

# IDENTIFYING AND ADDRESSING DEVELOPMENTAL-BEHAVIORAL PROBLEMS:

A Practical Guide for Medical and Non-Medical  
Professionals, Trainees, Researchers and Advocates

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# CHAPTER 1: WHY EARLY DETECTION IS CRUCIAL: INTERVENTION OUTCOMES AND SERVICES

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## CHAPTER HIGHLIGHTS

### IN THIS CHAPTER WE ADDRESS:

- The economic and social benefits of early intervention, whether through services for children with special needs, or through programs such as Head Start that focus on children with psychosocial risk factors;
- Federal policy on services for children with delays and disabilities, including eligibility requirements;
- Terms (and abbreviations) you need for understanding federally mandated intervention services;
- Terms you need to know for working with early detection and American Academy of Pediatrics policy;
- Programs dealing with children who don't qualify for special needs services but still have problems in need of intervention;
- Common questions about policy and early detection raised by primary care providers.

## INTRODUCTION

Our goals, whether we are parents or professionals, are to prevent, detect, and intervene with developmental-behavioral problems as early as possible. For children with severe and life-long disabilities, as well as with those whose development is likely to be derailed by psychosocial risk factors (such as limited parental education, problematic parenting skills, parental depression, poverty, etc.), intervention helps and helps enormously. In providing intervention, we facilitate children's success in life, whether academic or vocational. If we can help children do well in something (although facilitating mastery of school skills is invaluable), they are far more likely to circumvent health risks (such as smoking and drug abuse), graduate from high school and hold jobs, and less likely to engage in teen pregnancy and criminal behavior or take steps toward suicide.

There is a strong consensus among researchers who study high-quality early childhood intervention (of which there are many different kinds of services), that these programs have substantial payoffs. Early detection and intervention confer not only enormous social benefits but also save tax payers enormous amounts of money. For every \$1 we spend on early intervention, we save between \$3.78 (Abecedarian study) to \$17.07 (Perry preschool study), well above the 1:1 ratio needed to justify such programs.<sup>1</sup> If every low-income 3- to 4-year-old-child in the USA (about 20% of the U.S. population is classified as low-income) received two years of a quality early child development program, this 'investment' is predicted to generate a 16% annual return rate in cost savings to society.<sup>1</sup> Early child development programs provide economic benefits to society by decreasing elementary school remediation rates, frequency of high school drop-out, tobacco use, alcohol and drug abuse, teenage pregnancy and criminality. Early childhood development programs provide economic benefits by decreasing the chance of childhood abuse and neglect (and therefore, the number of children in foster care). Over time, such benefits translate into less poverty, less welfare dependency, a more educated work force, a higher national gross domestic product and a more stable U.S. economy.

Even economists who are skeptical about government programs make an exception for high-quality early childhood services. Well-respected economic analysts like Rolnick and Grunewald concluded that "Future proposed economic development should have early childhood development at the top."<sup>1,2</sup> A publicly financed, comprehensive early childhood development program for all children from low-income families (e.g., Head Start without a waiting list) would cost billions of dollars annually, but would create much larger budget savings over time. By about the 17-year mark, the net effect on budgets for all levels of government combined would have a positive return on investments. Within 25 years, if a nationwide program were started next year, the budget benefits would exceed costs by \$31 billion (in

2004 dollars). By 2050, the net budget savings would reach \$61 billion.<sup>1</sup>

In addition to Head Start and Early Head Start, America is fortunate to have enacted, in 1976, what is now known as the Individuals with Disabilities Education Act (IDEA). IDEA guarantees a free and appropriate education for children with disabilities starting at birth until age 21. IDEA is divided into two age-groups: Part C addressing services for children birth to 3 years of age and is commonly referred to (with capital letters to distinguish it from other types of intervention such as Head Start), as Early Intervention (EI); and Part B covering services for children 3 to 22 years of age, which is commonly referred to as special education, and in general involves public schools.

Overall, IDEA ensures that children with disabilities are guaranteed a free, appropriate, public education, just as for children without disabilities. The education of children with special needs is designed to address their unique learning requirements while preparing them for further education, employment and independent living.

