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## Racial and Ethnic Disparities in Intensive Autism Services in the State of Wisconsin

### Sandy Magaña

La Follette School of Public Affairs faculty affiliate; associate professor,  
School of Social Work, Waisman Center, University of Wisconsin-Madison

[magana@waisman.wisc.edu](mailto:magana@waisman.wisc.edu)

### Molly Stapleton

Undergraduate research scholar, University of Wisconsin-Madison

### Alex Garcia

Undergraduate research scholar, University of Wisconsin-Madison



**ROBERT M. LA FOLLETTE**  
**SCHOOL OF PUBLIC AFFAIRS**  
University of Wisconsin-Madison

1225 Observatory Drive, Madison, Wisconsin 53706  
Phone: 608.262.3581 / Fax: 608.265-3233  
[info@lafollette.wisc.edu](mailto:info@lafollette.wisc.edu) / <http://www.lafollette.wisc.edu>  
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# **Racial and Ethnic Disparities in Intensive Autism Services in the State of Wisconsin**

Sandy Magaña, PhD, University of Wisconsin Madison  
Molly Stapleton, Undergraduate Research Scholar  
Alex Garcia, Undergraduate Research Scholar

This project was conducted by students from the Undergraduate Research Scholars Program at the University of Wisconsin-Madison in 2006. The students collected and compiled the data, and contributed to the writing of this report under the direction of Sandy Magaña, Associate Professor of Social Work and the Waisman Center.

## Abstract

The number of children diagnosed with an autism spectrum disorder is increasing and services for this population are expanding. There is some evidence of disparities in receipt of services for children from different racial and ethnic groups. The state of Wisconsin uses the Medicaid Waiver Program to offer intensive therapy to children with autism who are under 8 years old. The aim of this study was to determine how representative the racial and ethnic breakdown of children receiving intensive autism services are within each county and for the state of Wisconsin as compared to the census data for each county and for the state. We contacted the 72 Wisconsin counties and requested racial and ethnic demographic information on children currently receiving autism services through the waiver. The data from the 49 counties that responded were analyzed. We found disparities in the more diverse counties, some of which showed disparities for African American, and others for Latinos. Statewide data also reveal low numbers of American Indian children receiving autism services. These findings may help the state and counties in Wisconsin to target underrepresented groups and to consider access and cultural issues.

## **Introduction**

Autism Spectrum Disorders (ASDs) are considered to be neurodevelopmental disorders that are characterized by impairments in social interaction, communication, and restricted and repetitive behaviors and interests (DSM-IV-TR, 2000). Generally, ASD hinders a child's social and communication skills. Common symptoms of a child with autism include the inability to perceive others' feelings or thoughts, repetitive or restricted interests and behaviors, difficulty integrating different senses, hyperactivity, struggles with playing and interacting, or the inability to communicate in certain ways. However, all of symptoms vary and no two children's needs are alike (ASA, 2006).

The diagnosis of a child with ASD can usually be determined within their first three years. However, because ASD is exhibited through a spectrum of symptoms, the disorder can remain untreated or misdiagnosed for several years. The earlier a child is diagnosed, the higher chance they have to improve his or her level of functioning. Unfortunately, ASD is on average not recognized until age 6 (Howlin & Moore, 1997), which prevents access to early intervention programs. The age of diagnosis may also vary between different racial and ethnic groups, which may lead to disparities in the amount and quality of services that different demographics receive (Mandell, 2002). The symptoms of autism may be misdiagnosed as mental retardation or a behavioral disorder which could result in children not being eligible for autism services. For example, Shattuck (2006) found evidence to suggest that there may be a substitution effect in which some children who would have been diagnosed with mental retardation in the past are now being diagnosed with autism. The extent to which these trends affect all children with autism is unknown.

Although relatively little is known about the prevalence or causes of ASD, we know even less about ASD among individuals and families from different racial and ethnic communities because most research is based on information about non-Hispanic white children and families. This lack of information on ASD in populations of minority children means that we know little about how to better serve minority children with autism and their families.

