

SELECTED TERMS RELATED TO THE HEALTHY MENTAL DEVELOPMENT OF YOUNG CHILDREN

Young children with and at risk of developmental problems have a vast array of services and programs available to them, and an equally bewildering number of federal agencies that oversee these programs. Those that work in the area of early childhood development must be familiar with the broad range of federal and state programs, laws, and funding sources in addition to terms that identify different kinds of interventions. Furthermore, people from different fields (e.g., education and health) on occasion use the same terms to refer to different things. Invariably, this hinders the ability to collaborate in ways that improve care for young children. Professionals new to the field can also find the use of acronyms and terms to be confusing. And even seasoned professionals may not fully comprehend how related systems make care available to young children.

In order to help remedy these issues, NASHP, with the advice of states participating in the ABCD II consortium, has created this glossary of terms commonly used in the field of early childhood development. Many of the definitions included here are direct quotes from agency Web sites and other widely circulated materials. These definitions are footnoted; many of the source materials offer additional relevant information and clarification. It is important to note that this glossary is a work in progress and is not intended to be the authoritative source for the definition of these terms, nor is it meant to be a comprehensive list of all the terms used by those who work in this area. Instead it is meant to help those who are interested in ensuring young children's healthy development to communicate more effectively by identifying terms that are not used consistently across disciplines and programs—and to create a context for understanding these terms the way NASHP uses them in its work.

Assessment (and Evaluation)

“Assessment: The ongoing process by which qualified professionals, together with families, through standardized tests and observation, look at all areas of a child's development: motor, language, intellectual, social/emotional and self-help skills, including dressing, toileting, etc. Both areas of strength and those requiring support and intervention are identified.”¹

There are different types of assessments and information gathered during the assessment process can serve multiple functions. It can be used to assign a diagnosis code to a child's condition, develop a plan of treatment for a child, or contribute to an evaluation designed to determine whether a child is eligible for a specific program. Important points to remember about this term include:

- An “assessment” is often described as the appropriate follow-up for a child who screens positive for a potential developmental delay.
- The term “assessment” is often interchanged with the term “evaluation.”

- The laws governing public programs often include specific definitions of both of these terms. The Individuals with Disabilities Education Act (IDEA), for example, defines assessment and evaluation as follows.
 - “**Assessment** means the ongoing procedures used by appropriate qualified personnel throughout the period of a child's eligibility to identify—
 - (i) The child's unique strengths and needs and the services appropriate to meet those needs; and
 - (ii) The resources, priorities, and concerns of the family and the supports and services necessary to enhance the family's capacity to meet the developmental needs of their infant or toddler with a disability.”
 - “**Evaluation** means the procedures used by appropriate qualified personnel to determine a child's initial and continuing eligibility under this part, consistent with the definition of ‘infants and toddlers with disabilities’ ...”²
- Medicaid requirements for Early and Periodic Screening Diagnosis and Treatment (EPSDT—see below) include a requirement for developmental assessment, that is commonly misunderstood. The definition of developmental assessment in EPSDT includes both the routine screening in the course of a well-child visit (EPSDT Screen) *and* a more in-depth assessment conducted by the professional to whom a child with a positive screen is sent.³

Case Management (includes Targeted Case Management)

Case management is a term used in different disciplines and programs—and there are several different definitions of the term that are relevant to the delivery of developmental services, including those below.

