

Urbanicity-related Variation in Help-seeking and Services Utilization among Preschool-age Children with Autism in Taiwan

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Abstract The present study examines urbanicity-related differences in help-seeking process among preschool children with autism and investigates the factors associated with utilization of autism-related services within the year of diagnosis. Using the 1997–2004 National Health Insurance Research Database (NHIRD) in Taiwan, we identified a total of 3495 autistic children born in 1997–1999 and 13964 matched controls. Results indicate that suburban and rural autism tended to receive the diagnosis at an older age and to have a longer diagnosis process as compared with urban counterparts. Male gender, a younger age of diagnosis, and being diagnosed by psychiatric specialty strongly predict subsequent greater utilization of autism-specific services (all $p < 0.05$). Health policy makers and other service providers should address the needs of children with early-onset neurodevelopmental disorders in rural areas, particularly those from disadvantaged families.

Keywords Autism · Health services · Urbanicity · Children

There is considerable evidence that the number of children diagnosed with autism has been remarkably increasing in the past decade (Costello et al. 2006; Rutter 2005). In conjunction with this rising prevalence rate, a growing concern has been raised regarding unmet needs for services among autism-affected children and their families. Given that autism is an early-onset disease which affects many spheres of child development and functioning (e.g., language and social communication), the ideal care program serving autistic children usually involves comprehensive services which are offered and managed on a developmental stage approach (Aman 2005; Howlin 1998). Various approaches have demonstrated some effectiveness in ameliorating core symptoms of autism and in reducing behavioral or emotional problems, including pharmacotherapy, speech and language therapy, and behavioral intervention (Aman 2005; Howlin 1998; McConnell 2002; King and Bostic 2006; Volkmar et al. 2006). Since the gains in the improvement of adaptive behaviors, social skills, cognition, or other comorbid problems are believed crucial before autistic children start school, treatment and intervention programs are usually encouraged initiated shortly after diagnosis and sustained, at least, throughout the school years (Hollander et al. 2003; Volkmar et al. 2006).

Although effective medical management and interventions are available, a higher proportion of autistic children and their families do not receive such health services (Committee on Educational Interventions for Children with Autism 2001; Howlin 2005; Williams White et al. 2006). Prior research has linked the characteristics of children and families, care providers, and health resources and system with differential help seeking and services utilization (Lavigne et al. 1998; Leslie et al. 2005; Mandell and Novak 2005; Owens et al. 2002; Rubble et al. 2005; Simpson et al. 2005; Zwaanswijk et al. 2003). While the relative

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contribution of each of these explanatory factors cannot be discerned, some subpopulations appear to have more barriers accessing or utilizing mental health services. For instance, due to the lack of specialty care providers, rural families are often required to travel long distances to obtain specialized mental health services, at considerable personal and financial costs. Therefore, rural children with mental health problems or special needs may be at a greater risk to receive a delayed diagnosis and to experience fragmented and discontinued care, especially if they were from disadvantaged family backgrounds (Boydell et al. 2006; Costello and Janiszewski 1990; Farmer et al. 2005; Petti and Leviton 1986; Petrou and Kupek 2007).

On March 1, 1995, Taiwan implemented the National Health Insurance Program (NHIP) to provide all civilian residents with mandatory comprehensive medical care coverage (Department of Health [DOH] 2004). A recent estimate of the NHIP coverage rate for children under 19 years of age was approximately 98.7% (Chen et al. 2007). Over the past ten years, there is little doubt that the NHIP has increased access to health care and utilization of health services for children and families from disadvantaged socioeconomic backgrounds (Chen and Liu 2005; Cheng 2003). Although the availability of health insurance has been suggested as a significant factor affecting whether or not services are accessible or utilized, health insurance alone may not be enough to ensure the access to comprehensive and specialized health care services for children in different social groups, such as urbanicity. To date, little has been known about non-insurance barriers for autistic children and families while seeking medical help and accessing health services, particularly among preschool children. To fill this gap, we turned to the National Health Insurance Research Database (NHIRD) in Taiwan. On the basis of population-based study design, the goals of this study are (i) to examine medical help-seeking amongst children with autistic problems across strata defined by urbanicity, and (ii) to investigate the characteristics of children and service providers in relation to autism-related health service within the year of the diagnosis.