### **Increase in Prevalence**

Autism was once considered a rare disorder but statistics over the last 20 years show that its prevalence is higher than once thought and is still on the rise. According to a report released by the Center for Disease Control and Prevention (2007), one out of 150 babies are born with ASD. This estimate, which is taken from a large scale study of many communities around the United States, confirms that ASD is much more common than once thought. Another study by the US Department of Education discusses the exponential increase in the prevalence of autism throughout the 1990s. In the school year of 1998-1999, the rate of special education autism services had increased 500% from 1991-1992. Compared with other developmental disabilities, which increased 16% during the same time, autism prevalence grew 172% (US Dept of Education, 1999).

### **Racial and Ethnic Disparities in Prevalence and Diagnosis of Autism**

There is some evidence of racial and ethnic disparities in prevalence rates, diagnosis of autism and services use. Data from the US Department of Education (1999) show that African Americans and Asian/ Pacific Islanders make up 13% of people with autism, more than twice the national average and yet, they are less likely to receive education services under IDEA. Several studies show low prevalence rates of autism

among Hispanic and Native American children (CDC, 2007; US Department of Education 1999). These findings may be reflecting barriers to receiving diagnoses more than actual prevalence in these populations. Research suggests that later diagnosis may be more prevalent in minority populations. This is very problematic because evidence suggests that early detection greatly influences the ability of the child to recover to normal functioning. A study by Mandell, Listerud, Levy, & Pinto- Martin (2002) focused on disparities in diagnosis using Medicaid data. This study found that the average age of diagnosis for white children is 6.3 years with 50% receiving the diagnosis by the age of five. The average age among African American children is 7.9 years with only 28% receiving a diagnosis by age five, and the age of first diagnosis is at 7.4 years for Latino/a children. Furthermore, 72% of white children received their diagnosis during their first mental health visit while only 57% of the African American sample did so.

### **Services in State of WI**

In Wisconsin, there is a wide array of services available to children with autism depending their family's insurance coverage and whether they qualify for Medicaid and get on the right waiting lists. The major service available to children with autism in Wisconsin is the intensive in-home therapy program paid for by Medicaid through the Children's Waiver, which is the focus of this analysis. To be eligible for this service, children must meet diagnostic criteria and be under 8 years old. While technically, children can receive a variety of behaviorally based therapy models consistent with best practice and research on effectiveness, there are typically only 1 or 2 certified providers in a particular region or county. Intensive therapy services typically include 20 to 35

hours of face-to-face contacts per week. Once the child receiving intensive services has completed this program (after 3 years or when the child is no longer making progress), he or she is able transition to other home and community based waiver services. Therefore, receipt of intensive services becomes an entry point or gateway to receiving other important services the child will need as he or she gets older.

Because these services are publicly funded and are very important to the functioning of the child with autism and their families, it is essential that administrators and providers make the services available to children from all racial and ethnic groups in the State of Wisconsin. Our main research question in this study is, “Are there racial and ethnic disparities in the receipt of autism intensive therapy services covered by the Children’s Waiver.” With the results of this study, we can inform policy makers, administrators and providers about where there may be disparities in services so they can target those populations for increased access.

### **Methods**

In our study, the data on the racial and ethnic backgrounds of each child receiving intensive autism services was collected by calling the contact person in each of the 72 counties of Wisconsin that was in charge of the children’s waivers and administration of the intensive autism services. We first contacted them by phone and requested them to complete a mailed-out survey that asked for the number of children receiving intensive services under the waiver program in their county. The survey asked for the total number of children receiving intensive autism services in their county, and number of children in each racial or ethnic group receiving autism services, which was broken down into five

categories: African American/Black, Non-Hispanic White, Latino/Hispanic, Asian American, and Indian American.

For the 49 counties that responded, the collected data were compared to the actual demographics of that particular county from the 2005 Census in order to determine if any significant disparities existed. The racial/ethnic categories of each county were also totaled as a whole in order to compare these results with state Census information. Many of the 23 counties that did not respond had an insignificant minority population and were likely to have few or no minorities in their autism waiver programs. However, several counties that did not respond had fairly significant American Indian populations (Sawyer County, 15.8%; Jackson, 6.1%); and Latino populations (Kenosha, 8.1%; Brown, 5.2%; Jefferson, 5.1%).

