

Independence Support Services for Patients with Specific Chronic Pediatric Diseases

The new system now lightens the burdens for children and families who are faced with chronic diseases. It also supports independence and growth in children who are undertaking long-term treatment. These endeavors are made possible by utilizing regional social resources while also providing care based on the environment and other considerations relevant to the user.

(Aims and details of the services)

By providing support, the services are intended to promote independence in children who are experiencing a delay in their access to education and social skills at school and who face obstacles in becoming independent due to chronic diseases suffered since early childhood.

(Implementing bodies)

Prefectures, designated cities, core cities

(Relevant legislation)

Child Welfare Act: Article 19 (22), Article 53

Necessary Services (Article 19 [22], Item 1)

Counseling Support Services

The primary details concerning counseling services are provided below. However, the prefectural governments or other relevant body will maintain and put into practice appropriate counseling support systems, in light of conditions in the region.

1. Rehabilitation Guidance Counseling

Based on the rehabilitation guidance contact form, a physician or similar person will provide guidance to the families of patients with specific chronic pediatric diseases regarding nursing, food and nutrition, and dental health, in addition to counseling providing information on the welfare system and mental support, maintaining contact with schools, and other details necessary for everyday life.

2. Visiting Guidance Counseling

There are some patients whose situation makes it difficult to provide social services. It is necessary to provide rehabilitation and counseling in their homes for patients such as these. For patients with specific chronic pediatric diseases who are in this situation, an assigned specialist physician or similar person will form a rehabilitation guidance team and will undertake trips and visits to give guidance counseling while maintaining contact with the relevant institutions. The physician will provide guidance via home visits as necessary.

3. Peer Counseling

This service is intended to relieve the worry felt by families with children who have specific pediatric chronic diseases. It does so by connecting them with people who have experience raising children with specific pediatric chronic diseases, and who can give counseling and advice about everyday life and school.

4. Counseling to Encourage Independence

Children with specific chronic pediatric diseases deal with society while being burdened by their disease. This service provides psychological and other counseling to raise awareness about symptoms, help build relationships with family and surrounding people, and encourage independence.

5. Provision of Correspondence and Information for Counseling from Schools, Industries, Regional Affiliates, and Others

This service provides support counseling for schools, industries, and other institutions that receive patients with specific chronic pediatric diseases. It also provides information and promotes public understanding and awareness of these diseases.

Independence Support Members for Patients with Specific Chronic Pediatric Diseases

1. Creation and Follow-up of Plans Used for Policies Resulting in Independence Support

This service implements support and follow-up, leading to the formation of plans to encourage independence in patients with specific chronic pediatric diseases, while managing implementing institutions. By doing so, the service aims to empower the patients to achieve independence and employment on their own terms.

2. Managing Communication with Related Institutions

As an individual support for patients with specific chronic pediatric diseases, this service maintains

communication with schools, industries, and other institutions, as well as providing information about the support policies implemented by various institutions and groups.

3. Participation in the Regional Support Conference for Children with Chronic Diseases

As members of the Regional Support Conference for Children with Chronic Diseases, patients can participate in discussions, and can also report on initiatives and state their opinions.

Optional Services (Article 19 [22], Item 2)

Recovery Support Service

Aim: To improve the recovery of patients and to provide patients with surroundings in which they feel comfortable so that families and patients with specific chronic pediatric diseases can live in their local neighborhood and feel a sense of wellbeing.

Details: This service places patients with specific chronic pediatric diseases temporarily in a medical institution or otherwise appropriate facility and provides necessary support, including recovery maintenance and assistance in everyday life.

For example, the service provides respite services from medical and other institutions. (Article 19 [22], Item 2 [1])

Mutual Communication Support Service

Aim: To encourage independence and enable the cultivation of communication skills, information gathering skills, and social skills through mutual communication between patients with specific chronic pediatric diseases.

Details: This service provides a chance for mutual communication and other accommodations.

For example, the service holds workshops and provides opportunities for patients with specific chronic pediatric diseases to communicate with each other. It also provides opportunities for persons who have contracted specific chronic pediatric diseases and the families of other patients to communicate. (Article 19 [22], Item 2 [2])

Employment Support Service

Aim: For patients with specific chronic pediatric diseases who wish to work but face obstacles

finding employment due to long-term, chronic disease, this service aims to provide employment support and expand general employment opportunities in cooperation with regional associates. By doing so, the service aims to promote an increase in the independence and social participation of patients with specific chronic pediatric diseases.

