2030
Male	91.5 years	95.1 years	63 years	76 years
Female	93.6 years	96.6 years	66 years	78 years
Other	–	–	–	–

Source: a compilation from various documents

in Sorensen & Black, 2001), thereby raising the alarm to economists concerned with life cycle patterns, production, and consumption; in a welfare state older people do not produce as much as they consume and exert more pressure on the fiscus (Holstein, 2013; Takao, 2009), thus exacerbating the need for sustainable solutions. An explanation of the fundamental definition in this context as follows:

Disability is defined from a social model perspective as a social situation that perpetuates social oppression imposed on people with impairments due to environmental barriers that exclude them from participating in society. Such is entirely distinguished from their impairment (Kazou, 2017). World Health organization's International Classification of Functioning (WHO-ICF) interprets disability as a multidimensional and interactive experience from difficulties in functioning, and arising out of the complex interaction between health conditions, personal factors, and barriers in the physical and social environment (WHO-ICF 2001). Disability comes in because aging people can acquire impairment, while disabled people can grow old. Therefore, based on this social model perspective, this literature will use the terms "persons/people with disabilities" and "disabled people/persons" interchangeably to refer to this population group with functional limitations or impairments which in interaction with environmental barriers hinder their full participation on an equal basis with others (UNCRPD 2006).

Aging is defined as a persistent decline in the age-specific fitness components of an organism due to internal physiological deterioration (Rose et al., 2012). At the same time, ageism is understood as negative and positive stereotypes, prejudices, and discrimination against (or to the advantage of) older adults based on a perception of being senior or elderly (Rose et al., 2012).

Sustainable and resilient community living is, according to Metaxas and Psarropoulou (2021), a combination of words that refers to ensuring dignified living conditions while upholding human rights through creating and maintaining viable options in life. The principle of fairness for present and future generations should be considered in using resources. The chapter presents the methodology, findings, and conclusion as follows.

Methodology

A qualitative research design enabled a narrative literature review strategy to examine the extent of literature. The particular focus was on advocacy and activism and on interconnectedness. The review process considered the chronological and regional scope of the literature from high-ranked academic databases in answering the following questions:

- a) What critical thinking around institutionalized and independent living arrangements can enhance sustainability and resilience in community living arrangements?
- b) How can movements by persons with disabilities bring social innovation on activism and advocacy for sustainable and resilient community living arrangements for aging with disability and disability with aging population groups?

- c) What can be learned from each population group's advocacy to the others for the adoption toward sustainable and resilient community living arrangements while enhancing the socio-economic activeness of the population mentioned above groups?

The researchers conducted a literature search in the following electronic databases: African Journals (Sabinet Online), Emerald Insight Journals, Google Scholar, and Scopus. International, regional, national, and organizational reports, podcasts, publications, campaign materials, social media and websites columns, and personal and unpublished narratives of individuals and organizations concerned (activists and advocates) about aging with disability and disability with aging augmented the scientific documented-scholarly views. Keywords like aging and disability, independent living, institutionalization, sustainable and resilient community living, socio-cultural-economic involvement, and participation were used in the search. A balance of five regional (continental) journals with full text written in English was considered in the present review. A predetermined inclusion of data sources entails (i) published and (ii) unpublished work on activism and advocacy on aging with disability and disability with aging. Exclusion criteria entail activism and advocacy on disabled children, and youth was used in the screening process. The first and second authors independently review each identified data source to determine eligibility and extract study information. The third and fourth authors verified the collected data while refining the chapter to prepare it for publication. Several studies identified, screened, and included or excluded at each stage of study selection shall be established, as shown in Fig. 1. Based on Fig. 1, the researchers retrieved data. They adopted three steps: (a) electronic literature search and screening of research material from the 1970s to 2022, such were augmented with gray literature done using hand searching print, online and social media, and reports of an international organization. (b) Data were extracted and analyzed manually following thematic approach as advised by Miles and Huberman (1994) and *in vivo* coding (Holton, 2007); based on Saldana (2013), analytical memos were developed, as part of the researchers' reflections concerning the codes, the phenomenon, and their interrelations that distinguished coding from analysis and results. Following Saldana (2013), the memos were based on intuition, reflexivity, and serendipitous occurrences related to disability-skewed independent living. While the coding process and analytical memorizing enable the emergence of patterns in the data, it only enabled and did not determine them as advised by Saldaña (2013). Atlas.ti.8 was used as a computer-aid analytic tool that allowed for immersing data for in-depth analysis and (c) writing the literature review.

Findings

Profiling the Resources Used for the Study

The findings highlight a total of 10,119 academic work, of which 42 met inclusion criteria. Table 2 shows the literature's overview profile on advocacy and activism in developed and developing countries.