The Case Management Society of America: “Case management is a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual’s health needs through communication and available resources to promote quality cost-effective outcomes.”⁴

The IDEA of 1997 (Early Intervention program): “Service coordination [case management] means the activities carried out by a service coordinator to assist and enable a child eligible under this part [i.e., eligible for the Early Intervention Program] and the child's family to receive the rights, procedural safeguards, and services that are authorized to be provided under the State's early intervention program.”⁵

Title XIX of the SSA (Medicaid Program): “[Targeted] Case management services are services which will assist individuals eligible under the [state’s Medicaid] plan in gaining access to needed medical, social, educational, and other services”⁶

It should be noted that the Federal Medicaid manual (which provides guidance to states on implementing federal Medicaid requirements) contains a definition of case management that is slightly different than that in the SSA, “Case management is an activity which assists individuals eligible for Medicaid in gaining and coordinating access to necessary care and services appropriate to the needs of an individual.” The manual further specifies that several different types of case management are allowable in state

Medicaid programs, including case management provided as an integral part of another service (e.g., a treatment plan developed by a home health agency) and that provided under a 1915(c), “Home and community-based services” waiver. Perhaps most pertinent for those interested in promoting young children’s healthy development is targeted case management. The definition from the SSA (above) is specific to targeted case management (TCM). TCM is an optional service that states can choose to provide to a defined subset of Medicaid beneficiaries without need of a waiver. The Medicaid manual specifically identifies “Children between the ages of birth and up to age 3 who are experiencing developmental delays or disorder behaviors as measured and verified by diagnostic instruments and procedures” as a group that is receiving TCM services.⁷

Children with Special Health Care Needs (CSHCN)

There are many different definitions for children with special health care needs that are used for different purposes. One of the most commonly accepted is that recommended by the federal MCH bureau for use in planning for Title V services:

Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.⁸

Development, including Social and Emotional Development

Development is “The process of how a child acquires skills in the areas of social, emotional, intellectual, speech and language and physical development including fine and gross motor skills.”⁹ The development process can be divided into areas or “domains” and children can experience delays in acquiring skills in one or more domains. NASHP’s ABCD II collaborative work is focused on supporting young children’s development of social and emotional skills—referred to as social and emotional development.

Developmental services

In NASHP’s ABCD II work developmental services are “preventive pediatric services focused on optimizing healthy development. These services are distinct from other, more traditional preventive services, such as immunizations and lead screening, because of their potential contribution to early learning, healthy development, and school readiness. Developmental services include:

- Assessment to identify developmental risks and problems. Includes reviewing parental concerns, which may lead to periodic structured evaluation (often referred to as developmental screening) and diagnostic assessment, if warranted.
- Education for parents on child development and ways of promoting learning and growth. Also called anticipatory guidance or health supervision.
- Intervention for developmental concerns, either within the pediatric practice or by specialists or community programs.
- Coordination of intervention and treatment services, including referral and follow-up.¹⁰

Early Intervention (EI) (www.ed.gov)

The term early intervention is used to refer both to a set of services and a publicly funded program authorized by **Part C of the Individuals with Disabilities Education Improvement Act of 2004 or IDEA**.

Early Intervention Services: “Refers to the range of services designed to enhance the development of infants and toddlers (aged 0-3) with disabilities or at risk of developmental delay.”¹¹

Early Intervention Program: The Early Intervention Program for Infants and Toddlers with Disabilities is a program that was authorized by Congress under Part C of the IDEA, (The program itself is also often referred to as “Part C”). This program is administered at the federal level by the Department of Education and at the state level by a lead agency designated by each state, usually the education, health, or social services department. The Early Intervention program helps states fund and provide early intervention services to children under age three with a developmental delay or a diagnosed mental or physical condition that is likely to result in a delay, and their families. States define developmental delay and choose whether or not to serve children at risk for a developmental delay.¹² Thus there is variation among the states in which children qualify for the program.¹³

Early and Periodic Screening Diagnosis and Treatment (EPSDT) (www.cms.hhs.gov)

EPSDT is “one of the services that states are required to include in their basic benefits package for all Medicaid-eligible children under age 21. EPSDT services include periodic screenings to identify physical and mental conditions as well as vision, hearing, and dental problems.”¹⁴ This is a particularly important benefit for children with or at risk for developmental delays as under Medicaid law (1) an EPSDT screen must include a developmental assessment and (2) a state must provide any service that it could choose to cover under federal Medicaid law that is needed to “correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services” even if the state has chosen not to cover those services under other conditions.¹⁵

EPSDT-mandated services that fall outside the standard Medicaid benefit in a state are sometimes referred to as “supplemental EPSDT services.”

