Editorial

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Challenges in Japan's dual systems of support for pediatric and adult intractable diseases

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SUMMARY: Japan has developed two separate frameworks to support patients with chronic and rare diseases: the Specified Pediatric Chronic Diseases (SPCD) Program and the Designated Intractable Diseases (DID) System. Although both aim to provide medical and social assistance, they differ in age of eligibility, diseases covered, and administrative procedures. The SPCD Program provides support to individuals under 18 years of age (extendable to 20) with 858 eligible conditions, whereas the DID System, with 348 designated diseases, applies to all ages. These structural discrepancies create a critical policy gap when pediatric patients transition into adulthood. Those whose conditions are not listed under the DID System lose their eligibility for public subsidies, resulting in sudden financial strain and reduced social participation. Additional issues include inconsistencies in diagnostic criteria, limited access to transitional care facilities — currently established in only 12 prefectures — and insufficient family-centered support, especially for siblings acting as young carers. To achieve continuity of care and equity, Japan must harmonize disease definitions and transition criteria, introduce temporary relief measures for non-designated patients, increase the number of Transitional Care Support Centers in regions, and institutionalize family-inclusive assistance. Establishing a seamless policy framework over a patient's life will not only encourage patients' independence but also strengthen the sustainability of Japan's healthcare system in the face of an aging population.

Keywords: specified pediatric chronic diseases, designated intractable diseases, transitional care, subsidy for medical expenses, family support

1. Introduction

Rare and intractable diseases pose a significant global public health challenge, affecting an estimated 3.5 to 5.9% of the population, yet only around 5% of these conditions have effective therapeutic options. These diseases are characterized by a low prevalence, a complex diagnosis, and limited availability of treatment, which together impose substantial medical, psychological, and social burdens on patients and their families (*1,2*). Over the past decade, numerous countries have sought to improve care and support for rare and intractable diseases through the establishment of national programs and policy frameworks (*3-5*).

Until the 2010s, Japan lacked a comprehensive legal framework specifically addressing medical care and support for patients with intractable and rare diseases. This changed with the enactment of the Act on Medical Care for Patients with Intractable/Rare Diseases in 2014, which came into force on January 1, 2015. This legislation established a foundation for promoting research, improving the quality of medical care, and strengthening support for patients' independence (*6*). In the same year, a separate legal system — the Measures for Specified Pediatric Chronic Diseases — was introduced to provide medical and welfare support for minors, principally those under 18 years of age (*7*).

Although both systems aim to ensure medical and social support for patients with chronic and intractable conditions, they differ in the scope of diseases covered and operate independently without coordination. Consequently, when patients with Specified Pediatric Chronic Diseases (SPCD) reach adulthood, they may lose eligibility for public subsidies if their condition is not listed among the Designated Intractable Diseases (DID). This discontinuity often results in a sudden increase in personal medical expenses, placing greater socioeconomic strain on individuals already facing a long-term illness and limited opportunities for education or employment.

This editorial outlines the structures of Japan's two major support systems and discusses issues with them.

Table 1. Comparison between the Specified Pediatric Chronic Diseases (SPCD) Program and Designated Intractable Diseases (DID) System in Japan

Category	SPCD Program	DID System
Legal basis	Child Welfare Act	Act on Medical Care for Patients with Intractable/Rare Diseases
Eligible age group	Under 18 years (extendable to under 20 if continuous treatment is required)	All ages
Number of diseases covered (as of April 2025)	858 diseases	348 diseases
Subsidy for medical expenses	Income-based copayment ceiling applies	Income-based copayment ceiling applies
Transitional support	Transitional Care Support Centers established in only 12 prefectures	Not incorporated institutionally
Key features	Emphasizes support for independence and social participation	Emphasizes ensuring access to quality medical care

2. National programs for support of SPCD and DID

The SPCD Program targets diseases that develop during childhood, persist chronically, and may threaten life over the long term. These conditions typically require prolonged treatment and impose a significant financial and psychological burden on both patients and their families. Under this scheme, patients younger than 18 years are eligible for subsidies for medical expenses, assistive equipment, and programs to encourage independence. If continued treatment is deemed necessary, financial assistance may be extended until the age of 20. As of April 2025, 858 diseases are covered under this program (*8*).

