Ageing with a Disability: Care Arrangements and Support Needs in Contemporary Ghana

Augustina Naami¹ & Abigail Adubea Mills¹

¹Department of Social Work, University of Ghana

Abstract

The population of older people is increasing globally, and it is expected that in Africa, the population of older persons would increase from 69 million in 2017 to 226 million by 2050. The United Nations estimates that over 46 per cent of older persons have disabilities, the majority of whom experience moderate to severe disability. Given the increasing trends of older people and the vulnerability of older people to a disability, the population of persons with disabilities could increase. Ghana is yet to develop holistic measures that could adequately address the needs of both persons with disabilities and older people as distinct groups, and uniquely for older persons with disabilities. For example, although the Persons with Disability Act was passed in 2006, a legislative instrument has not yet been developed to operationalize the Act, nor has the Act been harmonized to align with international laws. Persons with disabilities in Ghana face many barriers to full and equal participation in society, including stigma, discrimination, physical and information barriers. On the part of older persons, although there is the National Ageing Policy (2010), more work is required to enforce its implementation to give older persons in Ghana a better quality of life. Undoubtedly, age-related challenges could adversely worsen the plight of older persons with disabilities. Guided by the theory of intersectionality, the life-course theory of ageing, and the social model of disability, content analysis and personal conversations, this paper explores the vulnerabilities and needs of older persons with disabilities in Ghana and provides recommendations to address their unmet needs.

Corresponding author: anaami@ug.edu.gh

Introduction

Globally, more than forty-six per cent of older persons have disabilities; and more than 250 million older people experience moderate to severe disability (UNDESA, 2021). The United Nations (2015) report on population suggests that the number of older persons continues to increase in most countries and regions, and this growth is expected to accelerate in the coming decades. In Africa alone, the population of older persons is projected to increase from 69 million in 2017 to 226 million by 2050 (UNDESA, 2021), with many of them living in West Africa (Ayete-Nyampong, 2015). The number of elderly persons in Ghana is also rapidly increasing and is likely to witness the most rapid rise in the population of older adults in the West African sub-region (Ayete-Nyampong, 2015). Since older people are susceptible to acquiring a disability, this has implications for the population dynamics of persons with disabilities (PWDs) as well. Consequently, the population of persons with disabilities could increase, given the increasing trends of older people. Meanwhile, the inclusion of PWDs continues to be challenging, especially in Ghana due to prevailing negative social-cultural beliefs and perceptions leading to stigma and discrimination; as well as inaccessibility/limited access to the physical environment, transportation, and information (Badu, Agyei-Baffour & Peprah, 2016; Mills, 2018; Naami, 2019; Naami, 2015; Tijm, Cornielje, & Edusei, 2011).

Furthermore, in Ghana, whereas families have historically been the major sources of support for their vulnerable members, there is growing evidence that kinship care is declining due to modernization, urbanization, and migration (Dako-Gyeke, 2014), and to make matters worse, research suggests that PWDs are receiving less support from their families because of stigma and discrimination (Naami & Liese, 2012). These dynamics have implications for the extent of familial care and support that older persons with disabilities could receive, being one of the vulnerable populations in Ghana.

The population of older persons with disabilities are arguably an important subpopulation whose needs ought to be assessed (McCausland et al., 2010), in view of the multiple vulnerabilities they experience stemming from the intersection of old age and disability. Some existing studies report on various deprivations among older persons with disabilities, including social relationships, information, healthcare, basic literacy and numeracy skills, personal activities, and material well-being (McCausland et al., 2010; Mitra et al., 2020; Strydom et al., 2005). Other studies assert that the occurrence of disability has implications on the quality life of older people (Calmels et al., 2003; Peruzza et al., 2003); while other research indicate that older people with disabilities may have poor perceptions about their health levels (Johnson & Wolinsky, 1993), thereby increasing their dependence on indoor life (Inoue & Matsumoto, 2001).

