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DISABILITY RIGHTS IN CHINA AND IN THE WORLD

THE WAY WALKED WITH CHILDREN: MEDICAL TREATMENT AND REHABILITATION

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Abstract Due to obstacles in expression and communication, as well as a societal lack of humanitarian spirit and deficiencies in system design, children with intellectual disabilities are confronted with various problems when seeking medical treatment. The dilemma of medical treatment seriously restricts the survival and development of disabled groups. By reviewing the way in which a mother accompanied her disabled child for 28 years together, this article analyzed the reasons for the dilemmas of medical treatment, and appealed to improve the living conditions of persons with intellectual disabilities to guarantee their rights for rehabilitation. In addition, by introducing the recreational and sports activities that parents' spontaneous organization created for children with intellectual disabilities, it put forward the proposal to prevent in advance the possible deterioration of conditions caused by social isolation, which is definitely a

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融爱融乐 (Rong Ai Rong Le) is a volunteer public organization funded by parents of persons with intellectual disabilities in Beijing. It was set up in May 2011, and registered in Jul. 2012. The organization has been launched and operated by ordinary parents for four years. Up until now, it has grown to a professional public organization with 20 employees, which developed clear strategic positioning. It promoted parents and society advocacy from the perspective of rights, and created a working mode that changes society by organizing a lot of cultural and sports activities. It also created a new solution to provide employment support for persons with intellectual disabilities. Add: Room 534, Building 1, Courtyard 62, Balizhuang Road, Haidian District, Beijing 100142, China. Contact: website: http://www.co-inclusion.org. Tele/Fax: 010-63962366. E-mail: rongairongle@co-inclusion.org. WeChat account: weiaiyi2908.

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preferable remedy for persons with disabilities.

Keywords disability rights, children with intellectual disabilities, medical rehabilitation, social inclusion

INTRODUCTION

Unlike physically disabled and deaf-mute children, those with intellectual disabilities receive less sympathy from society, and have more difficulties striving for and protecting their own rights. Consequently, most of them cannot live independently. Confronted with pressure stemming from their children's medical treatment, education, employment, and marriage, many mothers are overwhelmed with sorrow. Nevertheless, encouraged by instinct and conscience as parents, they still choose to bear with inherent inequality with their children all the time. As one such parent, I (HAN Wanchuan) share directly in the experience. In this paper, I want to share some personal points about the issues of medical treatment that puzzle and challenge every family with disabled children.

I. THE HARDEST DECISION

Children are the hopes of families. Twenty-seven years ago, my son, Xiaohu, was sent to the Intensive Care Unit just three days after he was born. We were informed by the doctor that the child was dying because of a bad prognosis, which meant there was a high probability that my son would become disabled for life, and we had to immediately decide whether to save his life. It was a sentence to little life. After painful struggles in our heart, my husband and I decided not to give up on him, which was definitely the most difficult decision of our lives.

After that, like many parents whose children are disabled, we began the crazy road of

seeking medical treatment everywhere. Our footprints remain in almost every famous hospital from the countryside to cities, at home and abroad, and we spent nearly all we had. Due to the lack of a clear early diagnosis, treatment and scientific training, my son did not receive systematic professional guidance in the evaluation of his physical condition and needs, and he lost many most precious and best recovery periods. We blindly sought all kinds of doctors and tried every possible method, because we could not bear to see our son's panic and desperate eyes anymore when doctors raised needles or scissors, and we could not bear to see him suffering from pain anymore. Due to a low immunity, my son contracted almost every epidemic disease, such as varicella, mumps, scabies, and pinkeye. But he survived. We even sincerely wish that our son could leave this world before us, so that we could die in peace without any worry left behind in this world.

II. MEDICAL DILEMMA RESTRICTS THE SURVIVAL AND DEVELOPMENT OF THE DISABLED GROUP

Multifarious problems that disabled children face during the treatment process are not only challenges to families and medical workers, but also to the system designers and the humanitarian spirit of the whole society.

A. Dilemma Comes from Children with Intellectual Disabilities Themselves

Compared with normal people, children with intellectual disabilities have different feelings of pain. In their consciousness, they do not know what a disease or even pain is. Invariably, it was not until the syringes were pulled out, that the children feel the pain and then cry out. Due to their limited consciousness and communication abilities, once their bodies feel uncomfortable, they have to vent the pain through actions like biting or screaming, and even several nurses cannot calm them down. Sometimes routine blood tests are unable to be carried out. Without appropriate safety measures, there is high risk in treatment. Due to such concern and worries, in all kind of operations, we could only administer general anesthesia instead of local anesthesia. Thus, unless absolutely compelled, parents and children are not willing to go to the hospital, which leads to some minor diseases developing into more serious ones.

