

ORIGINAL RESEARCH ARTICLE

# On Children with Rare Diseases: “Dislocation” and “Replacement” in Delivery of Welfare Services from the Perspective of State Parental Power

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**Keywords:** State Parental Power, Children with Rare Diseases, Young Family, rare diseases, social care, social security, China

## ABSTRACT

### Background:

China's child welfare system is a the process of transition from compensation-type to moderate inclusive type. However, it still heavily relies on the path of compensation-type. Based on insufficient national governance capabilities, the core of welfare in China is being challenged and it has lead to the dislocation and insufficiency of welfare supply to children with rare diseases. A multi-coordinated national care service system is urgently in need to be developed.

### Objectives:

In the context of state parental power, what is the current situation of welfare of children with rare diseases in China? What are the characteristics? How to play a coordinated role of all stakeholders in the care delivered to children with rare diseases?

### Methods:

The methods of interview, literature review and questionnaire survey were used to understand the basic situation of children with rare diseases and the interaction between the welfare provider and the providing mechanism. Basic information on children with rare diseases, family status and needs were collected. Relevant literature on the protection of children with rare diseases from the central government was analyzed.

### Results:

Fourfold dislocation impedes the provision of resources for the welfare delivered to children with rare diseases. Economically, the government's basic welfare services for children with rare diseases seems insufficient In the healthcare field, the quality of specific services offered by healthcare organizations is uneven. In terms of timing, children with rare diseases face the effects of having few caregivers allocated.

### Main Contribution to Evidence-Based Practice:

This paper analyzes the status quo of welfare services and healthcare delivered to children with rare diseases. It analyzes the causes of difficulties and insufficiency of the welfare services and policies for the children with rare disease and puts together knowledge for evidence-based practice and policy-making for children with rare diseases.

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**What do we already know about this topic?**

Available evidence supports an overview of the current welfare policies aiming to support children with rare diseases.

**What is the main contribution to Evidence-Based Practice from this article?**

This article analyzes the status quo of the welfare policy for children with rare diseases. This paper analyzes the status quo of welfare services and healthcare delivered to children with rare diseases. It analyzes the causes of difficulties and insufficiency of the welfare services.

**What are the implications towards theory, practice, or policy?**

The article puts together knowledge for evidence-based practice and policy-making for children with rare diseases

**Author' Contributions Statement:** Ji conceptualized and drafted the article. Wang, LI & LI undertook the research through the method applied and revised the article.

*The* term "Rare disease" refers to the low prevalence of some diseases, usually chronic and serious diseases, can lead to disability, and even life-threatening. Currently, about 6-8% of the world's population suffers from rare diseases, and there are 10-20 million such cases in China. Other statistics show that 30 percent of rare disease patients in China involve nearly 20,000 families, and about 50 percent of the patients are children.

With the changes of family structure and family relationship, traditional family security and service functions are weakened. Particularly in the context of the social welfare model for persons with disabilities developed since the reform, which is based on a network of family and social relations and involves the lower levels of the state in selective assistance, families with children with rare diseases bear the burden of overwhelming medical difficulties, lack of alternative care and social exclusion (Liu Jitong, 2008).

At present, the path dependence of child welfare is still serious. Children's welfare is one of the most indebted and underdeveloped areas in China's history, the most backward development and the weakest welfare (Yao Jianping, 2015). So, in the context of state parental power, what is the current welfare status of young Chinese families with rare childhood illnesses? What are these features? How can synergy be achieved in the care of children with rare diseases in young families? These are the concerns of this article.

2. LITERATURE REVIEW

(1) parental rights in the State

"Parental power" is a set of rights and obligations derived from specific status, which refers to the rights and obligations of the parties to their minor children's

personal rights, property rights and interests according to their parents' status. (Zhang Hongwei, 2014).

Parental authority of the state refers to the right of the state to take the place of the legal guardian if the parents or legal guardian of the minor can not properly fulfill their obligations. Generally speaking, parents are the first duty person, professional personnel are important duty person, the state is duty person, the society is duty person. The role of social workers in the social work of children is to represent the state in the exercise of the rights of the state's parents, and their functions include monitoring the fulfilment of their duties and assessing the capacities of parents, supplementary support is provided to families with insufficient capacity for guardianship and temporary or permanent alternative care is provided to families with insufficient or insufficient capacity for guardianship in accordance with legal procedures.

