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Ensuring Family Support in Disability Services through a Case Study of Caregivers for Individuals with Mental Disabilities

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Abstract

Over the past few years, China has seen a growing prevalence of mental disabilities, with the number of affected individuals increasing each year. These individuals often require extended periods of rehabilitation, which places considerable caregiving responsibilities on their families. Rooted in traditional Chinese culture, families typically assume the role of primary caregivers, driven by a sense of duty and the societal stigma surrounding disabilities. This stigma fosters a cultural norm of keeping family issues private, leading families to operate within a socially insulated space shaped by persons with disabilities and service providers. The prolonged caregiving responsibilities also highlight the need for support systems that extend to caregivers. However, existing support structures in China largely focus on individuals with mental disabilities, overlooking the rights and protections needed by their caregivers. This study employs social ecological system theory to explore the challenges faced by family caregivers. Additionally, it draws on Esping-Andersen's welfare regime framework to analyze the welfare protections available to caregivers of persons with mental disabilities in the UK, considering four key dimensions: rights support, economic assistance, time-related support, and service provision. The goal is to offer insights and recommendations for enhancing China's welfare protection system for caregivers.

Keywords: Mental disability, welfare system, social ecological system theory

I. Introduction

According to the China Mental Health Survey (CMHS) reported by Professor Huang Yueqin of Peking University Sixth Hospital, one in seven residents in China will experience a mental disorder, totaling approximately 173 million individuals. The number of people with common mental disorders and psychological and behavioral problems is increasing annually, with the prevalence of depression at 2.1% and anxiety disorders at 4.98%. By the end of 2017, 5.81 million people with severe mental disorders were registered nationwide. Persons with mental disabilities refer to those whose mental disabilities persist for more than a year without recovery, affecting cognition, emotions, and behavior, and impacting daily life and social participation. This includes conditions such as schizophrenia, depression, anxiety, and obsessive-compulsive disorder (Chen Gong et al., 2014). The family is a crucial system for the care and survival of persons with mental disabilities, and family caregivers face a significant and long-term caregiving burden (Hua Hongqin, 2015). Including family members/caregivers as recipients of disability service protections has become a trend in disability policies in many countries/regions (Chou et al., 2009; Foster et al., 2016). In 2020, Hong Kong introduced the "Disability and Rehabilitation Programme Plan," which proposed community support measures for family members or caregivers. However, China has not yet introduced protection policies for caregivers of persons with mental disabilities. Family caregiving for persons with mental disabilities is a long-term stress event, and the negative impact of prolonged caregiving pressure indicates that families also need support. Establishing a related protection system can help promote family stability, harmonious relationships, and public well-being (Leng et al., 2019).

II. Caregivers of Persons with Mental Disabilities from the Perspective of Social Ecological System Theory

Social ecological system theory divides the human social ecosystem into micro, meso, and macro systems. The micro system includes physiological, psychological, and social systems that directly affect individuals. The meso system refers to small groups that influence individuals, such as families, workgroups, and social groups. The macro system encompasses larger groups and systems than meso systems, such as organizations, institutions, policies, and cultures. In ecological system theory, human behavior is interconnected and influenced by the social environment (Lian Yan et al., 2013; Zhuo Caiqin, 2013). Influenced by traditional beliefs and the primary social function of families to provide care for members, family members, including spouses and parents, play a key role in the caregiving system when a family member experiences long-term illness (Huang Chenxi et al., 2019; Tong Xueli, 2018).

