

Research in Brief



Issue No 2023-10

Publication Date October 20 2023

ISSN 2092-7117

Building D, 370 Sicheong-daero, Sejong City 30147 KOREA **Korea Institute for Health & Social Affairs**

The Direction for Disability Care in Times of Endemic Covid-19: Lessons from the Pandemic¹⁾

Juhee Hwang

Research Fellow, KIHASA

The Covid-19 pandemic has brought on significant changes in the lives of both non-disabled people and individuals living with disabilities. Throughout and following quarantine, screening, self-imposed isolation, or testing positive for the virus, people with disabilities, in particular, have experienced unequal access to and exclusion from response resources, along with anxiety and depressive symptoms at varying degrees depending on their functional limitations, as well as a higher burden of care on their families. Disability care has been recognized as crucial not only for people with disabilities, who rely heavily on it in much of their daily life, but also for their families. This study assesses the limitations of the current disability care system and, in light of how the system fell short during the pandemic situation in Korea and by drawing lessons from how the UK and the US responded to the needs of people with disabilities during the height of Covid-19, proposes the direction in which Korea should be going. Disability care in these times of endemic Covid-19 should be structured in a way that promotes, with a focus on “locality,” flexible community-led care and the participation of disabled community members themselves.

.....

1) This is an abridged reworking of *Diagnosis and Challenges of Community-Based Care Services for the People with Disabilities in the Post-COVID-19 Era* (2022) by :Chapter 3 of *A Study on the Causes of Changes in Income Distribution and the Effect of Income Security for Persons with Disabilities* (2022), by Ukchan Oh, Wonjin Lee, and Dawon Um.



Introduction

The Covid-19 pandemic in its wake has exposed the importance of care for people living with disabilities. Disabled people rely on care in much of their daily lives, which has made them more vulnerable in the pandemic situation. The significance of disability care has grown further as the impact of the pandemic has extended into families with disabled members.

By the end of 2022 in Korea, there were a total of 2.65 million people—or 5.2 percent of the national population—registered as disabled, among whom 32.1 percent were identified in a survey as needing assistance with some or all of their daily activities.²⁾ The demand for disability care is expected to increase over time with the aging of, and the increasing share of one-person households among, the population with disabilities.

The spread of an infectious disease like Covid-19 results in a deterioration of the ecosystem, which in turn raises the possibility of another pandemic. Therefore, it is necessary to explore the direction in which Korea’s disability care system should move as we face the increasing likelihood of pandemics in the future.

This study examines ways in which Korea’s disability care fell short in the pandemic situation and how the US and the UK responded to disability care needs while in the grip of the pandemic, and thereby suggests the future direction for the care system to go beyond its current limitations.



Limitations of disability care as revealed in covid-19 situations

In a crisis situation, disabled people suffer more difficulties than they typically do because of their disabilities. The covid-19 pandemic has revealed the vulnerability of people with disabilities all the more clearly. People with disabilities across the world have experienced unequal access to and exclusion from response resources during and after quarantine, screening, self-imposed isolation, or testing positive for the virus.³⁾ Many countries, including Korea, have implemented measures to provide emergency relief to their citizens during Covid-19 lockdowns. However, the lack of preparedness in government emergency assistance meant that disabled people did not have proper access to information and broadcast messages about purchasing daily necessities, receiving public quarantine supplies, following social distancing measures, getting screened, and receiving treatment. People with disabilities were left particularly vulnerable when it came to support provided for hospitalization after testing positive for