In addition, the Americans with Disabilities Act (ADA, now amended to ADAAG) and Section 504 of the Rehabilitation Act guarantees “right to access.” ADA and Section 504 are responsible for services such as wheel-chair ramps, tape-recorded and large print books for children with visual impairment and reading disabilities, and behavior management programs in regular education classrooms (e.g., to help children with attention-deficit disorder succeed at grade level).

Below is a glossary of terms in early detection, intervention and federal mandates. It is designed to help you get familiar with the tenets of federal policy and with the terms used throughout this book to describe the early detection and intervention process.

**Table 1-1. Glossary of Terms in Detection, Intervention and Policy**

<b>Term/Abbreviation</b>	<b>Definition/Description</b>
<b>IDEA</b>	Individuals with Disabilities Education Act is the US federal law mandating a free and appropriate education for children with disabilities from birth to 22 years of age. IDEA has two submandates, Part B and Part C.
<b>Part B of IDEA (special education)</b>	Refers to services for conditions covered by IDEA for children 3 years to 22 years of age through the public schools, and is generally referred to as special education.
<b>Part C of IDEA (EI or Early Intervention)</b>	Serves children from birth to 3 years of age and is often referred to as Early Intervention (EI). As with Part B, different States have slightly different eligibility criteria. But, nevertheless, all IDEA programs provide free evaluations to determine whether a child qualifies.
<b>Individual Family Service Plan (IFSP)</b>	An ISFP is created within IDEA birth to 3 programs (aka Part C) to delineate specific services, goals, objectives and time frames for children’s and families’ progress. The goal of an IFSP for a child is to provide services, aligned with the goals of the family.
<b>Individual Education Program (IEP)</b>	Individual Education Program is used in IDEA programs for children 3 years to 22 years (aka Part B or special education) to delineate specific services, goals, objectives, and time frames for determining child’s progress. An IEP differs from an IFSP in that it focuses only on the child’s needs, not the family’s needs (although families have input into goal-setting via the multidisciplinary meeting where the IEP is created and approved by all).

table continues...

**Table 1.1. Cont'd**

<b>Least Restrictive Environment (LRE)</b>	Maintaining children in the Least Restrictive Environment is the goal of IDEA programs which strive to keep children with special needs integrated with typically developing children as much as possible.
<b>Early Intervention (EI)</b>	EI, when capitalized, means services under IDEA Part C, but when appearing without capitalization refers to any service designed to promote healthy development and behavior for children who do not qualify for IDEA programs (e.g., Head Start, Early Head Start, Triple P: Positive Parenting Program, etc.).
<b>ADAAA/Section 504</b>	Americans with Disabilities Act Amendments Act (ADAAA) and Section 504 of the Rehabilitation Act, ensure right to access (e.g., wheelchair ramps, large print books for students with low vision, behavior modification in the classroom for students with ADHD).
<b>Medical Risk Factors and Conditions</b>	Many states ensure eligibility for IDEA services on the basis of health and biological conditions (e.g., extremely low birth weight, genetic conditions associated with a high probability of a developmental delay, in-utero exposure to a teratogenic substance, a significant health or physical impairment, traumatic brain injury, etc.).
<b>Psychosocial Risk Factors</b>	These are issues sometimes associated with developmental delay but otherwise are harbingers of delays in the future. Psychosocial risk factors include parents who have not graduated from high school, single or teen parents, parents with mental health problems (including depression and anxiety), housing/food/or employment instability, parents who don't speak English, lack social support, and most significantly, parents who lack skills in positive parent-child interactions and who may not promote development effectively. Children with risk factors are not likely to qualify for IDEA services but still need other forms of intervention.
<b>Developmental-Behavioral Protective Factors or Resilience</b>	Protective factors are positive parent-child interactions that enhance development such as frequent book sharing, parent-child conversations, vocal play, etc.
<b>Development</b>	Refers to all aspects of children's learning across all domains, including receptive and expressive language, fine and gross motor, cognitive, adaptive/self-help. The term "development" is also inclusive of behavior, social-emotional and mental health domains. At times, the term "developmental-behavioral" is used merely to emphasize that development includes social-emotional, behavior and mental health.
<b>Developmental-Behavioral Screening and Surveillance</b>	Screening is the use of accurate, validated tests to indicate the probable presence or absence of difficulties. Surveillance is a flexible, longitudinal, continuous and cumulative process whereby knowledgeable providers detect and address current problems, as well as predictors of potential problems not yet manifest. Accurate surveillance depends on screening tests and other validated measures to ensure evidentiary support for decisions. This means that the same measures can and should be used over time for both longitudinal surveillance and for immediate decision-making via the results of screens, physical exam findings, etc.

