

# EDUCATIONAL TOOLBOX



THE UNIVERSITY OF ARIZONA  
COLLEGE OF MEDICINE TUCSON  
**ArizonaLEND**

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*This educational toolbox was developed based on results of an assessment provided to ArizonaLEND Family faculty and fellows. Data from the assessment guided both the selection of topics and the extent of resources provided under each topic. All topics selected were done so with the family participant in mind.*

## **Advocacy**

See 'Policy & Advocacy'

## **Affordable Care Act**

### **Definition:**

**Key Features of the Affordable Care Act:** On March 23, 2010, President Obama signed the Affordable Care Act. The law put in place comprehensive health insurance reforms that put consumers back in charge of their health care. A new wave of powerful evidence points to one clear conclusion: The Affordable Care Act is working to make health care more affordable, accessible and of a higher quality, for families, seniors, businesses, and taxpayers alike. This includes previously uninsured Americans, and Americans who had insurance that didn't provide them adequate coverage and security. [Click here for an overview of the key features of the Affordable Care Act.](#)

**Affordable Care Act and HRSA Programs:** The 2015 Open Enrollment Period has ended. The 2016 Marketplace Open Enrollment period will begin November 1, 2015 and continue through January 31, 2016.

Between the 2015 and 2016 Open Enrollment periods, there are Special Enrollment Periods (SEPs) available for some individuals to sign up for coverage in the marketplace. SEPs are permitted for individuals with extenuating circumstances surrounding tax filing, as well as for individuals with qualifying life events. To learn more about SEPs and find out if you, or someone you know, qualify for a SEP, visit [Healthcare.gov](http://Healthcare.gov).

### **Articles, Guides, Additional Resources**

- [Women as Health Care Decision-Makers](#): Implications for Health Care Coverage in the United States
- [The Marketplace and the Safety Net](#) has what you need to know about the health insurance Marketplace, essential health benefits, private insurance market reforms and essential community providers.
- [Partnering with Community Health Centers on Outreach and Enrollment Activities](#) (PDF - 100 KB) tells you how you can work with HRSA-supported health centers to educate and consumers.
- [Rock Enroll](#) kicks off open enrollment at the Rock & Roll Hall of Fame with the HRSA administrator
- [Nurses Matter](#) national nursing call features the HHS Secretary, HRSA Administrator and four nurses who outline their successful outreach and education efforts
- **Provider Toolkit:**

Includes resources and materials you can use to learn more about the Marketplace and the Small Business Health Options Program (SHOP) and to educate patients about health insurance and their options.

- [Affordable Care Act Basics](#)

**Includes:** Overview of the Affordable Care Act and Health Insurance Marketplace; State-specific information; Marketplace enrollment timeline; Consumer assistance information

**Target Audience:** Providers; Administrators; Staff

- [Patient Handouts and Education](#)

**Includes:** Eligibility information; Consumer assistance resources; Information directing patients where they can go to enroll and find out more about new coverage options.

**Target Audience:** Patients

- [Business Operations](#)

**Includes:** Information about the Small Business Health Options Program (SHOP); the health care law; and business operations.

**Target Audience:** Administrators; Providers

- [Training and Education](#)

**Includes:** Sample slides, webinars and other materials that can be shared with health professionals.

**Target Audience:** Administrators; Providers; Staff

## Audiology

### **Definition:**

Audiologists are healthcare professionals who provide patient-centered care in the prevention, identification, diagnosis, and evidence-based treatment of hearing, balance, and other auditory disorders for people of all ages. Hearing and balance disorders are complex with medical, psychological, physical, social, educational, and employment implications. Treatment services require audiologists to have knowledge of existing and emerging technologies, as well as interpersonal skills to counsel and guide patients and their family members through the rehabilitative process. Audiologists provide professional and personalized services to minimize the negative impact of these disorders, leading to improved outcomes and quality of life. *American Speech-Hearing Association.*

### **Websites**

**American Speech-Hearing Association:** [www.asha.org](http://www.asha.org) Great resources. For, articles, and links, scroll to the bottom of the page and select 'Information for the Public.'

### **Articles, Guides, Additional Resources**

**Difference between Hearing Screening and Hearing Evaluation:** The difference between hearing screening and hearing evaluation can sometimes be confusing. A hearing screening is usually a preliminary step in which an individual's hearing is checked to see if further evaluation is required.

In other words, hearing screening is a quick and cost-effective way to separate people into two groups: a pass group and a fail group. Those who pass hearing screenings are presumed to have no hearing loss. Those who fail are in need of more detailed hearing evaluation by a qualified audiologist.

It is recommended that all hearing screening programs be conducted under the supervision of an audiologist holding the ASHA Certificate of Clinical Competence (CCC).

A hearing evaluation is an in-depth assessment of an individual's hearing by an audiologist. The purpose of this evaluation is to determine the nature and degree of the hearing loss and the best treatment options. Audiologists use a number of different tests in this evaluation.

**Videos:** <http://www.youtube.com/user/ArizonaSLHS>

## **Autism**

### **Definition:**

According to the Centers for Disease Control and Prevention (CDC) autism spectrum disorder (ASD) is a [developmental disability](#) that can cause significant social, communication and behavioral challenges. There is often nothing about how people with ASD look that sets them apart from other people, but people with ASD may communicate, interact, behave, and learn in ways that are different from most other people. The learning, thinking, and problem-solving abilities of people with ASD can range from gifted to severely challenged. Some people with ASD need a lot of help in their daily lives; others need less.

The American Psychiatric Association, in the fifth edition of the [Diagnostic and Statistical Manual of Mental Disorders \(DSM-5\)](#) (2013), uses the term "autism spectrum disorder (ASD)" to refer to a group of disorders that in the earlier edition (DSM-IV) includes autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified. Please note: the term "autism" is frequently used in the literature to describe ASD and therefore appears often following the usage of the source cited. See the DSM-5 fact sheet [Autism Spectrum Disorder](#) (2013) for more information.

The [Centers for Disease Control and Prevention \(CDC\)](#) estimates that 1 in 68 children has been identified with ASD. See [Autism Spectrum Disorders \(ASDs\): Data and Statistics](#) for a summary of prevalence, risk factors and characteristics, diagnosis, and economic costs.

### **Websites**

- **The Autism Society Website:** [autismsource.org](http://autismsource.org).
- **The Autism society of Southern Arizona:** <http://www.as-az.org>
- **Autism Speaks:** [www.autismspeaks.org](http://www.autismspeaks.org)
- **Autism NOW The National Autism Resource Center:** [www.autismnow.org](http://www.autismnow.org)
- **Autistic Self Advocacy Network:** [www.autisticadvocacy.org](http://www.autisticadvocacy.org)
- **Autism/Asperger's Network:** [www.aane.org](http://www.aane.org)
- **Centers for Disease Control and Prevention:** [www.cdc.gov](http://www.cdc.gov)
- **National Autism Center:** [www.nationalautismcenter.org](http://www.nationalautismcenter.org)
- **National Institutes of Health:** [Autism Spectrum Disorders](#)
- **National institutes of mental health:** [www.nimh.nih.org](http://www.nimh.nih.org).
- **National institute of neurological disorders and stroke:** [www.ninds.nih.gov](http://www.ninds.nih.gov)

- **Autism Research Foundation:** [www.nofone.org](http://www.nofone.org)
- **U.S. Department of Health and Human Services:** [HHS Autism Information](#)
- **Centers for Disease Control and Prevention:** [Autism Information Center ACT Early Curriculum](#)
- [Act Early Ambassadors](#) (Association of University Centers on Disabilities)
- [Interagency Autism Coordinating Committee](#) (U.S. Department of Health and Human Services)

## **Additional Information:**

**Autism CARES Act:** Implementation of the Autism CARES Act, a \$47 million effort, addresses some of the most urgent issues affecting people with autism and their families. A national evaluation is also being conducted to report to Congress on progress related to Autism Spectrum Disorder and other developmental disabilities.

