

Ten-year trend analysis of autism severity: A nationwide population-based register study

Jin-Ding Lin^{a,*}, Chang-Lin Sung^a, Lan-Ping Lin^b, Shang-Wei Hsu^c,
Wu-Chien Chien^a, Sui-Lung Su^a, Jia-Ling Wu^d

^aSchool of Public Health, National Defense Medical Center, Taipei, Taiwan

^bGraduate Institute of Life Sciences, National Defense Medical Center, No. 161, Min-Chun E. Rd., Sec. 6, Taipei, Taiwan

^cGraduate Institute of Healthcare Administration, Asia University, Taichung County, Taiwan

^dResearch Center for Intellectual Disabilities Taiwan, Chung-Hua Foundation for Persons with Intellectual Disabilities, Taipei County, Taiwan

ARTICLE INFO

Article history:

Received 23 May 2010

Accepted 16 June 2010

Keywords:

Autism spectrum disorder

Autism severity

Disability prevalence

ABSTRACT

The severity of autism spectrum disorder was strongly related to the education and service outcome. Without a clear profile of autistic population and its change, efforts to understand its nature and improve the quality of service or education will be impossible. The present study aims to describe the over time reported rate of autism severity based on a nationwide population-based 10 years register data in Taiwan. We obtained the national register data—the *Disabled Population by Aged and Grade* and the *Taiwan General Population by Age* to examine the overtime trend change of autism severity from 2000 to 2009. Results showed that the reported prevalence of autistic cases significantly increased from 0.93 to 3.96 per 10,000 population in 2000–2009. The group of mild disability grade was significant increasing from 33.4% to 56.2% in percentage of four disability levels in the year of 2000 and 2009, the other groups were decreasing percentage significantly at the same period ($p < 0.001$ in linear trend tests). However, the gender difference in the number of autism in all disability severity needed to be measured in the future study. The study highlights that it is needed to measure the effect of autism severity on the healthcare and education needs in the near future, to improve the quality service for people with autism spectrum disorder.

© 2011 Elsevier Ltd. All rights reserved.

1. Introduction

Persons with autism spectrum disorder (ASD) demonstrate deficits in social interaction, verbal and nonverbal communication, and repetitive behaviors or interests (National Institute of Mental Health, 2008), and it is a lifelong neurodevelopmental disorder characterized by early onset of many impairments. ASD is the second most common serious developmental disability after intellectual disability, and the impact of ASD is great for the families affected and for the community services that provide intervention and support for these families (National Center on Birth Defects and Developmental Disabilities, 2008).

Diagnosis of ASD is based exclusively on developmental pattern and behavioral observation (Schieve, Rice, Boyle, Visser, & Blumberg, 2006). According to many studies, ASD prevalence varied by type of ascertainment source, experts of US Centers for Disease Control measured children aged 8 years with ASD, indicating an overall average prevalence of 6.7 per 1000 in year

* Corresponding author. Tel.: +886 2 8792 3140x18447; fax: +886 2 8792 3147.

E-mail address: a530706@ndmctsgh.edu.tw (J.-D. Lin).

2000 (CDC, 2006), and 9.0 per 1000 in the year 2006 population (CDC, 2009), and the ratio of males to females ranged from 2.8:1 to 5.5:1 in year 2000 (CDC, 2006) and 3.2:1 to 7.6:1 in year 2006 (CDC, 2009). These results indicate that ASD are more common than was believed previously.

The increased number and prevalence of identified ASD can be regarded as an urgent public health concern in society. Precise reporting of ASD can also lead to greater awareness, encourage commitment by service providers and researchers, and help lead the way to more effective intervention and prevention of ASD (National Center on Birth Defects and Developmental Disabilities, 2008). Therefore, to set up a continued monitoring system is needed to document and understand changes over time; it is including the multiple ascertainment and potential risk factors likely to be contributing (CDC, 2009). The present study aims to describe the over time reported prevalence of ASD rate based on a nationwide population-based 10 years register data in Taiwan.

