

CO-DEVELOPERS OF THE SDIS

Student Participants and Sleep Clinics/Hospitals/ Sleep Directors in the Study

A total of 821 children and their parents participated in the development of the SDIS: Two-hundred twenty-six participated in the Pilot Study in the Tampa Bay, FL area and 595 students participated in the Main National Validation Study of the SDIS. These participants ranged in age from 2-through-18 years. The ethnic composition of participants in the Main Study was 74.58% Caucasian, 9.93% African-American, 7.91% Hispanic-American, 5% Multi- Cultural, 1.85% Asian-American, 0.34% Native-American, and 0.34% Other Ethnicity. Although family demographics of the Main Study participants were very similar to the 2000 U.S. Census, income and parents' education were slightly higher than the national average. There were Five Sampling Groups in the Main Study:

Group One

This was a retrospective sampling of children who had undergone a medical evaluation between January 1, 2000 and December 31, 2002 for any sleep problems at two of the five American Academy of Sleep Medicine (AASM) accredited sleep centers/clinics used in this study (rationale for selection of research sites will be presented in the next section). Parents were mailed the SDIS and a Demographic survey approximately 6 months to two years after their child had received a sleep study and diagnosis. This group was included in the Main Study for two reasons: (1) To obtain a sample of students whose sleep disorder was being treated or had been corrected to determine if their academic and/or behavioral performance improved after treatment, and (2) to acquire a larger sample of narcolepsy subjects.

Group Two

This was a prospective sampling of children undergoing a medical evaluation for sleep problems at one of the five American Academy of Sleep Medicine (AASM) accredited sleep centers/clinics selected for this study. Parents of these children were asked to complete the SDIS and Demographic surveys before the overnight sleep evaluation started, so that they would not know or be influenced by the outcome of the sleep study.

Group Three

This was a prospective sampling of students in the Pasco County School District undergoing a screening or psychoeducational evaluation by a school psychologist. Many of these students were found eligible for special education, gifted classes, or 504 Plan accommodations.

Student Participants and Sleep Clinics/Hospitals/ Sleep Directors in the Study

Group Four

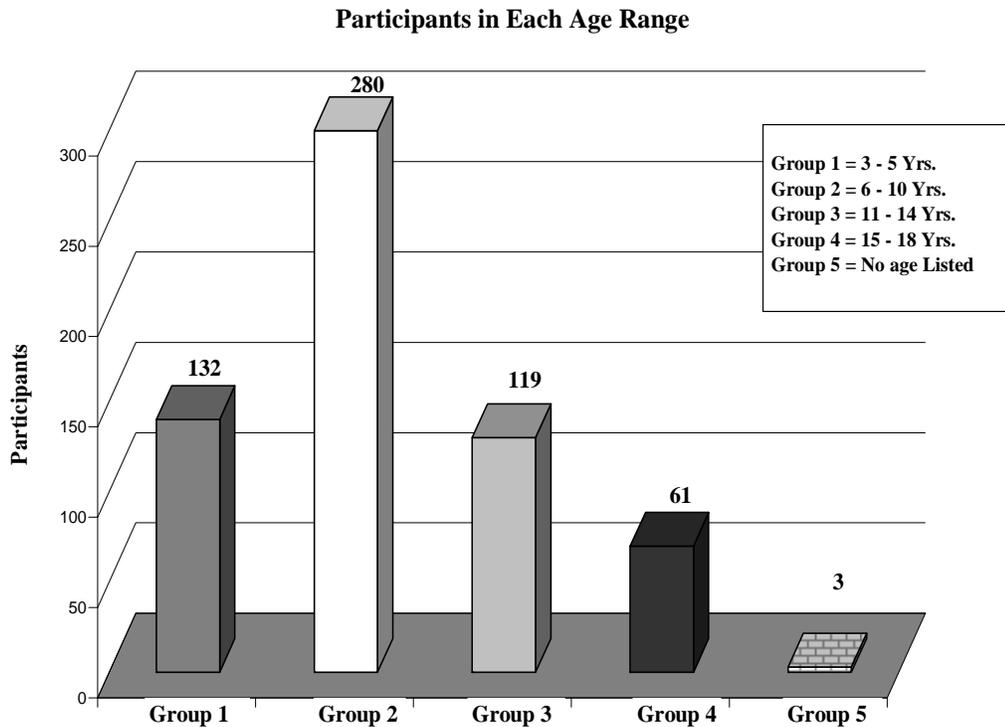
Group Four was a prospective sampling of children whose parents were Pasco County School District employees. This group was included to get a more normal sampling of children from the three-county Tampa Bay, FL area. The majority of these students were in general education classes and most of them did not appear to have sleep disorders.