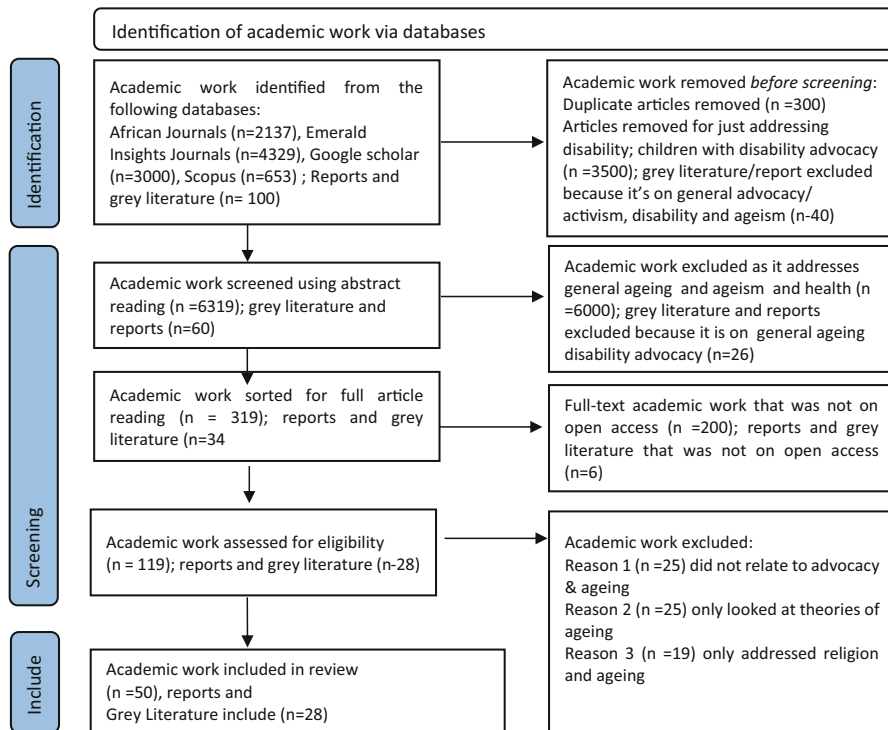


Fig. 1 Data collection and analysis. Source: Adopted in part from Page et al. (2021)

Table 2 shows a dearth of literature on aging advocacy and activism in developing countries, while contrast is observed in developed countries. Literature reflects a difference in demographic composition, social and cultural fabric, economic development, and political systems as determinants in this regard. Despite the differences, there is a shared view on feminism which dominated the rest of advocacy and activism of aging advocacy in all but Japan. The message is skewed on the emancipation of aging women through empowerment and participation in socio-cultural-economic and political spheres. Their voice is equally important as men within the living arrangement.

Literature-Review Discussion

According to Sorensen and Black (2001), advocacy on aging and ageism is dated back to the 1970s as formal, legal, medical-based arguments to probe for changes, where advocacy follows dimensions of (i) self-advocacy, (ii) individual advocacy, (iii) group advocacy, (iv) public interest advocacy provided by paid lawyers, unions, agencies, etc., (v) citizen advocacy by an unpaid citizen, and (vi) systemic advocacy,

Table 2 Overview profiles of results of the review on advocacy and activism on an aging population

Region	Focus areas in the advocacy and activism on aging	Approach used in assessing institutionalized living	Impact/effect and outcome	Lead participants	No. of academic work	No. of gray literature and reports
Developed countries	Japan	Health and social factors	Advocacy for policy reviews; health systems; labor market and employment; involvement, empowerment, and participation in community development	Lead participants Female aging cohort, lawyers, members of civil society, disabled people led	50	22
	Australia	Health and social factors				
	United Kingdom	Socio-economic factors from a feminist lens				
	Canada	Socio-economic dependence and health factors from a feminist lens				
	United States Europe	Socio-economic independence, dependence, and interdependence using feminist lens				
Developing countries	Still a dearth of literature	Health and social factors	Participation in community	Government and civil society	-	6

Source: Authors' compilation

which is designed to change the system, or laws, policies, procedures, or practices that cause or perpetuate injustice or inequality.

Rationale of Advocacy and Activism

Advocacy

People are not equal, and others are made more vulnerable, with the perceived and actual risk of abuse, than others (Veress & Bagirova, 2018). One such comes from realizing outcomes of advocacy; for example, in South Africa, social rights movements like the anti-Apartheid movement practiced advocacy on a large scale and lobbied for the change in the structures which deny groups of people certain rights based on race, age, (dis)ability, gender, religion, or sexuality. Freedom emerged from such advocacy (Veress & Bagirova, 2018). On the one hand, international organizations like the United Nations General Assembly recognized contributions made by older members of societies and their value to society by announcing 1999 as the International Year of Older People (Veress & Bagirova, 2018), thereby establishing five critical areas to be incorporated into the United Nations Principles for Older Persons (1991, in Office of Seniors' Interests, 1998), namely (i) independence, (ii) participation, (iii) care, (iv) self-fulfillment, and (v) dignity (Veress & Bagirova, 2018).

Activism

Casey (2014) believes activism is an activity that advocacy uses to reach the targeted stakeholders. People interchangeably use advocacy for activism (Casey & Mehrotra, 2011). The chapter regards other related terms which are sometimes used in association with advocacy like campaigning, engagement, consulting, giving voice, negotiating, policy work, lobbying, social action, organizing, and political action, which are used to describe attempts to directly influence (Casey, 2014; Casey & Mehrotra, 2011). Such has the essence of advocacy in some cases (Casey, 2014). Therefore, the current authors bring a historical overview to contextual understanding as presented next.

Historical Overview of Advocacy and Activism on Aging Population

The historical background of advocacy and activism on aging is traceable to multi-cases that highlighted the need for older adults to participate in politics, especially in the era before and post-World War II (Serrat et al., 2021). Charpentier et al. (2008) examined senior women's involvement experience in Quebec, Canada. Their study shed light on family history and continuity in the involvement trajectory, diversity in terms of group type, involvement practices, and gender differences. Unfortunately, the advocacy for the participation of senior women was worsened by the lack of evidence concerning the experience and meaning of their participation from the perspective of those involved, as disaggregated to gender.