Methods

Sample

The data for the present study are from the 1997 to 2004 NHIRD. For each NHIP beneficiary, a unique encrypted identification number was used to retrieve sociodemographic background data in the NHIP registration records, as well as ambulatory and inpatient services utilization in the NHI medical claim data files (such as medical diagnosis, the date of visit, specialty of visit, and payment for treatment). Through the medical claim data files of those NHIP benefi-

ciaries who had a Taiwan nationality and were born between 1997 and 1999 ($n = 887611$), a total of 3570 cases of autism (code = 299.0X) were identified on the basis of International Classification of Diseases, Ninth Revision, Clinical Modification (World Health Organization [WHO] 1992). The onset of autism was defined as the diagnosis code first appeared in the medical claim records, and the age at diagnosis was determined by subtracting birthdate from the corresponding visit date. Given the preschool age is a period in need of health care (Simpson et al. 2005), we excluded 75 ineligible children who had not received any outpatient service in the year before or after the diagnosis of autism to ensure subjects' eligibility for the NHIP and residence in Taiwan. Next, eligible controls were identified as children who had not received a diagnosis of autism and had received at least one outpatient services yearly from birthyear to 2004. Each autistic case was individually matched to controls in a ratio of 1:4 (Rothman 1986), by criteria of (i) birth year and month, (ii) gender, (iii) Enrollee' Category (EC, a proxy measure of socioeconomic status), (iv) urbanicity level, and (v) geographic area. In sum, the study sample is consisted of 3495 cases, and 13964 controls (24 cases were unable to obtain 1:4 matched controls).

Measures

According to the NHIP registration information, all study subjects were classified into four geographic areas (i.e., Northern, Central, Southern, and Eastern) and three urbanicity regions (i.e., urban, suburban, and rural). "Urbanicity" was derived from five indices: population density, percentages of residents with college or higher education, percentages of residents over 65-years old, percentage of residents who were agriculture workers, and the number of physicians per 100,000 people (Chen et al. 2007; Liu et al. 2006).

Given commonly used measures of socioeconomic status (SES) were not available in the NHIP (e.g., family income), the category for children's Enrollees (i.e., the ones who paid the insurance fee, such as the child's parents, grandparents, or social welfare institutions) was then adopted as a proxy measure of SES to subgroup children into four Enrollee's Categories (EC): "EC I (e.g., civil servants, fulltime or regularly paid personnel in governmental agencies and public schools)," "EC II (employees of privately owned enterprises or institutions)," "EC III (self-employed, other employees or paid personnel, and members of the Farmers or Fishers Associations)," and "EC IV (substitute service draftees, members of low-income families, and veterans)." On average, the payroll-related amount for the health insurance was highest for "EC I", followed by "EC II," "EC III," and "EC IV."

In order to understand medical help-seeking process and utilization of proper treatment, we restricted the study

period to one year before and after the date of autism diagnosis (index date), for both cases and their matched controls. Indicators of utilization pattern included the number of outpatient visits (excluding preventive services) and specialty (i.e., psychiatry, pediatrics, rehabilitation, and others). In Taiwan's National Health Insurance Program, no more than three diagnostic codes were allowed to be documented when contracted health care providers request outpatient services reimbursement from NHIP. In the present study, children who had any one of three diagnostic codes ranging from 290 to 319 (excluding 299.0x) in their medical claim datafiles were considered to have other diagnoses of mental problems (e.g., cognitive, emotional, or other behavioral problems). However, for mental health services, we decided to apply a stricter criterion that requires the first (or primary) diagnostic code should fall between 290 and 319 (excluding code=299.0x). The same "first diagnosis code" criterion was also utilized as we obtained health services specific to autism after diagnosis (i.e., first diagnostic code=299.0X).

Statistical Analyses

Contingency table analyses were first conducted to understand the distribution of sociodemographic background of autistic cases, matched controls, and the general population. The average of outpatient visits in the year pre- and post-diagnosis for autistic cases and their matched controls was first estimated with stratification by urbanicity level and specialty. Next, the processes of medical help-seeking prior to autism diagnosis were compared across three urbanicity strata via Chi-Square and Analysis of Variance (ANOVA) tests. As to the factors associated with autism-related services utilization within the year of diagnosis, we turned to Generalized Linear Models in a gamma distribution with a log link function given that an extremely skewed distribution of frequency of outpatient visits failed to satisfy the assumptions for ordinary least square regressions (Barber and Thompson 2004; Dunn et al. 2003). A comparison between the adjusted and unadjusted linear regression coefficients provides information about the extent to which the association between individual and care-provider factors with autism-related health care utilization might be independent of factors listed in the model. All data preparation and statistical analyses were carried out using SAS release 9.13 (SAS Institute Inc., 2005), and STATA version 8.02 (STATA Corporation 2005).