Group Five

This was a prospective sampling of children receiving psychoeducational evaluations or counseling from two private practices, one located in Pinellas County, FL and the other located in Hillsborough County, FL.

When combining all five groups, there were students represented from 45 schools in the Tampa Bay region and many other schools (number not specifically tracked) throughout the nation.

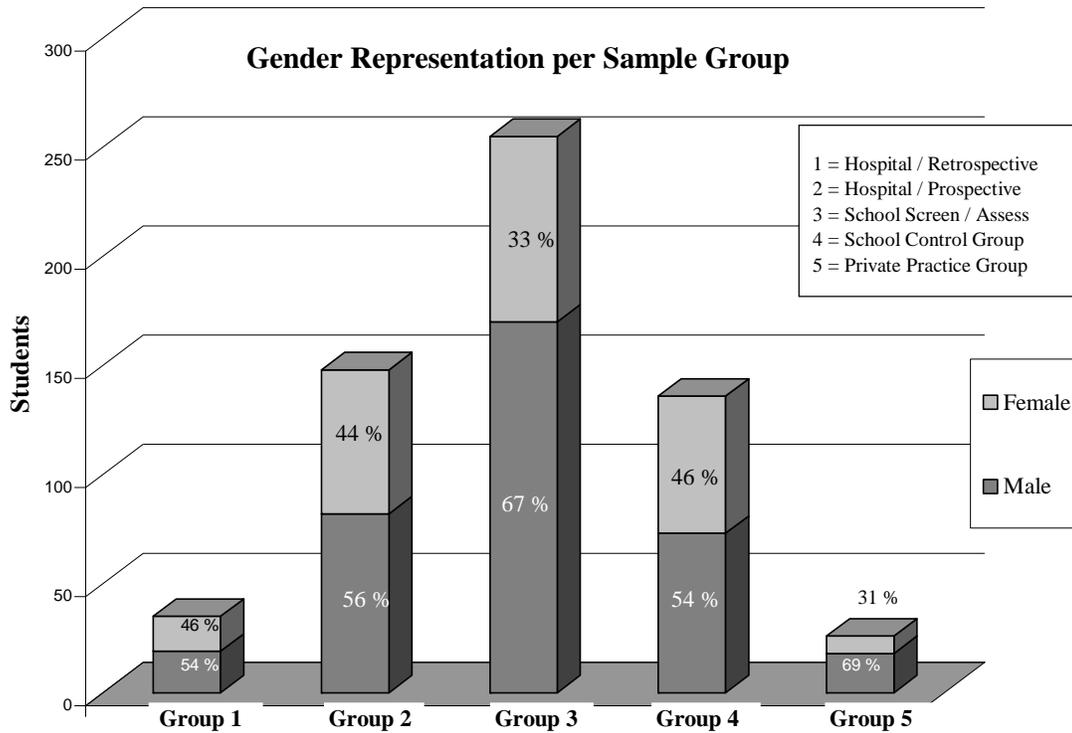
Some of the demographic data of the Main Study Students is listed below:



There were more children in Group 2 (ages 6-through-10 years) than the other age groups because more children of this age were referred to both sleep specialists and school psychologists for evaluations.

Student Participants and Sleep Clinics/Hospitals/ Sleep Directors in the Study

Gender Representation & Number of Children in the Five Sampling Groups



There were 359 male participants in the study (60.34%) and 236 female participants (39.66%). It appeared that there were a larger percentage of male participants referred to school psychologists and sleep clinics for screenings and evaluations, which explains the higher male-to-female ratio.

Student Participants and Sleep Clinics/Hospitals/ Sleep Directors in the Study

The following chart shows the breakdown of educational classifications for the School and Hospital Groups:

Summary of Educational Classification of Students from the School and Hospital Groups

Educational Classification	Schools & Private Practice		Hospitals		Total Study	
	Frequency	Percent	Frequency	Percent	Frequency	Percent
Total Number of Students . . .	<u>415</u>	69.7 %	<u>180</u>	30.3 %	<u>595</u>	100.0 %
Students not in Special Ed. (This includes Gifted & Preschoolers not in School) . .	275	66.0 %	100	55.0 %	375	62.8 %
Students in Special Ed.	139	34.0 %	80	45.0 %	220	37.2 %

Regular Education	204	49.5 %	97	53.8 %	301	50.8 %
Specific Learning Dis.	75	18.2 %	26	14.4 %	101	17.1 %
Speech/Lang. Impaired	67	16.3 %	38	21.1 %	105	17.7 %
Gifted	69	16.7 %	2	1.1 %	71	12.0 %
Developmentally Delayed . . .	26	6.3 %	12	6.6 %	38	6.4 %
Emotionally Handicapped or Behaviorally Disturbed . . .	24	5.8 %	14	7.8 %	38	6.4 %
Other Programs (PI, VI, DHH) . .	12	2.9 %	2	1.1 %	14	2.4 %

Note. The frequencies and percentages do not add up to 100% because some children received special education services from more than one program. Because this raises the percentages of special education classifications, this group could not be accurately compared to national averages.