Ghana is yet to develop holistic measures that could adequately address the needs of both persons with disabilities and older people as distinct groups, and uniquely for older persons with disabilities. For example, although the Persons with Disability Act was passed in 2006, a legislative instrument has not yet been developed to operationalize the Act, nor has the Act been harmonized to align with international laws. On the part of older persons, although there is the National Ageing Policy (2010), more work is required to enforce its implementation to

give older persons in Ghana a better quality of life. Undoubtedly, age-related challenges could adversely worsen the plight of older persons with disabilities, thereby requiring conscious and concerted efforts to provide better living conditions for older persons with disabilities. In summary, as the number of older persons continues to increase worldwide, so would the population of older persons with disabilities. Older people with disabilities would require unique care arrangements and support to mitigate the compounded vulnerabilities that the intersection of ageing and disability present.

Guided by the theory of intersectionality, the life-course theory of ageing, and the social model of disability, content analysis and personal conversations, this paper explores the vulnerabilities and needs of older persons with disabilities in Ghana and provides recommendations to address their unmet needs.

Definition of terms

- In this paper, persons with disabilities (PWDs) reflects the persons first language and the definition by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full-effective participation in society on an equal basis with others" (p. 4).
- Older adults are those who are 60 years and above. Sixty years in the retirement age in Ghana.

Theoretical Framework

The theory of intersectionality, the life-course theory, and the social model of disability guided this study. In combining these theories as a framework for the study, it is anticipated that issues resulting from the interaction of disability and ageing would be highlighted.

The theory of intersectionality was proposed in 1989 by a feminist legal scholar, Kimberle Crenshaw, who argued that single categorization of discrimination based on race, gender or any minority groupings could systematically omit the experiences of the more vulnerable groups. The proponents of intersectionality call for a re-examination of the definition of oppression to include the experiences of those who fall within multiple categories of vulnerabilities, such as ageing and disability. Exploring the intersection of ageing and disability is critical, as older persons with disabilities could experience vulnerabilities which stem from both the disability and old age. For example, aged individuals with disabilities will have significant health and financial problems commonly related to age, which require the support of additional services and resources, or which require the services of caregivers (Larkin et al., 2003). Unfortunately, professionals in ageing often lack knowledge about disability issues, while professionals in the field of disability often know little about ageing. Furthermore, intersections of ageing, disability, and factors such as gender, socio-economic status, presence, or absence of family support ought to be explored to comprehensively understand the lived experiences of older persons with disabilities in Ghana, and to understand the nexus at with care arrangements and supports should be developed.

Another lens through which this study seeks to understand the needs, opportunities, and challenges of older people with disabilities is the life-course perspective. The major tenets of the life-course perspective are that people's lives are unveiled over time, and that circumstances and events which occur in previous stages of life have lasting effects later in life (George, 2019). For example, acquiring a disability at an early age in life has long-term implications for the individual at the various phases of his or her life. This perspective examines developments in a person's life extending from birth to death (Komp, 2016). Inarguably, the risk of acquiring various kinds of impairments increases as people grow older (Jeppsson Grassman & Whitaker, 2013) and coupled with events in people's lives and the decisions they make, these events usually have a bearing on one another (Komp, 2016). Since individuals are exposed to different opportunities, constraints, and preferences (Komp, 2016), experiences of marginalization or discrimination would vary from one person to another. For instance, people who acquired disabilities earlier in their lives would have different lived experiences from those who acquire disability because of ageing. These are nuances that the study seeks to explore in connection with the unique care needs and supports required by older persons with disabilities in Ghana.

Additionally, the study employs the social model of disability to help appreciate barriers and facilitators in the Ghanaian society which create disabling environments for older persons with disabilities. Disability, according to the social model, is all the things that impose restrictions on people with disabilities, ranging from individual prejudices to institutional discrimination, from inaccessible public buildings to unusable transport systems, and so forth (Oliver, 1996). For example, while there might undeniably be physiological conditions which would require medical interventions, "empirical research on the role of the workplace, community, social networks, and cultural attitudes and beliefs is increasingly demonstrating the significant role that the environment plays in shaping life experiences of people

with physical impairments" (Putnam, 2002, p. 804). According to Putnam (2002), the social model of disability is useful in helping to make clear distinctions between physical impairment which is a personal characteristic; functional limitation, which refers to the person's ability to perform an activity regardless of the situational context; and disability, which is the situational variable. The social model of disability therefore highlights how an inaccessible environment for example, creates a disability for an individual with a physical impairment, thereby removing the responsibility of participation or otherwise from the person. The experiences of older persons with disabilities will be explored through these lenses as well to help understand their lived experiences in relation to the environments they live in.