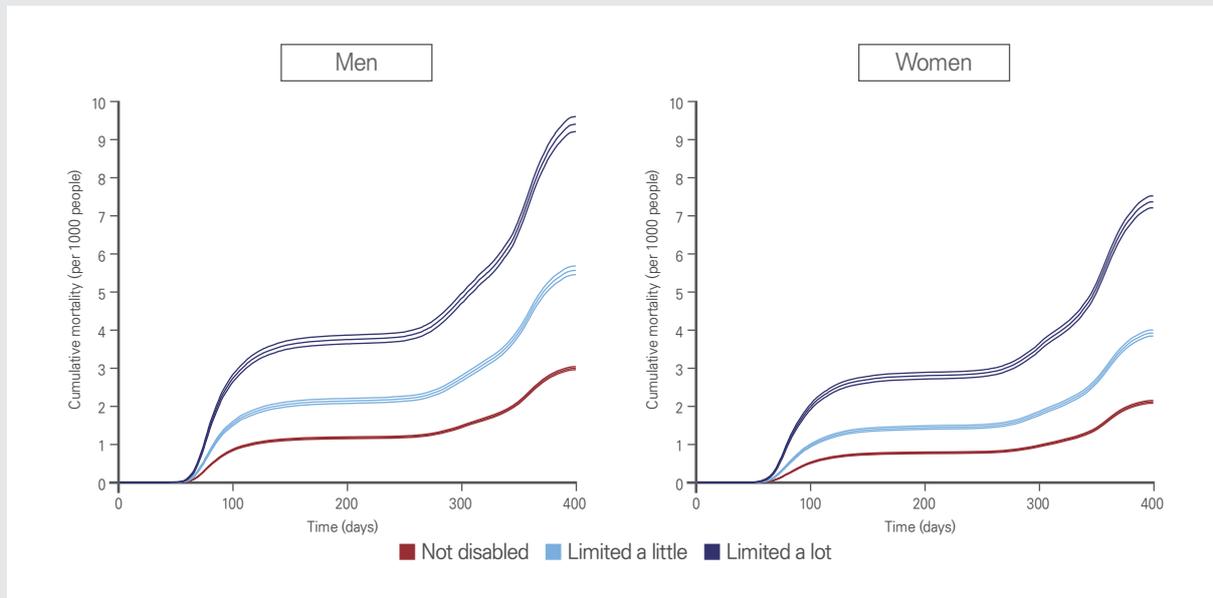
2) Ministry of Health and Welfare. The National Survey of Disabled Persons 2020. (2021).

3) Sabatello, M., Burke, T. B., McDonald, K. E., & Appelbaum, P. S. (2020). Disability, ethics, and health care in the COVID-19 pandemic. *American Journal of Public Health*, 110, 1523-1527; Jeon, Geun Bae. (2020). COVID-19 and the Lives of Disabled Persons: The Current Status and Countermeasures. *Journal of Critical Social Welfare*, 68, 173-207

Covid-19.⁴⁾ In a survey conducted in 2021 by the Ministry of Health and Welfare, people with disabilities reported reduced life satisfaction after covid-19, citing declined health levels and increased loneliness, anxiety, and depressive symptoms, as well as difficulties associated with care disruption and having hard time accessing information.

In the UK, disabled people have been found to be two to four times more likely than non-disabled people to die from Covid-19, depending on sex and the severity of the disability, with mortality increasing with the degree of functional limitation.⁵⁾ By comparison, disabled people in Korea are six times more likely than non-disabled people to die from Covid-19.

[Figure 1] Covid-19 mortality rates for England, by disability severity and sex



주: Graphs represent age-adjusted cumulative Covid-19 mortality rates for the period from Jan. 24, 2020 to Feb. 28, 2021.

Source: Bosworkth, M., Ayoubkhani, D., Nafilyan, V., Foubert, J., Myer Clickman, M., Davey, C., & Kuper, H. (2021). Deaths involving COVID-19 by self-reported disability status during the first two waves of the COVID-19 pandemic in England: a retrospective, population-based cohort study. *The Lancet Public Health*, 6(11), p. e820.

4) Araten-Bergman, T., & Shpigelman, C. N. (2021). Staying connected during COVID-19: Family engagement with adults with developmental disabilities in supported accommodation. *Research in Developmental Disabilities*, 108, 103812. <https://doi.org/10.1016/j.ridd.2020.103812>; Inclusion London. (2020). Abandoned, forgotten and ignored—The impact of Covid-19 on disabled people. *Inclusion Scotland*, 2020.; Kim, M. A., Jung, Y. J., Hwang, S. M., & Sung, J. (2021). A qualitative study on parents' concerns about adult children with intellectual disabilities amid the COVID-19 pandemic in South Korea. *Journal of Applied Research in Intellectual Disabilities*, 34, 1145–1155.; Sabatello, M., Burke, T. B., McDonald, K. E., & Appelbaum, P. S. (2020). Disability, ethics, and health care in the COVID-19 pandemic. *American Journal of Public Health*, 110, 1523–1527; Jeon, Geun Bae. (2020). COVID-19 and the Lives of Disabled Persons: The Current Status and Countermeasures. *Journal of Critical Social Welfare*, 68, 173–207; Jeon, Geun Bae. (2020). COVID-19 and the Lives of Disabled Persons: The Current Status and Countermeasures. *Journal of Critical Social Welfare*, 68, 173–207.