Results

Table 1 presents selected characteristics for young subjects in this study. Three birth cohorts born 1997–1999 were

predominately from EC II (47.1%), and over one half were in suburban region and the Northern area. Generally, an estimated 82% of identified cases were male, and about one half of autistic children had their health insurance paid by a family member in Enrollee's Category (EC) II. Roughly 40% of autistic cases had health insurance registered in the urban area, two thirds were from the Northern region, and only 1% of autistic cases were identified from the Eastern region of Taiwan. In comparison with the 1997–1999 birth cohorts enrolled in the National Health Insurance Program, our study subjects were more likely to be male, to come from a family with higher SES, and to have health insurance enrolled in urban regions and the Northern part of Taiwan (all $p < 0.001$).

Estimated utilization of outpatient services in the year preceding and following the diagnosis of autism are plotted in Fig. 1, with the estimates for urban, suburban, and rural children depicted as squares, circles, and triangles, respectively. The pre-diagnosis (left) and post-diagnosis (right) utilization of outpatient services for cases was connected by solid lines, and that for their matched controls was broken lines. A comparison of autistic cases with matched controls showed a consistent excess in the average of outpatient visits. To take the whole outpatient services as an example, the case-control differences were 5–6 visits in the year preceding diagnosis and 14–15 visits in the year after diagnosis. No clear relationship was found between urbanicity and outpatient services utilization among matched controls. In contrast, significant urbanicity-related differences were found in outpatient specialty services among autistic cases, such as in psychiatric specialty (both pre- and post-diagnosis) ($p < 0.001$), rehabilitative specialty (post-diagnosis only) ($p < 0.01$), and others (pre-diagnosis only) ($p < 0.01$). For example, prior to the diagnosis, children with autistic problems in urban regions had more visits in psychiatric specialty as compared with their non-urban peers who noticeably had more visits in specialties other than psychiatry, pediatrics, and rehabilitation. With statistical adjustment for gender, birthyear, socioeconomic status, and geographic area by linear regression analyses, urbanicity-related differences remained strong and significant in the utilization of psychiatric specialty services, for both pre- and post-diagnosis periods (all $p < 0.01$).

Although no statistical significances were found between urbanicity with other diagnoses prior to autism, a slightly lower percentage of autistic children in urban regions had received other diagnoses of mental problems prior to autism as compared with their peers in rural regions (66.1% vs. 70.3%) (Table 2). In contrast, the experiences of developmental disorder/mental problems other than autism among controls seemed more prevalent in urban regions (see the right panel of Table 2). More than half of autistic children

Table 1 Selected characteristics for autistic children, matched controls, and general population: the National Health Insurance Research Dataset, Taiwan

Variables	Autism ^a		Controls		Population	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Total	3495	(100.0)	13964	(100.0)	887611	(100.0)
Birth cohort						
1997	1301	(37.2)	5199	(37.2)	328875	(37.1)
1998	1098	(31.4)	4389	(31.4)	271982	(30.6)
1999	1096	(31.4)	4376	(31.3)	286754	(32.3)
Gender***						
Female	641	(18.3)	2559	(18.3)	424553	(47.8)
Male	2854	(81.7)	11405	(81.7)	463056	(52.2)
Enrollee’s Category (EC) ^{b,***}						
I	555	(15.9)	2220	(15.9)	87176	(9.8)
II	1743	(49.9)	6962	(49.9)	417819	(47.1)
III	793	(26.7)	3168	(26.7)	251985	(28.4)
IV	404	(11.6)	1614	(11.6)	130631	(14.7)
Geographical area***						
Eastern	34	(1.0)	135	(1.0)	21672	(2.4)
Southern	742	(21.2)	2966	(21.2)	240825	(27.1)
Central	444	(12.7)	1776	(12.7)	172218	(19.4)
Northern	2249	(64.4)	8983	(64.3)	446903	(50.3)
Unknown	26	(0.7)	104	(0.7)	5993	(0.7)
Urbanicity***						
Urban	1390	(39.8)	5551	(39.8)	250115	(28.2)
Suburban	1621	(46.4)	6478	(46.4)	445672	(50.2)
Rural	421	(12.1)	1684	(12.1)	174638	(19.7)
Unknown	63	(1.8)	251	(1.8)	16988	(1.9)

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

^a χ^2 -test was performed to compare autistic cases with general population

^b Enrollee’s category (EC): a proxy measure for socioeconomic status; the highest SES is EC I

