

A Comparative Study of Rurality and Urbanicity on Access to and Satisfaction with Services for Children with Autism Spectrum Disorders

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Abstract

Little is known about services for children with autism spectrum disorders (ASD) living in rural areas. The purpose of this study was to examine parent report of access to and satisfaction with services for children with ASD in rural areas and compare results to parents from urban areas. Parents in both groups reported children were diagnosed after the age of 3 and experienced challenges accessing services, trained professionals, and educators. Parents from rural areas reported significantly more difficulty accessing trained physicians and professionals in their areas. The implications of this study and needed future research are discussed.

Keywords: *autism, rural, urban, services, access, diagnosis, parent report*

Autism spectrum disorders (ASDs) represent a group of pervasive developmental disorders that severely impact social and communication development (American Psychiatric Association [APA], 2000) and affect as many as 1 out of 110 children (ADDM Network, 2009). Recent research has concentrated on the early identification of and intervention for children with autism (American Academy of Pediatrics, 2001; Blane & Borden, 2008; Corsello, 2005; Luiselli, Cannon, Ellis, & Sisson, 2000; Rogers & Vismara, 2008) and has resulted in reliable and valid diagnostic tools for preschool children (e.g., Cicchetti, Lord, Koenig, Klin & Volkmar, 2008; DeVincent, Gadow, Strong, Schwartz & Cuva, 2008; Kleinman et al., 2008) and research supported teaching methods (National Research Council, 2001; Odom, Collet-Klingenberg, Rogers, & Hatton, 2010). Clear evidence now exists for the link between early diagnosis, access to early intervention services, and positive development outcomes (Blane & Borden, 2008; Rogers & Vismara, 2008). Despite these achievements, there is growing concern that many children with autism remain unidentified (Liptak et al., 2008; Ruble, Heflinger, Renfrew, & Saunders, 2005), and many of those who are diagnosed, may not be able to access

specialized services (American Academy of Pediatrics, 2001; Kasari & Rotheram-Fuller, 2005; Liptak et al., 2008). Further, there is some evidence to suggest that these issues are especially problematic for children living in rural areas (Chen, Liu, Su, Huang, & Kim, 2008; Mandell, Novak, & Zubritsky, 2005).

Compared to children living in metropolitan areas, children residing in rural areas have access to fewer mental health and child pediatric services (e.g., Baldwin et al., 2006; Hendryx, 2008; Johnson, Brems, Warner, & Roberts, 2006; Thomas, & Holzer, 2006). Thomas and Holzer (2006), for example, found a large disparity between the number of child and adolescent psychiatrists in rural areas versus those available in urban areas. Further, Baldwin et al. (2006) identified nearly 3 times as many psychiatrists and 1.5 times as many nonpsychiatric mental health providers per 100,000 individuals in metropolitan areas compared to rural areas.

For ASDs specifically, researchers have identified disparities in the age of diagnosis based on geographic location. Mandell et al. (2005) found that children from rural areas received a diagnosis at a later age than children from urban areas. Chen et al. (2008) confirmed this finding and specified that children with ASD in rural areas engaged in a longer diagnostic process compared

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to their urban counterparts. Because the critical first step following the diagnosis is receipt of specialized intervention services, these findings suggest a need for more research about the diagnostic experiences regarding services used by children with autism in rural areas and subsequent effects on accessibility to specialist services. Research suggests that families used an average of 3.5 different community-based services within the past 6 months (Ruble & McGrew, 2007), a finding consistent with other research (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007; Thomas, Morrissey, & McLaurin, 2007).

Unlike medical and behavioral health care services, however, public education is the one single service system that all children with autism have access to regardless of geographic location, family income, and insurance status. Federal legislation from the Individuals with Disabilities Education Act (IDEA, P.L. 108-466, 2004) mandates a free and appropriate public education for all children with disabilities that includes special education and related services and therapies that often consist of social skills training, occupational therapy, and speech and language therapy (Bitterman, Daley, Misra, Carlson, & Markowitz, 2008). Public schools, that may be the only service provider for many children with autism, may pay up to \$50,000 a student per year for educational services (Ciavaglia, 2004). Research comparing special education services for children with disabilities across rural and urban areas is limited. Of the limited research available, Pennington, Horn, and Berrong (2009) found that children with disabilities in rural areas have less access to highly trained personnel in special education and other specialists compared to children in urban areas. Moreover, 80% of rural schools have shortages in special education teachers and staff (Knapczyk, Chapman, Rodes, & Chung, 2001). Jung and Bradley (2006) found that rurality accounted for differences in communication between parents of children with disabilities and school system personnel and teachers. In addition, Bulgren (2002) found that parents in rural areas were less satisfied with the special education services their children received compared to those receiving services in urban areas.