From a micro-level perspective, individuals with mental disabilities require prolonged treatment, and caregivers often experience constant tension and stress, leading to heavy psychological burdens, including feelings of guilt, anxiety, and helplessness. Their normal living state is disrupted, and for caregivers who need to provide long-term support due to

severe disabilities, they may have to forgo social circles and work opportunities, leading to physical and mental exhaustion. At the meso level, most services provided by hospitals or rehabilitation institutions are focused on individuals with mental disabilities, lacking training for caregivers on caregiving skills and attention to their mental health. Caregivers do not receive timely support and face dual pressures from the workplace and caregiving responsibilities. At the macro level, there is a lack of a systematic service system. Currently, rehabilitation and treatment for individuals with mental disabilities are primarily concentrated in hospitals and rehabilitation institutions, and caregivers are exhausted by running around. Additionally, society often views individuals with mental disabilities through a stigmatizing lens, associating them with irresponsibility, irrationality, aggression, deviance, danger, and other negative stereotypes, exaggerating their "abnormal" negative image, and rarely recognizing positive traits such as kindness and friendliness. In the context of traditional Chinese culture, individuals with mental disabilities and their families are often associated with being "burdens" or "shameful," leading to varying degrees of stigma, concealment of illness, and other behaviors (Holroyd, 2003; Chen Renxing, 2020; He Xin, 2019; Ma Qiqi et al., 2019; Yue Ying, Song Lisheng, 2000).

III. Establishing the Policy Analysis Framework

Esping-Andersen classified welfare state regimes into three types based on key indicators such as the degree of decommodification, social stratification, and the strength of relationships between the state, market, and family. The first type is the liberal welfare regime, seen in countries like the United Kingdom and the United States, which are primarily market-oriented. Under a "protectionist" approach to social rights, these countries apply strict eligibility criteria for social assistance, providing means-tested social assistance programs, limited social insurance, and employment-based welfare services. The conservative welfare regime, represented by countries such as France and Germany, features "performance-based social rights," with social insurance segmented by occupation, heavily influenced by corporatism. The principles of mutual aid and solidarity are particularly significant. The third type is the social democratic welfare regime, represented by countries like Sweden and Denmark, characterized by universal social rights and inclusive social welfare. These countries implement full employment policies and establish strong public social service networks, resulting in the lowest levels of social stratification (Esping-Andersen, 1990).

The UK is one of the earliest countries to implement a social security system, and its social security system is relatively advanced. Different welfare regime types prioritize different policy tools, forming distinct combinations of policy tools. A country's choice of policy tools reflects its policy philosophy, views on rights and responsibilities, and the distribution of responsibilities among the state, market, and family (Fang Lijie & Chen Huiling, 2021). As some countries legally protect the rights of persons with mental disabilities and their families, this paper includes rights support tools in the analysis. Rights support tools mainly promote equality, empowerment, and rights protection for

families of persons with mental disabilities through legal and policy provisions, ensuring equal opportunities, realization of social rights, and civic participation and social inclusion.

Economic support tools compensate caregivers (families) for the additional economic costs incurred from caring for persons with mental disabilities through measures such as social assistance, welfare allowances, and tax reductions, thereby alleviating the family's financial burden. Time support tools are reflected in the provision of parental leave, maternity leave, and flexible working hours, supporting persons with mental disabilities and their caregivers to participate in employment as fully as possible, maintaining a balance between family and work. Service support tools provide personalized service measures, such as respite services and caregiver support services, to meet the personalized and differentiated needs of persons with mental disabilities.

According to Esping-Andersen's classification, the UK is considered a liberal welfare regime, implementing a mixed family protection policy. Based on functional assessment and means-testing as eligibility criteria, the UK primarily provides welfare protection through economic support tools, with cash allowances and tax benefits as the policy foundation, and living allowances for persons with mental disabilities as a basic welfare benefit. Although the UK operates under a "weak state—strong market" relationship model, its level of social support for persons with mental disabilities is higher than that of other liberal welfare regimes, such as the United States, with families playing a significant caregiving role for persons with mental disabilities. The UK's current social security system, while improving the basic living conditions of persons with disabilities, also fully considers their social inclusion, providing corresponding support to ensure their normal lives (Yang Lixiong, 2014).

Social service programs in the UK are detailed and diverse, tailored to different age groups, degrees of disability, and service fields, centered on the needs of persons with mental disabilities, demonstrating personalized features to ensure service quality and effectiveness as much as possible. Social service programs include daily living services, rehabilitation services, special education needs assessment services, day care services, preferential services, garden care services, and home accessibility renovation services. From the provided service content, the UK effectively reduces the caregiving burden, pressure, and time for caregivers while providing professional services for persons with mental disabilities, fully protecting their rights. Therefore, analyzing some of the UK's policies is of great significance for drawing on the advanced achievements of Western societies and creating a social welfare system and social security framework with Chinese characteristics.

