

## Studying the Early Identification of Children's Developmental Disabilities

### Early Identification

Current estimates are that as many as 15 percent of U.S. children meet the definition for having a developmental disability. These disabilities include deafness (1/1000), severe vision impairment (1/1000), autism (now thought to affect 4-6/1000 children), severe mental health conditions (1-2 /100), mental retardation (1 -3 /100), language concerns (2-3/100), Attention Deficit Hyperactivity Disorder (ADHD; 4-6/100) and learning disabilities (5-6/100).

Increasing biologic and experiential evidence points to the importance of identifying these developmental concerns as early as possible. Prompt detection of difficulties allows families and professionals to intervene to remove noxious stimuli and to provide needed structure and stimulation. For some disabling conditions, there are effective treatments that can change the course of the children's lives (such as hearing aids for children with hearing loss and surgical correction for certain eye conditions). For other conditions, there are effective early interventions that can greatly improve the children's learning experience and avert secondary consequences for the child and family.

Early intervention starts with early identification. If a child's disabilities go unrecognized because of poor early detection systems or because of poor access to good systems, then the child cannot receive necessary treatments and interventions, and the family goes without support. As a result, in recent years, clinicians, scientists and policymakers have placed great emphasis on finding the best possible approaches to early identification. Policymakers, clinicians and researchers are interested in monitoring the timeliness of identification.

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For example, policymakers want to know whether new technologies, such as newborn hearing screening, are used consistently across the country. Likewise, there is policy interest in assessing the impact of having developmental expertise in pediatric offices and child-care settings. There is a need for an ongoing, real-time procedure that provides information back to the medical and education systems to allow improvements in early identification at the local, state and national levels. To delve into these issues, this report looks at two inter-related questions:

**Early intervention starts with early identification.**

1. Over the past 25 years, what have we learned about the early identification of children's developmental disabilities?
2. From a research point of view, what more do we to advance the practice of early identification?

### What We Have Learned

The past three decades have witnessed a great deal of scientific and policy interest in the issue of early identification of developmental disabilities among children 0-10 years old. **Appendix A** presents a bibliography of exemplary pediatric, educational and psychological

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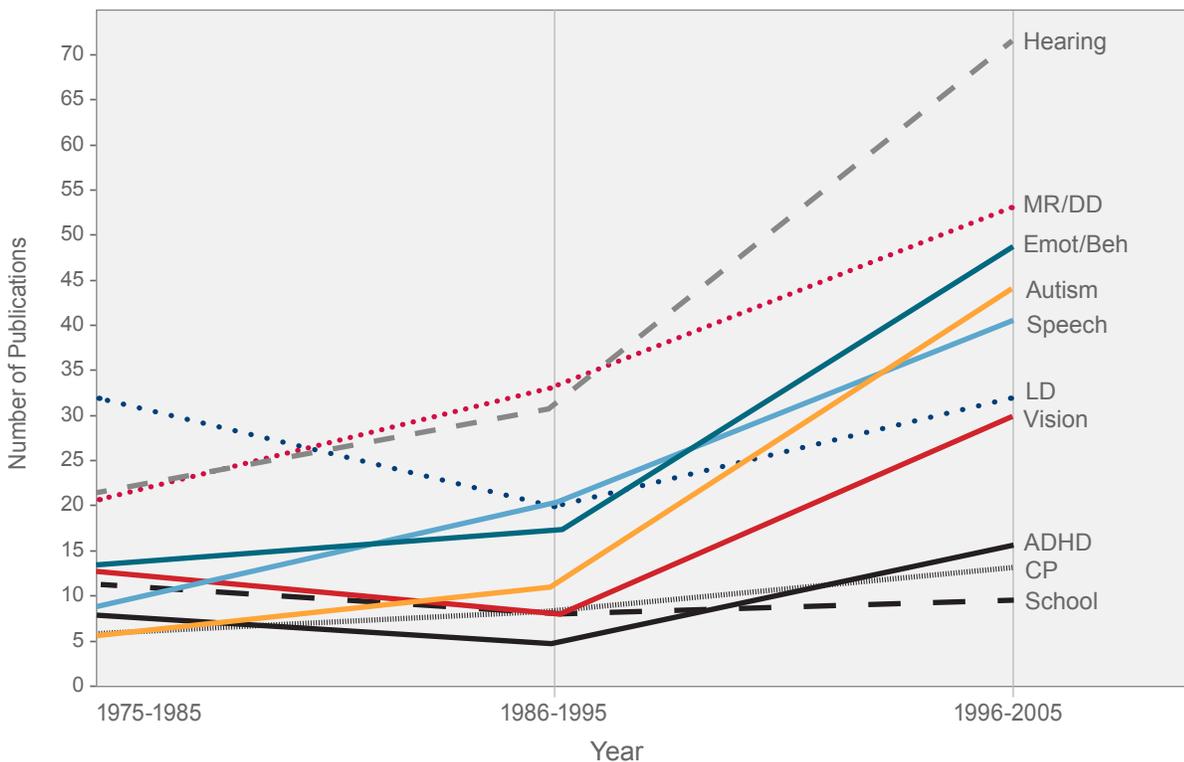
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**Figure 1: Articles on Early Identification by Disorder**