In summary, research suggests that, compared to children from urban areas, children with ASD living in rural areas may be diagnosed at later ages and have difficulty accessing specialized medical and behavioral health care services and their parents may be less satisfied with educational services. The purpose of this preliminary study was to provide comparative information on the impact of geographic location on parent reported access to and satisfaction with services for children with ASD. The researchers asked five questions: (a) Are children with ASD in rural areas diagnosed at a later age than their urban counterparts?

(b) Do services following a diagnosis for children with ASD in rural areas begin later than for children in urban areas? (c) Does accessibility of services for children with ASD differ for children in rural areas compared to children from urban areas? (d) Does parent satisfaction with educational services differ in rural areas compared to urban areas? and (e) Does parent report of prioritized needs for specific services differ in rural areas compared to urban areas?

Based on prior research, four directional hypotheses were offered. First, it was hypothesized that the age of diagnosis of children living in rural areas was later than the age of diagnosis of children from urban areas. Second, it was hypothesized that later age of diagnosis was associated with later age of onset of intervention. Third, it was hypothesized that access to services would be reported as being more limited in rural areas than urban areas. Finally, it was hypothesized that parents in rural areas would report less satisfaction with educational services than those in urban areas. Due to the limited research related to the last question of report priority of specific services, no a priori predictions were made.

Methods

The data analyzed for this study originated from an existing database that was designed to provide information to state policy makers about parents' and caregivers' experiences with the service system within one southern state in the United States (Ruble & McGrew, 2007). The independent variable in the current study, the geographic location of the area that the child with ASD resided, has not been analyzed in previous reports (Ruble & McGrew, 2007; Young, Ruble, & McGrew, 2009). The influence of geographic location was measured against five dependent variables described in detail below. The terms rural or non-metropolitan and urban or metropolitan are used interchangeably.

Participants

The researchers collected data from parents and caregivers of children with ASD from 46 out of 120 counties in one state using a variety of distribution methods. Specifically, they distributed information about the study at parent support groups, special educators' meetings, via mail using state databases from community mental health clinics, and via email through autism support group listservs in the state. In total, 112 parents and caregivers completed the survey. Of these, 16 participants did not indicate information related to rurality (i.e., county) and therefore were not included in the analysis. Participants were representative of the population sample in terms of demographic characteristics of marital status and race; however, education and income levels were slightly higher than

typical for the state. The most frequent diagnostic category was autism alone ($n = 49$), followed by Asperger's Disorder ($n = 11$) and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS, $n = 8$), and the mean age of the child with ASD was 10.2 years ($SD = 4.4$). The majority of children in the study were male (88.4%). See Table 1 for more demographic information.

Instrumentation

Survey. The variables analyzed for this study were selected from a 43-item survey that asked parents to provide various descriptive information about their child (e.g., age of diagnosis, age treatment began) and to report about services their child with ASD received in

the past 6 months (see Ruble & McGrew, 2007). The researchers developed the survey in collaboration with the State Interagency Council for Services to Children with an Emotional Disability (SIAAC), the Autism Spectrum Disorder Advisory Consortium (ASDAC), and the Kentucky Department of Mental Health and Mental Retardation Services (DMHMRS). The internal consistency of the measure was acceptable ($\alpha = .83$).

Diagnosis and onset of intervention. The researchers assessed age of diagnosis by a single item of the age the child was first diagnosed with ASD. Similarly, they assessed onset of intervention by a single inquiry regarding the age that treatment began. They treated both items as continuous variables in data analysis.

Table 1.