## **Results**

We focused our analysis on the most diverse counties in Wisconsin that had more than 20 children receiving intensive autism services (see Table 1). These included the following 10 counties: Adams, Dane, Dodge, Milwaukee, Outagamie, Racine, Rock, Shawano, Sheboygan, and Walworth. The 10 counties had white populations that range from 58.9% to 93.3% and out of these counties we found Milwaukee to be the most diverse with the highest populations of African Americans and Latinos. Sheboygan County had the most Asian Americans and Shawano had the most Native Americans.

The overall results for the state showed some disparities among African Americans, Latinos and American Indian populations receiving autism services (see Table 1). However these results are incomplete as 23 Counties did not provide data. We report disparities we found on a county level between the percentage of people living in a



county of a certain race or ethnicity compared to the percentage receiving autism services. For example, in Milwaukee County, 58.9% of the population was white, yet 72% of those receiving autism services were white. Although smaller in number, Asian Americans also received proportionally more autism services when compared to their population percentage in the county. The main group that was underrepresented in Milwaukee County was African Americans who represented 26.1% of the population and only received 14.2% of autism services. There were no disparities found for Latinos in Milwaukee County.

In Dane County, the opposite pattern emerged between African Americans and Latinos in which African Americans were not underrepresented in autism services and Latinos were. Asian Americans were slightly overrepresented again in Dane County, and white children receiving autism services were reflective of the white population of the County.

In addition to Dane County, other counties that showed disparities between the number of Latino children living in a county and the number in the autism waiver program were Walworth, Waushara and Waukesha counties. Walworth County reported only one Latino child receiving autism services (3.7 percent) compared to 8.1 percent of the county population.

Differences were found in several counties in addition to Milwaukee between the percent of African Americans that make up the population and the percent receiving autism services. Racine County reported disparities among African Americans who made up 10.9 percent of the population, but were only 3.5 percent of the group receiving autism services. Sheboygan and Dodge Counties also had some disparities in which African

Americans received proportionally less services, however the overall numbers are lower.

A somewhat disturbing finding was the number of American Indian children receiving autism services in the State of Wisconsin. We counted only seven American Indian children in the entire state who were receiving autism services. Menominee County has the largest population of American Indians (84.1%) and reported no use of autism intensive services in the county.

Other important factors when looking at the overall state data is that while Latinos are slightly underrepresented in autism services, the percentage of Latinos in the population is likely to be an underestimate. This is because the Census historically undercounts Latinos due in part to fears that undocumented immigrants may have of census takers. Also, three counties that have higher percentages of Latinos did not respond to the questionnaire (Brown, Jefferson and Kenosha Counties), which may influence the overall numbers. Therefore, the true disparities for Latinos are likely to be greater than what is reflected in the numbers. Furthermore, Latino children who are not born in the US and do not have legal status are not eligible for autism services.

### **Discussion**

In this study, we assessed the racial and ethnic breakdown of children receiving Medicaid funded intensive autism services in 49 counties in the State of Wisconsin and compared this data with demographics in each county on race and ethnicity based on the Census. We found racial and ethnic disparities in some of the more diverse counties in Wisconsin. African American and Latino children were underrepresented in the receipt of intensive autism services in several counties. White and Asian American children were more likely to be overrepresented in the receipt of autism services. However it is

important to note that the percentage of Asian Americans is very small. American Indians were poorly represented in the receipt of autism services in the State of Wisconsin.

While the overall state data did not reflect large disparities, we only had data from 68% of the counties. However, when examining each individual county, especially the more diverse ones, we can see that disparities do exist in autism services for African Americans and Latinos.

These results can serve as an indicator to each county on the effectiveness of their outreach of autism programs to different minority groups. The data also more than likely reflects the issues of early screening and diagnosis among minority populations discussed earlier in this paper. This is especially important for counties with higher Latino or African American populations, such as Dane and Milwaukee. Although both of these counties have strengths, more could be done to make programs accessible for underrepresented populations. In Dane County where Latinos are underrepresented, providers may want to focus on early detection and screening and on making the autism waiver programs more accessible for this population. Providing community awareness education about autism may be useful. Having bilingual service providers for all programs is important including Birth to Three programs that may make initial referrals, case manager for the County Developmental Disability Service agency, and line therapists for the intensive autism program.