Using the theory of intersectionality, the life-course perspective and the social model of disability, the experiences of older persons with disabilities will be explored to draw out societal and environmental barriers which impact older persons with disabilities in Ghana and the opportunities available for designing and developing lasting interventions.

Method

Content analysis and personal conversations were utilised in this study. The researchers held conversations with two individuals, a social worker, and a service provider. For the content analysis, 15 organisations were sampled from three sources (1) google search for agencies providing services for the elderly in Ghana, (2) the database of the field practicum of the Department of Social Work of one of the universities, and the Centre for Ageing Studies at the University in Ghana. All the organisations were private. Out of this number, a third (n=5) were non-governmental organisations (NGOs), and the rest were for-profit. Out of the NGOs providing elderly care, one agency operates from a foundation borne out

of corporate social responsibility. The rest depended on the generosity of philanthropists and volunteers to provide free care for the elderly. Ten of the agencies operate for-profit, but none of them was accredited to accept payment under the National Health Insurance Scheme (NHIS), which aims to guarantee access to healthcare for all Ghanaian residents.

Results

The results indicate that there were no systematic and coordinated care arrangements for elderly persons in Ghana, although private and government agencies provided services.

Private services

The study revealed that home care, healthcare, respite care, transportation, and other services were provided by the private agencies sampled. Both the NGOs and for-profit agencies provided home care. However, home care services provided by the NGOs were basic services to help the elderly manage life at home. These services included personal care, homemaking, and home management, which were identified as challenging for the elderly because of the decline in functional ability and health issues (Braimah & Rosenberg, 2021). Besides the above home care services, the for-profit agencies offered recovery home care, live-in, sleep-in, live-out and waking night services and day care services. Trained specialists provided homecare services offered by the for-profit agencies, including nurses and other professionals, whilst many NGOs engaged volunteers.

Also, healthcare services provided were geared toward the physiological well-being of the elderly consistent with the lifecourse theory (George, 2019). The NGOs mostly organised occasional free medical screening and medication for the elderly. They also assisted elderly persons with their hospital appointments and other medical-related errands. The for-profit agencies provided a range of healthcare services, including inhospital personal care, home care/nursing services and recovery care at home services, medication administration, monitoring, and other healthcare services such as physiotherapy.

Given that most Ghanaians 60 years and over live in poverty (Gyasi, Phillips, & Buor, 2020) and not all of them are eligible for the NHIS (Braimah & Rosenberg, 2021, WHO, 2014), it implies that few of them could afford healthcare services provided by for-profit organisations. Similarly, the association of disability and poverty is emphasised in the literature (Mitra, Posarac & Vick, 2012; Mizunoya & Mitra 2012, WHO, 2011) and not all persons with disabilities are covered under the NHIS (Naami & Nfoafo-M'Charty, 2020). Therefore, the intersection of disability and ageing could complicate the healthcare experiences of elderly persons with disabilities.

Further, the results suggest that respite care is mostly provided by for-profit agencies. This type of service offers temporal home or institutional care for the elderly, providing relief for their usual carers. Respite care is an essential service for families of elderly persons because it enables them to engage in other things while care is provided for their loved ones. Also, elderly persons can mingle with their peers, thereby reducing the isolation or boredom that characterises their experiences (Braimah & Rosenberg, 2021). Further, it is noteworthy that three agencies, one NGO and two for-profits, provided residential services. However, the duration of this service was unclear, (i.e., short, or long term. Disability and ageing based poverty could impact the experiences of older adults with disabilities.

In addition, two for-profit agencies indicated they provided transportation services for the elderly. Transportation is important for everyone (Naami, 2019), most especially for the elderly, who have reduced ability to drive because of the decline in physiological functioning, increase diseases, the need for regular hospital visits, and to run their errands (Aboderin & Beard, 2015; Braimah & Rosenberg, 2021; Mudege & Ezeh, 2009). Out of the two agencies, only one was specific about the service provided; aiding elderly persons to run errands, go for regular hospital appointments, or engage in activities of their choice. The lack of transportation services for older persons could add a layer of vulnerabilities to those with disabilities since most public transportation systems are inaccessible (Naami, 2019; Tijm et al., 2011). Persons with disabilities mostly rely on taxis and other private services (Naami, 2019).

