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

Der-Chung Lai\textsuperscript{a,b}, Yen-Cheng Tseng\textsuperscript{c}, How-Ran Guo\textsuperscript{d,e,*}

\textsuperscript{a} Department of Physical Medicine and Rehabilitation, Ditmanson Medical Foundation Chia-Yi Christian Hospital, Chia-Yi, Taiwan
\textsuperscript{b} Department of Senior Citizen Service Management, Chia Nan University of Pharmacy & Science, Tainan, Taiwan
\textsuperscript{c} Department of Business Administration and Language Education Center, Chang Jung Christian University, Tainan, Taiwan
\textsuperscript{d} Department of Environmental and Occupational Health, National Cheng Kung University, Tainan, Taiwan
\textsuperscript{e} Department of Occupational and Environmental Medicine, National Cheng Kung University Hospital, Tainan, Taiwan

\textbf{A B S T R A C T}

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.

© 2013 Elsevier Ltd. All rights reserved.
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 autism, 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).
the remaining seven categories of disabilities,” of which the trends were not evaluated in the current study.

Of the 16 categories of disabilities, 7 (balance disability, chronic psychiatric disorders, dementia, facial damage, intractable epilepsy, rare diseases with physical or mental disabilities listed by the Department of Health, and vegetative state) have relatively small numbers of childhood cases, and therefore their criteria are not listed in this table. (See Ref. for details.)

Table 1
Minimum criteria of receiving disability benefits for different disability category.

<table>
<thead>
<tr>
<th>Type</th>
<th>Minimum criteria of receiving disability benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism spectrum disorders</td>
<td>During the study period, most cases were diagnosed on the basis of Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (DSM-IV) or DSM-IV-TR, and the registry included the entirety of autism spectrum disorders.</td>
</tr>
<tr>
<td>Disability of limbs</td>
<td>(1) A joint with significant functional impairment (defined as a joint with a loss of range of motion over 70% or muscle strength of 2 or 3 on the Medical Research Council scale) in the shoulder, elbow, knee, or hip. (2) A joint with complete loss of function (defined as a joint with complete ankylosis or muscle strength of 0 or 1 on the Medical Research Council scale) in the wrist or ankle. (3) Complete loss of function in the index finger and thumb of one hand, in three fingers of one hand including the thumb, or in both thumb. (4) Bilateral joints with significant functional impairment in the wrist or ankle. (5) Absence of limbs at or above the level of the wrist or ankle. (6) Absence of the index finger and thumb of one hand, three fingers of one hand including the index finger or thumb, five fingers or more in both hands combined, or all toes in both feet. (7) A leg length discrepancy of 5 cm (or one fifteenth) or more. (8) Abnormal tone or involuntary movement which interferes with standing or gait. (Brief abstract, see Ref. for details.)</td>
</tr>
<tr>
<td>Hearing impairment</td>
<td>An average hearing loss at 500, 1000, and 2000 Hz of 55 decibels or more in the better ear in pure-tone audiogram.</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>An intellectual quotient score below 70 (more than 2 standard deviations below the mean).</td>
</tr>
<tr>
<td>Loss of function of major organs</td>
<td>A major organ (heart, liver, kidney, stomach, bowel, or urinary bladder), the swallowing function, or the hematopoietic system with significant functional impairment which interferes with activities of daily living. (Brief abstract, see Ref. for details.)</td>
</tr>
<tr>
<td>Multiple disabilities</td>
<td>Having disabilities belonging to two categories or more.</td>
</tr>
<tr>
<td>Other disabilities listed by the Department of Health</td>
<td>An intellectual quotient score below 70 with chromosome abnormalities, congenital metabolic diseases, or other congenital anomalies.</td>
</tr>
<tr>
<td>Speech or language impairment</td>
<td>Significant impairment in language comprehension, verbal expression, speech intelligibility, speech fluency, or vocal quality which interferes with communication.</td>
</tr>
<tr>
<td>Visual impairment</td>
<td>(1) Visual acuity of 0.2 (20/100) or worse in the better eye with correction. (2) Visual field less than 20 degrees. (3) One eye blindness and the other eye with visual acuity of 0.4 (20/50) or worse. (4) An average loss of more than 10 decibels in the better eye in the central 30 degree static visual field test.</td>
</tr>
</tbody>
</table>

Of the 16 categories of disabilities, 7 (balance disability, chronic psychiatric disorders, dementia, facial damage, intractable epilepsy, rare diseases with physical or mental disabilities listed by the Department of Health, and vegetative state) have relatively small numbers of childhood cases, and therefore their criteria are not listed in this table. (See Ref. for details.)

According to the law, the local governments began to certify residents with disabilities and provide various services in 1980. Patients with disabilities can make applications for certification through the local government office in the residential area, and the local governments report cases to the central government. The Ministry of the Interior of the central government maintains a registry of certified cases and publishes summary data each year (Department of Statistics, 2011b).

2.2. Case definition

When a child is suspected to have disability, the parents or guardians can apply for certification through the local government office in the residential area. Before a certificate can be issued, a patient needs to fit the criteria listed by the government (Table 1) and be confirmed by a doctor who was accredited by the government (Department of Health, 2008a, 2008b).

2.3. Data collection

The Department of Statistics of the Ministry of the Interior publishes Statistical Yearbook of Interior each year, and we analyzed the data from 2000 to 2011 (Department of Statistics, 2011b). The information includes the number of cases by age and disability category. Because the government generally discourages the certification under 3 years of age and many childhood disabilities are not recognized before that age for various other reasons, we limited our analyses to those who were at least 3 years old (Department of Health, 2002a). To calculate the prevalence rate, we obtained the data on total population in each age group from the Monthly Bulletin of Interior Statistics (Department of Statistics, 2011a).

2.4. Data analysis

We estimated the age-specific prevalence of all disabilities combined by dividing the number of cases by the number of individuals in a specific group (3–5 year, 6–11 year, 12–14 year, and 15–17 year as categorized in the annual reports) in each year from 2000 to 2011 and evaluated the trends over the years (Table 2). We also calculated the prevalence rate and the proportion (in all disabilities combined) for each disability category and evaluated their trends over the years (Table 3).

Among the 16 categories of disabilities, 7 (balance disability, chronic psychiatric disorders, dementia, facial damage, intractable epilepsy, rare diseases with physical or mental disabilities listed by the Department of Health, and vegetative state) have relatively small numbers of childhood cases in all the years, and therefore we combined them into one category—“the remaining seven categories of disabilities,” of which the trends were not evaluated in the current study.
We presented descriptive statistics of the variables as numbers or percentages and used the chi-square test for trend to evaluate the trends of changes in prevalence rates and proportions over the years as well as the trends of changes in prevalence rates across age groups. All the analyses were conducted using SAS 9.1, and all the statistical tests were performed at the two-tailed significance level of 0.05. This study was reviewed and approved by the Institution Review Board of the Dittman Medical Foundation Chia-Yi Christian Hospital.

3. Results

From 2000 to 2011, the number of registered cases between 3 and 17 years old ranged from 49,242 to 61,717 (Table 2), with an increasing trend from 2000 to 2008, and then a decreasing trend from 2008 to 2011 most likely due to a decrease in...
The prevalence of all disabilities combined between 3 and 17 years old increased constantly from 9.98/1000 in 2000 to 15.41/1000 in 2011 ($p < 0.01$). The prevalence rates in the age groups 3–5 years, 6–11 years, 12–14 years, and 15–17 years were 6.05–10.37/1000, 10.31–16.14/1000, 11.20–16.44/1000, and 11.84–16.92/1000 respectively, and the rates generally increased over the years in all age groups ($p < 0.01$ for all age groups). Furthermore, the prevalence rates generally increased with age in each year ($p < 0.01$ in all calendar years).

In 2000, the top 5 disability categories were ID, multiple disabilities, disability of limbs, hearing impairment, and loss of function of major organ (Table 3). However, the proportion of ASD had been increasing rapidly over the last decade and become the third leading disability in 2011. From 2000 to 2011, the proportions of ID, ASD, and speech or language impairment had been increasing ($p < 0.01$ for evaluation of the trend in all three categories of disability), and in particular the proportion of ASD had increased nearly four folds (3.73% in 2000 to 14.36% in 2011). In fact, most of the disabilities other than these three had a decreasing trend in the proportions.

In term of prevalence, ID, multiple disabilities, ASD, speech or language impairment, and other disabilities listed by the Department of Health had an increasing trend ($p < 0.01$ for all the five categories). The prevalence rates of disability of limbs, hearing impairment, loss of function of major organs, and visual impairment had an increasing trend followed by a decreasing trend, but they reached the peak in different calendar years. The increasing trend in the prevalence rate of all disabilities combined from 2000 to 2011 could largely be attributable to the increases in ID and ASD, with a 64.17% and a 497.30% increase in prevalence respectively over the period. Disability of limbs was the only major category with a remarkable decrease (10.56%) in prevalence during the period.

