Autism Spectrum Disorders Among Preschool Children Participating in the Minneapolis Public Schools Early Childhood Special Education Programs

Minnesota Department of Health

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Protecting, maintaining and improving the health of all Minnesotans

March 31, 2009

Dear Fellow Minnesotans:

In 2008, Somali parents and others in the Twin Cities area raised concerns about disproportionately high participation rates of young Somali children in an Early Childhood Special Education Citywide (ECSC) Autism Spectrum (ASD) Classroom Program operated by the Minneapolis Public Schools (MPS). Acting on the concerns of community members, experts from the Minnesota Department of Health spoke with several members of the community, including parents of children who were diagnosed with ASD, participated in a community forum to explore the issue and met with representatives of MPS to seek answers to the questions being raised.

Two things quickly became clear. First and foremost, the concern of many members of the Somali community that the prevalence of this severe developmental condition might be elevated in their children is important and legitimate. Since there are many unknowns about autism, I and MDH share their desire to better understand this condition for the sake of all our children.

Second, we quickly understood that there were more questions than answers. More than anything else, members of the Somali community, the school district, other Minnesotans and MDH needed and deserved better information.

It was on this basis that we began our exploration. The attached study was conducted in collaboration with the MPS Special Education Department, educational and health professionals and epidemiologists at the Minnesota Department of Health, the Minnesota Department of Education, the University of Minnesota, and the Centers for Disease Control and Prevention.

It is important to recognize this study for what it is – a first step in understanding and responding to the questions around the prevalence of ASD in the Somali community. The scope of this study by its nature was very limited, focusing on the percentage of Minneapolis children ages three and four who participated in MPS ECSC programs for children with ASD. This is known as "administrative prevalence." It provides some insights, but also is limited by the information we were able to study. For example, laws protecting the privacy of children and families made it impossible to quickly gain access to school and medical records that would identify all of the children ages three and four who had ASD. This means we could have undercounted or overcounted children with ASD. As a result, we were unable to determine the population prevalence of ASD among Somali children.

In addition, this study was not designed to identify the possible causes of ASD.

Recognizing these limitations, the MDH study underscores some important points that deserve further discussion and study:

- The administrative prevalence for three and four year old Somali children was significantly higher than for non-Somali children. This is consistent with the perceptions of the community that a larger number of Somali children were participating in ASD programs. Because of the study's limitations, it is not proof that more Somali children have autism than other children; however, it does raise an important question about why Somali children are participating in this program more than other children.
- The relative difference between Somali and non-Somali administrative prevalence decreased markedly over the three years covered by the study. It is unclear if this is an identification issue, a change in parental awareness for the need for developmental screening or some other issue.
- Administrative prevalence rates for the Asian and Native American groups were found to be "strikingly low." The reasons for these low rates are unknown, but they could be important to understanding whether the rate of ASD is higher among Somali children or underestimated among other children. In other words, the seemingly low prevalence rate among Asian and Native American children may artificially boost the comparative rate among Somali children, distorting a true understanding of all groups involved.

We know the above information leaves many questions unanswered, but we recognize this study is only the first step on a very long journey. To better understand whether there is, indeed, a higher occurrence of ASD in Somali children as compared with non-Somali children, a wide range of skills, expertise and knowledge of the community and environment are needed. Issues to be explored include:

- Exploring the feasibility of developing a population-based public health ASD surveillance system in Minnesota.
- Estimating administrative ASD prevalence for a larger geographic area in Minnesota and elsewhere in the country.
- Learning more about how children come into the system and whether there are cultural differences in how behavioral and developmental problems are addressed.
- Conducting additional analyses to address pending study questions.

While addressing these issues will assist in estimating the population prevalence of ASD in the Somali community and in Minnesota, MDH, along with the Somali community and a wide range of partners, will continue work to:

- Improve access to culturally competent, coordinated care.
- Increase access to information about child development and available resources for children with special health care needs.
- Ensure that physicians and other providers have the right tools to diagnose and refer children with ASD to appropriate services.

While this study is only a beginning, we are committed to working with the community, researchers, health and education professionals and others to continue shining a light on the important issue of autism.

Sincerely,

Sanne Magnan, MD, PhD
Minnesota Commissioner of Health

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Executive Summary

Background

In 2008, Somali parents and others in the Twin Cities area raised concerns about disproportionately high participation rates of Somali children in a preschool program for children receiving Autism Spectrum Disorder (ASD) special education services. The preschool program in which the Somali children were participating was the Early Childhood Special Education (ECSE) Citywide ASD Classroom Program, operated by the Minneapolis Public Schools (MPS). A particular source of concern was the high percentage of children participating in this program who were Somali, compared with the overall percentage of children who were Somali in the city's public schools.

The Minnesota Department of Health (MDH) shared the community's concerns about a possible elevation in ASD rates in Somali children, and agreed to assess the occurrence of ASD among preschool-age Somali children in Minneapolis. Although a source of great concern both within and outside the Somali community, the apparent over-representation of Somali children in the ECSE Citywide ASD Classroom Program was difficult to interpret. To calculate the prevalence of a disease or condition in a particular group, it is necessary to determine the number of people within the group who have the condition at a particular point in time or during a specific time period. That number is then divided by the total number of people in the group. To determine whether the prevalence is unusually high or low, it is necessary to compare it with the prevalence in another group (preferably all people), calculated in the same way.

Simply comparing the percentage of preschool children who are Somali participating in the ECSE Citywide ASD Classroom Program with the percentage of children in the school system who are Somali did not provide sufficient information to allow for the kind of comparison that would indicate whether ASD rates were truly elevated among Somali preschool children as compared to other, non-Somali children.

MDH undertook the analysis described in this report in an effort to develop a clearer, more scientifically grounded picture of ASD prevalence among Somali preschool children, ages 3 and 4, who were living in Minneapolis. Identification of cause or risk factors for ASD was beyond the scope of this study.

Methods

For a majority of states, there is a lack of valid and reliable data on the occurrence of ASD in the population. Estimation of the *population prevalence* requires a public health surveillance system where data are collected from both public school special education programs and medical facilities to determine the number of ASD cases occurring among the population and dividing by the estimated size of that population. Minnesota does not have a public health surveillance system for ASD in place which prevented MDH from estimating the population prevalence of ASD among Somali and non-Somali children. Additionally, the rapid increase in the size of Minnesota's Somali population over the last several years made it difficult to accurately estimate the size of that population for the purpose of calculating disease prevalence. Instead, MDH calculated the *administrative*

prevalence of ASD for defined birth cohorts of Somali children, non-Somali children, and children in several different race/ethnic categories.

Administrative prevalence for ASD, in this study, refers to the percentage of preschool age children, ages 3 and 4, in Minneapolis who are eligible to receive ASD-related services through any of the several MPS ECSE programs that provide those services. These children were identified using MPS ECSE program participation data that is used routinely for administrative purposes such as planning budgets and meeting federal reporting requirements – hence the term "administrative prevalence." Program eligibility is determined through Minnesota Statutes and Rules that define eligibility for receiving free special education services for the ASD disability category in Minnesota's public school system.

Children included in the count participate in the MPS ASD-related special education programs and could have had primary, secondary, and tertiary ASD disability. These children were divided into Somali and non-Somali groups based on whether Somali was the primary language spoken in the child's home. They were also divided in to Asian, black, Hispanic, Native American and white, using MPS data.

The number of children in each of these groups was then divided by the overall number of children in the appropriate ethnic/racial category and age group (3 and 4 years of age) as determined from birth certificate data. Children were counted as Somali if their mothers were born in Somalia. The prevalence was estimated for each of three consecutive school years (05-06, 06-07, and 07-08), for children who were 3 and 4 years of age and eligible for ASD-related services during each one-year period.

The overall number of children in each racial/ethnic category represented birth cohorts, and included all children whose mothers were residents of Minneapolis at the time of the child's birth. The mother's residency was identified from the child's birth certificate. Because it was not possible to link children who were identified using MPS administrative data with their birth certificate data, four different sets of assumptions were used to determine which children should be included in the different groups, based on each child's birthplace and their school district residency. Separate prevalence estimates were calculated for each set of assumptions, in each of the three school years considered in the study.

Results

This analysis was limited to estimating ASD prevalence among children aged 3 and 4 who were members of defined birth cohorts using MPS administrative data for three consecutive school years. No attempt was made to obtain or analyze data from other parts of Minnesota or the U.S. with large Somali populations. Because of the limitations described below, MDH urges caution in attempting to generalize the findings of this study to the larger Somali population. The results of the analysis were as follows:

A. Administrative ASD prevalence estimates – that is, the percentage of children 3 and 4 years of age in a birth cohort who were receiving services in any MPS ASD program during any given school year – ranged from 0.27% to 0.78% for all

children, 0.21% to 0.72% for non-Somali children, and 0.93% to 1.54% for Somali children.

B. Depending on the assumptions used to determine whether a child should be included in the group, the relative difference in the administrative prevalence estimates for Somali children was approximately 2 to nearly 7 times the administrative prevalence for non-Somali children.

C. These relative differences between Somali and non-Somali children decreased markedly over the 3-year period, meaning that differences in administrative prevalence between Somali children relative to non-Somali children decreased in a short amount of time.

D. The proportion of Asian and Native American children participating in the MPS ECSE ASD programs was strikingly low, as were their administrative ASD prevalence estimates.

E. Comparing this study's results with national survey data for 2005-2006, there was some suggestion that the administrative prevalence rates for Somali children might be similar to what would be expected for U.S. children ages 3 and 4, based on what parents responding to the survey reported. This comparison also suggested that the administrative prevalence for non-Somali children might be lower than what would be expected for this population of U.S. children.

Limitations

A. <u>The lack of baseline ASD rates for the population</u>.
Without data accurately characterizing baseline ASD rates for all children ages 3 and 4 in Minnesota, it is very difficult to interpret differences in administrative prevalence overall and by subgroup. Questions regarding the interpretation of our results underscore the importance of having valid and reliable baseline population ASD prevalence rates.

B. <u>Possible errors in identifying and counting ASD cases</u> (numerator data).

1. Differences in ASD prevalence estimates can arise because of differences in how ASD cases are defined for educational, medical and public health purposes. Undercounting ASD cases can result in an underestimation of administrative prevalence. Only counting children who receive services from MPS means that the count used in this study will not include any Minneapolis children who receive services outside of MPS. This will also result in an underestimation of administrative prevalence.
2. Misclassification errors are always a possibility in epidemiologic studies. The chance of a differential misclassification error occurring in a setting may be greater when clinicians are not familiar with the culture or with behaviors that are considered routine or normal, and widely accepted in minority racial and ethnic groups.
3. Identifying a child's country of descent based on the primary language spoken in the home would have misclassified children of Somali descent if they lived in homes where English was the primary language.
4. The case inclusion criteria used to define and count ASD cases (numerators) did not match exactly with the criteria used to define and enumerate individual

birth cohorts (denominators). To account for that discrepancy, multiple estimates of ASD administrative prevalence were generated based on differing assumptions, but under- and over-counting ASD cases probably still occurred.

C. Errors in estimating the population size (denominator).
   1. Rapid growth of the Somali population during the years since the 2000 U.S. decennial population census and the lack of recent data for secondary migration into Minnesota (i.e., migration to Minnesota after first immigrating to another state) made it especially difficult to obtain population data for Somali children.
   2. Small errors in estimating the size of the birth cohort populations by race/ethnicity and Somali descent occurred, but these errors would not have affected the overall Somali and non-Somali administrative prevalence estimates.

D. Other sources of systematic error in the data with the potential to bias study results.
   1. Systematic differences in how children in Minneapolis come to the attention of MPS preschool developmental screening or evaluation programs may potentially account for at least some of the variation observed in the administrative ASD prevalence estimates.
   2. Losses of ASD cases from MPS ECSE program enrollment – children leaving the program for any number of reasons – would result in an underestimation of administrative prevalence. Differential losses of ASD cases by population subgroups (e.g., race or ethnicity) would result in biased administrative prevalence estimates for those subgroups.

Conclusion

The administrative ASD prevalence estimates from this study – that is, the proportion of children receiving services in MPS ASD programs who were members of defined birth cohorts of children – were significantly higher for Somali children compared to non-Somali children across most analysis assumptions, school years, and ASD program types. These results are consistent with community reports of higher ECSE ASD program participation rates among Somali preschool children. Depending on the analysis assumptions and the ASD program type, the relative differences between the estimates as measured by administrative prevalence ratios, ranged from approximately 2 to 7 times higher for Somali children ages 3 to 4 years relative to non-Somali children. However, these prevalence ratios decreased markedly over the 3-year period, suggesting that the difference in administrative prevalence between Somali children relative to non-Somali children was decreasing with time. Such rapid declines over a short period of time might suggest that these results are driven, at least in part, by noncausal changes in program participation over the three school years.

This study, however, has significant limitations, as described above. Without baseline data to characterize the population prevalence of ASD among children in Minneapolis, MDH cannot determine whether the administrative ASD prevalence estimates for Somali

children are substantially different from what would be expected in the population of children ages 3 and 4. Given the limited scope of this study and the study limitations, we urge caution in attempting to generalize the findings of this study to the overall Somali population or to other racial and ethnic subgroups in Minnesota or the U.S. population.

Despite these limitations, this study represents an important step forward. Its findings are consistent with perceptions of parents and others in the Somali community regarding the participation of Somali children in ASD programs operated by MPS. This study has raised new, important questions that should help guide future research to help better understand this issue. Importantly, it also identified the type of data that would be required to more accurately estimate the number of ASD cases among children, as well as to obtain more accurate estimates of population ASD prevalence in Minnesota.

By applying appropriate scientific rigor to the study of this issue, MDH has attempted to lay a solid foundation for future efforts to understand autism, both in the Somali community and in the larger population. We are still near the beginning of a very long journey. It is hoped that this study will provide a useful beginning.

Next Steps

To better understand whether there is, indeed, a higher occurrence of ASD in Somali children than would be expected in the population of children, a wide range of skills, expertise, and knowledge of the community and environment needs to be brought to table. MDH will explore with the Centers for Disease Control and Prevention, the University of Minnesota and other state and national experts, Minneapolis Public Schools, members of the Somali community and other key stakeholders how best to move forward in addressing this issue. Additional research is needed to explore:

A. Learning more about how children come into the system and whether there are cultural differences in how behavioral and developmental problems are addressed.

B. Reviewing and systematically abstracting data from MPS educational records to learn more about evaluations for eligibility to receive special education services under the ASD disability category.

C. Conducting additional analyses to address pending questions, including:
   1. Can we better identify who is of Somali descent and/or mother's residency at the time of birth?
   2. Are there differences in population norms between Somalis and non-Somalis that might impact screening and evaluation results?
   3. What are the barriers to assessment by race, ethnicity, and language spoken in the home? Is there a difference among Somali and non-Somali children by age at first screening, evaluation, and ideally diagnosis?
   4. What methods are used for MPS Child Find? Are there differences in participation rates for the 348-TOTS and Screen by 3 screening programs or the referral rates by race, ethnicity, and language spoken in the home?

5. How many children are lost to the MPS program? What private providers offer early intervention services to children with ASD? What are the demographic characteristics of these children and do they also receive services from MPS?

D. Estimating administrative ASD prevalence for a larger geographic area, e.g. Hennepin County, that includes other communities with relatively large populations of Somali residents to address the question: are disproportionate numbers of Somali children in other parts of Minnesota also attending special education programs for ASD?

E. Estimating administrative ASD prevalence in other U.S. communities with large populations of Somali residents to answer the question: are disproportionate numbers of Somali children in other parts of the country also attending special education programs for ASD?

F. The feasibility of developing a population-based public health ASD surveillance system in Minnesota.

While addressing these issues will assist in estimating the true prevalence of ASD in the Somali community and in Minnesota, MDH, along with the broader community, will continue working to:

- Improve access to culturally competent, coordinated care.
- Increase access to information about child development and available resources for children with special health care needs.
- Ensure that physicians and other providers have the right tools to diagnose and refer children with ASD to appropriate services.

Background

In 2008, Somali parents and others in the Twin Cities area raised concerns about disproportionately high participation rates of Somali children in a preschool program for children receiving Autism Spectrum Disorder (ASD) special education services. The preschool program in which the Somali children were participating was the Early Childhood Special Education (ECSE) Citywide ASD Classroom Program, operated by the Minneapolis Public Schools (MPS). A particular source of concern was the high percentage of children participating in this program who were Somali, compared with the overall percentage of children who were Somali in the city's public schools.

A number of potential causes were suggested for the apparent elevation, including vaccinations, exposures to lead, and low levels of vitamin D and/or sun exposure. These observations gave rise to a very real sense of urgency and heightened concern in the Somali community.

After closer scrutiny of the data, it was determined that the statistics cited were not actually estimates of population ASD prevalence among Somali children compared with non-Somali children living in Minneapolis. Instead, they represented program participation rates of a selected group of children between the ages of 3-4, who attended MPS ECSE programs and were eligible to receive ASD special education services.

Interpreting differences in program participation rates can be challenging. The fact that a child is participating in an ASD early childhood program is an indicator of educational need, but that child may or may not have a medically diagnosed ASD. Children are assigned to participate in special education programs based not only on the specific educational needs and disability that the child may have, but also on a consideration of which program would most benefit the individual child. In addition, the fact that any given child in this age group is not participating in an ASD program does not necessarily mean that this child does not have an ASD. Some children may not have come to the attention of the school system and others who have been identified with an ASD might initially receive services under other special education disability categories such as Developmental Delay or Speech and Language Disorders.

Further, Minnesota's public school open enrollment policy allows children to attend special education programs in school districts where they are not residents. This raised the question of whether participation rates for Somali children might appear higher than the participation rates for non-Somali children because of an influx of Somali children who are not residents of the Minneapolis school district attending MPS ECSE programs for ASD.

Current statistics accurately characterizing baseline ASD prevalence in populations of preschool children were not available for Minnesota or the U.S. Therefore, the MDH determined that a reanalysis of the MPS dataset using epidemiological methods and definitions was a necessary first step toward better understanding the occurrence of ASD among children attending MPS preschool programs.

The primary goal of this effort was to use defined population and ASD case criteria to estimate administrative ASD prevalence using MPS special education records. MDH did **not** identify potential risk factors or causes of ASD that might explain why greater proportions of Somali children participated in MPS early childhood special education programs for ASD. These analyses were conducted in collaboration with the MPS Special Education Department, health professionals and epidemiologists at the Minnesota Department of Health, the Minnesota Department of Education, the University of Minnesota, and the Centers for Disease Control and Prevention (CDC). Objectives were to: (1) estimate the administrative ASD prevalence among birth cohorts for different racial and ethnic populations in Minneapolis using MPS administrative special education data; and (2) characterize the limitations of these analyses and identify questions that might need additional research or analysis.

The purpose of this report is to present the methods, findings, and limitations of this investigation, and to provide next steps. Prior to presenting this information, general background information is provided on the descriptive and risk factor epidemiology of ASD, special education administrative data, and the estimation of population prevalence versus administrative prevalence.

Autism Spectrum Disorders

Autism spectrum disorders (ASD) are developmental disorders characterized by impairments in social skills and communication, and unusual repetitive or stereotyped behaviors (1). ASD typically includes autistic disorder, Asperger syndrome, and pervasive developmental disorder, not otherwise specified (PDD-NOS). The diagnosis of ASD is based on observation of behavior, and currently there are no biologic diagnostic tests for ASD (1). Symptoms of ASD can be subtle and vary widely in severity across the spectrum. Common symptoms of ASD include lack of eye contact, lack of response to hearing one's name, lack of communicative gestures, repetition of the speech of others (echolalia), repetitive motions with hands, arms, or other body parts, strong adherence to routine, and restricted interest in particular objects or topics (2). At 15-18 months about 25% to 30% of children with ASD have an initial presentation in which they experience gradual or sudden regression of social and communication skills (3).

About 5-10% of ASD cases occur secondary to other primary health conditions. Examples of other primary health conditions that can cause secondary ASD include the presence of certain genetic conditions (e.g., fragile X syndrome), metabolic conditions (e.g., untreated phenylketonuria (PKU)), malformations in the brain (e.g., tuberous sclerosis), and neurological damage during gestation (e.g., fetal alcohol syndrome) (1,3,4). The exact causes of the majority of ASD cases are unknown, although a strong heritable component to ASD risk has been established (3). Risk factors associated with a greater risk of idiopathic ASD include having an identical twin or sibling with ASD, or having an older mother or father (1,3).

Recent estimates of the prevalence of ASD in North America and Europe average approximately 6 per 1,000 (1,3,5). Boys are four times more likely to be affected by ASD than girls, although the male-to-female ratio is lower among those with greater cognitive impairment (1). ASD occurs in all racial and ethnic groups and at all levels of socioeconomic status (SES) (2). Autistic disorder and ASD prevalence estimates have varied widely between studies, and have increased over time. These differences are attributable to, in part, significant changes over time in diagnostic criteria and classification of ASD, variability in case-finding methods between studies, increased awareness of ASD among professionals and the general public, and other factors (1, 4).

Data on variability of ASD prevalence by race, ethnicity, and SES is limited and inconclusive, and apparent differences between racial and ethnic populations may largely be due to differences in case finding and service provision (1). Although elevations in ASD prevalence among children of immigrant parents have been previously reported, these findings are subject to question because these studies were based on small numbers and/or were methodologically flawed (5). More recent studies examining ASD prevalence among children of immigrants of Somali (6) or Ethiopian (7) descent may share similar methodological limitations: analyses based on samples that do not reflect the entire spectrum of ASD cases in the population, convenience samples of immigrant populations, and possible selection bias. As discussed later, the children included in these two studies likely represented non-representative samples of populations because of the

selection of ASD cases from a center where children with two subtypes of ASD and learning disabilities receive services, or the selection of subsets of populations who immigrated to Israel.

Special Education Administrative Data

Administrative special education data collected by public school districts are developed and utilized for planning programs, budgets, and staffing needs, reimbursement, and for meeting federal and state reporting requirements for compliance with the Individuals with Disabilities Education Act (IDEA) (8). An understanding of how and why these data are developed is essential to estimating and interpreting administrative prevalence statistics. A brief description of this data source and key definitions are provided below.

IDEA guarantees a free, appropriate public education for every child in the U.S. ages birth to 21 with a disability. Children and youth ages 3 to 21 receive services under Part B of IDEA, while early intervention services for infants and toddlers ages birth through 2 are covered under Part C of IDEA. State departments of education are required to annually report data about the children served under Part B and Part C of IDEA to the U.S. Department of Education. These data are gathered by local school districts and reported to state departments of education, including MDE. The reports include counts of children participating in public school special education services as of December 1 of each school year. This is referred to as the "Child Count."

Part C of IDEA requires each state to have a comprehensive, interagency "Child Find" system to identify and evaluate all children with disabilities or in need of early intervention services. In Minneapolis, 348-TOTS is the service that provides screening and referral to early intervention services for children ages birth through 2. In Minnesota, comprehensive developmental and health screening prior to entrance to public school kindergarten is required by MN Statute 121A.17. The MPS "Screen at 3" Program provides early childhood screening for preschool for children ages 3 through 5 years.