Descriptive Characteristics of Sample by Metropolitan and Non-Metropolitan Status (N = 96)

Respondent Characteristics	Metropolitan N (%)	Non-Metropolitan N (%)
Marital Status ¹		
Not Married	10 (10.5)	9 (9.5)
Married	43 (45.3)	33 (34.7)
Level of Income ²		
< 10,000	2 (2.2)	4 (4.3)
10,000-24,999	4 (4.3)	9 (9.7)
25,000-49,999	9 (9.7)	17 (18.3)
50,000-100,000	26 (28.0)	9 (9.7)
100,000 +	10 (10.8)	3 (3.2)
Level of Education		
College / Graduate School	35 (36.4)	21 (21.9)
Some College	11 (11.5)	7 (7.3)
High School	7 (7.3)	14 (14.6)
< High School	0 (0)	1 (1.0)
Race of Child ³		
Caucasian	50 (52.6)	42 (44.2)
African American	1 (1.1)	0 (0)
Multicultural	1 (1.1)	0 (0)
Native American	0 (0)	1 (1.1)
Diagnosis		
Autism	40 (42.1)	32 (33.3)
PDD-NOS	6 (6.3)	4 (4.2)
Rett's	0 (0)	1 (1.1)
Asperger's	7 (7.4)	6 (6.3)
Mean Age (SD)	10.33 (4.7)	10.05 (4.1)

¹missing = 1; ²missing = 3; ³missing = 1

Access. The researchers determined access by (a) access to services, (b) access to qualified educators, and (c) access to trained professionals. They used a 5-point Likert scale of 1 (Strongly Disagree) to 5 (Strongly Agree) for rating these variables. For access to services, they aggregated two survey items into one and used the mean score to create a general “access to services” variable: “I am able to access the services my child needs within my community” and “I am able to access the services my child needs within 30 miles.” They assessed access to trained educators with the single item “I have had no problem finding educators in my area who are trained in the latest methods of teaching children with ASD.” They assessed access to trained professionals with the single item “Finding physicians or professionals in my area of the state who are trained in treating autism spectrum disorders has not been a problem for me.” The internal consistency of these items was acceptable ($\alpha = .79$).

Parent satisfaction with educational services. The researchers assessed parent satisfaction using a single item: “Overall, I am happy with my child’s educational program at school.” They used a 5-point Likert scale of 1 (Strongly Disagree) to 5 (Strongly Agree) for rating this item.

Parent report of prioritized needs for specific services. The researchers asked parents to rank-order a list of seven services (i.e., respite care, speech and language therapy, social skills therapy, occupational therapy, counseling, case management, in-home therapeutic support, and behavior management) on a scale from 1 to 8, with 1 representing their highest priority of service they would like to “get or increase” from either the school system or from outside services and 8 representing their lowest priority or need. Higher scores on this scale indicated lower need, and lower scores indicated higher need. The researchers calculated the mean score or ranking for each type of service for data analysis.

Geographic location. The researchers defined the independent variable, geographic location, according to the Rural-Urban Continuum codes (Butler & Beale, 1993). The Rural-Urban Continuum codes take into account both a county’s population size and proximity to a metropolitan area. These codes are based on the most recent Census data using a 9-point scale, with 1 representing the most urban areas and 9 representing the most rural areas. The codes used for this study were updated in 2003 and are available through the United States Department of Agriculture website (USDA, 2003). The researchers determined the geographic location code for each participant from the zip code provided by the caregiver. They then linked the zip code to the county, which they then matched to its

corresponding Rural-Urban Continuum code to provide the level of rurality of the area in which the parent or caregiver resided. The researchers then generated a new variable for geographic location of a county to use for data analysis. Due to the relatively small N of the sample ($N = 96$), they dichotomized counties into metropolitan (codes 1-3) and non-metropolitan (4-9) to allow for larger sample sizes. The codes generated within their sample ranged from one to six, indicating that the families who responded to the survey were not from the most rural areas possible. According to this new grouping, 55.2% of the sample resided in a metropolitan area and 44.8% resided in a non-metropolitan area.