The program aims to:

- Increase awareness
- Reduce barriers to screening and diagnosis;
- Support research on evidence-based interventions for children and adolescents with Autism Spectrum Disorder or other developmental disabilities;
- Promote evidence-based guideline development for interventions; and
- Train professionals to utilize valid screening tools to diagnose and to provide evidence based interventions.

Goals:

- Enable all infants, children and adolescents who have, or are at risk for developing, Autism Spectrum Disorder and other developmental disabilities to reach their full potential by
- **developing a system of service** that includes screening children early for possible Autism Spectrum Disorder and other developmental disorders;
- **conducting early, interdisciplinary, evaluations** to confirm or rule out Autism Spectrum Disorder and other developmental disorders; and,
- **Providing evidence-based, early interventions** when a diagnosis is confirmed.

## **Online Courses:**

[Autism Case Training: Web-Based Continuing Education Course](#) --Association of University Centers on Disabilities.

# **Cultural Competency**

## **Definition:**

There is no one definition of cultural competence. Definitions of cultural competence have evolved from diverse perspectives, interests and needs and are incorporated in state legislation, Federal statutes and programs, private sector organizations and academic settings. The seminal work of Cross et al in 1989 offered a definition of cultural competence that established a solid foundation for the field. The definition has been widely adapted and modified during the past 15 years. However, the core concepts and principles espoused in this framework remain constant as they are viewed as universally applicable across multiple systems.

A number of definitions and descriptions of cultural competence were reviewed to compile the selected list. The following definitions are highlighted because they represent or are based on original and exemplary work and because of their potential impact to the field of health and human services.

**Cross et al, 1989:** Cultural competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency or among professionals and enable that system, agency or those professions to work effectively in cross-cultural situations.

The word **culture** is used because it implies the integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values and institutions of a racial, ethnic, religious or social group. The word **competence** is used because it implies having the capacity to function effectively.

Five essential elements contribute to a system's institutions or agency's ability to become more culturally competent which include:

- Valuing diversity
- Having the capacity for cultural self-assessment
- Being conscious of the dynamics inherent when cultures interact
- Having institutionalized culture knowledge
- Having developed adaptations to service delivery reflecting an understanding of cultural diversity

These five elements should be manifested at every level of an organization including policy making, administrative, and practice. Further these elements should be reflected in the attitudes, structures, policies and services of the organization.

**National Center for Cultural Competence, 1998, modified from Cross et al:** Cultural competence requires that organizations:

- Have a defined set of values and principles, and demonstrate behaviors, attitudes, policies, and structures that enable them to work effectively cross-culturally.
- Have the capacity to (1) value diversity, (2) conduct self-assessment, (3) manage the dynamics of difference, (4) acquire and institutionalize cultural knowledge, and (5) adapt to diversity and the cultural contexts of communities they serve.
- Incorporate the above in all aspects of policy-making, administration, practice and service delivery, systematically involve consumers, families and communities.

Cultural competence is a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, knowledge and skills along the cultural competence continuum.

**References/Sources:** Cross, T., Bazron, B., Dennis, K., & Isaacs, M., (1989). *Towards A Culturally Competent System of Care, Volume I*. Washington, DC: Georgetown University Child Development Center, CASSP Technical Assistance Center.

## Websites:

**National Center for Cultural Competence:** [nccc.georgetown.edu](http://nccc.georgetown.edu)

## Articles, Guides, Additional Resources

- **Think Cultural Health:** Training. Promoting Healthy Choices and Community Changes: An E-learning Program for Promotores De Salud--[https://promotores.thinkculturalhealth.hhs.gov/default\\_en.asp](https://promotores.thinkculturalhealth.hhs.gov/default_en.asp)

This bilingual program develops culturally and linguistically competent messengers, advocates and educators to promote health and wellness among their peers and within their communities. [English](#) | [Español](#).

- **Leadership Institute’s Web-Based Learning & Reflection Forums (Georgetown UCEDD)**  
<http://nccc.georgetown.edu/leadership/web-based-learning.html> The Georgetown University National Center for Cultural Competence is pleased to announce a series of web-based learning and reflection forums (webinar format) that will be open to the first 300 registrants. The forums will be archived and available on this page. The forums are designed to address salient issues related to advancing and sustaining cultural and linguistic competence, increasing cultural and linguistic diversity, and addressing systemic barriers to such policies and practices within the I/DD network. Each forum will feature individuals that are leading such efforts within their respective organizations, states, and at the national level. In addition to sharing concrete approaches that you can personally do to support these efforts, the forums will offer reflections on what is the role of the leader to bring about needed change. **Registration for the first forum “Influencing Change in Public and Organizational Policy in Support of Cultural Diversity and Cultural and Linguistic Competence” is now open.**

## Dentistry

### **Definition:**

Pediatric dentistry is an age-defined specialty that provides both primary and comprehensive preventive and therapeutic oral health care for infants and children through adolescence, including those with special health care needs. *American Academy of Pediatric Dentistry.*

### **Websites**

- **Oral Hygiene:** [Healthy Smiles for Autism \(free oral hygiene guide\)](#)
- **Overview - American Academy of Pediatric Dentistry:** [www.aapd.org/media/Policies\\_Guidelines/Intro1.pdf](http://www.aapd.org/media/Policies_Guidelines/Intro1.pdf)
- **American Academy of Pediatric Dentistry:** [www.aapd.org](http://www.aapd.org)
- [www.mychildrensteeth.org](http://www.mychildrensteeth.org) ( sponsored by the American Academy of Pediatric Dentistry)

## Disability Studies

### **Definition:**

American Educational Research Association, Disability Studies in Education Special Interest Group--The mission of the Disability Studies in Education Special Interest Group is to promote the understanding of disability from a social model perspective drawing on social, cultural, historical, discursive, philosophical, literary, aesthetic, artistic, and other traditions to challenge medical, scientific, and psychological models of disability as they relate to education.

