

## **The Health and Global Policy Institute Dementia Policy Project**

### **Discussion Points for Intensifying Efforts for Early Detection, Intervention and Support in the Future**

Early detection, intervention and support have been key topics in dementia policy since the formulation of the Five-Year Plan for the Promotion of Dementia Measures (the Orange Plan) in 2012, and they remain prominent issues in this area today. Currently, efforts for early detection, intervention and support are advancing under a system in which local governments (those classified as basic municipalities) play central roles in comprehensive support programs as part of Community Support Projects within the long-term care insurance system, while prefectures (or local governments serving wider areas) provide support for those programs. This means progress in those initiatives is greatly influenced by the capacities of local governments. However, in addition to the capacities of local governments to promote early detection, intervention and support, our case research has identified a number of issues influencing such efforts, including individual attitudes toward dementia; links within communities or with family doctors; and the utilization of technology from private companies. There were also challenges faced by these projects that are dependent on local governments. Based on our findings, we recommend the following actions and directions to take for early detection of and early intervention and support for dementia.

#### **1 Accept the messages being communicated by people living with dementia today and leave outdated views of dementia behind**

To promote early detection, intervention and support for dementia, it will be important for each individual to learn about the underlying causes and symptoms of dementia and be able to notice abnormalities in themselves or the people close to them. However, there are many cases in which people noticing dementia symptoms early does not result in early detection, intervention and support. It is well-known that people face psychological hurdles toward seeking medical examinations at healthcare institutions, even after developing suspicions of dementia. This hesitancy is based on negative attitudes toward dementia such as, “If a person develops dementia, they cannot understand anything.” We refer to such attitudes as “outdated views of dementia.” To overcome such issues and encourage early detection and diagnosis, in addition to helping people acquire an accurate understanding of dementia symptoms, it will also be necessary to build awareness toward the knowledge needed to enable people living with dementia and their families to continue living happy lives by disseminating information from people living with dementia.

#### **2 Identify sources of consultation that people can trust, such as their community or their family doctor**

Anyone can develop dementia, so it is important for us to be prepared. In addition, being prepared does not only refer to dementia; it is also necessary for us to be ready to respond to all sorts of challenges that can impact our daily lives, like if our health fails or if we begin to face financial hardships. A particular concern in recent years has been the dilution of communities. This has occurred due to the influence of various factors such as changes in daily lifestyles and family structures, and there is no easy solution to this issue. Therefore, it is vital to first establish ties with one’s community, starting with those nearby, and to maintain personal connections outside of the family or workplace. (In recent years, there has been growing attention for having a “third place,” which is another term for this concept.)

It is also vital to be aware of how people stay in touch with health and welfare services such as family doctors and integrated community support centers. Having a family doctor gives people someone to consult when experiencing minor changes to their health during regular checkups. This will aid in early detection of physical and mental changes, including dementia. Furthermore, consultation services like integrated community support centers provide a variety of information using tools like newsletters or brochures from local governments. As a form of preparation, it is important for people to know where to seek advice when they need it through such information resources.

### **3 Engage in collaboration spanning Government, civil society, and the parties most affected that aims to implement the use of digital technologies and other new solutions from the private sector**

One characteristic of dementia is that many of the early signs of declining cognitive function or its other underlying causes cannot be conveyed in a clear numerical form. This can make it difficult for people to recognize these signs on their own at early stages. Given these circumstances, efforts to utilize digital technologies to detect dementia early and accurately have flourished in recent years. As digital technologies can be used easily outside of clinical settings to measure cognitive function at regular intervals, there is growing interest in their potential to serve as supplementary tools for evaluating and measuring cognitive function before definitive diagnoses are provided. However, such technologies are outside the scope of diagnosis and treatment, which means they are not eligible for public health insurance coverage. Implementing the use of such technologies in society will require support through public policies as well as efforts to scientifically validate their ability to evaluate and measure cognitive function.

There are also high expectations for agile and flexible joint initiatives from Government, civil society, and the parties most affected in the development and implementation processes. In particular, it will be necessary to consider the perspectives of people living with dementia to achieve digital transformation (DX) that improves the lives of the affected parties. It is common for technologies and systems designed and developed without involvement from the people most affected to end up being difficult for them to use or for those technologies and systems to diverge from the support those parties want to receive. The perspectives of the people most affected must be incorporated into the various stages of R&D or when examining measures, and DX must be advanced in a manner that is closer to their daily lives.