2. Methods

Autism is a complex developmental disability that affects a child's ability to communicate, understand language, play, and relate to others. Based on to the Taiwan "Physically and Mentally Disabled Citizens Protection Act (1997)" which issued by Ministry of the Interior (MOI), it regulates that autism is one of 16 officially registered disabilities in Taiwan. Those persons with autism are characterized by impaired social interaction, problems with verbal and nonverbal communication, and unusual, repetitive, or severely limited activities and interests (DOH, 2006). The autistic cases divide into four levels (mild, moderate, severe and profound) of disability according to their above characteristics. When underwriting the disability, the degree of intellectual disability is assessed first based on intellectual quotient (IQ) as a starting point to classify the disability level as either:

- Mild disability – IQ above 70. Able to live independently. Minimal, if any, impairment in sensory-motor ability and good language skills.
- Moderate disability – IQ 50–70. May able to live independently. Has acquired some communication skills with training and can attend to personal care. Some early school academic achievement. Significant social impairment but may be able to perform unskilled or semi-skilled labor under supervision.
- Severe disability – IQ 30–50. Poor motor development and little, if any, speech or communication skills. Cannot live independently and may need assistance or with some supervision.
- Profound disability – IQ below 30. Requires living in a closely supervised setting.

Those cases with autism are classified and identified by the health authorities, and then registered by the social welfare authorities in the administrative procedure. A diagnosis of ASD is often provided by psychiatrists who have experience in autism course trainings, or the authorities can organize evaluation team (physicians, occupational therapist, psychologist, social worker, and special educator) to evaluate the autistic case if necessary. At the time of diagnosis, a comprehensive evaluation is typically arranged. Such an evaluation usually includes a neurological examination, tests for mental functions and IQ, language and social skills. A battery of developmental and educational evaluations is also conducted to help the comprehensive diagnosis. Those registered autistic cases can apply to receive disability benefits including a living allowance or related welfare benefits from the governments. The present study analyzed data mainly from the public web-access

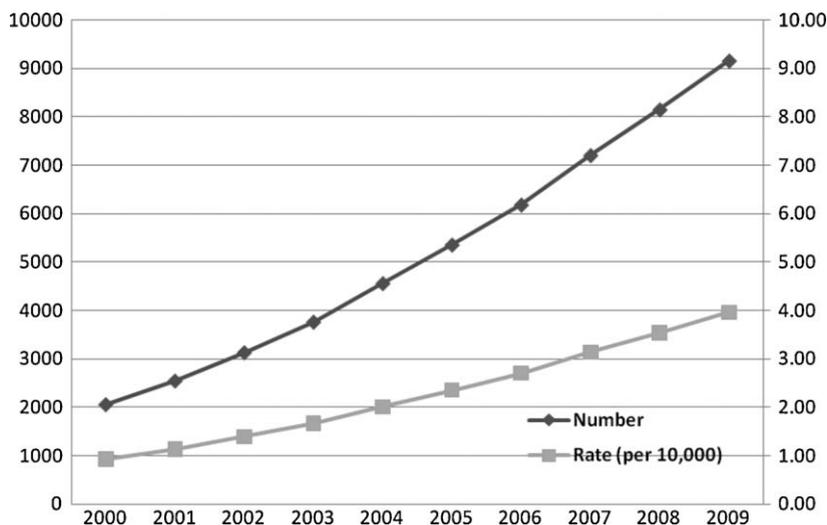


Fig. 1. Reported cases and prevalence of persons with autism, 2000–2009 ($p < 0.001$ in linear trend tests).

Table 1
Disability level in different gender among person with ASD, 2000–2009.