B. Dilemma Comes from Social Discrimination

National fertility policy stipulates that families with disabled children can have a second child, which indicates the siblings' inherent obligation of caring for their disabled brother or sister. Thus, children with intellectual disabilities are inevitably regarded as a burden on families. When the China Disabled Persons' Federation holds its representative congressional meeting, physically disabled committee members can attend with an escort, but only relatives can represent those with intellectual disabilities, which is substantially a kind of legal inequality.

A large number of children with intellectual disabilities do not have good hygiene practices. They do not know how to blow their noses, wash their hands before meals or after visiting the toilet, or even do not brush their teeth. All such behaviors are difficult for ordinary people to bear. The rejection of the public, as well as the language violation, leads to spiritual trauma and deeper feelings of inferiority for children with intellectual disabilities. When they enter puberty, combined with emotional anxiety and depression, the curiosity towards the opposite sex engenders further misunderstanding and rejection from society, which in turn aggravates their mental symptoms and isolation from society.

C. Dilemma Comes from Shortage of Medical Care Services

Hospitals tend to avoid undertaking the risks of treating persons with intellectual disabilities, in consideration of their unlikely cooperation, as well as poor experience and training of relevant medical workers. Doctors refuse to give treatment even for common diseases, merely because of children's identities as disabled, which leads to the delay of treatment. According to a survey conducted by our Parents Association in 2012, some children have not had physical examination tests for up to ten years. Furthermore, 80% of people believe that there is insufficient support for intellectually disabled people in terms of dental and ophthalmology medical services.

III. MEDICAL REHABILITATION SERVICES NEED URGENT GUARANTEES

Since 2008, the whole country has enlarged the scope of the social security system for the intellectually disabled. People in urban areas participated in local medical insurance, and those in rural areas participated in rural cooperative medical service. However, the society still holds a comparatively negative attitude towards persons with intellectual disabilities. Some conceptions and discriminations create obstacles for medical rehabilitation, medical care services, and social participation for persons with intellectual disabilities. Their medical rehabilitation services need urgent guarantees.

A. Walk out of Isolated Space

Due to their own disabilities and fear of being discriminated, persons with disabilities lose many opportunities to participate in social life. Some persons with intellectual disabilities, together with their relatives, also lack the willingness to participate. Parents with disabled children sometimes adopt the mistaken assumption that locking their children in the house is the safest way to protect them. Although governments at all levels set up lots of initiatives like "Occupational Recovery Station" and "Warm Home," in order to offer places for persons with mild intellectual disabilities after they graduate from school, problems of clustering and closeness still exist. Additionally, many children with moderate or severe intellectual disabilities are still rejected by the "Warm House." These children do not have any access to communication with normal peers other than their parents and relatives in society. In general, they suffer isolation from society and are

regarded as a social burden and obstacle of care and relief, not to mention their diminished personal value and human rights. We strongly appeal to improve the living environment and promote de-institutionalization, so as to improve the medical care services and enable the disabled to participate in society and live independently under a supportive community system.

B. Provide Basic Survival Conditions and Medical Care for Overwhelmed Families

In 2013 we investigated 120 children in our organization and found that 83% of them had no job or source of income. The number of "old and disabled" families are increasing. Although they can enjoy hospitalization and medical subsidies, they still cannot cover the remainder of hospital and medical expenses. As a result, children cannot receive timely medical treatment and their conditions become worse and worse. According to the results of law enforcement inspection of the Law of the People's Republic of China on the Protection of Disabled Persons, conducted in 2011, more than 40% of persons with disabilities in rural areas live below the poverty line, of which the national standard is RMB2,300. The average income per capita of families of persons with disabilities is only around 60% of the national average, while the medical expenses per capita of families of the disabled in urban and rural areas are respectively 1.56 and 2.09 times more than the national average. The Engel coefficient of families of persons with disabilities is 8.1%[1] higher than the national Engel coefficient level. Thus, we strongly appeal that the government should reduce the standard medical reimbursement amount, and provide better medical health welfare, such as physical therapy, occupational therapy, speech therapy, recovery therapy, and rehabilitation. Additionally, the training of related medical workers should also be strengthened.

C. Provide Special Support and Key Security Institutionally

Up until now, not all people with intellectual disabilities have been included in urban medical insurance, employment injury insurance, and maternity insurance. The entry criteria for these insurances have not comprehensively included the disability types and levels of intellectual disabilities unconditionally. For example, those with mental retardation disease cannot be reimbursed in the medical insurance system. The long-term, expensive medical treatment fees discourage some families from continuing the rehabilitation treatment. Therefore, families of persons with intellectual disabilities have urgent need for social insurance and security support that are more targeted towards their

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[1] LI Jianguo, Vice Chairman and Secretary General of China's NPC Standing Committee, 全国人民代表大会常务委员会执法检查组关于检查《中华人民共和国残疾人保障法》实施情况的报告 (*The Report of Examination on Implementation of the Law of the People's Republic of China on the Protection of Disabled Persons Conducted by China's NPC Standing Committee Inspection Group*), 11th Session of the 28th Meeting of China's NPC Standing Committee, Aug. 27, 2012, available at http://www.npc.gov.cn/ (last visited Sep. 22, 2015).

special needs.

