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Children with Autism





United States Government Accountability Office Washington, DC 20548

January 14, 2005

The Honorable Dan Burton Chairman The Honorable Diane E. Watson Ranking Minority Member Subcommittee on Human Rights and Wellness Committee on Government Reform House of Representatives

According to the Autism Society of America, about 1.5 million Americans are currently living with some form of autism. This figure includes over 100,000 school-aged children diagnosed with autism served under the Individuals with Disabilities Education Act (IDEA), the primary federal legislation that addresses the educational needs of children with disabilities. As the number of children diagnosed with autism has increased, interest in understanding how children diagnosed with autism are being served under IDEA has grown.

You expressed an interest in the education of children with autism, and in this report we are describing the trend in the number of children diagnosed with autism served under IDEA, the services provided to these children, the estimated per pupil expenditures for educating children with autism, and approaches to their education.

To determine the number of children diagnosed with autism served under IDEA, we relied on data collected for the Department of Education (Education). To describe the services provided to children with autism, we reviewed relevant literature and spoke with Education officials. To describe the estimates of per pupil expenditures for educating children with autism, we reviewed data collected and analyzed by the Special Education Expenditure Project (SEEP), which was funded by Education and was the only national source of this type of data. We spoke with Education officials about the proper use and reliability of the data we used and found them to be sufficiently reliable for the purposes of this report. However, some weaknesses with the SEEP data exist, including a low survey response rate, potential response bias, and limited documentation. Finally, to describe approaches to the education of children with autism, we reviewed a 2001 report by the National Research Council on the education of children with autism. We conducted our work between

November and December 2004 in accordance with generally accepted government auditing standards.

On December 13, 2004, we briefed your staff on the results of our study. This report formally conveys the information provided during that briefing. In summary, we found:

The number of children diagnosed with autism served under IDEA has increased by more than 500 percent in the last decade. In 2002, data collected for the Department of Education indicated that nearly 120,000 children diagnosed with autism were being served under IDEA. This substantial increase may be due to a number of factors, including better diagnoses and a broader definition of autism.

The services provided to children with autism depend on the needs of the child. These services may include speech therapy, occupational therapy, and the services of special education teachers. As with other children with disabilities, children with autism are eligible for special education services under IDEA in accordance with their individualized education programs (programs established by a team familiar with the needs of the child).

The average per pupil expenditure for educating a child with autism was estimated by SEEP to be over \$18,000 in the 1999-2000 school year, the most recent year for which data were available. This estimate was nearly three times the expenditure for a typical regular education student who did not receive special education services and was among the highest per pupil expenditures for school-age children receiving special education services in public schools.

Finally, the National Research Council report offered several key features of successful approaches to the education of children with autism, including early intervention soon after the diagnosis of autism, which can generally occur by the age of 3. The report also offered guidelines regarding educational objectives for children with autism, including the development of social skills and expressive and receptive language and communication skills.

We provided a draft of this briefing to officials at Education for their technical review and incorporated their comments where appropriate.

Unless you publicly announce its contents earlier, we plan no further distribution until 30 days after the date of this report. At that time, we will send copies of this report to the Secretary of Education, relevant congressional committees, and other interested parties and will make copies available to others upon request. In addition, the report will be available at no charge on GAO's Web site at http://www.gao.gov.

If you or your staff have any questions about this report, please contact Marnie Shaul or Deborah Edwards at (202) 512-7215. Nagla'a El-Hodiri and Art Merriam also made key contributions to this report.

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Education of Children with Autism

Briefing for Staff of Rep. Dan Burton, Chairman and

Rep. Diane E. Watson, Ranking Minority Member Subcommittee on Human Rights & Wellness Committee on Government Reform House of Representatives

December 13, 2004



Introduction

- The Individuals with Disabilities Education Act (IDEA) is the primary federal legislation that addresses educational needs of children with disabilities, including autism.
- It is estimated that more than 1.5 million Americans live with some form of autism, including more than 100,000 children served under IDEA.
- Given the above numbers, there has been growing interest in the education of children with autism.