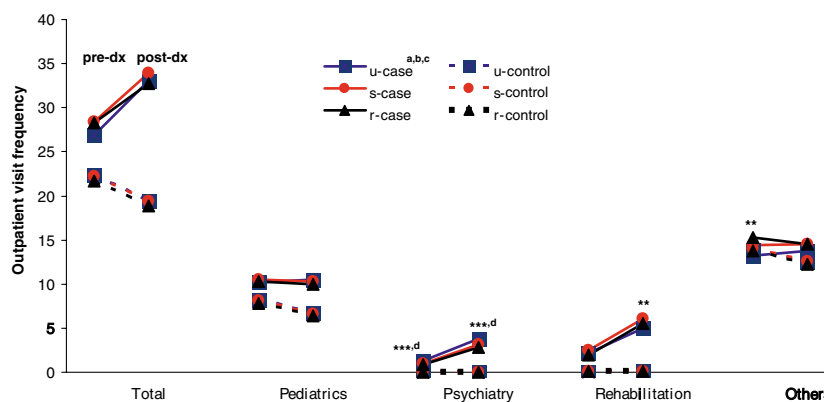


Fig. 1 Pre- and post-diagnosis utilization of outpatient services among autistic children and matched controls, stratified by urbanicity and specialty. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. (a) U: urban; S: suburban; R: rural. (b) Utilization of outpatient health services for autistic children was all significantly greater than controls in three urbanicity strata. (c) Urbanicity-related differences in the average

frequency of outpatient visit were only found in autistic cases (all $p < 0.001$). (d) Urbanicity-related differences in the average frequency of outpatient visit among autistic cases were found after statistical adjustment for gender, birthyear, SES, and geographic areas, by multivariate linear regression analyses (all $p < 0.01$)

Table 2 Comparison of diagnostic processes for autism among preschool children by urbanicity, Taiwan

Variables	Autism				Control				p
	Urban	Sub-urban	Rural	p	Urban	Sub-urban	Rural	p	
N	1390	1621	1621		5551	6478	1684		0.004
Other diagnoses of mental problems prior to autism ^{a,b,c,d}				0.276					
None	471 (33.9)	535 (33.0)	125 (29.7)		5268 (94.9)	6177 (95.4)	1631 (96.9)		
Other dev. speech or language disorder (315.39)	49 (3.5)	57 (3.6)	30 (7.1)		17 (0.3)	19 (0.3)	5 (0.3)		
Unsp. delay in development (315.9)	38 (2.7)	54 (3.3)	19 (4.5)		25 (0.5)	36 (0.6)	6 (0.4)		
Mixed development disorder (315.5)	58 (4.2)	42 (2.6)	9 (2.1)		9 (0.2)	6 (0.1)	0 (0.0)		
Developmental Speech or Language Disorder only (315.3)	36 (2.6)	56 (3.5)	6 (1.4)		23 (0.4)	27 (0.4)	1 (0.1)		
Others	738 (53.1)	877 (54.1)	232 (55.1)		209 (3.8)	213 (3.3)	41 (2.4)		0.52
Age at first diagnosis of mental problems (years) ^{a,c,e}				0.68					
N	919	1086	296		283	301	53		
Mean (SD)	2.76 (1.3)	2.77 (1.3)	2.69 (1.3)		2.71 (1.6)	2.65 (1.6)	2.44 (1.7)		
Range	(0.07–7.16)	(0.05–7.47)	(0.44–7.29)		(0.02–6.83)	(0.04–6.95)	(0.08–6.55)		
Use of mental health services in the year prior to diagnosis ^{b,f}				<0.001					0.04
No	562 (40.4)	684 (42.2)	169 (40.1)		5205 (97.8)	6285 (98.0)	1665 (98.9)		
Yes (Psychiatry)	571 (41.1)	511 (31.5)	132 (31.4)		45 (0.9)	38 (0.6)	5 (0.3)		
Yes (Other specialties)	257 (18.5)	426 (26.3)	120 (28.5)		70 (1.3)	89 (1.4)	14 (0.8)		
Autism diagnosis				0.027					
Age at first diagnosis (years) ^e									
Mean (SD)	3.72 (1.4)	3.84 (1.4)	3.86 (1.4)						
Range	(0.71–7.54)	(0.19–7.70)	(0.92–7.47)						
By hospital level ^b				<0.001					
Medical centers	617 (44.4)	678 (41.8)	153 (36.3)						
Metropolitan hospitals	603 (43.4)	648 (40.0)	160 (38.0)						
Community hospitals	101 (7.3)	213 (13.1)	92 (21.9)						
Physician clinics	69 (5.0)	82 (5.1)	16 (3.8)						
By specialty ^b				<0.001					
Psychiatry	935 (67.2)	937 (57.8)	216 (51.3)						
Pediatrics	127 (9.1)	247 (15.2)	89 (21.1)						
Others	328 (23.6)	437 (27.0)	116 (27.6)						
Gap between the first psychiatric problem and autism (months) ^{a,e}				0.004					
Mean (SD)	13.9 (15.1)	16.3 (15.9)	15.5 (15.7)						
Range	(0.03–74.05)	(0.03–82.40)	(0.03–68.83)						