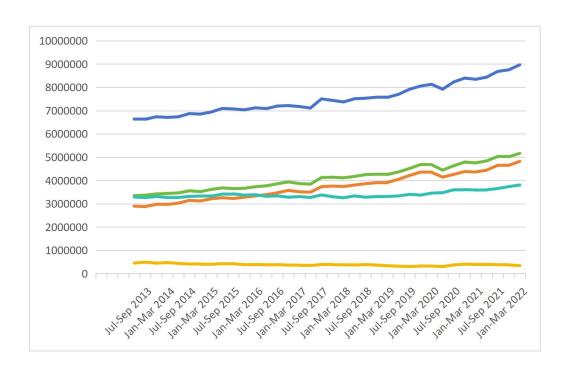


Figure 1 Employment status of people with disabilities in the UK

· Blue Line: Harmonised Standard Definition Disabled1 Total

Orange Line: In Employment Yellow Line: Unemployed

Green Line: Economically active Teal Line: Economically inactive

Reference: https://www.ons.gov.uk/employment and labour market/people in work/employment and demployee types/datasets/labour market status of disabled people a08

IV. The UK: Mixed Family Support Policy

1. Rights Support Tools: Empowerment and Legalization of Caregivers' Rights

(1) Empowerment and Legal Protection of Rights for Disabled Children and Their Families

The 1970 Chronically Sick and Disabled Persons Act is considered the foundation of disability legislation in the UK. It ensures that persons with mental disabilities have access to social welfare, community services, education rights, and accessibility facilities. The Disability Discrimination Act (DDA), implemented in 1996, further specifies the rights of persons with disabilities and aims to address the discrimination they face. It refines the definition of disability and sets legal grounds across various fields, including employment, rehabilitation, and education. It requires employers and service providers to adopt fair and flexible attitudes, taking practical steps to eliminate barriers for persons with disabilities. If discrimination against persons with disabilities is proven in court,

businesses may face fines ranging from tens of thousands to hundreds of thousands of euros, ensuring that the rights of persons with disabilities in employment are protected. The Equality Act of 2010 further improved anti-discrimination laws, making them easier to apply and understand, aiming to eliminate discrimination against persons with mental disabilities in public life. The Special Educational Needs and Disability Act of 2001 protects the legal rights of mentally disabled children with special educational needs during compulsory education and in education, training, and other educational services beyond the age of 16.

(2) Clarification of Caregiver Rights and Legalization of Social Support for Caregivers

The Carers (Recognition and Services) Act of 1995 officially established the rights and legal status of family caregivers, supporting the assessment of their caregiving abilities. It mandates that the government pays for services to meet the needs identified in the care assessment, providing flexible support to caregivers in areas such as leisure, education, training, and employment. The UK's Mental Health Act of 1983 states that persons with mental illness are entitled to protection from assessment and treatment to rights, and they can receive care at home and in the community. Only patients with severe mental illness meeting the Act's criteria can be compulsorily detained for treatment (Yue Chen, 2008). The Mental Capacity Act, effective from 2007, affirms that everyone has the right to make decisions for themselves and provides guidance for caregivers and doctors on who can make decisions in cases where individuals are unable to do so due to cognitive difficulties or mental illness, respecting the autonomy of persons with mental disabilities.

2. Economic Support Tools: Welfare Allowances and Tax Relief

The UK government provides two main types of allowances for persons with mental disabilities: the Disability Living Allowance (DLA) and tax relief. The Disability Living Allowance mainly includes the Care Component and the Mobility Component. The Care Component is paid to persons with mental disabilities who require additional care and support. The Mobility Component, based on a means test assessing the degree of disability and care needs of the mentally disabled person, compensates caregivers who spend at least 35 hours per week caring for them and covers additional costs incurred by persons with disabilities when going out.