As time progressed, Narushima (2004) and Sawchuk (2009) explored social activism by older Canadian women that implicated later life learning, namely the Raging Grannies in Canada. Despite the heterogeneity among "older women,"

society tends to pathologize them as a part of the “problem” of aging and languishing welfare societies – that is, stereotyped as passive recipients of welfare and healthcare services in Canada (Narushima, 2004). Elderly women can be part of the “answer” to the challenges faced by societies as they have stock of wisdom from indigenous knowledge on strategies, activities, and the process gained from lived experiences through years at work, traveling, and at home (society) (Sawchuk, 2009). Hence activism on ageism led by females dominated the 1970s and 1980s in developed countries like the United States through the Gray Panthers (Ciafone, 2021). Therefore, it furthered the emancipation and representation of old age in US media as correcting ageism. Ciafone (2021) believes that the senior citizens’ movement realized the geographical reach, power, and influence of media and, hence, established their Media Watch Task Force and local committees to monitor media and raise awareness on anti-ageism. They conduct media literacy campaigns and even produce their media content to construct an alternative vision of aging. According to Ciafone (2021), the mid-1980s witnessed a change that was visible even on television as older women appeared as active, successful, sexual beings – like *The Golden Girls* – leading some to ponder whether there was a representational shift on TV, even a “waning devotion to youth.” Ciafone (2021) interprets such to have contributed to the positive reframing of old age overturned portrayals of them as sick, poor, and dependent and contributed to emerging discourses of an old age that could be “successful,” “active,” self-reliant, healthy, and even sexy (ageism).

Based on the social-contemporary trends at community level, ageism can be transformed by establishing the value of choice, dignity, and independence from the senior citizens’ perspectives. Developed countries like Canada still have a mandatory retirement system within the advocacy discourse. That policy debate is monopolized by the premise of “older people” as post-productive service recipients (Sorensen & Black, 2001). Hence, opportunities to utilize the skills and strengths of older people have been limited by structural factors (Sorensen & Black, 2001). In short, older people, regardless of gender, are alienated from the mainstream, while the social roles and cultural meaning of “old age” are neglected (Sorensen & Black, 2001).

Rationale for Advocacy and Activism for Aging Population

No agreed age defines aging as a phenomenon with physiological and social dimensions (Wentzell, 2020; Wiggin et al., 2021); however, various sources are consistent that the minimum years to be considered senior is 50 or above (Wentzell, 2020). Growing older is associated with negative images (Serrat et al., 2021; Wentzell, 2020); these are physiological and social, like retirement from the paid workforce, which may influence changes in earning capacity, status, and involvement in the community (Serrat et al., 2021; Wentzell, 2020). Therefore, ageism has had unfavorable consequences for older people in our society (Serrat et al., 2021; Wentzell, 2020; Wiggin et al., 2021). It generated and reinforced denigration of the aging process and has given rise to negative stereotypes and presumptions regarding the competence of older people and their need for protection (Serrat et al., 2021; Wentzell, 2020; Wiggin et al., 2021). Studies have found that ageism has made it

more difficult for older people to find employment and remain valued members of the paid workforce (Martin, 2018; Serrat et al., 2021; Wentzell, 2020; Wiggin et al., 2021). However, the common perception that workers over 60 years of age are less competent than younger workers is more a myth than reality (Martin, 2018). The chapter attempts to discuss elements of advocacy and activism on aging in the context of aging with disability and disability with aging.

Aging with Disability and Disability with Aging Advocacy and Activism

Viljanen et al. (2021) brought data used in aging advocacy. Their study established challenges posed to healthcare and elderly services as multimorbidity associated with institutionalization. Viljanen et al. (2021) assessed chronic conditions among home-dwelling older people with and without dementia. Viljanen et al. (2021) found that the mean age of the participants ($n = 820$) was 74.7 years. During the follow-up, 328 (40%) were institutionalized. Dementia, mood disorders, neurological disorders, and multimorbidity were chronic conditions associated with a higher risk of institutionalization in all the participants (Viljanen et al., 2021). In people without dementia, mood disorders and neurological disorders increase the risk of institutionalization. This, therefore, implies that risk factors should be recognized when providing and targeting care and support for older people still living at home. The above notion perpetuated institutionalized living as a solution that addressed ageism among senior citizens, thereby bringing the need to explore how disabled people have managed to have a balance in institutionalized and community living from an advocacy perspective, as discussed below. Therefore, it is essential to note that in lessons learned from other population groups, these differences must be contextualized in community living solutions to be considered.

Overview of Advocacy and Activism on Disabled People and Community Living

The present authors used academic and gray literature to show evidence that community living has been part of advocacy and activism which led to its implementation, especially in the United States through the independent living concept, targeting community living of disabled people. In general, advocacy and activism are centered on government-public and private sectors and civil society to uphold the fundamental principles of independent living as (i) control, (ii) choice, (iii) freedom, and (iv) dignity (Doncel-García et al., 2022). It has been documented that the early inspiration for the independent living movement (ILM) was drawn from the African American civil rights movement of the 1950s and the 1960s because of the similarities they share in both discrimination and stereotypes in housing, education, transportation, and employment (Hayman, 2019). Although other social movements such as deinstitutionalization based on the principles of normalization developed by Wolf Wolfensberger, led by service providers and parents of people with disabilities, had been in existence, disabled people led the independent living movement themselves (McDonald & Oxford, 1995). Accomplishments of Independent Living include legislation, control, services, and dignity to individuals. Awareness-raising

communities have been cited as the most significant independent living movement principles accomplishment.