5) Bosworkth, M., Ayoubkhani, D., Nafilyan, V., Foubert, J., Myer Clickman, M., Davey, C., & Kuper, H. (2021). Deaths involving COVID-19 by self-reported disability status during the first two waves of the COVID-19 pandemic in England: a retrospective, population-based cohort study. *The Lancet Public Health*, 6(11), e817–e825

Several studies conducted in the US have found that people with intellectual disabilities are two to eight times more likely to die from covid-19 than those without such disabilities. These studies attribute the higher likelihood of Covid-19-related mortality to several factors, including: a higher prevalence of respiratory, endocrine, and circulatory diseases among Covid-19 patients with intellectual disabilities; an environment where caregiving is not readily available; and limited access to health care. In short, the absence of care is identified as one of the key factors contributing to increased mortality among people with disabilities.⁶⁾

People with disabilities are particularly vulnerable in crisis situations, where their need for care⁷⁾ becomes even more critical. However, the care system in its current state falls short in meeting the needs of people with disabilities during such circumstances. In the 2020 survey of “Lives of People with Developmental Disabilities and Their Families During the Covid-19 Pandemic”, conducted by the National Human Rights Commission, 97 percent of the 1,174 parents of individuals with developmental disabilities reported having been unable to access services from their local welfare centers for the disabled due to pandemic-related closures. The government responded to this situation with a delayed implementation of additional emergency caregiving services and a special activities-of-daily-living allowance, which, as was found, reached only a small number of users. Some 60.3 percent of parents with children with developmental disabilities said they had had no opportunity to use emergency caregiving services because schools concerned never provided them, and one in every two of these parents said they were not aware of the special activities-of-daily-living allowance, on account of which it can hardly be said that the measures taken for emergency care services were sufficient as a response to the crisis situation.

Such care disruptions have effectively increased the burden of care on families. Most individuals using disability care services in community settings are those living with developmental disabilities. As a result of COVID-19-related closures, families who had previously relied on community-based facilities for care services for their members with developmental disabilities were inevitably burdened with additional caregiving responsibilities. One example of what came of this was that in one in four families with children with developmental disabilities, either or both of the parents had to stop working to take on their increased care responsibilities. Individuals with developmental disabilities are particularly sensitive to changes, with their stress and anxiety levels heightening markedly in the face of acute changes. The difficulties and care responsibilities that families with members with developmental disabilities encounter in the crisis situation have become so formidably weighty that some individuals in these families have chosen to end their lives on their own.

Continuous care is essential for people with disabilities to lead their everyday lives. In Korea, disability care is structured so that users can choose from a range of service options that are standardized by the

6) Courtenay, K. & Perera, B. (2020). COVID-19 and people with intellectual disability: impacts of a pandemic. *Irish journal of psychological medicine*, 37(3), 231-236;
 Landes, S., Turk, M., Woong, A. (2021). COVID-19 outcomes among people with intellectual and developmental disability living in California: The importance of types of residence and skilled nursing care needs. *Disability Health*, 14(2). 1-5. doi: 10.1016/j.dhjo.2020.101051

7) Disability care refers to services that are provided in community settings to people with disabilities at their residence. These services may encompass the whole gamut of social services targeting individuals with disabilities, but the purview of this study is limited to services that are closely related to the everyday lives of disabled people, such as daily living assistance, family assistance, health-related assistance, and housing support.

government in terms of what is provided, in what quantity, and at what price, as specified in the Act on Welfare of Persons with Disabilities, the Act on Activity Assistant Services for Persons with Disabilities, and the Act on Guarantee of Rights of and Support for Persons with Developmental Disabilities. As illustrated in Table 1, most care services for disabled people are subsidized by the national government, while there are some that are either run by local governments in accordance with the 2015 devolution agreement or planned and implemented at smaller localities, financed with local resources.

Korea's care service sector has grown rapidly since discussions began in the late 2000s on the need for social care, propelled thereafter by the introduction of care services targeting disabled people and older adults. However, the services delegated to local governments lack flexibility in delivery, as they are administered according to national government guidelines.