(2) State care for children

First of all, the state care for children is based on the concept of protecting children's rights. Since the promulgation of the United Nations Convention on the rights of the child, the concept that the family and the state should share the responsibility for the care of children has been widely accepted in all countries of the world, state intervention in child care has legal implications (Boy Scouts, 2018); second, state care for children needs to be based on a set of laws and regulations. For example, western welfare states such as the United Kingdom and the United States have specific child welfare regulations (Holiting, 2018); national childcare must then have a specific organizational structure to ensure implementation. The scouts propose four levels of protection: Discovery Monitoring, reporting assessment, response intervention and return placement, each with its own



organizational unit. Finally, the state's allocation of resources for child care consists mainly of the human, financial, material and equipment resources available for child intervention and protection. This is a prerequisite and necessary preparation for service development (Liu Jitong, 2007).

Guided by this theory, what is the welfare status of children in young families with rare diseases? Is there any corresponding allocation of resources, including personnel, property and equipment, that can be used to intervene and protect children? The purpose of this study is to give full play to the role of the state in child care, to highlight the functions of social welfare services and mental security, and to explore new ways to construct welfare policies, to provide preventive and supportive welfare services for children with rare diseases in young families and to improve the welfare level of children with rare diseases in young families.

### (3) Child Welfare Services

Child welfare services consist of two parts: one is services for children with normal family life, such as day-care services and rehabilitation services for children with serious illnesses. A large proportion of child welfare services are also targeted at children who do not have access to normal family care and those who have suffered physical and emotional trauma.

Some scholars believe that the modern inclusive child welfare service hierarchy consists of three levels: macro, broad child welfare refers to the level of all ministries involved in children, family services; Middle-level child welfare services refer to medical and health services; micro-and narrow-level child welfare services refer to maternal and child health (Liu Jitong, 2020).

Scholars Kadushin and Martin divide child welfare services into supportive child services, complementary child services and alternative child services. Taiwanese scholar Ding Biyun divides child welfare into General Child Welfare Service and special child welfare service (Ding Biyun, 1975). Xiong Huiying, a scholar in Taiwan, divides child welfare services into four categories: judicial protection, medical care, education and welfare services. Lee Jong-won, a Taiwanese academic, divides child welfare into three categories: counselling, support and alternative services.

Counselling services are mainly for the promotion of children's education and ancillary services include child health care and disease prevention and treatment, alternative services include the establishment of nurseries, the introduction of family allowances, the

establishment of nurseries and foster family services (Lee Jong-won, 1983). According to the Taiwanese scholar Ke Sanji, the scope of child welfare services includes: foster care, adoption, child care, protection services and family subsidies, family services, child protection and seven categories (ke Sanji, 1986).

On the basis of the classification of child welfare services by the above-mentioned scholars, and according to the special needs of children suffering from serious diseases, the child welfare services of families with rare diseases were divided into three levels: basic welfare, supportive welfare and developmental welfare. In this study, support provided by the state/Society to Families/parents of young children with rare diseases (in the form of action studies) and support provided by patient groups were selected as medical benefits and care services for basic welfare services, educational Welfare and rehabilitation training of developing welfare services are the focus of the study.

In this study, the subjects were defined as children aged 0-18 years with a rare disease that severely threatens their life and health. August 25, 2019. As of 20 September 2019, 13,235 valid questionnaires were received, of which 5,088 were completed by patients with rare diseases themselves and 8,147 by family members or other primary carers. Combined with data processing and analysis, this paper probes into the status quo of child welfare service resource allocation in families with rare diseases from the aspects of economy, medical treatment, time and environmental construction, etc.

This study analyzed the medical status of children with rare diseases according to whether they were hospitalized, the times of seeing a doctor, the frequency of seeing a doctor and the difficulties they encountered in the past year. Data show that in the past year, 34.6% of patients did not go to medical facilities for treatment of rare diseases. Patients often go to the medical institutions are municipal hospitals or specialized rehabilitation hospitals. They chose these hospitals mainly because of good medical technology (47.7%), convenient treatment (17%), high reimbursement rate (1.6%) and good quality of service (1.7%)(see Table 1).

At present, China's child welfare system is in the process of transition from gap-filling model to moderate inclusive model, but the gap-filling model is still very prominent. At any time, there is the possibility of "Disease leading to poverty". However, health insurance coverage for children in young families with rare diseases is very low and minimum subsistence allowance coverage is very low, the MSA is also far from sufficient to meet the needs of families with children with rare diseases.

