

## Health and Global Policy Institute (HGPI) Dementia Policy Project Policy Recommendations Three Necessary Perspectives for Formulating the Basic Plan for the Promotion of Policies on Dementia: Creating a Society That is Inclusive for All People at All Times



### Background to these recommendations

In our capacity as a non-profit, independent, non-partisan health policy think-tank, Health and Global Policy Institute (HGPI) views all issues related to population aging starting with dementia as global-level health policy issues and has worked continuously to advance dementia policy around the world. Through our collaborative efforts with the World Dementia Council (WDC) and a number of domestic patient advocacy organizations, HGPI has also backed efforts from civil society to encourage policy progress in this area.

For many years, the HGPI Dementia Policy Project has been involved in activities aiming to promote multi-stakeholder collaboration to advance dementia policy based on three pillars: (1) emphasize the perspectives of those most affected; (2) build a global platform; and (3) identify and disseminate policy issues. Through multi-stakeholder discussions centered on people living with dementia and their families, we have offered policy options to policymakers as well as to greater society. We believe that these activities have had some impact on dementia policy in Japan and overseas and have contributed to policy progress in this area. In 2014, our recommendations emphasized the importance of dementia policy that spans multiple ministries and agencies, which can be linked to the subsequent development of the National Framework for Promotion of Dementia Policies. During the formulation of The Basic Act on Dementia to Promote an Inclusive Society (the Dementia Basic Act), which was enacted in June 2023, HGPI acted early to provide discussion opportunities with legislators and other parties and presented a number of recommendations to publicize our views as a think tank. In the end, many of our recommendations were reflected in the Act.

The Dementia Basic Act came into effect on January 1, 2024, and the Government plans to formulate the Basic Plan for the Promotion of Policies on Dementia around fall 2024. Following the formulation of the Basic Plan, prefectural and municipal governments are expected to formulate their own plans for the promotion of dementia policies. The Ministerial Council on the Promotion of Dementia Care Policies, which is chaired by the Prime Minister, held its first meeting in accordance with the Dementia Basic Act on January 26, 2024. There are also future plans for meetings of the Stakeholder Committee for the Promotion of Policies for Dementia, which will include people living with dementia, their family members, and other affected parties, and discussions on the formulation of the Basic Plan for the Promotion of Policies on Dementia will begin in earnest. The Dementia Basic Act has already set a basic direction for dementia policies and includes discussion points related to each measure. A number of discussion points were also identified during the process of its passage into law. For our part, HGPI presented an urgent proposal titled “Enact the Basic Act for Dementia to Reshape Perceptions of Dementia” in September 2022 and joint policy recommendations formulated with the Association of People with Dementia, their Family Members, and Supporters titled, “Ensuring the Basic Act for Dementia Encourages Involvement for People Living with Dementia and their Supporters” in January 2023. In addition to offering policy recommendations, HGPI has been engaged in various advocacy activities to further our mission of providing policy options to society.

These recommendations are based on past discussions and are meant to convey a concise message on perspectives that were not positioned as key issues but must be kept in mind when creating a society where all people can continue living true to themselves at all times and in all places. While it goes without saying that further discussions will be required to examine the details of each point, we believe these are discussion points that many related parties should keep in mind as the start of full-scale discussions on the Basic Plan for the Promotion of Policies on Dementia draws near.

## Policy recommendations

### Perspective 1

#### Looking ahead to disasters and other emergencies, expand emergency-related measures based on the Dementia Basic Act.

Natural disasters are frequent in Japan. In addition to earthquakes, there have also been many reports of damage caused by typhoons and torrential rains in recent years. Disasters harm people and damage homes and infrastructure, and regardless of whether a disaster is predicted or not, a lack of disaster preparedness can be fatal for residents of Japan. Furthermore, certain groups of people are especially vulnerable to disasters. Emphasizing support for such people, the Cabinet Office has established guidelines for supporting evacuation efforts using the term “People Requiring Assistance.” This term includes pregnant and nursing mothers, senior citizens, and people living with dementia. However, for the latter group, the guidelines attach the condition that their condition must be “severe.” On top of this, many other guidelines do not even mention dementia. A wide variety of symptoms are associated with dementia, so when establishing disaster support systems for dementia, another fact that must be kept in mind is that there are people living with dementia, their family members, and related parties who must manage various symptoms.