The movement's most significant contribution is that it has given disabled persons a voice in their own future and has fostered a new sense of dignity and pride that for too long has been denied them. This will continue to be its most important contribution in the years to come. (DeJong, 1979)

Indeed, almost two decades later, a Canadian study on the impact of independent living centers on individuals and the community confirmed the spread of independent living centers across the country and impact (Hutchison et al., 1997) where on an individual level, the Independent Living Resources provided a feeling of being empowered, thereby increasing competence and confidence (Lord, 1991) and an increase in community participation (Friedman, 1992).

The Convention was adopted by the United Nations General Assembly on December 13, 2006. As of December 2021, it had 163 signatories and 184 parties, 183 states, and the European Union (United Nations Department of Economic and Social Affairs, 2022). One of the articles that these state countries are obligated to be article 19 on living independently and being included in the community with states: *“States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that: disabled people have opportunity to choose their place of residence, where and with whom they live on an equal basis with others, as they are not obliged to live in a particular living arrangement; neither to have access to in-home, nor residential among other community-based support services, like personal assistance needed to support living, inclusion in the community, prevent isolation and segregation; Community services, and facilities for the general population are available on an equal basis for disabled people as responsive to their needs”* (UNDESA, 2022). Since the first reported independent living center (ILC) in Berkley, in the United States, the country saw an increase to over 400 centers nationally. Other countries like Japan reported over 125 centers; Canada, over 25; Australia over 7; Zimbabwe, 1; and South Africa, 3.

Cases of Advocacy and Activism by Disabled Persons on Community Living

Print Media

In the **United States**, according to Ed Roberts, who is widely known as the father of independent living, the University of California at Berkeley hesitated to admit him when he applied, as he had polio. He managed to get the story out using media and was reluctantly admitted in 1962. In 1972, the Berkeley Center for Independent Living (CIL) was started (John, n.d.).

In 1998, a **Japanese** man born without arms and legs authored the book *No One's Perfect*, which became a third best-selling book a year after publishing and has been noted to have contributed to shaping societies' views toward disability, as expressed by over 10,000 letters that he received from society (Los Angeles Times, 1999).

Public Demonstrations and Protests

On April 5, 1977, disabled people in the **United States** held what was called the 504 sit-ins to demand anti-discrimination regulations on the Rehabilitation Act of 1973, they stayed until May 1 after a review and approval of the regulations, paving way for the Americans with Disabilities Act (New York Times, 2020). The San Francisco contingent of over 100 people entered Health Education and Welfare (HEW) offices and stayed for weeks. In 1978, the rehabilitation act was amended to provide consumer-controlled centers for independent living.

In Japan "Kawasaki Bus Toso" in 1977 emerged after members of Aoi Shiba stopped 78 buses in Kawasaki that had refused to transport passengers using wheelchairs. Aoi Shiba members occupied and lay on the ground in front of buses to protest the denial of transportation. Their defiance was symbolic as the issue of accessibility later played a leading role in the disability movements in Japan (Iwakuma 2011).

On June 27, 2017, demonstrations are still viewed as an effective form of activism; Wheelchair Sports Camp MC Kalyn Hefferman and seven members of the disability rights group American Disabled for Attendant Programs Today (ADAPT) began a sit-in at the US senator's office. The group demanded the senator's vote against the healthcare bill that would replace President Obama's Affordable one; the new measure was scheduled to be voted on that week. During the sit-in, the Senate announced the vote be moved to after the 4th of July (Westword: Activism, 2017). On July 26, 2017, the Senate rejected a proposal to repeal significant parts of the Affordable Care Act without providing a replacement (The New York Times, 2017).

Global United Nations (UN) Observances

In 1983, John Evans left Cheshire Home to live in his own home in a community, which marked the start of the independent living movement in the **United Kingdom**. This change was achieved through a group known as "Project 81" because the United Nations designated International Year for Disabled People (Leeds University, 2003), thereby influencing independent living and deinstitutionalization.

Lawsuits

Attorney John Holland had filed a lawsuit in 1977 on behalf of Atlantis Community against Regional Transportation District (RTD), arguing that approximately one-third of the fleet should be fully accessible to people in wheelchairs. The district court later ruled against Atlantis (Atlantis Community, Inc. v Adams, 1978); Atlantis appealed and settled with RTD, where the transportation agency agreed to retrofit all buses with wheelchair lifts (Hearings Before the Committee on the Judiciary United States Senate, 1996). Congress passed the **Americans** with Disabilities Act in 1990.

Support by Other Organizations, Research, and Position Papers

In 2012 **Moldova**'s government had taken historic steps to move disabled people out of institutions through Regulations HG351 aimed at directing financial resources to community-based care (Open Society Foundations, 2012). Disability organizations in 2020 reported a slow level of deinstitutionalization and provision of social support services. Seven organizations documented a position paper called "Deinstitutionalization of Persons with Disabilities in the Republic of Moldova" (Keystone Human Services, 2020), calling for **European Union** (EU) support for deinstitutionalization in the Republic of Moldova. In 1981, disabled individuals from the **United Kingdom** raised funds to travel to the United States and gain a firsthand understanding of establishing an ILC to replicate in the United Kingdom (Independent Living Institute, 2003).