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**Table 1.1. Cont'd**

<b>Developmental-Behavioral Promotion</b>	Developmental-behavioral promotion means addressing parents' concerns (e.g., about disciplinary methods) and actively teaching parents skills associated with typical development, such as how to talk and share books with children. Developmental-behavioral promotion is a critical part of early detection and should be provided at every well-visit.
<b>Medical Home</b>	Per the American Academy of Pediatrics, the "Medical Home" is where primary care providers establish centralized, comprehensive care for children with disabilities and chronic illness (whose care would otherwise be fragmented across services and thus absent the "big picture" of family's and children's needs and issues). The Medical Home coordinates care across subspecialists and services, communicates with agencies, maintains all records, and helps plan needed interventions.
<b>HIPAA</b>	The Health Insurance Portability and Accountability Act of 1996 protects the privacy of individually identifiable health information and sets national standards for the security of electronically gathered health data.
<b>FERPA</b>	The Family Educational Rights and Privacy Act protects the privacy of students' education records. Schools must have written permission from the parent (or the student if 18 years or older), in order to release any information from a student's education record. Parents and families have the right to inspect records and make corrections if they deem them misleading.
<b>EPSDT</b>	The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program is the child health component of Medicaid, required in every state, and designed to improve the health of low-income children. Screening services "to detect physical and mental conditions must be provided at established, periodic intervals (periodic screens) and whenever a problem is suspected (inter-periodic screens). Screening also includes a comprehensive health and developmental history, an unclothed physical exam, appropriate immunizations, laboratory tests, dental, vision, and hearing screens, and health education.
<b>CAPTA</b>	The Child Abuse Prevention and Treatment Act provides Federal funding to States in support of prevention, assessment, investigation, prosecution, and treatment activities for children who are maltreated, born to substance abusing mothers, who are homeless, etc. CAPTA grants establish reporting requirements for healthcare, education, and other agencies.

## EARLY INTERVENTION ENROLLMENT RATES AND THE ENORMOUS PROBLEM OF UNDER-DETECTION

Although the effectiveness of early intervention is well established and services are available, most States' Early Intervention enrollment rates are about 50% less than the prevalence figures established by the Centers for Disease Control, [www.cdc.gov](http://www.cdc.gov), (which are 2% by age 1 year, 4% by age 2, and 8% by age 3). Public school special education enrollment is about 30% less than prevalence figures (which are 12% by age 5, and 16 – 18% by age 9 and older). This means that early detection and referral to IDEA is hugely problematic: Half of all children with special needs are not detected until kindergarten or later. Thus they've lost opportunities for earlier intervention—intervention that would have either eliminated or ameliorated their problems and facilitated school success.

Although IDEA legislation includes child-find services such as free screening for children suspected of problems, IDEA programs do not have access to all children in the way healthcare providers do. Since health care is “where the kids are,” many States mandate that healthcare providers improve the methods by which they identify children with difficulties. In general, these mandates take the form of increased reimbursement when quality screens are administered, along with a list of approved (and non-approved, non-reimbursable) measures. Class action suits (e.g. against Cigna for failing to reimburse for screening in health care) are compelling private payers to comply. Meanwhile, the advocacy arm of the American Academy of Pediatrics is battling (in Congress, State legislatures, and with private payers) for appropriate reimbursement for screening—at all well-visits.