Year	Mild level			Moderate level			Severe level			Profound level		
	Total	Male (%)	Female (%)	Total	Male (%)	Female (%)	Total	Male (%)	Female (%)	Total	Male (%)	Female (%)
2000	689	606 (88.0)	83 (12.0)	772	681 (88.2)	91 (11.8)	516	426 (82.6)	90 (17.4)	85	62 (72.9)	23 (27.1)
2001	926	819 (88.4)	107 (11.6)	983	854 (86.9)	129 (13.1)	547	439 (80.3)	108 (19.7)	94	73 (77.7)	21 (22.3)
2002	1197	1060 (88.6)	137 (11.4)	1173	1018 (86.8)	155 (13.2)	648	522 (80.6)	126 (19.4)	117	94 (80.3)	23 (19.7)
2003	1536	1372 (89.3)	164 (10.7)	1354	1170 (86.4)	184 (13.6)	758	621 (81.9)	137 (18.1)	118	96 (81.4)	22 (18.6)
2004	1988	1774 (89.2)	214 (10.8)	1602	1374 (85.8)	228 (14.2)	852	690 (81.0)	162 (19.0)	120	97 (80.8)	23 (19.2)
2005	2493	2207 (88.5)	286 (11.5)	1820	1561 (85.8)	259 (14.2)	930	756 (81.3)	174 (18.7)	116	93 (80.2)	23 (19.8)
2006	3026	2701 (89.3)	325 (10.7)	2017	1727 (85.6)	290 (14.4)	1017	831 (81.7)	186 (18.3)	125	99 (79.2)	26 (20.8)
2007	3756	3351 (89.2)	405 (10.8)	2220	1908 (85.9)	312 (14.1)	1096	893 (81.5)	203 (18.5)	135	103 (76.3)	32 (23.7)
2008	4448	3969 (89.2)	479 (10.8)	2383	2058 (86.4)	325 (13.6)	1174	956 (81.4)	218 (18.6)	146	111 (76.0)	35 (24.0)
2009	5146	4598 (89.4)	548 (10.6)	2576	2226 (86.4)	350 (13.6)	1278	1039 (81.3)	239 (18.7)	160	123 (76.9)	37 (23.1)

Data compiled by the authors based on MOI Department of Statistics (2010a).

information which collected by the Taiwan MOI. We obtained the national register data in two ways for 2000–2009: *the Disabled Population by Aged and Grade* (MOI Department of Statistics, 2010a) and *the Taiwan General Population by Age* (MOI Department of Statistics, 2010b). We used case number, percentage, overtime trend figure and linear trend test to describe or examine the overtime change of reported numbers and disability levels in persons with autism from 2000 through 2009 in Taiwan.

3. Results

The official reporting data in Fig. 1 illustrated that the registered autistic cases drastically increased from 2062 to 9160 according to the governmental statistics reported from 2000 to 2009 in Taiwan. The reported prevalence of autistic cases significantly increased from 0.93 to 3.96 per 10,000 people at the same period ($p < 0.001$).

Table 1 presents the disability level difference by gender, the results showed the male cases occupied most of the autistic numbers in the study. The reported male/female ratio was 7.3–8.4 in mild disability group, 5.9–7.5 in moderate disability group, 4.1–4.7 in severe disability group, 2.7–4.4 in profound disability group. With regard to the disability level distribution in people with autism, Fig. 2 showed that the group of mild disability grade was increasing from 33.4% to 56.2% in percentage of four disability levels in the year of 2000 and 2009, the other groups were decreasing percentage significantly ($p < 0.001$). The moderate disability grade was decreasing from 37.4% to 28.1%, severe disability grade was 25.0% to 14.0% and profound disability grade was 4.1% to 1.7% in year 2000–2009. In the year of 2000 and 2001, the moderate disability level of autistic cases had the most cases among different disability levels. However, the mild disability level replaced the moderate level of disability to be the most cases among all disability levels.

Figs. 3 and 4 illustrated the disability level distribution by different gender in people with autism. Among the male cases, the group of mild disability grade was increasing from 34.1% in 2000 to 57.6% in 2009, the other groups were decreasing

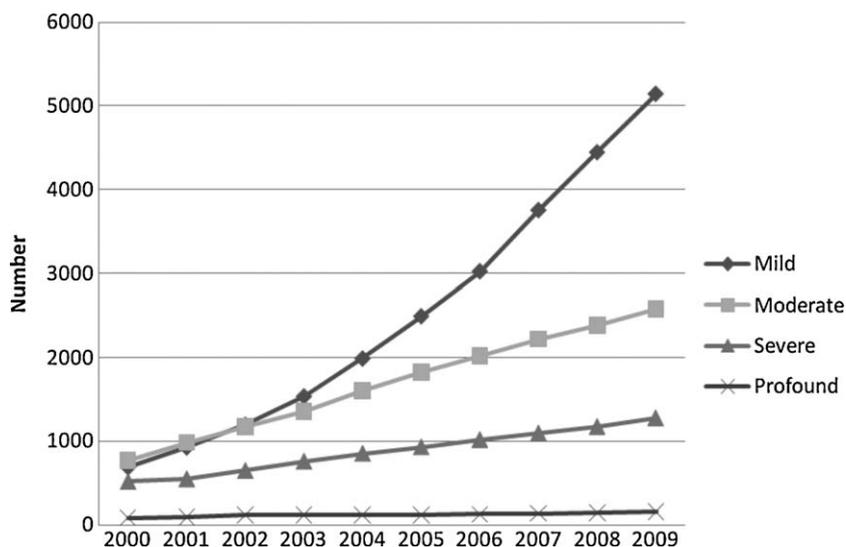


Fig. 2. Level of disability among persons with autism, 2000–2009 ($p < 0.001$ in linear trend tests of all four disability levels).

