

# ***Research on the Stress and Countermeasure of Home Caregivers of Rural Mentally Retarded Children***

Zhe Wang

School of Political Science and Law  
University of Jinan  
Jinan City, Shandong Province, China

Xiaojie Gong

School of Political Science and Law  
University of Jinan  
Jinan City, Shandong Province, China

Xiaofeng Cong

School of Political Science and Law  
University of Jinan  
Jinan City, Shandong Province, China

**Abstract**—Considering the young age, home caregivers need more time and energy to care for mentally retarded children than ordinary disabled people, which causes home caregivers' various stress and problems during long-term care. Based on the awareness of economic, physical, psychological and social participation stress of home caregivers, the research explores influence factors and proposes the establishment of welfare policies for mentally retarded children and day-care center, providing psychological counseling for home caregivers to help families of mentally retarded children to relieve stress.

**Keywords**—mentally retarded; home caregivers; care stress

## I. RESEARCH BACKGROUND

With a large number of disabled people in China, there were 8.547 million disabled children, including 141,239 disabled children from 0 to 6 years old in 2017. There were 883,000 visually impaired people, 407,000 hearing disabled people, 43,000 speech disabled people, 4.846 million physically disabled people, 713,000 intellectual disabled people, 1.259 million mentally retarded people and 355,000 people with multiple disabilities.<sup>[1]</sup> Due to the certain degree of deficiencies in intelligence and social adaptability, mentally retarded children can't express their ideas clearly and home caregivers become the only bond between mentally retarded children and society. Because of the difference between resource allocation and economic development, rural home caregivers have more stress and problems compared with the urban area. Therefore, it is pressing and necessary to help home caregivers of rural mentally retarded children to solve their problems and build confidence in life.

## II. BIBLIOGRAPHY REVIEW

Foreign scholars -- Pickett (1997), Happe and Berger (2002) have studied and investigated how the burden of home caregivers affects different aspects of their life. In these researches, burden was a regulator of other research variables,

showing a close correlation with sleep disorders and the depressive symptoms of caregivers.<sup>[2-3]</sup>

The domestic scholar, Zhao Lihong (2013) pointed out that urban elderly home caregivers often encounter stress in physical power, work, interpersonal relationship, housing issue and other aspects in the elderly caring process.<sup>[4]</sup> Wu Xia (2016) in the interview of main caregivers of children with cerebral palsy rehabilitation also found that home caregivers face great economic stress.<sup>[5]</sup> Li Zonghua (2009) in the research of autistic child caregivers and social support pointed out that because of the caregiver's attribution of the child's pathogenesis, different training attitudes, unclear labor division, etc., home caregivers are faced with the strained relations among family members.<sup>[6]</sup>

The above-mentioned researches on home caregivers mainly focus on the stress research of elderly home caregivers, followed by home caregivers who pay attention to special children of cerebral palsy and autism, and a few on home caregivers of mentally retarded children. Therefore, this paper intends to research home caregivers of mentally retarded children in rural areas.

## III. RESEARCH OBJECT

In S County, we interviewed 8 home caregivers of mentally retarded children. The home caregiver is abbreviated to HC as a sample code. There is 1 female home caregiver (abbreviated to FHC) and 7 male home caregivers (abbreviated to MHC). Their marital status is all married. The age of home caregivers is from 40 to 60 years old with lower education degree. The relationships between the children and home caregivers were mostly mothers and children or grandparents and grandsons.

**TABLE I. BASIC INFORMATION ON HOME CAREGIVERS OF MENTALLY RETARDED CHILDREN**

Code	Age	Sex	Education degree	Work situation	Marital status	Relationship with MRC	Age of MRC	MRC disability level
FHC001	47	♀	SHS	State-owned	♂♀	Mother-daughter	6	4th
FHC002	52	♀	PS	/	♂♀	Grandparents-grandchildren	7	4th
FHC003	41	♀	JHSU	/	♂♀	Mother-daughter	6	2nd
FHC004	45	♀	JHS	/	♂♀	Mother-daughter	5	2nd
FHC005	54	♀	JHS	/	♂♀	Grandparents-grandchildren	4	2nd
FHC006	63	♀	Illiteracy	/	♂♀	Grandparents-grandchildren	5	2nd
FHC007	43	♀	PS	/	♂♀	Mother-daughter	5	2nd
MHC001	45	♂	TSS	Public welfare	♂♀	Father-son	6	2nd

Note: The full name of education degree: SHS refers to senior high school, PS is primary school, JHSU is junior high school undergraduate, JHS is junior high school and TSS is technical secondary school.

#### IV. RURAL HOME CAREGIVERS' CARE STRESS OF MENTALLY RETARDED CHILDREN

##### A. *The economic burden of home caregivers*

A mentally retarded child requires at least one family member, thus forming a model that one cares for the child and the other earns money. Moreover, the rural population has a low education level. Even if they go out to work, they are just engaged in simple manual labor with limited income.