Several States (e.g., Tennessee, North Carolina, Hawaii, Massachusetts, Texas, Connecticut, Oregon, Minnesota) established their own mandates dictating the use of quality screens along with initiatives to train providers. Note that States' IDEA programs have differing eligibility requirements and some are far more stringent than others. Nevertheless, States with strong training initiatives, mandates, and reimbursement plans that cover the costs of early detection, clearly have higher enrollment rates than do States without such efforts. Table 2 shows examples using data from 2007 ([www.ideadata.org](http://www.ideadata.org)).

**Table 1-2. State Enrollment in IDEA Part C (0 - 3-years) Eligibility Criteria by Presence or Absence of Mandates/Initiatives\***

STATE	CRITERIA	MANDATES/INITIATIVES*	ENROLLMENT RATE (FOR BIRTH TO THREE)
Hawaii	broad	yes	6.94%
Mississippi	broad	no	1.34%
Rhode Island	moderate	yes	4.61%
Louisiana	moderate	no	1.78%
Connecticut	narrow	yes	3.35%
Washington, DC	narrow	no	1.19%

\* Initiatives include Help Me Grow (Connecticut), AAP State Chapter (Hawaii), KidsCount and other programs (Rhode Island).

Clearly, States with mandates for use of quality screens in primary care have more than three times the enrollment rate in IDEA programs than do States without mandates. But honestly, with or without mandates, we should do the right thing by families and children, i.e., use effective methods to detect problems and refer whenever we find difficulties. We'll guide you in subsequent chapters on how to best detect problems, but we know that one obstacle to referral is not knowing much about what's available. So for now, we continue with information on how IDEA works and how to obtain services for your patients.

## THE PROCESS OF OBTAINING IDEA SERVICES

**IDEA's Part C Programs (birth to 3-years)** do not require a specific diagnosis. Instead, children receive a general classification of "developmental delay." This fact can present a conceptual challenge for healthcare providers who are accustomed to making a diagnosis before devising a treatment plan. But treating first and diagnosing later makes sense when it comes to young children because new delays can emerge with time and the defining characteristics of disabilities may not be evident immediately. For example, a delay in language development may be a precursor to deficits in cognitive skills that are not yet fully manifested. Time, intervention, progress tracking, and further evaluations will eventually identify the specific type of problem(s).

Even so, autism spectrum disorders (ASD) is one condition that should be diagnosed as early as possible so that highly focused interventions can be implemented. The diagnosis of ASD typically requires a multidisciplinary team, which often includes a physician, a developmental psychologist, and a speech-language pathologist. So when you suspect ASD, first refer to IDEA services (so that children receive prompt intervention even while waiting for a diagnosis), but simultaneously refer to ASD specialists (e.g., developmental-behavioral pediatricians, neurodevelopmental pediatricians, pediatric psychologists, speech-language centers, audiologists, autism subspecialty services of which many are within teaching hospitals' developmental evaluation clinics). Note that many such private services have lengthy waiting lists, so again, it is essential to get children enrolled in EI and treated while they wait (typically 4 to 9 months or longer) for a diagnostic evaluation.

**Eligibility criteria for EI** (which varies across States) is generally determined by:

- (a) the presence of a condition that places a child at very high risk for future developmental challenges (e.g., a chronic or fixed health condition like Down Syndrome) and/or;
- (b) the degree of delay across domains (e.g., a 25% delay in two domains, or a 40% delay in one domain).

See [www.ectacenter.org](http://www.ectacenter.org) for links to IDEA programs and their eligibility requirements, State by State.

**Here's what providers need to know and do:**

1. When a high risk medical condition is present, refer to IDEA via a referral letter in which you document findings, identify known or suspected conditions, and include suggestions for follow-up evaluations (e.g., speech-language, physical therapy). Refer also to subspecialty medical services when indicated.
2. In the absence of medical contributors to the delays you've identified via screening/surveillance, document the results of measures you've administered, your clinical observations, suggested avenues for further evaluations, and then refer to IDEA.
3. In either of the above situations, you will need to document vision and hearing status. IDEA programs can provide audiological and functional vision evaluations if recommended. But they are understandably reluctant to test a child who, for example, has an unrecognized hearing deficit, that might lead to a false conclusion that intellectual disabilities are present.