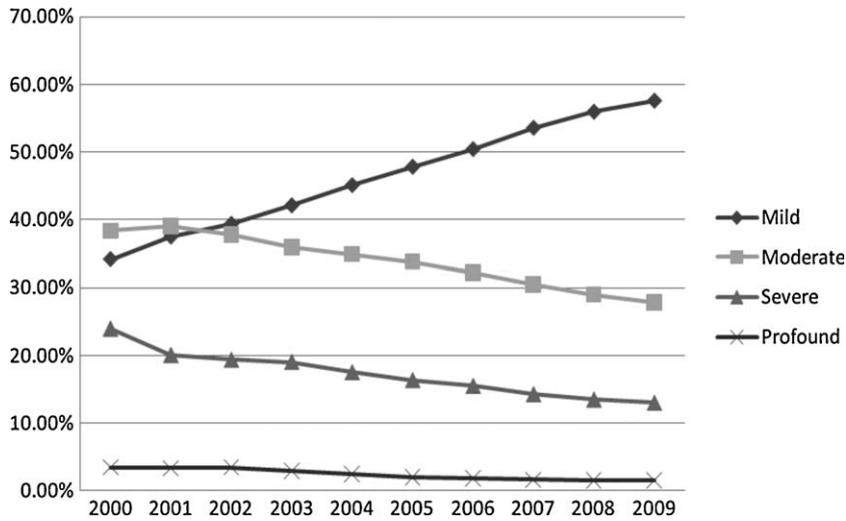


Fig. 3. Disability level in male persons with ASD, 2000–2009 ($p < 0.001$ in linear trend tests of all four disability levels).

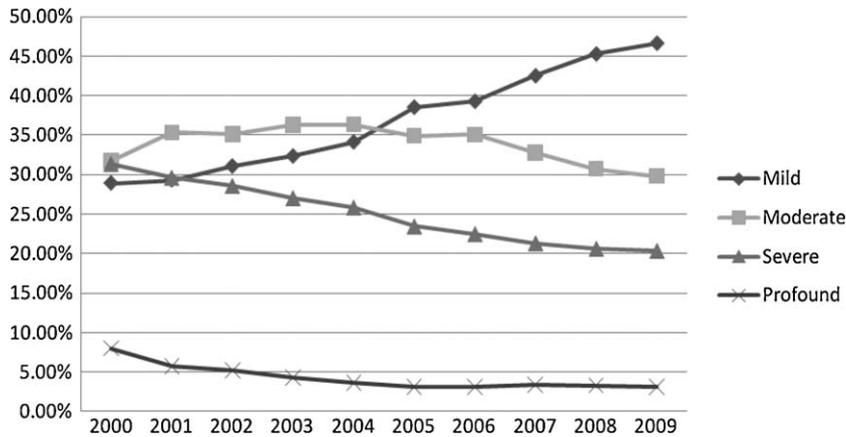


Fig. 4. Disability level in female persons with ASD, 2000–2009 ($p < 0.001$ in linear trend tests of subgroups of mild, severe, and profound disability levels).

significantly in disability level percentage ($p < 0.001$). The moderate disability grade was decreasing from 38.4% to 27.9%, severe disability grade was 24.0% to 13.0% and profound disability grade was 3.5% to 1.5% in year 2000–2009 ($p < 0.001$). In the female cases, the group of mild disability grade was also increasing from 28.9% to 46.7% of 2000–2009 in percentage structure of disability level ($p < 0.001$). The severe disability grade was significantly decreasing from 31.4% to 20.4% and profound disability grade was decreasing from 8.0% to 3.2% in year 2000–2009 ($p < 0.001$). However, the moderate disability grade in female cases was not significantly change over time in the percentage distribution of disability level.