### **Tenets**

To engage in research, policy, and action that

- contextualizes disability within political and social environments
- privilege the interest, agendas, and voices of people labeled with disability/disabled people

- promote social justice, equitable and inclusive educational opportunities, and full and meaningful access to all aspects of society for people labeled with disability/disabled people
- assume competence and reject deficit models of disability

## Websites

- **American Educational Research Association (AERA)**—type Disability Studies into the search box on the top right. <http://www.aera.net>
- **Society for Disability Studies**— <http://www.disstudies.org>

## Articles, Guides, Additional Resources

- **DOL Launches Disability Historical Timeline for ADA 25th Anniversary:** <http://www.dol.gov/featured/ada/>  
The U.S. Department of Labor (DOL) has unveiled a disability historical timeline called "Advancing Equal Access to Opportunity" as a start to its celebration of the 25th anniversary of the Americans with Disabilities Act (ADA). The timeline highlights the laws related to disability employment from 1920 to the present. In addition to the timeline, DOL is featuring personal stories submitted by workers with disabilities who have been affected by the ADA in their lives and careers. Meredith Ausenbaugh, an intern at DOL, has written a blog on "3 Things You Can Do to Celebrate 25 Years of the ADA," including submitting your own story to be shared.
- *Disability Studies in Education: Readings in Theory and Method* by Susan Lynn Gabel (ed.) 2005. Peter Lang Publishing, Inc. NY:NY.
- *Vital questions facing Disability Studies in Education* (2008) Scott Danforth & Susan Gabel (Eds.) Peter Lang Publishing, Inc. NY:NY.
- Disability Studies and inclusive education-implications for theory, research and practice in *International Journal of Inclusive Education*, Vol. 12 (5-6) (2008). This entire issue is devoted to Disability Studies in Education
- Ware, L. (2002). A moral conversation on Disability: Risking the personal in educational contexts. *Hypatia*, 17(3), 143-171.



A moral conversation  
on disability.pdf

## Epidemiology

### Definition:

Epidemiology is the study of the distribution and determinants of health-related states or events (including disease), and the application of this study to the control of diseases and other health problems. Various methods can be used to carry out epidemiological investigations: surveillance and descriptive studies can be used to study distribution; analytical studies are used to study determinants. *World Health Organization*.

Epidemiology is the study of the distribution and determinants of health-related states or events in specified populations, and the application of this study to the control of health problems. *Centers for Disease Control & Prevention*.

## Online Courses:

- **Online Course given by the Centers for Disease Control & Prevention: Principles of Epidemiology in Public Health Practice**

Educators use [Principles of Epidemiology](#) [6.01MB] as a foundational resource to learn about methods to investigate public health problems.

*Principles in Epidemiology:*

- Describes basic epidemiology principles, concepts, and procedures
  - Provides a solid foundation for the study and teaching of applied epidemiology
  - Explains how to calculate and interpret frequency measures (ratios, proportions and rates) and measures of central tendency
  - Uses tables, graphs, and charts to organize, summarize, and display data
- **Basic Epidemiology:** <http://www.training-source.org/search/node/epidemiology#overlay=training/courses/epidemiology/basic-epidemiology>  
*Date Developed:* 8/18/2010. *Source:* Upper Midwest Preparedness and Emergency Response Learning Center. *Presenter(s):* Iowa Department of Public Health. *Type:* Online Course. *Level:* Introductory. *Length:* 120 minutes.

## Websites

**American Academy of Pediatrics, Section on Epidemiology**—go to [www.aap.org](http://www.aap.org), type 'epidemiology' into the search function.

## Articles, Guides, Additional Resources

**Fact Sheets:** CDC

- [The Importance of Epidemiology](#)
- [Disease Detectives](#)



## Family Centered Care

### Definition:

Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services. *Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs*

**Principles of Family Centered Care for Children:** The foundation of family-centered care is the partnership between families and professionals. Key to this partnership are the following principles:

- Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role.
- Everyone respects the skills and expertise brought to the relationship.
- Trust is acknowledged as fundamental.
- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a **willingness to negotiate**.

Based on this partnership, family-centered care:

- Acknowledges the family as the constant in a child's life.
- Builds on family strengths.
- Supports the child in learning about and participating in his/her care and decision-making.
- Honors cultural diversity and family traditions.
- Recognizes the importance of community-based services.
- Promotes an individual and developmental approach.
- Encourages family-to-family and peer support.
- Supports youth as they transition to adulthood.
- Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
- Celebrates successes.

Sources: National Center for Family-Centered Care. *Family-Centered Care for Children with Special Health Care Needs*. (1989). Bethesda, MD: Association for the Care of Children's Health.

Bishop, Woll and Arango (1993). *Family/Professional Collaboration for Children with Special Health Care Needs and their Families*. Burlington, VT: University of Vermont, Department of Social Work.

Family-Centered Care Projects 1 and 2 (2002-2004). Bishop, Woll, Arango. Algodones, NM; Algodones Associates

## Websites

- **Family Voices:** [www.familyvoices.org](http://www.familyvoices.org)
- **National Center for Family Centered Care:** [www.ncccp.georgetown.edu](http://www.ncccp.georgetown.edu)

## Articles, Guides, Additional Resources

- **The Family-Centered Care Self-Assessment Tool – User's Guide:**

[http://www.familyvoices.org/admin/work\\_family\\_centered/files/fcca\\_userguide.pdf](http://www.familyvoices.org/admin/work_family_centered/files/fcca_userguide.pdf)

The User's Guide provides a detailed set of steps to use the Family and Provider Tools for a full assessment of a practice setting or family. In addition, the tool may be used as an educational tool to build awareness and knowledge of family-centered care for families, youth, providers, health plans and policy-makers. The items of the tool may also be used in defining family-centered care for policies, contracts and quality standards and can be used to compare a family-centered approach with other care models. The Tools are intended to assess care for all

children and youth and also has some questions that are specific to the needs of children and youth with special health care needs and their families. *Family Voices*.

- **The Family-Centered Care Self-Assessment Tool – Family Tool:**

[http://www.familyvoices.org/admin/work\\_family\\_centered/files/fcca\\_familytool.pdf](http://www.familyvoices.org/admin/work_family_centered/files/fcca_familytool.pdf)

Families, both individually and within family support and advocacy organizations, can use this tool to increase awareness and knowledge of the specifics of family-centered care to more effectively: Assess the quality of the care that they and their children receive; Share knowledge about family-centered care with other families, with providers, with health plans and with policy makers to create a shared vision for improving the health care system; Advocate for changes within health care settings, health plans and public agencies to more effectively support families and their children in the process of receiving care.

- **The Family-Centered Care Self-Assessment Tool – Provider Tool:**

[http://www.familyvoices.org/work/family\\_care?id=0005](http://www.familyvoices.org/work/family_care?id=0005) Health care settings can use this structured tool in quality improvement activities and to support development of the first key component of a medical home as defined by the American Academy of Pediatrics—“provision of family-centered care through developing a trusting partnership with families, respecting their diversity, and recognizing that they are the constant in a child’s life” (AAP, 2002). This tool can be used to increase family satisfaction with the care setting and to increase its standing in the community.

- **New Journal Article on the Family-Centered Care Assessment Tool:** The article, *Psychometric Evaluation of a Consumer-Developed Family-Centered Care Assessment Tool*, has recently been published online in the Maternal and Child Health Journal. This study describes the process that yielded **a robust and psychometrically sound instrument** for which there has been substantial interest from health care providers, researchers, and family groups. The FCCA provides **an important alternative to existing measures of families’ experiences of health care, including the CAHPS, which does not address the full range of topical areas deemed important to families, and the MHFI, which lacks the rigorous psychometric evaluation of the FCCA.** The findings from this study also provide **compelling evidence of the value of families taking substantive roles as researchers in the development of quality measures.** The high level of validity of the family-created questions in this study indicates how consistent the concepts in the developed questions are with the expectations of families across all demographic groups. This model of partnership in research, with consumers themselves in the lead, provides an important model for future quality measure development.

Learn more about the FCCA, including requesting access to use the tool [here](#).

