

Wyoming Children with Developmental Disabilities: Prevalence
and Relation to Ethnicity and Race: Final Report

Submitted to

Wyoming Department of Health
Office of Multicultural Health

October 22, 2010

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A. Introduction

Previous researchers report ethnic and racial disparities in the diagnosis of a variety of health conditions, including developmental disabilities (Boyle, Yeargin-Allsopp, Dorenberg, Holmgren, Murphy, & Schendel, 1996; Centers for Disease Control and Prevention, 2007; Mandell et al., 2009). For example, Boyle et al. (1996) reported that black children, ages 3-10 years, were at greater risk for mental retardation, cerebral palsy, and auditory impairment in comparison with white children of the same age included in the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP). A study of mental retardation of unknown cause conducted in California revealed that children born to Hispanic, black, or Asian mothers have increased risk for severe mental retardation compared with children of white mothers (Croen, Grether, & Selvin, 2001). However, there is mixed evidence regarding racial/ethnic disparities for autism spectrum disorders (ASDs) (Mandel, Wiggins, Carpenter et al., 2009).

Much of what is known regarding the epidemiology of developmental disabilities within the United States emerges from studies conducted with data from the MADDSP. Although this research program has superb epidemiologic characteristics, the findings may not generalize fully to other geographic regions of the United States where the populations are predominantly Hispanic or white, non-Hispanic and live in rural or frontier settings. This project was undertaken to compare childhood prevalence rates of autism, cerebral palsy, epilepsy/seizure disorder, intellectual disability, and sensory impairment among ethnic and racial groups in

Wyoming. The conditions included in this project are the same as those reported through the MADDSP surveillance program funded by the Centers for Disease Control and Prevention. The *National Survey of Children with Special Health Care Needs*, the Wyoming Special Education Student Count by District data base, and a database developed by the Wyoming Institute for Disabilities were used in this project.

B. Databases

- (1) The *National Survey of Children with Special Health Care Needs* includes several diagnoses of interest in this project. The survey is conducted by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration. The most recent *National Survey of Children with Special Health Care Needs* was conducted in 2005/06. The survey is conducted by random-digit dialing of telephone numbers in all 50 states and the District of Columbia. The survey goal is to identify approximately 750 households in each state or district in which at least one child ages 0-17 years meets the definition of a child or youth with special health care needs (CSHCN). Specifically, children and youth with special health care needs are “*those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally*” (McPherson, Arango, Fox, et al., 1998).

The identification process begins with a five-item parent report screening instrument (CSHCN Screener) that reflects the elements of the MCHB definition of CSHCN provided above. The screener identifies children’s health care status with questions that inquire about need or use of services, prescription medications,

specialized therapies, and functional difficulties due to an ongoing condition. Families with children who meet the criteria for special health care needs are questioned further. Families whose children do not meet the criteria do not participate further in the survey. The availability of both groups allows the calculation of prevalence rates for specific conditions within each state or district. Moreover, given that the survey is conducted nationally, Wyoming data can be compared directly to the region as well as the entire United States.

Given that the screener adopts a needs-based definition of children with special health care needs, as opposed to one defined by specific diagnoses, there is a possibility that children with diagnosed conditions, who do not meet the definition of CSHCN, are not identified. With this caveat, the prevalence rates presented in this report represent *minimal* estimates.

For Wyoming, 6,707 families participated in the screening. Of those, 14.4% met criteria for CSHCN. Males (59%) outnumbered females (41%). Among the children with CSHCN, 83.6% were identified as white, non-Hispanic, 10.3% were Hispanic, <1% were black, 2.5% were multi-racial, non-Hispanic, and 2.8% were other, non-Hispanic. The diagnosed conditions included in the *CSHCN Survey* that relate to this project are autism spectrum disorder, cerebral palsy, epilepsy, and mental retardation/developmental delay.