Research Questions

- 1. What is the trend in numbers of children with autism receiving services under IDEA?
- 2. What services are provided in educating these children?
- 3. What are the estimated per pupil expenditures for educating children with autism in public schools?
- 4. What approaches are used in educating children with autism?



Scope and Methodology

- To determine the trend in the number of children with autism receiving services under IDEA, we reviewed and analyzed Department of Education data. We interviewed officials from the Office of Special Education Programs (OSEP) about the proper use and reliability of the data.
- To determine the range of services provided to educate children with autism, we reviewed relevant literature and interviewed OSEP officials.



Scope and Methodology

- To determine the estimated expenditures associated with the education of children with autism, we reviewed existing Special Education Expenditure Project (SEEP) reports that analyzed expenditures by disability. In addition, we interviewed officials from OSEP regarding the proper use and reliability of the data.
- We found the study to be sufficient for informational purposes; however, the reliability of these data is undetermined for policy analysis. We are reporting on this study because the number of children with disabilities covered by the survey is sizeable and the results provide information about the magnitude of expenditures a "ballpark estimate." However, weaknesses in this study exist, including a low survey response rate, potential response bias, as well as limited documentation.
- To describe what is known about approaches to educating children with autism, we reviewed the recent report Educating Children with Autism (National Research Council) and spoke with Education officials.
- We conducted our work from November to December 2004 in accordance with generally accepted government auditing standards.



Summary of Results

- Data collected for the Department of Education indicate that the number of children ages 6 through 21 diagnosed with autism served under the IDEA has increased by more than 500 percent in the last decade.
- A variety of services, such as speech therapy and counseling, are made available to support the education of children with autism, in accordance with the child's needs.



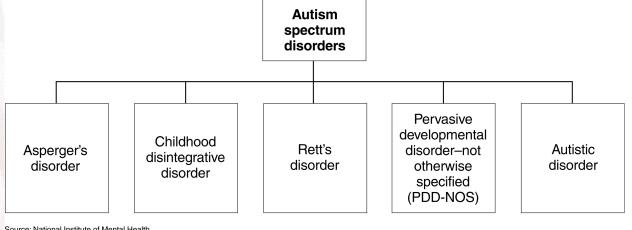
Summary of Results

- The SEEP report estimated that the average per pupil expenditure for educating a child with autism was more than \$18,000 in the 1999-2000 school year. This amount is almost three times the average per pupil expenditure of educating a child who does not receive any special education services.
- According to a 2001 National Research Council report, intervention at an early age is a key feature of successful approaches to educating children with autism.



 Autism spectrum disorders (ASD) are complex and include a number of disorders.

Figure 1: Disorders Included in the Range of ASD



Source: National Institute of Mental Health.



- Estimates of the prevalence of ASD range from 2 to 6 per 1,000 children.
- Characteristics of ASD are generally present by the age of 3 and include
 - deficits in social interaction,
 - deficits in verbal and nonverbal communication, and
 - · repetitive behaviors or interests.
- Often children with ASD have unusual responses to sensory stimulation.



- Currently, there is no consensus about the cause of ASD.
- Theories regarding the causes of ASD include genetic components, environmental components, and some combination of genetics and the environment.
- While no known cure for ASD exists, the general agreement is that early diagnosis followed by appropriate treatment can improve outcomes for later years for most children with ASD.



- IDEA is the primary federal law that addresses the unique needs of children with disabilities, including autism.
- The act
 - mandates the availability of a free appropriate public education for all eligible children with disabilities,
 - requires an individualized education program (IEP) for eligible children with disabilities,
 - requires the inclusion of students with disabilities in statewide and districtwide academic assessment programs, and
 - requires the placement of students in the least restrictive environment.



- SEEP was funded by Education to examine the nation's spending on special education and related services.
- SEEP reports are based on the analyses of data for the 1999-2000 school year. Data were collected by surveys at the state, district, and school levels. The databases include a sample of approximately 10,000 students with disabilities.



Research Question 1

What is the trend in numbers of children with autism receiving services under IDEA?