Head Start (including Early Head Start) (<http://www2.acf.dhhs.gov/programs/hsb/>)

“Created in 1965, Head Start is the most successful, longest-running, national school readiness program in the United States. It provides comprehensive education, health, nutrition, and parent involvement services to low-income children and their families. More than 22 million pre-school aged children have benefited from Head Start.”¹⁶ Head Start is geared towards children aged 3-5; Early Head Start is geared towards children aged 0-3.

Healthy Start (www.healthystartassoc.org)

The Healthy Start Program is housed in the Maternal and Child Health Bureau of the Health Resources and Services Administration. Initially designed to address disparities in infant mortality, Healthy Start is a grant program to local rural and urban sites to address five major issues: Perinatal Health, Border Health, Interconceptional Care,

Perinatal Depression, and Family Violence. There are 96 projects nation-wide.¹⁷ Perinatal health and Perinatal depression have the greatest bearing on early childhood healthy mental development. Healthy Start may therefore provide additional resources in states (and/or communities) coordinating services for the healthy development of young children.

Individualized Education Plan (IEP)

“An IEP is a written plan describing the special education and related services designed to meet the unique educational needs of a student with a disability. It contains goals and objectives based on the student’s present levels of educational performance, specifies the education placement and setting, and describes the related services and supports necessary for the student to benefit from the special education program.”¹⁸

Among other things, an IEP defines the conditions to be treated and corresponding services for which children are eligible under the IDEA.¹⁹ Generally, school-aged children are eligible for an IEP; states may extend eligibility for children to the year in which s/he turns three, bringing the lower boundary of eligibility to sometime after a child’s second birthday.²⁰

Individualized Family Service Plan (IFSP)

An IFSP defines the conditions and corresponding Early Intervention services for which the family is eligible under Part C of the IDEA (or the Early Intervention Program). Whereas an IEP defines the services for individual children generally three or older, an IFSP defines services for the whole family of an infant aged zero to three—a more appropriate object for those services designed to improve developmental outcomes for infants and young children. By statute, the IFSP must be in writing and contain detailed information on the child’s current health and developmental status, the family’s capacity to serve the child’s needs, intended outcomes, referral for specific services, a case manager, and other information relevant to the proper care of a child with disabilities and preparing him/her for school.²¹ The Early Intervention Program, which only serves those children through age 2, will only fund those covered services that are identified in the IFSP.

Infant Mental Health

“Infant mental health is the developing capacity of the child from birth to age 3 to:

- experience, regulate, and express emotions;
- form close and secure interpersonal relationships; and
- explore the environment and learn—

all in the context of family, community, and cultural expectations for young children. Infant mental health is synonymous with healthy social and emotional development.”²²

Maternal and Child Health Block Grant, (MCH Block Grant, also known as Title V)

Administered by The Maternal and Child Health Bureau of the Health Resources and Services Administration, the MCH Block Grant was created in 1981 when seven different programs (themselves created through Title V of the Social Security Act) were consolidated into a single block grant. The programs included:

- Maternal and Child Health and services for Children with Special Health Care Needs (See *CSHCN*);
- Supplemental security income for children with disabilities ;
- Lead-based paint poisoning prevention programs;
- Genetic disease programs; and
- Hemophilia treatment centers.