The care disruptions that occurred during the pandemic period may be attributed to the lack of responsiveness of care services in crisis situations. Services that were devolved to local governments, intended though they were to respond with increased autonomy to community needs, proved to be less flexible than earlier assumed. In her 2015 study, Kim⁸⁾ observed that an ideal form of care would involve creating a complementary connection between what she termed "institutional care" and a community-based approach that facilitates user participation.

Institutional care, as a component of the public sector, inherently involves red tape, an attribute that makes it challenging for an institutional care system to maintain the necessary flexibility and responsiveness when delivering services in rapidly changing situations. Consequently, disabled individuals and their families facing care disruptions often have to cope on their own with the difficulty of meeting their care needs while alternative solutions are in the works at the central government. Furthermore, during the pandemic, the national government, significantly less informed than local governments, was unable to even monitor whether the additional care services were deployed as intended.

.....

8) Kim, Eunjeong. A Community Approach for Establishing an Effective Social Care System. *Korean Journal of Social Welfare Studies*, 46(2), 153-176.

[Table 1] Community care for disabled persons

Community care for disabled persons	
Nationally subsidized	<ul style="list-style-type: none"> • Activities of daily living assistance for disabled persons • Specialized assistance for people with developmental disabilities (day activities, after-school activities, counseling for parents, family respite. etc.) • DD rehabilitation • Health care management for people with disabilities (Community-based rehabilitation, Family physician programs, family dentist programs, rehabilitation hospitals, etc.) • Female housekeeping assistant dispatch programs • Support programs for families with disabled children • Residential facilities for disabled people • Pilot projects on integrated community care (disability care) • Pilot projects for supporting de-institutionalized individuals with disabilities <ul style="list-style-type: none"> • Community social service investment project (disability division) • Community centers for persons with developmental disabilities • Community centers for children with disabilities (limited to some areas) • Centers for disability advocacy • Centers for the independent living of disabled persons • Centers for assistive devices for disabled persons
Devolved	<ul style="list-style-type: none"> • Day care centers • Group homes for people with disabilities • Short-term care facilities for people with disabilities • Welfare centers for people with disabilities (rehabilitation and training) <ul style="list-style-type: none"> • Occupational rehabilitation facilities for people with disabilities • Centers for supporting the mobility of people with visual impairment • Sign language interpretation centers
Community-based projects	<ul style="list-style-type: none"> • Additional daily living activities assistance • Support for behaviorally-challenging individuals with developmental disabilities with • Support centers for families with disabled members <ul style="list-style-type: none"> • Continuing-education centers for disabled people • Housing support
Financed by local communities	<ul style="list-style-type: none"> • Disability support programs and community integration projects run by social economic organizations • Welfare center for disabled people (“Small Spark”, “Ongshimi”, etc.)
Local government projects	<ul style="list-style-type: none"> • Outreach welfare services • Emergency care responses to Covid-19 (time-limited, with applications accepted at smaller community levels) • The operation of local social welfare councils

Source: by the author



What to do to improve care for people with disabilities?—lessons from the UK and the US

Care for people with disabilities needs to be provided on a continuous basis, and continuity of care can be secured by integrating more community-based approaches into institutional care. Disability care, which is a service meant to assist disabled individuals in their daily living activities, should be flexible to meet their everyday care needs, which may change depending on the situation.

Table 2 lists the features of institutional care and community-led care in Korea. In order for the system of institutional care to become more flexible, it requires attributes of community-based care; in order for community care to secure stability and sustainability, it must remain flexibly linked to institutional care.