^a The ICD-9-CM code ranges from 290 to 319 (299.0x was excluded)

^b χ^2 -test

^c Cover all three diagnostic codes in the NHIP ambulatory datafiles

^d p-values were derived from the comparison of prior diagnoses other than autism (yes/none) in relation to urbanicity

^e Analysis of variance (ANOVA) test

^f Limited to the first (primary) diagnostic code in the NHIP ambulatory datafiles

had utilized mental health services prior to the diagnosis, and the estimate for urban cases receiving such services from psychiatric specialty is remarkably higher than that of rural cases (70%, 571/828 vs. 53%, 132/252). In general, urban children were more likely to receive the autism diagnosis at a younger age, from a higher hospital level (e.g., medical institution), and to have a shorter diagnosis process (i.e., time gap between the diagnosis of other developmental disorders/mental problems and autism) as compared with suburban and rural ones. The urbanicity variation in the age of autism diagnosis and the length of diagnosis processes remained significant after statistical adjustment for birth-year, sex, and SES (data not shown in Table).

To determine possible factors influencing the use of autism-related outpatient services following the first year

of diagnosis, we used the Generalized Linear Model analyses to estimate the magnitude of relationship. As presented in the left column of Table 3, the unadjusted model shows that gender, geographic area, socioeconomic status, age at diagnosis, prior diagnosis of mental problems, hospital level, and specialty were associated with a greater number of autism-related outpatient visits. With all listed covariates adjusted simultaneously, the frequency of autism-specialized health services for autistic boys was 16% greater than for girls ($e^{0.15} = 1.16$ 95% CI: 1.05, 1.41, $p = 0.04$). As compared with those who was diagnosed of autism at the first two years of their lives, children who received a diagnosis at ages 3–4 years had an estimated 23% reduction in utilization of autism-related services ($e^{-0.26} = 0.77$, 95% CI: 0.68, 0.87, $p < 0.001$).

Table 3 Factors associated with utilization of autism-related outpatient services, Taiwan

Variables	Autism-related health services ^a	
	Univariate β (95% CI) ^b	Adjusted β (95% CI) ^{b,c,d}
Gender (ref: female)		
Male	0.22 (0.07, 0.36)**	0.15 (0.01, 0.30)*
Enrollee's category ^e (ref: I)		
II	-0.20 (-0.36, -0.04)*	-0.14 (-0.30, 0.02)
III	-0.23 (-0.41, -0.04)*	-0.17 (-0.35, 0.01)
IV	-0.06 (-0.28, 0.16)	-0.04 (-0.26, 0.18)
Geographic area (ref: Eastern)		
Southern	0.50 (-0.07, 1.07)	0.38 (-0.19, 0.95)
Central	0.93 (0.34, 1.51)**	0.85 (0.27, 1.43)**
Northern	0.58 (0.01, 1.14)*	0.47 (-0.09, 1.04)
Age at autism diagnosis (ref: < 3 year)		
3–4 years	-0.23 (-0.36, -0.10)***	-0.26 (-0.39, -0.13)***
5 years or above	-0.67 (-0.83, -0.51)***	-0.80 (-0.96, -0.64)***
Other diagnoses prior to autism (ref: no)		
Yes	0.11 (-0.01, 0.23)	0.19 (0.07, 0.32)**
Hospital level to diagnose autism (ref: med. center)		
Metropolitan hospitals	-0.20 (-0.32, -0.08)***	-0.16 (-0.28, -0.03)*
Local community hospitals	0.25 (0.07, 0.43)**	0.29 (0.10, 0.49)*
Physician clinics	-0.11 (-0.38, 0.15)	0.15 (-0.13, 0.43)
Specialty to diagnose autism (ref: psychiatry)		
Others	-0.15 (-0.26, -0.04)*	-0.21 (-0.33, -0.09)***
Urbanicity level (ref: urban regions)		
Suburban regions	-0.01 (-0.13, 0.11)	-
Rural regions	-0.01 (-0.20, 0.17)	-

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

^a Autism was the first (primary) diagnostic code in the NHIP ambulatory datafiles

^b The coefficients β s were obtained via generalized linear models in a gamma distribution and log link function

^c The variables listed in the final model were determined by a p-value of 0.1 or less for univariate association

^d All the listed variables were adjusted simultaneously

^e Enrollee's category (EC): a proxy measure for socioeconomic status; the highest SES is EC I

Discussion

Building upon the 1997–2004 National Health Insurance Research Database in Taiwan, the results of our study suggest that urbanicity disparity may exist in medical help-seeking process for autistic children and their families, as manifested by the observation that suburban and rural autism tended to receive diagnosis at an older age and to have a longer diagnosis process as compared with urban ones. Within the year of diagnosis, factors associated with greater utilization of autism-related ambulatory services include male gender, a younger age at first diagnosis, prior diagnoses of developmental disorders/mental problems, and being diagnosed by psychiatric specialty.