- **Guidelines for Establishing a Family Advisory Board:**



Guidelines\_for\_Establishing\_Family\_Advisory\_Boards\_MCHB.pdf

## **Family**

### **Definition:**

Over the past decade there has been an emerging role in LEND programs for a Family faculty member to provide interdisciplinary teams with an invaluable perspective in the scope of their training: the perspective of the family. This role is unique in that the experience of being a family member or parent of an individual with a developmental disability cannot be learned in any university course. The family’s experience is an irreplaceable body of knowledge and

represents qualifications to improve service to families beyond what any degree or certification might provide. Additionally, families frequently benefit first-hand from parent-to-parent support. As a result of that experience, families appreciate the value of, and are able to provide, such support.

As knowledge of the benefits of this role become more widely known across the LEND network, many programs have taken or are taking steps to hire family members as faculty and to train family members to participate on their interdisciplinary teams. Family/professional partnerships are now part of the MCHB strategic plan<sup>1</sup> and the MCHB LEND grant application. The Omnibus Budget Reconciliation Act of 1989 (OBRA) mandates health programs supported by MCHB “provide and promote family centered, community-based, coordinated care”. MCHB’s 005 LEND guidance mandates family faculty or a family consultant for LEND programs. Family faculty members provide front line support to family trainees and may be assigned supervisory responsibility for these trainees. *Family Discipline Competencies, LEND: Leadership Education in Neurodevelopmental and Related Disabilities.*

**The Family ‘Discipline’:** “...that body of knowledge about the child/family member with a disability, that is inherent to the family, acquired by life experience and affected by culture and community.” *Center for Learning and Leadership, 2006*

## Websites

- **The Gray Center**-website by Carol Gray, the creator of the Social Story: [www.thegraycenter.org](http://www.thegraycenter.org)
- **Organization for Autism Research:** [www.researchautism.org](http://www.researchautism.org)
- **Ellen Notbohm**, author of several books on autism and the family: [www.ellennotbohm.com](http://www.ellennotbohm.com)
- **Love That Max**-a popular blog written for parents, by a parent and writer: [www.lovethatmax.com](http://www.lovethatmax.com)
- **Social Thinking** by Michelle Garcia Winner-popular methodology used by families and schools: [www.socialthinking.org](http://www.socialthinking.org)
- **Pilot Parents of Southern Arizona:** [www.pilotparents.org](http://www.pilotparents.org)
- **The Mighty** a website by parents: articles submitted by families and professionals highlighting issues faced by families of children with special needs: [www.themighty.org](http://www.themighty.org)
- Council for Exceptional Children—The Voice and Vision of Special Education—[www.cec.sped.org](http://www.cec.sped.org)
- **Including Samuel:** [www.includingsamuel.com](http://www.includingsamuel.com)

## Articles, Guides, Additional Resources

- **Parent Checklist to Help Ensure that Children Thrive at School:** <http://www2.ed.gov/documents/family-community/parent-checklist.pdf>

This new [Parent Checklist](#) includes key questions, tips, and resources that parents and caregivers can use to help ensure that their children are getting the education they deserve. It was developed by the U.S. Department of Education in collaboration with America Achieves, National Council of La Raza, National PTA, and the United Negro College Fund. A blog in [English](#) and [Spanish](#) provides more information. The checklist follows the recent release of the [Set of Rights](#) from the Department outlining what families should be able to expect for their children's education - from access to quality preschool to an affordable, quality college degree. *US Department of Education.*

- **Parent and Community Engagement Framework:** The fourth quarter of the school year is generally a time of preparation for schools and districts as they finalize next year's budget, student and teacher schedules, and professional development for the upcoming school year. During this time of preparation, it is important that schools and districts discuss ways that they can support parents and the community in helping students to achieve success.

To help in this work, the U.S. Department of Education is proud to release a framework for schools and the broader communities they serve to build parent and community engagement. Across the country, less than a quarter of residents are 18 years old or younger, and all of us have a responsibility for helping our schools succeed. The Dual Capacity framework, a process used to teach school and district staff to effectively engage parents and for parents to work successfully with the schools to increase student achievement, provides a model that schools and districts can use to build the type of effective community engagement that will make schools the center of our communities.

An example of how the elements of the framework can lead to improved engagement is exhibited in my hometown of Baltimore. Baltimore City Public Schools worked to support 12,000 pre-kindergarten and kindergarten homes, and to engage families in home-based literacy practices. Each week students received a different bag filled with award-winning children's books, exposing children, on average, to more than 100 books per year. The book rotation also includes parent training and information on how to share books effectively to promote children's early literacy skills and nurture a love of learning. Through the program, families are also connected with their local public and school libraries. At the culmination of the program, children receive a permanent bag to keep and continue the practice of borrowing books and building a lifelong habit of reading.

For more information on the Dual Capacity Framework, as well as an introductory video from Secretary of Education Arne Duncan, please take some time and review our website at [www.ed.gov/family-and-community-engagement](http://www.ed.gov/family-and-community-engagement). In the coming months, we will provide additional resources and information, so that schools, districts, communities, and parents can learn more about family and community engagement, as well as, share the wonderful work they are doing to build parent, school, and community capacity that supports all students.

[Read a Spanish version of this post.](#)

## Genetics

### **Definition:**

Genetics research studies how individual genes or groups of genes are involved in health and disease. Understanding genetic factors and genetic disorders is important in learning more about preventing birth defects, developmental disabilities, and other unique conditions among children.

Some genetic changes have been associated with an increased risk of having a child with a birth defect or developmental disability. Genetics also can help us understand how birth defects and developmental disabilities happen.

People get (inherit) their *chromosomes*, which contain their *genes*, from their parents. Chromosomes come in pairs and humans have 46 chromosomes, in 23 pairs. Children randomly get one of each pair of chromosomes from their mother and one of each pair from their father. The chromosomes that form the 23rd pair are called the sex chromosomes. They decide if a person is male or female. A female has two X chromosomes, and a male has one X and one Y chromosome. Each daughter gets an X from her mother and an X from her father. Each son gets an X from his mother and a Y from his father. *Centers for Disease Control & Prevention.*

## Websites

- [Educational Materials about Genetics and Genomics](#): This National Human Genome Research Institute website offers a talking glossary of genetic terms, fact sheets, and other genetics-related resources.
- [G2C2 Genetics/Genomics Competency Center for Educators](#) : The mission of G2C2 is to provide high quality educational resources for group instruction or self-directed learning in genetics/genomics by health care educators and practitioners.
- [Genes in Life](#): Genes in Life was created by Genetic Alliance to answer your questions about health and genetics.
- [Six Things Everyone Should Know About Genetics](#): This American Society of Human Genetics website provides basic genetics information and resources.

## Articles, Guides, Additional Resources



What you should know about genetics.

## Life Course Theory

### Definition:

Life Course looks at health as an integrated continuum and suggests that a complex interplay of biological, behavioral, psychological, social, and environmental factors contribute to health outcomes across the course of a person's life. It builds on recent social science and public health literature that posits that each life stage influences the next and that social, economic, and physical environments interacting across the life course have a profound impact on individual and community health. *HRSA, MCHB (Health Resources & Services Administration, Maternal & Child Health Bureau.)*

**Life Course Perspective for Families of Children and Youth with Special Health Care Needs:** Viewing events through a life-course perspective can be useful to better understand the experiences of families with children and youth with special healthcare needs. Providing culturally and linguistically competent and family-centered care is greatly enhanced by considering the total life course of the child and other family members. The life course model changes the focus from discrete events of illness or wellness for an individual to the person's life trajectory beginning with the generations before as a continuum within which events occur. This same refocusing can help better support families and children and youth with special health care needs.