4. Discussion

People with developmental disabilities carry a greater burden of diseases/disorders and require more attention in healthcare than the general populations (Lin et al., 2009; Lin, Lin, Yen, Loh, & Chwo, 2009; Hsu et al., 2009; Yen, Lin, Loh, Shi, & Hsu, 2009; Lin et al., 2010a,b,c,d). Therefore, the population surveillance systems and their demographic databases are important in healthcare decision making, they can provide valuable and cost-effective epidemiological information. However, they are often limited by under-ascertainment of the autistic cases currently (Harrison, O'Hare, Campbell, Adamson, & McNeillage, 2006). Without a clear picture of the population with autism and its overtime change, efforts to understand its nature and improve their quality of services will be impossible (Lin, Lin, et al., 2009). The present study examined the over time reported prevalence of ASD severity based on a nationwide population-based 10 years register data in Taiwan. The registered autistic cases significantly increased from 2062 to 9160, and reported prevalence increased from 0.93 to 3.96 per 10,000 people from 2000 to 2009 in Taiwan.

Comparing to other studies, Fombonne (1999) reviewed 23 epidemiological surveys of autism published in the English language between 1966 and 1998, he found the median prevalence estimate was 5.2/10,000. Finally, he concluded that

prevalence rates of ASD significantly increased with publication year, reflecting changes in case definition and improved recognition. Another study in California, a prevalence of 11.0 per 10,000, the researchers Croen, Grether, Hoogstrate, and Selvin (2002) suggested that improvements in detection and changes in diagnosis account for the observed increase in ASD; whether there has also been a true increase in incidence is not known. Our previous analysis revealed that the registered number of people with autism drastically increased 249.5% from 2000 to 2007 in Taiwan, particularly in children between 6 and 11 years of age, occupying about 43.9–49.5% of the autistic population. The reported prevalence of each age group, aged 0–5 years was 2.4–7.8/10,000, aged 6–11 was 5.0–17.3/10,000, and aged 12–17 years was 2.1–10.4/10,000 from year 2000 to 2007 (Lin, Lin, et al., 2009). But many experts, Lauritsen, Pedersen and Mortensen (2002) were still concerned that the estimated ASD were probably underestimated.

Our present study also showed that the group of mild disability level was increasing significantly from 33.4% to 56.2% in percentage of four disability levels in 2000–2009, the other groups were decreasing percentage significantly. These figures reveal that the case identification skills in medical practice are improving during the past decade. As our knowledge, it is easier to identify the more severe case than the mild degree case according to the characteristics of the cases. However, the gender difference in the number of autism in all disability severity needed to be measured in the future study.

Ben-Itzhak and Zachor (2007) emphasized the autism severity was strongly related to the intervention outcome. They found that children with higher initial cognitive levels and children with fewer measured early social interaction deficits showed better acquisition of skills in receptive language, expressive language and play skills. However, the results also revealed that the effectiveness of intensive intervention in very early age across autism severity range. Schieve et al. (2006) surveyed parents who reported that their children had autism in US, they reported these children experienced moderate or high levels of social, emotional, and behavioral difficulties and needed special medical, mental health, education services (90.1%) than children reported without autism (10.5%). For the future policy formulation to improve the quality service for people with ASD, it is needed to measure the effect of autism severity on the healthcare and education needs in Taiwan.