MN Statute 125A.02 defines a "child with a disability" for educational purposes as every child who meets criteria for one of twelve disability categories or for developmental delay (Appendix A). Children under age three, and at local district discretion from age three through age six, meet the criteria for developmental delay if they have a substantial measurable delay, or if they have "a diagnosed physical or mental condition or disorder that has a high probability of resulting in developmental delay regardless of whether the child has a demonstrated need or delay" (MN Rule 3525.1350).

MN Administrative Rule 3525.1325 (Appendix B) defines ASD and establishes the eligibility criteria to receive special educational services under the ASD disability category, and outlines requirements for an educational evaluation to determine service eligibility. Subpart 5 of MN Rule 3525.1325 states that "pupils with various educational profiles and related clinical diagnoses may meet the criteria of ASD under subpart 3. However, **a clinical or medical diagnosis is not required** [emphasis added] for a pupil to be eligible for special education services, and even with a clinical or medical diagnosis, a pupil must meet the criteria in subpart 3 to be eligible."

The 343 independent Minnesota school districts use a variety of psychometric tests and other tools that are in compliance with MN Administrative Rule 3525.1325 for evaluating

students to determine if they meet the behavioral indicators established for eligibility under the educational criteria for ASD. The tools utilized to evaluate children for eligibility in MPS ASD programs are listed in Appendix C. The checklist used by all Minnesota public schools to document a child's eligibility for ASD special education programs can be found in Appendix D.

After an educational evaluation establishes special education eligibility, a multidisciplinary team develops an Individual Education Plan (IEP) for children 3 or more years of age or an Individual Family Service Plan (IFSP) for children between birth through 2 years of age. A child with special educational needs may meet the criteria for more than one disability category, and the educational plan developed typically guides the IEP team in determining **the program option and service setting to best benefit that child**. For instance, a child meeting the criteria for ASD and developmental delay may participate in a setting designed to meet the needs of children with developmental delay (the child's primary disability category) and not to a program designed specifically for children with ASD (the child's secondary disability category). Furthermore, children with genetic, medical, or other developmental conditions (such as Fragile X, PKU, language delay, and intellectual disability) may also be placed in a program for children with ASD even though these children may or may not have an ASD based on standard medical criteria (i.e., DSM-IV) (Dr. Andy Barnes, personal communication). These placements would be made if the IEP team determined that participation in an ASD program was the best option for these children.

Additionally, parents are members of the IEP team and can influence what disability categories are assigned to their child. Published guidelines (9) instruct educators to "allow parents to reject the identification of ASD and, instead, qualify for services under DD [Developmental Delay] (ECSE) or another category." Although this practice is thought to be infrequent, it can occur (MDE, personal communication). Thus, it is important to recognize that administrative data do not necessarily reflect a medical diagnosis and may not lead to an accurate count of specific conditions or disabilities among children. These data will, however, always reflect special education program participation.

Minneapolis Public Schools Special Education Programs

MPS serves approximately 35,000 children from birth to age 21. MPS offers a range of programs and services to approximately 6,000 children who meet state eligibility criteria for special education services. For preschool age children (birth to kindergarten entrance) eligible to participate in ECSE programs, MPS offers four service models: home based, community based, center based, and autism (10). Children eligible to participate in ASD programs may participate in any of these options depending on their individual needs. The 348-TOTS and Screen at 3 programs are the initial points of contact with MPS for many of the preschool children who participate in MPS ECSE programs (MPS staff, personal communication). See Appendix E for a detailed description of the MPS ECSE Programs offered to children eligible to receive special education services.

Population Prevalence versus Administrative Prevalence

The prevalence of a disease or condition of interest measures the proportion of a specified population that has an incident (new) or prevalent (existing) case of the disease or condition at a specified point in time (point prevalence) or during a period of time (period prevalence) (11). Population prevalence is estimated by dividing the number of cases of a disease or condition of interest that exist in a specified population at a given time by the size of that population at that time. Complex probability surveys based on representative samples of populations are conducted to estimate the prevalence of many diseases and risk factors in U.S. or state populations. When no other relevant data on the occurrence of a disease or condition are available, prevalence can also be estimated using administrative program data, which are collected for purposes other than estimating prevalence. Data estimating the size of the population needed in calculating administrative prevalence can be obtained from U.S. census population data, birth cohort data, or the administrative dataset itself, depending on the aims of the study and the analysis conducted. Prevalence estimates based on administrative datasets are referred to as administrative prevalence to distinguish them from population prevalence.

Because a majority of U.S. states do not have public health surveillance systems to collect valid and reliable data on ASD or other developmental disabilities, special education administrative data have been used to track and monitor ASD prevalence and trends (12,13). Administrative ASD prevalence is calculated as the number of children in a specified population who are participating in an ASD program offered by one or more public school districts divided by the total number of children in that population. Administrative ASD prevalence reflects the percentage of children in a specified population who are participating in the ASD program(s) offered by the school district(s) under consideration.

As shown in Appendix F, **administrative prevalence will estimate population prevalence only if everyone in the population with the disease or condition of interest participates in the program from which the administrative data are obtained**. With regard to special education data, this means that administrative ASD prevalence will underestimate population prevalence unless every child with an ASD in the population of interest participates in the ASD programs offered by that school district.

Losses of ASD cases from program enrollment could result in an underestimation of administrative prevalence. Losses of children from MPS ASD programs could occur for a variety of reasons, including: a child could receive services under a different primary special education disability category (e.g., developmental delay); a child improved and was no longer eligible to receive special education services; a child could receive ASD intervention services from a private provider without any involvement from MPS (i.e., the child would not have a current IEP or IFSP from MPS); or a child's family might receive services from another school district (i.e., move to another Minnesota school district and receive services there or move to another state). Differential losses of ASD cases by population subgroups (e.g., race or ethnicity) would result in an underestimation of administrative prevalence for only those subgroups, thereby complicating the

comparison of administrative ASD prevalence estimates by subgroup. Given these considerations, caution must be exercised in interpreting differences in administrative ASD prevalence estimates.

Methods

The primary aim in this analysis was to rigorously examine the appearance of elevated ASD occurrence among Somali children attending preschool special education programs offered by MPS. MPS special education administrative data was used to estimate administrative ASD prevalence in birth cohorts of children 3 and 4 years of age in a specified school year, by race/ethnicity, and Somali versus non-Somali descent for three consecutive school years, 2005-2006, 2006-2007, and 2007-2008. Detailed MPS data from individual child records for all three years, beginning with the 2005-2006 school year, were available for analysis. Administrative prevalence, rather than population prevalence, was estimated because Minnesota does not have a centralized source for obtaining valid and reliable data on ASD occurrence. A birth cohort approach was chosen because current population data for Minneapolis children, ages 3 and 4 by race, ethnicity, and country of origin was not available. Reliable data for estimating the size of the Minneapolis Somali population was not available because much of the Somali community arrived in Minneapolis after the 2000 decennial census of the U.S. population.

In the following section, the methods used to compute administrative ASD prevalence in this analysis are described. Input from stakeholders was solicited through in-person meetings and external review of these analyses.

Data Sources and Inclusion Criteria:

MN Birth Certificates: To identify birth cohorts for this analysis, we obtained birth certificate data from the MDH Office of the State Registrar, which issues certificates of live birth to all children born in the state. As mentioned, reliable population data for children 3 and 4 years of age, residing within MPS district boundaries (which are coterminous with the City of Minneapolis) by race, ethnicity, and country of origin were not available.

Children eligible for inclusion in a birth cohort were those children with a Minnesota certificate of live birth whose mothers were residents of Minneapolis at the time of birth, and who were 3 or 4 years of age on two different index dates of a given school year. The index dates for these analyses were September 1, the cutoff date for age eligibility for attending kindergarten, and December 1, the federal government's date for the annual Child Count enumeration of all children who are receiving at least some of their special education services in public school programs funded by IDEA.

Children were considered to be of Somali descent if the birth certificate listed their mothers' location of birth as Somalia. Children were assigned the race and ethnicity status of their mother as indicated on the birth certificate, and collapsed into the categories used by MPS: Asian, black, Hispanic, Native American, and white. The black race category included the majority of Somali children (>95%), but a small number of these children were classified into non-black and "unknown" or "other" race categories.

No information was available to assess the accuracy of the mother's race on the birth certificate.

All Somali and non-Somali children who were classified as "unknown" or "other" race were not included in the race-specific analyses (see Results, "B" Tables) because there were no corresponding categories for "unknown" or "other" race in the MPS dataset. Although these exclusions had no effect on the counts of ASD cases (i.e., the numerator), they slightly decreased the size of a birth cohort (i.e., the denominator) used in estimating race-specific administrative prevalence estimates, as shown in Table 6.

Enumeration of ASD cases using MPS administrative data: To enumerate children with ASD, MPS de-identified individual child administrative records containing selected information on a child's ASD disability category, special education program enrollment, location of birth, school district residency during each school year, primary language spoken in the home, and race/ethnicity for three consecutive school years were obtained.

Children were counted as "ASD cases" for a given year if they were identified by MPS as receiving special education services under the ASD disability category, and were 3 or 4 years of age on the index dates (above) of a given school year. Because the MPS dataset did not have data on the mother's city of residence at the time of birth and we did not have personal identifying information (e.g., a child's name and date of birth) from MPS to link with birth certificate data, we used the MPS birthplace and school district residency variables to compute administrative prevalence estimates based on four different sets of birthplace and school district residency assumptions. The assumptions varied slightly in the extent to which potentially eligible children were included and excluded from the calculations (Appendix G), and were used to examine the robustness of patterns in the administrative ASD prevalence estimates between Somali versus non-Somali children. The individual analyses performed based on these assumptions are referred throughout this report as: (1) Analysis 1: born in Minneapolis and resident of Minneapolis (most restrictive); (2) Analysis 2: born in Minneapolis and no school district residency restrictions; (3) Analysis 3: born anywhere in Minnesota and resident of Minneapolis, and (4) Analysis 4: born anywhere in Minnesota and no school district residency restrictions (most inclusive).

Children receiving MPS special education services for ASD were identified based on their participation in MPS ECSE ASD programs, which were classified for these analyses as "ECSE Citywide ASD Classroom Program" or "All ASD Programs" combined. Participation in the former category represented enrollment in the ECSE Citywide Autism Classroom Program, a specific program providing individualized attention for preschool aged children with high needs. Participation in the latter category represented enrollment in any MPS ECSE program. Children in this category included those who participated in the ECSE Citywide ASD Classroom Program, as well as children who received services in any other MPS ASD program setting (i.e., home-based services, educational support in community preschools such as Head Start, or private programs if the child had an IEP from MPS) (14). Of the children participating in "All ASD Programs" combined, those participating in programs other than the ECSE Citywide

ASD Classroom Program were identified based on their ASD disability category. All children with either a primary, secondary, or tertiary ASD disability category were included to ensure that all children identified by MPS as eligible to receive special education services under the ASD disability category were enumerated. Children were considered to be of Somali descent if Somali was listed as the primary language spoken in the home. The race and ethnicity data were those from the MPS dataset. All Somali children are classified in the black race category.

Statistical Analyses:

Based on the definitions above, administrative ASD prevalence was calculated for each school year as the number of children who received services under the ASD disability category divided by the size of the birth cohort for that school year. Exact 95% binomial confidence intervals (CI) were also computed to yield a range of likely values into which the 'true' administrative ASD prevalence estimate could fall with 95% probability. Exact two-sample tests of independent proportions based on the binomial distribution (15) were used to assess whether the administrative ASD prevalence estimates were statistically different between Somali versus non-Somali children. Only descriptive analyses were carried out to compare administrative prevalence estimates stratified by race/ethnicity, and primary language spoken in the home because of small numbers in some subgroups, uncertainty over which reference group was most appropriate, and the exclusions of individuals of "unknown" and "other" race from the birth cohort populations. Statistical analyses were carried out using SAS, version 9.1 (16) and a *p*-value less than 0.05 was deemed statistically significant. Because statistical testing was conducted with the aim of data description (17), no adjustments were made for multiple comparisons.

Differences were characterized in administrative prevalence estimates in terms of administrative prevalence ratios, which quantify the difference in administrative ASD prevalence among Somali children **relative** to a comparison group (e.g., non-Somali children). Ratios greater than the null or neutral value of 1.0, indicate that administrative prevalence for Somali children was greater than the administrative prevalence for the comparison group; ratios less than 1.0 indicate that the administrative prevalence of the comparison group was greater than the administrative prevalence for Somali children; and ratios equal to 1.0, indicate there was no difference between the administrative prevalence for Somali and the comparison group (e.g., non-Somali children).

Using the data from Analysis 4, independent 2-sample t-tests (18) to assess the significance of differences in the average age at first contact with MPS between Somali and non-Somali children for the three school years were performed. A *p*-value less than 0.05 was deemed statistically significant.

Additional (External) Comparison Data:

For additional perspective, the U.S. parental reported ASD prevalence for children 3 and 4 years of age were estimated using data from the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) (19), sponsored by the U.S.

Health Resources and Services Administration (HRSA). Beginning in 2001 and conducted every 4 years, the NS-CSHCN is a component of the State and Local Area Integrated Telephone Survey (SLAITS) system administered by the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC) (20). The NS-CSHCN was designed to provide state and national data on the health and wellbeing of children ages birth to 17 years.

In the NS-CSHCN, ASD prevalence was assessed based on parental response to, "To the best of your knowledge, does [CHILD's NAME] currently have Autism or Autism Spectrum Disorder?" Because state special education eligibility criteria vary widely across the US (21), Minnesota-specific prevalence from this survey were considered a more appropriate comparison group for these analyses than a national prevalence estimate. However, the number of Minnesota survey respondents identifying a child 3 or 4 years of age with autism or ASD was too small (N=5) to provide a reliable state-specific population estimate, and the parental reported ASD prevalence for the U.S. combined was used instead.

To calculate the U.S. parental reported ASD prevalence for children with special health care needs (CSHCN) 3 and 4 years of age, the sum of the sampling weights for all U.S. children ages 3 and 4 in the NCHS screener file was used as the denominator (S. Blumberg PhD, NCHS, personal communication). These weights were designed to match the March 2006 Current Population Survey Annual Demographic Survey projections, and ensure that the sum of the weights would equal the estimated number of children nationally and in each state (20). The numerator was calculated from the NCHS interview file and represents the weighted number of CSHCN ages 3 and 4 reported as having an ASD in the survey. SUDAAN version 10.0 (22) was used to estimate the U.S. parental reported ASD prevalence in a weighted analysis to account for the complex survey design. All analyses and interpretations of the 2005-2006 NS-CSHCN data are the responsibility of MDH, and not of NCHS.

Results

Only slight differences in the results from the September 1 and December 1 index dates were found. These differences represent changes occurring during the first 3 months of a school year as new students are identified in evaluations pending from the summer or as other students transfer into MPS from other school districts. Therefore, this report will focus solely on the results for the December 1 index date. Results from the September 1 index date can be found in Appendix H.

Of the 319 child records in the original MPS dataset, 9 Somali speaking and 37 non-Somali speaking children were excluded from these analyses because they were born outside of Minnesota according to MPS records (Figure 1). Additionally, 4 Somali speaking and 69 non-Somali speaking children were excluded from the December 1 analyses because they were not 3 or 4 years of age on December 1 during the three school years. Figures 2 through 4 display flowcharts showing how children in the MPS dataset were selected for the December 1 analyses for each of the school years considered.

The demographic data summarized in Table 1 are based on the data used in Analysis 4, the most inclusive set of birthplace and school district residency assumptions. Among children included in this analysis, the majority was male, had a primary ASD disability category, and spoke English as the primary language in their homes (i.e., were classified as non-Somali). All children who did not have an ASD disability category were non-Somali (data not shown) and participated in the ECSE Citywide ASD Classroom Program. Participation in MPS programs, overall and by primary language spoken in the home, was highest during the 2007-2008 school year. In this most inclusive analysis, only a small proportion of children who were not residents of the Minneapolis school district participated in MPS ASD programs (see the row labeled 'Resident School District'), and the proportion of children born outside of Minneapolis participating in MPS ASD programs ranged from approximately 30-40% (see the row labeled 'Birthplace').

Among children participating in all ASD programs combined who were included in Analysis 4, the average age of first contact with MPS among Somali children declined initially from 3.38 years in 2005-2006 and remained fairly stable thereafter (2.76 years in 2006-2007 and 2.82 years in 2007-2008). There was little change in the average age of first contact for non-Somali children, which ranged from 2.63 to 2.74 years. In the 2005-2006 school year, the difference in the average age of first contact for Somali versus non-Somali children was statistically significantly different (3.38 versus 2.73, $p=0.03$, respectively). The average ages of first contact of Somali and non-Somali children were not statistically significantly different in subsequent school years (2006-2007: 2.76 versus 2.74, $p=0.95$, respectively; 2007-2008: 2.82 versus 2.63, $p=0.4$, respectively).

Patterns in the administrative prevalence estimates were found to be quite consistent across the four sets of birthplace and school district residency assumptions. The magnitude of the estimates may have changed with the number of children included in each set of assumptions, but the overall patterns were generally consistent. Therefore, to simplify the presentation of results, these patterns will be highlighted across the various

analysis assumptions and provide illustrations from a single analysis (Analysis 4, Table 5A) whenever possible for the reader's convenience.

The 4 sets of results tables (Tables 2-5) for the December 1 index date are ordered from the most restrictive to most inclusive set of birthplace and school district residency assumptions. For each analysis, the "A" tables display administrative ASD prevalence estimates stratified by language spoken in the home (Somali versus non-Somali) and MPS ASD program type (ECSE Citywide ASD Classroom Program or all programs combined); and the "B" tables display administrative prevalence estimates stratified by MPS ASD program type, and race/ethnicity groups, and include a breakdown of black children by primary language spoken in the home (i.e., Somali versus non-Somali).

Temporal Trends in Administrative Prevalence Estimates:

Overall administrative prevalence in the ECSE Citywide ASD Classroom Program ranged from 0.22% to 0.55%, while administrative prevalence for all children in all ASD programs ranged from 0.27% to 0.78%. Consistent with national trends, administrative ASD prevalence estimates for each MPS program type generally increased over the 3 school years ("A" tables, columns labeled "All Children"). For example, among all children participating in the ECSE Citywide ASD Classroom Program, administrative prevalence increased from 0.34% during the 2005-2006 school year, to 0.50% during 2006-2007, and to 0.55% during 2007-2008 (Table 5A). Whereas the administrative prevalence estimates for non-Somali children consistently increased over time across analysis assumptions, the temporal patterns in administrative ASD prevalence were not consistent across assumptions for Somali children. Between the 2005-2006 and 2007-2008 school years, administrative prevalence estimates for Somali children decreased somewhat in Analyses 1 and 2 and then increased in Analyses 3 and 4 (when the birthplace assumption was less restrictive). By race/ethnicity, increases were observed among black and Hispanic children attending the ECSE Citywide ASD Classroom Program, and among white, black and Hispanic children attending all ASD programs combined (see the "B" Tables). The number of children of Asian and Native American race/ethnicity participating in MPS ASD programs was too small to obtain reliable results.

Administrative Prevalence Estimates for Somali Versus Non-Somali Children ("A" Tables):

Across all analyses, administrative ASD prevalence estimates for Somali children in the ECSE Citywide ASD Classroom Program ranged from 0.93% to 1.54%, while administrative prevalence for non-Somali children in the same program ranged from 0.16% to 0.47%. Administrative ASD prevalence for Somali children in all ASD programs ranged from 0.93% to 1.54%, and administrative prevalence for non-Somali children in all ASD programs ranged from 0.21% to 0.72%. With the exception of the 2007-2008 school year for Analyses 1 and 2, administrative prevalence estimates for Somali children were statistically significantly different from those for non-Somali children for both categories of MPS ASD programs. The precision of the administrative

prevalence estimates for Somali children was lower than that for the non-Somali children, evidenced by the wide 95% confidence intervals (CI) around the estimates for Somali children. Further, the relative difference between the administrative prevalence estimates for Somalis versus non-Somalis decreased markedly between 2005-2006 and 2007-2008, as reflected in decreasing prevalence ratios. For example, in Table 5A, the Somali to non-Somali administrative prevalence ratios drop from 4.2 (=1.15/0.27) to 3.3 (=1.54/0.47) for the ECSE Citywide ASD Classroom Program and from 3.2 to 2.2 for all ASD programs combined. The declines were not monotonic in all instances (e.g., Table 5A, 2007-2008 ECSE Citywide ASD Classroom Program). The administrative prevalence ratios were highest in Analysis 1 and lowest in Analysis 4, and appeared to decrease in magnitude as the birthplace assumption became more inclusive. To illustrate, in Analysis 1 (Table 2A) the prevalence ratios for the ECSE Citywide ASD Classroom Program range from 6.6 to 3.3, whereas in Analysis 4 (Table 5A), the prevalence ratios range from 4.2 to 3.3.

Number of Somali Versus Non-Somali Children Participating in MPS Programs ("A" Tables):

In each school year, nearly all of the Somali children participated in the ECSE Citywide ASD Classroom Program. Between 63 and 84% of non-Somali children participated in the Citywide ASD Classroom Program. To illustrate, in Analysis 4 (Table 5A), 15 of 15 (100%) of Somali children participated in the Citywide ASD Classroom Program, but 56 of 86 (65%) of non-Somali children participated in this program during the 2007-2008 school year. Each analysis also shows that, between 2005-2006 and 2007-2008, the percent increase in the number of non-Somali children participating in ASD programs was greater than the corresponding percent increase in the number of Somali children. For example, from the 2005-2006 to 2007-2008 school years, the percent increases among non-Somali and Somali children in the ECSE Citywide ASD Classroom Program were 70% (=(56-33)/33*100%) and 36% (=(15-11)/11*100%), respectively, and 100% (=(86-43)/43*100%) and 36% (=(15-11)/11*100%), among non-Somali and Somali children in all ASD programs combined, respectively (Table 5A).

In comparing the number of children included in Analysis 1 with 2 and Analysis 3 with 4, the "A" Tables also show that relaxing the MPS school district residency requirement did not change the number of Somali children in the analyses and only slightly increased the number of non-Somali children. In comparing the number of children included in Analysis 1 with 3 and Analysis 2 with 4, these tables show that changing the birthplace assumption from Minneapolis to Minnesota resulted in larger increases in the number of non-Somali children included in the analyses compared with Somali children.

Race/Ethnicity ("B" Tables):

Across all assumptions, school years, and ASD program types, administrative ASD prevalence was highest among black children overall (this category includes Somali children) and lowest among Asian and Native American children. Administrative prevalence for white and Hispanic children fell between these two extremes. In addition,

administrative ASD prevalence estimates for black Somali children were consistently higher than the estimates for all other children including black non-Somali children. Finally, the administrative ASD prevalence estimates for black non-Somali children tended to be greater than estimates for white and Hispanic children, but the differences between the estimates for these 3 groups seemed more pronounced for children in the ECSE Citywide ASD Classroom Program, especially in the 2007-2008 school year. (Note: The population totals in the "B" Tables do not add up to the same population totals in the "A" Tables, as indicated in the methods.)