Details: This service provides the support necessary for gaining employment. It also provides employment information.

For example, the service organizes work experience, work site visits, and provides support in acquiring employment skills. Additionally, it provides and collects information about employment support policies, among other functions. (Article 19 [22], Item 2 [3])

Caregiver Support Service

Aim: To improve welfare for patients with specific chronic pediatric diseases by reducing the physical and mental burden on caregivers and, as a result, improve recovery and family environments.

Details: This service provides the support necessary to reduce the burdens on caregivers.

For example, the service provides support in attending patients with specific chronic pediatric diseases during hospital visits. It also provides support with accommodations for family members accompanying patients, as well as support in looking after the patient's siblings. The service also includes practical nursing courses for families. (Article 19 [22], Item 2 [4])

Other Independence Support Services

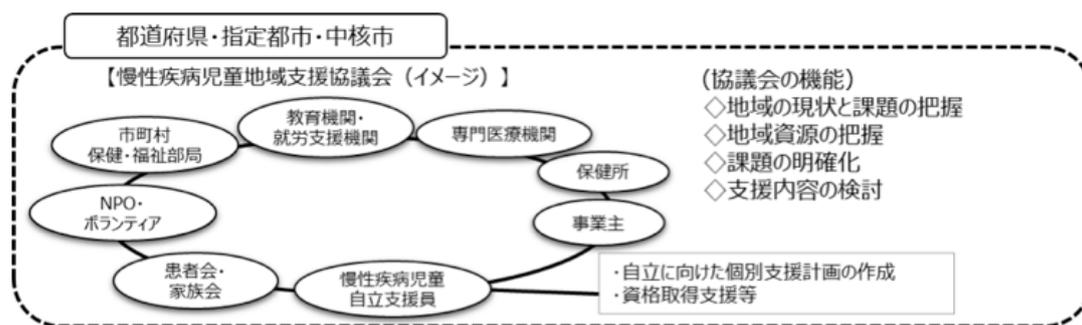
Aim: To provide support other than the services above for children and other patients who face obstacles in becoming independent and have a delay in their access to education and social skills at school due to chronic disease.

Details: The services provide the support necessary for independence.

For example, the services provide learning support for instances such as delayed learning due to circumstances including long-term hospitalization, as well as support for body strengthening. The services also include health management classes to enable independence, as well as support for the improvement of communication skills. (Article 19 [22], Item 2 [5])

Management Service for the Regional Support Conference for Children with Chronic Diseases

The new system has put into place a structure for affiliates to undertake discussions about the support details and other matters for patients with specific chronic pediatric diseases in their region. Each implementing institution (prefectures, designated cities, core cities) has established a “Regional Support Conference for Children with Chronic Diseases” which seeks to ascertain the situation and issues in the region, understand regional resources, clarify issues, and examine support details. In doing so, the institutions promotes the “Independence Support Services for Patients with Specific Chronic Pediatric Diseases”.



※上記画像内の翻訳は以下の表にてご確認ください。※

日本語	English
都道府県・指定都市・中核市	Prefectures, designated cities, core cities
慢性疾病児童地域支援協議会（イメージ）	Regional Support Conference for Children with Chronic Diseases (image)
市町村保健・福祉部局	Municipal health and welfare bureaus
教育機関・就労支援機関	Education institutions and employment support institutions
専門医療機関	Specialist medical institutions
保健所	Health care center
事業主	Service provider
<ul style="list-style-type: none"> ・ 自立に向けた個別支援計画の作成 ・ 資格取得支援等 	<ul style="list-style-type: none"> • Creation of individual support plans for independence • Support and other activities for resource acquisition
慢性疾病児童自立支援員	Independence support member for children with chronic diseases
患者会・家族会	Patient meetings and family meetings
NPO・ボランティア	NPOs and volunteers

<p>協議会の機能</p> <ul style="list-style-type: none"> • 地域の現状と課題の把握 • 地域資源の把握 • 課題の明確化 • 支援内容の検討 	<p>Functions of conferences:</p> <ul style="list-style-type: none"> • Understanding the situation and issues of the region. • Understanding regional resources. • Clarification of issues. • Examining support details.
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