In 2013, **South Africa**, through a Japanese non-government organization, a Japanese development agency, provided technical and financial support for the development of an ILC in South Africa (JICA, 2013). The process involved supporting South African activists to undergo independent living training in Japan and visit an ILC in Japan and engage with pioneers of the movement. Soon after that, an ILC was established in South Africa. In a South African study on economic costs of disability by the Department of Women, Youth and Persons with Disabilities, the leaders of the ILC reported they had succeeded in arranging for financial support from the Department of Social Development to deploy personal assistants (Department of Women Youth and Persons with Disabilities, United Nations Development Agency, 2022).

Online Workshops

In 2021, the **European** Network on Independent Living hosted webinars on deinstitutionalization to reach a wider global audience and create an opportunity for sharing experiences on independent living and learning globally (ENIL, 2021).

Social Media

National **American** ADAPT Twitter feed has 1700+ followers, with a Facebook page having 1600+ friends. When ADAPT protested Medicaid changes in Washington, DC, in early May, it live-tweeted the proceedings, including about 100 disability activists (Haller, 2011). Since 2009, the Disability Rights Education and Defense Fund (DREDF) has had a YouTube channel with 734 subscribers. One of its videos reached 12,000 views, though this was rare. DREDF's activism primarily takes place in the courtroom and through lobbying and public policy development and has embraced social media (Haller, 2011).

Inclusion International on international disability day in 2021 launched a global report on self-advocates experiences, ideas, and expectations on calling for deinstitutionalization; this video had 428 views at the time of writing of this chapter and was tweeted (Inclusion International, 2021).

In short, disabled people's advocacy and activism on community living was skewed toward independent living through (a) deinstitutionalization, (b) accessible transport, (c) change in attitudes and raising awareness of challenges faced by

disabled people, (d) medical aid policy amendments, and (e) control over funds allocated – over the years taken shape through print media. However, in many countries, public demonstrations seem to have had more significant documented impacts as they drew media attention and that of society; public demonstrations have also been prevalent in recent years. Although we have seen several types of reforms that have followed these activists, this chapter is not intending to suggest a direct correlation. Recently, social media became a common platform for activism as online workshops broadcasted via online platforms such as YouTube channels, live Facebook, Twitter, and closed sessions via virtual meeting tools have been observed. Nonetheless, current authors have not found literature that shows the impact of social media and online activities on this advocacy and activism.

Community Living Advocacy and Activism Opportunities on Aging Population

According to D’cruz and Banerjee (2020), the COVID-19 pandemic exposed the aging population’s institutional living challenges, presenting an opportunity for community living advocacy and activism toward deinstitutionalization of those who wish to live in the community. D’cruz and Banerjee (2020) believe older adults are at disproportionate risk of severe infection and mortality and are vulnerable to loneliness and social exclusion during the pandemic. Age and ageism can act as significant risk factors during the pandemic that increases perceived and actual risk to the physical and psychosocial burden on the elderly (D’cruz & Banerjee, 2020).

Understanding Institutionalized Living’s Setbacks

Doncel-García et al. (2022) acknowledge ageism as being studied extensively in community-dwelling older adults but remains poorly understood in institutionalized older adults. Therefore, they have compared the physical, psychological, and social variables associated with self-reported age-based biases in community-dwelling older adults and those living in nursing homes. Doncel-García et al. (2022) found negative stereotypes of aging and different multidimensional variables. The variables differ between institutionalized and non-institutionalized adults and between men and women (Doncel-García et al., 2022). Doncel-García et al. (2022), as a first comparative study, levels of ageism in older people living in two different social environments provide a framework to combat this type of discrimination. Promising strategies include anti-ageism policies and laws, educational interventions, and increased intergenerational contact to inform advocacy and activism on aging.

Rabuffetti et al. (2022) examined the relationship between age-related factors and postural stabilization performance after a transition movement. They established controlled elements in the experiment as (1) assistance in living (independent living for community-dwelling subjects vs. assisted living for institutionalized subjects in nursing homes) and (2) age of institutionalized individuals by comparing groups with different age ranges. Rabuffetti et al. (2022) found that when comparing age-matched subjects from the two groups, the residents in nursing homes were characterized by a worse stabilization performance: (i) stabilization time more than doubled and (ii) instability increased by 39%.

There was no difference between the two age groups of residents in the nursing homes; however, a potential confounding effect has been identified in the unequal mortality rates between the two groups. Nakagawa et al. (2022) believes that in Asia, particularly Japan, where autonomous decision-making is not traditionally well accepted; little is known about individuals' preferences on where and how they can receive care. Hence, older adults were asked about their desired place of care (facility, home, or other) if confined to bed. Nakagawa et al. (2022) found that individuals' "aging in place" (community living) preferences tend to be considered under the long-term care insurance system; hence individuals' priorities should be shared with families and clinicians when deciding the place of care and as such play a role in advocacy and activism on aging. Noguchi et al. (2022) recruited a study cohort of non-institutionalized older adults from the Japan Gerontological Evaluation Study, established in 2013, and institutionalized older adults. Noguchi et al. (2022) assessed three aspects of community-level social capital (civic participation, social cohesion, and reciprocity). Noguchi et al. (2022) found that living in a community with rich civic involvement and participation in social activities is associated with lower frailty onset among older adults and fosters social participation. Such data are crucial in decision-making and approaches to living arrangements for the aging population.