Comparison with U.S. Parental Reported ASD Prevalence for Children Ages 3 and 4 Years:

Based on 2005-2006 NS-CSHCN data, U.S. parental reported ASD prevalence for 3 and 4 year old children was estimated to be 69,077 ASD cases out of 8,977,301 children screened for the survey, or 0.77% (95% CI: 0.60%-0.94%). Of those who reported a child with autism or an ASD, 84% of parents reported that their child had an IEP (observed N=142, weighted N=55,625 children).

Across all analysis assumptions and ASD program types, the 2005-2006 administrative ASD prevalence estimates for Somali children (range: 0.93-1.54%) were consistently higher than the 2005-2006 U.S. NS-CSHCN parental reported ASD prevalence. All of the 95% confidence intervals for the Somali administrative prevalence estimates were wide and most contained the value of the U.S. parental reported ASD prevalence estimate (0.77%) (see the few exceptions in Analyses 3 and 4 for 2007-2008). By contrast, across all analysis assumptions and ASD program types, the administrative prevalence estimates for non-Somali children and for all children combined (see "Total" columns) were consistently lower than U.S. parental reported ASD prevalence, and nearly all of the 95% confidence intervals for these estimates excluded the value of 0.77%.

Discussion

As part of the MDH response to concerns of elevated ASD occurrence among Somali children in Minneapolis, a reanalysis of MPS administrative special education data was conducted to estimate the administrative prevalence of ASD among children, ages 3 and 4, who were attending MPS ECSE programs. Other estimates had been widely reported, but these statistics represented ASD program participation rates computed for administrative purposes. Epidemiological definitions and methods to estimate administrative ASD prevalence within birth cohorts were used in an attempt to accurately estimate the size of the population of preschool children of Minneapolis, and included counts of children with primary, secondary, and tertiary ASD disability categories to obtain a more complete enumeration of the children participating in the MPS ASD programs. In addition, it was recognized that discrepancies existed in key variables between the MPS and birth certificate datasets, and administrative prevalence estimates for a series of birthplace and school district residency assumptions were computed to provide insight into patterns that might be missed in analyses based on a single administrative ASD prevalence estimate.

The administrative ASD prevalence estimates from this study – that is, the proportion of children receiving services in MPS ASD programs who were members of defined birth cohorts of children – were significantly higher for Somali children compared to non-Somali children across all analysis assumptions, school years, and ASD program types. These results are consistent with earlier community reports of higher ECSE ASD program participation rates among Somali preschool children. Depending on the specific analysis assumptions and the ASD program type, the relative differences between the estimates as measured by administrative prevalence ratios, ranged from approximately 2 to 7 times higher for Somali children ages 3 and 4 years relative to non-Somali children. However, the prevalence ratios decreased markedly over the 3-year period, suggesting that the difference in administrative prevalence between Somali children relative to non-Somali children was decreasing with time. Such rapid declines over a short period of time might suggest that these results are driven, at least in part, by noncausal changes in program participation over the three school years.

Differences in prevalence among population subgroups have been explained by differences in age at first diagnosis. Parner, et al., found that temporal trends toward higher prevalence among children diagnosed before 9 years of age were associated with increasingly earlier ages at first diagnosis (23). Others have noted differences in ASD prevalence or service utilization by age at diagnosis (24) or age at first visit (25) among different racial and ethnic groups. Only age at first contact with MPS was available for this analysis. Age at first contact represents the age of a child on the date when a record for that child was first entered into the MPS student accounting database. Based on the data used in Analysis 4 for all children, the average age of contact for Somali speaking children was slightly older than that for non-Somali speaking children in 2005-2006, but not in the two subsequent school years. The difference in average ages between the two groups was slight and may not explain the differences observed in the administrative ASD prevalence estimates for Somali and non-Somali children from this study. Although

the date of first contact should be close to the referral date, it does not necessarily represent the date of first screen or evaluation at MPS, nor does it take into account any screening or evaluations that might have occurred outside of MPS. Nonetheless, these results seem to suggest that the Somali children were entering into the school system at younger ages over time, which could indicate increased parental and/or provider awareness of the need for developmental screening and evaluation of children in the Somali community.

Previous studies of elevated ASD prevalence rates among immigrants have been reviewed by Fombonne (5), who noted several limitations with these analyses, including: imprecise prevalence estimates with wide 95% confidence intervals and a lack of statistically significant differences between the groups compared; estimating prevalence in dynamic populations with rapid changes in immigration and emigration; differential referral patterns resulting in potential selection bias; small numbers of cases; a lack of an appropriate comparison group; potential bias because of differences in age distributions (i.e., confounding by age). Recently, two additional studies reported on elevations in ASD prevalence among immigrants from Somalia and Ethiopia. These more recent studies have similar potential limitations.

Barnevik-Olsson, et al (6) investigated the prevalence of autism among Swedish-born children of Somali descent. Data from records of children, ages 7 to 17 years, who were attending two habilitation centers were analyzed to estimate the prevalence of two ASD subtypes, autistic disorder or PDD-NOS. The children receiving intervention and follow-up at these centers were diagnosed based on the DSM-IV, and all were reported to have learning disabilities (i.e., mental retardation, Dr. Andy Barnes, personal communication). The reported prevalence for these two ASD subtypes was 0.7% (95% CI: 0.37-1.03%) for Somali children and 0.19% (95% CI: 0.18-0.21%) for non-Somali children, yielding an overall prevalence of 0.198% (=501/253,000) or approximately 1 in 500. The prevalence estimates overall and for non-Somali children were notably lower than the previously published 1989-1994 population prevalence estimate (26) for the 2 ASD subtypes, 0.734% (= 0.353% (autistic disorder) + 0.384% (PDD-NOS)). By contrast, the prevalence estimate for Somali children appeared comparable with the published population estimate. The difference between the results of this study and the previous population estimate suggests that systematic differences in how cases were selected for the study (i.e., selection bias) may explain the differences in prevalence observed between Somali and non-Somali children in this study. For example, because mental retardation does not occur concurrently with all ASD, the children attending these habilitation centers may not reflect the type of cases seen in the general Swedish population. Finally, only the records for the 17 Somali children were validated. The authors indicated that the remaining 484 records for the non-Somali children still needed review and cautioned readers that their findings “must be seen as preliminary.” Thus, although this timely study provides perspective, the question of whether the prevalence of ASD differs between Somali and non-Somali children from Sweden needs further study.

Using administrative claims data, Kamer, et al. (7), estimated the prevalence of ASD for Israeli children, born between 1983 and 1997, who fell into one of four groups: born in

Ethiopia and immigrated to Israel; born elsewhere abroad and immigrated to Israel; born in Israel to parents of Ethiopian descent; born in Israel to parents of other (non-Ethiopian) descent. The resulting administrative prevalence estimates fell in a gradient from lowest for children born in Ethiopia who immigrated to Israel (0.0 per 10,000), to intermediate for children born abroad who were born to parents of non-Ethiopian descent (5.3 per 10,000) and for children born in Israel to parents of Ethiopian descent (8.3 per 10,000), to highest for children of non-Ethiopian descent who were born in Israel (9.0 per 10,000). However, these ASD diagnoses spanned a 14-year period during which time the classification of ASD changed and expanded, and there is no indication that the diagnoses are comparable between the groups. Additionally, the two immigrant groups of children likely represent non-representative samples from their original birth cohort populations who along with their families undoubtedly passed through numerous bureaucratic and other steps to ultimately reside in Israel. Finally, some of the statistical results from this analysis are in error; contrary to published results, there was no statistically significant difference between the prevalence estimates for children of Ethiopian descent born in Israel and children of other (non-Ethiopian) descent also born in Israel, Mantel-Haenszel chi-square = 0.08, p=0.8; Yates corrected chi-square = 0.02, p=0.9 (27).

The limitations evident in these previous investigations point to the need for a better understanding of the true ASD prevalence in populations. The analyses summarized herein also have a number of limitations that must be considered. These fall into the following categories: (1) lack of information about baseline ASD rates in the population; (2) errors in estimating the number of ASD cases (numerator data); (3) errors in estimating the size of the birth cohorts (denominator data); (4) other sources of systematic error in the data with the potential to bias study results. Additional limitations relate to specific goals of this analysis and ability to generalize these findings. In the remainder of this report, these limitations are considered and next steps are presented.

1. Lack of Information about Baseline ASD Rates in the Population

The differences in administrative ASD prevalence estimates from these analyses overall and across population subgroups were striking, but without baseline ASD prevalence rates for the population of Minnesota children ages 3 and 4 years during the school years considered, interpreting these differences is challenging. Although 1 in 150 children or 0.67% is often cited in the popular press, as well as in scientific and medical literature, as the expected ASD prevalence for children, this statistic actually represents the average ASD prevalence during 2002 for children 8 years of age who reside in the combined geographic regions within the U.S. states that participate in the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. Because of the differences in age groups and time periods, the CDC's estimate is not an appropriate comparison statistic for interpreting the results of this study. Further, the states participating in the ADDM Network were chosen based on their capacity to implement the CDC surveillance protocol, and not whether the group of participating states would be representative of the nation as a whole (28).

To add additional perspective, results were compared with the U.S. parental reported ASD prevalence for children ages 3 and 4, computed from 2005-2006 NS-CSHCN data. Across all assumptions and ASD program types, administrative ASD prevalence estimates for Somali children were uniformly higher than the U.S. parental reported ASD prevalence, but most of the 95% confidence intervals corresponding to the administrative prevalence estimates for Somali children contained the value of the U.S. parental reported ASD prevalence estimate – suggesting that the 2005-2006 administrative ASD prevalence for Somali children might be **no different from what would be expected** in the U.S. population of children ages 3 and 4 based on parental report. By contrast, all of the 2005-2006 administrative ASD prevalence estimates for non-Somali children were consistently lower than the U.S. parental reported ASD prevalence estimate, and nearly all 95% confidence intervals did not contain the value of parental reported ASD prevalence estimate. These findings suggest that 2005-2006 administrative ASD prevalence for non-Somali children was actually **lower than expected** in the U.S. population of children ages 3 and 4 based on parental report. Therefore, the observed elevations in the Somali to non-Somali prevalence ratios could be explained by substantially lower than expected administrative ASD prevalence among non-Somali children, rather than by higher than expected administrative prevalence among Somali children.

These findings illustrate the inferential errors that might be made when making assumptions about baseline ASD prevalence rates. The uncertainty and difficulties in interpreting the results of this analysis underscore the importance of having valid and reliable population baseline ASD rates. A caveat to these findings is that the case definitions and methods used to collect data differed between the NS-CSHCN and MPS dataset. Thus, our results should be confirmed with valid and reliable population-based ASD prevalence statistics for children ages 3 and 4.

2. Errors in Estimating the Number of ASD Cases (Numerator Data)

2a. Medical diagnosis, educational evaluations, and public health surveillance: As previously mentioned, differences exist between a medical diagnosis of an ASD and an educational evaluation of eligibility for special education services under the ASD disability category (29). Indeed, it is the impression of many clinicians that around 25-30% of children with an educational disability seen for a medical diagnosis of ASD do not receive that diagnosis after an in depth medical evaluation (Dr. Michael Reiff, personal communication). One question relevant to accurately estimating ASD prevalence that might be asked is: Which of the two processes yield the correct count of ASD cases? The answer to this question depends on the purpose of and criteria needed to: (a) make a medical ASD diagnosis, (b) establish special education eligibility under the ASD disability category, and (c) accurately estimate ASD prevalence and trends in the population were reviewed.

> (i) The purpose of a medical diagnosis of ASD is to identify and treat the specific core disorder that an individual may have (Amy Esler Ph.D., personal communication). This determination is made on the basis of both clinical testing

and behavioral observation (3). The medical and genetic tests performed can help rule out other primary health problems or identify important concurrent medical conditions that might also need treatment or therapy. Identifying the particular ASD subtype is also part of the diagnostic process. To this end, behavioral observation is performed to identify the number and specific types of impairments an individual may have. These impairments fall into the three behavioral impairment domains mentioned in the background section of this report: social functioning; communication; or restricted, repetitive, and stereotyped behaviors. Appendix I displays the criteria used to classify the ASD subtypes. Of the subtypes (see Appendix I), autistic disorder has the largest required number of impairments overall that must be distributed among all three of the behavioral impairment domains, while PDD-NOS has the smallest required number of overall impairments, one of which must fall into the social impairment behavioral domain. Thus, a medical diagnosis involves evaluating a child's health status, and identifies specific ASD subtypes and other medical conditions that may need treatment.

(ii) As mentioned before, the purpose of evaluating a child for developmental delay in a special education setting is to determine whether the child is eligible to receive free, appropriate special education services in the public school system, not to arrive at medical diagnoses of conditions. Established in MN Rule (see Appendix B), the criteria for determining eligibility to receive special education services under the ASD disability category are equivalent to those used in a clinical setting to identify the PDD-NOS subtype mentioned above. To receive free special education services under the ASD disability category in the Minnesota public school system, a child needs to have the smallest required number of impairments in the behavioral impairment domain found in the medical ASD subtype classification system mentioned above. A medical diagnosis of ASD is not required in the Minnesota special education eligibility criteria. The determination of whether a child who meets the Minnesota ASD eligibility criteria is classified as such also depends whether the IEP team considers participation in this program the best option for that child. Eligibility for the receipt of services under a different disability category may be preferred if the alternative program offers special education services deemed to better meet the individual needs of a child. Clinicians support schools in making these broader designations of ASD because special education services are often appropriate for many children who do not receive the medical diagnosis (Robin Rumsey Ph.D., personal communication). Because educational assessments are based on a broader ASD classification, differences between subgroups should not be interpreted to imply an underlying etiology. A more uniform ASD case definition, such as that obtained using a medical case definition, is needed in studies investigating the causes of ASD.

(iii) Finally, one primary purpose of public health surveillance is to accurately estimate and track population ASD prevalence. Because children with ASD receive intervention services from the public school system and many are not

medically diagnosed, the most complete counts of ASD cases for the purpose of estimating population prevalence are derived from both medical and special education data sources. To ensure that any changes observed in population ASD prevalence accurately reflect real changes in ASD occurrence in a population, the ASD surveillance case definition implemented is uniform, well-defined, and often adapted from the DSM-IV-TR criteria. The criteria establishing eligibility for receiving special education services under the ASD disability category are not specific enough to yield accurate ASD case counts for public health surveillance. The example mentioned in the background section describing policies that allow parents to reject the ASD disability category and have their children qualify under another category illustrates this point. Without other information, these children would not be identified and enumerated for ASD case counts in public health surveillance. If parents in one racial or ethnic group or other identifiable group systematically reject the ASD disability category, the population ASD prevalence for children of this group would be underestimated. Thus, assigning the DD category instead of the ASD category to a child who truly has ASD would be considered an error of classification for the purposes of public health surveillance. Part of the challenge in assessing ASD prevalence and trends in Minnesota is that the state does not have a standard surveillance case definition, and differences of opinion will arise over what is considered a 'true' ASD case in tracking prevalence and trends.

2b. Misclassification: Even when a case definition is clear and unambiguous, misclassification errors are always a possibility in epidemiologic studies because measuring tools and instruments are never perfect. Misclassification can occur whenever the sensitivity and specificity of an instrument is less than 100%. A quick review of the psychometric properties of ASD screening and evaluation instruments widely used across all settings in Minnesota (30) will show that these tools may lead to misclassification errors.

Differential misclassification occurs when misclassification errors systematically occur more often in one group compared with another and can lead to statistically biased results and invalid conclusions (11). Previous research shows that differential misclassification can occur in a medical setting when clinicians are not familiar with the culture or routine behaviors that are considered normal or widely accepted in minority racial and ethnic groups (31,32,33). Although efforts are underway in Minnesota to standardize the Ages and Stages Questionnaire (34) – Social Emotional Component to the Somali population (Katie Tastad, Interagency Developmental Screening Task Force, personal communication), the majority of instruments used in Minnesota have not been translated into the Somali language, and they were not normed for the Somali population. Therefore, the use of these tools may result in the systematic misclassification of Somali children into ASD disability categories.

Physicians and other clinicians interviewed for this study expressed substantial concerns over a lack of knowledge about cultural norms for typical developmental landmarks or norms for "eye contact, use of gestures, use of facial expressions, parents expectations

about toddlers and preschoolers sharing their joy with their parents, play patterns, whether imaginary play is encouraged or discouraged" (Dr. Michael Reiff, personal communication). They also expressed concerns about the cultural sensitivity of screening instruments and diagnostic criteria (DSM-IV-TR) (Drs. Anne Edwards, Michael Reiff, personal communication), and indicated that "interviews of Somali speaking families are wrought with difficulty going through a translator" (Dr. Michael Reiff, personal communication).

MPS staff interviewed for this study indicated that in evaluating children for eligibility to receive special education services under the ASD disability category, they focus on universal behaviors that all children should display during development. Their staff is experienced, which should minimize errors of misclassification. Nonetheless, because of the limitations in screening instruments and the barriers faced in communicating through interpreters, the possibility of systematic misclassification of Somali children cannot be ruled out. To better understand the impact of potential systematic misclassification in these results, evaluations of the validity and reliability of screening and evaluation instruments used in the Somali population should be undertaken in future work.

2c. Inaccurate counts of Somali versus non-Somali ASD cases: Identifying children's country of descent based on the primary language spoken in the home would have misclassified children who are of Somali descent as non-Somali if English was the primary language spoken in the child's home. More Somali families are reported to speak English as the primary language in their homes (Huda Farah, personal communication), but the extent to which this is occurring is unknown. If widespread, the effect of this error would have simultaneously underestimated administrative ASD prevalence among Somali children and overestimated administrative ASD prevalence among non-Somali speaking children, accentuating the decreasing trends in Somali to non-Somali administrative ASD prevalence ratios observed in this study. Without better data on a child's background or cultural heritage, it is difficult to know exactly the magnitude and direction of this error on administrative ASD prevalence estimates.

2d. Assumptions used to estimate administrative prevalence: As described in the methods section, the case inclusion criteria used to define and count ASD cases (numerators) did not match exactly with the criteria used to define and enumerate individual birth cohorts (denominators). The numerator and denominator inclusion criteria differed because the MPS dataset did not have data on the mother's birthplace, which was a key variable used for enumerating birth cohorts. Because data needed to link records between the 2 datasets were unavailable, a set of assumptions were developed and used to estimate a series of administrative ASD prevalence estimates for a child's birthplace and school district residency. This approach had the potential to both erroneously include some and exclude other ASD cases (Appendix G). For example, Analysis 1 restricted the set of ASD cases enumerated to those children who were born in Minneapolis and were MPS school district residents during a given school year. This analysis attempted to correctly exclude any Somali and non-Somali speaking children who were attending ECSE programs because of open enrollment, but who were not members of a birth cohort for a given school year. This analysis also had the potential to erroneously exclude both Somali and

non-Somali speaking children who were born in suburban (non-Minneapolis) birthing hospitals but whose mothers were actually residents of Minneapolis at the time of their child's birth. To account for these erroneous exclusions, Analysis 4 includes in the ASD count any child who was born in non-Minneapolis birthing hospitals, but this analysis now potentially (erroneously) includes any child whose mother was not a Minneapolis resident at the time of birth.

Only small changes in the number of ASD cases enumerated occurred when the MPS school district residency assumption was relaxed, indicating this assumption had an equally minimal impact on administrative prevalence estimates for both Somali and non-Somali children. Further, any influx of students into MPS from open enrollment probably would not differentially inflate ASD prevalence estimates in this analysis. On the other hand, relaxing the birthplace assumption (from birth in Minneapolis to Minnesota) resulted in small changes in the administrative prevalence estimates for Somali children and relatively larger changes for non-Somali children. These findings suggest that inability to accurately identify membership in a birth cohort may have a differential impact on administrative ASD prevalence estimated in these analyses. Based on MPS data, the majority of the non-Somali children born outside of Minneapolis were born in suburban hospitals and were residents of MPS, but no other information is available to indicate whether these children were truly members of the birth cohorts.

Despite the limitations related to inadequate information regarding birth cohort membership, information was learned about the consistency of the patterns in administrative prevalence estimates overall and stratified by race/ethnicity, primary language spoken in the home, ASD program type, and school year. Importantly, these analyses also identified the type of data that would be required to more accurately estimate the number of ASD cases in the population, as well as obtain more accurate estimates of ASD population prevalence in Minnesota.

3. Errors in Estimating the Size of the Population (Denominator)

To compute period or point ASD prevalence using MPS ECSE administrative data, accurate estimates of the size of the Somali and non-Somali populations for children between the ages of 3 and 4 who were residents of Minneapolis during the 3 consecutive school years were needed. During intercensal years, accurate city-level population data for specific age groups overall and stratified by race/ethnicity or country of origin are difficult to obtain. Rapid growth of the Somali population during the years since the 2000 U.S. decennial population census and the lack of recent data for secondary migration into Minnesota made it especially difficult to obtain population data for Somali children.

According to the MDH Office of Refugee Health, the first Somali refugees arrived in Minnesota in 1993 and more than 16,000 Somali refugees had arrived in the state by 2007 (35) Additional arrivals to Minnesota came through secondary migration in which Somali refugees moved from the state of first arrival in the U.S. A 2000 report by the Wilder Foundation (36) indicated that approximately 60% of Minnesota Somalis responding to the survey had lived elsewhere in the U.S. before moving to Minnesota, but

no recent data on secondary migration data were available. Census population estimates have increased steadily since the 2000 U.S. decennial census, from 11,164 in 2000 (37), to 25,000 in 2004 based on school enrollment data and demographic analyses taking into account the age distribution using an age-based multiplier (37), to 32,283 from the 2007 American Community Survey of the U.S. Census Bureau (38). Community estimates have been reported to be even higher, ranging from 60,000-80,000 (39,40).

Small errors in estimating the size of the birth cohort could have occurred if either a mother's city of residence or her location of birth were incorrect on the birth certificate. To our knowledge, no studies characterizing the validity of either of these two variables on Minnesota birth certificates have been performed to date. Staff from the MDH Office of the State Registrar indicated that an error in a mother's birthplace location is more likely among undocumented workers or others who are in the U.S. illegally compared with those who are legal residents or citizens of the U.S. (Joanne Wesley**,** personal communication). With no information available on immigration status available on the birth certificate, the errors in this variable were assumed to be minor.

Small errors in the classification of birth cohort populations by race/ethnicity likely occurred as well. Table 6 displays potential errors resulting from classifying members of birth cohorts who were of Somali descent into race/ethnicity categories for each of the 3 school years. The table shows that 3 children of Somali descent in the birth cohort for the school year 2005-2006 were assigned to the Asian race/ethnicity category and one was assigned to the Asian category for 2006-2007. In analyses stratified by race/ethnicity and Somali descent, these children would have been included in the birth cohorts (denominators) for the race/ethnicity categories to which they were assigned. Other children of Somali descent were classified into the "unknown" or "other" categories for race/ethnicity, including 9 children for the 2005-2006 school year, 2 for 2006-2007, and 9 for 2007-2008. Children identified as Somali and non-Somali in the birth cohorts who were classified as having "unknown" or "other" race were excluded from the analyses because there were no corresponding "unknown" or "other" race categories in the MPS dataset (i.e., numerator data). Assuming that all children of Somali descent should have been classified in the "black" category for race/ethnicity, the effect of these exclusions would be to slightly decrease the size of the denominator, thereby slightly inflating the race/ethnicity-specific administrative prevalence estimates (i.e., the estimates for black Somali children). These exclusions would have no effect on the overall estimates for Somali children.