##### 1) *Low family income*

FHC005 is a part-time worker at a local textile factory to subsidize households. From the moment of the birth, his grandson was diagnosed as mental retardation. FHC001 has never gone out to work. His daughter-in-law is frail and sick all the year round. In the past few years, she was found to have pituitary tumors and lost her job, increasing the burden of the whole family. At present, the family's economic income mainly depends on FHC005's husband and son who go out to work all the year round. The economic situation looks blue.

*FHC005 said, "That child has spent too much money in curing the disease. His father is a salesman and makes more money. But how does he afford the household expense? His mother is sick in bed. My husband has to work outside. Nothing can be done without money."*

##### 2) *High cost of mentally retarded children*

At present, many mentally retarded children have multiple episodes such as epilepsy, attention deficit hyperactivity syndrome and language defects. Epilepsy symptoms are particularly serious when mentally retarded children break out, who require long-term drug therapy and regular physical examinations. Otherwise, it will cause an irreversible damage to their brain.

*FHC005 said, "Suddenly, his lips appear blue. He was found to have epilepsy. He comes back without taking medicine at the first time. At that night, he was sick again. Then we sent him to hospital and received treatment for nine days. And he was sent to hospital constantly."*

##### B. *Physiological pressure of home caregivers*

Most mentally retarded children have poor mental development and grow slower than their peers. Mentally retarded children can walk and run by themselves, which becomes the trouble for home caregivers. Caregivers must pay more attention to mentally retarded children, which makes them physically tired, especially for home caregivers who are older and in poor physical condition.

##### 1) *Sleep disorders*

Due to the particularity of recipients, home caregivers of mentally retarded children are often in a state of alert. As long as the child moves, the caregiver immediately gets up. The long-term sleep disorder is a great pressure for the caregiver.

FHC005's grandson has symptoms of ADHD (attention deficit hyperactivity disorder) with frequent incontinence. He often takes a rest at one or two in the night. In order to avoid discomfort caused by incontinence, FHC005 often takes care of him at night by shortening the sleep duration and decreasing the sleep quality.

*FHC005 said, "No child sleeps at one or two in the night except him. What a naughty boy he is! We can't wake him up in the morning. At night, he often pees and shits abed. I must get up to check what happened."*

##### 2) *Long-term physical exhaustion*

Mentally retarded children grow relatively slower than ordinary children, especially for walking. Caring for mentally retarded children as soon as he could walk, caregivers need to spend more energy. Home caregivers tend to hold or carry children, suffering from backache for a long time. Most women caregivers are overwhelmed.

FHC003 is in poor physical condition. The neck muscle is seriously strained during their previous work. Since the beginning of taking care the sick son, her waist joints have some problems.

*FHC003 said, "My waist, three sections of lumber discs are severely stood out and the cervical vertebra is not good."*

*And I can't stand up quickly and have to slow a few minutes. He likes moving. At noon, I have a rest for holding down."*

### C. Family caregivers' psychological stress

Under physiological stress, home caregivers bear the heavy emotional stress. During the interview, it was found that the psychological stress of caregivers is roughly divided into two aspects. One is the long-term care anxious for mentally retarded children. The other is the worry about no improvement of the disease.

#### 1) Worry about the future of mentally retarded children

Once mental retardation occurs almost lasting for a lifetime. Nowadays, there is no effective treatment for mentally retarded children. With imperfect welfare systems, mentally retarded children can only rely on their family, which directly leads to the worry about children's future.

*FHC007 said, "I don't ask her to finish the endowment for us. But when we are old, she can support herself by learning and doing something, so that we don't have to worry about her."*

#### 2) The fatigue of home caregivers

Many home caregivers are more or less irritated and anxious when caring for mentally retarded children.

*MHC001 said, "My mind and body are fully fatigued. After his mother getting off the work, I will look after the child for a while. You don't know that this child is too skinny. If we don't stare at him, he will run away without a word. What can I do?"*

### D. Social participation pressure of home caregivers

Home caregivers have taken a long time to look after mentally retarded children. They didn't have enough time to join social activities and was dumbed down by society.

#### 1) Less social interactions

They are introverted and rarely communicate with others. Many home caregivers said that caring for mentally retarded children makes them seldom connect with friends or participate in social activities. On the one hand, they don't have time to join activities. On the other hand, the caregiver is worried about the child's physical condition.

*FHC001 said, "Normal children at the same age basically go to kindergarten. If you go to school, you will be obedient. If you have a child like him, you can't leave him alone. After that, friends will not ask you out."*

#### 2) No work participation

The sample was taken from the countryside. Among 8 people, there are only 2 people who have formal jobs: FHC001 works in a township enterprise, and MHC001 works in a township public welfare post. The remaining 6 people have to give up the work or resign their jobs for mentally retarded children.