Some potential limitations of this study should be noted before further discussion. First, since the NHIRD exclusively relied on National Health Insurance Program (NHIP), we were not able to identify the cases (i) who seek help from physicians who were not contracted by the NHIP, or (ii) who obtained services via out-of-pocket costs. Second, although the NHIRD is the most comprehensive database of health services utilization at the national level in Taiwan, we were limited to variables included in those records. For instance, when urbanicity level was defined on the basis of individual records of health insurance enrollment, possible urbanicity discrepancies may exist. In the case when a child who was a dependent of the insured employed in the Northern urban region but was raised by someone living in the Southern or Eastern rural regions (e.g., grandparents) in Taiwan, we would not be able to differentiate this misclassification from our records. Third, we do not have the information necessary to determine the clinical validity for autism diagnosis, which may possibly vary across hospital level and specialty. On a similar note, for children with developmental disorders/mental health problems prior to autism, we cannot tell whether the diagnoses were transitional (e.g., developmental delay), actual comorbid conditions (e.g., mental retardation), or even misdiagnoses. Finally, one should be cautious in generalizing our results to other countries or societies with different health insurance markets and health delivery systems.

These limitations notwithstanding, our study has some notable strength, mostly due to the robust nature of the NHIRD which involves a large, prospective, population-based comparison of health services utilization from birth onward. Because almost every child is covered by health insurance, we are able to examine long-term health services utilization while ruling out possible problems from insurance uncoverage or interrupted insurance. Also, as compared with prior studies primarily derived from children of school age, our study appears to be one of the first studies to investigate such issues in the preschool period

(i.e., 2–5-years old), which has been long considered as a crucial period for intervention aiming at early-onset neurodevelopmental disorders. Finally, our study expands on previous research by examining individual and care provider-associated factors that may influence the utilization of health care services within the very first year of receiving a diagnosis of autism—a critical stage to devise individual-tailored intervention programs and treatment plans.

Consistent with the documented shortage of psychiatric specialty in the suburban and rural regions of Taiwan (DOH 2005), our analyses have shown that urban-rural differences in health care utilization by children of autism in Taiwan were more an issue of lack of specialty and coordinated services. Prior evidence showed that, usually as a result of poor integration of services, lack of medical professionals, limited access to mental health, and disadvantaged backgrounds (Boydell et al. 2006; Farmer et al. 2005; Petti and Leviton 1986; Thomas and Holzer 2006), rural children with special needs were faced with marked difficulties in obtaining comprehensive and coordinated services. Given that medical service providers, particularly with specialty, are more concentrated in urban regions and the Northern areas of Taiwan, it is possible that families with an autistic child in rural regions experienced an array of barriers in seeking professional help, including limited access to quality psychiatric cares and waiting long periods for needed services in tertiary cares (Owens et al. 2002). These barriers may also be reflected in the observation that rural autistic cases tended to have a more prolonged period of diagnosis process and to be diagnosed at an older age (Mandell and Novak 2005; Mandell et al. 2005).

The characteristics of individuals and care-providers seem to play a significant role in determining utilization of autism-specific health care (Leslie et al. 2005; Mandell et al. 2002; Owens et al. 2002; Zwaanswijk et al. 2003). As compared with an estimate of 60% in autistic boys, only one half of autistic girls have utilized at least once autism-related health services within the year of diagnosis. This observed male-related excess in health service utilization may suggest a possibility of gender differentials in symptom recognition by primary care givers, clinical manifestation (e.g., co-occurring behavioral problems), and socio-cultural factors (Mandell et al. 2002; Mandell et al. 2005; Daley 2004). As to the inverse relationship between age at diagnosis and the utilization of medical care specialized to autism, this finding may be, in part, explained by (i) differential clinical severity: children with mild autistic symptoms are more likely to be recognized and diagnosed later and therefore to need fewer medical treatments; and (ii) use of services outside the medical system: it is possible that a child diagnosed at an older age may seek help from professionals affiliated with the educational and social

welfare systems, which were impossible to be assessed in this study.