The potential for misclassification of race/ethnicity for non-Somali children was not examined so no information is available on how errors in race/ethnicity classifications would have impacted race/ethnicity-specific estimates for these children.

4. Other Sources of Systematic Error in the Data with the Potential to Bias Study Results

Bias in epidemiological studies is defined as a systematic error in the design, conduct, or analysis of a study that results in an estimate that is different than the 'true' population

value (11). The remaining section describes how selection bias may have biased the study results.

4a. Participation in screening and evaluation programs: Because the majority of Minneapolis children who are between the ages of 3 and 4 years do not routinely attend MPS preschool programs, children in this age group who attend MPS ECSE programs represent a subset of children selected from this Minneapolis population of children. Selection begins at the point of entry into MPS, which for most children who attend MPS ECSE programs occurs with developmental screening and evaluation in either the 348-TOTS Program (i.e., the IDEA, Part C-mandated Child Find system) or the MPS Screen at 3 preschool screening program. Systematic differences in how Minneapolis children come to the attention of these preschool developmental screening and evaluation programs may account for some of the differences in the administrative ASD prevalence estimates for Somali and non-Somali children in this study. To assess the plausibility of this hypothesis, a review of how the Child Find system in Minneapolis operates was performed and data from routine program reports from the two preschool screening programs were examined.

Appendix J summarizes the Child Find system outreach efforts developed and implemented in Minnesota since the late 1980s. Of note, beginning in 2002, MDH, in collaboration with the Minnesota Departments of Education and Human Services as well as others, had materials used in Child Find outreach efforts translated into Somali and developed training sessions on developmental screening for Somali and other professionals involved in screening large numbers of Somali refugee children. In addition, outreach materials were made available in Somali on DVD and programs for Somali language cable TV programs were developed, in recognition of the strong oral traditions of this community. These approaches are noteworthy because they represented the most intensive efforts carried out in preparation for any refugee population that had settled in Minnesota. Although other refugee populations from around the world have made Minnesota their home, Child Find efforts evolved subsequent to the arrival of some populations (e.g. Vietnamese refugees) and the arrival of other immigrant populations predated the establishment of early intervention screening programs in Minnesota for children birth to 5 years. In addition, the size of other populations who arrived later was small, so large scale outreach efforts into these communities were not carried out.

Therefore, these targeted outreach efforts may have resulted in proportionally more Somali children being screened and evaluated for developmental delay compared with children of other Minneapolis population subgroups. Although developmental screening may not have been widely accepted in the community initially, it is possible that Somali community sentiments may have changed, becoming more favorable over time.

Unfortunately, no program evaluation or other historical data from these intensive Child Find outreach efforts are available to test this hypothesis. As an alternative, anecdotal or qualitative information were gathered through informal interviews with MPS staff who implement Child Find outreach efforts for early intervention (birth through 2) in the diverse populations of Minneapolis to assess whether there were currently and/or

historically any perceived differences in developmental screening program participation by race, ethnicity, or country of descent (i.e., primary language spoken in the home). MPS staff generally agreed that participation in the early intervention screening and referral programs were widely accepted across all racial and ethnic subgroups in the population, as well as across different socioeconomic strata. However, they had mixed views about the participation of children of undocumented workers, who are largely of Hispanic ethnicity in Minneapolis, with some staff indicating that participation in developmental screening programs would be influenced by legal immigration status. This anecdotal information seemed to suggest that there were no major differences in MPS developmental screening and evaluation program participation among children ages birth through 2 years by race, ethnicity, and primary language spoken in the home.

Other information gathered during interviews confirmed that those screened in the 348-TOTS program and participating in MPS ECSE ASD programs not only represent a sample of the population of children in Minneapolis, but also a sample of those children who are eligible to receive ECSE services from MPS. Interviews with staff from Hennepin County and MPS identified as many as 5 different conditions that had to be met for a child to be included in a count of ASD program participants (Appendix K). If not met, each of these conditions will reduce the number of children participating in MPS ECSE Programs for ASD in at least some, if not all of any given school year. For instance, social impairments in ASD can be subtle, and some signs may not be readily identified as problems by parents (3) (Condition 1). MPS staff reported that children between the ages of birth through 2 who are screened in the 348-TOTS program tend to be those with obvious developmental delay and to those with obvious physical limitations or birth defects who were referred by their primary care providers (Condition 2) (348-TOTS staff, personal communication). Selection occurs after screening because not all children meet program eligibility criteria. For example, the 2007 annual report summarizing 348-TOTS program child find activities (41) indicated that only 54% of children evaluated for developmental delay were eligible for MPS early intervention services during the 2006-2007 school year (Condition 4). In addition, the report indicates that of the 46% of children who were not enrolled in early intervention, some children were excluded from program participation for reasons other than not meeting program eligibility criteria: 8% of children could not be located or missed appointments for evaluation; 6% of families refused services; and 3% either moved out of the MPS school district or were otherwise lost to follow-up (Conditions 2 and 3). The selection process can continue with families choosing to send their children to private and other providers instead of MPS (Condition 5).

Only limited summary information regarding preschool screening for the Screen at 3 Program was available for consideration. A report on MPS early childhood screening for 2007-2008 school year (42) indicated that the majority of children screened in that year were 4 years old (N=1,277, 44% of the total screened), and that the proportions of Native American, Hispanic, and Asian children ages 3 and 4 were underrepresented in the program. Information on referrals and refusal of services was not available by race/ethnicity or language spoken in the home. A separate section in the report also

indicated that 268 children entered kindergarten screening through Head Start, which was identified as an additional mechanism for preschool screening.

The results of these initial inquiries indicate the need for a better understanding of how children participating in MPS ECSE ASD programs came to the attention of the school system through developmental screening and evaluation, before examining how differential participation in these screening programs by Minneapolis population subgroups impacts administrative prevalence estimates from this study.

4b. Non-random losses from MPS ECSE programs (loss to follow-up): As mentioned in the Background section, administrative prevalence will be underestimated if there are any children who truly have ASD who do not participate in MPS ASD programs. Non-random or differential losses can bias comparisons of administrative prevalence estimates. Non-random (or differential losses) from MPS ECSE ASD program participation occur when systematically greater proportions of children with ASD from one population subgroup do not attend or continue to attend MPS ASD programs compared with one or more groups of children in the same population. For example, it has been reported that members of the Somali community perceive ASD as a stigma, and that some Somali parents refuse to accept the ASD disability category for their children who, in fact, meet the state educational criteria for ASD eligibility (Huda Farah, personal communication). Systematic losses would also occur if Somali families prefer to seek treatment for their children through the use of traditional healers (Huda Farah, personal communication), and these children do not receive any service from MPS or have a current IEP or IFSP. This practice has been observed in other cultures as well (28) and may account for under-identification of ASD among other minority children (e.g., Asian, Native American) who are residents of Minneapolis. Additional research is needed to confirm the use of traditional healers as alternatives to the special education services offered by MPS.

Similarly, compared with Somali speaking families, proportionally more families who speak English (i.e., non-Somali) as the primary language in their homes may have greater knowledge of or access to alternative ASD early intervention services offered by private providers. If proportionally more non-Somali children receive services from these alternative programs, and these children have neither a current IEP with MPS, nor receive any ASD services from MPS ECSE, they would be differentially excluded from the MPS administrative dataset. Hence, administrative prevalence estimates for non-Somali children would be erroneously underestimated or biased downward from the ‘true’ value. Special education administrators have confirmed that not all children in the school district with ASD or developmental delay attend MPS programs but no data were available at the time of this report to quantify the number of children lost to other programs.

Finally, differential losses from the cohort also have the potential to bias administrative ASD prevalence estimates. This would occur if one population subgroup (e.g., white, Asian, Native American) was more likely to move elsewhere, and neither have a current IEP nor attend MPS.

Beyond Administrative Prevalence Estimation: Scope of these Analyses, and the Ability to Compare and Generalize Findings

This reanalysis of MPS data was a necessary first analytic step in investigating the initial reports of elevated ASD occurrence in Somali preschool aged children attending MPS ECSE Programs. As such, the scope of this analysis was limited to estimating administrative ASD prevalence among children ages 3 and 4 who were members of defined birth cohorts using MPS administrative special education data for three consecutive school years. Attempts to identify risk factors or ASD causes to explain the administrative prevalence patterns observed in this study were deemed beyond the scope of this initial effort. In addition, this analysis did not attempt to obtain nor analyze data from other areas in the U.S., including Minnesota, with large populations of residents of Somali descent. Obtaining data from non-MPS school districts would have required more time and resources than were available for this study.

Given the limited scope of this study and the study limitations discussed above, caution is urged in attempts to generalize the findings of this study to the overall Somali population or to other racial and ethnic subgroups in Minnesota or the U.S. population. Because administrative ASD prevalence was estimated within birth cohorts, the estimates from this study may not be comparable with other period or point prevalence estimates or estimates based on different ASD case definitions.

Future efforts to better characterize the prevalence of ASD in Minnesota should adopt rigorous public health ASD surveillance methodology. Rutter (43) asserts that to obtain valid estimates of ASD occurrence five criteria must be met. These criteria include the requirement that the size of the population observed is large enough to yield precise estimates (i.e., narrow confidence intervals). The defined birth cohort populations for these analyses were likely too small overall and stratified by race/ethnicity and country of descent to meet this criterion. Another criterion requires a systematic standardized screening on the total population, which was clearly not performed in the population of children ages 3 and 4 in Minneapolis. Other criteria stress the need for valid, reliable assessments for the age group under consideration, and a diagnosis made using standardized research evaluation instruments performed by trained professionals. Although MPS ECSE Programs are exemplary and the dedicated staff highly skilled and experienced, administrative data from special education program participation do not meet enough of these criteria to adequately answer the pressing and fundamental questions regarding the differences observed between the administrative ASD prevalence estimates for Somali and non-Somali children attending MPS ECSE ASD programs.

Conclusion

Using MPS special education administrative data, administrative ASD prevalence within birth cohorts was estimated for three school years by race, ethnicity, and primary language spoken in the home serving as a proxy for country of descent. This study found that administrative ASD prevalence estimates – that is, the proportion of children receiving services in MPS ASD programs who were members of defined birth cohorts of children – were significantly higher for Somali children compared to non-Somali children. These results are consistent with community reports of higher ECSE ASD program participation rates among Somali preschool children. Depending on the analysis assumptions and the ASD program type, the relative differences between the estimates as measured by administrative prevalence ratios, ranged from approximately 2 to 7 times higher for Somali children ages 3 to 4 years relative to non-Somali children. Such rapid declines over a short period of time might suggest that these results are driven, at least in part, by noncausal changes in program participation over the three school years.

The number of ASD cases will be underestimated if any children who truly have ASD do not attend MPS ECSE ASD programs. Several other sources of possible error were also identified with the potential to impact the accuracy of the number of ASD cases identified overall and stratified by race/ethnicity and primary language spoken in the home, and to a lesser extent, the size of birth cohorts used in these analyses. Other concerns were raised regarding the potential for systematic errors in study results due to the misclassification of cases into special education disability categories; differential loss to follow-up; the lack of cultural sensitivity of screening and evaluation instruments and complications stemming from reliance on interpreters. If differential loss to follow-up of non-Somali children (e.g., Asian and Native American children more likely to either leave the MPS ECSE program or else never participate in at all) resulted in underestimating the prevalence of ASDs for this group, comparisons of Somali and non-Somali administrative ASD prevalence estimates would also be biased.

Results of this analysis seemed to suggest that whereas administrative ASD prevalence for Somali children was no different from what would be expected based on parental report in the U.S., administrative ASD prevalence for non-Somali children was lower than expected based on parental report. But population data are lacking and these results need to be confirmed with comparable population ASD prevalence statistics that are valid and reliable. Consequently, a number of important questions regarding the occurrence of ASD among children attending the MPS ECSE programs remain unanswered. Given these concerns and the limited scope of this investigation, MDH recommends caution in generalizing these findings to other racial and ethnic populations, including children of Somali descent.

Additional research is needed to further our understanding of this potential public health problem. Possible next steps are described in the next section.

Next Steps

To better understand whether there is, indeed, a higher occurrence of ASD in Somali children than would be expected in the population of children, a wide range of skills, expertise, and knowledge of the community and environment need to be brought to table. MDH will explore with the Centers for Disease Control and Prevention, the University of Minnesota and other state and national experts, Minneapolis Public Schools, members of the Somali community and other key stakeholders how best to move forward in addressing this issue. Additional research is needed to explore:

A. Learning more about how children come into the system and whether there are cultural differences in how behavioral and developmental problems are addressed.

B. Reviewing and systematically abstracting data from MPS educational records to learn more about evaluations for eligibility to receive special education services under the ASD disability category.

C. Conducting additional analyses to address pending questions, including:
   1. Can we better identify who is of Somali descent and/or mother's residency at the time of birth?
   2. Are there differences in population norms between Somalis and non-Somalis that might impact screening and evaluation results?
   3. What are the barriers to assessment by race, ethnicity, and language spoken in the home? Is there a difference among Somali and non-Somali children by age at first screening, evaluation, and ideally diagnosis?
   4. What methods are used for MPS Child Find? Are there differences in participation rates for the 348-TOTS and Screen by 3 screening programs or the referral rates by race, ethnicity, and language spoken in the home?
   5. How many children are lost to the MPS program? What private providers offer early intervention services to children with ASD? What are the demographic characteristics of these children and do they also receive services from MPS?

D. Estimating administrative ASD prevalence for a larger geographic area, e.g. Hennepin County, that includes other communities with relatively large populations of Somali residents to address the question: are disproportionate numbers of Somali children in other parts of Minnesota also attending special education programs for ASD?

E. Estimating administrative ASD prevalence in other U.S. communities with large populations of Somali residents to answer the question: are disproportionate numbers of Somali children in other parts of the country also attending special education programs for ASD?

F. The feasibility of developing a population-based public health ASD surveillance system in Minnesota.

While addressing these issues will assist in estimating the true prevalence of ASD in the Somali community and in Minnesota, MDH, along with the broader community, will continue working to:

- Improve access to culturally competent, coordinated care.
- Increase access to information about child development and available resources for children with special health care needs.
- Ensure that physicians and other providers have the right tools to diagnose and refer children with ASD to appropriate services.

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Figures

Autism Spectrum Disorders Among Preschool Children Participating in the Minneapolis Public Schools Early Childhood Special Education Programs

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Minnesota Department of Health

March 2009

Figure 1: Flowchart depicting ASD case selection from original MPS data

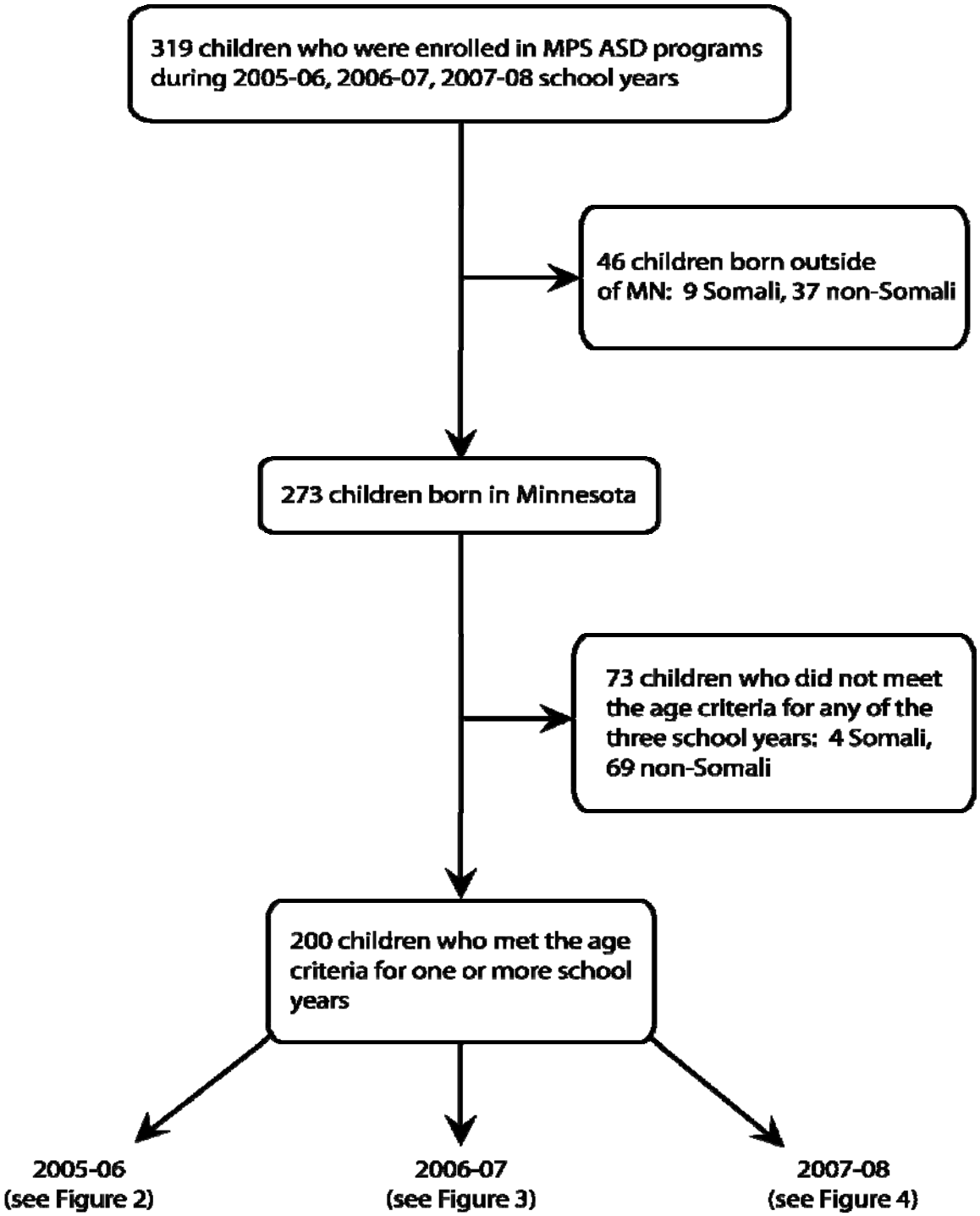


Figure 2: Flowchart depicting selection criteria for Analyses 1 through 4, 2005-06 school year

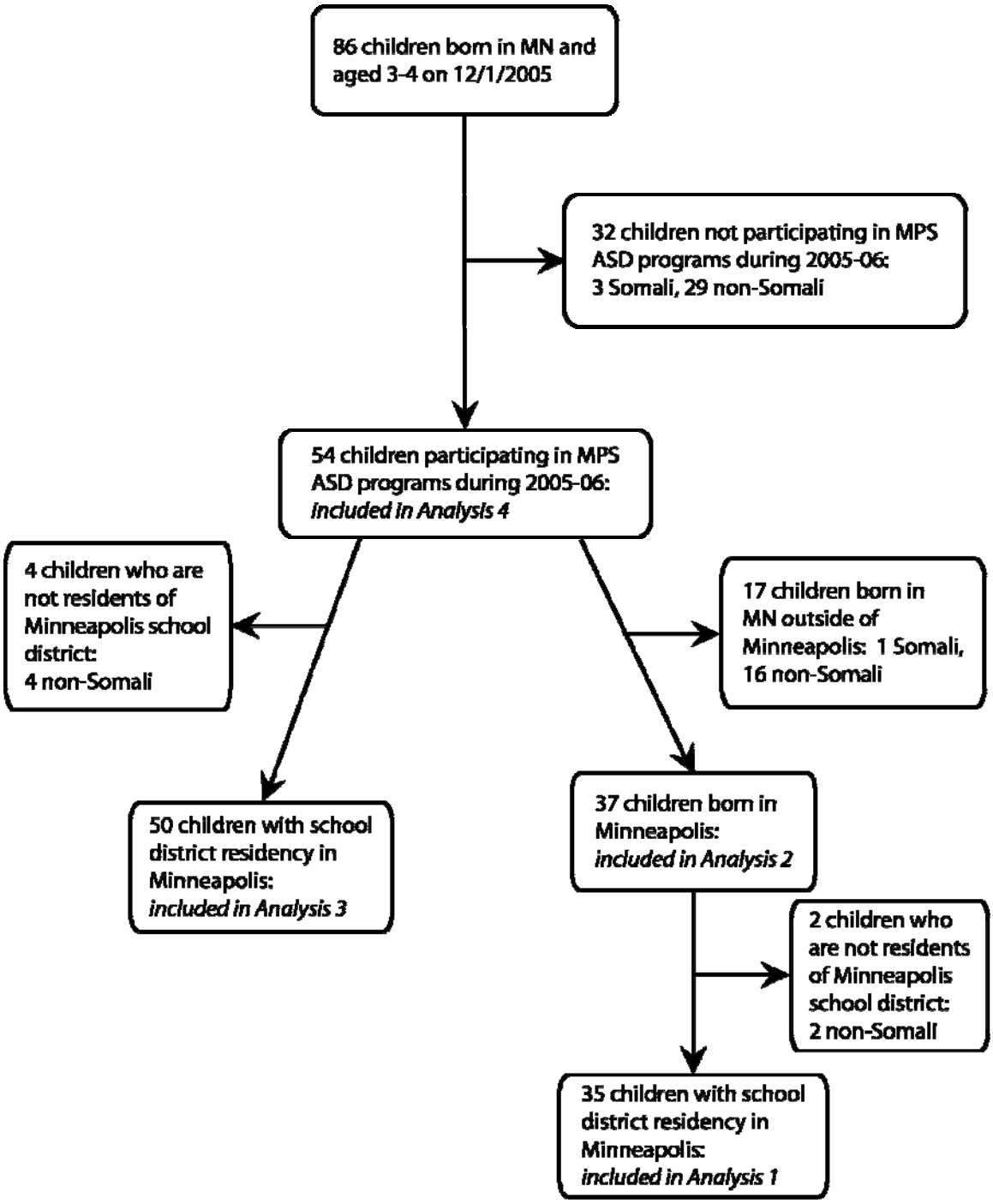


Figure 3: Flowchart depicting selection criteria for Analyses 1 through 4, 2006-07 school year