It is worth mentioning that only two out of the 15 agencies indicated that they provided services for persons with disabilities, and they are both for-profits. However, their target is not older persons with disabilities who have lived with disabilities for most or all their lives. Their focus is on age-related illnesses such as Alzheimer's, Dementia and Parkinson's disease and developmental disabilities (e.g., learning disability, Autism, Asperger's, and Global Developmental Delay).

Government services

Government services for elderly persons are few; NHIS and Livelihood Empowerment Against Poverty (LEAP). The National Health Insurance Scheme (NHIS), which was established from the National Health Insurance in 2003 under Act 650 guarantees free access to healthcare for the elderly by exempting them from paying premiums under the exempt category; "pregnant women, indigents, categories of differently-abled persons determined by the Minister responsible for Social Welfare, persons with mental disorder, Social Security and National Insurance Trust (SSNIT) contributors and SSNIT pensioners, persons above 70 years of age (the elderly) and other categories prescribed by the Minister" (Government of Ghana, 2020, p 20). There is evidence that not all older persons are eligible for the NHIS, and not many health problems are not covered (Braimah & Rosenberg, 2021, WHO, 2014). Likewise, not all persons with disabilities benefit from the NHIS neither are their mobilities aids covered (Agyire-Tettey et al., 2019; Naami & Nfoafo-M'Charty, 2020). The intersection of disability and ageing could complicate the experiences of older adults with disabilities.

The Livelihood for Empowerment Against Poverty (LEAP) programme is a cash transfer social protection programme (Government of Ghana, 2020). LEAP benefit is an area of concern as the floor benefit (GHC64, approximately US\$10.35) seems woefully inadequate to address the needs of the elderly. The eligibility criterion "person with a severe disability with no productive capacity" also means that the LEAP does not cover all persons with disabilities who are poor (Agyire-Tettey et al., 2019; Naami & Nfoafo-M'Charty, 2020). A personal conversation with Madam Kay, a social worker (A. Kay, personal communications on March 5th, 2022), indicates that older persons with disabilities may benefit from the District Assembly Common Fund (DCAF) for persons with disabilities. The DCAF is the only social protection programme that specifically targets persons with disabilities to minimise poverty, especially for those in the informal sector (National Council of Person with Disabilities, NCPD, 2010). Madam Kay stated that a key family member of the older person with a disability is empowered with an incomegenerating activity to enable them to provide for the older person with a disability.

Conclusion and recommendations

Older persons with disabilities would require unique care arrangements and support to mitigate the compounded vulnerabilities that the intersection of ageing and disability presents. However, as evident in the findings, there is no specific intervention geared towards elderly persons with disabilities. There is a need to conscientiously make provisions for the elderly persons with disabilities to provide for their unique needs arising from the intersection of ageing and disability. Considering this, we recommend the following interventions: medical care, home and daycare services, a government unit to coordinate issues of the elderly with disabilities, inclusion in decision making and future research.

Medical care

Given the high disability/health-related expenses (World Health Organization, 2016) and expenses relating to ageing (Aboderin & Beard, 2015; Braimah & Rosenberg, 2021; Mudege & Ezeh, 2009), it is recommended that the government support the health expenses of elderly persons with disabilities. This could reduce the burden of care for older adults with disabilities and their families and poverty among elderly persons with disabilities. The government could also establish hospitals or units in existing hospitals that could address the special needs of the elderly arising from old age and disability. The specialisation of care for the elderly, just as for children (paediatrics) could help address age-related health challenges which general practitioners cannot adequately manage (Ashirifi, Karikari, & Adamek, 2022).

Homes and day care services

Public or public-private partnership daycare centres are necessary for elderly persons with disabilities. The two personal conversations suggested that this intervention could engage the elderly, especially those with disability whose experiences over the life course is characterised by stigma and discrimination (Avoke, 2002, Naami, 2015; Ocloo, 2005; Slikker, 2009) and the prevalence of neglect of the elderly persons due to several factors including urbanisation/migration/poverty breakdown of the family system (Dako-Gyeke, 2014; Kpessa-Whyte & Tsekpo, 2020; Mudege & Ezeh, 2009). The state has one institution for the elderly and other vulnerable people in the Ashanti region of Ghana, the Bekwai Destitute Infirmary. The infirmary is said to be in a deplorable state (Joy News, 2018). Should this institution be revamped and staffed with interdisciplinary professionals to address the needs of elderly persons with disabilities?