D. Create an Inclusive Environment to Pursue a Happy Life

In 1999, I brought my son to the US to seek medical treatment and happened to attend the 20th Annual Meeting of World CdLS Foundation,[2] where I saw many children who were also diagnosed with CdLS living a very happy life. When the experts told me that this disease occurred in every family worldwide with a probability of 1/120,000, and that there was no cure, I gave up on the endless and ineffective road of seeking medical treatment. However, I realized that even though we cannot change the inherent disabilities of our children, we could create a better environment with less discrimination and more inclusion for them, which is essential to their rehabilitation. After returning to China, I volunteered to serve persons with disabilities. Since the establishment of the Rong Ai Rong Le organization, we have been providing free entertainment and cultural activities for persons with intellectual disabilities, and promoting the idea of active participation in society. With the support of many caring persons and organizations we created the following activities:

(1) Happy Camp. The program was introduced from the U.S., by our Board Chairman, WANG Xiaogeng. On the weekends (once every two weeks), volunteers and people with intellectual disabilities hold one-to-one sports games. In the last three years, there have been almost 300 persons with intellectual disabilities and 3,000 volunteers participating in this program.[3]

(2) Chorus of Shiny Relatives and Friends. Composed of the parents of disabled children, the chorus has performed on stage hundreds of times. Through this activity, the parents show their love, positive attitudes, and the resilience to fight against obstacles in life.

(3) Wind Drum Band. With parents who can play the drums as the guide teachers, intellectually disabled people's hand-eye coordination and audio-visual abilities have been significantly improved through playing the wind drum. In the 2014 World Persons with Intellectual Disabilities Art Festival, our children played drums as the opening act in the Grand Theatre of China, which made them feel pride in their success and increased their self-confidence and self-respect.

(4) Supportive Etiquette Service Team. With volunteers acting as etiquette guides, at every meeting location, persons with intellectual disabilities received on-site training on welcoming and guiding guests, organizing the meetings and handing out materials. The training taught them how to behave well and interact with others, and also increased their

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[2] It is available at http://www.cdlsusa.org/ (last visited Sep. 22, 2015).

[3] WANG Xiaogeng, 坚持带来改变，我们将继续前行——融爱融乐四周年纪念 (*Persistence Brings Change and We Will Continue to Move on: The Fourth Anniversary of Rong Ai Rong Le*), published on official WeChat account at weiaiyi2908, May 26, 2015.

working attitudes, habits, and abilities.

(5) Participation in the Gobi Challenge and Marathon Volunteer Service. On May 22, 2014, representatives of Rong Ai Rong Le first appeared on "Xuanzang Road" in China's vast Gobi,[4] and took part in the 9th Peking University Business School Gobi Challenge. Eight persons with intellectual disabilities, holding the hands of participants from Guanghua Management School of Peking University, completed a 30km journey under level-eight strong winds for eight consecutive hours. Xiaohu seldom communicates with others, but in the letters he wrote to his brothers and sisters from Guanghua, he said, "I liked walking in Olson Park, but I don't like walking in Gobi. In Gobi, the sky was filled with yellow sand and the ground was uneven. Several times I wanted to go home. Brother WANG Baosen and ZHU held my hand, and sister ZHANG also encouraged me a lot. Finally, I completed the journey and won glory on behalf of everyone." LI Wei, the leader from Guanghua Management School of Peking University, said, "We thought we helped Xiaohu and other intellectually disabled children. But in fact, we learned more from them." Every child is like a book, and this Gobi experience also shows a lot of the truths of life. The children experienced hardship and anxiety and learned how to cultivate persistence and courage to overcome these difficulties and finally achieve success and be proud. They may need some time to gradually understand these feelings and reap the benefits, but every step they made will definitely have a tremendously positive effect on their lives. Through this Business School Gobi Challenge, we provided a chance for social elites to develop a close connection with intellectually disabled people and to be touched. We hope they could make their own contributions to help children integrate into society and promote social progress in the future.

Gobi Challenge also kindled the children's enthusiasm to take part in inclusive sports activities. Every weekend, for a year in a half, in response to the organization of volunteer advocates, many families take part in a walking activity in Olson Park. From September 2014 to April 2015, many families in Rong Ai Rong Le also took part in more than ten national marathon competitions for public interest in the cities of Beijing, Haikou, Dalian, Suzhou, etc. In addition to taking part in the 10km marathon competition, more than a dozen of intellectually disabled people served as volunteers to provide water to competitors. Through this kind of active social inclusion they had connection with over 100,000 people from all walks of life, and showed their positive outlook to society. On the other hand, society also gained comprehensive understanding of persons with intellectual disabilities and created more chances and a more tolerant environment for them.

