HGPI Health and Global Policy Institute

Intractable & Rare Diseases 2025

10 Years After the Passing of the Intractable Diseases Act, Toward a Co-created Future

Health and Global Policy Institute (HGPI)
Intractable & Rare Diseases Project Discussion Paper

Considerations for Future Policy on Intractable & Rare Diseases

Reflections from the Perspective of Patients and the Public 10 Years After the Passing of the Intractable Diseases Act

Abstract of the discussion paper

This discussion paper is structured around five perspectives: social environment, healthcare, family & caregiver support, social participation, and innovation. Each of these perspectives is crucial in the context of policy for intractable and rare diseases, and were major themes raised at the symposium and in interviews conducted in FY2024. Common and central to all five perspectives are the viewpoints of diverse patients and people with lived experience of these diseases. Patients and people living with intractable and rare diseases come from a wide range of backgrounds and lead their daily lives in diverse living environments. We aim to consider the future direction of relevant policies with this reality in mind.

Viewpoints of diverse patients & people with lived experience

1 Social environment

2 Healthcare

3 Family & caregiver support

4 Social participation

5 Innovation

◀ **Read the full text of the paper here**

March 2025

Perspective 1 Social environment

Fostering a social environment that enables coexistence

1. From understanding to concrete systems: The need to reflect in policies the *real opinions* of patients and people affected by intractable and rare diseases
2. The need for activities to raise awareness of intractable and rare diseases among the next generation
3. The need to understand patients and people with lived experience of intractable and rare diseases who come from diverse backgrounds

Perspective 2 Healthcare

Creating a healthcare system that alleviates the worries of patients and people with lived experience

1. The need for more diverse access points such as pharmacies, local communities, schools, and workplaces, in order to shorten diagnosis lag
2. The need to promote technological innovation and cooperation among healthcare institutions to enable early diagnosis and treatment
3. The need to design systems based on a life-course approach that accommodates individual characteristics and long-term medical care

Perspective 3 Family & caregiver support

Developing policies that uphold the dignity of families and caregivers

1. The need to shed light on the circumstances of families and caregivers, help to reduce their burdens, and support social participation and self-actualization

Perspective 4 Social participation

Ensuring and enhancing opportunities for social participation (education and employment)

1. The need to guarantee diverse learning environments for children living with intractable and rare diseases, and to build flexible education systems
2. The need to establish diverse employment options to support the economic independence of patients and people with lived experience
3. The need for employment environments that enable medium- to long-term career-building while balancing treatment and work

Perspective 5 Innovation

Realizing a policy environment where patients and people with lived experience can benefit from innovation

1. The need to maintain a public health insurance system that supports society while re-evaluating cost-sharing arrangements
2. The need to establish systems that promote the development and implementation of new diagnostic and treatment technologies sought by patients and people with lived experience
3. The need for patients and people with lived experience to participate as *planning partners* in the advancement of medical science, healthcare, and policy

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