The child's needs are not discrete and separate from the life course of the family members who care for them. When a child with special health care needs arrives in a family, it is the beginning of that child's life story. However, that new story begins within the ongoing life course of the family and its existing members—parents, grandparents, siblings and others. Their life course creates the context within which the [child with SHCN's story](#) will play out and the arrival of a child with special health care needs in the family reshapes their life trajectory.

## Websites

**U.S. Department of Health & Human Services, Health Resources and Services Administration, Maternal and Child Health**-<http://www.mchb.hrsa.gov>

## Articles, Guides, Additional Resources

**Slide Library:** The following group of slides has been collected to serve as a resource for MCHB-funded training programs. These slides may be used in any order to support a better understanding of the life course perspective.

- **Section 1: The Social Determinants of Health:**

The social determinants of health are those factors which are outside of the individual; they are beyond genetic endowment and beyond individual behaviors. They are the context in which individual behaviors arise and in which individual behaviors convey risk. The social determinants of health include individual resources, neighborhood (place-based) or community (group-based) resources, hazards and toxic exposures, and opportunity structures.

DOWNLOAD

 The Social Determinants of Health.pptx(752KB) [\[download\]](#)

- **Section 2: The Life Course Model as an Organizational Framework:**

Life Course (vs. Life Cycle and Life Span) Risk and Protective Factors Pathways and Trajectories Early Programming Cumulative Impact Critical or Sensitive Periods

DOWNLOAD

 Life Course Model as an Organizational Framework.pptx(1,288KB) [\[download\]](#)

- **Section 3: Examples- PKU: A Life Course Development Perspective and Obesity and Child Health**

DOWNLOAD

 Examples of Life Course Development.pptx(174KB) [\[download\]](#)

## Neurodevelopmental Disabilities

### Definition:

The neurodevelopmental disorders are a group of conditions with onset in the developmental period. The disorders typically manifest early in development, often before the child enters grade school, and are characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning. The range of developmental deficits varies from very specific limitations of learning or control of executive functions to global impairments of social skills or intelligence. The neurodevelopmental disorders frequently co-occur; for example, individuals with autism spectrum disorder often have intellectual disability (intellectual developmental disorder), and many children with attention-deficit/hyperactivity disorder (ADHD) also have a specific learning disorder. For some disorders, the clinical presentation includes symptoms of excess as well as deficits and delays in achieving expected milestones. For example, autism spectrum disorder is diagnosed only when the characteristic deficits of social communication are accompanied by excessively repetitive behaviors, restricted interests, and insistence on sameness. *American Psychiatric Association.*

### Websites

- American Academy of Child & Adolescent Psychiatry [www.mobile.aacap.org](http://www.mobile.aacap.org) See 'Family and Youth Resources'
- Centers for Disease Control & Prevention: [www.http://www.cdc.gov](http://www.cdc.gov)
- The Autism Society Website: [autismsource.org](http://autismsource.org).
- The Autism society of Southern Arizona: <http://www.as-az.org>
- United Cerebral Palsy of Central Arizona: <http://www.ucpofcentralaz.org>
- SANDS-Southern Arizona Network for Down Syndrome: <http://www.sandsaz.org>
- Global Down Syndrome Foundation: <http://www.globaldownsyndrome.org>
- Down Syndrome Network of Arizona: <http://www.dsnetworkaz.org>

## Articles, Guides, Additional Resources

- Links to articles and information at the Centers for Disease Control and Prevention: [Home | Developmental Disabilities | NCBDDD | CDC www.cdc.gov/ncbddd/developmentaldisabilities/index.html](http://www.cdc.gov/ncbddd/developmentaldisabilities/index.html)
- [The importance of differential diagnosis in neurodevelopmental disorders: Implications for IDEA](#)  
Neurodevelopmental Disorders (NDDs) are disorders of brain function that affect emotion, learning, and memory.  
*Newsletter Article (April 2012)*

# Occupational Therapy

## Definition:

Occupational therapy practitioners ask, "What matters to you?" not, "What's the matter with you?"

In its simplest terms, occupational therapists and occupational therapy assistants help people across the lifespan participate in the things they want and need to do through the therapeutic use of everyday activities (occupations). Common occupational therapy interventions include helping children with disabilities to participate fully in school and social situations, helping people recovering from injury to regain skills, and providing supports for older adults experiencing physical and cognitive changes. Occupational therapy services typically include:

- an individualized evaluation, during which the client/family and occupational therapist determine the person's goals,
- customized intervention to improve the person's ability to perform daily activities and reach the goals, and
- an outcomes evaluation to ensure that the goals are being met and/or make changes to the intervention plan.

Occupational therapy services may include comprehensive evaluations of the client's home and other environments (e.g., workplace, school), recommendations for adaptive equipment and training in its use, and guidance and education for family members and caregivers. Occupational therapy practitioners have a holistic perspective, in which the focus is on adapting the environment to fit the person, and the person is an integral part of the therapy team.

**Sensory Integration:** The American Occupational Therapy Association supports a full spectrum of approaches and interventions used in occupational therapy practice as part of an intervention plan that focuses on the participation of the client, including the appropriate use of sensory integration therapy (SIT).

AOTA has made considerable efforts to address issues such as insurance coverage, the need for further research, and public understanding of the use of SIT as part of occupational therapy. AOTA has also advocated in various state and

federal contexts for appropriate recognition of occupational therapy, including the use of SIT, as an approach for particular diagnoses, such as autism. AOTA's practice guidelines and official documents recommend that occupational therapy practitioners using an SIT approach collaborate and coordinate with educational and interdisciplinary teams and other professionals to maximize participation in daily environments.

AOTA also recommends that practitioners using an SIT approach use clinical reasoning, existing evidence, and outcomes to create a comprehensive, individualized approach for each client, rather than using isolated, specific sensory strategies. See the links below for more on AOTA's educational and analysis materials on SIT and occupational therapy's role in addressing sensory integration disorders. See more at: <http://www.aota.org/Practice/Children-Youth/SI.aspx#sthash.nody0FCj.dpuf>

## Websites

The American Occupational Therapy Association, Inc. (AOTA): <http://www.aota.org/about-occupational-therapy.aspx#sthash.DrziQQzX.dpuf>

## Articles, Guides, Additional Resources

**Resources to Support Pediatric Practice - [Challenges and Opportunities for Children and Youth with an Autism Spectrum Disorder](#)**

### Pediatric Virtual Chats:

- [Future chats](#)
- [Recordings of past chat sessions](#)

### AOTA Official Documents:

- **AOTA Statement:** [Scope of Occupational Therapy Services for Individuals with an Autism Spectrum Disorder Across the Life course](#)
- **Sensory Integration:** [Providing Occupational Therapy Using Sensory Integration Theory and Methods in School Based Practice](#)

### Podcasts:

- [Autism](#)  
Ellen Harrington-Kane, OT, MS, HSM, assistant vice president of autism and medical rehabilitation at Easter Seals, and Janie Scott, MA, OT/L, FAOTA, an occupational therapy and aging-in-place consultant and lecturer at Towson University, discuss the role of occupational therapy in autism intervention.
- [Children's Mental Health](#)  
AOTA's pediatric coordinator, Sandra Schefkind and Susan Bazyk, professor of occupational therapy at Cleveland State University, discuss the role of occupational therapy in children's mental health.