Every person with a mental disability is eligible for a wide range of social assistance and allowance programs, including grants for disabled facilities, care allowances, caregiver allowances, infrastructure grants, and more than a dozen other subsidies, ensuring that persons with mental disabilities can live independently and reducing the financial burden on families providing care (Wu Yan, 2007).

Table 2 UK Disability Support Policies Table

POLICY AREA POLICY POLICY CONTENT

	NAME	
	Living	Tax exemption subsidies for physical or mental disabilities,
	allowance	personal life assistance needs or walking difficulties, and
	for the	individuals aged 65 and below, respectively, care and
FAMILY LIFE	disabled	activity;
	Independent	Helping with severe disability (including mental disability)
	Living Fund	pay for personal and family care,
		And the subsidy can only be used to pay for the expenses
		of hiring others to take care of them;
	Subsidy for	Provide corresponding subsidies for people with
	disabled	disabilities when transforming or improving their home
	facilities	environment;
	Relief	People with disabilities or mental disabilities in a family or
TAX ALLOWANCE	program for	tenant may apply for household tax relief;
AND EXEMPTION	the disabled	
	Tax relief	Families with disabilities with an annual income of under
	for children	£58,000 are exempt from childrens tax;
		People with disabilities can apply for subsidies by
	vehicle	purchasing or renting cars, wheelchairs, motorcycles and
TRANSPORTATION		other vehicles;
PREFERENTIAL		Persons with disabilities can have a free tax certificate for
TREATMENT		all vehicles and other vehicles;
	Public	People with disabilities can take free buses during off-peak
	transport	hours;
	concessions	People with disabilities can get a third reduction in train
		fares with adults who accompany them;
		Care must be physically or mentally disabled and unable to
	Nursing	take care of themselves; £47.10 per week and £70.35 per
	subsidies	day;

MEDICAL	Care	Over 16 years old who provide at least 35 hours of nursing
REHABILITATION	provider	care per week for people with disabilities and who receive
	subsidies	£53.10 per week;

Table Content Reference: https://www.gov.uk/browse/benefits/disability.htm; Zhou Yun, 2010

3. Time Support Tools: Balancing Family and Work

The UK provides unique support services for caregivers of families with persons with mental disabilities, mainly by offering caregivers more caregiving time, balancing work and caregiving responsibilities, and protecting the rights of persons with mental disabilities and their families. The main policies include three aspects:

Short Break Vouchers: These vouchers provide flexible respite time and services for caregivers, along with relevant intervention services for both caregivers and persons with mental disabilities during the respite period.

Shared Parental Leave: According to the 2013 Children and Families Act, if a child (under 16) has a (mental) disability, both parents are entitled to corresponding leave, encouraging both parents to participate fully in the caregiving of their disabled child.

Flexible Working Time Support: Caregivers have the right to request flexible working schedules from their employers to help balance caregiving responsibilities and work.

4. Service Support Tools: Family Support Programs

The UK's NHS and Community Care Act of 1990 provides a legal framework for the care of persons with mental disabilities, primarily offering community care for them and their families. Traditionally, institutional care was the main approach for caring for individuals with mental illness and psychological disorders. This often involved merging or separately caring for orphans, persons with mental disabilities, and the elderly, isolating them from community life and weakening family structure functions. Institutional staff sometimes exerted control or even mistreatment over residents, leading to varying degrees of emotional, social, and intellectual harm to those in care (Lu Xinpeng, 2005). To maintain autonomy and avoid the "abnormal" life of institutions, community care has gained importance. It is not only a method of social service but also a social work model advocated under changes in the UK's welfare state policies. Community care allows care recipients to remain in their familiar community environment while receiving services. It mobilizes community resources and leverages interpersonal relationships, such as support from neighbors and non-kin residents, to provide appropriate services (Xia Xueluan, 1996). Community integration of social

resources ensures precise assessment of diverse needs and provides timely, comprehensive responsive services and social support, including health, social services, and education. In terms of healthcare, the Beveridge Report proposed establishing comprehensive healthcare services, including post-treatment rehabilitation for all disabled individuals, regardless of the cause of disability. Subsidies during rehabilitation should cover necessary expenses, such as transportation and accommodation. Social insurance contributors needing medical treatment are covered, including dependents such as housewives and children. The report also suggested regulations for the supply and replacement periods of various assistive devices, both to encourage careful use by users and to prompt relevant departments to supply the necessary devices on time.