Lessons from Disability Movement on Community Living – The Independent Living Movement (ILM)

The present authors perceive that advocacy and activism on aging can consider lessons from the ILM. The ILM emerged as an element of the broader disability rights movement in the 1980s and ascribed to the precept that people with even the most severe impairments should have the same choices that every citizen has (White et al., 2010). A primary goal is the right to choose to live independently, using paid personal assistance services, while living in a community, instead of being institutionalized. Independent living advocates for removing all barriers – in public attitudes, transportation, and architecture – that interfere with full community living (White et al., 2010). Eventually, it became a widely accepted model for centers for independent living (White et al., 2010). This, therefore, draws back to the causes for such an approach to be developed, because of shared similarities in experiences between aging population and disabled people, and advocacy and activism seek to bring initiating voices for a change.

Scholars believe the independent living concept was captured in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) because of its position toward enhancing disabled people to live their life "with choices equal to others" (United Nations, 2019). A critical aspect of the ILM philosophy is reframing how we understand disability – from a medical model to a social (or independent living) model (Slasberg & Beresford, 2020). The medical model seeks only to use a medical cure or healing to normalize a person's condition (Slasberg & Beresford, 2020) while ignoring social factors and perceiving disabled people and seniors as lacking and disempowered (DiGennaro Reed et al., 2014). For a long time, the medical model was associated with isolation and segregation

through the institutionalization of societal members because of disability and ageism (DiGennaro Reed et al., 2014).

The chapter identified independent living as a noteworthy preliminary point for aging advocacy and activism to learn and contextualize social innovative ways for their living arrangements. Although advocacy and activism on aging and independent living have numerous common areas of interest, the medical versus social model issue has further unified both groups. Both desire access to independence, dignity, and choice – and their collective activism has moved the system forward. Both groups perceive a need to change the primary legislation to make the resources for independent living a legal right for all (Slasberg & Beresford, 2020). But the activism and advocacy to secure the said assertions may face unknown/fear of perceived lack of incentive, motivation, and interest to have computable costs (Slasberg & Beresford, 2020). Perpetuated ignorance among societal members regarding independent living as costing the government and making funding for social care through a budget cease and move to “open cheque” funding produces unfavorable outcomes (Slasberg & Beresford, 2020).

Framing Aging in Advocacy and Activism for Sustainable and Resilient Community Living

Mah et al. (2021) believe older adults want to live at home if possible, even in circumstances that limit their autonomy. The assertion concurs with DiGennaro Reed et al. (2014) that home care services reflect this emergent preference, allowing older adults to “age in place” in familiar settings rather than receiving care for chronic health conditions or aging needs in an institutionalized environment.

Akosile et al. (2021) believe physical activity (PA), fear of falling (FOF), and quality of life (QOL) are fundamental constructs in geriatrics. The interplay among these constructs may vary between community-dwelling and assisted-living older adults (Akosile et al., 2021). However, studies comparing the well-being of community-dwelling older adults with those residing in assisted-living facilities (ALFs) are rare, especially from developing countries. Thus, Akosile et al. (2021) compared PA, FOF, and QOL between assisted-living and community-dwelling older adults and determined the correlations amongst the constructs for each group. Akosile et al. (2021) found that older adults in the ALFs had lower PA and QOL scores with a higher prevalence of FOF than their community-dwelling counterparts. Akosile et al. (2021) suggest that aging in place (community living) ensures better health outcomes than institutionalized aging. Older adults should be encouraged to age in place rather than move into assisted-living facilities (ALFs).

Marengoni et al. (2021) recruited 2571 community-dwelling older adults grouped at baseline according to their underlying multimorbidity patterns. They followed up for six years to test the association between multimorbidity patterns and institutionalization. Marengoni et al. (2021) found that six patterns of multimorbidity were identified. In total, 110 (4.3%) participants were institutionalized during the follow-up (Marengoni et al., 2021). Marengoni et al. (2021) concluded that older persons

suffering from specific multimorbidity patterns have a higher risk of institutionalization if they lack formal or informal care. Therefore, interventions to prevent the clustering of diseases could reduce the associated burden on residential long-term care. Formal and informal care provision in community living can effectively reduce the risk of institutionalization. The essence of the above paragraphs provides evidence-based support for aging advocacy and activism to enhance the availability of living arrangement choices and relevant support to their lives.

Conceptualizing a Framework Toward Community Living of the Aging Population Informed by Literature Review

Similarities, Difference, and the Interconnection in Disability and Aging Activism

The authors raised advocacy and activism on aging from different dimensions. However, the discussion established that advocacy and activism on ageism share common ground with a disability based on shared stereotyping, marginalization, alienation, and discrimination, which emerged as less prevalent, according to Gelders (2015), in discussions on disability and ageism. Averill (2012) brought a rural perspective on older adults in the rural southwestern United States and identified themes needing action, including sustained access to prescriptions, transportation solutions for older adults in isolated communities, inadequate access to care, poor infrastructure and coordination of services, scarce assisted-living and in-home care for frail older adults, and barriers related to culture and economics. An interconnection is observed in literature as associated to age, gender, sexuality, rural settings which directly and indirectly align to the state of physical access, legislation, transport, access to services, labor, and stigma (see Fig. 2).

Figure 2 summarizes the literature review outcome by presenting themes that support learning from independent living among disabled people for the same approach that needs to be contextualized for older adults living in communities instead of institutions. Therefore, Fig. 2 is an input to the conceptual framework for the said people preferring to stay in their homes and communities to the institutionalized living arrangement.