The distribution of rehabilitation institutions is unbalanced and the basic conditions are quite simple. Basic welfare services include basic medical and rehabilitation welfare services which can protect children from rare diseases in young families. The limited number of institutions providing rehabilitation training for children with rare diseases, coupled with the fact that rehabilitation training for children with hearing impairment and other special needs usually requires one-on-one professional training, very few children with rare diseases actually receive rehabilitation training. The survey found that small classes in rehabilitation facilities are also taught by two or three children at the same time, with few one-on-one classes. At the same time, the phenomenon of hospital beds has also emerged due to the large number of children with disabilities in hospitals. Basic Medical and rehabilitation welfare services as basic welfare services do not fully protect the interests and needs of young families with children with rare diseases. The division of labour in the family and the multiple demands on the time and energy of the caregiver result in the lack of rehabilitation, education and social integration of the caregiver, and the corresponding rehabilitation of children with rare diseases can not be carried out normally or continuously, especially 0-6 years old is the best period of rehabilitation intervention for children with rare diseases. Since care for children with rare diseases can only be provided by families, young families spend most of their time and energy caring for children with rare diseases, which limits the range of employment options and family income levels. At the same time, the drugs and rehabilitation measures needed by children with rare diseases are a considerable expense for families, creating a vicious circle in which families can not make ends meet. However, supportive welfare services do not work as well as they should and do not meet the needs of young families caring for children with rare

diseases due to problems with care.

The development of welfare services focuses on the rehabilitation of young families with rare diseases and children with a bright future, including educational benefits, rehabilitation training and recreation. The survey shows that the social participation of the children with rare diseases in their families is not high and the leisure and entertainment mode is monotonous. The top three most popular entertainment activities were watching TV (61.8%) , surfing the internet (41.3%) , reading books, newspapers and magazines (31.1%) . The frequency distribution of other recreational activities was as follows: Listening to music (29.6%) , shopping (16%) , painting and calligraphy (15.7%) , sports (8%) (see Figure 1) .

Due to the physical disability of many rare disease sufferers, the country still lacks barrier-free facilities or a barrier-free social environment, and there are fewer recreational facilities and services suitable for young families of rare disease children, the social participation of children with rare diseases in young families is not high, and the ways of leisure and entertainment are relatively monotonous. The creation of a child-friendly social environment can only be achieved through the formulation of policies at the national level. It was clear that the state was not doing a very good job in allocating resources in terms of adequate accessibility and recreational facilities.

In order to make up for the rights of children with rare diseases, this paper argues that under the realistic condition of the "Separation" of the main services and responsibilities of child welfare providers, from the perspective of "National parental rights", emphasizing the role of the state in providing coverage for the well-being of children with rare diseases, actively guiding governments in cross-sectoral cooperation, encouraging and guiding the participation of social forces in the provision of benefits, and coordinating relevant national nursing policies, strengthen support for families so that children with rare diseases can grow up in the same "Sunshine" as their peers, as shown in Figure 2.

From the perspective of the history of child welfare, the values of our country's children's medical policy-making have experienced the processes of "Children are the appendages of family and parents", "Children are independent civil subjects" and "Children are the

groups that need special protection and special treatment". Therefore, the leading role of the state in the welfare system for children with rare diseases should be emphasized, to provide life support, medical care, educational support and social welfare services for families of children with rare diseases.

Among the most urgent support policies for families with children with rare diseases is state support for research, development and dissemination of drugs for rare diseases.

Secondly, the definition and legislation of rare diseases should be clarified as soon as possible. As an unrelated disease group, we can only make an authoritative definition and legislation on rare diseases as soon as possible, so as to do a good job in the next step of the incidence of disease, disease spectrum, the number of patients with information screening statistics, and so on, to establish the national database of rare diseases, improve the level of diagnosis and treatment of rare diseases, and safeguard the social security rights of rare disease patients.

Third, from the perspective of development-oriented social policies and investment in human resources, special attention should be paid to strengthening source-based interventions and implementing a three-tier prevention system to prevent birth defects and reduce the incidence of rare diseases. Through regional cooperation and remote support, we hope to improve the comprehensive diagnosis and treatment of rare diseases in hospitals at all levels, and gradually realize the goal of early detection, early diagnosis, early treatment and management of rare diseases.