References

- Ben-Itzhak, E., & Zachor, D. A. (2007). The effects of intellectual functioning and autism severity on outcome of early behavioral intervention for children with autism. *Research in Developmental Disabilities*, 28, 287–303.
- CDC. (2006). Prevalence of autism spectrum disorders—Autism and developmental disabilities monitoring network, six sites, United States, 2000. *Morbidity and Mortality Weekly Report*, 56, S1–S10.
- CDC. (2009). Prevalence of autism spectrum disorders – Autism and developmental disabilities monitoring network, United States, 2006. *Morbidity and Mortality Weekly Report*, 58, S1–S24.
- Croen, L. A., Grether, J. K., Hoogstrate, J., & Selvin, S. (2002). The changing prevalence of autism in California. *Journal of Autism and Developmental Disorders*, 32, 207–215.
- DOH. (2006). *Disability level and classification*. Taiwan, Republic of China: Department of Health no 0952801549.
- Fombonne, E. (1999). The epidemiology of autism: A review. *Psychological Medicine*, 29, 769–786.
- Harrison, M. J., O'Hare, A. E., Campbell, H., Adamson, A., & McNeillage, J. (2006). Prevalence of autistic spectrum disorders in Lothian, Scotland: An estimate using the "capture-recapture" technique. *Achieves of Disease in Childhood*, 91, 16–19.
- Hsu, S. W., Lin, Y. W., Chwo, M. J., Huang, H. C., Yen, C. F., Lin, L. P., et al. (2009). Emergency department utilization and determinants of use by 0 to 6-year-old children with disabilities in Taipei. *Research in Developmental Disabilities*, 30, 774–781.
- Lauritsen, M. B., Pedersen, C. B., & Mortensen, P. B. (2002). The incidence and prevalence of pervasive developmental disorders: A Danish population-based study. *Psychological Medicine*, 34, 1339–1346.
- Lin, J. D., Lee, T. N., Loh, C. H., Yen, C. F., Hsu, S. W., Wu, J. L., et al. (2009). Physical and mental health status of staff working for people with intellectual disabilities in Taiwan: Measurement with the 36-Item Short-Form (SF-36) health survey. *Research in Developmental Disabilities*, 30, 538–546.
- Lin, J. D., Lin, P. Y., Chen, L. M., Fang, W. H., Lin, L. P., & Loh, C. H. (2010). Serum glutamic oxaloacetic transaminase (GOT) and glutamic pyruvic transaminase (GPT) levels in children and adolescents with intellectual disabilities. *Research in Developmental Disabilities*, 31, 172–177.
- Lin, P. Y., Lin, L. P., & Lin, J. D. (2010). Hypertension, hyperglycemia, and hyperlipemia among adolescents with intellectual disabilities. *Research in Developmental Disabilities*, 31, 545–550.
- Lin, J. D., Lin, P. Y., Lin, L. P., Chang, Y. Y., Wu, S. R., & Wu, J. L. (2010). Physical activity and its determinants among adolescents with intellectual disabilities. *Research in Developmental Disabilities*, 31, 263–269.
- Lin, J. D., Lin, P. Y., Lin, L. P., Hsu, S. W., Loh, C. H., Yen, C. F., et al. (2010). Prevalence and associated risk factors of anemia in children and adolescents with intellectual disabilities. *Research in Developmental Disabilities*, 31, 25–32.
- Lin, J. D., Lin, Y. W., Yen, C. F., Loh, C. H., & Chwo, M. J. (2009). Received, understanding and satisfaction of national health insurance premium subsidy scheme by families of children with disabilities: A census study in Taipei City. *Research in Developmental Disabilities*, 30, 275–283.
- Lin, J. D., Lin, L. P., & Wu, J. L. (2009). Administrative prevalence of autism spectrum disorders based on national disability registers in Taiwan. *Research in Autism Spectrum Disorders*, 3, 269–274.
- MOI Department of Statistics. (2010a). *Data 04-18: The physically and mentally disabled population by aged and grade* Accessed on 18.03.2010 www.moi.gov.tw/stat/index.asp.
- MOI Department of Statistics. (2010b). *Data 02-01: Taiwan general population by age* Accessed on 18.03.2010 www.moi.gov.tw/stat/index.asp.
- National Institute of Mental Health. (2008). *Autism spectrum disorders: Pervasive developmental disorders*. Bethesda, MD: National Institute of Mental Health.
- National Center on Birth Defects and Developmental Disabilities. (2008). *Frequently asked questions—Prevalence of autism spectrum disorders (ASDs)* Accessed on 22.05.2010 www.tourettesyndrome.net/Files/CDC_AutPrevalence.pdf.
- Physically and Mentally Disabled Citizens Protection Act. (1997). President Order Hua-Tsung-Yi-Tzu no.8600097810, April 23, 1997, Taiwan, Republic of China.
- Schieve, L. A., Rice, C., Boyle, C., Visser, S. N., & Blumberg, S. J. (2006). Parental report of diagnosed autism in children aged 4–17 Years—United States, 2003–2004. *Morbidity and Mortality Weekly Report*, 55, 481–486.
- Yen, C. F., Lin, J. D., Loh, C. H., Shi, L., & Shu, S. W. (2009). Determinants of prescription drug use by adolescents with intellectual disabilities in Taiwan. *Research in Developmental Disabilities*, 30, 1354–1366.