Government unit to coordinate issues of the elderly with disabilities

A unit to coordinate all services for elderly persons with disabilities is necessary given the numerous barriers that they encounter daily. Wrap-around services could minimise the daily struggles of elderly persons with disabilities relating to inaccessibility/limited access to the physical environment, transportation, and information (Badu, Agyei-Baffour & Peprah, 2016; Mills, 2018; Naami, 2019; Naami, 2015; Tijm, Cornielje, & Edusei, 2011).

Inclusion in decision making

Elderly persons with disabilities must be included in decision making, especially those that concern them. This is because they are expert knowers of their lived experiences and could best help design interventions that could address their needs. Stakeholders must make efforts to ensure that elderly persons with several types of disabilities, including women, are part of the decision making to help identify their unique needs and facilitate interventions that could effectively address those needs.

Future research

More research is required to understand the dynamics of the unique daily experiences of older persons with disabilities. Understanding their experiences relating to family life, healthcare, social relationships, material, and psychological well-being could enable social workers and other stakeholders in Ghana to position themselves to embrace the challenge and collaborate to improve the lives of older persons with disabilities in the country.

References

- Aboderin, I. A., & Beard, J. R. (2015). Older people's health in sub-Saharan Africa. The Lancet, 385(9968), e9-e11.
- Agyire-Tettey, E. E, Naami, A., Wissenbach, L & Schädler, J. (2019). Challenges of inclusion: Local support systems and social service arrangements for persons with disabilities in Suhum, Ghana: Baseline study report. University of Siegen: Germany. Retrieved March 1st, 2022 from, https://dspace. ub.unisiegen.de/bitstream/ubsi/1486/2/Challenges of Inclusion ZPE 52.pdfhttp://dx.doi.org/10.25819/ubsi/33
- Ashirifi, G. D., Karikari, G., & Adamek, M. E. (2022). Prioritizing the national aging policy in Ghana: Critical Next Steps. Journal of Aging & Social Policy, 34(1), 127 144.

- Avoke, M. (2002). Models of disability in the labelling and attitudinal discourse in Ghana. *Disability & Society*, 17(7), 769-777.
- Ayete-Nyampong, S. (2014). A study of pastoral care of the elderly in Africa: An interdisciplinary approach with focus on Ghana. Author House.
- Badu E, Agyei-Baffour P, Peprah Opoku M (2016). Access barriers to healthcare among people with disabilities in the Kumasi Metropolis of Ghana. *Canadian Journal of Disability Studies*, *5*(2), 131–151.
- Braimah, J. A., & Rosenberg, M. W. (2021). "They do not care about us anymore": Understanding the situation of older people in Ghana. *International Journal of Environmental Research and Public Health*, 18(5), 2337.
- Dako-Gyeke, M. (2014). Future direction of the social work profession. In C.A. Sottie, M. Dako-Gyeke & J.N. Walls (Eds.), *Social work in a changing world*. Social Sciences Series, 7, pp. 185-188. Woeli Publishing.
- Ghana Government. (2004). *National health insurance regulations* (*LI 1809*). Ghana Publishing Corporation.
- Government of Ghana. (2020). National health insurance scheme. Retrieved March 2020, from http://nhid.gov.gh/membership.aspx
- Gyasi, R. M., Phillips, D. R., & Buor, D. (2020). The role of a health protection scheme in health services utilization among community-dwelling older persons in Ghana. *Journals of Gerontology: Series B*, 75(3), 661–673.https://doi.org/10.1093/geronb/gby082