As sudden changes in living environments and prolonged periods of disrupted everyday life can aggravate symptoms and cause secondary harm, disasters can actually be life-threatening for people living with dementia. Furthermore, recovery and reconstruction efforts must be made after disasters, and it is common for people to carry out such efforts while juggling normal daily life, including work, long-term care, and child-rearing. This means family caregivers and other parties must handle recovery and reconstruction while continuing to care for people living with dementia. However, the support provided to people living with dementia and their family members during recovery and reconstruction through existing support systems is insufficient.

People living with dementia and their families are vulnerable to various effects caused by disasters. Given their need for help to maintain daily lives and care as close to normal as possible, to ensure people living with dementia and their families can live with peace of mind during emergencies, measures and support must be provided from various angles through various laws and systems for disasters while following the principles of the Dementia Basic Act.

By sheer coincidence, the 2024 Noto Peninsula Earthquake occurred on January 1, 2024, the same day that the Dementia Basic Act came into effect. The unique topography of the region affected by the disaster resulted in slower support than other disasters and some people are now experiencing prolonged evacuation. When discussing infrastructure for daily life in Japan, it is essential to incorporate discussions that anticipate emergencies, and we must work to build a highly resilient and inclusive society.

### Perspective 2

#### Reflect a diversity of voices from affected parties and implement measures that are tailored to each party.

The Dementia Basic Act states that the Stakeholder Committee for the Promotion of Policies for Dementia must include people living with dementia and their family members among its members. It has also outlined concrete plans for involving people living with dementia and their families in the policy-making process by obligating prefectural and municipal governments to gather opinions from these parties when formulating plans. HGPI has continuously emphasized these actions in our proposals and we believe they are vital perspectives for civil society. In the future, there are high expectations for sufficient consideration to be given to the diversity of people living with dementia so their participation in such policy-making processes can be effectively promoted. It is estimated that there are 7 million people living with dementia in Japan today, each with their own living environment, challenges, experiences, and opinions. In other words, there is great diversity in their circumstances. Stereotyping those who participate in meetings and other forums for discussion must be avoided if we are to reflect as much of this diversity in the policy formulation process as possible. Doing so will require dedicated efforts from the government as well as proactive efforts from civil society.

In addition, “people living with dementia and their families” includes people living with physical disabilities as well as sexual and ethnic minorities. Organizations involved with social minorities have already been actively working to communicate this fact to society, and in a society where anyone can develop dementia, expectations are high for

deeper mutual understanding. When formulating regional and local plans and introducing the measures that follow them, it will be necessary for local governments to be well-informed about ethnic minorities living in the community and to take steps to help them live with peace of mind, such as by providing information and consultation services in their native languages.

In the dementia-friendly and inclusive society we aim to build in the future, it will be crucial that we avoid developing a fixed image of “people living with dementia and their families,” keep in mind the fact that affected parties come from diverse backgrounds, and establish a social environment that enables their participation.

### Perspective 3

#### **Establish employment and support systems that enable people living with dementia and family caregivers to stay in the workforce.**

In the modern era of 100-year life expectancies, there are high expectations for efforts to secure sufficient human resources for economic growth as well as to enable people to be able to continue working even as they age. The Act on Stabilization of Employment of Elderly Persons obligates employers to secure employment opportunities until age 65 as well as to endeavor to secure them until age 70. As the rate of dementia onset generally increases as people get older, employers must learn to anticipate and respond to cases in which their employees develop dementia. It will be particularly important to secure employment opportunities for people who develop early-onset dementia to help them support dependent family members as well as to maintain their future livelihoods. Against this backdrop, Article 16, Paragraph 2 of the Dementia Basic Act obligates the national Government and local governments to implement necessary measures that help people stay in the workforce and that facilitate hiring.