*FHC002 said, "I used to go out and do odd jobs. Who wouldn't go out to work in the village like me? But if you have such a baby, nothing can be done. Nobody wants to look after mentally retarded children. Although we can't make more money, caring for our child is the urgent affair."*

## V. REASON ANALYSIS FOR THE CARE STRESS OF RURAL HOME CAREGIVERS OF MENTALLY RETARDED CHILDREN

### A. Welfare policy shortage for mentally retarded children

Nowadays, there is no special and integrated child welfare law in China to protect the rights and interests of the disabled children including mentally retarded children. From the existing law, it is even difficult to find laws designed specifically for the disabled child welfare. The content related to disabled child is only a few subsidiary provisions. Some provisions are just at the level of laws and regulations, lacking the effective assistance for mentally retarded children and home caregivers.

### B. Home caregivers lacking rest

Mentally retarded children need overall and long-term care of family members. They can't take care of themselves and require parents to accompany them all day. Male parents of mentally retarded children go out to work for family expenses, and female parents take care of children. However, the long-term care of a single caregiver bears great physical and mental stress and lacks rest.

### C. Home caregivers lacking psychological counseling

Mentally retarded children will make parents fragile and sensitive. As time went by, they have accepted this fact and have a feeling of depression. Most home caregivers are unwilling to contact with people and seek help from others to protect their children from danger, which directly leads to a closed heart and brings them psychological stress. In rural area, home caregivers are short of professional psychological counselors and social workers, as well as the lack of a platform for home caregivers to communicate, which also causes the excessive psychological stress.

## VI. COUNTERMEASURES AND RECOMMENDATIONS

### A. Establishing welfare policies for mentally retarded children

At present, the life guarantee for mentally retarded children in China is realized through social assistance with limited coverage and low guarantee level. It is difficult to meet the needs of mentally retarded children, lacking life assistance for them in the original family. By visiting families of 8 mentally retarded children in S County, it can be seen that mentally retarded children living in the original family are looked after by home caregivers. With the changes in family size, structure and social competition, home caregivers face challenges. Caring for mentally retarded children, home caregivers are under tremendous economic pressure. Therefore, it is effective to increase the subsidies for mentally retarded children and home caregivers.

### B. Providing psychological counseling for home caregivers

Through the psychological counseling of local Disabled Persons' Federation and township special education schools, home caregivers of mentally retarded children relieve their stress. S County can use the important platform -- special education schools. On the one hand, professional therapists in rehabilitation institutions are provided to give lectures for home caregivers and invite psychological experts for a

long-term cooperative relationship with the social work profession of colleges and universities. On the other hand, the Disabled Persons' Federation and local volunteers in S County can make parents help each other and establish a parent association for mentally retarded children.

### *C. Establishing a day-care center*

Township retirement organizations can broaden the forms of day care to meet home caregivers' necessity of rural mentally retarded children. For the care of mentally retarded children, we can learn from the experience of the elder day-care center to build a day care institution for them. Caregivers of mentally retarded children in rural areas generally have their own land. S County can establish a day-care area for mentally retarded children relying on special funds of Disabled Persons' Federation for public nursing homes in townships. Caregivers can send mentally retarded children to the day-care area, with dedicated personnel for centralized care. At night, home caregivers take children to home. And home caregivers have more time to work and take care of mentally retarded children.

## VII. SUMMARY

Society should pay close attention to rural home caregivers of mentally retarded children. Taking 8 rural home caregivers

of mentally retarded children in S County as the research object, this paper explores the reasons behind the stress and proposes countermeasures to improve their ability in managing the stress and alleviate the pain caused by stress. Meanwhile, society should care for home caregivers and regains their confidence for a better future.

## REFERENCES

- [1] China statistical bulletin on the development of disabled people in 2017 (<http://finance.sina.com.cn/roll/2018-04-26/doc-ifztkpin4431026.shtml>).
- [2] Pickett, S.A, Cook, J.A., Cohler J. Positive parent adult child relationships: impact of severe mental illness and caregiving burden[J]. *Orthopsychiatry*, 1997,67: 220-230.
- [3] Happe S.,Berger K., The association between caregiver burden and sleep disturbances in partners of patients with Parkinson's disease[J]. *Oxford University Press Country of Publication* 2002,31: 349-354.
- [4] Zhao Lihong. Research on social support of urban elderly caregivers in the perspective of aged social work [J]. *Academic Exchange* 2013,231(6): 167-170.
- [5] Wu Xia. Care experience for main caregivers of children with cerebral palsy rehabilitation [J]. *Journal of Taishan University* 2016:36-39.
- [6] Li Zonghua, Xu Yongxia. Strategies for parents of autistic children in the perspective of caring for caregivers [J]. *Education for Chinese After-school* 2009:8-9.