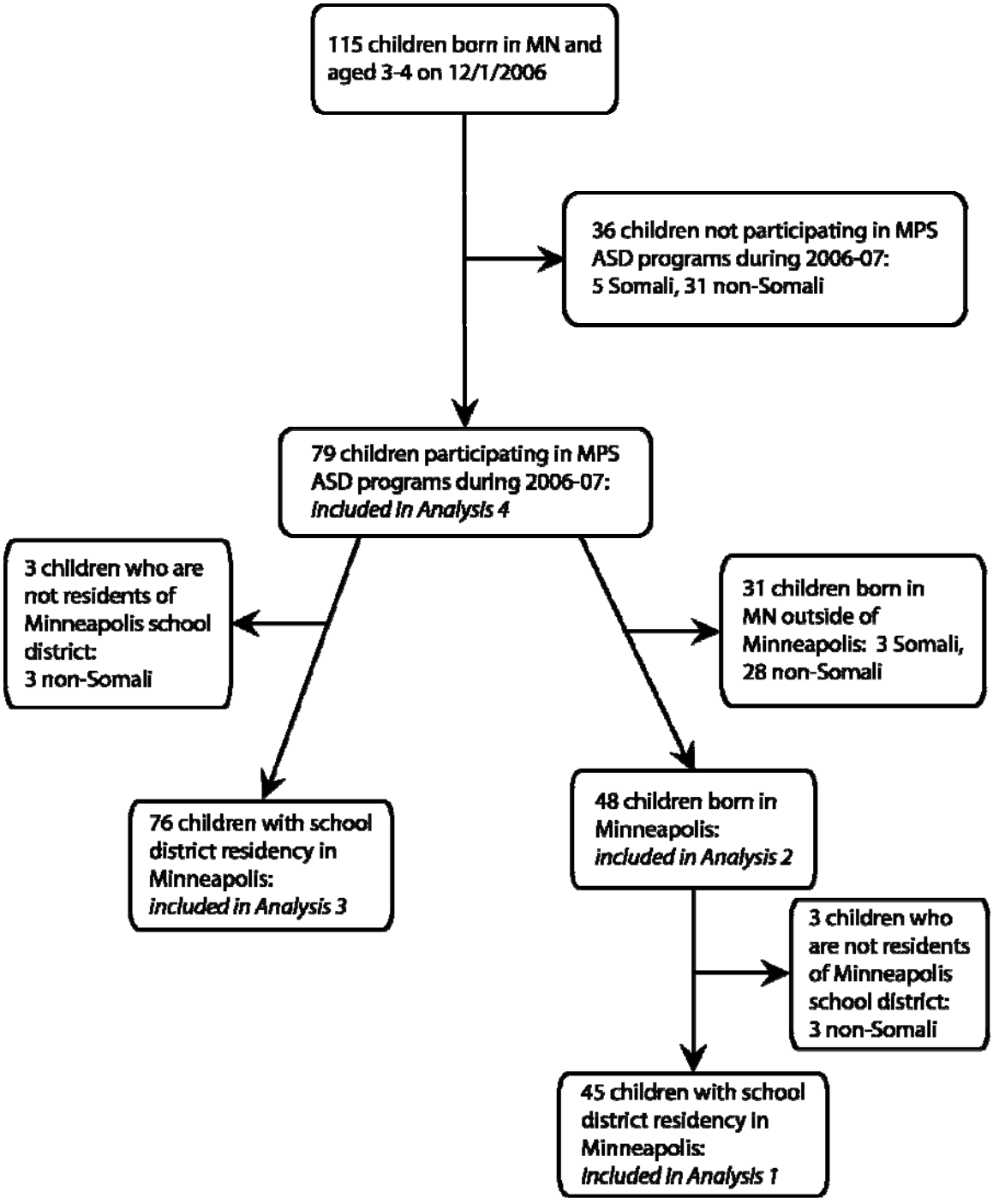
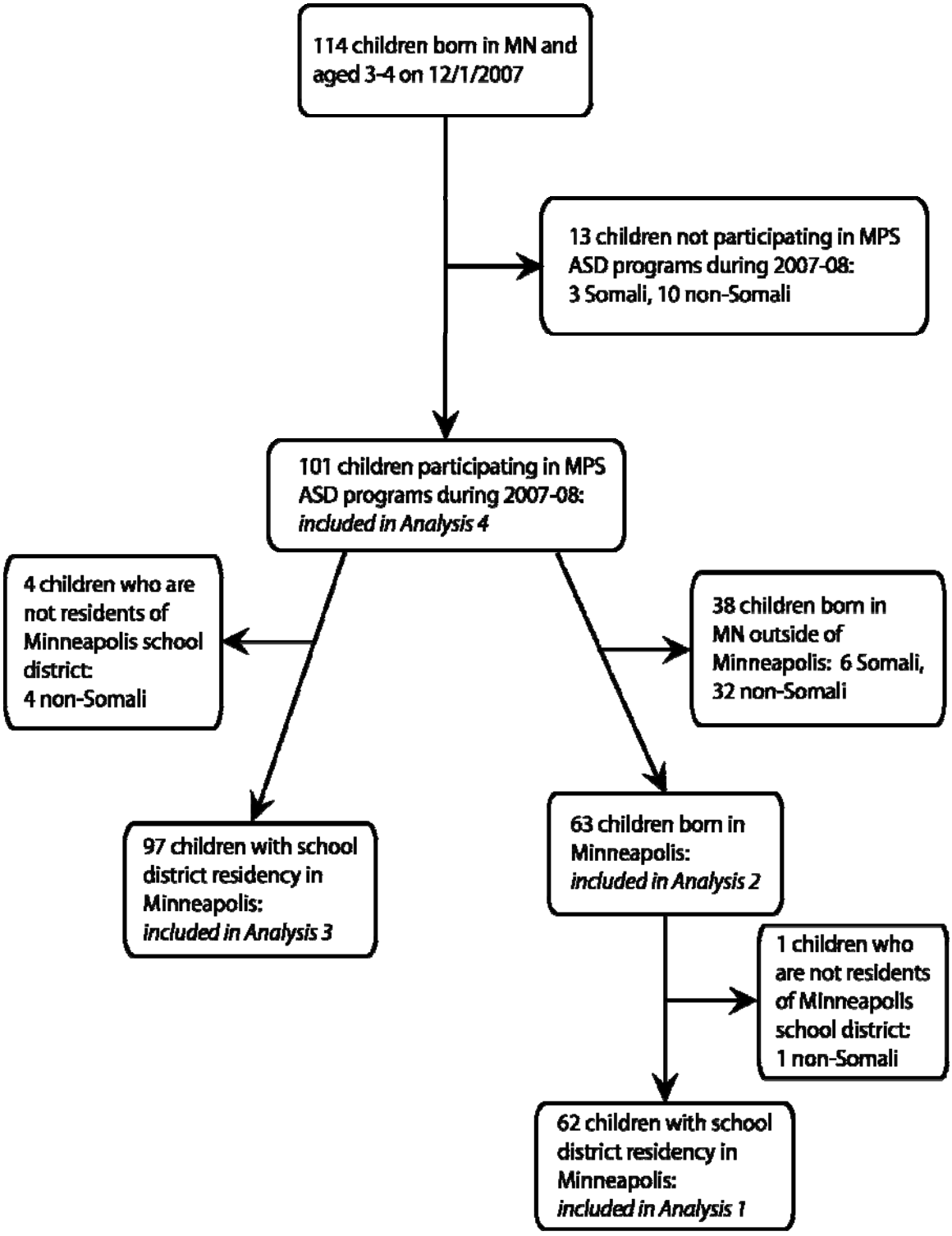


Figure 4: Flowchart depicting selection criteria for Analyses 1 through 4, 2007-08 school year



Tables

Autism Spectrum Disorders Among Preschool Children Participating in the Minneapolis Public Schools Early Childhood Special Education Programs

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Minnesota Department of Health

March 2009

Table 1. Characteristics of children attending MPS ECSE programs for ASD included in Analysis 4: aged 3 and 4 years on December 1 of each school year, born in MN, with no school district residency requirement.

	ECSE Citywide ASD Classroom Program						All MPS ASD Programs					
	2005-06 (N=44)		2006-07 (N=64)		2007-08 (N=71)		2005-06 (N=54)		2006-07 (N=79)		2007-08 (N=101)	
	Number (percent)											
Language spoken at home:												
English	29	(65.9)	46	(71.9)	43	(60.6)	39	(72.2)	59	(74.7)	72	(71.3)
Somali	11	(25.0)	13	(20.3)	15	(21.1)	11	(20.4)	14	(17.7)	15	(14.9)
Other languages	4	(9.1)	5	(7.8)	13	(18.3)	4	(7.4)	6	(7.6)	14	(13.9)
ASD disability label:												
No label	3	(6.8)	4	(6.3)	6	(8.5)	3	(5.6)	4	(5.1)	6	(5.9)
Primary	39	(88.6)	54	(84.4)	58	(81.7)	47	(87.0)	65	(82.3)	81	(80.2)
Secondary	2	(4.5)	4	(6.3)	2	(2.8)	4	(7.4)	6	(7.6)	7	(6.9)
Tertiary	0	(0.0)	2	(3.1)	5	(7.0)	0	(0.0)	4	(5.1)	7	(6.9)
Sex:												
Male	36	(81.8)	54	(84.4)	55	(77.5)	45	(83.3)	64	(81.0)	77	(76.2)
Female	8	(18.2)	10	(15.6)	16	(22.5)	9	(16.7)	15	(19.0)	24	(23.8)
Age on December 1:												
36-47 months	24	(54.5)	33	(51.6)	34	(47.9)	25	(46.3)	39	(49.4)	48	(47.5)
48-59 months	20	(45.5)	31	(48.4)	37	(52.1)	29	(53.7)	40	(50.6)	53	(52.5)
Birthplace:												
Minneapolis	31	(70.5)	42	(65.6)	43	(60.6)	37	(68.5)	48	(60.8)	63	(62.4)
MN, outside of Minneapolis	13	(29.5)	22	(34.4)	28	(39.4)	17	(31.5)	31	(39.2)	38	(37.6)
Resident School District:												
Minneapolis	41	(93.2)	61	(95.3)	71	(100.0)	50	(92.6)	76	(96.2)	97	(96.0)
Other	3	(6.8)	3	(4.7)	0	(0.0)	4	(7.4)	3	(3.8)	4	(4.0)
Race/ethnicity:												
Black, non-Hispanic	21	(47.7)	29	(45.3)	34	(47.9)	23	(42.6)	31	(39.2)	38	(37.6)
White, non-Hispanic	19	(43.2)	27	(42.2)	24	(33.8)	26	(48.1)	38	(48.1)	50	(49.5)
Other (includes Hispanic)	4	(9.1)	8	(12.5)	13	(18.3)	5	(9.3)	10	(12.7)	13	(12.9)

Table 2A. Analysis 1, December 1 index date: Birthplace and school district residency restricted to Minneapolis. Administrative ASD prevalence for Somali and non-Somali children by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

	ECSE Citywide ASD Classroom Program				All MPS ASD Programs			
	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)
2005-2006 School Year								
Cases/ Population	29/ 12965	19/ 12006	10/ 959	6.6 (2.7-14.9)	35/ 12965	25/ 12006	10/ 959	5.0 (2.2-10.8)
Percent (95% CI)	0.22% (0.15-0.32%)	0.16% (0.10-0.25%)	1.04%* (0.50-1.91%)		0.27% (0.19-0.38%)	0.21% (0.13-0.31%)	1.04%* (0.50-1.91%)	
2006-2007 School Year								
Cases/ Population	39/ 12869	28/ 11920	11/ 949	4.9 (2.2-10.2)	45/ 12869	34/ 11920	11/ 949	4.1 (1.9-8.2)
Percent (95% CI)	0.30% (0.22-0.41%)	0.23% (0.16-0.34%)	1.16%* (0.58-2.06%)		0.35% (0.26-0.47%)	0.29% (0.20-0.40%)	1.16%* (0.58-2.06%)	
2007-2008 School Year								
Cases/ Population	43/ 12966	34/ 11995	9/ 971	3.3 (1.4-7.0)	62/ 12966	53/ 11995	9/ 971	2.1 (0.9-4.3)
Percent (95% CI)	0.33% (0.24-0.45%)	0.28% (0.20-0.40)	0.93%* (0.42-1.75%)		0.48% (0.37-0.61%)	0.44% (0.33-0.58%)	0.93% (0.42-1.75%)	

PR = Prevalence Ratio; CI=Confidence Interval.
*Two-sided $p<0.05$ for comparison with non-Somali children.

Table 2B. Analysis 1, December 1 index date: Birthplace and school district residency restricted to Minneapolis. Administrative ASD prevalence for race/ethnic groups by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

ECSE Citywide ASD Classroom Program							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	0/ 939	4/ 2380	0/ 431	9/ 5467	16/ 3450	10/ 947	6/ 2503
Percent (95% CI)	0.00% (0.00-0.39%)	0.17% (0.05-0.43%)	0.00% (0.00-0.85%)	0.16% (0.08-0.31%)	0.46% (0.27-0.75%)	1.06% (0.51-1.93%)	0.24% (0.09-0.52%)
2006-2007 School Year							
Cases/ Population	2/ 933	6/ 2368	0/ 434	11/ 5479	20/ 3439	11/ 946	9/ 2493
Percent (95% CI)	0.21% (0.03-0.77%)	0.25% (0.09-0.55%)	0.00% (0.00-0.85%)	0.20% (0.10-0.36%)	0.58% (0.36-0.90%)	1.16% (0.58-2.07%)	0.36% (0.17-0.68%)
2007-2008 School Year							
Cases/ Population	0/ 937	9/ 2392	1/ 421	11/ 5532	22/ 3463	9/ 962	13/ 2501
Percent (95% CI)	0.00% (0.00-0.39%)	0.38% (0.17-0.71%)	0.24% (0.01-1.32%)	0.20% (0.10-0.36%)	0.64% (0.40-0.96%)	0.94% (0.43-1.77%)	0.52% (0.28-0.89%)
All MPS ASD Programs							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	0/ 939	4/ 2380	0/ 431	15/ 5467	16/ 3450	10/ 947	6/ 2503
Percent (95% CI)	0.00% (0.00-0.39%)	0.17% (0.05-0.43%)	0.00% (0.00-0.85%)	0.27% (0.15-0.45%)	0.46% (0.27-0.75%)	1.06% (0.51-1.93%)	0.24% (0.09-0.52%)
2006-2007 School Year							
Cases/ Population	2/ 933	6/ 2368	0/ 434	16/ 5479	21/ 3439	11/ 946	10/ 2493
Percent (95% CI)	0.21% (0.03-0.77%)	0.25% (0.09-0.55%)	0.00% (0.00-0.85%)	0.29% (0.17-0.47%)	0.61% (0.38-0.93%)	1.16% (0.58-2.07%)	0.40% (0.19-0.74%)
2007-2008 School Year							
Cases/ Population	0/ 937	9/ 2392	1/ 421	26/ 5532	26/ 3463	9/ 962	17/ 2501
Percent (95% CI)	0.00% (0.00-0.39%)	0.38% (0.17-0.71%)	0.24% (0.01-1.32%)	0.47% (0.31-0.69%)	0.75% (0.49-1.10%)	0.94% (0.43-1.77%)	0.68% (0.40-1.09%)

CI=Confidence Interval.
Note: Children of mothers who were classified as "unknown" race or Hispanic ethnicity or "other" race in birth records are not included in denominators in this table.

Table 3A. Analysis 2, December 1 index date: Birthplace restricted to Minneapolis, no school district residency restriction. Administrative ASD prevalence for Somali and non-Somali children by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

	ECSE Citywide ASD Classroom Program				All ASD Programs			
	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)
2005-2006 School Year								
Cases/ Population	31/ 12965	21/ 12006	10/ 959	6.0 (2.5-13.2)	37/ 12965	27/ 12006	10/ 959	4.6 (2.0-9.9)
Percent (95% CI)	0.24% (0.16-0.34%)	0.17% (0.11-0.27%)	1.04%* (0.50-1.91%)		0.29% (0.20-0.39%)	0.22% (0.15-0.33%)	1.04%* (0.50-1.91%)	
2006-2007 School Year								
Cases/ Population	42/ 12869	31/ 11920	11/ 949	4.5 (2.0-9.1)	48/ 12869	37/ 11920	11/ 949	3.7 (1.7-7.5)
Percent (95% CI)	0.33% (0.24-0.44%)	0.26% (0.18-0.37%)	1.16%* (0.58-2.06%)		0.37% (0.28-0.49%)	0.31% (0.22-0.43%)	1.16%* (0.58-2.06%)	
2007-2008 School Year								
Cases/ Population	43/ 12966	34/ 11995	9/ 971	3.3 (1.4-7.0)	63/ 12966	54/ 11995	9/ 971	2.1 (0.9-4.2)
Percent (95% CI)	0.33% (0.24-0.45%)	0.28% (0.20-0.40)	0.93%* (0.42-1.75%)		0.49% (0.37-0.62%)	0.45% (0.34-0.59%)	0.93% (0.42-1.75%)	

PR = Prevalence Ratio; CI=Confidence Interval.
*Two-sided $p<0.05$ for comparison with non-Somali children.

Table 3B. Analysis 2, December 1 index date: Birthplace restricted to Minneapolis, no school district residency restriction. Administrative ASD prevalence for race/ethnic groups by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

ECSE Citywide ASD Classroom Program							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	0/ 939	4/ 2380	0/ 431	9/ 5467	18/ 3450	10/ 947	8/ 2503
Percent (95% CI)	0.00% (0.00-0.39%)	0.17% (0.05-0.43%)	0.00% (0.00-0.85%)	0.16% (0.08-0.31%)	0.52% (0.31-0.82%)	1.06% (0.51-1.93%)	0.32% (0.14-0.63%)
2006-2007 School Year							
Cases/ Population	2/ 933	6/ 2368	0/ 434	12/ 5479	22/ 3439	11/ 946	11/ 2493
Percent (95% CI)	0.21% (0.03-0.77%)	0.25% (0.09-0.55%)	0.00% (0.00-0.85%)	0.22% (0.11-0.38%)	0.64% (0.40-0.97%)	1.16% (0.58-2.07%)	0.44% (0.22-0.79%)
2007-2008 School Year							
Cases/ Population	0/ 937	9/ 2392	1/ 421	11/ 5532	22/ 3463	9/ 962	13/ 2501
Percent (95% CI)	0.00% (0.00-0.39%)	0.38% (0.17-0.71%)	0.24% (0.01-1.32%)	0.20% (0.10-0.36%)	0.64% (0.40-0.96%)	0.94% (0.43-1.77%)	0.52% (0.28-0.89%)
All MPS ASD Programs							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	0/ 939	4/ 2380	0/ 431	15/ 5467	18/ 3450	10/ 947	8/ 2503
Percent (95% CI)	0.00% (0.00-0.39%)	0.17% (0.05-0.43%)	0.00% (0.00-0.85%)	0.275 (0.15-0.45%)	0.52% (0.31-0.82%)	1.06% (0.51-1.93%)	0.32% (0.14-0.63%)
2006-2007 School Year							
Cases/ Population	2/ 933	6/ 2368	0/ 434	17/ 5479	23/ 3439	11/ 946	12/ 2493
Percent (95% CI)	0.21% (0.03-0.77%)	0.25% (0.09-0.55%)	0.00% (0.00-0.85%)	0.31% (0.18-0.50%)	0.67% (0.42-1.00%)	1.16% (0.58-2.07%)	0.48% (0.25-0.84%)
2007-2008 School Year							
Cases/ Population	0/ 937	9/ 2392	1/ 421	27/ 5532	26/ 3463	9/ 962	17/ 2501
Percent (95% CI)	0.00% (0.00-0.39%)	0.38% (0.17-0.71%)	0.24% (0.01-1.32%)	0.49% (0.32-0.71%)	0.75% (0.49-1.10%)	0.94% (0.43-1.77%)	0.68% (0.40-1.09%)

CI=Confidence Interval.

Note: Children of mothers who were classified as "unknown" race or Hispanic ethnicity or "other" race in birth records are not included in denominators in this table.

Table 4A. Analysis 3, December 1 index date: Birthplace restricted to Minnesota, school district residency restricted to Minneapolis. Administrative ASD prevalence for Somali and non-Somali children by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

	ECSE Citywide ASD Classroom Program				All ASD Programs			
	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)
2005-2006 School Year								
Cases/ Population	41/ 12965	30/ 12006	11/ 959	4.6	50/ 12965	39/ 12006	11/ 959	3.5
Percent (95% CI)	0.32% (0.23-0.43%)	0.25% (0.17-0.36%)	1.15%* (0.57-2.04%)	(2.1-9.4)	0.39% (0.29-0.51%)	0.32% (0.23-0.44%)	1.15%* (0.57-2.04%)	(1.6-7.0)
2006-2007 School Year								
Cases/ Population	61/ 12869	48/ 11920	13/ 949	3.4	76/ 12869	62/ 11920	14/ 949	2.8
Percent (95% CI)	0.47% (0.36-0.61%)	0.40% (0.30-0.53%)	1.37%* (0.73-2.33%)	(1.7-6.4)	0.59% (0.47-0.74%)	0.52% (0.40-0.67%)	1.48%* (0.81-2.46%)	(1.5-5.1)
2007-2008 School Year								
Cases/ Population	71/ 12966	56/ 11995	15/ 971	3.3	97/ 12966	82/ 11995	15/ 971	2.6
Percent (95% CI)	0.55% (0.43-0.69%)	0.47% (0.35-0.61%)	1.54%* (0.87-2.54%)	(1.7-5.9)	0.75% (0.61-0.91%)	0.68% (0.54-0.85%)	1.54%* (0.87-2.54%)	(1.2-3.9)

PR = Prevalence Ratio; CI=Confidence Interval.
*Two-sided $p<0.05$ for comparison with non-Somali children.

Table 4B. Analysis 3, December 1 index date: Birthplace restricted to Minnesota, school district residency restricted to Minneapolis. Administrative ASD prevalence for race/ethnic groups by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

ECSE Citywide ASD Classroom Program							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	0/ 939	4/ 2380	0/ 431	19/ 5467	18/ 3450	11/ 947	7/ 2503
Percent (95% CI)	0.00% (0.00-0.39%)	0.17% (0.05-0.43%)	0.00% (0.00-0.85%)	0.35% (0.21-0.54%)	0.52% (0.31-0.82%)	1.16% (0.58-2.07%)	0.28% (0.11-0.58%)
2006-2007 School Year							
Cases/ Population	2/ 933	6/ 2368	0/ 434	26/ 5479	27/ 3439	13/ 946	14/ 2493
Percent (95% CI)	0.21% (0.03-0.77%)	0.25% (0.09-0.55%)	0.00% (0.00-0.85%)	0.47% (0.31-0.69%)	0.79% (0.52-1.14%)	1.37% (0.73-2.34%)	0.56% (0.31-0.94%)
2007-2008 School Year							
Cases/ Population	1/ 937	11/ 2392	1/ 421	24/ 5532	34/ 3463	15/ 962	19/ 2501
Percent (95% CI)	0.11% (0.00-0.59%)	0.46% (0.23-0.82%)	0.24% (0.01-1.32%)	0.43% (0.28-0.64%)	0.98% (0.68-1.37%)	1.56% (0.88-2.56%)	0.76% (0.46-1.18%)
All MPS ASD Programs							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	0/ 939	4/ 2380	1/ 431	25/ 5467	20/ 3450	11/ 947	9/ 2503
Percent (95% CI)	0.00% (0.00-0.39%)	0.17% (0.05-0.43%)	0.23% (0.01-1.29%)	0.46% (0.30-0.67%)	0.58% (0.35-0.89%)	1.16% (0.58-2.07%)	0.36% (0.16-0.68%)
2006-2007 School Year							
Cases/ Population	2/ 933	6/ 2368	2/ 434	37/ 5479	29/ 3439	14/ 946	15/ 2493
Percent (95% CI)	0.21% (0.03-0.77%)	0.25% (0.09-0.55%)	0.46% (0.06-1.65%)	0.68% (0.48-0.93%)	0.84% (0.57-1.21%)	1.48% (0.81-2.47%)	0.60% (0.34-0.99%)
2007-2008 School Year							
Cases/ Population	1/ 937	11/ 2392	1/ 421	46/ 5532	38/ 3463	15/ 962	23/ 2501
Percent (95% CI)	0.11% (0.00-0.59%)	0.46% (0.23-0.82%)	0.24% (0.01-1.32%)	0.83% (0.61-1.11%)	1.10% (0.78-1.50%)	1.56% (0.88-2.56%)	0.92% (0.58-1.38%)

CI=Confidence Interval.