Government Coordination: cross-sectoral collaboration to ensure a comprehensive network of rehabilitation services for children with rare diseases

Organizations and departments at various levels, including the relevant departments, the Working Committee on Women and children, the office for the protection of minors, the Communist Youth League, the Public Security Law, the Federation of Persons with disabilities, the health system and the education system, are all involved in the welfare of children with rare diseases, there is an urgent need for a executive branch to organize and coordinate some of the work that has not yet been done. At the same time, a large number of charitable organizations and non-governmental organization in the field of the welfare of children with rare diseases are also actively involved in the diagnosis and treatment of diseases, medical assistance and

other welfare services.

It is an important step to establish a national charity information platform for RARE disease children to integrate resources and improve the work of rare disease children relief. Among them, a national screening system for children with disabilities must be established and the maternal and child health network in the health sector must be effectively linked to the rehabilitation services network for children with disabilities in the China Disabled Persons' Federation sector.

As non-governmental organization or associations of "Localised communities", social welfare service organisations act as a bridge and intermediary between the state, the market and individuals, it has played an active role in the development of citizens' participation in public life to express themselves and is the third way to achieve the transition from the welfare state to a welfare society, and is an important force in supporting children in need and their families.

In the future, the government needs to increase its support for various patient organizations to promote the training of professional personnel, and various self-help organizations need to further unite, strengthen self-help awareness and self-help culture, and strengthen professional support and supervision, improve the running ability of the organization. From management to welfare governance, from traditional hierarchies to the establishment of a cooperative network between the public and private sectors.

(4) family support: to co-ordinate the relevant care policies to alleviate the pressure on families with young children to take care of their children

As shown in Figure 3, according to Plumer's classification of children, adolescents and their young families, foster homes and children's homes, and the range of services subsequently provided by professional care providers, supporting Young families is the first choice for child care. The first part of the care system, the family support system, as the most basic child care subject, is also under great pressure to replace the state in fulfilling its care obligations.

( see Figure 3 on the continuity of care)

The welfare of children with rare diseases in young families therefore requires a five-in-one policy. First, to clarify the responsibilities of the state, the family and society in the welfare of children, and to emphasize the leading role of the state in the welfare system for children with rare diseases, to formulate and revise the

regulations and policies on the definition of rare diseases, drug research and development, disability identification standards and so on, to strengthen the construction of the three-level prevention system of birth defects, and to reduce the incidence of major diseases; Second, actively guide the government to carry out cross-sectoral cooperation to ensure the implementation of the improvement of the network of rehabilitation services for children with rare diseases initiatives. Finally, we should strengthen the support to the family, coordinate the current national nursing policy, share the nursing expenses of the rare disease children, and reduce the nursing pressure of the young children's families.

### CONCLUSIONS AND RECOMMENDATIONS

In the process of social transformation in China, the risks faced by children have greatly increased, and children with rare diseases need special protection as victims of risks. Compared with the well-developed child care policy in the west, the target groups of China's child care policy are mostly abandoned infants, orphans and children in distress, and the policy arrangement is fragmented. At present, there are some weaknesses in the provision of welfare service resources, delivery in the level of income, the cost and efficiency of medical rehabilitation, the guarantee of care time and the support of service resources for families with rare disease children. Therefore, it is urgent to explore the system of welfare service resources production, delivery and reception from the perspective of national parental rights. First, to reduce the cost of diagnosis and treatment for children with rare diseases and provide economic security; second, to improve the efficiency of diagnosis and treatment for children with rare diseases and provide medical security; third, to coordinate relevant care policies and provide time security for children with rare diseases; Fourthly, we should improve the coordination ability of departments and social organizations and provide service guarantee. problem that needs further research and debate.

