



認知症関係当事者・
支援者連絡会議



HGPI Health and Global
Policy Institute

January 24, 2023

The Association of People with Dementia, their Family Members, and Supporters and Health and Policy Global Institute **Present Recommendations on the Basic Act for Dementia** **“Ensuring the Basic Act for Dementia Encourages Involvement for People Living with Dementia and their Supporters”**

Diet discussions on the Basic Act for Dementia are now in full swing with the Parliamentary Association for Promoting Dementia Policies for an Inclusive Society playing a central role in efforts to examine its framework. However, looking at the course of past discussions on this topic, we believe certain points must be reinforced if we are to achieve a society that is truly inclusive for dementia. As such, we offer the following three recommendations as points of particular importance for ensuring the Basic Act for Dementia further promotes social involvement for people living with dementia and their family members when it is enacted.

- 1. Make clear mention of establishing a “Joint Committee for the Advancement of Measures for Dementia” (tentative name) within the Government of Japan and specify that patient advocates will be members of that committee.**

To ensure people living with dementia or their family members are involved when advancing measures for dementia, when formulating basic plans, it will be vital to **implement committee structures that include representatives of people living with dementia and their family members instead of “gathering opinions” during limited periods of time.** Furthermore, rather than limiting their involvement to the formulation of plans, also make it possible for them to be able to continuously participate in efforts to check progress or to follow up on those measures.

- 2. Obligate local and prefectural governments to ensure people living with dementia, their family members, and related parties are involved when formulating plans.**

Efforts to formulate administrative plans at local and prefectural governments are likely to advance after the Basic Act for Dementia is enacted. While the actual formulation of those plans should be left to the autonomy of each government, steps must be taken to **make certain that people living with dementia and their families are involved in formulating those plans** to promote participation from the parties most affected in each community and to ensure effective plans can be created.

- 3. Make clear mention of “Patient and Public Involvement (PPI)” in research and development.**

To promote innovation from Japan in the field of dementia, it will be essential to conduct research and development that reflects the needs of people living with dementia, their families, and civil society. In recent years, there has been a significant increase in **Patient and Public Involvement (PPI)** in medical research and the Japan Agency for Medical Research and Development (AMED) is now working to promote PPI in Japan. Europe and the U.S. are leaders in research and development and are making progress in PPI in the field of dementia. **Promoting PPI in research and development will be a critical step for achieving innovations that are based on the perspectives of the parties most affected** and for deepening mutual understanding among people living with dementia, their families, and other members of civil society and researchers at universities, research institutions, and companies.