V. Conclusion and Discussion: Constructing Family Support Policies for Mental Disabilities in China

Recommendations for caregiver protections should first focus on enhancing welfare protections for persons with mental disabilities. The UK has established a relatively comprehensive social security system, which, when adapted to China's context, holds significant implications for improving and developing China's welfare system. The foundation of family support policies for persons with mental disabilities is legislation and rights protection. Policy development and service delivery should view persons with mental disabilities as equal citizens rather than mere recipients of social assistance. A family-centered approach is not only a policy concept but also a means of service delivery, as supporting families often proves more effective and sustainable than supporting individual disabled children. The person-centered care philosophy should be integrated into the social ecological system theory, encompassing the macro system (government organizations, legal systems, regulations), meso system (communities, hospitals, professional social groups), and micro system (family caregivers). Solutions should be sought from the perspective of persons with mental disabilities, reducing conflicts and easing the multifaceted pressures on caregivers, while preserving the dignity of persons with mental disabilities. Whether care is provided by families or professional institutions, it should align with the actual needs of individuals, minimizing non-cooperation or even aggressive behaviors arising from unmet needs, thus reducing the burden on family caregivers.

(A) Shift from Individuals to Caregivers: Accurately Identifying the Needs of Mental Disability Caregivers and Building a Caregiver Support System

Through precise needs assessments of caregivers for persons with mental disabilities, personalized social support plans and "tailored services" should be developed to build a caregiver support system that maintains family-work balance.

Economic Support Policies for Caregivers: Establish a tiered family allowance system for persons with mental disabilities, where cash allowances and tax

incentives serve as inclusive subsidy policies. Allowances should be provided according to the severity of mental disability but should be distinguished from minimum living guarantees, ensuring coordination between the two systems to compensate for income loss due to caregiving. Additional subsidies should also be provided for assistive devices, with appropriate allowances for persons with special needs requiring customized assistive equipment.

Personalized Caregiver Service Support: Develop and cultivate professional institutions to offer a variety of services, including respite services, short break vouchers, high-quality daycare services, and home care services. These services should include technical training, information support, professional care skills training for caregivers, and psychological counseling through mutual aid groups or individual cases to alleviate caregiving stress.

Employment Support Policies for Caregivers: This includes welfare projects based on working parents' rights, such as flexible working hours and employment options.

(B) Integrate Multiple Resources and Develop Community Care

Community care was introduced in China in the late 20th century and has gradually developed. However, due to the absence of a well-established scientific management and operational system, inadequate basic community facilities, and a shortage of professional talents, the full potential of community care has not been realized (Rong Zengju, 2013). In grassroots Chinese society, village and residential committees often play a role as essential components of government management. However, they tend to be overwhelmed by administrative tasks and operate within a bureaucratic framework, limiting their social role. They often lack an understanding of the meaning of community care and fail to meet residents' needs, let alone provide professional support services for persons with mental disabilities and their caregivers (Cui Yueqin, Zhang Yiwen, 2022). In recent years, Beijing has developed diverse inclusive services like elderly service stations and hardship support offices, relying on social work institutions. However, there are no dedicated institutions or departments providing specialized services for persons with disabilities within communities. Observations at Liulang Elderly Service Station and Haidian Town Hardship Support Office reveal that while there is significant investment in hardware, software development is overlooked, and staff often lack professional skills, failing to meet residents' service demands. Most services offered are basic, such as haircuts and house cleaning (partially subsidized by the government), without linking professional rehabilitation resources to provide daily care services for those in need. Consequently, care for persons with mental disabilities often remains within the family or relies on hired caregivers, with regular hospital follow-ups, failing to fully leverage the advantages of community care.