The state maternal and child health agency is the recipient and applicant for block grant funds.²³

Medicaid (Also known as: **Title XIX of the Social Security Act**)
www.cms.hhs.gov/medicaid)

Medicaid is a program that pays for medical benefits for certain low-income people, including families and children. It is jointly funded by federal and state governments. According to the Centers for Medicare & Medicaid Services, which is the federal agency responsible for the program: “Within broad national guidelines established by Federal statutes, regulations, and policies, each State (1) establishes its own eligibility standards; (2) determines the type, amount, duration, and scope of services; (3) sets the rate of payment for services; and (4) administers its own program.”²⁴

Screening

The American Academy of Pediatrics quotes Boyle, Decoufle, and Yeargin-Allsoop as defining behavioral developmental screening in young children as a “brief assessment procedure designed to identify children who should receive more intensive diagnosis or assessment.”²⁵

In order to more clearly distinguish between an assessment and a screen, NASHP, for purposes of its ABCD program, defines screening as a component of developmental surveillance that is designed to systematically test individuals for developmental problems. Assessment, also a component of developmental surveillance, describes a process that involves a more thorough cataloging of individual strengths and deficits. (See *surveillance* and *assessment*.)

Note: EPSDT screening is also an important term and should not be confused with the type of ‘screening’ defined here. An EPSDT screen is analogous to a well-child visit and, by federal Medicaid law, includes a developmental assessment. (See *assessment*.) An EPSDT screen is also an important concept because Medicaid eligible children are entitled to certain services that are not part of their state’s standard Medicaid benefit package if the service will correct or ameliorate a condition identified in the EPSDT screening. (See *EPSDT*.)

State Children’s Health Insurance Program (SCHIP or CHIP; sometimes Title XXI)

SCHIP is designed to provide health insurance coverage to uninsured children in low-income families (those generally earning less than 200% of the Federal Poverty Level) that do not qualify for Medicaid (see *Medicaid*). Like Medicaid, SCHIP is a federal-state

partnership that provides states with a high degree of latitude to design and implement programs that suit state needs.²⁶

State Early Childhood Comprehensive Systems Grant (SECCS)

SECCS grants are available to states through the Health Resources and Services Administration. “The purpose of the State Maternal and Child Health Early Childhood Comprehensive Systems (SECCS) Grant Program is to assist States and territories in their efforts to build and implement Statewide Early Childhood Comprehensive Systems that support families and communities in their development of children that are healthy and ready to learn at school entry. These systems must address the five critical components of early childhood systems development identified in the Maternal and Child Health Bureau’s Strategic Plan for Early Childhood Health. They are:

1. Access to Health Insurance and Medical Homes;
2. Mental Health and Social-Emotional Development;
3. Early Care and Education/Child Care;
4. Parenting Education;
5. Family support.”²⁷

Starting Early Starting Smart (SESS) (www.health.org/promos/sess/)

“Starting Early Starting Smart (SESS) is a knowledge development initiative designed to create and test a new model for providing integrated behavioral health services (mental health and substance abuse prevention and treatment) for young children (birth to 7 years) and their families, and to inform practitioners and policymakers of successful interventions and promising practices from the multiyear study, which lay a critical foundation for the positive growth and development of very young children.”²⁸

When it began in 1997, SESS was a joint project of the Substance Abuse and Mental Health Administration and Casey Family Programs providing “an integrated system of child-centered, family-focused, and community-based services targeted to at-risk children...at twelve sites across the country.”²⁹ It has since expanded to include additional sites.

Surveillance or Developmental Surveillance

Developmental surveillance is "a flexible, continuous process whereby knowledgeable professionals perform skilled observations of children during the provision of health care. The components of developmental surveillance include eliciting and attending to parental concerns, obtaining a relevant developmental history, making accurate and informative observations of children, and sharing opinions and concerns with other relevant professionals."³⁰ Developmental surveillance also includes the use of formal developmental screening tools, and comprehensive assessments. (See *screening and assessment*.)

¹ <http://www.zerotothree.org/glossary.html> (9/23/2005).