Among autistic children in Taiwan, socioeconomic status was found in no significant relationship with autism-related health utilization within the year of diagnosis. In addition to the imperfect validity of Enrollee's Category, this observation was possibly a de facto result of socioeconomic forces given that families with higher SES may directly seek treatment or health service via out-of-pocket costs in order to skip the long waiting list for autism services provided by the NHIP contracted medical professionals. We did not observe differences in health utilization within 1 year of diagnosis according to urbanicity, which may seem surprising. The lack of differences may be explained by the mixed results of differential access to specialty services and specialty-related heterogeneity in claiming reimbursement. Another intriguing finding was the less frequent utilization of autism-related health services among autistic children who had received diagnosis from non-psychiatry specialty. This may raise some issues regarding the referral process (e.g., inefficient or ineffective) in pediatric or mental healthcare system, or it may indicate the existence of specialty variations in planning treatment programs for autism in Taiwan.

This study shed the light on possible challenges faced by preschool children with autism and their families while seeking quality medical care and some problems encountered in obtaining continuous specialized health services. Future research may consider adopting long-term follow-up of children with developmental problems and their families with detailed information regarding the characteristics of individuals (e.g., socioeconomic status, perceived barriers, clinical manifestation of autism), health resources/systems (e.g., referral process, distribution of specialty), and care providers (e.g., training and specialty) (Costello and Janiszewski 1990; Halfon et al. 1995; Rubble et al. 2005), in order to understand more about non-insurance barriers to mental health care for families with children with early-onset neurodevelopmental disorders.

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References

- Aman, M. G. (2005). Treatment planning for patients with autism spectrum disorders. *The Journal of Clinical Psychiatry*, 66(Suppl.), 38–45.
- Barber, J., & Thompson, S. (2004). Multiple regression of cost data: Use of generalised linear models. *Journal of Health Services Research & Policy*, 9, 197–204.
- Boydell, K. M., Pong, R., Volpe, T., Tilleczek, K., Wilson, E., & Lemieux, S. (2006). Family perspectives on pathways to mental health care for children and youth in rural communities. *The Journal of Rural Health*, 22, 182–188.
- Chen, C. S., & Liu, T. C. (2005). The Taiwan national health insurance program and full infant immunization coverage. *American Journal of Public Health*, 95, 305–311.
- Chen, C. Y., Liu, C. Y., Su, W. C., Huang, S. L., & Lin, K. M. (2007). Factors associated with the diagnosis of neurodevelopmental disorders: A population-based longitudinal study. *Pediatrics*, 119, 435–443.
- Cheng, T. M. (2003). Taiwan's new national health insurance program: genesis and experience so far. *Health Affairs (Project Hope)*, 22, 61–76.
- Committee on Educational Interventions for Children with Autism. (2001). *Educating Children with Autism*. Washington, DC: National Research Council.
- Costello, E. J., Foley, D. L., & Angold, A. (2006). 10-year research update review: The epidemiology of child and adolescent psychiatric disorders: II. Developmental epidemiology. *Journal of the American Academy of Child and Adolescent Psychiatry*, 45, 8–25.
- Costello, E. J., & Janiszewski, S. (1990). Who gets treated? Factors associated with referral in children with psychiatric disorders. *Acta Psychiatrica Scandinavica*, 81, 523–529.
- Daley, T. C. (2004). From symptom recognition to diagnosis: Children with autism in urban India. *Social Science & Medicine*, 58, 1323–1335.
- Department of Health (2004). *General health statistics, Taiwan area, R.O.C. Taipei, Taiwan*. Retrieved Sep 18, 2006, from Department of Health, the Executive Yuan, Taipei, Taiwan Web site: http://www.doh.gov.tw/EN2006/Statistics_Publications/Statistics_list01.aspx?dept=R&now_fod_list_no=8385&class_no=254&level_no=2&divNo=&divCount=.
- Department of Health (2005). Health statistics: The Statistical Annual Report of Medical Care Institution's Status & Hospital's Utilization, Taiwan area. R.O.C. Retrieved May 30, 2007, from Department of Health, the Executive Yuan, Taipei, Taiwan Web site: http://www.doh.gov.tw/EN2006/Statistics_Publications/Statistics_list01.aspx?dept=R&now_fod_list_no=8323&class_no=349&level_no=2&divNo=&divCount=.
- Dunn, G., Mirandola, M., Amaddeo, F., & Tansella, M. (2003). Describing, explaining or predicting mental health care costs: A guide to regression models. Methodological review. *The British Journal of Psychiatry*, 183, 398–404.
- Farmer, J. E., Clark, M. J., Sherman, A., Marien, W. E., & Selva, T. J. (2005). Comprehensive primary care for children with special health care needs in rural areas. *Pediatrics*, 116, 649–656.
- Halfon, N., Inkelas, M., & Wood, D. (1995). Nonfinancial barriers to care for children and youth. *Annual Review of Public Health*, 16, 447–472.
- Hollander, E., Phillips, A. T., & Yeh, C. C. (2003). Targeted treatments for symptom domains in child and adolescent autism. *Lancet*, 362, 732–734.
- Howlin, P. (1998). Practitioner review: Psychological and educational treatments for autism. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 39, 307–322.
- Howlin, P. (2005). The effectiveness of interventions for children with autism. *Journal of Neural Transmission*, 69(Suppl.), 101–119.
- King, B. H., & Bostic, J. Q. (2006). An update on pharmacologic treatments for autism spectrum disorders. *Child and Adolescent Psychiatric Clinics of North America*, 15, 161–175.
- Lavigne, J. V., Arend, R., Rosenbaum, D., Binns, H. J., Christoffel, K. K., Burns, A., & Smith, A. (1998). Mental health service use among young children receiving pediatric primary care. *Journal of the American Academy of Child and Adolescent Psychiatry*, 37, 1175–1183.