Note: Children of mothers who were classified as "unknown" race or Hispanic ethnicity or "other" race in birth records are not included in denominators in this table.

Table 5A. Analysis 4, December 1 index date: Birthplace restricted to Minnesota, no school district residency restriction. Administrative ASD prevalence for Somali and non-Somali children by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

	ECSE Citywide ASD Classroom Program				All ASD Programs			
	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)
2005-2006 School Year								
Cases/ Population	44/ 12965	33/ 12006	11/ 959	4.2	54/ 12965	43/ 12006	11/ 959	3.2
Percent (95% CI)	0.34% (0.25-0.46%)	0.27% (0.19-0.39%)	1.15%* (0.57-2.04%)	(1.9-8.5)	0.42% (0.31-0.54%)	0.36% (0.26-0.48%)	1.15%* (0.57-2.04%)	(1.5-6.3)
2006-2007 School Year								
Cases/ Population	64/ 12869	51/ 11920	13/ 949	3.2	79/ 12869	65/ 11920	14/ 949	2.7
Percent (95% CI)	0.50% (0.38-0.63%)	0.43% (0.32-0.56%)	1.37%* (0.73-2.33%)	(1.6-6.0)	0.61% (0.49-0.76%)	0.55% (0.42-0.69%)	1.48%* (0.81-2.46%)	(1.4-4.9)
2007-2008 School Year								
Cases/ Population	71/ 12966	56/ 11995	15/ 971	3.3	101/ 12966	86/ 11995	15/ 971	2.2
Percent (95% CI)	0.55% (0.43-0.69%)	0.47% (0.35-0.61%)	1.54%* (0.87-2.54%)	(1.7-5.9)	0.78% (0.63-0.95%)	0.72% (0.57-0.88%)	1.54%* (0.87-2.54%)	(1.2-3.8)

PR = Prevalence Ratio; CI=Confidence Interval.
*Two-sided $p<0.05$ for comparison with non-Somali children.

Table 5B. Analysis 4, December 1 index date: Birthplace restricted to Minnesota, no school district residency restriction. Administrative ASD prevalence for race/ethnic groups by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

ECSE Citywide ASD Classroom Program							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	0/ 939	4/ 2380	0/ 431	19/ 5467	21/ 3450	11/ 947	10/ 2503
Percent (95% CI)	0.00% (0.00-0.39%)	0.17% (0.05-0.43%)	0.00% (0.00-0.85%)	0.35% (0.21-0.54%)	0.61% (0.38-0.93%)	1.16% (0.58-2.07%)	0.40% (0.19-0.73%)
2006-2007 School Year							
Cases/ Population	2/ 933	6/ 2368	0/ 434	27/ 5479	29/ 3439	13/ 946	16/ 2493
Percent (95% CI)	0.21% (0.03-0.77%)	0.25% (0.09-0.55%)	0.00% (0.00-0.85%)	0.49% (0.32-0.72%)	0.84% (0.57-1.21%)	1.37% (0.73-2.34%)	0.64% (0.37-1.04%)
2007-2008 School Year							
Cases/ Population	1/ 937	11/ 2392	1/ 421	24/ 5532	34/ 3463	15/ 962	19/ 2501
Percent (95% CI)	0.11% (0.00-0.59%)	0.46% (0.23-0.82%)	0.24% (0.01-1.32%)	0.43% (0.28-0.64%)	0.98% (0.68-1.37%)	1.56% (0.88-2.56%)	0.76% (0.46-1.18%)
All MPS ASD Programs							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	0/ 939	4/ 2380	1/ 431	26/ 5467	23/ 3450	11/ 947	12/ 2503
Percent (95% CI)	0.00% (0.00-0.39%)	0.17% (0.05-0.43%)	0.23% (0.01-1.29%)	0.48% (0.31-0.70%)	0.67% (0.42-1.00%)	1.16% (0.58-2.07%)	0.48% (0.25-0.84%)
2006-2007 School Year							
Cases/ Population	2/ 933	6/ 2368	2/ 434	38/ 5479	31/ 3439	14/ 946	17/ 2493
Percent (95% CI)	0.21% (0.03-0.77%)	0.25% (0.09-0.55%)	0.46% (0.06-1.65%)	0.69% (0.49-0.95%)	0.90% (0.61-1.28%)	1.48% (0.81-2.47%)	0.68% (0.40-1.09%)
2007-2008 School Year							
Cases/ Population	1/ 937	11/ 2392	1/ 421	50/ 5532	38/ 3463	15/ 962	23/ 2501
Percent (95% CI)	0.11% (0.00-0.59%)	0.46% (0.23-0.82%)	0.24% (0.01-1.32%)	0.90% (0.67-1.19%)	1.10% (0.78-1.50%)	1.56% (0.88-2.56%)	0.92% (0.58-1.38%)

CI=Confidence Interval.

Note: Children of mothers who were classified as "unknown" race or Hispanic ethnicity or "other" race in birth records are not included in denominators in this table.

Table 6. Classification of birth cohorts (December 1 index date) by school year, race/ethnicity reported in birth records, and Somali ancestry as determined by mother's birthplace in birth records.

		2005-2006		2006-2007		2007-2008	
Race/Ethnicity	Somali Ancestry (Yes/No)	Births in cohort	Totals by race	Births in cohort	Totals by race	Births in cohort	Totals by race
Asian	Yes	3	939	1	933	0	937
	No	936		932		937	
Black	Yes	947	3450	946	3439	962	3463
	No	2503		2493		2501	
Hispanic	Yes	0	2380	0	2368	0	2392
	No	2380		2368		2392	
Native American	Yes	0	431	0	434	0	421
	No	431		434		421	
White	Yes	0	5467	0	5479	0	5532
	No	5467		5479		5532	
Missing	Yes	9	298	2	216	9	221
	No	289		214		212	
Total in "A" Tables	Yes	959	12965	949	12869	971	12966
	No	12006		11920		11995	
Total in "B" Tables	Yes	950	12667	947	12653	962	12745
	No	11717		11706		11783	

Appendices

Autism Spectrum Disorders Among Preschool Children Participating in the Minneapolis Public Schools Early Childhood Special Education Programs

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Minnesota Department of Health

March 2009

Appendix A: Disabilities that qualify children for special education services in Minnesota under Minnesota Statute 125A.02, with corresponding Minnesota Administrative Rules containing criteria for each disability category

MN Statute 125A.02	**MN Administrative Rules Chapter 3525**
Hearing impairment	3525.1331 Deaf and hard of hearing
Blindness/Visual disability	3525.1345 Visually impaired
Speech or language impairment	3525.1343 Speech or language impairment
Physical disability	3525.1337 Physically impaired
Other health impairment	3525.1335 Other health disabilities
Mental disability	3525.1333 Developmental cognitive disability; categorized as 1) mild-moderate or 2) severe-profound
Emotional/behavioral disorder	3525.1329 Emotional or behavioral disorders
Specific learning disability	3525.1341 Specific learning disabilities
Autism	3525.1325 Autism spectrum disorders (ASD)
Traumatic brain injury	3525.1348 Traumatic brain injury (TBI)
Multiple disabilities	3525.1339 Severely multiply disabled
Deaf/blind disability	3525.1327 Deaf-blind
Developmental delay (up to age 6 only)	3525.1350 Infant and toddler intervention services; 3525.1351 Intervention services for ages 3 through 6

Appendix B: Minnesota Administrative Rule 3525.1325*

3525.1325 AUTISM SPECTRUM DISORDERS (ASD)

Subpart 1. **Definition.** "Autism spectrum disorders (ASD)" means a range of pervasive developmental disorders, with onset in childhood, that adversely affect a pupil's functioning and result in the need for special education instruction and related services. ASD is a disability category characterized by an uneven developmental profile and a pattern of qualitative impairments in several areas of development, including social interaction, communication, or the presence of restricted, repetitive, and stereotyped patterns of behavior, interests, and activities. These core features may present themselves in a wide variety of combinations that range from mild to severe, and the number of behavioral indicators present may vary. ASD may include Autistic Disorder, Childhood Autism, Atypical Autism, Pervasive Developmental Disorder Not Otherwise Specified, Asperger's Disorder, or other related pervasive developmental disorders.

Subp. 2. [Repealed, 24 SR 1799]

Subp. 3. **Criteria.** A multidisciplinary team shall determine that pupil is eligible and in need of special education instruction and related services if the pupil meets the criteria in items A and B. A determination of eligibility must be supported by information collected from multiple settings and sources.

A. An educational evaluation must address all three core features in subitems (1) to (3). The team must document that the pupil demonstrates patterns of behavior described in at least two of these subitems, one of which must be subitem (1).

The behavioral indicators demonstrated must be atypical for the pupil's developmental level. The team shall document behavioral indicators through at least two of these methods: structured interviews with parents, autism checklists, communication and developmental rating scales, functional behavior assessments, application of diagnostic criteria from the current Diagnostic and Statistical Manual (DSM), informal and standardized evaluation instruments, or intellectual testing.

(1) Qualitative impairment in social interaction, as documented by two or more behavioral indicators, for example: limited joint attention and limited use of facial expressions directed toward others; does not show or bring things to others to indicate an interest in the activity; demonstrates difficulties in relating to people, objects, and events; a gross impairment in ability to make and keep friends; significant vulnerability and safety issues due to social naivete; may appear to prefer isolated or solitary activities; misinterprets others' behaviors and social cues.

(2) Qualitative impairment in communication, as documented by one or more behavioral indicators, for example: not using finger to point or request; using others' hand or body as a tool; showing lack of spontaneous imitations or lack of varied imaginative play; absence or delay of spoken language; limited understanding and use of nonverbal communication skills such as gestures, facial expressions, or voice tone;

(Appendix B cont'd: Minnesota Administrative Rule 3525.1325)

* Available at https://www.revisor.leg.state.mn.us/rules/?id=3525.1325

odd production of speech including intonation, volume, rhythm, or rate; repetitive or idiosyncratic language or inability to initiate or maintain a conversation when speech is present.

(3) Restricted, repetitive, or stereotyped patterns of behavior, interest, and activities, as documented by one or more behavioral indicators, for example: insistence on following routines or rituals; demonstrating distress or resistance to changes in activity; repetitive hand or finger mannerism; lack of true imaginative play versus reenactment; overreaction or under-reaction to sensory stimuli; rigid or rule-bound thinking; an intense, focused preoccupation with a limited range of play, interests, or conversation topics.

B. The team shall document and summarize in an evaluation report that ASD adversely affects a pupil's performance and that the pupil is in need of special education instruction and related services. Documentation must include:

(1) an evaluation of the pupil's present levels of performance and educational needs in each of the core features identified by the team in item A. In addition, the team must consider all other areas of educational concern related to the suspected disability;

(2) observations of the pupil in two different settings, on two different days; and

(3) a summary of the pupil's developmental history and behavior patterns.

Subp. 4. **Team membership.** The team determining eligibility and educational programming must include at least one professional with experience and expertise in the area of ASD due to the complexity of this disability and the specialized intervention methods. The team must include a school professional knowledgeable of the range of possible special education eligibility criteria.

Subp. 5. **Implementation.** Pupils with various educational profiles and related clinical diagnoses may meet the criteria of ASD under subpart 3. However, a clinical or medical diagnosis is not required for a pupil to be eligible for special education services, and even with a clinical or medical diagnosis, a pupil must meet the criteria in subpart 3 to be eligible.

Statutory Authority: *MS s 14.389; 120.17; L 1999 c 123 s 19,20*

History: *16 SR 1543; L 1998 c 397 art 11 s 3; 24 SR 1799; 26 SR 657*

Posted: *October 12, 2007*

Appendix C: ASD Evaluation Tools used by the Minneapolis Public Schools Special Education Department

Birth – 3 years	**3 – 5 years**
Bayley Scales of Infant and Toddler Development-3rd edition	Battelle Developmental Inventory-2 (or portions of)
Sequenced Inventory of Communication Development-revised	Sensory Profile and companion, if needed
Language sample	Creative Curriculum
Language Development Survey	Kaufman Test of Educational Achievement, 2nd edition
Sensory Profile and companion, if needed	Language Development Survey
Peabody Developmental Motor Scales (used infrequently)	Preschool Language Scale
CSBS DP Infant-Toddler Checklist (6-24 months)	Language sample
Observation	Test for Auditory Comprehension of Language-3
Developmental history/parent interview	Peabody Developmental Motor Scales
Autism Diagnostic Observation Schedule (ADOS)	Developmental Test of Visual-Motor Integration
Criteria review	Clinical Evaluation for Language Fundamentals/Preschool 2
	Observation
	Developmental history/parent interview
	Autism Diagnostic Observation Schedule (ADOS)
	Criteria review

Appendix D: Minnesota ASD Eligibility Checklist*

7/2000

3.4.1 AUTISM SPECTRUM DISORDERS (ASD)

Evaluation ___ Reevaluation ___ Date of Evaluation Report _____

Name _____

Federal Setting _____ DOB _____ **ELIGIBLE : YES NO**

A student is considered eligible for Special Education when the student meets criteria items A and B.

A. Documentation in evaluation report of at least two of these subitems; one must be subitem 1. The evaluation must address all three subitems collected from multiple settings:

1. Qualitative impairment of reciprocal social interactions: (two or more indicators) **Yes** **No**

__ limited use of facial expressions towards others
__ gross impairment in ability to make friends
__ appears to prefer isolated or solitary activities
__ misinterprets others' behaviors and social cues
__ significant vulnerability and safety issues due to social naivete
__ does not show or bring things to others to indicate interest in activity
__ limited joint attention
__ difficulty relating to people
__other_____

2. Qualitative impairment in communication: (one or more indicator) **Yes** **No**

__ not using finger to point or request
__ absence or delay of spoken language
__ inability to initiate or maintain conversation
__ odd production of speech (intonation, rhythm, rate)
__ showing lack of spontaneous imitations of lack of varied imaginative play
__ limited understanding of nonverbal communication skills(gestures,facial expressions,tone of voice
__ using others' hand or body as a tool
__ repetitive, idiosyncratic language
__other_____

3. Restricted, repetitive or stereotyped patterns of behavior, interests, activities: (one or more indicator) **Yes** **No**

__ repetitive hand or finger mannerisms
__ lack of true imaginative play vs. reenactment
__ demonstrating distress or resistance to change
__ over-reaction or under-reaction to sensory stimuli
__ intense, focused preoccupation with a limited range, interests, or conversation topics
__ rigid, rule-bound thinking
__ insistence on following routines or rituals
__other_____

Behavioral indicators in item A must include the use of at least two of the methods below: **Yes** **No**

__ structured interview with parents
__ autism rating scales or checklist(s)
__ communication and developmental scales
__ functional behavior evaluation
__ application of DSM-IV diagnostic criteria
__ informal and standardized evaluation instruments:
__ intellectual testing:

AND

B. Verification that ASD adversely affects the pupil's present level of performance; data from each of these:

1. Education needs in each core feature identified in A **Yes** **No**

and

2. Observation in two different settings on two different days **Yes** **No**

and

3. Historical summary of developmental information and behavior patterns **Yes** **No**

For complete information regarding eligibility requirements, refer to Minnesota Rule 3525.1325

*Source: Promising Practices for the Identification of Individuals with Autism Spectrum Disorders, MN Department of Children, Families and Learning, November 2000. Available at: http://www.mnlowincidenceprojects.org/asdresources.html.

Appendix E: Description of Minneapolis Public Schools Early Childhood Special Education Programs

Mission Statement:
The Minneapolis Public Schools Early Childhood Special Education Program is committed to providing a quality education for children birth to age seven that meet's each child's individual needs.

Vision Statement:
The Minneapolis Public Schools Early Childhood Special Education staff, working together with families and coordinating services with other agencies, will ensure that all ECSE students are taught the necessary skills to succeed in their grade school years and beyond.

Initial Eligibility of Autism Spectrum Disorders:
When a child is referred for a special education evaluation, a multidisciplinary team completes a comprehensive evaluation. The evaluation includes observations in two different settings, parent interview regarding developmental history, and an Autism Diagnostic Observation Schedule. The team meets to review the criteria for Autism Spectrum Disorders and documents the student's present level of performance and needs in the three core features of Autism. Other developmental, sensory, motor and communication testing is completed as needed. Parent consent is obtained for both evaluation and services. After the child is found eligible for special educations services, an Individual Education Plan is developed.

Standards:
The program uses the Early Childhood Indicators of Progress: Minnesota's Early Learning Guidelines for infants to preschoolers to provide a framework for understanding and communicating a common set of developmental appropriate expectations.

Curriculum:
The Creative Curriculum for Preschool is a comprehensive curriculum that guides teachers in designing a preschool program in which children learn social competence and skills in the areas of literacy, math, science, social studies, the arts, and technology. The Curriculum framework guides teachers in setting up a classroom and structuring the school day, in selecting learning experiences for children, in working with children at different developmental levels, and involving families in the program. Curriculum and assessment are linked by *The Creative Curriculum Developmental Continuum* Assessment System, based on *The Creative Curriculum Developmental Continuum for Ages 3.5.* The *Developmental Continuum* contains 10 goals and 50 objectives for children ages 3.5. Each objective is broken down into a three step sequence. For those children who score below the typical range, a Forerunner checklist is available. The developmental steps help teachers to determine each child's current development in relation to each objective, and to decide what specific support and kinds of experiences

will enable each child to develop and learn. All of the Minnesota Early Childhood Indicators of Progress align with the content of *The Creative Curriculum for Preschool.*

Interventions:
The program's child-focused intervention strategies are based upon the three guiding principles from the Council for Exceptional Children Division of Early Childhood Recommended Practices (2005):

1. Special Education Staff design environments to promote children's safety, active engagement, learning, participation, and membership.
    - Physical space and materials are structured and adapted to promote play, interaction, learning and engagement.
    - Routines and transitions are structured using naturalistic time delay, interrupted chain procedure, transition-based teaching and visual cue systems.
    - Environments are provided that foster positive relationships.

2. Special Education Staff use ongoing data to individualize and adapt interventions to meet each child's changing needs.
    - Interventions are individualized for each child.
    - Data-based decisions are used to make modifications in the interventions.
    - Children's behavior is recognized, interpreted in context, and responded to contingently, and opportunities are provided for expansion of behavior by imitating the behavior, waiting for the child's responses, modeling, and prompting.
    - Staff uses systematic procedures within and across environments, activities, and routines to promote children's learning and participation.
    - Staff promote and accelerate learning throughout the following phases:
        - Acquisition – learning how to do the skill
        - Fluency – learning to do the skill smoothly and at natural rates
        - Maintenance – learning to do the skill after instruction has stopped
        - Generalization – learning to apply the skill whenever and wherever it is needed
    - Staff planning occurs prior to implementation and considers the situation in which the intervention will be applied.

3. Interventions are research based, respectful and sensitive to cultural and linguistic issues. Responses to children's behavior are structured to increase the complexity and duration of the child's play, engagement, appropriate behavior, and learning by using differential reinforcement, response shaping, high-probability procedures and correspondence training.
    - Systematic naturalistic teaching procedures such as models, expansions, incidental teaching, mand-model procedure, and naturalistic time delay are used to promote acquisition and use of communication and social skills.

(Appendix E cont'd: Description of MPS ECSE programs)

- Prompting and prompt fading procedures are used to ensure acquisition and use of communicative, self-care, cognitive, and social skills.
- Recommended instructional strategies are used with sufficient fidelity, consistency, frequency, and intensity to ensure high levels of behavior occurring frequently.
- For problem behaviors, staff assesses the behavior in context to identify its function, and then devise interventions that are comprehensive so that the behavior becomes irrelevant, inefficient and ineffective.

Autism Specific Interventions:
Strategies used will address the areas of acquisition of skills, response training, initiation training, communication and interaction development and a functional approach to behavior challenges. Facilitating a high level of engaged time for each student is a priority. Classroom curriculum from the following programs or intervention techniques will be utilized:

- TEACCH Methodology
- Picture Exchange Communication System
- Direct Teaching/Discrete Trial Training
- Functional Behavioral Analysis
- Reinforcement Schedules
- LEAP Project
- Social Stories
- Social Skills Instruction
- Relationship Intervention with Young Children (Gutstein)
- Greenspan's Floor time Model
- Sensory Motor Strategies
- Visual Supports

Family Involvement:
Family members and professionals work together to develop appropriate goals and plans to achieve those goals. Together, we build relationships that are responsive to cultural, language and other family characteristics. The program works with families to:

- Promote their choice and decision making
- Build their confidence in obtaining supports and resources
- Make connections to achieve their family's desired outcomes
- Promote parenting knowledge and skills for their family's participation in the community

Staff will:

- Provide direct, highly supported, parent-child instruction opportunities
- Promote parent involvement in the classroom setting
- Elicit parent feedback regarding their child's programming

(Appendix E cont'd: Description of MPS ECSE programs)

- Utilize Routines Based Interviewing strategies for development of a child and family focused plan

Service Delivery Models:
MPS offers a continuum of ECSE service settings reflecting the natural progression of growth from infancy, when babies are typically at home or in a daycare setting with one primary caregiver, to preschoolers who are often in preschools or daycare during a portion of their day and have a number of familiar primary adult caregivers. These settings are home based, community based, and center based classrooms.

HOME BASED: The home-based program recognizes that the child is a member of a family system as well as a specific community. Services are offered in the child's primary environment focusing on the strengths and priorities of the parents and primary caregivers in their communities.
PARENT CHILD GROUP: While receiving home based services, the parent and child also participate in a group experience. The group is structured to promote a young child's success while the parent attends an educational support group.
COMMUNITY: The placement of children in the community is determined by the IFSP/IEP team based on child's IEP goals and objectives, number of minutes of special education services needed to meet these goals, and the least restrictive environment. Children are served at Head Start, community preschools, and Early Childhood Family Education classes. Some students access social skills training, which is then generalized to the community setting.
CENTER BASED: The placement of a child in an ECSE classroom is determined by the IFSP/IEP team based on individual need. Children placed in a center-based classroom are in need of a high level of adult facilitation and guidance in both learning and their interactions with peers. ECSE center based classrooms are non-categorical and have a variety of inclusion opportunities. ECSE classrooms are located in elementary school buildings throughout MPS.
The ECSE Autism Program offers self-contained classes for students whose behavior and skills require a highly structured classroom environment with predictability and visual supports in order to make progress on their educational plan.