² 34 CFR 303.322 <http://www.nectac.org/~pdfs/idea/303pp.pdf> (9/23/2005)

³ CMS State Medicaid Manual, Chapter 5, EPSDT §5123.2(A)(1)

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- ⁴ <http://www.cmsa.org/AboutUs/CMDefinition.aspx> (9/23/2005)
- ⁵ 34 CFR 303.23 <http://www.nectac.org/~pdfs/idea/303pp.pdf> (9/23/2005)
- ⁶ §1915(g)(2) of the SSA
- ⁷ All information and quotes in this paragraph are from §4302 of the Medicaid manual www.cms.hhs.gov/manuals/45_smm/pub45toc.asp? 9/27/2005
- ⁸ This definition appears in McPherson et al., “A New Definition of Children with Special Health Care Needs,” 102 *Pediatrics*, No. 1 July 1998. It was endorsed in a workgroup convened by the Association of Maternal and Child Health Programs and the Maternal and Child Health Bureau on October 18, 1998
- ⁹ <http://www.zerotothree.org/glossary.html> (9/23/2005)
- ¹⁰ N. Halfon, et al. *Quality of Preventive Health Care for Young Children: Strategies for Improvement*, (New York: The Commonwealth Fund, May 2005) http://www.cmwf.org/publications/publications_show.htm?doc_id=275484 (9/26/2005)
- ¹¹ <http://www.zerotothree.org/glossary.html> (9/23/2005)
- ¹² <http://www.nectac.org/partc/partc.asp> (8/30/2005)
- ¹³ J. Shackelford. *State and Jurisdictional Eligibility Definitions for Infants and Toddlers with Disabilities Under IDEA*, NECTAC Notes No.18. (Chapel Hill: The University of North Carolina, FPG Child Development Institute, National Early Childhood Technical Assistance Center, 2005) <http://www.nectac.org/~pdfs/pubs/nnotes18.pdf> (9/30/2005)
- ¹⁴ Kaiser Commission on Medicaid and the Uninsured, “The Medicaid Resource Book” (July 2002) pg. 107
- ¹⁵ §1905(r)(5) of the SSA. www.ssa.gov/OP_Home/ssact/title19/1905.htm (9/27/2005)
- ¹⁶ <http://www.nhsa.org/about/index.htm> (8/30/2005)
- ¹⁷ <http://www.healthystartassoc.org/hswpp6.html> (9/13/2005)
- ¹⁸ Jellinek M, Patel BP, Proehle MC, eds. 2002 *Bright Futures in Practice: Mental Health—Volume II. Took Kit*. Arlington, VA: National Center for Education in Maternal and Child Health. pg 120
- ¹⁹ Individuals with Disabilities Education Act Part (C), §614(d)
- ²⁰ 34 CFR §300.343
- ²¹ Individuals with Disabilities Education Act Part (C), §636(d)
- ²² <http://www.zerotothree.org/imh/definition.html> (8/31/2005)
- ²³ <ftp://ftp.hrsa.gov/mchb/blockgrant/bgguideforms.pdf> (9/12/2005)
- ²⁴ <http://www.cms.hhs.gov/publications/overview-medicare-medicaid/default4.asp> (9/23/2005)
- ²⁵ Boyle CA, Decoufle P, Yeargin-Allsoop MY. Prevalence and health impact of developmental disabilities. *Pediatrics*. 1994;93:863–865 in American Academy of Pediatrics, Committee on Children With Disabilities “Developmental Surveillance and Screening of Infants and Young Children” July 2001
- ²⁶ <http://www.cms.hhs.gov/schip/about-SCHIP.asp> (8/31/2005)
- ²⁷ <http://www.hrsa.gov/grants/preview/guidancemch/hrsa05033.htm#1> (8/31/2005)
- ²⁸ <http://www.health.org/promos/sess/about.html> (8/31/2005)
- ²⁹ <http://ncadi.samhsa.gov/promos/sess/EarlyFindingsSummary.aspx#Starting> (8/31/2005)
- ³⁰ Dworkin PH. Detection of behavioral, developmental, and psychosocial problems in pediatric primary care practice. *Curr Opin Pediatr* 1993; 5:531-536