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on

Autism & Related Disorders



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Ensuring Fair & Equal Access to Regional Center Services for ASD

April 30, 2012 (10AM to Noon) The State Capitol Building, Room 3191

BACKGROUND & REVIEW OF THE LITERATURE

The Autism Epidemic

Autism spectrum disorders (ASD) are complex neurological disorders that have an onset in infancy and can cause mild to severe difficulties in childhood development, including language delays, communication problems, limited social skills, and repetitive and other unusual behaviors. Although the etiology of ASD is unknown, experts believe there is more than one cause for ASD. Genetics appear to play a role, and there is growing scientific evidence about the role of environmental influences. Research is underway to investigate the extent genetic and environmental factors contribute to ASD.

The dramatic growth in the number of children diagnosed with ASD in California and the United States is a public health crisis that must be addressed. A recent study (TAB 1) by the U.S. Centers for Disease Control & Prevention (CDC) reported that the prevalence of ASD, based on data analyzed from 2008, had risen to 1 in every 88 children (1.13 percent). Within this study that included 337,093 children, one in 54 boys and one in 252 girls were identified with ASD. This report indicated that ASD prevalence had increased 23 percent from the prior analysis in 2006 and that the incidence of ASD has almost doubled in just six years (2002 incidence 6.4 per 1,000 vs. 2008 incidence 11.4 per thousand.) The increase in ASD over the past six year was similar for both males and females. During the past two years of this study there was a marked spike in the prevalence of ASD among children of color with 42 percent increase among black children; a 29 percent increase among Hispanic children, and only a 16 percent ASD prevalence increase among white children.

Racial & Ethnic Disparities in ASD

(The demographic and ethnic/racial terms used in the following discussion will vary to appropriately reflect the designations used in each of the studies that are cited)

According to the CDC (TAB 1), the prevalence of ASD also varies significantly by racial/ethnic demographics and can be summarized as follows: non-Hispanic white children = 1.2 percent or one for every 83 children; non-Hispanic black children = 1.02 percent or one per 98 children; Hispanic children = .08 percent or one per 127 children. Only two of the 14 CDC monitoring sites reported an incidence of ASD among Hispanic children that was comparable to the incidence noted in non-Hispanic white children.

Children of color with ASD are also diagnosed at an older age. In 2002 Dr. Mandell and colleagues reported *{Race Differences in the Age at Diagnosis Among Medicaid-Eligible Children with Autism, J Am. Acad. Child Adolesc. Psychiatry (2002) 14:12, 1447-1453}* that among 406 children receiving Medicaid services, white children with ASD were diagnosed at an average age of 6.3 years as compared to 7.9 years for black children and 8.8 years for Latino children. Seventy-two percent of white children and 58 percent of African-American children were diagnosed with ASD on their first mental health evaluation. Black children required three times the number of visits over a period three times as long, while Latino children required twice as many visits as white children before being appropriately diagnosed with ASD. These authors concluded that important sociocultural factors were associated with the appropriate evaluation and diagnosis of ASD.

A study of 406 ASD children *{Mandell, Disparities in Diagnoses Received Prior to a Diagnosis of ASD, J Autism Dev. Disord. (2007) 37:9, 1795-1802}* confirmed that African-American children were 2.6 times less likely than white children to be appropriately diagnosed with ASD on their first specialty evaluation. Importantly, this study noted that racial disparities existed during the evaluation process and that African-American children were nearly three times more likely than white children to receive another diagnosis, which most often was considered to be a "conduct or adjustment disorder."

A subsequent study of 2568 children with ASD *{Mandel, Racial/Ethnic Disparities in the Identification of Children with Autism Spectrum Disorders, Am. J. of Public Health (2009) 99:3, 493-498}* also concluded that significant racial/ethnic disparities existed in the recognition of ASD and that children who were black had a significantly greater degree of intellectual impairment while children who were Hispanic or of other ethnicity manifested a high incidence of co-occurring intellectual disabilities. These authors suggested that "racial differences in diagnostic patterns might be attributable to

institutional factors such as access to health care, general prejudices held by clinician, clinicians' and families' interpretation of symptoms and clinicians' erroneous interpretation of algorithms on the likelihood of a child having ASD." The study emphasized the important of identifying and implementing strategies that will lead the early identification of children with ASD who currently are overlooked.

The significance of socioeconomic, psychosocial, and cultural factors in the evaluation and treatment of ASD are considered to be very important, but unresolved, issues. According to data from the National Survey of Children's Health (Tab 1), the prevalence of ASD was lower for Latinos than for non-Latinos while children that were white and African-American had comparable rates. Latinos and poor families rated their children's autism as being more severe. Being black, Latino, or poor was associated with decreased access to services.