### OT Fact Sheets from AOTA:

The Fact Sheets below provide information on occupational therapy's role with a variety of conditions affecting children and families.

- **Occupational Therapy for All Children**
  - [Occupational Therapy's Role in Sleep](#) - pdf, 603 kb
  - [The Occupational Therapy Role in Driving and Community Mobility Across the Lifespan](#)
  - [Occupational Therapy's Role in Health Promotion](#) - pdf, 3.1 mb
  - [The Role of Occupational Therapy with Children and Youth](#) - pdf, 511 kb
  - [Into the Swing of Things](#)
- **Autism**
  - [Occupational Therapy's Role With Autism](#) - pdf, 484 kb
  - [Tips for Educators for Students With Autism](#) - pdf, 359 kb
  - [Supporting Parents of Children With Autism: The Role of Occupational Therapy](#)
  - [Addressing Sensory Integration Across the Lifespan Through Occupational Therapy](#) - pdf, 176 kb
- **School-Based Occupational Therapy**
  - [The Role of Occupational Therapy in Providing Assistive Technology Devices and Services](#) - pdf
  - [Students With Disabilities in Postsecondary Education Settings: How Occupational Therapy Can Help](#)
  - [Occupational Therapy and School Mental Health](#) - pdf, 561 kb
  - [Occupational Therapy in School Settings](#) - pdf, 497 kb
  - [Transitions for Children and Youth](#) - pdf, 349 kb
  - [What Parents Need to Know About School-Based Occupational Therapy](#)
  - [Homework Help From Occupational Therapy](#)
  - [Response to Intervention Consumer Brochure](#) - pdf, 1 mb
  - [Occupational Therapy and Universal Design for Learning](#) - pdf, 1002 kb
  - [Frequently Asked Questions for Educators - Help All Students Achieve Greater Success in Academic Performance and Social Participation](#) - pdf, 86 kb
- **Early Intervention**
  - [The Role of Occupational Therapy With Children and Youth](#) - pdf
  - [Occupational Therapy in Early Intervention: Helping Children Succeed](#)
  - [AOTA Practice Advisory on Occupational Therapy in Early Intervention](#) - pdf, 40 kb
- **Developmental Disabilities**
  - [The Role of Occupational Therapy in Facilitating Employment of Individuals With Developmental Disabilities](#) - pdf, 764 kb
  - [The Role of OT With Persons With Down Syndrome](#)
- **Children's Mental Health**
  - [Mental Health in Children and Youth: The Benefit and Role of Occupational Therapy](#) - pdf, 1.9 mb

#### **Autism Spectrum Disorder-Articles from The American Journal of Occupational Therapy**

- **AJOT Article:** [Evidence-Based Review of Interventions for Autism Used in or of Relevance to Occupational Therapy](#). Jane Case-Smith and Marian Arbesman (July/August 2008)

#### **Mental Health: -Articles from The American Journal of Occupational Therapy**

- **AJOT Article:** [Systematic review of occupational therapy and mental health promotion, prevention, and intervention for children and youth](#). *Marian Arbesman, Susan Bazyk, and Susan M. Nochajski (November/December 2013)*

### Sensory Processing and Sensory Integration-Articles from The American Journal of Occupational Therapy

- **AJOT Article:** [Examining the Neuroscience Evidence for Sensory-Driven Neuroplasticity: Implications for Sensory-Based Occupational Therapy for Children and Adolescents](#). *Shelly J. Lane and Roseann C. Schaaf (May/June 2010)*
- **AJOT Article:** [Evidence Review to Investigate the Support for Subtypes of Children With Difficulty Processing and Integrating Sensory Information](#). *Patricia L. Davies and Rebecca Tucker (May/June 2010)*
- **AJOT Article:** [Systematic Review of the Research Evidence Examining the Effectiveness of Interventions Using a Sensory Integrative Approach for Children](#). *Teresa A. May-Benson and Jane A. Koomar (May/June 2010)*
- **AJOT Article:** [Performance Challenges for Children and Adolescents With Difficulty Processing and Integrating Sensory Information: A Systematic Review](#). *Kristie Patten Koenig and Sarah G. Rudney (May/June 2010)*

## Physical Therapy

### Definition:

Pediatric physical therapists (PTs) work with children and their families to assist each child in reaching their maximum potential to function independently and to promote active participation in home, school, and community environments. Physical therapists use their expertise in movement and apply clinical reasoning through the process of examination, evaluation, diagnosis, and intervention. As primary health care providers, PTs also promote health and wellness as they implement a wide variety of supports for children from infancy through adolescence in collaboration with their families and other medical, educational, developmental, and rehabilitation specialists.

Pediatric physical therapy promotes independence, increases participation, facilitates motor development and function, improves strength and endurance, enhances learning opportunities, and eases challenges with daily caregiving.

**What Role Does the Family Play?** Parents and families have the primary role in their child's development. The pediatric PT collaborates with the family to promote development and implement an individualized intervention program for the child. Families are supported through coordination of services, advocacy, and assistance to enhance the development of their child. This can include:

- Positioning during daily routines and activities
- Adapting toys for play
- Expanding mobility options
- Using equipment effectively
- Facilitating safety for the home and community
- Providing information on the child's physical and health care needs
- Smoothing transitions from early childhood to school and into adult life

### Websites

American Physical Therapy Association-Section on Pediatrics. [www.pediatricapta.org](http://www.pediatricapta.org)

## Articles, Guides, Additional Resources

Article: [Treating Kids with Autism](#)

Fact Sheets from American Physical Therapy Association-Section on Pediatrics <https://pediatricapta.org/includes/fact-sheets/pdfs/09%20ABCs%20of%20Ped%20PT.pdf>

## Policy & Advocacy

### Definition:

Many organizations have information on their association websites regarding advocacy on a national level, and in some cases locally. One example is the American Speech-Language-Hearing Association at [www.asha.org](http://www.asha.org); select the Advocacy button from the top 'bar'

### Websites

- **American Educational Research Association**—click on the 'Policy & Advocacy' tab on the top, <http://www.aera.net>
- **Disability Rights Education & Defense Fund (DREDF)**—a national civil rights law and policy center directed by individuals with disabilities and parents who have children with disabilities-- <http://dredf.org>
- **PACER Center** (Parent Advocacy Coalition for Educational Rights)— <http://www.pacer.org>
- **"Be an Advocate" project of the National Center for Learning Disabilities** <http://www.understood.org>
- **Kids as Self-Advocates:** Leadership by and for youth and young adults with disabilities (a division of Family Voices): [www.fvkasa.org](http://www.fvkasa.org)
- **The Wrightslaw** website provides advocacy information written by special education lawyers: [www.wrightslaw.org](http://www.wrightslaw.org)
- **Local resource serving Southern Arizona--Pilot Parents of Southern Arizona:** [www.pilotparents.org](http://www.pilotparents.org)
- **National organization: Family Voices:** [www.fv.org](http://www.fv.org)
- **Autistic Self Advocacy Network:** [www.autisticadvocacy.org](http://www.autisticadvocacy.org)
- **Arizona Center for Disability Law:** <http://www.azdisabilitylaw.org>

## Articles, Guides, Additional Resources

- Ware, L. (2002). A moral conversation on Disability: Risking the personal in educational contexts. *Hypatia*, 17(3), 143-171.



