

Working with Infants and Toddlers with Special Healthcare Needs

Participant Handouts

It's the 'Person First' Then the Disability

What do you see first?

- *The wheelchair?*
- *The physical problem?*
- *The person?*



If you saw a person in a wheelchair unable to get up the stairs into a building, would you say “There is a handicapped person unable to find a ramp?” Or would you say “There is a person with a disability who is handicapped by an inaccessible building?”

What is the proper way to speak to or about someone who has a disability?

Consider how you would introduce someone—Jane Doe—who doesn't have a disability. You would give her name, where she lives, what she does or what she is interested in: she likes swimming, or eating Mexican food, or watching movies.

Why say it differently for a person with a disability? Every person is made up of many characteristics—mental as well as physical. Few people want to be identified only by their ability to play tennis or by their love for fried onions.

In speaking or writing, remember that children or adults with disabilities are like everyone else—except they happen to have a disability. Therefore, here are a few tips for improving your language related to people with disabilities.

1. Speak of the person first, then the disability.
2. Emphasize abilities, not limitations.
3. Do not label people as part of a disability group. Don't say "the disabled;" say "people with disabilities."
4. Don't give excessive praise or attention to a person with a disability; don't patronize them.
5. Choice and independence are important. Let the person do or speak for him or herself as much as possible.
6. A *disability* is a functional limitation that interferes with a person's ability to walk, hear, talk, learn, etc. Use *handicap* to describe a situation or barrier imposed by society, the environment, or oneself.

Excerpt from PACER

SAY:	INSTEAD OF:
Child with a disability	Disabled or handicapped
Person with cerebral palsy	C.P., or spastic
Person who is deaf or hard of hearing	Deaf and dumb
Person with a cognitive disability	Mentally retarded; intellectual retard
Person with epilepsy or person with a seizure disorder	Epileptic
Person who has ... from, victim	Afflicted, suffers
Without speech, nonverbal	Mute, dumb
Developmental delay	Slow
Emotional disorder, or mentally ill	Crazy, insane
Uses a wheelchair	Confined to a wheelchair
With Down Syndrome	Mongoloid, retard
Has a learning disability	Is learning disabled
Nondisabled	Normal, healthy
Has a physical disability	Crippled
Congenital disability	Birth defect
Condition	Disease (unless it IS a disease)
Seizures	Fits or spells
Cleft lip	Hare lip
Mobility impaired	Lame
Medically involved, or has a chronic illness	Sickly
Paralyzed	Invalid or paralytic
Has hemiplegia	Hemiplegic
Has quadriplegia	Quadriplegic



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
U.S. DEPARTMENT OF EDUCATION

**POLICY STATEMENT ON
INCLUSION OF CHILDREN WITH DISABILITIES IN
EARLY CHILDHOOD PROGRAMS**

September 14, 2015

This article can be downloaded from the internet at:

<http://www2.ed.gov/policy/speced/guid/earlylearning/joint-statement-full-text.pdf>

PURPOSE

The purpose of this policy statement is to set a vision and provide recommendations to States, local educational agencies (LEAs), schools, and public and private early childhood programs, from the U.S. Departments of Education (ED) and Health and Human Services (HHS) (the Departments), for increasing the inclusion of infants, toddlers, and preschool children with disabilities in high-quality early childhood programs.ⁱ

It is the Departments' position that all young children with disabilities should have access to inclusive high-quality early childhood programs, where they are provided with individualized and appropriate support in meeting high expectations. This joint ED and HHS policy statement aims to advance this position by:

- Setting an expectation for high-quality inclusion in early childhood programs;
- Increasing public understanding of the science that supports meaningful inclusion of children with disabilities, from the earliest ages, in early childhood programs;
- Highlighting the legal foundations supporting inclusion in high-quality early childhood programs;
- Providing recommendations to States, LEAs, schools, and early childhood programs for increasing inclusive early learning opportunities for all children; and
- Identifying free resources for States, programs, early childhood personnelⁱⁱ, and families to support high-quality individualized programming and inclusion of children with disabilities in early childhood programs.

Excerpt from full document

Working with Infants and Toddlers with Special Health Care Needs

Glossary of terms

Bili lights: specialized lights to treat jaundice

Child Find: process to find, refer, and evaluate infants and toddlers suspected of having or known to have a developmental delay or disability

Cleft palate: split or opening in the roof of the mouth; can involve the hard palate (the bony front portion of the roof of the mouth), and/or the soft palate (the soft back portion of the roof of the mouth); affects speech production and feeding.

Continuous positive airway pressure (CPAP): treatment that uses mild air pressure to keep the airways open

Early Intervention services: services which provide support for an infant or toddler's developmental and medical needs, parent training and education and access to resources.

Extracorporeal membrane oxygenation (ECMO): treatment used for infants with life-threatening heart and/or lung problems; tubing moves blood from an infant to the "ECMO lung" and back to the infant

Extremely low birth weight infants (ELBW): born less than 1000 grams

Individualized Family Service Plan (IFSP): legal plan describing the services and supports a family will receive for their infant or toddler with a disability or delays

Individuals with Disabilities Education Improvement Act (IDEA): was enacted by Congress in 1975 to ensure that children with disabilities have the opportunity to receive a free appropriate public education.