Procedures

The researchers provided surveys to participants using a variety of distribution strategies. They dispersed both hard copies and information on access to an electronic version of the survey at parent support group meetings and special education teacher meetings across the state, via mail using existing databases of parent contact information, and via listservs for parent support groups. They used a non-clinical sample to eliminate the possibility of selection biases and oversampling of participants from a specific area.

Data Analysis

The researchers cleaned and reviewed data for coding errors and checked for statistical assumptions (skewness, kurtosis, distribution). Analysis of the assumptions indicated that the data were not normally distributed; therefore, the researchers used non-parametric statistical tests. They used a series of Mann-Whitney U -tests and Chi-Square analyses to compare metropolitan and nonmetropolitan counties against the variables of interest, including age of diagnosis, age treatment began, access to community-based services, parental perception of education quality, parent report of prioritized needs for specific services, and parent satisfaction with educational services. They used a p -value of less than .05 to determine if the findings were significant.

Results

Age of Diagnosis and Onset of Intervention

The average age of diagnosis in this sample was 3.65 years ($SD = 2.7$). The researchers observed no significant differences between the urban and rural groups for the age at which the child was diagnosed or the age at which treatment was initiated (see Table 2). It is of note that the age treatment began for both groups ($M = 3.41$) was younger than the age at diagnosis ($M = 3.65$), suggesting that some children received services prior to the obtaining a diagnosis of ASD.

Table 2.*Results of Mann-Whitney U-Test for Variables of Interest*

Variable	M_{metro}	$M_{non-metro}$	U	p -value
Age at diagnosis	3.67	3.63	1081.50	.91
Age treatment began	3.66	3.16	981.00	.37
Satisfaction with educational services†	3.02	3.26	952.50	.33
Access to services†	2.56	2.53	1056.50	.78
Access to trained professionals†	2.38	1.79	835.00	.03*
Access to trained educators†	1.90	2.00	1099.00	.88
Ranking of the priority of behavior management services	4.63	3.35	635.00	.01*
Ranking of the priority of speech and language services	3.15	3.40	442.00	.04*

Note † = Based on 5-point Likert 1 “strongly disagree” to 5 “strongly agree”

* = $p < .05$

Access

Parent report of general accessibility, access to trained educators, and access to trained professionals or physicians indicated a significant difference for only 1 of the 3 measures of access (see Table 2). Regardless of geographic location, parents from both groups indicated overall disagreement with ease of accessibility ($M = 2.55$, $SD = 1.17$), access to trained educators ($M = 1.95$, $SD = 1.01$), and access to trained professionals or physicians ($M = 2.12$, $SD = 1.18$). Even though ease of finding a physician or professional in their area who was trained in treating autism spectrum disorders was rated low for both groups, a significant difference was found between participants residing in metropolitan counties ($M_{metro} = 2.38$) compared to those residing in a non-metropolitan counties ($M_{non-metro} = 1.79$; $U = 835$, $p = .03$) where the access was more problematic.

Satisfaction

The researchers observed no significant differences between the metropolitan and non-metropolitan groups for parent satisfaction with education services (see Table 2). Parents from both groups indicated a relative lack of satisfaction with their children’s educational services ($M = 2.12$, $SD = 1.18$) using the 5-point Likert scale of 1 (Strongly Disagree) to 5 (Strongly Agree).

Parent Report of Prioritized Needs

The researchers used mean rank scores to examine parent report of needed services. A portion of participants ($n = 19$) ranked more than one service as their highest priority and, therefore, were excluded from significance testing. A review of the data indicated that the distribution of participants ranking more than one service as their highest priority of need (i.e., ranking of one) was evenly distributed across metropolitan and non-metropolitan participants ($N_{non-metro} = 10$; $N_{metro} = 9$). Of these participants who listed multiple services as their highest need, respite care ($n = 6$) and social skills training ($n = 8$) were the most frequently duplicated services identified.

Analysis of the remaining data indicated that both urban and rural parents reported social skills training as the highest need compared to other services, but parents in rural areas also reported behavior management services as an equally high need. In fact, out of the seven services, behavior management was the only service that participants in non-metropolitan counties rated as a significantly higher need ($M_{non-metro} = 3.35$) compared to participants in metropolitan counties ($M_{metro} = 4.63$; $U = 635.5$, $p = .013$). In total, 30% of parents in non-metropolitan areas ranked behavioral management services as their highest priority based on mean scores in comparison to 15.4% of parents in metropolitan areas.