Continuous Progress Monitoring Systems:
Data Collection based on the student's special education goals and objectives
Individual Growth and Development Indicators
Creative Curriculum Developmental Continuum Assessment
Minnesota Early Childhood Outcomes

Appendix F: Relationship between population prevalence, administrative prevalence, and program participation "rates"

This technical appendix uses Figure F.1 to illustrate how to calculate three different prevalence statistics that measure the occurrence of ASD in a group of children: (1) population ASD prevalence, (2) administrative ASD prevalence, and (3) ASD program participation rate. This appendix will also show why the three estimates are not equal and do not measure the same things.

Figure F.1 depicts the total number of children in the population of interest ("N"). The blue circle ("A") represents the number of children in this population who truly have ASD. The green circle ("M") represents the number of children in this population who are receiving ASD services from MPS. The children in the green circle represent two groups: those who truly do not have ASD but are receiving ASD services from MPS (the part of the green circle that does not overlap with the blue circle), and those who truly have ASD and are receiving ASD services from MPS (the overlap of the blue and green circles). Children who do not truly have ASD but receive ASD services represent "false positive" cases. The "C" circle represents all children in the population who are enrolled in the MPS ECSE programs. The size of this group is smaller than that of the entire population because most preschool children in Minneapolis do not attend MPS ECSE programs. The other group of children in this population is those who truly have ASD and are enrolled in MPS ECSE programs, but they are not receiving services for ASD (located in the overlap between the blue and "C" circles but not the green circle.) These counts represent "false negative" cases.

(1) Population ASD prevalence: Population prevalence indicates how many children (%) in a defined population have ASD during a specified time. To compare ASD occurrence between groups of children, this is the preferred measure of prevalence. Population prevalence is calculated as the total number of children in the specified population who have ASD ("A") divided by the total number of children in the population ("N") at a specified time.

- **Population prevalence = A ÷ N**

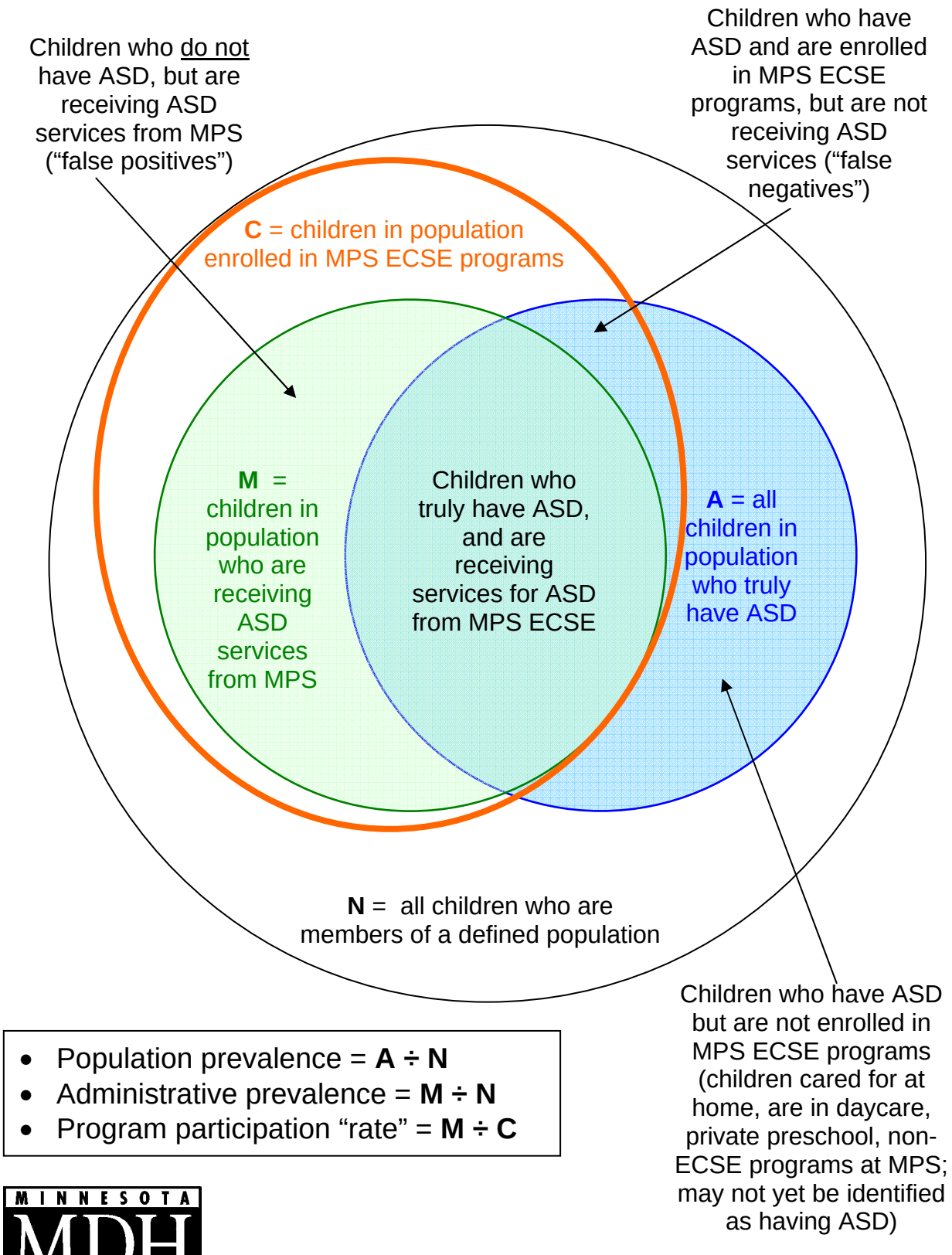
(2) Administrative ASD prevalence: Administrative prevalence indicates how many children (%) in a defined population are receiving ASD special education services from MPS**.** In this study, administrative prevalence was calculated using data from MPS for the counts of ASD cases and birth certificate data for the population size. Administrative prevalence is calculated as the total number of ASD cases who are receiving ASD services from MPS programs ("M") divided by the number of children in the specified population ("N").

- **Administrative prevalence = M ÷ N**

(**3) ASD program participation "rate":** A program participation rate indicates how many children (%) in the population of interest who are enrolled in MPS ECSE programs are receiving ASD special education services from MPS. A participation rate is an example of type of statistic that is calculated and reported to state and federal governments in compliance with IDEA reporting requirements. The ASD program participation rate is calculated as the total number of ASD cases who are receiving ASD services from MPS programs ("M") divided by the number of children in the population of interest who are enrolled in MPS ECSE programs ("C").

- **ASD program participation "rate" = M ÷ C**

Figure F1. ASD Prevalence and Program Participation Rate Estimation in Minneapolis.



- Population prevalence = **A ÷ N**
- Administrative prevalence = **M ÷ N**
- Program participation "rate" = **M ÷ C**

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For illustration purposes only – figure not to scale.

NOTES for figure:

- Population prevalence = **A ÷ N**
- Administrative prevalence = **M ÷ N**
- Program participation "rate" = **M ÷ C**

- Children in **A** but not in **C** : these are children who truly have ASD but are not enrolled in MPS ECSE. These children could be those who are cared for at home, are in daycare, private preschool, or non-ECSE early childhood programs. These may also be children who are not yet identified as having ASD. These children are in the ideal population prevalence estimate, but are not included in administrative prevalence or in program participation rates.

- Children in **A** and **C** but not in **M** : these are "false negatives" – they truly have ASD and are enrolled in MPS ECSE but are not receiving services for ASD (but are receiving other special education services). These children are in the ideal population prevalence estimate, but are not included in administrative prevalence or in program participation rates.

- Children in **M** and **C** but not in **A** : these are "false positives" – they <u>do not</u> have ASD, but are receiving services for ASD from MPS ECSE. These children would not be included in the ideal population prevalence estimate, but are included in administrative prevalence and in program participation rates.

- Children in **A** and **M** (and **C**) : these children truly have ASD and are receiving services for ASD from MPS ECSE. These children are in the ideal population prevalence estimate, and are also included in administrative prevalence and in program participation rates.

Appendix G: Inclusion criteria for birth cohorts and ASD cases reflecting birthplace and school district residency assumptions applied to Minneapolis Public Schools special education participation data

Birth cohort inclusion criteria:

- Age: 3 to 4 years on December 1 of the school year according to date of birth
- Birthplace: Minnesota (state=024 on birth record)
- Residency: Minneapolis (state=024, county=027, city=041 for maternal place of residence on birth record)
- Somali children are identified as those whose mother's birthplace was Somalia (country code=788 on birth record)

Analysis 1 ASD case criteria:

- Children enrolled in the Minneapolis Public School District
- Who were enrolled in the ECSE Citywide Autism program during the school year (ECSE Citywide ASD Program/Classroom), OR had an ASD disability label and/or were enrolled in the ECSE Citywide Autism program (All ASD programs)
- Age: 3 to 4 years on December 1 of the school year
- Birthplace: Minneapolis listed as birthplace in school records
- Residency: Minneapolis Public School District, during the school year listed
- Somali children are identified as those whose home language is Somali

Analysis 2 ASD case criteria:

- Same as for Analysis 1, except with no residency requirement

Analysis 3 ASD case criteria:

- Same as for Analysis 1, except with birthplace anywhere in Minnesota

Analysis 4 ASD case criteria:

- Same as for Analysis 3, except with no residency requirement

(**Appendix G cont'd:** Inclusion criteria **)**

Analysis	Birthplace	School district residency for a given school year	Description of potential erroneous inclusions and exclusions
1	Minneapolis	Minneapolis	- Erroneously excludes children born in suburban birthing hospitals whose mothers were residents of Minneapolis at the time of birth. - Erroneously excludes children born in out-of-state hospitals whose mothers were residents of Minneapolis at the time of birth. - Erroneously excludes children who are members of the cohort but moved to another school district (lost to follow-up). - Erroneously includes children who attend MPS through open enrollment and who were born in a Minneapolis birthing hospital but whose mothers were non-residents at the time of birth.
2	Minneapolis	None	- Erroneously excludes children born in suburban birthing hospitals whose mothers were residents of Minneapolis at the time of birth. - Erroneously excludes children born in out-of-state hospitals whose mothers were residents of Minneapolis at the time of birth. - Erroneously excludes children who are members of the cohort but moved to another school district (lost to follow-up). - Erroneously includes children who attend MPS through open enrollment and who were born in at Minneapolis birthing hospital but whose mothers were non-residents at the time of birth
3	Minnesota	Minneapolis	- Erroneously excludes children born in out-of-state hospitals whose mothers were residents of Minneapolis at the time of birth. - Erroneously excludes children who are members of the cohort but moved to another school district (lost to follow-up). - Erroneously includes children whose mothers were non-residents at the time of birth.
4	Minnesota	None	- Erroneously excludes children born in out-of-state hospitals whose mothers were residents of Minneapolis at the time of birth. - Erroneously excludes children who are members of the cohort but moved to another school district (lost to follow-up). - Erroneously includes children who have residency in another school district but attend MPS through open enrollment. - Erroneously includes children whose mothers were non-residents at the time of birth.

Appendix H: Results tables, September 1 index date

Table H1. Analysis 1, September 1 index date: Birthplace and school district residency restricted to Minneapolis. Administrative ASD prevalence for Somali and non-Somali children by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

	ECSE Citywide ASD Classroom Program				All MPS ASD Programs			
	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)
2005-2006 School Year								
Cases/ Population	31/ 13054	22/ 12088	9/ 966	5.1 (2.1-11.6)	38/ 13054	29/ 12088	9/ 966	3.9 (1.6-8.4)
Percent (95% CI)	0.24% (0.16-0.34%)	0.18% (0.11-%0.28)	0.93%* (0.43-1.76%)		0.29% (0.21-0.40%)	0.24% (0.16-0.34%)	0.93%* (0.43-1.76%)	
2006-2007 School Year								
Cases/ Population	32/ 12955	24/ 11982	8/ 973	4.1 (1.6-9.4)	37/ 12955	29/ 11982	8/ 973	3.4 (1.4-7.6)
Percent (95% CI)	0.25% (0.17-0.35%)	0.20% (0.13-0.30%)	0.82%* (0.36-1.61%)		0.29% (0.20-0.39%)	0.24% (0.16-0.35%)	0.82%* (0.36-1.61%)	
2007-2008 School Year								
Cases/ Population	42/ 12906	32/ 11957	10/ 949	3.9 (1.7-8.2)	62/ 12906	52/ 11957	10/ 949	2.4 (1.1-4.8)
Percent (95% CI)	0.33% (0.23-0.44%)	0.27% (0.18-0.38%)	1.05%* (0.51-1.93%)		0.48% (0.37-0.62%)	0.43% (0.32-0.57%)	1.05%* (0.51-1.93%)	

PR = Prevalence Ratio; CI=Confidence Interval.
*Two-sided $p<0.05$ for comparison with non-Somali children.

Table H2. Analysis 1, September 1 index date: Birthplace and school district residency restricted to Minneapolis. Administrative ASD prevalence for race/ethnic groups by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

ECSE Citywide ASD Classroom Program							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	1/ 924	4/ 2365	0/ 418	10/ 5535	16/ 3406	9/ 910	7/ 2496
Percent (95% CI)	0.11% (0.00-0.60%)	0.17% (0.05-0.43%)	0.00% (0.00-0.88%)	0.18% (0.09-0.33%)	0.47% (0.27-0.76%)	0.99% (0.45-1.87%)	0.28% (0.11-0.58%)
2006-2007 School Year							
Cases/ Population	2/ 948	5/ 2384	0/ 427	9/ 5532	16/ 3435	8/ 968	8/ 2467
Percent (95% CI)	0.21% (0.03-0.76%)	0.21% (0.07-0.49%)	0.00% (0.00-0.86%)	0.16% (0.07-0.31%)	0.47% (0.27-0.76%)	0.83% (0.36-1.62%)	0.32% (0.14-0.64%)
2007-2008 School Year							
Cases/ Population	1/ 946	8/ 2357	1/ 443	9/ 5495	23/ 3434	10/ 941	13/ 2493
Percent (95% CI)	0.11% (0.00-0.59%)	0.34% (0.15-0.67%)	0.23% (0.01-1.25%)	0.16% (0.07-0.31%)	0.67% (0.43-1.00%)	1.06% (0.51-1.95%)	0.52% (0.28-0.89%)
All MPS ASD Programs							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	1/ 924	4/ 2365	0/ 418	17/ 5535	16/ 3406	9/ 910	7/ 2496
Percent (95% CI)	0.11% (0.00-0.60%)	0.17% (0.05-0.43%)	0.00% (0.00-0.88%)	0.31% (0.18-0.49%)	0.47% (0.27-0.76%)	0.99% (0.45-1.87%)	0.28% (0.11-0.58%)
2006-2007 School Year							
Cases/ Population	2/ 948	5/ 2384	0/ 427	14/ 5532	16/ 3435	8/ 968	8/ 2467
Percent (95% CI)	0.21% (0.03-0.76%)	0.21% (0.07-0.49%)	0.00% (0.00-0.86%)	0.25% (0.14-0.42%)	0.47% (0.27-0.76%)	0.83% (0.36-1.62%)	0.32% (0.14-0.64%)
2007-2008 School Year							
Cases/ Population	2/ 946	8/ 2357	1/ 443	24/ 5495	27/ 3434	10/ 941	17/ 2493
Percent (95% CI)	0.21% (0.03-0.76%)	0.34% (0.15-0.67%)	0.23% (0.01-1.25%)	0.44% (0.28-0.65%)	0.79% (0.52-1.14%)	1.06% (0.51-1.95%)	0.68% (0.40-1.09%)

CI=Confidence Interval.
Note: Children of mothers who were classified as "unknown" race or Hispanic ethnicity or "other" race in birth records are not included in denominators in this table.

Table H3. Analysis 2, September 1 index date: Birthplace restricted to Minneapolis, no school district residency restriction. Administrative ASD prevalence for Somali and non-Somali children by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

	ECSE Citywide ASD Classroom Program				All MPS ASD Programs			
	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)
2005-2006 School Year								
Cases/ Population	33/ 13054	24/ 12088	9/ 966	4.7 (1.9-10.4)	40/ 13054	31/ 12088	9/ 966	3.6 (1.5-7.8)
Percent (95% CI)	0.25% (0.17-0.35%)	0.20% (0.13-0.30%)	0.93%* (0.43-1.76%)		0.31% (0.22-0.42%)	0.26% (0.17-0.36%)	0.93%* (0.43-1.76%)	
2006-2007 School Year								
Cases/ Population	36/ 12955	28/ 11982	8/ 973	3.5 (1.4-7.9)	42/ 12955	34/ 11982	8/ 973	2.9 (1.2-6.4)
Percent (95% CI)	0.28% (0.19-0.38%)	0.23% (0.16-0.34%)	0.82%* (0.36-1.61%)		0.32% (0.23-0.44%)	0.28% (0.20-0.40%)	0.82%* (0.36-1.61%)	
2007-2008 School Year								
Cases/ Population	42/ 12906	32/ 11957	10/ 949	3.9 (1.7-8.2)	63/ 12906	53/ 11957	10/ 949	2.4 (1.1-4.7)
Percent (95% CI)	0.33% (0.23-0.44%)	0.27% (0.18-0.38%)	1.05%* (0.51-1.93%)		0.49% (0.38-0.62%)	0.44% (0.33-0.58%)	1.05%* (0.51-1.93%)	

PR = Prevalence Ratio; CI=Confidence Interval.
*Two-sided $p<0.05$ for comparison with non-Somali children.

Table H4. Analysis 2, September 1 index date: Birthplace restricted to Minneapolis, no school district residency restriction. Administrative ASD prevalence for race/ethnic groups by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

ECSE Citywide ASD Classroom Program							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	1/ 924	4/ 2365	0/ 418	10/ 5535	18/ 3406	9/ 910	9/ 2496
Percent (95% CI)	0.11% (0.00-0.60%)	0.17% (0.05-0.43%)	0.00% (0.00-0.88%)	0.18% (0.09-0.33%)	0.53% (0.31-0.83%)	0.99% (0.45-1.87%)	0.36% (0.17-0.68%)
2006-2007 School Year							
Cases/ Population	2/ 948	5/ 2384	0/ 427	10/ 5532	19/ 3435	8/ 968	11/ 2467
Percent (95% CI)	0.21% (0.03-0.76%)	0.21% (0.07-0.49%)	0.00% (0.00-0.86%)	0.18% (0.09-0.33%)	0.55% (0.33-0.86%)	0.83% (0.36-1.62%)	0.45% (0.22-0.80%)
2007-2008 School Year							
Cases/ Population	1/ 946	8/ 2357	1/ 443	9/ 5495	23/ 3434	10/ 941	13/ 2493
Percent (95% CI)	0.11% (0.00-0.59%)	0.34% (0.15-0.67%)	0.23% (0.01-1.25%)	0.16% (0.07-0.31%)	0.67% (0.43-1.00%)	1.06% (0.51-1.95%)	0.52% (0.28-0.89%)
All MPS ASD Programs							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	1/ 924	4/ 2365	0/ 418	17/ 5535	18/ 3406	9/ 910	9/ 2496
Percent (95% CI)	0.11% (0.00-0.60%)	0.17% (0.05-0.43%)	0.00% (0.00-0.88%)	0.31% (0.18-0.49%)	0.53% (0.31-0.83%)	0.99% (0.45-1.87%)	0.36% (0.17-0.68%)
2006-2007 School Year							
Cases/ Population	3/ 948	5/ 2384	0/ 427	15/ 5532	19/ 3435	8/ 968	11/ 2467
Percent (95% CI)	0.32% (0.07-0.92%)	0.21% (0.07-0.49%)	0.00% (0.00-0.86%)	0.27% (0.15-0.45%)	0.55% (0.33-0.86%)	0.83% (0.36-1.62%)	0.45% (0.22-0.80%)
2007-2008 School Year							
Cases/ Population	2/ 946	8/ 2357	1/ 443	25/ 5495	27/ 3434	10/ 941	17/ 2493
Percent (95% CI)	0.21% (0.03-0.76%)	0.34% (0.15-0.67%)	0.23% (0.01-1.25%)	0.45% (0.29-0.67%)	0.79% (0.52-1.14%)	1.06% (0.51-1.95%)	0.68% (0.40-1.09%)

CI=Confidence Interval.
Note: Children of mothers who were classified as "unknown" race or Hispanic ethnicity or "other" race in birth records are not included in denominators in this table.

Table H5. Analysis 3, September 1 index date: Birthplace restricted to Minnesota, school district residency restricted to Minneapolis. Administrative ASD prevalence for Somali and non-Somali children by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

	ECSE Citywide ASD Classroom Program				All MPS ASD Programs			
	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)
2005-2006 School Year								
Cases/ Population	43/ 13054	33/ 12088	10/ 966	3.8 (1.7-7.9)	55/ 13054	45/ 12088	10/ 966	2.8 (1.2-5.6)
Percent (95% CI)	0.33% (0.24-0.44%)	0.27% (0.19-0.38%)	1.04%* (0.50-1.90%)		0.42% (0.32-0.55%)	0.37% (0.27-0.50%)	1.04%* (0.50-1.90%)	
2006-2007 School Year								
Cases/ Population	54/ 12955	44/ 11982	10/ 973	2.8 (1.3-5.6)	67/ 12955	55/ 11982	12/ 973	2.7 (1.3-5.1)
Percent (95% CI)	0.42% (0.31-0.54%)	0.37% (0.27-0.49%)	1.03%* (0.49-1.88%)		0.52% (0.40-0.66%)	0.46% (0.35-0.60%)	1.23%* (0.64-2.14%)	
2007-2008 School Year								
Cases/ Population	67/ 12906	54/ 11957	13/ 949	3.0 (1.5-5.6)	97/ 12906	84/ 11957	13/ 949	1.9 (1.0-3.5)
Percent (95% CI)	0.52% (0.40-0.66%)	0.45% (0.34-0.59%)	1.37%* (0.73-2.33%)		0.75% (0.61-0.92%)	0.70% (0.56-0.87%)	1.37% (0.73-%)	

PR = Prevalence Ratio; CI=Confidence Interval.
*Two-sided $p<0.05$ for comparison with non-Somali children.