Conceptual Framework

The findings upheld the development of a conceptual framework based on similar concerns between disabled people and the aging population that may call for advocacy and activism. In addition, traditional solutions resort to institutionalized living arrangements for both population segments in this regard. The literature examined reflects critical analysis on institutionalized living that informed the researchers to bring independent living as a point to learn in community living advocacy for the aging population. Such can be of value if the existing data are utilized to augment the voice of the affected population groups, however, taking cognizance of interconnection, heterogeneity, and socio-economic inequalities. Figure 3 is a conceptual framework derived from the reflection on literature, showing

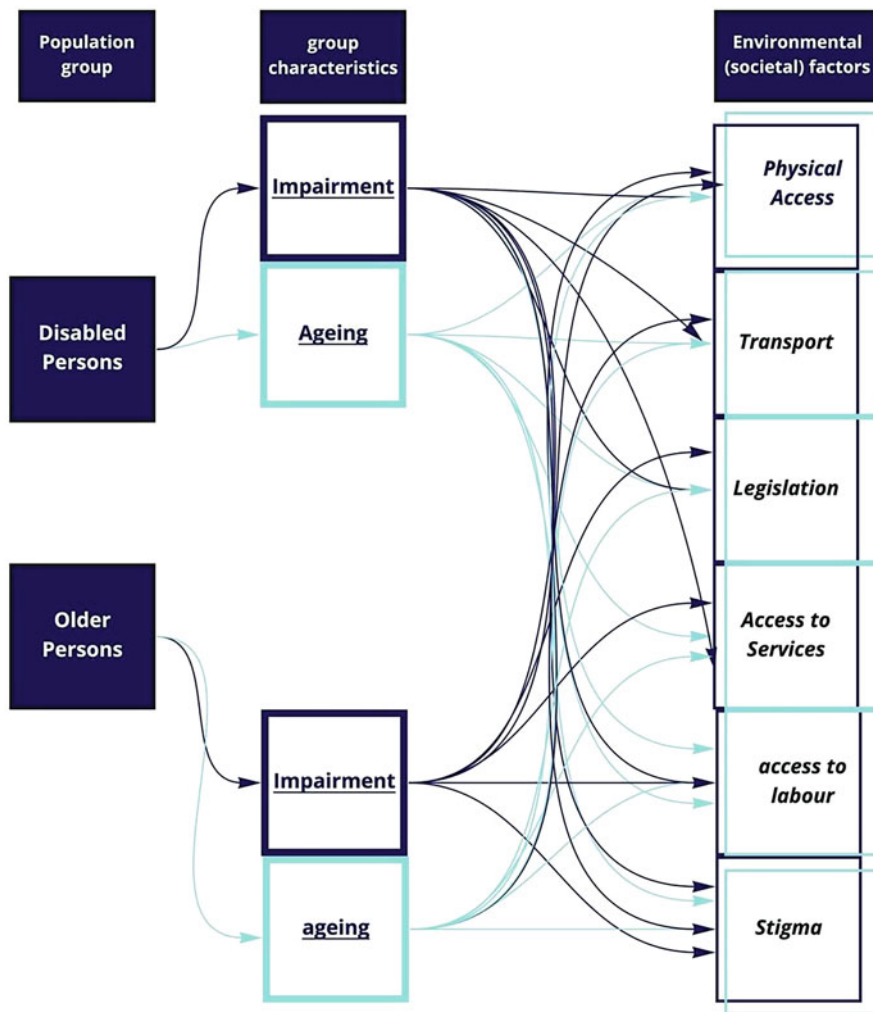


Fig. 2 Disability and aging – the shared similarities and interconnections. Source: Authors’ compilation from literature

critical social how interactive factors perpetuating community living arrangement – independent living, impact the following dimensions: (i) individual, (ii) relationships, (iii) community, and (iv) societal levels. When found in institutionalized living, the said elements compromise choices, control, and involvement in decision-making in the said facets. Nonetheless, the review presents advocacy as an enhancer for a similar evolution in the disability movement, to be part of advocacy and activism for aging citizens, as disabled and aging (disability by aging and aging with a disability included) share a societal (socio-economic) negative image,

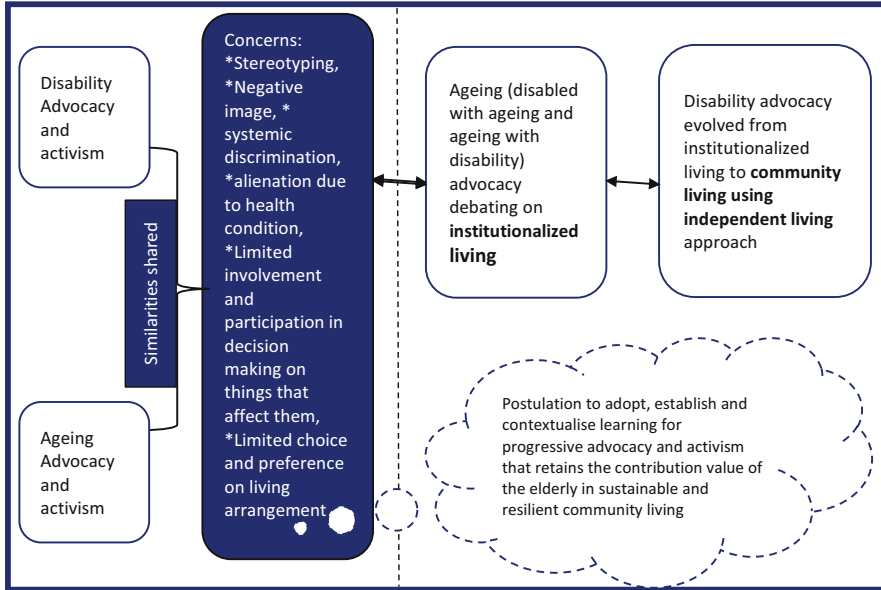


Fig. 3 Conceptual framework toward community living of aging population informed by present literature review. Source: Authors' compilation

stereotyping, and systemic discrimination. Advocacy for independent living regards such people as heterogeneous and hence should have control, choice, decision-making on a preferential living arrangement contextualized to the environment regardless of either growing old or acquiring impairment (see Fig. 3).