[Table 2] Institutional care and community-based care

Institutional or community-based	Classification	Sub-classification	Characteristics
Institutional	Unit of service provision	Individual	Assistance in activities of daily living
		Group	Operational support for Welfare Centers for the Disabled
	Government type	National government	State-subsidized services (nationally standardized)
		Local government	Devolved or locally developed services
	Direct or indirect service	Direct service	Direct care services
		Indirect service	Eligibility determination, case management, etc.
Pros and cons	Pros	Predictable, stable	
	Cons	Rigid, lacking responsiveness to individual needs	
Community-based	Direct or indirect care	Direct	Co-productive care (“town meeting room for disabled residents”)
		Indirect	Interest representation, capacity building, advocacy, etc. (Parents with Disabled Children Self-Help Groups)
	Care provider	Service user	Care services for users and their families (community mutual-care groups)
		Third-person	Care for families with disabled members (Community-led)
	Connection to institutional care	Little	Almost no connection
		Loose	Indirectly related (financial and administrative support)
	Pros and cons	Pros	flexible, responsive to individual needs
		Cons	Unstable, Unpredictable

Source: by the author

To provide care services flexibly in response to changing circumstances would require expanding the role of the local government located near service users. It has been consistently pointed out that Korea’s welfare system has a strong national government but lacks local government capacity. This assessment highlights a top-down approach characterized by strong strategic planning capacity present in various

stages of policy planning, including developing policy visions and goals, defining target groups and deciding on project components, and setting up and staffing groups to work on the implementation of the project. However, as the capacity for planning projects aimed at assisting community residents in their everyday lives consists in securing and embodying the flexibility with which the projects can respond to changing circumstances, how closely the public sector can work in contact with community partners in its project planning becomes increasingly important. Once a climate is created where disabled individuals can access support from nearby local governments or community neighbors, at least a minimum level of care can continue even in circumstances where formal care goes down.

From the last century on, the focus of care in advanced countries has shifted to the role of governments that are close to community members and to linking communal efforts and activities in tailored units to public organizations and human resources in the community.

In the UK, care responsibilities have been decentralized to local governments since the beginning of devolution in the 1970s, and since the 2000s, the trend toward “double devolution” has gained increasing momentum as a way to reallocating roles across different tiers of local administration⁹⁾.

Double devolution means delegating care responsibilities to lower-tier local administrations and facilitates the development of a framework that can collect requests for assistance and volunteer activities from community members, making it possible to monitor residents’ needs at the hyperlocal or neighborhood level¹⁰⁾. In the UK during the Covid-19 pandemic, local governments, with the financial support of the national government’s Infection Control Fund and Rapid Testing Fund, could acquire the flexibility required to identify the issues facing vulnerable groups in the community and plan and implement services to address them. In the process, community volunteers and community mutual-aid groups have played important roles¹¹⁾.

In the 1970s, the US, under the banner of New Federalism, making more of the efficiency of local welfare provision than centralized provision, transferred its care responsibilities from the federal government to state governments. Since then, care services have been provided in an increasingly diverse range to meet the needs of people with disabilities at the local level¹²⁾. During the Covid-19 pandemic, the Biden Administration, pursuant to its American Rescue Plan Act, provided financial support to local governments for their Covid-19 responses and increased the federal matching rate by 10 percentage points for expenditures on Home and Community Based Services (HCBS), enabling state governments to avail themselves of more Medicaid funding. As a result, state governments could on their own organize and develop services in ways that are tailored to the needs of their residents, thereby

9) Mulgan, G., & Bury F. (2006). *Double Devolution: The renewal of local government*, Edited by Geoff Mulgan and Fran Bury of the Young Foundation, Published by the Smith Institute.

10) Buonfino A., & Hilder P. (2006). *Neighbouring in Contemporary Britain*. York: Joseph Rowntree Foundation; McCabe, A., Wilson, M., & Macmillan, R. (2020). *Stronger than anyone thought: communities responding to COVID-19*. Local Trust.

11) Comas-Herrera, A., Fernandez, J. L., Hancock, R., Hatton, C., Knapp, M., McDaid, D., Malley, J., Wistow, G., & Wittenberg, R. (2020). COVID-19: Implications for the support of people with social care needs in England. *Journal of Aging & Social Policy*, 32(4-5), 365-372; British Academy. (2021). *The COVID Decade: understanding the long-term societal impacts of COVID-19*. The British Academy. *COVID-decade-understanding-long-term-societal-impacts-COVID-19.pdf* (thebritishacademy.ac.uk).

12) National Council on Disability. (2014). *Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community*. https://ncd.gov/sites/default/files/HCBS%20Report_FINAL.pdf OECD. (2019). *Health at a Glance 2019*. Retrieved from <http://www.oecd-ilibrary.org> 2021. 8. 11.

effectively allocating funds within their communities to where needs were acute¹³⁾.