### FIGURES AND TABLES

Figure 1: Family entertainment for children with rare diseases

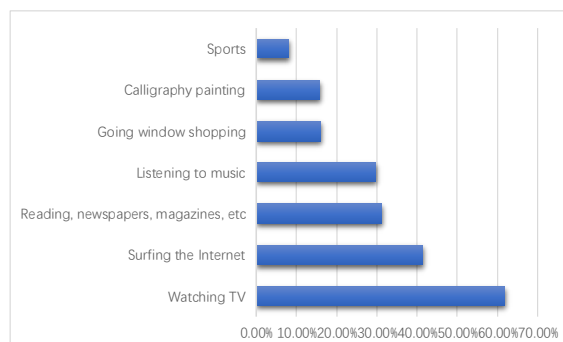


Figure 2: Multi-complement Welfare Service Resource Delivery Chart

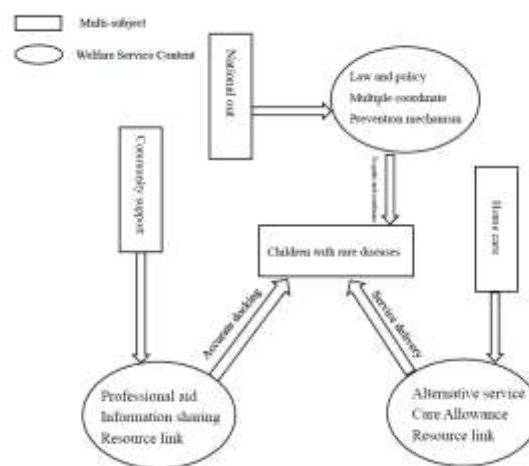


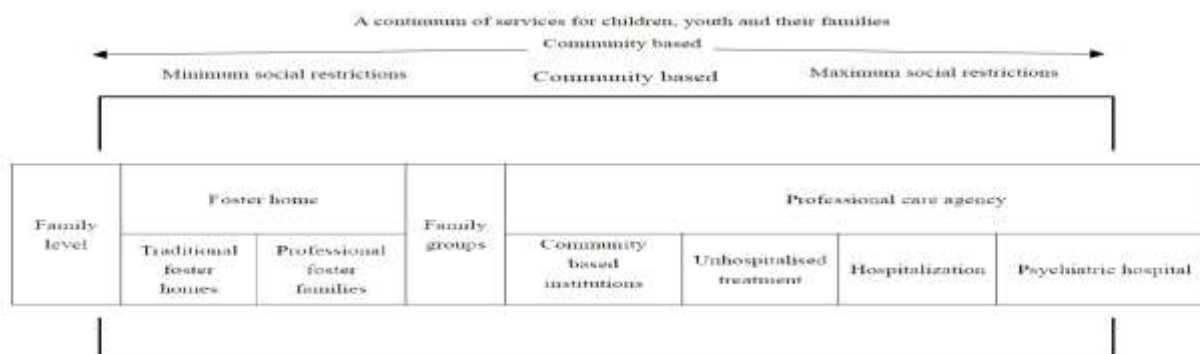
Table 1: clinical information status of children with rare diseases (units: %)

Medical consultation of children with rare diseases	Sample size	Percentage
Have you been hospitalized for treatment of this rare disease in the past year		
No	555	69.0
Yes	249	31.0
Have you attended a medical facility for treatment of this rare disease in the past year		
No	279	34.6
Yes	527	65.4
The most frequently visited medical facilities for rare diseases are		
Private clinics, private hospitals	49	6.2
Hospitals below county level	55	7.1
District/municipal hospitals or specialized rehabilitation hospitals	568	72.3
I Don' t go to the hospital much	114	14.5
The greatest difficulty you have in treating a rare disease		
The hospital is too far away	56	7.5
The cost of treatment is prohibitive	239	32.2
Lack of medical skills	148	19.9
Registration difficult	24	3.2
Can' t get the right medicine or the price is too high	183	24.7
There are no major obstacles	15	2.0
In the news	77	10.4

Table 2: policies supporting drug R & D for rare diseases in different countries

National area Or organization	Regulatory (time of promulgation)	policy of population classified as rare	Number of cases per10,000	Pharmaceutical Market exclusive period	Tax deduction	Health care system
The United States	Medication for rare diseases (1983)		7.5	Seven years	Yes: 50% of the cost of clinical research	Government health care plan, Commercial Insurance
European Union	ECN141/2000 Rule (2000)		5	10 years	Member States are encouraged to grant tax preferences	The 27 member countries have different policies
Australia	Guidelines for the administration of rare diseases (1998)		1.1	5 years	No	Life Saving Drugs Fund scheme
Japan	Administration system for rare diseases (1993)		4	10 years	Yes: 6% of total drug development costs + no more than 10% of corporate tax	The National Health Insurance (NHI) offers a 10% discount on drug prices
Korea	Medication guidance for rare diseases (2003)		4	6 years	No	Medicare, two-thirds

Figure 3: continuum of care



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