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Trends in the prevalence of childhood disability: Analysis of data from the national disability registry of Taiwan, 2000–2011

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ABSTRACT

Childhood disability is not uncommon, but data at the national level are limited, especially those on the changes in the prevalence over time. On the basis of the Disabled Welfare Act, Taiwan began to certify disabled residents and provide various services in 1980. All the cases receiving services are registered, and the registry provides a rare opportunity for studying childhood disability at the national level. Using the data from 2000 to 2011, we calculated the age-specific prevalence of all disability combined and assessed the changes over time. We also calculated the prevalence rate and the proportion in all disabilities combined for each disability category and assessed the trends. As certification before 3 years old is generally discouraged by the government, we limited analyses to children between 3 and 17 years old. We found that the registered cases ranged from 49,242 to 61,717 from 2000 to 2011 and that intellectual disability (ID), had been the leading category all through the years. The proportion of autism spectrum disorders (ASD) had been increasing rapidly and become the third leading disability in 2011. The prevalence of all disabilities combined increased constantly from 9.98/1000 to 15.41/1000 ($p < 0.01$), and increases were generally observed every year in all age groups ($p < 0.01$). The increase could largely be attributable to the increases in ID and ASD, while the increasing trends were also significant in "multiple disabilities," "speech or language impairment," and "other disabilities listed by the Department of Health" ($p < 0.01$ for all the five categories). An increase with age in the prevalence of all disabilities combined could be observed all through the years ($p < 0.01$ in all calendar years). We concluded that the prevalence of childhood disability has been increasing in Taiwan, with ID contributing the most cases and ASD as an emerging problem. However, the increase of prevalence cannot be attributed entirely to the increase in the occurrence of cases, and an increase in the proportion of cases registered was an more important factor, which may be in turn attributable to a better service of the related agencies, lower discrimination against the patients, higher awareness of the disorder, and more willingness of the guardians to register.

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1. Introduction

With the improvement in medical care in recent decades, many infants with critical conditions such as congenital anomalies and very low birth weight have survived (Ahmad, Lopez, & Inoue, 2000; Goldenberg & Culhane, 2007; Liu, Joseph, & Wen, 2002). However, these children generally have higher proportion of disabilities (Msall & Tremont, 2002), and therefore issues regarding childhood disability has drawn more and more attention from both clinical practitioners and public health authorities and become an important part of childhood health (Gottlieb, Maenner, Cappa, & Durkin, 2009; Maulik & Darmstadt, 2007).

The definitions of disability have evolved in recent decades, shifting from "medical model," which views "disability as a problem of the person, directly caused by disease, trauma or other health condition," to "social model," which views "disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment"(Iezzoni & Freedman, 2008; World Health Organization, 2001). Currently, the International Classification of Functioning, Disability and Health integrated both medical and social models and defines "disability as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors," including both personal and environmental factors (Iezzoni & Freedman, 2008; World Health Organization, 2001). Likewise, the United Nations Convention on the Rights of Persons with Disabilities (UN enable, 2012) proposed that "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." Therefore, disability is no longer simply considered as a medical condition, but rather as a result of the interaction between persons with impairments and environmental barriers. Consequently, service provision is not considered as welfare, but rather as a human right. In Taiwan, the government took one step further and put service provision as a responsibility of the government and changed the governing regulation from the Disabled Welfare Act (1980) to the Physically and Mentally Disabled Citizens Protection Act (1997), and then to the People with Disabilities Rights Protection Act (2007).

Because childhood disability generally lasts for life, a disabled child usually becomes a heavy burden to the family. Many countries provide supports such as social welfare, special education, and health care to relieve the burden of the family and facilitate the child's participation in society (Jeevanandam, 2009). As these services require a lot of resources, estimating the prevalence of childhood disability correctly is helpful in planning the allocation of resources (Larson et al., 2001).

Although childhood disability is not uncommon, prevalence data from large scale studies are rare, and the reported prevalence varies widely (Gottlieb et al., 2009; Maulik & Darmstadt, 2007). The variations in prevalence may be attributable to factors including the differences in case definition, age range, and case-finding method (Durkin, 2002). For example, the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) included only cerebral palsy, mental retardation, visual impairment, and hearing impairment and found the prevalence was as low as 1.5% in 2000 (Bhasin, Brocksen, Avchen, & Van Naarden Braun, 2006). In contrast, the National Health Interview Survey (NHIS) of the U.S.A. extended the inclusion to autism, attention deficit hyperactivity disorder, seizures, stuttering or stammering, learning disability, and other developmental delays and reported a prevalence of 13.87% in 1997–2008 (Boyle et al., 2011). Likewise, data on the prevalence of childhood disability in Taiwan are limited, and the reported prevalence varies widely. A census study included all children between 0 and 6 years of age in 1998 in Taiwan (1,909,352 children) identified 9299 cases of developmental delays and reported a prevalence of 0.49% (Wang, Liao, Tsai, & Lu, 1999). When Chen (2009) studied 3687 children under 12 years of age from the 2005 Taiwan National Health Interview Survey and extended the inclusion to learning disability, attention-deficit hyperactivity disorder, and sensory integration dysfunction, they reported a prevalence rate of 3.50%.

In 1980, according to the Disabled Welfare Act, the local governments in Taiwan began to certify the disabled residents and provide various services, and the Department of Interior keeps a registry of certified cases. The registry data present a rare opportunity for studying the epidemiology of various categories of childhood disability at the national level. Therefore, we adopted the data from 2000 to 2011 to assess the changes in prevalence of all disabilities combined and study the changes in the prevalence and proportion (in all disabilities) of each category of disability in Taiwanese children over time.

2. Methods

2.1. The disability registry system in Taiwan

The promulgation of the Disabled Welfare Act in 1980 is a milestone in the history of promoting disability registry in Taiwan. Initially, the registry included seven categories of disabilities: "visual impairment," "hearing impairment or balance disability," "speech or language impairment," "disability of limbs," "intellectual disability" (ID), "multiple disabilities," (defined as having disabilities belonging to two or more categories) and "other disabilities listed by the Department of Health" (Disabled Welfare Act, 1980). "Autism spectrum disorders" (ASD), "loss of function of major organs," "facial damage," "vegetative state," and "dementia" were added in 1990. "Chronic psychiatric disorders" was added in 1995. "Hearing impairment or balance disability" was divided into "hearing impairment" and "balance disability" in 1997 (Physically & Mentally Disabled Citizens Protection Act, 1997). "Intractable epilepsy," and "rare diseases with physical or mental disabilities listed by the Department of Health." were added in 2001 (Physically & Mentally Disabled Citizens Protection Act, 2001).