The DID System provides support for diseases that are rare, lack an established treatment, require long-term management, have a defined diagnostic standard and severity classification, and affect a small patient population. Assistance includes subsidies for medical expenses, provision of devices to assist with daily life, and employment assistance, without any age restriction. As of April 2025, 348 diseases have been officially designated as DID (*9*).

3. Structural discrepancies and policy gaps

3.1. Discontinuity and inconsistency between the two systems

Table 1 summarizes the major structural differences between the two systems. One of the most serious issues lies in the discontinuity of support for medical expenses arising from the age limit of the SPCD Program and the differing lists of eligible diseases. Patients can receive subsidies under the pediatric system until age 20 at the latest; if, however, their condition does not fall under the DID System, then their subsidies are terminated upon reaching adulthood. As a result, patients who already face educational and occupational barriers due to chronic illness must also bear substantial medical costs. This policy gap threatens not only patients' health and financial stability but also their long-term social participation and the amassing of clinical and research knowledge regarding these diseases.

Another issue is the inconsistency in disease definitions and diagnostic criteria between the two systems. The SPCD Program list includes 858 diseases, while the DID System covers 348, and many diseases and criteria differ between the two. For patients and families without medical expertise, understanding which system applies can be confusing and may lead to under-utilization of available support. Harmonization of disease nomenclature and rationalization of overlapping categories are urgently needed.

3.2. Issues with transition and family support

Even when a transition from the pediatric to the adult support system is possible, additional barriers remain. The transition period coincides with the developmental shift from adolescence to adulthood, during which patients must often change both medical departments and institutions. Because each system requires certification by designated medical facilities, those diagnosed under the pediatric system may have to seek new hospitals or specialists once they transition to the adult system. To address this, Japan has begun establishing Transitional Care Support Centers, which facilitate coordination between pediatric and adult healthcare providers and promote self-management among patients. However, as shown in Figure 1, as of June 2025 only 12 of Japan's 47 prefectures have such centers, most of which are concentrated in metropolitan areas such as Tokyo and Osaka (*10*). The map was created using the National Land Numerical Information. Patients in rural regions therefore continue to face significant disparities in access to transitional support.