An even greater challenge will be supporting people who continue working while caring for a family member with dementia. The Long-Term Care Insurance System was introduced in 2000 with the mission of “the socialization of long-term care,” but due to financial strain caused by increased demand and a chronic shortage of long-term care workers, it has yet to relieve families of the burden of providing long-term care. As noted in research on the welfare state, attitudes toward caregiving in Japan include a strong and persistent tendency to view caregiving from the perspective that the family should take precedence over the individual. In recent years, the MHLW has been advancing measures to help people balance caregiving and employment, but the number of people who left the workforce due to caregiving and related reasons was approximately 106,000 people in 2022. There is a long way to go to achieve the Government’s 2015 goal of reducing the number of people who leave their jobs to provide long-term care to zero. On top of this, according to 2023 data from the Ministry of Economy, Trade and Industry (METI), the number of people who continue working while providing family care (referred to as “business carers”) was projected to increase to approximately 3.18 million people by 2030. It was also estimated that reduced productivity due to long-term care results in national economic losses of approximately 9 trillion yen.

In the past, the roles of companies in dementia policy have mostly centered on supporting people living with dementia through barrier-free access as a form of social contribution and fulfilling corporate social responsibility (CSR), or by serving as suppliers of products and services. However, to achieve the broad basic principles of the Dementia Basic Act, while advancing government-led initiatives to support companies, the companies themselves must work to recognize dementia as an issue that affects them and take steps to further enhance the employment environment and support.

Local regulations for dementia provide examples of measures for dementia from local governments, which have been formulated in over 20 prefectures and municipalities. Some include measures to help people remain in the workforce even if they develop dementia or have to care for a family member who has developed dementia. We hope clear mention of these measures is also included in the Basic Plan for the Promotion of Policies on Dementia formulated in accordance with the Dementia Basic Act.

Health and Productivity Management initiatives, which aim to enhance corporate value by maintaining and improving health for employees and other parties, should also include dementia measures as one way to encourage independent, company-driven efforts. Specifically, including dementia response as an evaluation indicator in Health and Productivity Management Surveys is likely to encourage companies to improve their dementia response capabilities. While major companies and some small and medium-sized companies have been proactive about pursuing Health and Productivity Management, many companies and organizations have room for future progress.

These initiatives may place heavy burdens on companies and organizations that are short on staff, so instead of only raising awareness, it will also be necessary to consider measures to reduce the workloads that accompany the implementation of these initiatives.

Another area that will require action is the recent increase in the number of non-regular employees. This has been pointed out as an existing structural issue in the Japanese economy, and it goes without saying that this requires improvements in and revisions of the labor market. Essential actions for addressing this include recent government initiatives for supporting new or continued employment to prevent the economic hardship that occurs when people leave the workforce or reduce working hours because they have developed dementia or must care for a family member.

## About Health and Global Policy Institute

Health and Global Policy Institute (HGPI) is a non-profit, independent, non-partisan health policy think tank established in 2004. In its capacity as a neutral think-tank, HGPI involves stakeholders from wide-ranging fields of expertise to provide policy options to the public to successfully create citizen-focused healthcare policies. Looking to the future, HGPI produces novel ideas and values from a standpoint that offers a wide perspective. It aims to realize a healthy and fair society while holding fast to its independence to avoid being bound to the specific interests of political parties and other organizations. HGPI intends for its policy options to be effective not only in Japan, but also in the wider world, and in this vein the institute will continue to be very active in creating policies for resolving global health challenges. HGPI's activities have received global recognition. It was ranked second in the "Domestic Health Policy Think Tanks" category and third in the "Global Health Policy Think Tanks" category in the Global Go To Think Tank Index Report presented by the University of Pennsylvania (as of January 2021, the most recent report).

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