



State Data: ADDM and the ASD Prevalence Study

The University of Minnesota (UMN) is an Autism Developmental Disabilities Monitoring (ADDM) Network site. The MN ADDM project tracks rates of ASD in MN. The specific goals of MN ADDM are to:

- 1) Estimate the prevalence of 8-year-olds with ASD with intellectual disabilities (ID) in Hennepin and Ramsey Counties, and identify other characteristics such as ethnicity and co-occurring conditions;
- 2) Identify disparities in prevalence, characteristics and age of diagnosis across demographic groups, including two large racial/ethnic groups unique to MN – Somali and Hmong children;
- 3) Use project data to improve services for children with ASD/ID in their community.

ADDM data provides a significant step forward in understanding ASD prevalence and characteristics in MN. Limitations are geographic scope and small sample size limiting analysis of subpopulations. Minnesotans outside the Twin Cities report delays in screening and diagnosis as well as unmet service needs. Future MN-ADDM goals include increased timeliness of ADDM data and the need for expansion to greater Minnesota. Other connections have been both MN Act Early and MN Help Me Grow to decrease the age of identification.

QI with EIDBI

In 2013, the Minnesota legislature authorized the Department of Human Services (DHS) to develop and implement the Early Intensive Developmental and Behavioral Intervention (EIDBI) benefit for children and youth under 21 years of age who are on Medical Assistance (MA), Minnesota’s Medicaid benefit. The EIDBI service is intended to provide medically-necessary intensive intervention as early as possible for children with ASD and related conditions and their families.

EIDBI services include rigorous progress monitoring to ensure best outcomes for child and family. Involvement of a broad and diverse community of ASD stakeholders was key to the process of developing the EIDBI benefit, as well a critical component of QI. DHS implemented an extensive, intentional stakeholder input process that included parents, advocates, clinicians, professionals, state agencies and individual stakeholders, DHS ASD Advisory Council, and smaller focus groups to seek input on the EIDBI benefit. Over one third of EIDBI agencies serve culturally-specific groups such as Somali or American Indian communities. Additionally, DHS monitors demographics and outcomes of families enrolled in EIDBI benefit with a focus of identifying and addressing inequities.

Prevalence Estimate by Race and Ethnicity

Race and ethnicity	Children with ASD identified/ Total population	Prevalence estimate (prevalence per 1,000 children)
Overall	255 of 12,329	1 in 48 (20.7 per 1,000)
Somali	31 of 1,007	1 in 32 (30.8 per 1,000)
White	120 of 4,336	1 in 36 (27.7 per 1,000)
Black (non-Somali)	53 of 3,312	1 in 62 (16 per 1,000)
Hispanic	30 of 2,399	1 in 80 (12.5 per 1,000)

ID/IQ by Race and Ethnicity

	Percentage of children with ID	Percentage of children missing IQ scores
Overall	33%	28%
Somali	100%	35%
White	20%	26%
Black (non-Somali)	30%	19%
Hispanic	22%	40%

ASD Prevalence by race and ethnicity



Engaging Communities through an Advisory Group

Minnesota has recently reestablished a legislative working group to focus on issues related to individuals with ASD and their families. To better understand the unique needs of specific cultural communities, there are a number of individuals representing their diverse backgrounds on the ASD Working Group. Representatives include those from Somali and South Asian cultural backgrounds as well as neurodiverse individuals that vary by gender, ages, and race.