(2) The *Wyoming Department of Education (WDE) Special Education Student Count by District data base*. The WDE collects data each November 1st on the number of children being served by each school district for 12 disability categories (Autism Spectrum Disorder, Cognitive Disability, Developmental Delay, Emotional

Disability, Hearing Impairment, Multiple Disabilities, Orthopedic Impairment, Other Health Impairment, Specific Learning Disability, Speech or Language Impairment, Traumatic Brain Injury, and Visual Impairment). The most recent data collection, in 2009, identifies 12,405 students with disabilities among the 87,420 students enrolled between the ages of 6 and 21 years. Among the students with disabilities, 80.5% were white, 12.0% Hispanic, 4.3% Native American, and 1.5% black. The remainder (1.7%) was identified as Asian, Pacific Islander, or endorsed “multi-category.” For the purpose of this project, the categories of autism spectrum disorder, cognitive disability, developmental disability, hearing impairment and visual impairment are available. The diagnoses of cerebral palsy and epilepsy or other seizure disorder cannot be abstracted from the educational disability categories database.

- (3) The *ICAP data base*. The Wyoming Institute for Disabilities at the University of Wyoming has been collecting data for children being considered for the developmental disabilities waiver program since 2004. The ICAP is only administered if there is documented evidence of mental retardation, or a related condition, such as cerebral palsy or seizure disorder that meets the criteria for a developmental disability. As part of the waiver determination process, people familiar with children’s daily functioning participates in the completion of the Inventory for Client and Agency Planning (ICAP – Bruininks, Hill, Weatherman, & Woodcock, 1986). This standardized measure yields an estimate of each child’s adaptive functioning, the extent of behavior problems that may limit their inclusion in various settings, as well as a systematic review of all available evaluation data. The latter category includes all five types of developmental disability of interest to this project.

ICAP data are available for 1,289 children and youth. There are 833 males and 456 females in the database. The average age of the participants is 11.25 years (3 months to 21 years). With regard to race, the group is similar to the overall Wyoming population (91% white, 2% black, <1% Asian or Pacific Islander, 3% Native American, and 3% other). With regard to ethnicity, 8.5% of the group was Hispanic. Accordingly, the data base permits within group comparisons to determine whether racial or ethnic disparities exist in the diagnosis of the various types of developmental disabilities. The ICAP data base does not permit the calculation of overall prevalence rates that can be compared with other data sets.

The three data sets are compared on relevant variables in Table 1.

Table 1. Ages, Data Sources, and Conditions Represented by Data Base

Developmental Disability Conditions¹

Database	Ages	Data Source	ASD	CP	Epilepsy	HI	MR/DD	VI
CSHCN	0-17	Telephone Informant Interview	X	X	X		X	
WDE	3-21	District	X			X	X	X
ICAP	0-21	Psychological Report & Informant Interview	X	X	X	X	X	X

¹ASD= Autism Spectrum Disorder, CP=Cerebral Palsy, HI = Hearing Impairment, MR/DD=Mental Retardation or developmental delay, VI = Visual Impairment

C. Findings:

As a first step in the process of determining whether there are racial or ethnic disparities in the prevalence of developmental disabilities among Wyoming children, Table 2 provides the overall prevalence rates (per thousand children) for each state in the Health and Human Services

Region 8 as well as the national rates using data from the *CSHCN Survey*. There is some variability among the various diagnostic categories across the states. Wyoming is somewhat lower than the national average and the neighboring states of Montana and Utah in the prevalence of ASD. In contrast, there are somewhat higher prevalence rates of cerebral palsy and epilepsy in the Wyoming cohort. The largest absolute difference in comparison with the national average is in the category of mental retardation/developmental delay (2.7 per 1000 children), although the differences are somewhat greater between Wyoming and most of the comparison states (as much as 5.3 per 1000 children). However, recall that the values presented in Table 2 are based on cases per thousand and therefore the absolute differences are magnified by a factor of 10 in relation to the percentage of children involved. Given these data, it appears that the Wyoming prevalence rates for the various disability conditions are quite similar to the national and regional comparison groups.