To provide necessary rehabilitation and counseling services for persons with mental disabilities and their caregivers, community care needs further development. Services

should be based within the community, leveraging social workers, health personnel, and home nurses to organize community-based services under government coordination and support, establishing a management system similar to the UK's community care: administrators—staff—caregivers. Family caregiving, known as "reciprocal caregiving," is a foundation of traditional Chinese culture. Influenced by community mutual aid concepts like "care for the elderly as one cares for one's own," Chinese society has formed a caregiving model primarily based on family, supplemented by neighborly support, making community care especially important (Qian Ning, 2003). The government should encourage non-governmental organizations and volunteer groups to participate in community care services, strengthen the professional workforce, and enhance the functions of civil society organizations. Professionalization should be emphasized to avoid service duplication, fragmentation, and waste. Additionally, support for community care organizations should be actively fostered, with relaxed entry requirements and policy benefits related to land use, credit, and taxation to ensure normal operations and reduce the impact of public emergencies like pandemics on these organizations. Furthermore, a multi-party cooperative sharing platform should be built to promote communication between formal and informal networks, efficiently utilizing government and social resources to feedback into community care. This would encourage coordinated development of professional institution-based care, institutional care, and family care, providing assistance services to those in need (Li Weifeng, Liang Lixia, 2008; Zhou Pei, 2002).

(C) Provide Personalized Services, Adhere to Government Leadership, and Promote the Construction of Service Systems for Persons with Mental Disabilities

The UK's services for persons with mental disabilities are classified according to different age groups and service areas. Some services are government-run, while others are led by government-supported non-governmental organizations. Regardless of the project settings or service content, the principle of meeting the needs of persons with mental disabilities is fully reflected, avoiding putting them in a passive position of receiving services and maximizing service quality and effectiveness.

In advancing the construction of the support system for persons with mental disabilities in China, a service platform for persons with mental disabilities should be established under government guidance, adhering to a people-centered principle, with service content targeted to meet actual needs. In previous support systems, the government and society often played the role of "saviors," providing services and assistance to recipients of aid, often resulting in a loss of dignity and rights for the recipients (Yang Lixiong, 2014). Therefore, beyond considering material security, greater respect for the self-esteem needs of persons with mental disabilities and responses to their developmental demands are necessary, along with the removal of barriers to their social participation. On the other hand, persons with mental disabilities should be encouraged to take responsibility for themselves and contribute to society, actively and proactively changing themselves to improve their quality of life. The government should provide substantial support and assistance across various fields, including rights, education,

rehabilitation, employment, and public transportation. A widespread mechanism for purchasing government services for persons with mental disabilities should be established, guiding professional social organizations and technically competent professional service teams to participate extensively in this service field. The aim should be to deliver high-quality, widely accessible services and establish corresponding management systems, including project service content management and service evaluation and supervision systems, to ensure service quality. This would create a basic structure where government management is the lead, the needs of persons with mental disabilities are the foundation, and social service organizations serve as the backbone, providing "empowerment" professional services to individuals and constructing a comprehensive, well-organized, and high-quality support system.

VI. Reflection and Summary

The legal provisions mentioned in this paper are primarily sourced from literature retrieved from CNKI, with some data referenced from ONS. The scope and depth of data collection were somewhat lacking, and its authority is insufficient. Some policies apply to all persons with disabilities and are not specifically designed for persons with mental disabilities and their caregivers. Additionally, most of the relevant data found dates back to before 2015, making it uncertain whether the policies mentioned have been adjusted or are still applicable today. Moreover, the four dimensions used to construct the analysis framework in this paper did not comprehensively review the literature (mainly because not all relevant papers were found). Instead, the paper directly adopted the three dimensions (time support tools, economic support tools, and service support tools) mentioned in the article by Professor Fang Lijie, with the rights support tool supplemented independently, leading to insufficient evidence for the argumentation.

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