- Leslie, L. K., Hurlburt, M. S., James, S., Landsverk, J., Slymen, D. J., & Zhang, J. (2005). Relationship between entry into child welfare and mental health service use. *Psychiatric Services, 56*, 981–987.
- Liu, C. Y., Hung, Y. T., Chuang, Y. L., Chen, Y. J., Weng, W. S., Liu, J. S., Liang, K. Y. (2006). Incorporating development stratification of Taiwan townships into sampling design of large scale health interview survey. *Journal of Health Management, 4*, 1–22.
- Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*, 1447–1453.
- Mandell, D. S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews, 11*, 110–115.
- Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics, 116*, 1480–1486.
- McConnell, S. R. (2002). Interventions to facilitate social interaction for young children with autism: Review of available research and recommendations for educational intervention and future research. *Journal of Autism and Developmental Disorders, 32*, 351–372.
- Owens, P. L., Hoagwood, K., Horwitz, S. M., Leaf, P. J., Poduska, J. M., Kellam, S. G., & Ialongo, N. S. (2002). Barriers to children's mental health services. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*, 731–738.
- Petrou, S., & Kupek, E. (2007). Socioeconomic differences in childhood hospital inpatient service utilisation and costs: prospective cohort study. *Journal of Epidemiology and Community Health, 59*, 591–597.
- Petti, T. A., & Leviton, L. C. (1986). Re-thinking rural mental health services for children and adolescents. *Journal of Public Health Policy, 7*, 58–77.
- Rothman, K. J. (1986). *Modern Epidemiology*. Boston: Little, Brown & Company.
- Rutter, M. (2005). Incidence of autism spectrum disorders: Changes over time and their meaning. *Acta Paediatrica, 94*, 2–15.
- Rubble, L. A., Heflinger, C. A., Renfrew, J. W., Saunders, R. C. (2005). Access and service use by children with autism spectrum disorders in Medicaid Managed Care. *Journal of Autism and Developmental Disorders, 35*, 3–13.
- SAS Institute Inc. (2005). *SAS (STAT), Version 9.13*. Cary, NC: SAS Institute Inc.
- Simpson, L., Owens, P. L., Zodet, M. W., Chevarley, F. M., Dougherty, D., Elixhauser, A., McCormick, M. C. (2005). Health care for children and youth in the United States: Annual report on patterns of coverage, utilization, quality, and expenditures by income. *Ambulatory Pediatrics, 5*, 6–44.
- STATA Corporation. (2005). *Stata Statistical Software, Release 8.02*. College Station, TX: Stata Corporation.
- Thomas, C. R., & Holzer, C. E., 3rd. (2006). The continuing shortage of child and adolescent psychiatrists. *Journal of the American Academy of Child and Adolescent Psychiatry, 45*, 1023–1031.
- Volkmar, F. R., Wiesner, L. A., & Westphal, A. (2006). Healthcare issues for children on the autism spectrum. *Current Opinion in Psychiatry, 19*, 361–366.
- Williams White, S., Keonig, K., & Scahill, L. (2006). Social skills development in children with autism spectrum disorders: A review of the intervention research. *Journal of Autism and Developmental Disorders, 36*, 1065–1076.
- World Health Organization. (1992). *International Statistical Classification of Disease and Health Related Problems, Ninth Revision*. Geneva: WHO.
- Zwaanswijk, M., Verhaak, P. F., Bensing, J. M., van der Ende, J., & Verhulst, F. C. (2003). Help seeking for emotional and behavioural problems in children and adolescents: A review of recent literature. *European Child & Adolescent Psychiatry, 12*, 153–161.