Table 2. Prevalence Rates¹ of Disability Conditions (per thousand children) by State²

<u>State</u>	<u>ASD</u>	<u>Disability Conditions³</u>		
		<u>CP</u>	<u>Epilepsy</u>	<u>MR/DD</u>
Colorado	3.9	1.6	3.8	8.7
Montana	5.0	2.2	3.4	9.6
North Dakota	3.5	1.8	3.2	9.1
South Dakota	4.5	1.1	3.3	8.5
Utah	5.6	1.9	4.0	10.2
Wyoming	4.7	2.2	5.2	13.8
Nationwide	5.8	1.9	4.0	11.7

¹Data derived from the 2005-06 *National Survey of Children with Special Health Care Needs* – ages 0-17 years

²Department of Health and Human Services Region 8 member states

³ASD= Autism Spectrum Disorder, CP=Cerebral Palsy, MR/DD=Mental Retardation or developmental delay

The data bases available from the Wyoming Department of Education (WDE) and Wyoming CSHCN overlap for two of the conditions of interest in this project. As shown in Table 3, the prevalence of ASD is somewhat higher for the WDE data (5.7/1000) than the CSHCN data (4.7/1000). Although this difference is rather small, there are two factors that could play a role in the higher prevalence of ASD within the WDE data. First, the *CSHCN Survey* data are 4 years older than the WDE data and there is considerable evidence that the prevalence of ASD diagnoses has increased dramatically in recent years (Kogan et al., 2009). Second, the age of the participants in the two data bases differ in that the *CSHCN Survey* includes children 0-17 years of age while the WDE data includes children 3-21 years, thus the *CSHCN Survey* includes younger children who may not yet have been old enough to receive a diagnosis of ASD.

The difference in prevalence for MR/DD between the two data sets can also be attributed to the ages of the cohorts represented in the data sets. The *CSHCN Survey* includes younger children (0-3) for whom a diagnosis of developmental delay could be quite likely. Furthermore, the source of data is more subjective in responding to the *CSHCN Survey* (parent report) than the data necessary for placement decisions by school districts (direct assessments).

Table 3. Comparison of Prevalence Rates for ASD and MR/DD¹ (per thousand children)

<u>Data Base</u>	<u>ASD</u>	<u>MR/DD</u>
Wyoming Dept. Education	5.7	9.7
Wyoming CSHCN ²	4.7	13.8

¹ASD= Autism Spectrum Disorder, MR/DD=Mental Retardation or developmental delay

²Data derived from the 2005-06 *National Survey of Children with Special Health Care Needs* – ages 0-17 years

Comparison of Ethnicity and Race

Given the information presented in Table 1, not all of the data sets permit comparisons among ethnicity and racial groups for all of the developmental disabilities conditions. Moreover, the small numbers of children from particular racial or ethnic groups represented in the data sets limited the possible comparisons for particular conditions. Therefore, the following tables consider each data set separately because of the substantial differences in the cohorts contributing to each.

The data available from the Wyoming Department of Education are presented in Table 4. In this data base Cognitive Disability (the current terminology for mental retardation) and developmental delay are reported separately. There are insufficient numbers of children in the Visual Impairment category to permit comparisons between race and ethnicity groups. Moreover, the prevalence values for the categories of Asian, black, multi-category, and Pacific Islander were not reported by WDE because of the low frequency of children. Comparisons can be made for only Hispanic, Native American, and white children.

The percentage of students receiving services in the categories of Cognitive Disability, Developmental Delay, and Hearing Impairment are remarkably similar across the three ethnicity/racial groupings. However, there are considerable differences in the percentages of students receiving services for Autism Spectrum Disorder, with the values for Hispanic and Native American students being less than half that of the white students. In terms of relative risk, White students are 2.35 times more likely than Hispanic students and 2.13 times more likely than Native American students to have ASD as a primary disability category.