Intraventricular hemorrhage: referred to as "brain bleed"; categorized Grades I-IV for severity; most often occur in infants born at less than 30 weeks gestation or under 1500 grams and during first days of life

Low birth weight (LBW): born between 1001 to 1500 grams (454 grams = one pound)

Medically fragile: infants and toddlers at increased risk of a chronic physical, developmental, behavioral, or emotional condition requiring ongoing health care and related services

Micrognathia: small jaw; can affect speech production as well as coordination of breathing and speech production; may affect ability to accept fluids and food items orally

Monitor: machines used to monitor an infant's breathing (respiration), blood pressure and oxygen level. The piece that connects the infant to the monitor may be attached to the skin or appendage (finger or toe).

Neonatal intensive care unit (NICU): specialized post-birth unit providing care for premature newborns and newborns who are medically fragile; designated by Level (1, 2, 3 and 4)

Prematurity – born before 36 weeks gestation

Scans: There are various types of scans that can be performed but require sedation and movement of an infant to another location in the hospital. The two most common types are computer assisted tomography – CAT scan – and magnetic resonance imaging – MRI.

Tube feeding: when a young child cannot accept fluids or solid foods by mouth, one or more types of tube feeding may be necessary; a gavage tube is placed in the mouth and connects to the stomach, a nasogastric tube is inserted into the nose, a gastrostomy tube provides nutrients directly to the stomach, intravenous feeding is through a vein via an infusion pump.

Ultrasound: creates detailed images of blood vessels, tissues, and organs such as the brain, heart and abdomen.

X-rays: used to produce images of internal tissues, bones and/or organs; can be used to check for obstructions and blockages.



Tip Sheets

IDEA Part C Primary Referral Source: Child Care



“Congress finds that there is an urgent and substantial need...to enhance the development of infants and toddlers with

disabilities, to minimize their potential for developmental delay, and to recognize the significant brain development that occurs during a child’s first 3 years of life...”

Infant or toddler with a disability is defined as an individual under 3 years of age who needs early intervention services because the child is experiencing a developmental delay in one or more area or the child has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay (such as Down syndrome).

IDEA (Individuals with Disabilities Education Act) Part C

IDEA is the federal law for special education. Part C is the part of the law describing early intervention services for infants and toddlers.

- Within Part C, *Child Find* identifies infants and toddlers who may need early intervention services.
- Primary referral sources are named under Part C.
- Primary referral sources include child care and early learning programs.

How Does the Referral Process Work?

Once child care or early learning programs make a referral to the local early intervention program:

- The family is contacted to arrange for a screening or evaluation to determine if the child is eligible for infant and toddler intervention or preschool special education services.
- Prior to any screening, evaluation, or provision of services, parental consent is required.
- Parents will receive a call to walk them through services and systems and gather more information.
- When parent consent is given the child will go through the screening and evaluation process to determine qualification for services, depending on the delay.

Parents may ask you questions about services and if their child has to leave your program to receive them. You can let parents know that Part C services for infants and toddlers are provided in *natural environments* which can include services provided within the child care setting.

“One of the ways in which professional caregivers can be most helpful to parents of newborn or newly identified children is to encourage and support parents as parents. Such reinforcement does as much as anything else to build a parent’s self-confidence as a parent, as a decision maker, and as a partner in the care and nurturing of the child.” --J. Gallagher

Communicating to Parents about your Role as a Primary Referral Source: Steps to Success

Communicate to parents up front that you are required to make a referral for screening if developmental concerns arise. You can inform them by putting a statement in your parent handbook. An example of a script is:

As a child care provider, we continually monitor the development of all children in our care through ongoing observation and recording. We want the best outcomes for all children. Child care providers are considered a primary referral source for early intervention under federal IDEA special education law. We are required to refer a child in our program who has been identified as having developmental concerns or a risk factor that warrants a referral as soon as possible, but in no case more than seven days after the identification. While this is a mandate, we want to keep open communication with parents and caregivers about their child and any concerns we have before a referral is made. We can assist the parent with the referral or partner with them in the referral process.

How to Make a Referral

- Make an online referral at: <http://www.helpmegrowmn.org/>
- Call your local early intervention/ECSE office

Additional Tip Sheets Related to this Topic

(found at www.inclusivechildcare.org/tipsheets):

- Sharing Concerns with Families
- Red Flags and Referral
- Addressing Educational Concerns: IDEA

For more information on IDEA Part C and referring children with special needs, visit our Learning Center at www.inclusivechildcare.org.

Copyright © 2013 Center for Inclusive Child Care, Concordia University, 1282 Concordia Ave, Saint Paul, MN 55104. These materials may be freely reproduced for educational purposes.

Funding provided by the Minnesota Department of Education.

Minnesota Department of
Education

help me