For both groups, speech and language therapy also was reported as a relatively high need service (ranked third for rural parents and second for urban parents). Metropolitan parents rated speech and language therapy as a significantly higher need ($M_{\text{metro}} = 3.15$) than non-metropolitan parents ($M_{\text{non-metro}} = 3.40$; $U = 442.0$, $p = .04$). Approximately 29% of metropolitan parents rated speech and language therapy services as their highest priority need compared to 13% of non-metropolitan parents.

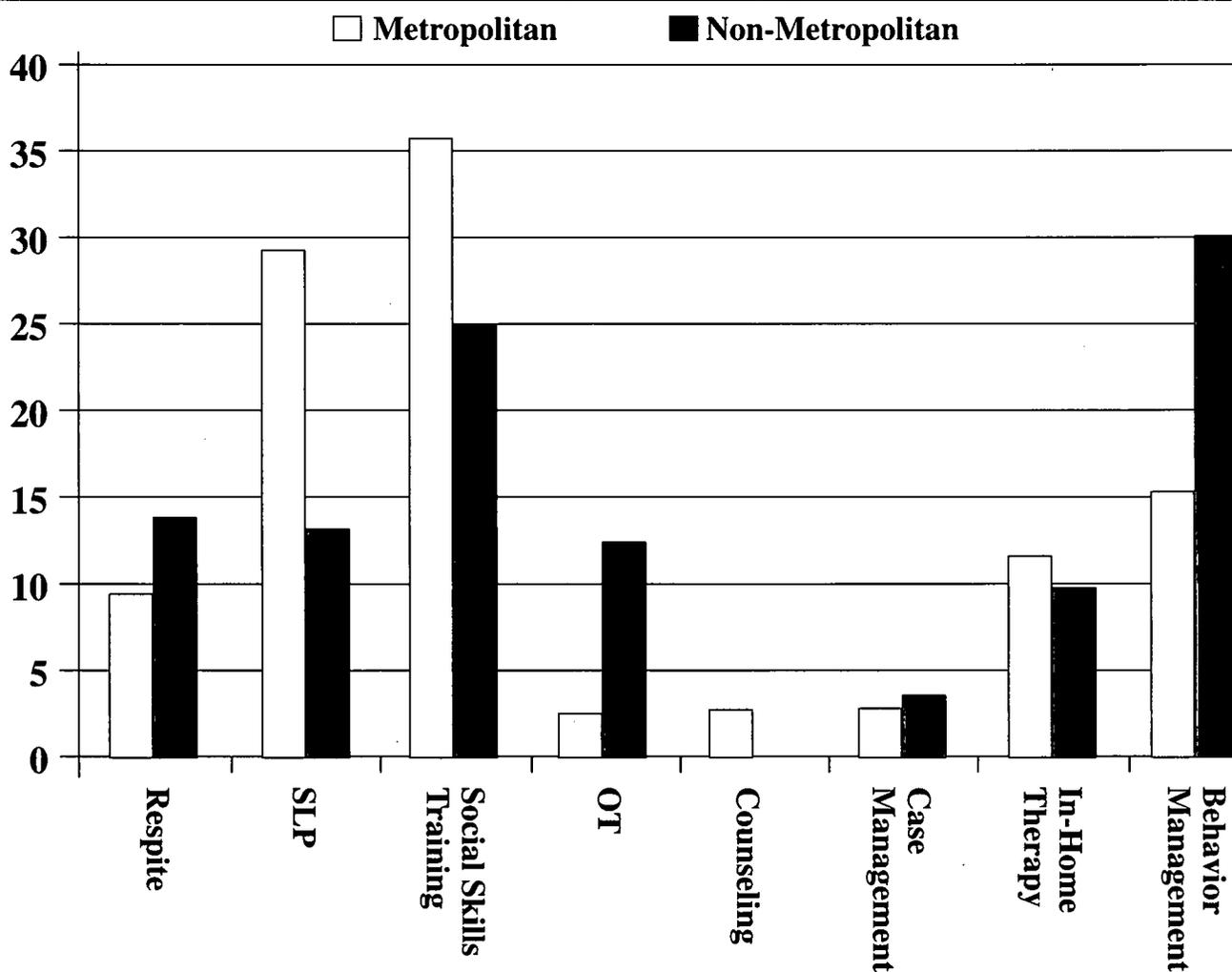
The researchers completed chi-square analyses to compare groups on the services that were ranked as their absolute highest priority needed service (i.e., ranking = 1, not the mean overall ranking). The proportion of caregivers who rated the eight services (respite care, speech and language therapy, social skills therapy, occupational therapy, counseling, case management, in-home therapeutic support, and behavior management) was not significantly different between metropolitan and nonmetropolitan caregivers (see Figure 1).