Table 4. Percentage of Students with Specific Disabilities by Ethnicity and Race

<u>Ethnicity/Race</u>	<u>ASD</u>	<u>Cognitive Disability</u> ¹	<u>Developmental Delay</u>	<u>Hearing Impairment</u>
Hispanic	1.88%	4.96%	2.21%	1.54%
Native American	2.06%	4.88%	2.06%	----
White	4.41%	4.49%	2.35%	1.21%

¹WDE uses the term cognitive disability rather than intellectual disability.

Switching to the *CSHCN Survey*, the only comparison possible was for ethnicity and MR/DD. In this data base, MR/DD was reported for 12.2% of the Hispanic children and 11.7% of the white, non-Hispanic children. This finding is consistent with that reported by Croen et al. (2001).

The *ICAP data base* permits additional consideration of the prevalence of developmental disability conditions among racial and ethnic groups. Recall that the cohort of children included in this data base is limited to only those children for whom there was already evidence of a developmental disability. Therefore, the proportions of children diagnosed with various conditions are substantially greater than those in the WDE or *CSHCN Survey* data bases.

Table 5 provides comparisons with regard to ethnicity in the ICAP data base. With the exception of Epilepsy/Seizure disorder, there is little variability among the conditions with regard to Hispanic ethnicity. Examination of those data reveals that Hispanic children are 1.32 times more likely to be diagnosed with epilepsy/seizure disorders in Wyoming. The reasons for this increased prevalence are not known.

While the previous analysis suggested that rates of identification of ASD were lower for Hispanic children in the WDE data base, the difference was considerably less among children in the ICAP data base (18.1 vs. 19.9%). Without further information regarding the children in the WDE data base identified with ASD, it is difficult to interpret this difference because the ICAP

data base includes only those children with ASD who also meet the criteria for developmental disability.

Table 5. Developmental Disabilities Diagnoses (%) by Ethnicity Status in the ICAP Database

	<u>Hispanic</u>	<u>Not Hispanic</u> ³
Autism Spectrum Disorder ¹	18.1%	19.9%
Cerebral Palsy	10.0%	10.4%
Epilepsy/Seizure Disorder	28.2%	20.6%
Hearing Impairment	6.4%	5.2%
Mental Retardation ²	72.7%	77.6%
Vision Impairment	17.3%	17.5%

¹The ICAP includes Autism as primary or secondary condition. Children for whom Asperger's Disorder or Pervasive Developmental Disorder were reported in the other category were also included. Given the requirements of the waiver, these values are limited to children with co-occurring autism and developmental disability.

²The ICAP was created before the introduction of the term intellectual disability.

³ n= 1,177 for non-Hispanic and n=110 for Hispanic

The ICAP data base permits a broader comparison among racial groups for Mental Retardation given the higher base rate of that condition in the data base. Table 6 shows that the percentage of children with mental retardation is substantially greater among children who are black or Native American than white children or children from other racial groups.

Given the relative infrequency of the remaining diagnoses (ASD, cerebral palsy, epilepsy/seizure disorder, and hearing and visual impairments) as well as the small number of children from the various racial groups, it was not possible to make valid comparisons given that the resulting cell sizes were less than 10 in nearly every case.

Table 6. Mental Retardation¹ by Race in the ICAP Database

<u>Race</u>	<u>Mental Retardation</u>
White	76.4%
Black	92.3%
Native American	90.4%
Other	81.1%

¹The ICAP was created before the introduction of the term intellectual disability.

D. Summary

A review of the data available from the *CSHCN Survey* indicates that the prevalence of autism spectrum disorder, cerebral palsy, epilepsy/other seizure disorder, hearing impairment, mental retardation/developmental delay, and vision impairment among Wyoming children is similar to the values reported nationally and in neighboring states in Health and Human Services Region 8. Among the conditions, mental retardation/developmental delay was the most common diagnosis followed by epilepsy, autism and cerebral palsy.