articles. Based on an analysis of these articles, **Figure 1** depicts the steep increase in publications over the 30 years, with a 2.5-fold growth in articles since 1986. Hearing and mental retardation/developmental delay (MR/DD) were the most discussed disorders, with each approximately doubling in the number of articles published in the past decade. The largest change since 1995 was the 5-fold increase in the number of articles related to the early identification of autism. Increases have also been seen for articles on the early detection of emotional/behavioral disorders, ADHD and vision disorders. The two disorders for which there has been a decreased interest in the academic literature are learning disabilities and severe school difficulties.

Trends in Article Types

Articles on early identification can be classified into three types:

- Type A: Discussions about the need for or potential benefits of early identification
- Type B: Information on the methodology of early identification
- Type C: Outcomes or observed impacts of early identification

**Figure 2** displays the bibliography's articles by these types for three 10-year windows of time plus a 15-year, pre-1975 window. Initially, there was a preponderance of studies arguing for the importance of early identification (type A). Over time, as the methodologies for identification became more sophisticated (e.g. the new technologies for hearing screening), there was increased experience to report as witnessed in the increases in type B studies. In the last time period, this experience began to show its effects in the form of articles that included specific data outcomes in type C studies.

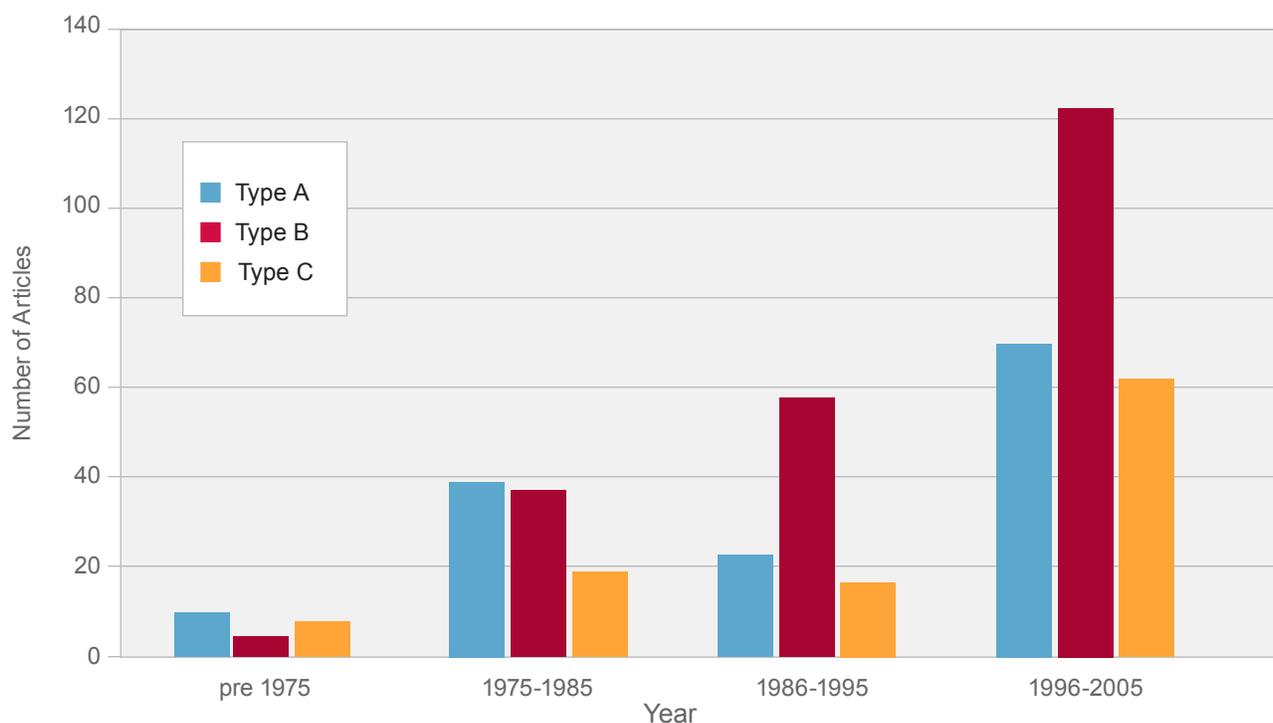
Among all three types, only 36 articles (7.7%) in the bibliography addressed the issue of disparities in the rates of early identification by race, language or economic condition.