### **4 Make consultation services at local governments one-stop solutions and reinforce collaborative systems to enable those services to be able to respond to diversified consultation needs**

Most of the people living with dementia are older adults and also live with chronic illnesses, so there is diversity among health conditions from person to person. People living with younger-onset dementia also face unique challenges in their daily lives in terms of employment or daily life planning. In addition, the issues perceived by the parties most affected and their underlying factors do not always match. It is necessary to provide support that is optimized to each person's needs while making effective use of various welfare services. However, it is not easy for people living with dementia to select, on their own, a single support or consultation service out of the many options that are available. It is difficult to imagine the burden they would experience if they had to visit different consultation offices one after another on their own. We must establish a system that coordinates with the appropriate departments to provide a one-stop solution to overcome the various challenges faced by people living with dementia and to deliver the support they require. To achieve this, expectations are high for local governments to actively work to encourage multi-disciplinary collaboration. It will be necessary for such systems to operate as hubs that provide effective coordination at community care councils and help build face-to-face relationships with local stakeholders.

### **5 Build a unified support system that spans the period from when people first notice the signs of dementia to before and after diagnosis**

#### **Redefining "Initial-phase Intensive Support Teams for Dementia," the heart of unified support**

The Initial-phase Intensive Support Team for Dementia system was established in FY2015 as an initiative to promote early detection, intervention and support through outreach activities involving multi-disciplinary collaboration. These teams focus on the early stages of dementia and aim to provide people with their initial contact with healthcare and long-term care services. However, according to a survey conducted by the National Center for Geriatrics and Gerontology, only about 60% of people who receive support from Initial-phase Intensive Support Teams were introduced to appropriate healthcare and long-term care services, and only about 10% were put in touch with services outside those covered by long-term care insurance. The main reasons people were unable to get in touch with healthcare and long-term care services were the physical conditions of the people receiving support and reluctance among those parties to receive support from specialists. The original purpose of

Initial-phase Intensive Support Teams for Dementia was not to provide ongoing healthcare or long-term care services. Rather, it was to provide support during the initial stages after diagnosis to help people to continue living familiar lifestyles at home for as long as possible. The National Framework for Promotion of Dementia Policies focuses on how effective Initial-phase Intensive Support Teams for Dementia are at connecting people to healthcare and long-term care services. Based on their original purpose, however, steps should be taken to consider expanding the objectives of those teams to include connecting people to peer support and other forms of informal care as well as various community resources. Furthermore, the support they provide should not only be limited to the person living with dementia, but should encompass wide-ranging forms of support including that provided to their families or integrated support targeting both the person living with dementia and their family members.

### **Positioning community dementia support promoters as coordinators of diverse community resources**

For Initial-phase Intensive Support Teams for Dementia to connect people to informal care and various community resources, it will be necessary to first organize and grasp what forms of informal care and resources are available in each community. Furthermore, when efforts to do so are insufficient, it will also be necessary to form plans to encourage activities through collaboration with community members and local organizations. Expectations are high for promoters, who are people who will serve as coordinators in efforts to advance community dementia support. The role of promoters is to help establish effective support systems for people living with dementia according to the needs of each community and local healthcare, long-term care, and welfare resources. Specifically, municipalities that appoint promoters have the flexibility to determine how to best utilize them according to circumstances in each community. As this makes their roles that much more diverse, it is difficult to evaluate their performances and determine if they are meeting their original objectives, so other issues include evaluating the quality of promoters and taking steps to achieve equity in support. With efforts from municipalities tailored to the conditions in each community serving as the basis, it will be necessary to consider how the national and prefectural governments should be involved and how to best share duties among governing parties to enhance the activities of promoters in all municipalities.

### **Disseminating peer support and improving its quality**

There are high expectations that connecting people to peer support in the early stages after diagnosis will help alleviate their feelings of anxiety and help them maintain social participation. Effective methods of achieving this include providing referrals from healthcare institutions that diagnose dementia or peer support and other forms of consultation support within healthcare institutions. In the field of oncology, the requirements that healthcare institutions must meet to be designated as “regional core hospitals for coordinated cancer care” include establishing Cancer Consultation Support Centers to offer consultation support and providing patients with explanations on consultation support during treatment. While referring to such best practices from other fields, we must promote collaboration between places that provide diagnoses like Medical Centers for Dementia as well as in consultation support during the early stages of dementia.

To ensure high-quality peer support can be provided nationwide, the necessary knowledge and skills for peer supporters to possess as professionals in this area should be systematized and efforts to establish requirements and training for peer supporters should be advanced. For example, it has been shown that support methods which utilize skills from cognitive behavioral therapy are effective in peer support, so peer staff must be given opportunities to build evidence-based skills like these. When considering this, steps must also be taken to rapidly establish a system for providing those opportunities while referring to existing good examples of peer support in the field of dementia and in areas like psychiatric disorders and oncology.

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### **About Health and Global Policy Institute**

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