Consideration of ethnic and racial differences in the prevalence of the six conditions associated with developmental disability considered in this project was quite limited due to the infrequency of the conditions and the homogeneity of the data bases with regard to ethnicity and race. However, the available data support three conclusions. First, there is little evidence of ethnic or racial disparity in the prevalence of conditions associated with developmental disability. Second, where disparity is evident, some obtained results are consistent with trends reported in the literature. Namely, the prevalence of MR/DD is greater among black children than their white counterparts (Bhasin, et al., 2006; Murphy, Boyle, Schendel, Decoufle, & Yeargin-Allsopp, 1998) and that Hispanic children are less likely to have a diagnosis of ASD

than white, non-Hispanic children (Kogan et al., 2009; Mandell et al., 2009; Palmer, Walker, Mandell, Bayles, & Miller, 2010). Third, the findings regarding Native Americans in Wyoming, if replicable, may represent new knowledge for the field given the apparent lack of published information on the prevalence of MR/DD or autism spectrum disorders for Native American children.

This project suffers from the same limitation as many epidemiologic studies in the field of developmental disabilities. That is, the prevalence rates of the various developmental disabilities were not adjusted for potential confounding factors (e.g., maternal education, socioeconomic status, and co-occurring medical conditions); consequently, the variation in prevalence rates may be due to variables that were not taken into consideration. For example, it is well known that there is an inverse relationship between socio-economic status and the prevalence of mental retardation (Yeargin-Allsopp et al., 1995). In particular, mild mental retardation, of unknown etiology, seems most highly correlated with low socioeconomic status. The *CSHCN Survey* did permit differentiation of MR/DD by household income. The results showed an inverse relation between prevalence and income such that Wyoming children living in families closest to the Federal Poverty Level (FPL) had higher rates of MR/DD (18.1%) than children from families that were 400% FPL or greater (7.5%). However, the analyses did not permit examination of ethnicity or race and household income simultaneously. Neither of the other data bases included variables associated with socioeconomic status. As an aside, there is strong evidence in support of variables, other than household income, that may drive this relationship. For example, Drews et al. (1995) indicated that maternal education actually was a stronger predictor than economic status in their study.

The finding that Hispanic children are less likely to be diagnosed with ASD than their white counterparts is a topic of considerable discussion in the literature for two reasons. First, the data have been inconsistent on this question but the majority of published studies support the finding of ethnic disparity. Second, it is not clear why such differences would exist. For example, Mandell et al. (2009) suggest that diagnostic substitution or misdiagnosis of autism may play a role in the under-diagnosis of ASD. They also suggest that service provision issues related to socioeconomic status and availability of local diagnosticians may also be related, particularly for underserved ethnic and racial minorities. Palmer et al. (2010) speculate whether there may be protective factors associated with Hispanic ethnicity, although the nature of these factors is not known. At present it is not possible to determine the factors responsible for the apparent disparity of ASD among Hispanic children in the Wyoming data bases. However, it is possible that under-identification is responsible in part.

Finally, given the low base rates of cerebral palsy, visual impairment, and hearing impairment, it was not possible to examine ethnic or racial disparity. The availability of a statewide data base might be useful in examining these questions more fully.

Moving forward, given limitations in the available data bases, it is unlikely that we will be able to address fully the question of racial and ethnic disparity. What is needed is a statewide data base that includes a larger segment of the child and youth population so that meaningful comparisons can be made. Also, given the importance of associated variables, it is crucial that the data base include proxies for socioeconomic status such as maternal education. One potential source of these proxies is aptly demonstrated in the study reported by Croen et al. (2001) in which birth certificate data were electronically linked with other data bases. Research on autism has gradually moved toward inclusion of Asperger's disorder and pervasive developmental

disorder – not otherwise specified and adoption of the umbrella term “autism spectrum disorder.”

While there may be considerable justification for such a composite, the ability to disaggregate into discreet diagnoses may be particularly useful, especially when considering co-morbidity with intellectual disability. Finally, there is ample reason in the epidemiologic literature to separate mental retardation (or intellectual disability) by severity level because socioeconomic factors predict differentially among children with mild or severe subtypes.

E. References

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