**What More is Needed?**

Despite great interest in the topic of early childhood disabilities by clinicians, families, policymakers and researchers, the following questions remain largely unanswered:

1. For each disabling condition, is there a *consistent pattern of onset* that will allow clinicians and parents a window of opportunity for identification?

Figure 2: Article Types by Year



2. *Who generally identifies* disabling conditions in children? Physicians, educators, parents, or others?
3. At the present time, what is the *mean age of identification* of each of the disabling conditions? What is the error around that mean?
4. Has there been change in the *mean age of identification* for any of the disabling conditions over a) the past five years, b) the past decade, or c) the past twenty-five years?
5. Have any of the major national or state health and education *initiatives had an impact on early identification* of children's disabilities [i.e. Individuals with Disabilities Education Improvement Act of 2004 (IDEA), No Child Left Behind, Early and Periodic Screening, Diagnostic, and Treatment (EPSDT), State Children's Health Insurance Program (S-CHIP)]?
6. Is there a close *linkage between the identification of conditions and the provision of services*?
7. What are the *patterns of identification of children's disability by race, ethnicity, language spoken in the home and socioeconomic status (SES)*?
8. Are "biologically-determined" and "environmentally-determined" conditions *identified differently by race, ethnicity, language spoken in the home and SES*?

## Opportunities to Expand Knowledge

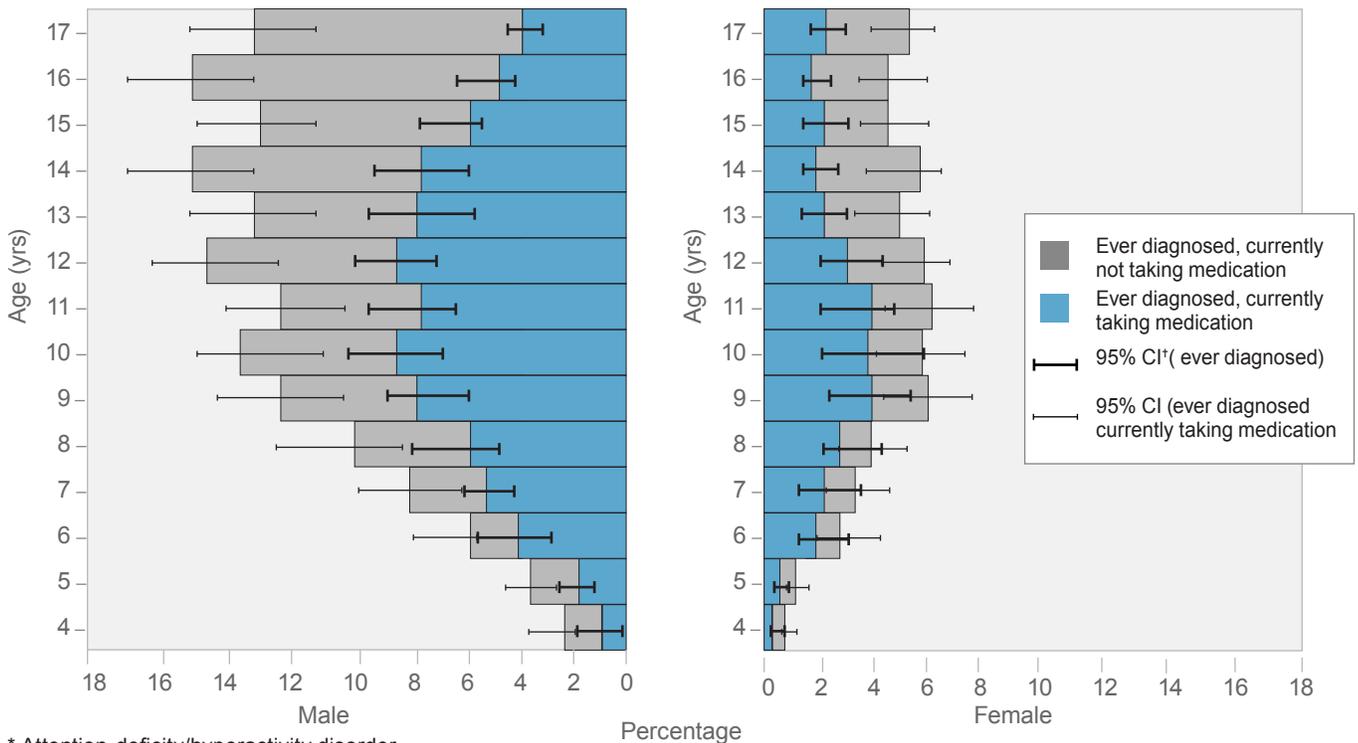
There are a number of excellent opportunities to address these questions. Consideration should be given to the following possibilities:

### Further analysis of extant databases:

#### 1. Prevalence trending—timing estimation

Because of the great interest in early identification of disabling conditions, both the health and educational communities have invested substantial effort in collecting data on the early emergence of concerns. **Appendix B** presents the rich source of data within large well-collected national health and education databases, including, for instance, [National Survey of Health in Early Childhood \(NSHEC; 2000\)](#), [National Survey of Children's Health \(NSCH; 2003\)](#), [National Health Interview Survey \(NHIS\)](#), [Early Childhood Longitudinal Study—Kindergarten \(ECLS-K\)](#), the [Special Education Elementary Longitudinal Study \(SEELS\)](#) as well as the comprehensive data presented annually by the Department of Education on the Individuals with Disabilities Education Act. While some of this information has been analyzed, much of the data still have not been reviewed, and some of the information is not easily available to clinicians and policymakers. Further analysis of the extant data could

**Figure 3. Percentage of children aged 4-17 years ever diagnosed with ADHD,\* by age, sex, and medication treatment status—United States 2003**



\* Attention-deficity/hyperactivity disorder.  
 † Confidence Interval

shed increased light on the issue of early identification and help to elucidate facilitators of and barriers to best practices.

An example of the kind of analysis that can yield fruitful results is the one conducted by researchers at the Centers for Disease Control and Prevention (CDC) on children with ADHD using the NSCH 2003 database. The figure below<sup>1</sup> shows that very few of the 4-year old children (~2 percent) had “ever been diagnosed” with ADHD. By contrast, 14 percent of boys ages 8 through 13 had “ever been diagnosed” as having ADHD, suggesting that the identification of ADHD is most likely to occur around 7-8 years of age.

The National Survey of Health in Early Childhood contains probes about referral to therapeutic and educational programs. Analysis of these data by age of the child in months could give additional evidence about the timing of early professional concerns. Since there are nearly five decades’ worth of information collected on the National Health Interview Survey, a study looking at the changes in prevalence of conditions might give a view into how disability has been recog-

nized over time. The questions on the Early Childhood Longitudinal Study—Kindergarten that pertain to diagnosis of ADHD, autism, emotional/behavioral disorders, hearing, learning disability, MR/DD, speech and vision would be very germane to analyze. The Special Education Elementary Longitudinal Study (SEELS) dataset includes direct questions about early parental concerns (“About how old was [CHILD] when he/she started having this/these difficulty/ies or condition?”). Since the children in the SEELS sample were ages 6-13 at the start of the study, there is the possibility of building an estimated secular trend from the information. A team at the Survey Research Institute (SRI) has begun such investigation. Using the SEELS data on “all conditions,” they have looked at *age of identification by age of the student at the time of the interview*. In a trending analysis, the authors show that the percentage of children identified between birth and age two was 30 percent for children who were 6 at the time of the interview as opposed to 18 percent for children who were 13 at the time of the interview. This finding suggests a trend toward improved early identification and diagnosis over time.

1. Reproduced from Morbidity and Mortality Weekly Report (MMWR), September 2, 2005/54(34): 842-847.

## 2. Disparities analysis

Further analysis of a number of the extant databases can help examine the complex issue of whether some groups of children have improved access to identification and services and others do not. The SES markers on the NSCH (2003) database allow for inquiries regarding socioeconomic effects. Three-way analyses of the age of identification by race and income should also be possible using data from the Morbidity and Mortality Weekly Report (MMWR) study on ADHD as well as the SEELS. Also, an analysis of the amount of time between identification and provision of services by income and by race could provide substantial insight into the occurrence (or lack) of disparity in service delivery for children of racially and economically diverse backgrounds.

## 3. Addition of new questions to on-going data collection efforts

The extant databases could profitably be augmented with additional questions that address the timing of early identification, the time to services, the way in which the identification and referral were made as well as barriers to identification and referral. Additional questions could also examine regional differences in identification patterns and look for biases and disparities in identification rates based on racial, ethnic, and socioeconomic status. The National Health Survey of Children with Special Health Care Needs (CSCHN SLAITS) is a good candidate for such additional questions. The advantage is that the sample generation through use of the CSHCN screener ensures that there will be sufficient numbers of children in the analyses to avoid small cell problems. Even with 40,000 children and youth with identified problems, it will still probably be necessary to oversample for very low prevalence conditions such as deafness and blindness to ensure adequate sample sizes. The current questionnaire that includes questions about specific conditions will allow such special sampling. The questions should probe:

- The exact time that the parents first became concerned about the problem
- The time at which a professional diagnosed (confirmed, named) the condition
- The time that services for the condition were first rendered

## New Studies

Here we outline three possible study types that could produce valuable information about early identification.