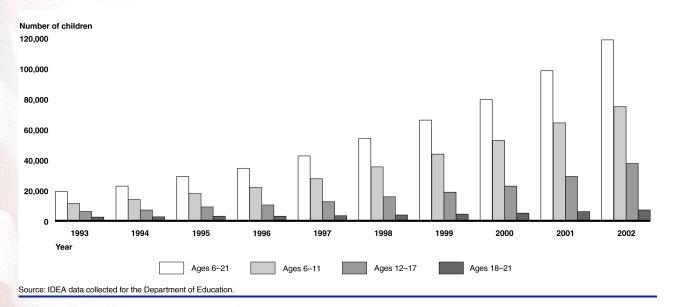
Increased Numbers of Children Diagnosed with Autism Receiving Services under IDEA

- The number of children ages 6 through 21 diagnosed with autism receiving services under IDEA has increased more than 500 percent over the past 10 years, from under 20,000 in 1993 to almost 120,000 in 2002, according to data collected for the Department of Education.
- Possible reasons for this increase include:
 - The advent of better diagnoses.
 - A wider range of conditions being categorized as ASD.
 - A higher incidence of autism in the general population.



Increased Numbers of Children Diagnosed with Autism Receiving Services under IDEA

Figure 2: Trend in Number of Children Ages 6 – 21 Diagnosed with Autism Served under IDEA by Age.





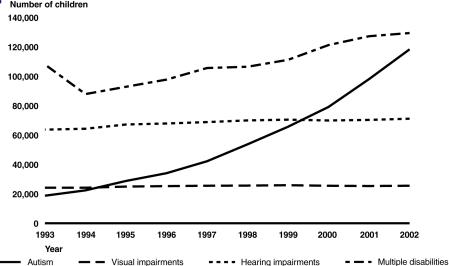
Increased Numbers of Children Diagnosed with Autism Receiving Services under IDEA

 The number of children ages 6 through 21 diagnosed with autism receiving services under IDEA has grown at a higher rate than the number of children diagnosed with certain other "low-incidence" disabilities (see fig. 3).



Increased Numbers of Children Diagnosed with Autism Receiving Services under IDEA

Figure 3: Trend in the Number of Children Ages 6-21 with Certain Low-Incidence Disabilities $_{\text{Number of children}}$



Source: IDEA data collected for the Department of Education.



Research Question 2

What services are provided in educating children with autism?



- A wide range of services can be available for children with autism, including
 - special education teachers/aides,
 - speech therapists,
 - behavioral therapists,
 - occupational therapists,
 - physical therapists, and
 - counselors/psychologists.



- Children with ASD may demonstrate a variety of manifestations of the disorder and need services accordingly. For example:
 - A child with autistic disorder may have great difficulty communicating and may need services focused on speech development.
 - A child with Asperger's disorder may be more verbal than other children with autism and may have average or above average intelligence, yet still be in need of services.
- In addition, services required for an individual child with autism can change over time.



- Children with autism are generally eligible for services under IDEA, including early intervention, preschool and school-age programs, and transitional services.
- IDEA Part C promotes early intervention for children with autism by funding early intervention services (birth to age 3).
- Early intervention services
 - are administered by a state-designated lead-agency,
 - include of a range of allowable services to address developmental delays,
 - can be provided in home and in community settings, and
 - provide a transition to preschool.



- IDEA Part B supports the educational needs of children with autism, ages 3 through 21.
- Preschool and school-age instructional and related services (3 through 21 years):
 - are administered by state and local education agencies and
 - include a range of allowable instructional and related services to address a student's individual educational needs.
- School age postsecondary transition services (generally 14 through 21 years):
 - are administered by state and local education agencies,
 - provide movement from school to post-school activities, and
 - identify the role of agencies in providing and funding transition services.



Research Question 3

What are the estimated per pupil expenditures for educating children with autism in public schools?