Discussion

The current study examined the influence of geographic location on the following variables: (a) age at diagnosis, (b) age treatment began, (c) access to services, (d) parent satisfaction with educational services, and (e) parent report of prioritized needs for specific services. Analysis revealed surprisingly few differences between groups that may be explained by factors unrelated to geographic location. Although some of the results were consistent with previous research, several findings were not replicated. The hypothesis that the age of diagnosis for children with ASD in metropolitan would be earlier compared to those from non-metropolitan areas (Chen et al., 2008; Mandell et al., 2005) was not supported. Several explanations are offered, including differences in sampling and methods of identification of children with ASD. The sample in the Chen et al. (2008) study was composed of individuals who participated in the National Health Insurance Research Database

Figure 1.

Percentage of parents ranking service as highest priority by geographic location.



(NHIRD) in Taiwan where medical claim data (including medical codes) were the only source of information regarding the child's date of diagnosis. Thus, findings from data gathered from a different country may not be generalizable to other countries or samples. Mandell et al. (2005) also utilized a parent survey to determine age at diagnosis, but their sample was significantly larger ($N = 969$) and found to be representative of the population of parents of children with ASD younger than 21 years in the state studied (i.e., a Northeastern U.S. state). Differences in state policy and practice could result in differences in findings. Another explanation might come from the range of geographic locations. Our sample was not representative of the full range of rurality described in the Rural-Urban Continuum codes and was limited to codes 1 through 6.

The second hypothesis that age of onset of treatment would be later for individuals in non-metropolitan compared to those in metropolitan areas was not supported. This finding, although unexpected, is not surprising given that our first hypothesis of age of diagnosis did not differ between groups.

Despite the well-established research regarding the limited availability of mental health providers (e.g., Baldwin et al., 2006; Hendryx, 2008; Johnson et al., 2006; Thomas, & Holzer, 2006), and qualified special educators (Knapczyk et al., 2001; Ludlow, Conner, & Schechter, 2005; Pennington et al., 2009) in rural areas, the only significant difference found between metropolitan and non-metropolitan groups was parental report of the ease of finding a physician or professional in their area who was trained in treating ASD. Sampling methods could account for the lack of group differences for the other access variables. The researchers based these data on parent report while the studies referenced utilized large data sets collected by state and national agencies of the number of physicians or teachers in a region or school's report of shortages. Another explanation is the overall relative disagreement in ease of access to specialists as scores ranged for both groups between 1.9 and 2.5 out of a total of 5. These findings are largely consistent with previous research that has repeatedly demonstrated that individuals living in rural or non-metropolitan areas have access to fewer helping professionals than those in metropolitan areas (Baldwin et al., 2006; Hendryx, 2008; Johnson et al., 2006; Thomas & Holzer, 2006) and that individuals with ASD in metropolitan as well as rural areas have similar experiences of limited access to specialized professionals and services.

The hypothesis that parent satisfaction with educational services would differ based on the area they lived was not confirmed. Unlike the relative negative parent report of ease of access to services and specialists, parents' mean rating of satisfaction was

generally neutral (mean score of 3.0 [urban] and 3.3 [rural] out of 5). One explanation for the lack of findings is that Bulgren's (2002) sample was not specific to special education services for students with autism.