Selection of Sampling Locations

This Main Study was a national study with hospitals targeted in different regions of the USA. Although five different regions were chosen in an attempt to get a more representative sampling throughout the nation, the hospitals in this study were primarily chosen because of the expertise of their sleep directors and physicians in the field of sleep medicine. They had extensive knowledge of the accurate diagnostic criteria for children and teens in regard to the specific sleep disorders being investigated in this research study. This was a purposive critical case nonprobability sample that is frequently used with research of diseases or medical disorders. This form of sampling is used when it is more important to find participants who have been given an accurate diagnosis, rather than have an exact normative or representative sample of the population.

Sleep Directors of five AASM hospitals agreed to participate in the national study. These five hospitals and their participating sleep directors were: (1) Carle Regional Sleep Disorders Center in Urbana, IL, (2) Johns Hopkins Pediatric Sleep Center in Baltimore, MD, (3) Miami Children’s Hospital in Miami, FL, (4) Stanford Sleep Disorders Clinic in Stanford, CA, and (5) University Community Hospital in Tampa, FL. These hospitals were chosen primarily for their excellent reputation in sleep medicine and for their regional representation and expertise regarding a specific sleep disorder.

Student Participants and Sleep Clinics/Hospitals/ Sleep Directors in the Study

(1) Carle Regional Sleep Disorders Center in Urbana, IL represented the Midwestern USA. The director of the sleep clinic, Daniel Picchietti, M.D., is nationally known for his extensive research and numerous professional articles focused on Periodic Limb Movement Disorder and Restless Legs Syndrome. All types of sleep disorders are evaluated at Carle Regional, but more students suspected of having PLMD or RLS are sent to Carle due to Dr. Picchietti's expertise in this area.

(2) Johns Hopkins Pediatric Sleep Center represented the Northeastern USA. The director of the data collection was Assistant Professor of Pediatrics, Ann Halbower, M.D. Johns Hopkins is professionally acknowledged for her expertise in diagnosing OSAS; however, all sleep disorders are evaluated at Johns Hopkins. Dr. Marcus, who is the sleep clinic director, has helped establish the AASM criteria for diagnosis of OSAS in children. Furthermore, Johns Hopkins serves a fairly large population of African-American patients (approximately 40%), which was an under-represented group in the Pilot Study.

(3) Miami Children's Hospital (MCH) represented the Southern region of the USA and evaluates all sleep disorders. This hospital was reported by sleep specialists in the Tampa Bay region to be a leader in identifying sleep disorders in children in the Southeastern USA. Since the Pilot Study was under-represented with Hispanic-American students, and it was believed that more Hispanic-American students should be added to the Main Study, MCH met this need. Approximately 70% of the MCH patients were Hispanic-American. A Spanish form of the SDIS was developed with the help of MCH.

(4) Stanford Sleep Disorders Clinic, CA represented the Western USA and is highly specialized in the diagnosis of Narcolepsy, although all types of sleep disorders are evaluated at Stanford. The director of Stanford Sleep Disorders Clinic, Rafael Pelayo, M.D., has been one of the most prolific national and international researchers of narcolepsy. Furthermore, Emmanuel Mignot, M.D., Ph.D., is also a world renowned researcher in the fields of sleep medicine, psychiatry, and molecular biology who recently discovered the genetic link for the cause of narcolepsy.

(5) University Community Hospital, Tampa, FL was added to the Southeastern sample to acquire more English-speaking participants and also increase the amount of narcolepsy and DSPS cases. Dr. William Kohler is a well-known sleep specialist who is director of the Pediatric Sleep Clinic and a pediatric neurologist specialized in sleep disorders

All of these sleep specialists at these four hospitals supported and assisted this principal investigator with the Main Study data collection, as well as offering invaluable recommendations about the process and development of the SDIS.

Student Participants and Sleep Clinics/Hospitals/ Sleep Directors in the Study

Sleep Disorder Diagnoses for the Main Study

There were only 180 children/teens in the Hospital Diagnosed Samples, but 27 of these children received two sleep diagnoses, which explains why there are 207 diagnoses mentioned below:

