



## Gender and geographic differences in developmental delays among young children: Analysis of the data from the national registry in Taiwan

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### ABSTRACT

Although developmental delays are not uncommon in children, the incidence is seldom assessed, and the reported prevalence varies widely. In Taiwan, the government mandates the reporting of suspected cases. Using the national registry data, we conducted a study to estimate the incidence and prevalence of developmental delays in young children in Taiwan and to assess the gender and geographic differences. According to the law, each city and county in Taiwan needs to establish a reporting and referral center. The Department of Interior constructed a surveillance system on the basis of these centers and publishes the registry data annually. We analyzed the data from 2003 to 2008. From 2003 to 2008, 73,084 new cases were registered, and the incidence was 5.7–11.1 per 1000 person-year under 3 years of age and 7.9–11.4 per 1000 person-year at 3–5 years of age. The estimated prevalence was 8.6–16.6 per 1000 under 3 years of age and 26.2–47.6 per 1000 at 3–5 years of age. The average age at reporting decreased from 3.4 years in 2003 to 3.1 years in 2008. In addition, we found that boys had higher incidence than girls all through the years. Rural areas had higher incidence than urban areas, except for 2003.

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### 1. Introduction

Developmental delays are not uncommon in children, but there are few, if any, reports of incidence data (Durkin, 2002). Although the prevalence data are more often reported, the reported prevalence varies widely (Gottlieb, Maenner, Cappa, & Durkin, 2009; Yeargin-Allsopp, Murphy, Oakley, & Sikes, 1992), and differences in case definition, age range, and case-finding method are the major factors contributing to the variation (Durkin, 2002; Lipkin, 1996). For example, the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) adopted more restrictive criteria which included cerebral palsy, mental retardation, vision impairment, and hearing impairment only and found the prevalence was only 1–2% (Bhasin, Brocksen, Avchen, & Van Naarden Braun, 2006; Boyle et al., 1996). In contrast, the National Health Interview Survey-Child Health Supplement (NHIS-CH) of the whole U.S.A. extended the inclusion to cerebral palsy, delay in growth or development, blindness, deafness, epilepsy, speech defects, stuttering, learning disability, and emotional or behavioral problem and reported the prevalence as 17% (Boyle, Decoufle, & Yeargin-Allsopp, 1994). Age range was another contributing

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factor because different developmental disorders are identified at different ages, and the prevalence of developmental delays generally increases with age (Durkin, 2002). For example, among the National Health Interview Surveys, the NHIS-CH covered all children under 18 years of age and reported the prevalence as 17% (Boyle et al., 1994), while the National Health Interview Survey on Disability (NHIS-D) included children under 5 years only and reported the prevalence as 3.3–3.4% (Simpson, Colpe, & Greenspan, 2003). The case-finding method is also a contributing factor with respect to prevalence. In the U.S.A., population-based survey is a common method of estimating prevalence (Larson, Lakin, Anderson, Kwak Lee, & Anderson, 2001), including the National Health Interview Survey and Survey of Income and Program Participation (SIPP). In this approach, a sample is studied, and the results are generalized to represent the whole target population, which introduce some uncertainties. A case registry, which generally includes all cases in the target population and thus should be able to provide more accurate data, is often applied to assess the incidence of a disease or condition that is more specifically defined. This approach is commonly used in the studies of cancer, infectious disease, and birth defect (Kirby, Brewster, Canino, & Pavin, 1995), and has been applied to study specific developmental disabilities, such as cerebral palsy (Lipkin, 1996) and intellectual disability (Larson et al., 2001). In addition, case registries often require a lot of resources, and so there are few countries in the world that have registration of all kinds of developmental delays.

The amendment of *The Children Welfare Law* (1993) is a milestone in the history of promoting the national registry of children with developmental delays in Taiwan. The Law mandates the government establish a reporting system for children with developmental delays, and accordingly the city and county authorities started to establish local Early Intervention Reporting and Referral Center (EIRRC) for the registration and service of children with developmental delays. The establishment of all 25 EIRRCs in Taiwan was completed by the end of 2001, and *The Children and Youth Welfare Law* (2003) was promulgated in 2003. This Law mandates the welfare, educational and medical institutions report all children suspected to have developmental delays to the EIRRC when they encounter new cases. On the basis of the EIRRCs, the Department of Interior has constructed a national reporting registry system for children with developmental delays. According to *The By-laws of Children and Youth Welfare Law* (2004), a child with developmental delays (retarded development) is defined as one who is “allegedly or expected abnormal development in respect of cognitive development, physiological development, language and communication development, psycho-social development or self-governing skills that have been judged and confirmed by the accredited medical institutes under health authority.”

Although incidence is more precise than prevalence in investigating risk factors, most studies on developmental delays use prevalence data, most likely because incidence data were more difficult to obtain (Durkin, 2002). The registry data of Taiwan present a rare opportunity for studying the epidemiology of developmental delays at a national level. Therefore, we conducted a study using the national registry data to estimate the incidence and prevalence of young children with developmental delays and to assess the gender and geographic differences in incidence.

## 2. Methods

### 2.1. Case definition

The parents and relevant institutes (defined as “welfare, educational and medical institutions” by *The Children and Youth Welfare Law* (2003)) may report suspected cases with developmental delays to EIRRCs, but the EIRRCs only register those who was issued with a certificate after the confirmation by a hospital accredited by the governmental authority, and those who had received assessment by trained social workers in the EIRRCs and been found to have abnormalities (Child Welfare Bureau, 2007).

### 2.2. Data collection

The Department of Statistics, Ministry of the Interior, Taiwan publishes Statistical Yearbook of Interior (Department of Statistics, 2010b) each year, and we analyzed the data from 2003 to 2008 according to the methods of data collection (Department of Statistics, 2009a). In short, the registry collected the data on newly reported cases from 25 EIRRCs without duplicates (Child Welfare Bureau, 2007; Department of Statistics, 2009a), and the information includes the numbers of cases by age at reporting, reporting area (city/county), and gender.

Ages at reporting were categorized into three groups: under 3 years, 3–5 years, and 6 years and above. In Taiwan, “early intervention” is defined as intervention introduced before 6 years of age (*The Bye-laws of Children and Youth Welfare Law*, 2004), and the “6 years and above” group include only those who are 6 years or older but have not yet entered primary school (Department of Statistics, 2009a). Therefore, we excluded cases in this group from our study. We classified the 25 areas in Taiwan into urban and rural areas and defined an “urban area” as one with more than 50% of the population living in metropolitan areas. In other words, a “rural area” was defined as one with 50% or less of the population living in metropolitan areas, which are defined by the Directorate-General of Budget, Accounting and Statistics of Taiwan (Department of Statistics, 2009b). The EIRRCs receive the case reports from multiple sources, and the Yearbook classifies the sources as “medical organizations,” which include public health centers, hospitals, and clinics; “householder and guardian”; “kindergarten”; “nursery”; “social welfare organizations,” which include organizations of early intervention, social workers, and welfare institutions; and “others,” which include community leaders, child care-givers, relatives, friends, and policemen (Department of Statistics, 2009a).

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