Figure 3 presents findings that reflect the need for effort to retain the value of every member of society; however, current solutions contradict this goal. It is clear from findings that costs are reduced with living in communities instead of institutions, coupled with better resilience of health conditions due to improved social interactions. Yet, other countries are undertaking fiscal consolidation reform like their pension systems for cost savings by reducing benefits, while others are in dire need of an increase in the labor force. If advocacy and activism do not use data to inform social action, ignorance and fear of costs on community living will be prevalent.

Conclusion

The chapter presented a consolidation of developed and developing countries' perspectives to enhance and provide the reader with a comprehensive background for understanding current knowledge and highlighting the significance of new research, especially empirical research on addressing interconnecting categories of the aging population beyond impairment characteristics but gender and other factors

depending on context. This implies for an aging population to benchmark on independent living movement through, for instance, making plans for physical visits to other centers globally or locally. The chapter encourages the aging population to spearhead activism and advocacy for their voice to be directed to stakeholders like policy-makers while correcting the image stereotyping among other societal members for greater social cohesion in developed and developing countries.

The chapter looked at the *critical thinking around institutionalized and independent living arrangements that can enhance sustainability and resilience in community living arrangements*, where it became clear that ageism, advocacy, and activism on aging share a similar image, stereotyping, marginalization, alienation, and systemic discrimination in line with access and availability of choice and preferences on living arrangements. For freedom of choice, institutionalized living does not have to be eliminated, however solutions towards independence of the aging population should consider their right to choose to participate in the community, and foster innovation due to the value from their experience, wisdom and human capital stock accumulated throughout their life stages. The involvement of senior citizens can enhance a sustainable and resilient community that can exploit the value of aging, which comes with indigenous knowledge systems in addressing life challenges. However, advocacy and activism are vital in changing attitudes (perceptions) and behaviors toward the aging population while considering contextual factors, inter-connection, and the choice of the older adult involved.

The aging population's predetermined inclusion and exclusion are influenced by perceived value and perceived costs. However, in addressing issues of sustainability raised by others such as economists, though others have adopted the "working longer agenda," this may not be attained if an enabling environment freely chosen by the aging population is not created. The chapter highlighted challenges posed by environmental barriers that force aging with disability and disability with aging population segments into institutionalized living arrangements. Nonetheless, developed countries have focused on aging and ageism activism and advocacy from the legislative, self, and group to civic dimensions. This contrasts with developing countries, as the two fraternities have different average life expectancy and socio-economic fabric. In addition, governments are undertaking fiscal consolidation reform like their pension systems for cost savings by reducing benefits, thereby concluding that the aging population prefers to stay in their homes and communities, hence the need for social innovative advocacy and activism, instead of moving to institutions for those who choose to live and participate in the community.

In attempting to address concerns on *how movements led by disabled persons bring social innovation on activism and advocacy for sustainable and resilient community living arrangements for the aging population groups*, the chapter concludes that the disability movement has demonstrated to have a long historical movement aimed at deinstitutionalization and providing choice for living arrangements for disabled people. This group has experience in advocacy and activism geared particularly toward calling for community living, followed by international treaties and legislative reforms, not only on social services and the economic participation of disabled people through employment quota policies and systems

and changes in programs and social services. The concept of independent living used by disabled people provides insights for socio-economic innovation in advocacy and activism for the aging population as they share similarities. Such contemporary platforms like social media can be of use to the movements led by aging people while consequently playing a role in shaping advocacy, activism, and implementation of standards set by international organizations.

In addressing *what can be learned from each population group's advocacy to the others for adoption toward sustainable and resilient community living arrangement while enhancing socio-economic activeness of the population mentioned above groups*, in both population groups, it became clear that unless advocacy emerges from the affected parties, decision-makers' ignorance can be perpetuated due to a lack of lived experience-based opinions (voice). Therefore, just as in history, an aging population has demonstrated the capability to advocate for their issues. Hence, the calls for community living should be led by them. Lessons from the disability movement can be considered as the independent living concept is applied in over 500 independent living centers globally. Although there are fewer studies on the impact of independent living centers, those conducted have demonstrated impact on the community and individuals. Guidelines and handbooks on establishing these IL centers already exist in line with the general comments on article 19 on living independently and being included in the community by the Committee on the Rights of Persons with Disabilities in 2017, emphasizing self-representation. However, the existing data are not sufficiently utilized to inform activism and advocacy on aging, causal effects, and impacts of institutionalized living arrangements, and what socio-economic participation could change if community living is enhanced. The chapter was limited because it was developed from desk-top research; hence the authors recommend further empirical research, a longitudinal study that samples developed and developing countries.

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