### 1. In-depth Process-Level Study

A process-level study of early identification might be conducted in 2 to 5 states. The research team would identify the children through a sample of the CSHCN SLAITS weighted to include adequate numbers of children with both high and low prevalence conditions. The researchers would probe health records, school records, family survey and survey with the child's physician to determine when the child's disability was first identified. This in-depth study would provide valid information on the exact path from concern to diagnosis to referral.

### 2. Practice-Level Study

A study based in pediatric practices would be instructive to understand more fully the potential strengths and weaknesses of pediatric practices in the early identification process. Because of the national recommendations that pediatric practices become more adept at early identification and referral, it should be possible to identify a number of sites which are actively involved in a rigorous formal identification process. These sites could be designated as First Wave Sites. Candidate practices would be those who have been involved in one of the national networks such as that sponsored by the Commonwealth Foundation in conjunction with the American Academy of Pediatrics Bright Futures Project or practices that have taken part in the Learning Collaboratives associated with the National Initiative on Child Health Quality (NICHQ) program on developmental assessment. These sites could be compared with Second Wave Sites who were not as fully involved in screening on outcomes such as:

- Timing of identification,
- Percentage of false negative and false positive referrals,
- Disparities in identification timing based on race, ethnicity, language and
- SES presence of a formal developmental screening process in the practice

2. Exhibit 9, SEELS, Disability Profiles of Elementary and Middle School Students with Disabilities; accessed at [http://www.seels.net/designdocs/SEELS\\_disability\\_profile.pdf](http://www.seels.net/designdocs/SEELS_disability_profile.pdf) on December 29, 2005.

### 3. Systems-Level Study

A third type of study would involve assessment of best practices at the systems level. States vary in their approach to early identification for the purpose of enrolling young children in early intervention programs. States can be divided into 3 categories: 1) those with very inclusive criteria (which include an at-risk category), 2) those with moderately inclusive criteria, and 3) those with restrictive eligibility criteria.

A systems-level study could be constructed to explore whether the states with more inclusive criteria are more likely to have established systems for the earlier identification of developmental concerns. One of the national databases that includes a representative sample from the 50 states could be analyzed by state (stratified into the 3 eligibility criteria) to determine whether the predicted relationship exists of earlier identification in the more inclusive states.

Hypotheses would be:

- States with more inclusive policies for early identification are more likely to identify children with disabilities at earlier ages than are states that have moderate or restrictive guidelines.
- There are fewer racial, ethnic, language and SES disparities in early identification in states with inclusive criteria for early identification than in states with moderate and restrictive criteria.

A follow-on activity of describing the best practice states could be instructive for deriving the elements of state-level policy that support early identification activities. A small sample of best practice states could be picked for further qualitative assessment of their systems' respective approaches to early identification. For those best practice states, the investigators would interview key informants in the state agencies, professionals working in the field of early childhood and parents of children with disabilities.

### Where Will the Research Lead?

A major outcome of the research on early identification may be the promotion of Standards for the Early Identification of Children's Developmental Disabilities. Such standards would be much like the Healthy People 2000 and 2010 guidelines: based on the best information available to the fields of pediatrics, education and psychology. A benchmarking exercise of best practices would lead to measurable objectives such as the following potential examples:

- Hearing: Within a *given practice, region, or state*, by one year of age, 80-90 percent of children with congenital hearing loss of any level should have been detected and should be receiving language-enhancing services.
- Mental retardation/developmental delay: Within a *given practice, region, or state*, by three years of age, 85 percent of children with developmental delays of six months or more should be identified and should be receiving services to optimize their learning.
- ADHD: Within a *given practice, region, or state*, by seven years of age, 75 percent of children with attention deficit hyperactivity disorder should be diagnosed according to the American Academy of Pediatrics Guidelines and should be receiving appropriate multi-modal treatment.

Such a standard-setting activity could have a major influence on clinicians, as it would provide clear guidance for the direction and priority of their screening and health promotion efforts. It would provide a platform for monitoring for public health and education authorities at the regional and state levels and it might provide a target of opportunity for Health Plan Employer Data and Information Set (HEDIS®) measurement linked to payment for developmental monitoring.