A further concern is the limited support available

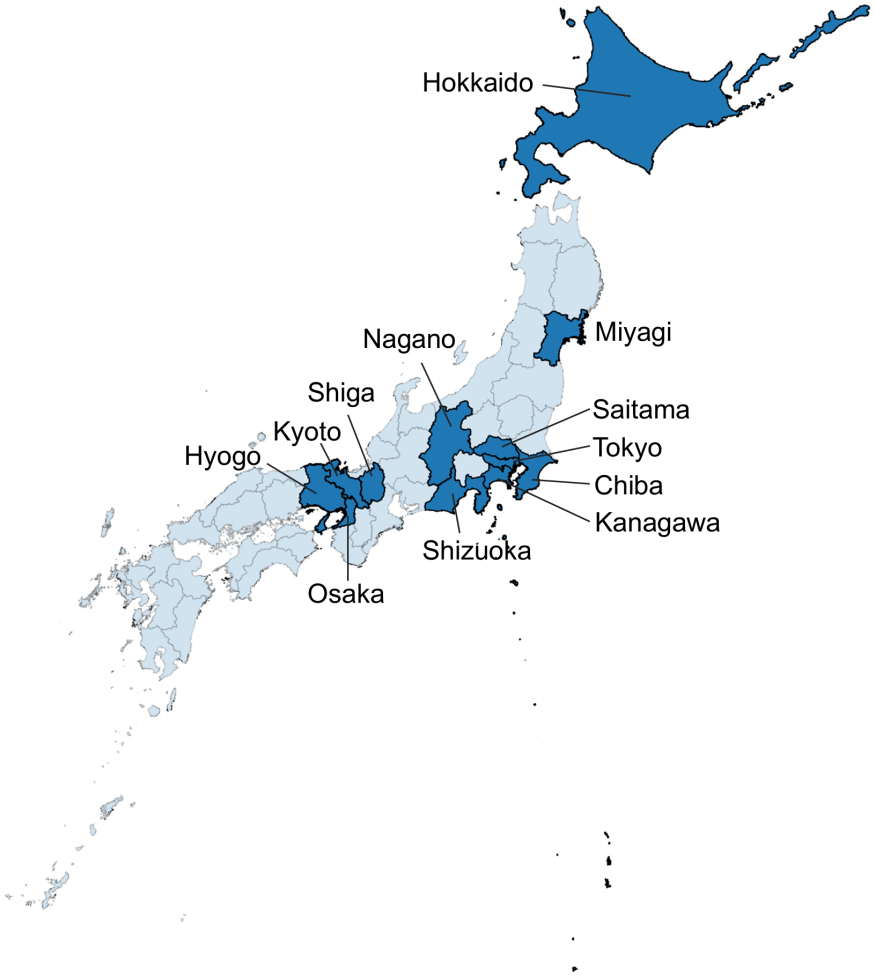

Figure 1. Prefectures that are home to Transitional Care Support Centers in Japan. Highlighted prefectures include Hokkaido, Miyagi, Saitama, Chiba, Tokyo, Kanagawa, Nagano, Shizuoka, Shiga, Kyoto, Osaka, and Hyogo. The figure was produced using the National Land Numerical Information, provided by the Ministry of Land, Infrastructure, Transport, and Tourism, Japan.

for families, and particularly siblings of affected children. In families with multiple children, siblings may serve as young carers, taking on caregiving responsibilities that can impose psychological burdens and interfere with schooling and daily life. Current frameworks provide little systematic assistance for these family members. Future policies should expand from patient-centered to family-inclusive support, addressing the holistic needs of households living with chronic pediatric diseases.

3.3. Policy implications and recommended actions

Based on the current situation, four policies are urgently required:

i) Clarification of the transition criteria between the SPCD Program and the DID System and standardization of disease nomenclature;

ii) Establishment of relief measures for SPCD patients whose conditions are not included among DID (*e.g.*, temporary extension of subsidies);

iii) An increase in the number of Transitional Care Support Centers nationwide and the creation of multiple regional hubs to reduce geographic disparities;

iv) Institutionalization of family-inclusive support, extending assistance to siblings and caregivers.

4. Conclusion

Patients with SPCD inevitably reach adulthood. Designing a policy framework that provides support over their course of their life is essential not only to promoting patients' independence and social participation but also to enhancing the long-term sustainability of Japan's healthcare system. Bridging institutional gaps and strengthening transitional care should therefore be considered a critical priority for Japan's rare and intractable disease policy.

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References

1. Karako K. Artificial intelligence applications in rare and intractable diseases: Advances, challenges, and future directions. Intractable Rare Dis Res. 2025; 14:88-92.
2. Liu Y, Ren Y, Song P. Traditional Chinese medicine for intractable and rare diseases: Research progress and future strategies. Intractable Rare Dis Res. 2025; 14:109-121.
3. Song P, Gao J, Inagaki Y, Kokudo N, Tang W. Intractable and rare diseases research in Asia. Biosci Trends. 2012; 6:48-51.
4. He A, Chen M, Song P, Wu Q, Jin C, He J. Protecting the socioeconomic rights and interests of patients with rare diseases based on an innovative payment mechanism. Intractable Rare Dis Res. 2024; 13:203-207.
5. Tang M, Yang Y, Ye Z, Song P, Jin C, Kang Q, He J. Release and impact of China's "Second List of Rare Diseases". Intractable Rare Dis Res. 2023; 12:251-256.
6. Ministry of Health, Labour, and Welfare, Japan. Rare disease countermeasures. *https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/kenkou_iryou/kenkou/nanbyou/index.html* (accessed September 15, 2025). (in Japanese)
7. National Center for Child Health and Development. Information Center for Specified Pediatric Chronic Diseases. Child Welfare Act (Legal Basis). *https://www.shouman.jp/about/law* (accessed September 15, 2025). (in Japanese)
8. National Center for Child Health and Development. Specified Pediatric Chronic Disease Information Center. List of designated diseases that are specified pediatric chronic diseases. *https://www.shouman.jp/disease/search/disease_list* (accessed September 15, 2025). (in Japanese)
9. Ministry of Health, Labor, and Welfare, Japan. Designated intractable diseases effective April 1, 2025 (Notification Nos. 1–348). *https://www.mhlw.go.jp/stf/newpage_53881.html* (accessed September 15, 2025). (in Japanese)
10. Transition Support Center. Transition Medicine Support Center map. *https://transition-support.jp/map* (accessed September 15, 2025). (in Japanese)

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