A moral conversation  
on disability.pdf

# Psychology

## **Definition:**

**What Is a Psychologist?:** Psychologists hold a doctoral degree such as a PhD or PsyD. They study both normal and abnormal functioning and treat patients with mental and emotional problems. They also study and encourage behaviors that build wellness and emotional resilience.

Today, more and more psychologists are teaming with other health care providers to provide whole-person health care for patients.

**Society of Pediatric Psychology:** Division 54: Society of Pediatric Psychology members are part of an integrated field of science and practice in which the principles of psychology are applied within the context of pediatric health. The field aims to promote the health and development of children, adolescents, and their families through use of evidence-based methods.

Areas of expertise within the field include, but are not limited to: psychosocial, developmental and contextual factors contributing to the etiology, course and outcome of pediatric medical conditions; assessment and treatment of behavioral and emotional concomitants of illness, injury, and developmental disorders; prevention of illness and injury; promotion of health and health-related behaviors; education, training and mentoring of psychologists and providers of medical care; improvement of health care delivery systems and advocacy for public policy that serves the needs of children, adolescents, and their families.

## **Websites**

- American Academy of Child & Adolescent Psychiatry [www.mobile.aacap.org](http://www.mobile.aacap.org) See 'Family and Youth Resources'
- American Psychological Association: [www.apa.org](http://www.apa.org)
- National Association of School Psychologists: [www.nasponline.org](http://www.nasponline.org)

## **Articles, Guides, Additional Resources**

Klin, A., Sauliner, C. Tsatsanis, K., & Volkmar, F. (2005). *Clinical Evaluation in Autism Spectrum Disorders: Psychological Assessment with a Transdisciplinary Framework*. 772-798.

# Public Health System

## **Definition:**

Public health systems are commonly defined as “all public, private, and voluntary entities that contribute to the delivery of essential public health services within a jurisdiction.” This concept ensures that all entities’ contributions to the health and well-being of the community or state are recognized in assessing the provision of public health services.

The public health system includes:

- Public health agencies at state and local levels
- Healthcare providers
- Public safety agencies

- Human service and charity organizations
- Education and youth development organizations
- Recreation and arts-related organizations
- Economic and philanthropic organizations
- Environmental agencies and organizations

**The 10 Essential Public Health Services:** The 10 Essential Public Health Services describe the public health activities that all communities should undertake and serve as the framework for the NPHPS instruments. Public health systems should

1. Monitor health status to identify and solve community health problems.
2. Diagnose and investigate health problems and health hazards in the community.
3. Inform, educate, and empower people about health issues.
4. Mobilize community partnerships and action to identify and solve health problems.
5. Develop policies and plans that support individual and community health efforts.
6. Enforce laws and regulations that protect health and ensure safety.
7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable.
8. Assure competent public and personal health care workforce.
9. Evaluate effectiveness, accessibility, and quality of personal and population-based health services.
10. Research for new insights and innovative solutions to health problems.

## Websites

- **American Public Health Association**— <http://www.apha.org>
- **Announcing the MCH Navigator's 5-Minute MCH!** <http://bit.ly/1Hldwop>. As busy MCH professionals, we recognize the value of time and the importance of receiving quality, tailored information and resources quickly. With that in mind, we have designed a new program to improve your knowledge and skills of the 12 MCH Leadership Competencies. Beginning in July 2015, the MCH Navigator will conduct a monthly series that explores each competency, provides learning opportunities and implementation strategies, and culminates in an interactive learning session with an expert from the field. Intensive learning sessions emailed to you each week and available through the Navigator's web portal

## Articles, Guides, Additional Resources

- **America's Children: Key National Indicators of Well-Being, 2015--** <https://www.nichd.nih.gov/news/releases/Pages/071315-americas-children-report.aspx>. The number of American infants born before the 37th week of pregnancy dropped slightly in 2013, as did the percentage of children with asthma under the age of 17. The percentage of teens who experienced a major depressive episode increased. These and other findings are described in America's Children: Key National Indicators of Well-Being, 2015. The report was compiled by the Federal Interagency Forum on Child and Family Statistics, which includes participants from 23 federal agencies. The forum fosters coordination, collaboration, and integration of federal efforts to collect and report data on children and families.

- **10 Things Every Health Official Should Know Video:** Watch this new video of CDC Director Thomas R. Frieden, MD, MPH, as he shares 10 things every health official should know. [Learn More](#)



- **Centers for Disease Control & Prevention:** Learn more about CDC's organizational structure and access factsheets and leadership bios. [About CDC](#)

## Online Course

**Public Health 101** ([PPT\[3.15MB\]](#), [PDF\[1.27MB\]](#))

Learn about the components of the US public health system and how they work together to improve the nation's health. You may customize and use this presentation for your own informational and educational purposes.

# Research Methods

## Websites:

U.S. Office of Research Integrity, US Dept. of Health & Human Services: [www.ori.hhs.gov](http://www.ori.hhs.gov)

## Articles, Guides, Additional Resources

- [Laboratory Management Video Vignettes by the University of California, Davis](#) by the University of California, Davis
- [CITI Responsible Conduct of Research Program](#) by the Collaborative Institutional Training Initiative, University of Miami
- [A Guide to Research for Undergraduates](#) by Northeastern University
- [Open Seminar in Research Ethics](#) by the Land Grant University Research Ethics Education Project
- [ORI Introduction to the Responsible Conduct of Research](#) Nicholas Steneck
- [Online RCR Study Guide](#) by University of New Hampshire
- [Online Research Ethics Course](#) by University of Montana
- [Administrators and the Responsible Conduct of Research](#) by Boston College
- [Basic Research Concepts for New Research Staff](#) by San Diego State University
- [Lab Management: Safety, Mentorship, Writing Skills, Data, and Administration](#) by Washington State University

- [Research Ethics: A Novel Approach](#) by Jan Allen

## Social Work

### Definition:

**Global Definition of the Social Work Profession:** “Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing.

**Social Worker:** Graduates of schools of social work (in the U.S.A. with either bachelor’s, master’s or doctoral degrees) who use their knowledge and skills to provide social services for clients (who may be individuals, families, groups, communities, organizations, or society in general). Social workers help people increase their capacities for problem solving and coping, and they help them obtain needed resources, facilitate interactions between individuals and between people and their environments, make organizations responsible to people, and influence social policies. Social workers may work directly with clients addressing individual, family and community issues, or they may work at a systems level on regulations and policy development, or as administrators and planners of large social service systems (Barker, 2003). *National Association of Social Workers*.

The above definition may be amplified at national and/or regional levels”. *International Federation of Social Workers*

### Websites:

- **International Federation of Social Workers**--[www.ifsw.org](http://www.ifsw.org)
- **National Association of Social Workers**-- [www.socialworkers.org](http://www.socialworkers.org)

### Articles, Guides, Additional Resources

Pisula, E., & Kossalowska, Z. (2010). *Sense of Coherence and Coping with Stress Among Mothers and Fathers of Children with Autism*.