- According to SEEP, the estimated expenditure per child with autism was \$18,790 in the 1999-2000 school year, the most recent year for which data are available. For the same school year, per pupil expenditures for the typical regular education student were \$6,556.
- Included in this amount are expenditures associated with:
 - Instruction
 - Regular education
 - Special education
 - Administration and support
 - School and district levels
 - Special education program
 - Regular and special transportation services
 - School facilities



 According to SEEP, the estimated average annual expenditures of educating a child with autism were generally greater than those of educating a child with other disabilities in public school settings.

Table 1: Estimated per pupil expenditure by disability in 1999-2000 (in dollars), rounded to the nearest hundred.

	Average special education student	Autism	Emotional disorders	Mental retardation	Multiple disabilities
Average per pupil expenditures	12,500 ^a	18,800	14,100	15,000	20,100

Source: Special Education Expenditure Project.

Note: Apparent differences may not be statistically significant.

^a This figure represents the average expenditures for students with disabilities including those listed in this table as well as other disabilities.



- According to SEEP estimates:
 - Approximately 68 percent of total per pupil expenditures for children with autism in 1999-2000 (an estimated \$12,773) was used on instruction and related services.
 - Ninety percent of that amount (an estimated \$11,543)
 was used for special education services, while the
 remaining 10 percent (an estimated \$1,230) was used for
 regular education services.



- According to SEEP, expenditures for special education services can be categorized as follows:
 - special education classes classes designed specifically for students with disabilities, taught by special education teachers;
 - resource specialists includes special education teachers who either pull students with disabilities out of regular education classes or go into regular education classrooms to work with students with disabilities;
 - related services school psychologists, social workers, school nurses, speech/language specialists, and physical/occupational and other therapists; and
 - other special education services community-based training, extended time services, and summer school.



- Of the estimated \$11,543 spent per pupil on special education instructional services for children with autism, SEEP estimated that
 - 43% was spent on special education classes,
 - 24% was spent on related services,
 - 19% was spent on resource specialists, and
 - 14% was spent on other special education services.



Research Question 4

What approaches are used in educating children with autism?



- The National Research Council (NRC) report provides an overview of practices and challenges in educating children with autism.
 Among other topics, the study focuses on
 - intervention at an early age,
 - diagnosis and classification,
 - the rights of children with autism under IDEA, and
 - assistive technology.
- The report was based on existing research studies, model interventions, and workshops with researchers, educators, and others.



- NRC reported a general consensus that the following features were key to the education of children with autism across preschool programs:
 - Intervention programs as soon as an autism spectrum disorder is seriously considered.
 - Active engagement in intensive instructional programming— a minimum of a full school day, at least 5 days (25 hours)/week, full year.
 - Repeated teaching organized around short intervals with oneto-one and very small group instructions.
 - Inclusion of a family component.
 - Mechanisms for ongoing evaluation of program and children's progress, with adjustments made accordingly.



- Goals for educating children with autism are the same as goals for educating other children, that is
 - personal independence and
 - social responsibility.
- In addition, NRC found that the IEP for children with autism should include educational objectives that are
 - observable and measurable;
 - accomplishable within 1 year; and
 - affect a child's participation in education, community, and family life.
- Finally, progress should be monitored frequently and objectives adjusted accordingly.



- Educational objectives for children with autism should include the development of
 - social skills;
 - expressive verbal language, receptive language, nonverbal communications skills;
 - a functional symbolic communication system;
 - engagement and flexibility in developmentally appropriate tasks and play;
 - fine and gross motor skills;
 - cognitive skills (symbolic play and academic skills);
 - conventional/appropriate behaviors; and
 - independent organizational skills and skills for success in a regular classroom.



- In addition to sponsoring the NRC report, the Department of Education supports improving educational experiences of children with autism through a number of programs. For instance:
 - Education reports that they provide information and advocacy for families of children with ASD through Parent Training and Information Projects and Community-Parent Resource Centers.
 - Education has supported research regarding early identification of children with autism in order to increase the possibility that such children will receive services at a younger age.
 - To help prepare personnel, Education has funded some professional development programs focused on the education of children with autism.
 - Education participates in the Interagency Autism Coordinating Committee, established by the Children's Health Act of 2000.

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