(6) Supportive Employment. Rong Ai Rong Le has been running a domestic supportive employment program since April 2013. In over two years, 12 young adults

[4] YUAN Jiansheng, 和小虎走出风沙 (*Waling out from Windy and Dusty with Xiaohu*), 知行客 (*Explorer*), 28 (Jul. 2014).

with intellectual disabilities were hired with the help of employment counselors, and 8 young people signed contracts with companies.[5]

(7) Advocacy Activities. As the core power for social integration, the improvement of parents' ideas is crucial. We took part in the training of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the proposal collection of mental health law, and gave our own proposals for the revision of the education bill for the disabled. We also took part in the parent growth plan of the Harvard Law School Project of Disability (HPOD). Through these activities, more and more parents became active participants in social change and progress.

In April 2004, we participated in the "Life Ethics, Biotechnology and Biological Safety" Conference held by United Nations Educational, Scientific and Cultural Organization. We gave a speech titled "*Blood Sample Providers' Rights to Know, Beneficial Rights, and Rights of Privacy*." This paper was also published in July in the Chinese Core Journal *Medicine and Philosophy*.

In 2009, we proposed that the retirement age of intellectually disabled people should be increased to the age of 40. The reasons are as follows:

Firstly, according to the Beijing Health Development Statistics Bulletin in 2011, the average lifespan of people living in Beijing is 81.12 years,[6] 56.9 years old for ordinary disabled persons, and 42 years for people with multiple disabilities. The data was provided by GAO Xiaodi, a member of the national committee, based on related subject research. We found that the lifespan gap is within the range of 24.22 to 39.12 years. Based on the women's standard retirement age of 50, the years that healthy people can receive pension insurance are 31.12, while only 6.9 for persons with disabilities. As for disabled males, and those with multiple disabilities, there is no chance to receive pension insurance before they die, which obviously violates the principle of equal rights and obligations.

Secondly, even if a couple get married when the man reaches 22 years old and the woman reaches 20 years old (which are the minimum legal ages for marriage in China, respectively), they will be at least 81 years old when their children retire. By that time, they would be unable to help their children deal with retirement procedures. Worse still, since the parents of disabled children devote their entire lives to parenting their children, they are generally in bad health. As such it remains questionable whether they could actually live up to that age at all.

Consequently, to avoid the appearance of such an unreasonable and unfair situation, we suggest that the retirement age of intellectually disabled people, irrespective of their

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[5] See 融爱融乐支持性就业项目总结 (*The Summary of Rong Ai Rong Le Supportive Employment Program*), published on the official WeChat account at wiaiyi2908, Jan. 30, 2014.

[6] Beijing Municipal Health Bureau, 2011 年北京市卫生事业发展统计公报 (*2011 Beijing Health Care Service Development Statistical Bulletin*), Apr. 26, 2012.

sex, should be adjusted to 40 years of age under Labor Law. Under such a stipulation, most parents of disabled children would be able to help their children deal with retirement procedures when they reach the age of 65 to 70 years old. They could also arrange for their children's elderly life properly and could enjoy a better life in their old age.

In 2015, we proposed that severely disabled families should enjoy the same rights and welfare of minimum assurance families. We believe that if we can solve the basic living problems of disabled families, we can diminish a lot of social problems and create a harmonious and healthy social environment for the growth of disabled children.

CONCLUSION

In the past few years, we received much support and guidance from social professional organizations and predecessors. We led people with intellectual disabilities to overcome obstacles and pursue happiness. Hugely beneficial to them, we took advance measures to prevent their conditions worsening due to social isolation through creating a healthy environment with a range of accessible activities. A single mother of a child with severe autism once said, "Rong Ai Rong Le not only helped me walk out of depression, but also provided support for me and my son. We finally found a home in Beijing, which was a prosperous metropolis without any relatives. Through participation with Rong Ai Rong Le, we took part in various activities despite bad weather and distant journey, through which my son has made an extremely obvious progress, and I also feel much happier now. Rong Ai Rong Le has grown up to three years old, while I feel I have become three years younger."[7] "This organization not only saves the children, but also the parents!"

We firmly believe that the problem is not the disability itself, but the social stereotypes and discrimination. As per the original intentions and goals set by Rong Ai Rong Le, as long as we work together to promote social inclusion and increase the degree of social civilization, persons with intellectual disabilities will definitely enjoy a higher quality of life and due dignity brought about by the progress of society as a whole.

[7] See 融爱 2014 年 7 月简报 (*Bulletin of Rong Ai Rong Le*), Jul. 2014.