Table H6. Analysis 3, September 1 index date: Birthplace restricted to Minnesota, school district residency restricted to Minneapolis. Administrative ASD prevalence for race/ethnic groups by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

ECSE Citywide ASD Classroom Program							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	1/ 924	4/ 2365	0/ 418	20/ 5535	18/ 3406	10/ 910	8/ 2496
Percent (95% CI)	0.11% (0.00-0.60%)	0.17% (0.05-0.43%)	0.00% (0.00-0.88%)	0.36% (0.22-0.56%)	0.53% (0.31-0.83%)	1.10% (0.53-2.01%)	0.32% (0.14-0.63%)
2006-2007 School Year							
Cases/ Population	2/ 948	5/ 2384	0/ 427	23/ 5532	24/ 3435	10/ 968	14/ 2467
Percent (95% CI)	0.21% (0.03-0.76%)	0.21% (0.07-0.49%)	0.00% (0.00-0.86%)	0.42% (0.26-0.62%)	0.70% (0.45-1.04%)	1.03% (0.50-1.89%)	0.57% (0.31-0.95%)
2007-2008 School Year							
Cases/ Population	2/ 946	10/ 2357	1/ 443	22/ 5495	32/ 3434	13/ 941	19/ 2493
Percent (95% CI)	0.21% (0.03-0.76%)	0.42% (0.20-0.78%)	0.23% (0.01-1.25%)	0.40% (0.25-0.61%)	0.93% (0.64-1.31%)	1.38% (0.74-2.35%)	0.76% (0.46-1.19%)
All MPS ASD Programs							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	1/ 924	4/ 2365	1/ 418	28/ 5535	21/ 3406	10/ 910	11/ 2496
Percent (95% CI)	0.11% (0.00-0.60%)	0.17% (0.05-0.43%)	0.24% (0.01-1.33%)	0.51% (0.34-0.73%)	0.62% (0.38-0.94%)	1.10% (0.53-2.01%)	0.44% (0.22-0.79%)
2006-2007 School Year							
Cases/ Population	2/ 948	5/ 2384	2/ 427	32/ 5532	26/ 3435	12/ 968	14/ 2467
Percent (95% CI)	0.21% (0.03-0.76%)	0.21% (0.07-0.49%)	0.47% (0.06-1.68%)	0.58% (0.40-0.82%)	0.76% (0.50-1.11%)	1.24% (0.64-2.16%)	0.57% (0.31-0.95%)
2007-2008 School Year							
Cases/ Population	3/ 946	10/ 2357	2/ 443	46/ 5495	36/ 3434	13/ 941	23/ 2493
Percent (95% CI)	0.32% (0.07-0.92%)	0.42% (0.20-0.78%)	0.45% (0.05-1.62%)	0.84% (0.61-1.12%)	1.05% (0.74-1.45%)	1.38% (0.74-2.35%)	0.92% (0.59-1.38%)

CI=Confidence Interval.
Note: Children of mothers who were classified as "unknown" race or Hispanic ethnicity or "other" race in birth records are not included in denominators in this table.

Table H7. Analysis 4, September 1 index date: Birthplace restricted to Minnesota, no school district residency restriction. Administrative ASD prevalence for Somali and non-Somali children by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

	ECSE Citywide ASD Classroom Program				All MPS ASD Programs			
	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)	All Children	Non-Somali	Somali	PR (Somali/ Non-Somali) (95% CI)
2005-2006 School Year								
Cases/ Population	46/ 13054	36/ 12088	10/ 966	3.5 (1.5-7.2)	59/ 13054	49/ 12088	10/ 966	2.6 (1.2-5.1)
Percent (95% CI)	0.35% (0.26-0.47%)	0.30% (0.21-0.41%)	1.04%* (0.50-1.90%)		0.45% (0.34-0.58%)	0.41% (0.30-0.54%)	1.04%* (0.50-1.90%)	
2006-2007 School Year								
Cases/ Population	59/ 12955	49/ 11982	10/ 973	2.5 (1.1-5.0)	73/ 12955	61/ 11982	12/ 973	2.4 (1.2-4.5)
Percent (95% CI)	0.46% (0.35-0.59%)	0.41% (0.30-0.54%)	1.03%* (0.49-1.88%)		0.56% (0.44-0.71%)	0.51% (0.39-0.65%)	1.23%* (0.64-2.14%)	
2007-2008 School Year								
Cases/ Population	67/ 12906	54/ 11957	13/ 949	3.0 (1.5-5.6)	101/ 12906	88/ 11957	13/ 949	1.9 (1.0-3.4)
Percent (95% CI)	0.52% (0.40-0.66%)	0.45% (0.34-0.59%)	1.37%* (0.73-2.33%)		0.78% (0.64-0.95%)	0.74% (0.59-0.91%)	1.37% (0.73-2.33%)	

PR = Prevalence Ratio; CI=Confidence Interval.
*Two-sided $p<0.05$ for comparison with non-Somali children.

Table H8. Analysis 4, September 1 index date: Birthplace restricted to Minnesota, no school district residency restriction. Administrative ASD prevalence for race/ethnic groups by ASD program participation, 3 and 4 year olds, Minneapolis Public Schools.

ECSE Citywide ASD Classroom Program							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	1/ 924	4/ 2365	0/ 418	20/ 5535	21/ 3406	10/ 910	11/ 2496
Percent (95% CI)	0.11% (0.00-0.60%)	0.17% (0.05-0.43%)	0.00% (0.00-0.88%)	0.36% (0.22-0.56%)	0.62% (0.38-0.94%)	1.10% (0.53-2.01%)	0.44% (0.22-0.79%)
2006-2007 School Year							
Cases/ Population	2/ 948	5/ 2384	0/ 427	25/ 5532	27/ 3435	10/ 968	17/ 2467
Percent (95% CI)	0.21% (0.03-0.76%)	0.21% (0.07-0.49%)	0.00% (0.00-0.86%)	0.45% (0.29-0.67%)	0.79% (0.52-1.14%)	1.03% (0.50-1.89%)	0.69% (0.40-1.10%)
2007-2008 School Year							
Cases/ Population	2/ 946	10/ 2357	1/ 443	22/ 5495	32/ 3434	13/ 941	19/ 2493
Percent (95% CI)	0.21% (0.03-0.76%)	0.42% (0.20-0.78%)	0.23% (0.01-1.25%)	0.40% (0.25-0.61%)	0.93% (0.64-1.31%)	1.38% (0.74-2.35%)	0.76% (0.46-1.19%)
All MPS ASD Programs							
	Asian	Hispanic	Native American	White	Black	Black and Somali	Black and non-Somali
2005-2006 School Year							
Cases/ Population	1/ 924	4/ 2365	1/ 418	29/ 5535	24/ 3406	10/ 910	14/ 2496
Percent (95% CI)	0.11% (0.00-0.60%)	0.17% (0.05-0.43%)	0.24% (0.01-1.33%)	0.52% (0.35-0.75%)	0.70% (0.45-1.05%)	1.10% (0.53-2.01%)	0.56% (0.31-0.94%)
2006-2007 School Year							
Cases/ Population	3/ 948	5/ 2384	2/ 427	34/ 5532	29/ 3435	12 968	17/ 2467
Percent (95% CI)	0.32% (0.07-0.92%)	0.21% (0.07-0.49%)	0.47% (0.06-1.68%)	0.61% (0.43-0.86%)	0.84% (0.57-1.21%)	1.24% (0.64-2.16%)	0.69% (0.40-1.10%)
2007-2008 School Year							
Cases/ Population	3/ 946	10/ 2357	2/ 443	50/ 5495	36/ 3434	13/ 941	23/ 2493
Percent (95% CI)	0.32% (0.07-0.92%)	0.42% (0.20-0.78%)	0.45% (0.05-1.62%)	0.91% (0.68-1.20%)	1.05% (0.74-1.45%)	1.38% (0.74-2.35%)	0.92% (0.59-1.38%)

CI=Confidence Interval.
Note: Children of mothers who were classified as "unknown" race or Hispanic ethnicity or "other" race in birth records are not included in denominators in this table.

Appendix I: Comparison of medical and educational qualitative criteria for autism

Column 1: Clinical Criteria for "Autistic Disorder" from DSM-IV-TR	Column 2: MN Educational Administrative Criteria for "Autism Spectrum Disorder (ASD)"
Total of at least *6 impairments** with ≥ 2 from (A) and ≥ 1 from *both* (B) *and* (C)	Total of at least 3 impairments, with ≥ 2 from (A)** and ≥ 1 from (B) or (C)
(A) Social interaction	
• Lack of socially-regulating nonverbal behaviors, eye-to-eye gaze, facial expressions, postures, gestures • Failure of developmentally-appropriate peer relationship formation • Lack of seeking out shared enjoyment, interests, or achievements with others by not showing, bringing, or pointing out items of interest • *Lack of social or emotional reciprocity*	• Lack of joint attention and facial expressions directed at others • Not showing or bringing items to others to share interest • Difficulty relating to people, objects, and events • Difficulty making and keeping friends • Vulnerable and unsafe due to social naïveté • Prefer to be isolated or enjoy solitary activities; misinterpreting the social and behavioral cues of others
(B) Communication	
• Delay or lack of speech (*not compensated by attempts at gestures or mime)* • Inability to initiate and sustain conversation if able to speak • Stereotyped, idiosyncratic, or repetitive use of language • Lack of varied, developmentally-appropriate, spontaneous make-believe or socially imitative play	• Not pointing to show interest or request • Using others' body parts as a tool • Lack of spontaneously imitative or varied imaginative play; delay or lack of spoken language • Limited understanding and use of nonverbal gestures, facial expressions, tone of voice • Odd tone, volume, rhythm, or rate of speech • Repetitive or idiosyncratic language • Inability to initiate or maintain conversation if able to speak
(C) Restricted, repetitive, and stereotyped patterns of behavior	
• Preoccupation with one or more stereotyped and restricted interest that is abnormally focused or intense • Inflexibly adherent to specific,	• Insistence on routines or rituals • Distress or resistance to changes in activity • Repetitive hand or finger mannerisms

nonfunctional routines or rituals • Stereotyped and repetitive motor mannerisms such and hand or finger flapping, or complex whole-body movements • Persistent preoccupation with parts of objects	• Lack of imaginative play vs. simple reenactment • Over- or under-reaction to sensory stimuli; rigid or rule-bound thinking • <u>Intense, focused preoccupation with limited interests or topics</u>

Notes	
* *Italicized* items are not explicitly accounted for in Minnesota's educational criteria (Column 2). Disturbance must have been present prior to age 3 in ≥ 1 from (A), (B), or (C), and should not be better accounted for by another primary psychiatric disorder, Rett's Disorder, Childhood Disintegrative Disorder, Schizophrenia, or Schizotypal or Avoidant Personality Disorders. "PDD-NOS" or "atypical autism" must meet at least 1 criterion for social-interaction impairment and have impaired communication and/or stereotyped patterns of behavior. "Asperger's Disorder" must meet at least 2 criteria for social-interaction impairments and at least 1 criterion for stereotyped behaviors, without any historical evidence of language or cognitive/adaptive delays.	** <u>Underlined</u> items are worded similarly to analogous DSM-IV clinical criteria (Column 1). A multidisciplinary educational team must review information from multiple sources and settings, addressing all 3 areas, via ≥ 2 methods (i.e. structured parent interview, autism checklists, developmental-behavioral rating scales, functional behavior assessments, DSM criteria, informal or standardized observation instruments, or intellectual testing). Autistic behaviors must be atypical for the child's developmental level; account for special educational needs; and be verified in at least 2 different settings on 2 different days. MN educational criteria do not differentiate between Autistic Disorder, Asperger's, and PDD-NOS or atypical autism. However, MN educational criteria are comparable to DSM-IV-TR criteria for PDD-NOS.

Appendix J: Early Intervention State-Level Child Find Activities, Birth to 5 Programs

Minnesota began its participation in the Federal Infant and Toddler Early Intervention Program of the Individuals with Disabilities Education Act (IDEA) in 1987. As a condition of participation, states were required to develop a Child Find System to include a public awareness campaign and a central directory of early childhood services. The goal of the child find system is "that eligible young children with disabilities and their families are identified, evaluated and referred for appropriate services."

With its roots in public health practice, the child find system components include:

- Public Awareness – creating awareness of an issue and what can be done about it
- Screening – indentifying individuals with an unrecognized health risk or asymptomatic disease or condition
- Outreach – locating population of interest or at-risk and providing information about the concern, what can be done about it and how services can be obtained
- Referral – assisting in the identification of and access to resource to prevent or resolve concerns
- Follow-up – determining if the services were obtained and if they were useful

In 1988, the state developed the public awareness campaign, "Not All Kids are Cut out to Develop the Same Way" to encourage local participation in the early intervention system and to provide materials for distribution to families and physicians through the local partners – public health, special education and human services.

That same year, grants were provided to local communities to develop their own child find system. Project KIT (Keep-In-Touch) was targeted to NICU graduates and included developmental screening and referral; 348-TOTS was designed as one phone number that Minneapolis parents could call if they concerns about their child's development; The Follow-Along Program established periodical developmental screenings in Southwestern Minnesota.

Through the late 1980s the early intervention system continued to evolve toward meeting the federal standards for full implementation in IDEA Infant and Toddler Early Intervention – then known as "Part H", now referred to as "Part C". In 1991, the Minnesota Department of Health was named as the lead agency for Child Find activities required under Part H.

Initial efforts were directed toward increasing awareness among health care providers and included a two-pronged approach: Increase awareness of early childhood developmental issues and what to do if a developmental problem is suspected. This was done by regular distribution of the newsletter "Best Foot Forward" to all pediatricians.

In 1994, Minnesota Children with Special Health Needs (MCSHN) at MDH received funding to develop a Information and Referral System where families and professionals could call for information on services and resources for children with special health

(Appendix J cont'd: Early Intervention State-Level Child Find Activities, Birth to 5 Programs)

needs. That same year a recommendation endorsed that Tracking and Follow-Along Program go statewide based on a study finding that those areas with a Follow Along Program identified more children in need of services and assured those children received services.

In 1995, the Minnesota legislature moved to fully implement Part C of IDEA and all that it requires.

In 2005, the Federal Office of Special Education Programs issued a finding that Minnesota was not implementing eligibility criteria for Early Intervention Services that were consistent with IDEA and required that the eligibility criteria be changed – thus increasing the number of children who are potentially eligible for services. Throughout the program's history, children have primarily been served in the Developmental Delay special education criteria available only through the age of 7.

In 2007 the Minnesota eligibility criteria rule was changed.

Public Awareness Activities
Developmental Wheels
Newsletters / Issue Briefs
Presentations to Parent Organizations
Materials for Physicians
Outreach to Physician Organizations

Screening Activities
Newborn metabolic screening
Newborn hearing screening
Follow Along Program

Outreach Activities
Local Public Health – CSHCN component sees about 5,000 at-risk infants and young children each year
Birth Defects Information System follow-up contacts
Central Directory of Services for Young Children with Disabilities

Referral / Follow-up Activities
Information and assistance line
MCSHN Clinics
BDIS, Hearing and Metabolic Screening - ongoing contact for children with confirmed diagnosis

(Appendix J cont'd: Early Intervention State-Level Child Find Activities, Birth to 5 Programs)

Chronology of Outreach to Somali and other Non-English Speaking Communities Related to Child Find Activities

2002

- Follow-Along Program Brochure and activity sheets available in Somali

2003

- Early Hearing Detection / Intervention Brochures and Speech and Language checklists available in Hmong, Somali, Spanish, English
- Wheels and Fact Sheets translated to Spanish

2004

- Follow-Along Program staff and C and TC Staff Provide major training (held at the Metrodome) for Somali professionals and volunteers on developmental screening
- Individual Family Service Plan Document (required by Part C) available in Somali

2005

- ECHO Productions (Somali, Hmong, Spanish and others)
    - Child and Teen Check Up
    - Mental Health Help

2007

- Somali Language: Developmental Red Flags DVD
- Developmental Red Flags Training for People Working with Somali Families in St. Paul, St. Cloud and Rochester.
- Wheels and Fact Sheets are translated to Somali
- ECHO Productions
    - Early Childhood Screening
- Birth Defects information system materials translated to Somali, Spanish and Hmong

2008

- ECHO Productions
    - Special Education Help for Young Children
- Facilitate validation of ASQ / ASQ-SE in Somali – Head Start/Brookes Publishing

Appendix K: Conditions that need to be met for a child to be included in the MPS dataset

1. A parent, guardian, or health care or other professional must have noticed a potential developmental problem.
2. A child must have been screened for a potential disability or developmental delay.
3. A child must have been evaluated for an ASD by a public school or other medical professional.
4. A child's condition must have met the eligibility criteria to receive special education services consistent with M.S. 3525.1325.
5. A child who met the MN eligibility criteria actually received at least some of their special education services through the MPS.

Appendix L: Acronyms

ASD	Autism Spectrum Disorder
CDC	Centers for Disease Control and Prevention
CI	Confidence Interval
CSHCN	Children with Special Health Care Needs
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, 4th Edition
ECSE	Early Childhood Special Education
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Plan
IFSP	Individual Family Service Plan
IQ	Intelligence Quotient
MDE	Minnesota Department of Education
MDH	Minnesota Department of Health
MDHS	Minnesota Department of Human Services
MPS	Minneapolis Public Schools
NCHS	National Center for Health Statistics
NS-CSHCN	National Survey of Children with Special Health Care Needs
PDD-NOS	Pervasive Developmental Disorder – Not Otherwise Specified
SLAITS	State and Local Area Integrated Telephone Survey

Appendix M: Glossary

Administrative Prevalence: the proportion of a specified population that has a disease or condition of interest at a particular time, based on administrative program data. See also "Population Prevalence."

Asperger Syndrome: part of autism spectrum disorders (ASD), Asperger syndrome is a developmental disorder in which people have severe difficulties understanding how to interact socially. http://www.webmd.com/brain/autism/tc/aspergers-syndrome-topic-overview

Assumptions: in statistics, specific conditions that should be satisfied for the application of certain statistical procedures in order to produce valid statistical results.

Autism Spectrum Disorders (ASD): a group of developmental disabilities that are characterized by impaired social and communication skills, and unusual repetitive behaviors and routines. ASD are also known as pervasive developmental disorders, and include autistic disorder, Asperger Syndrome, and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS).

Bias: distortion of statistical estimates from the true value. Bias can be the result of problems with data collection, selection of persons for a study, or the analysis or interpretation of results.

Birth cohort: a group of people born in a certain defined period of time. Birth cohorts can be additionally defined by geographic area.

Child Count: the annual count of children and youth, ages birth through 21, in Minnesota who are eligible for and receiving special education and related services. The Minnesota Department of Education completes this count on December 1 of each year, and the data are reported to the US Department of Education.

Denominator: the lower number in a fraction used to calculate a proportion. In a proportion such as population prevalence, the denominator indicates the size of a population.

Epidemiology: the study of the distribution and causes of disease in a population and the methods and techniques for acquiring such knowledge.

Estimate: an estimate is used to make inference about a target population whose true parameter value is unknown. Estimation is the process of using information from sample data in order to estimate the numerical values of unknown parameters in a population.

Etiology: the science of the causes or origins of disease.

Exact 95% Confidence Interval (Exact 95% CI): a measure of the reliability of an estimate. In statistical terms, it is the range of values within which the true value would be expected to fall 95 times out of 100. The width of a confidence interval is dependent on the number of individuals included in the analysis; estimates based on smaller numbers of individuals have wider confidence intervals. The "exact" 95% confidence interval is based on the binomial distribution, which is appropriate for small numbers of cases. See also "Statistical Significance."

Coterminous: having a boundary in common.

Decennial: pertaining to or lasting for ten years; occurring every ten years.

DSM-IV-TR: the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision, is published by the American Psychiatric Association and is the standard classification of mental disorders used by mental health professionals in the United States.
http://www.psych.org/MainMenu/Research/DSMIV.aspx

Fetal Alcohol Spectrum Disorder: FASD, also called fetal alcohol exposure (FAE) or fetal alcohol syndrome (FAS), is a term used to describe a range of mild to severe problems that a growing fetus can develop if the mother drinks alcohol while she is pregnant.
http://www.webmd.com/baby/tc/alcohol-effects-on-a-fetus-exams-and-tests

Fragile X Syndrome: FXS is the most common known cause of intellectual disability, also known as mental retardation, and developmental disability that can be inherited (passed from one generation to the next).
http://www.cdc.gov/ncbddd/single_gene/fragilex.htm

Individuals with Disabilities Education Act (IDEA): The Individuals with Disabilities Education Act (IDEA) is a law ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities. Infants and toddlers with disabilities (birth-2) and their families receive early intervention services under IDEA Part C. Children and youth (ages 3-21) receive special education and related services under IDEA Part B.
http://idea.ed.gov/

Monotonic: describes values that are consistently changing in one direction. A series of values is monotonically increasing if each value is larger than the previous value. Similarly, a series of values is monotonically decreasing if each value is smaller than the previous value.

National Survey of Children with Special Health Care Needs (NS-CSHCN): a national survey conduced by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics. The goal of the survey is to assess the prevalence and impact of special health care needs among children in all 50 states

and the District of Columbia. The NS-CSHCN was conducted in 2000-2002 and in 2005-2006.
http://mchb.hrsa.gov/cshcn05/index.htm

Numerator: the upper number in a fraction used to calculate a proportion. In a proportion such as population prevalence, the numerator indicates the number of cases in the population at a specified time.

Pervasive developmental disorder: The term "pervasive development disorders" (PDDs) refers to

a group of conditions that involve delays in the development of many basic skills, most notably the ability to socialize with others, to communicate and to use imagination. Children with these conditions often are confused in their thinking and generally have problems understanding the world around them. PDDs include autism spectrum disorders (ASDs).
http://www.webmd.com/brain/autism/development-disorder

Phenylketonuria: PKU is a genetic disorder in which a baby lacks or has very low levels of the enzyme phenylalanine hydroxylase (PAH).
http://children.webmd.com/tc/phenylketonuria-pku-topic-overview

Population Prevalence: the proportion of a specified population that has a disease or condition of interest at a particular time. The particular time can be a specific point in time (*point prevalence*) or a period of time (*period prevalence*). Population prevalence is estimated by dividing the number of cases of a disease or condition of interest at a particular time, by the size of the specified population at that time. See also "Administrative Prevalence."

Psychometric: concerning the measurement of psychological variables, such as intelligence, aptitude, and emotional disturbance.

p-value: the probability of obtaining a difference between the value of the test statistic and the hypothesized value of the parameter that is greater than or equal to the difference actually observed.

Robustness: a term used to describe the property of a statistical procedure if it is relatively insensitive to violation of certain assumptions on which it depends. Such a method remains useful even when one (or more) of its assumptions is (are) violated.

Sampling weights: adjustment factors applied to data from complex sample surveys (such as the NS-CSHCN) that account for the probability that a given individual in a population will be selected to participate in the survey. Sampling weights are used to calculate the prevalence of a characteristic in a population from the sample of persons that participated in the survey.

SLAITS: State and Local Area Integrated Telephone Survey system implemented by the National Center for Statistics (NCHS). http://www.cdc.gov/nchs/slaits.htm

Statistical Significance: use of statistics to determine whether a difference in values (e.g., means or proportions) is likely to exist. If a difference between two values is statistically significant, it means that it is unlikely that the difference between the two is due to chance.

Two-sample t test: this test is used to compare the means (central tendency of a data set) of two groups of subjects sampled independently. It is used to test the null hypothesis that the two groups have equal means.

Tuberous sclerosis: it is a rare genetic multisystem disorder that is typically apparent shortly after birth.
http://children.webmd.com/tuberous-sclerosis-10961