Researchers in Atlanta, Georgia, that followed children with ASD in from 2000 to 2006, concluded that non-Hispanic black children had more severe manifestations of ASD than white children. However, the potential underlying causes and precipitating factors for these disparities remain issues of ongoing investigation. For example, data from the Texas Educational Agency {Palmer, *Explaining Low Rates of Autism Among Hispanic Schoolchildren in Texas*, Am. J of Public Health (2010) 100:2, 270-272} indicate that although ASD rates were two to three times higher among non-Hispanic whites as among Hispanics, socioeconomic factors failed to explain the much lower ASD prevalence among Hispanic schoolchildren in Texas. In contrast, a recent study {Fountain, *Six Developmental Trajectories Characterize Children with Autism*, Pediatrics (2012) 129:5, 2011-2020} underscored the potential significance of socioeconomic factors. In the longitudinal evaluation of 6,000 children with ASD receiving regional center services, researchers concluded that low-functioning children were more likely to have mother who were minority/foreign born, less educated, and on Medi-Cal while high-functioning children were more likely to have mother who were white, more educated and not on Medi-Cal.

Disparities in Mental Health Services

The U.S. Surgeon General, in an extensive 200-page report published in 2001, noted that minorities and underserved communities face significant challenges in obtaining mental health services and that these groups are more likely to receive poor quality care. The key findings of this report included:

- Disproportionate numbers of African Americans are represented in the most vulnerable segments of the population – people who are homeless, incarcerated,

in the child welfare system, victims of trauma – all populations with increased risks for mental disorders;

- Most Hispanic-Americans have limited access to ethnically or linguistically similar providers.
- The suicide rate among American Indians/Alaska Natives is 50 percent higher than the national rate
- Asian Americans/Pacific Islanders who seek care for a mental illness often present with more severe illnesses than do other racial or ethnic groups.

A study by Dr. Aguilar-Gaxiola (*Disparities in Mental Health Status and Care in the U.S. Population Mental Health: Evidence, Policy, and Public Health Practice*; (2010) Taylor & Francis Books, 69-91) also provides a comprehensive review of disparities in the mental health status and care in the U.S. This study notes that while minorities (Latino, African-American, Asian American and Pacific Islanders) tend to have a lower prevalence of psychiatric disorders, these groups tend to have more persistent illnesses, with symptoms that may be more severe and disabling. Furthermore, immigrants were less likely to see physicians and also to use medications than their U.S.-born counterparts but it was unclear whether these disparities were related to stigma, lack of access to medical care and outpatient therapy for mental health issues, or fragmented case management.

The National Institute on Minority Health & Health Disparities states that disparate mental health status can be attributed to a complex interaction among multiple factors. Socioeconomic differences are largely responsible for the widening differences in health status among racial and ethnic lines. But, even after controlling for socioeconomic status, there seem to be other factors that further influence health disparities, including gender, genetics, environment, and racial bias. Access, utilization, and quality of medical care contribute to these inequities. And, language and culture pose additional barriers to good health for racial and ethnic minorities and other medically-underserved individuals. Barriers to mental health care include the cost of care, societal stigma, and the fragmented organization of services. Additional barriers include the client's fear and mistrust of treatment.

Researchers (Tab 1) have provided specific strategies to mitigate and correct these racial and ethnic disparities in pediatric mental health that include:

1. Appointing a government taskforce to address the current gaps and unmet needs.

2. Evaluating the role of community-sources of care such as schools and community agencies.
3. Providing culturally appropriate information to assist parents and families in making informed decisions about mental health evaluation and therapy.
4. Evaluating treatment preferences among minority youths and their families and ensuring that minority parents collaborate with providers in order to ensure that cultural values are acknowledged and maintained.
5. Providing assessment instruments that are culturally appropriate for minority populations.