4. Discussion

The prevalence of all disabilities combined in Taiwanese children increased every year from 2000 to 2011. We believe the increase cannot be attributed entirely to the increase in the occurrence of cases, because the major risk factors in the whole country such as medical care, genetic construct, and socioeconomic status did not change remarkably over the study period (Hou, Wang, & Chuang, 1998; Murphy, Boyle, Schendel, Decouflé, & Yeargin-Allsopp, 1998). In fact, most of these factors moved toward the favorable direction (i.e. better medical care and socio-economic status) gradually over the years. The increase is more likely to be largely attributable to an increase in the proportion of cases registered, which may be in turn attributable to a better service of the related agencies, lower discrimination against the patients, higher awareness of the disorder, more willingness of the guardians to register, etc. (Lai, Tseng, & Guo, 2011; Lai, Tseng, Hou, & Guo, 2012a, 2012b). For example, some researchers argued that in an area where the quantity and quality of service are high, the administrative prevalence is likely to approach the “true prevalence” (Yeargin-Allsopp, Murphy, Oakley, & Sikes, 1992), and the quantity and quality of service had improved during the studies period in Taiwan. In addition, the laws and regulations protecting the rights of persons with disabilities had been more and more strictly enforced (People with Disabilities Rights Protection Act, 2007), and the discrimination against the disabled has been decreasing. Furthermore, increasing awareness of certain disorders such as ASD by parents and professionals increased the registration of the cases (Fombonne, 2009; Wing & Potter, 2002).

Data on the trends in the prevalence of various categories of childhood disability are scarce (Boyle et al., 2011). In this study, we observed increasing trends in the prevalence of ID, multiple disabilities, ASD, speech or language impairment, and other disabilities listed by the Department of Health from 2000 to 2011. In Taiwan, ID is the leading childhood disability, which is compatible with a national survey in China (Chen & Simeonsson, 1993) and the MADDSP in U.S.A. (Bhasin et al., 2006). In fact, ID contributed the most to the increasing trend in the prevalence of all disabilities combined in Taiwan, accounting for about 2.31 of the 5.43 (42.5%) increase per 1000 from 2000 to 2011. We believed the increase can largely be attributable to improving service, and deceasing discrimination, and increasing willingness of the guardians to register (Lai et al., 2012b). ASD was the second largest contributor to the increasing trend in the prevalence of all disabilities combined in Taiwan, accounting for about 1.84 of the 5.43 (33.9%) increase per 1000 from 2000 to 2011. The dramatic increase of prevalence of ASD in Taiwan in the recent years (a 497.30% increase in prevalence from 2000 to 2011 vs. the 54.40% increase in the prevalence of all disability combined) was also found in other countries (Matson & Kozlowski, 2011; Sun & Allison, 2010). In comparison with other disabilities, we believed the increase in ASD is more prominently affected by the changes in diagnostic criteria, widening of the diagnostic concept, and improving awareness of the disease (Matson & Kozlowski, 2011; Rutter, 2005; Wing & Potter, 2002). In comparison with other disabilities, we believe the increase in multiple disabilities was more prominently affected by the improvement in certification processing. For example, a cerebral palsy patient with ID could be reasonably categorized as a case of multiple disabilities, but in the past the patient had to wait for several months to receive intelligence test for certifying ID after the evaluation of disability of limbs. In cases with severe disabilities, the additional benefits coming with the certification of additional disabilities are minimum. Our experiences showed that some parents chose giving up the intelligence test so that their children could receive the benefits of disability earlier. Under such a circumstance, the patient would be categorized as a case of disability of limbs. As more and more clinical psychologists practicing, the waiting time has become shorter and shorter, which has been promoting the willingness of certifying additional disabilities of the same patient.

Disability of limbs was the only major category with a remarkable decrease in prevalence during the study period. More precisely, the prevalence had increased constantly from 2000 to 2004, reached a plateau between 2004 and 2006, and then
The prevalence of childhood disability has been increasing in Taiwan in the recent years. The increase could largely be attributable to the increases in ID and ASD, of which ID contributed to the most cases and ASD was an emerging problem with the most rapid increasing trend. While data on the trend of ID are scarce, the data on ASD outside Taiwan showed similar increases. The increasing trend in ASD observed in our study might indicate that ASD is an emerging global issue.

5. Conclusions

The prevalence of childhood disability has been increasing in Taiwan in the recent years. The increase could largely be attributable to the increases in ID and ASD, of which ID contributed to the most cases and ASD was an emerging problem with the most rapid increasing trend. While data on the trend of ID are scarce, the data on ASD outside Taiwan showed similar increases. The increasing trend in ASD observed in our study might indicate that ASD is an emerging global issue.

Acknowledgment

We would like to thank Department of Statistics of Ministry of the Interior for providing the registry data and Mr. Cheng-Hsing Yeh for his assistance in statistical analysis.

References