Parents from both groups reported a need for social skills intervention, followed by speech and language therapy and behavior management (for rural parents). Social skills are a core impairment in autism and an essential skill that must be taught. Many parents rely on educational services and their children's IEPs to target social skills, but information suggests that social skills may not be a focus of educational programs for all students with ASD (Ruble, McGrew, Dalrymple, & Jung 2010) and parents often seek out these services in their communities. Given these findings of a high need for social skills instruction, schools have the opportunity of providing this essential instruction. Of particular importance was the gap in availability of behavior management services and speech language therapy services for rural vs. urban parents. Behavioral interventions are an essential service that parents have rated as having the most effective impact for their child in both home and school environments (Ruble & McGrew, 2007). Behavior services may be pursued as a comprehensive treatment approach (i.e., applied behavior analysis [ABA]) or as a means for reducing problematic behaviors (Brosnan & Healy, 2011). In both cases, behavioral interventions are at the foundation of child, family, school, and community participation (Eldevik et al., 2009) and may reduce the long-term costs of educational services (Jacobson & Mulick, 2000). The difference between urban and rural parent report for the need of speech language therapy (with urban parents indicating higher need) represents the shortages of specialists across regional areas for students with ASD. Overall, based on parent report, three primary therapies reported as areas of high need—social skills, speech and language, and behavior therapies—are central to facilitating the development of children with autism (National Research Council, 2001).

Implications

These findings offer specific insight into parent report of experiences with the service system in one state. Unlike previous reports based on large administrative data sets and claims data, these results come directly from parents. Although many of the findings did not support the apriori hypotheses, the importance of the public school system for children with ASD who reside in both metropolitan and non-metropolitan areas cannot be understated. These data suggest that families have difficulty accessing local services outside of schools regardless of geographic location. Schools provide a safety net for children with

disabilities, but it is not clear how effective public school services are for children with autism. Of the limited research available, difficulty retaining highly qualified teachers is a national problem and has been found to be more severe for non-metropolitan areas (Knapczyk et al., 2001; Ludlow et al., 2005). Further concerning is recent research that suggests that many special education teachers of students with autism have limited knowledge of scientifically based interventions (Barnhill, Polloway, & Sumutka, 2011; Morrier, Hess, & Heflin, 2011). Given the federal mandate to provide individualized education programs, the magnitude and scope of services provided, and the associated costs with educating children with autism, it is surprising that little comparative research is available concerning school-based services for children with ASD in non-metropolitan vs. urban areas.

The results provide further support for the need for initiatives to recruit specialists in social skills, behavior, speech and language therapy, occupational therapy, and medical health care specialists in rural areas for children with ASD, a finding that has been repeatedly demonstrated for other populations (Baldwin et al., 2006; Hendryx, 2008; Johnson et al., 2006; Thomas, & Holzer, 2006). It is often difficult to attract mental health professionals and other service providers to rural areas due to the characteristics of rural communities. For example, professionals in rural areas often must cope with dual relationships with clients (Pathman, Konrad, Dann & Koch, 2004) due to the small size of the community, as well as higher case loads and lower pay (Pennington et al., 2009) compared to those in urban areas. The use of additional incentives for attracting and recruiting helping professionals to non-metropolitan areas are

issues for policy makers, service providers, and educational administrators.

Finally, our findings highlight the need for more research that specifically identifies resources needed for families and children with ASD in rural areas, as well as the need of evaluations of the services offered to children with ASD in the public school system, as school may be the only available source of services for children with ASD in non-metropolitan areas. Research from larger samples of the types of services used, the frequency with which they occur, as well as parental satisfaction is necessary.

Limitations

One limitation of the current study was the sampling procedures. Although the researchers varied the distribution methods, they were unable to report on nonresponders. The parents who responded had higher educational and income levels compared to state demographics. Thus, findings may be limited due to issues of internal validity and generalization. Future research should include alternative strategies for collecting information, especially means by which to collect data from low income, less educated parents from rural areas.

Conclusions

The research completed is one of few studies that shed light on statewide services for children with ASD in metro and non-metropolitan areas. The results demonstrate the importance of further research and efforts that aid individuals in non-metropolitan areas with ASD and highlight the need of investigating alternative methods to treatment and services for this population, as well as additional methods of recruitment for specialized services.

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