In Milwaukee County, where African Americans are underrepresented in the autism programs, the administrators and service providers may need to concentrate more on similar outreach to that population. The State should seriously examine the situation for

American Indian children who may have autism and are not receiving services.

It should be noted that since the administration of intensive autism services changed in 2004, there may be more diversity in the receipt of autism services in the future.

Previously, families accessed intensive services by going to the private providers directly.

The providers then helped families with the application process. Currently, most counties (and not private providers) administer the program by assessing eligibility, helping

families find providers, and submitting applications to the State. Many of the counties

have more diverse case management staff, some of whom are bilingual. Counties may be

more sensitive to the inclusion of diverse populations than the private providers. The

current study did not request information on waiting lists for intensive services which

may have given us some idea of future trends.

There may be other barriers to receipt of autism services for minority and low income groups besides lack of outreach and knowledge about services such as design of the service, access issues and cultural barriers. For example, if parents are working two jobs, it may not be practical for them to arrange 25 hours of in-home therapy. Families of color may be distrustful of having a stranger come into their home as it may feel intrusive to them. Families from different ethnic and cultural backgrounds may also have different interpretations of disability and autism and how to treat them. These are important topics for future research, and for thinking about whether the design of the intensive service model is culturally appropriate.

## **Conclusion**

We have limited knowledge about how to better serve families of color who may have a child on the autism spectrum because limited research is available. Some research

points to disparities in diagnosis, age of diagnosis and service use. The state of Wisconsin offers high quality services to children with autism, however little was known about whether these services are being provided to different ethnic and racial populations equally. The results of this study give us baseline information about how the state and counties are doing with respect to reducing disparities in service provision. Our findings indicate that there are disparities in some counties for African Americans, Latinos and for disparities for American Indians in the state. It is hoped that the state and counties use this information to better serve their residents.

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**Table 1**

**Representation by race/ethnicity in intensive autism services compared to 2005 US Census data for each county**  
 (the most diverse counties that have more than 20 autism waiver cases were selected for analysis)

County	White Census	White autism	African American Census	African American autism	Latino Census	Latino autism	Asian American Census	Asian American autism	American Indian Census	American Indian autism
Milwaukee	58.9	72.0 (157)	26.1	14.2 (31)	10.5	9.2 (20)	2.9	4.6 (10)	0.8	0
Racine	78.0	93.0 (53)	10.9	3.5 (2)	1.0	3.5 (2)	0.9	0	0.4	0
Dane	85.5	85.6 (196)	4.2	6.6 (15)	4.2	1.8 (4)	4.2	5.7 (13)	0.4	0.4 (1)
Rock	88.0	88.2 (45)	4.6	7.8 (4)	0.9	2.0 (1)	1.0	2.0 (1)	0.3	0
Sheboygan	89.7	95.5 (21)	1.2	0	1.1	4.6 (1)	3.8	0	0.4	0
Walworth	89.8	92.6 (25)	0.8	3.7 (1)	8.1	3.7 (1)	0.7	0	0.3	0
Shawano	90.3	87 (20)	0.3	0	4.3	0	0.5	0	0.4	13 (3)
Outagami, Marquette, Waushara	92.2 95.8 83.9	93.2 (82)	0.7 0.6 0.4	2.3 (2)	2.3 1.6 4.6	1.1 (1)	2.5 0.3 0.4	1.1 (1)	1.6 0.5 0.4	2.3 (2)
Waukesha	93.0	94.3 (198)	1.0	1.4 (3)	3.0	1.9 (4)	2.1	2.4 (5)	0.2	0
Dodge	93.3	95.7 (22)	2.8	0	2.9	4.4 (1)	0.4	0	0.4	0
Total (49 counties*)	86.2	88.6 (1109)	5.9	4.9 (62)	4.3	3.2 (40)	1.9	2.7 (34)	.90	.56 (6)

Autism columns include percent and number of those receiving services. Number is in parentheses.

\*compared to statewide census data

Highlighted areas indicate visible disparities