- Human Rights Watch. (2017). Ghana 2012 human rights report. Retrieved May 15, 2017, from https://www.state.gov/ documents/organization/204336.pdf
- Joy News. (2018). Deplorable conditions at the Bekwai Infirmary in Ashanti Region. Retrieved January 11, 2023, from https:// www.facebook.com/JoyNewsOnTV/videos/bekwaiinfirmary/275552233038222//
- Kassah A. K (2008). Disabled people and begging justifications in Accra-Ghana. Disability & Society, 23(2), 163-170.
- Kpessa-Whyte, M., & Tsekpo, K. (2020). Lived experiences of the elderly in Ghana: Analysis of ageing policies and options for reform. Journal of Cross-Cultural Gerontology, 35(3), 341-352.
- McCausland, D., Guerin, S., Tyrrell, J., Donohoe, C., O'Donoghue, I., & Dodd, P. (2010). Self-reported needs among older persons with intellectual disabilities in an Irish community-based service. Research in Developmental Disabilities, 31(2), 381-387.
- Mills, A. A. (2019). Inclusive education for children with intellectual disability in Ghana: Challenges and implications for social work. Advances in Social Work, 19(2), 329-348. http:// doi:10.18060/22539.
- Mills, A. A. (2018). Natural or supernatural: Beliefs about the causes of intellectual disability in Ghanaian society. Review of Social Studies (RoSS), 5(2), 23-38.
- Mizunoya, S., & Mitra, S. (2013). Is there a disability gap in employment rates in developing countries? World Development, 42, 28-43.
- Mudege, N. N., & Ezeh, A. C. (2009). Gender, aging, poverty, and health: Survival strategies of older men and women in Nairobi slums. Journal of Aging Studies, 23(4), 245 257. Time and Chance. (2022). All services. Retrieved from http://www.tcapc.org

- Naami, A. (2019). Access barriers encountered by persons with mobility disabilities in Accra, Ghana. *Journal of Social Inclusion*, 10(2), 70–86. https://josi.org.au/articles/abstract/149/
- Naami, A. & Mfoafo M'Charty, M. (2020). COVID-19: The vulnerabilities of persons with disabilities in Ghana. *African Journal of Social Work, 10*(3), 9-16.
- Naami, A. (2019). Access barriers encountered by persons with mobility disabilities in Accra, Ghana. *Journal of Social Inclusion*, 10(2), 70–86. https://josi.org.au/articles/abstract/149/
- Naami, A. (2015). Disability, gender, and employment relationships in Africa: The case of Ghana. *African Journal of Disability Studies,* 4(1), 1-11. file:///C:/Users/tina/Downloads/95-2186-1-PB%20 (1).pdf
- Naami, A., Hayashi, R., & Liese, H. (2012). The unemployment of women with physical disabilities in Ghana: issues and recommendations. *Disability & Society*, 27(2), 191-204.
- Mitra, S., Posarac, A., & Vick, B. C. (2011). Disability and poverty in developing countries: A snapshot from the world health survey. *World Bank social protection working paper*, (1109). Retrieved from http://www-/wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2011/06/16/0036194_20110616042613/Rendered/PDF/625640NWP0110900PUBLIC00BOX3614 B.pdf
- Ocloo, M. A., Mottey, D. A., & Boison, C. (2005). Comprehensive study notes on special education. *Salt and Light*.
- Slikker, J. (2009). Attitudes towards persons with disability in Ghana of persons with disability in Ghana. Retrieved May 19, 2017, from www.gfdgh.org/VSO%20Attitudes%20towards%20PWDS%20in%20Ghana.pdf

- Tijm M.M, Cornielje H, Edusei A.K (2011). 'Welcome to my life!' photovoice: Needs assessment of and by persons with physical disabilities in the Kumasi metropolis, Ghana. Disability, CBR and Inclusive Development, 22(1), 55-72.
- United Nations Department of Economic and Social Affairs, UNDESA, (2021). Ageing and disability. Retrieved September 24, 2021, from, https://www.un.org/ development/desa/disabilities/disability-and-ageing.html
- United Nations (2015). The World population prospects: 2015 revision. Retrieved May 23, 2020, from https:// www.un.org/en/development/desa/publications/worldpopulation-prospects-2015-revision.html#:~:text=The%20 current%20world%20population%20of,2015%20 Revision%E2%80%9D%2C%20launched%20today
- World Health Organization. (2015). Ghana country assessment report on ageing and health. World Health Organization.
- World Health Organization. (2011). World report on disability. Retrived June 17, 2017 from, http://www.who.int/ disabilities/world report/2011/report.pdf
- Organization. (2010). Community-based World Health CBR guidelines. In Community-based rehabilitation: rehabilitation: CBR guidelines (pp. 67-67).