Pottie, C. G., & Ingram, K. M. (2008). *Daily Stress, Coping and Well-Being in Parents with Autism: A Multi-level Modeling Approach*.

## Special Education

### Definition:

**Special education** means specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability, including-- (i) Instruction conducted in the classroom, in the home, in hospitals and institutions, and in other settings; and. (ii) Instruction in physical **education**. *U.S. department of Education, Office of Special Education and Rehabilitative Services (OSERS)--Office of Special Education Programs (OSEP)*

### Websites

- Council for Exceptional Children—The Voice and Vision of Special Education—[www.cec.sped.org](http://www.cec.sped.org)
- U.S. department of Education, Office of Special Education and Rehabilitative Services (OSERS)--Office of Special Education Programs (OSEP) [Www2.ed.gov](http://www2.ed.gov)
- [www.idea.ed.gov](http://www.idea.ed.gov)
- **Center for Assistive Technology Act Data Assistance:** [www.catada.info](http://www.catada.info)
- [Sec. 300.39 Special education. - IDEA - Building The Legacy of ...](#)

## Articles, Guides, Additional Resources

- **Video Illustrates the Importance of Inclusion for All Children:** <https://vimeo.com/128526973>. A new video on early childhood inclusion has been posted in the [General Interest](#) section of California's Desired Results access Project Video Library. The video illustrates how essential early childhood inclusion is for all children, including those who cannot be in close proximity to other children because of health concerns. It can be viewed online and downloaded at no cost for use in educational and professional development activities.
- [Getty's Window to Inclusion: The Chance To Be Just Like Any Other Kid](#) (Runtime 14:55minutes) - In this video, Kate Mathany describes how her daughter Getty virtually attends a typical preschool classroom every day using a device called a VGo. Kate and Eileen Sedilko, Getty's preschool teacher, illustrate how Getty's school day works from both home and classroom perspectives. They discuss preschool inclusion, parent leadership, the use of adaptations, collaboration, teamwork, and the benefits of inclusion for all children, families, and teachers

# Speech Language Pathology

## Definition:

Pediatric speech-language pathology includes the evaluation and treatment of patients from birth to 18 years old. As such, it can require specialized skills in several differing age groups, including infants, toddlers, preschoolers, school-aged children and adolescents. Common disorders found in the pediatric population, particularly in a medical setting, include apraxia and other articulation or phonology disorders, autism, language disorders, central auditory processing disorders, and stuttering. Dysphagia is very common in a pediatric medical setting. The evaluation and treatment of children with dysphagia requires a special knowledge of the anatomy and physiology of babies and children and the usual causes of dysphagia in the pediatric population.

Children referred for communication or swallowing problems often have one or more of the following etiological factors: cleft lip/palate, craniofacial anomalies, velopharyngeal insufficiency, dental malocclusion, macroglossia, oral-motor dysfunction, neurologic disease/dysfunction, head trauma, brain stem injury, respiratory compromise, tracheostomy, vocal fold pathology, paralysis/paresis of the vocal fold, developmental delay, mental retardation, prematurity, autism, psychosis, hearing loss/deafness, environmental deprivation, or traumatic birth history.

**Speech, Language, and Swallowing:** The professionals who are educated to assess speech and language development and to treat speech and language disorders are called speech-language pathologists (sometimes informally referred to as speech therapists). Speech-language pathologists can also help people with swallowing disorders.

**Child Speech and Language:** Children's speech and language development follows a typical pattern (see [How Does Your Child Hear and Talk](#) for more information). If you have concerns about your child's speech or language, consult a speech-language pathologist ([ASHA's Find a Professional](#)).

## Speech Disorders:

- [Childhood Apraxia of Speech](#)
- [Dysarthria](#)
- [Orofacial Myofunctional Disorders](#)
- [Speech Sound Disorders: Articulation and Phonological Processes](#)
- [Stuttering](#)
- [Voice](#)

### **Language Disorders**

- [Language-Based Learning Disabilities](#)
- [Preschool Language Disorders](#)
- [Selective Mutism](#)

### **Medical and Developmental Conditions**

- [Attention Deficit/Hyperactivity Disorder](#)
- [Autism \(Autism Spectrum Disorders\)](#)
- [Cleft Lip and Palate](#)
- [Right Hemisphere Brain Injury](#)
- [Traumatic Brain Injury](#)

### **Communication Options**

- [Augmentative and Alternative Communication](#)
- [Speech for People with Tracheostomies or Ventilators](#)

## **Websites**

The American Speech-Hearing Association: [www.asha.org](http://www.asha.org)

## **Articles, Guides, Additional Resources**

- [Helping Children with Communication Disorders in the Schools](#)
- [Speech Referral Guide](#)
- Videos: Typical Speech and Language Development (second video on the following page: <http://www.slhs.arizona.edu/services/talking-matters>)

# **Transition**

## **Definition:**

According to IDEA Section 300.29—

(a) Transition services means a coordinated set of activities for a student with a disability that-

- (1) Is designed within an outcome-oriented process, that promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;
- (2) Is based on the individual student's needs, taking into account the student's preferences and interests; and
- (3) Includes-
  - (i) Instruction; (ii) Related services; (iii) Community experiences; (iv) The development of employment and other post-school adult living objectives; and (v) If appropriate, acquisition of daily living skills and functional vocational evaluation.

(b) Transition services for students with disabilities may be special education, if provided as specially designed instruction, or related services, if required to assist a student with a disability to benefit from special education.

## Websites

**National Center on Secondary Education and Transition**— <http://www.ncset.org>

**National Association of Special Education Teachers**—click on 'Resources' and scroll to the bottom to select 'Transition' <http://www.naset.org>

**U.S. Department of Education, Building the Legacy: IDEA 2004 website**—scroll down on the left to 'Secondary Transition' <http://www.idea.ed.gov>

**U.S. Department of Education**—type 'Transition' into the search box top right. <http://www2.ed.gov>

**Wrightslaw**—a website for information about special education law, education law, and advocacy for children with disabilities— <http://www.wrightslaw.com>

**Ability Path** [www.abilitypath.org](http://www.abilitypath.org)

## Articles, Guides, Additional Resources

- **AUCD Report—A Collaborative Interagency, Interdisciplinary Approach to Transition from Adolescence to Adulthood (2012).**  
[http://www.aucd.org/template/news.cfm?news\\_id=8881&parent=16&parent\\_title=Home&url=/template/index.cfm?](http://www.aucd.org/template/news.cfm?news_id=8881&parent=16&parent_title=Home&url=/template/index.cfm?)
- **High Expectations: Transforming the American Workforce as the ADA Generation Comes of Age.**  
<http://www.help.senate.gov/imo/media/doc/ADA%20Gen%20Report.pdf>
- **Journey to Life After High School:** <http://www.abilitypath.org/areas-of-development/transition-to-adulthood/life-after-high-school/AbilityPath>, in partnership with [Best Buddies](#) and [Special Olympics](#), has published [The Journey to Life After High School: A Road Map for Parents of Children with Special Needs](#). This comprehensive guide examines the laws that impact a child with special needs, the importance of the individualized education plan, and the different paths a child can take as they transition to adulthood. The guide includes a national directory of state agencies that assist families to find the support services they need.
- **The College and Career Success Bible for Those with Physical Disabilities.** Julia Nelson. 2015. Justicia Press. (Ms. Nelson is an Arizona LEND alum.)