Racial & Ethnic Disparities in Healthcare

Information from the Agency for Healthcare Research and Quality (AHRQ) as well as the 2010 National Healthcare Disparities Report noted that disparities are most easily identified when there is a clear reference point for what is appropriate and reasonable to expect. Although there may be uncertainty regarding many aspects of clinical care, and variation in patients' medical conditions and severity of illness, there should be little deviation from specific quality measures associated with population. This report provided compelling evidence of healthcare inequalities in the U.S. and specific examples that included the following:

- About 30 percent of Hispanic and 20 percent of black Americans lack usual sources of healthcare as compared with less than 16 percent of whites; Hispanic children are nearly three times as likely as non-Hispanic white children to lack a usual healthcare source.
- African Americans and Hispanic Americans are far more likely to rely on hospitals or clinics for their usual source of healthcare (16 percent & 13 percent respectively vs. 8 percent for white Americans.)
- Minorities are more likely to be diagnosed with late-stage breast cancer colorectal cancer compared with whites.
- Patients of lower socioeconomic position are less likely to receive recommended diabetic services and more likely to be hospitalized for diabetes.
- When hospitalized for acute myocardial infarction, Hispanics are less likely to receive optimal care.
- Infants born to black women are 1.5 to 3 times more likely to die than infants born to women of other races/ethnicities.

- Many racial and ethnic minorities and persons of lower socioeconomic position are less likely to receive childhood immunizations.
- Many racial and ethnic minorities and individuals of lower socioeconomic status are less likely to receive recommended immunizations for influenza and pneumococcal disease.

These studies identified complicated interrelationships between race, ethnicity, and socioeconomic status that may result in healthcare disparities. However, a consistent and pervasive finding included the lack of information and knowledge that was provided to underserved communities and included the following examples:

- Significantly lower rates of smoking cessation offered to minority patients.
- Many racial and ethnic groups, as well as poor and less educated patients, reported having poor communication with their physicians and more problems with some aspects of patient-provider relationships.
- Asians, Hispanics, and those of lower socioeconomic status had greater difficulty accessing health care information, including information on prescription drugs.

There are also large racial/ethnic disparities in preventable hospitalizations with blacks experiencing a rate more than double that of whites. Data from the AHRQ indicates that eliminating these disparities would prevent approximately one million hospitalizations and save \$6.7 billion in healthcare costs annually. Furthermore, the Joint Center for Political & Economic Studies reported the following:

- Between 2003-2006, 30.6 percent of medical care expenditures for African Americans, Hispanics and Asians were excess costs due to health inequities.
- Between 2003-2006, the combined costs of health inequities and premature death in the U.S. were \$1.24 trillion.
- Eliminating health disparities for minorities would have reduced direct medical care expenditures by \$119.4 billion for the years 2003-2006.

Ethnic and social class disparities are evident across a broad spectrum of markers of psychological, behavioral and physical health (Tab 1). These patterns frequently involve complex interactions of numerous risk factors (e.g. poverty, lack of contextual diversity, linguistic barriers) and protective dynamics (e.g. family support, cultural identity.) Thus, any evaluation and analysis of services for ASD must be considered within the context of our current healthcare system.

The Series on Autism Reported in the Los Angeles Times

In December, 2011, the Los Angeles Times staff writer Alan Zarembo and his data team authored a four part series on autism (Tab 3) that was based on extensive interviews with researchers, parents, clinicians, educators and other stakeholders. In addition to an extensive review of scientific studies, Mr. Zarembo and his team apparently reviewed thousands of pages of information obtained from the California Department of Developmental Services (DDS) and other sources. The ensuing series included:

1. Part 1: An Epidemic of Disease or Discovery?
2. Part 2: Services Go to Those That Fight the Hardest.
3. Part 3: Families Chase the Dream of Recovery.
4. Part 4: Finding Traces of Autism in Earlier Eras.

The series provided a multifaceted and kaleidoscopic view of ASD. Furthermore, these articles provided data and information with regards to potential inequities in ASD services by regional centers that are highly relevant to this hearing and can be summarized as follows:

- For 3-6 year old children with ASD, DDS spent an average of \$11,723 per child on whites, compared with \$11,063 on Asians, \$7,634 on Latinos, and \$6,593 on blacks.
- In 2010 regional centers provided services to 16,367 autistic children 3-6 years of age with an average of \$9,751 per case statewide. However, these expenditures varied widely from an average of \$1,991 per child at the regional center in South Los Angeles to \$18,356 at the one in Orange County.
- At 14 of the 21 regional centers, average spending on white children exceeded that for both blacks and Latinos.
- At the Lanterman Regional Center spending on white youngsters with ASD averaged \$12,794 per child, compared with \$9,449 for Asians, \$5,094 for blacks, and \$4,652 for Latinos.
- Anecdotal reports that aggressive and informed parents are much more likely to obtain more extensive regional center services for ASD.
- Anecdotal indications that minorities and underserved communities face formidable challenges and barriers in accessing appropriate ASD

Disparities in accessing ASD services from school districts and other providers were also reviewed in the L.A. Times series. However, inequities in educational services and community-based supports, while of critical concern and importance, are beyond the scope of today's hearing.

Respectfully submitted,

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