During the pandemic, both in the UK and the US, local governments took the lead in responding to the situation by organizing activities at the hyperlocal or neighborhood level and making use of both institutional and community-based care services to the full extent.

Disability policies worldwide have increasingly emphasized the importance of the independent living paradigm as a social model of disability. This approach specifically focuses on promoting control and choice for disabled people and expanding opportunities for them to communicate, meet, and connect with non-disabled community members.

In Korea, care services are on track to transition from the independent living model to the interdependent living model. The disability policies and care services in their current stage of development require a greater emphasis on communitarian approaches and user participation. User participation is particularly important, as Korea's care services should evolve to address the specific needs of individual users.

Concluding remarks

In this era of endemic Covid-19 and beyond, Korea should continue to move toward strengthening its community-led care to remain flexible in responding to changing conditions. One notable outcome that emerged as community welfare centers across the country strove to address community needs, from the early chaotic stages of the pandemic onward, was the enhancement of community-led collaboration. "Community welfare centers harnessed and advanced intra-community collaboration to independently provide essential services while leveraging social media platforms to offer a wide range of support to specific groups in need. This development represents an embodiment, brought about during the pandemic, of what Kim¹⁴⁾ presented as a model for community-led care.

In the longer term, ways should be sought to make strategic use of community resources, networks, relationships and participation, as it becomes increasingly important to make care interventions in prompt response to emergency situations that might arise in the wake of a crisis like the previous pandemic. Korea's care system requires changes, especially as in its current state services are delivered in a fragmented manner, primarily funded by the national government, and local projects with devolved financing and operations are exclusively guided by national government oversight.

Disability care should shift its focus toward locality and promoting the participation of residents

13) CMS. (2021). American Rescue Plan Act of 2021 (ARP) Section 9817: Overview of State Spending Plans. www.medicaid.gov/medicaid/home-community-based-services/downloads/arp-sec9817-overview-infographic.pdf; Jewett, R., Mah, S., & Howell, M. (2021). Social Cohesion and Community Resilience During COVID-19 and Pandemics: A Rapid Scoping Review to Inform the United Nations Research Roadmap for COVID-19 Recovery. *International Journal of Health Services*, 51(3), 325-336; Georgia Health Policy Center. (2022). Maximizing Federal COVID-19 Recovery Investments for Resilience and Equity: Examples from Across the Nation. Georgia Health Policy Center. <https://ghpc.gsu.edu/download/maximizing-federal-covid-19-recovery-investments-for-resilience-and-equity-examples-from-across-the-nation>; Marshall, J. (2021). Resilience Re-Examined: Thoughts on the COVID-19 Pandemic's Lessons for Communities. *Journal of Comparative Urban Law and Policy*, 5(1), 52-62.

14) Kim, Eunjeong. A Community Approach for Establishing an Effective Social Care System. *Korean Journal of Social Welfare Studies*, 46(2), 153-176.

with disabilities. Increasing emphasis on locality means that resources will be developed so that they are highly responsive and effectively connected to the needs of community residents at the community level. This is to say that it will become increasingly important for the public sector to work closely with users when planning disability services. In Germany, for instance, many local governments have implemented a system whereby community residents are supported with long-term care funds to check in on older adults in their neighborhood. This approach has proven effective in improving the financial sustainability of long-term care services and promoting community volunteer networks for various activities. Learning from the German example, Korea should consider strengthening the capacity of its local governments so that they can establish effective relationships with community stakeholders involved in public policy planning. This would require adequate funding for financially constrained local governments and putting in place a legal framework on which local governments can unfold their capacity to plan goals and strategies.

There is a need to broaden the range of disability care services with increased community-led efforts. Ongoing efforts, primarily led by local social welfare councils, aim to increase public-private collaboration. However, further actions are required, such as funding and supporting community infrastructure, to better integrate community-based volunteer activities with various public policies. The first step in this direction is to establish and adequately staff agencies responsible for caregiving activities. Another important consideration is bolstering support for co-production, where service providers and users collaborate based on trust to produce services. During the co-production process, users engage firsthand, ensuring that their needs are heard and integrated into service development. This, in turn, contributes to the formation of community networks and the growth of community capacity. This approach is as much a way to embody the fundamental value of human dignity within the realm of caregiving as it is a way, as much emphasized in the framework of current disability policies, to empower service users.