

Frequently Asked Questions about Developmental and Intellectual Disabilities

What is a developmental disability?

Developmental disability is a term that includes disabilities that occur in the developmental years (before age 22). It may be caused by a mental or physical impairment or by a combination of both. Developmental disabilities cannot be cured—they are life-long and chronic. Developmental disabilities include, but are not limited to: intellectual disability, cerebral palsy, epilepsy, autism, Down Syndrome, or Prader-Willi Syndrome. It may also include head injury if the injury occurred before age 22 or other learning disabilities that are related to brain dysfunction. A person with a developmental disability will have substantial functional limitation in two or more of the following six areas of major life activities: self-care, receptive and expressive language development and use, learning, self-direction, capacity for independent living or economic self-sufficiency and mobility.

What is a developmental delay?

A developmental delay is considered to be slower than normal development in a child. In Missouri, if a child shows a 50% delay in one of the major areas of development (cognitive, physical, communication, social or emotional, or adaptive) he or she is considered to have a developmental delay that may benefit from early intervention services. A child may also be considered to have a developmental delay if he or she is diagnosed with a physical or mental condition associated with developmental disabilities or one that has a high probability of resulting in a developmental delay or disability.

What causes developmental disability?

Developmental disability has a variety of causes which can occur before, during or after birth. In many cases, a person may have a developmental disability that cannot be attributed to any specific cause. Genetic factors, inherited traits or environmental factors such as infections, injuries, lack of oxygen at birth, or exposure to toxic elements, drugs or alcohol may cause developmental disability. Sometimes developmental disability results from a combination of genetic and environmental factors.

Can developmental disability be prevented or can a person with a developmental disability be cured?

Developmental disabilities resulting from environmental factors (e.g. prenatal alcohol exposure, early lead exposure) alone can be prevented. In addition, the functional impact of developmental disability may be lessened through early intervention, education, training, therapy and adaptive measures.

What is "community living" for people with developmental disabilities?

Community-living refers to programs, services and other supports that enable children and adults with developmental disabilities to live much the same way that people without disabilities live. For children, this usually means living with their family in their own home and attending schools in their own communities. For adults, it usually means having opportunities and supports to live as independently as possible, in their own home or family home, and to participate in community activities as other people do.

What is "person-centered planning?"

Person-centered planning is a strategy or process that helps organizations design services for diverse individuals with personal needs and desires. It differs from traditional service planning because it emphasizes the rights of people with developmental disabilities to set individual goals and objectives that bring meaning to their own lives, instead of assigning standardized objectives to people based on an evaluation of deficits.

What is "people-first language?"

People-first language refers to a way of speaking about people with disabilities that emphasizes the person rather than the person's condition or diagnoses. It is a way of speaking that recognizes the uniqueness of each person and reflects the philosophy that each person, regardless of ability, is worthy of respect.

For example, people-first language means you would refer to someone as "a person who has autism" rather than as "an autistic" or "an autistic person." Because it is a sign of respect for and valuing of people with disabilities and their individual interests, hopes and dreams, the St. Louis Arc always uses people-first language.

What does "Arc" stand for?

Since its beginning in 1950, the organization known today as St. Louis Arc has gone by several different names. Originally, it was called the Mentally Retarded Children's Council. Later, to recognize its affiliation with a national organization, it became the St. Louis Association for Retarded Children. As the "children" of the founding families grew and its services expanded, the organization changed the wording of its name to "Citizens." Finally, because the organization actually served people who had many kinds of diagnoses, it began to go by the abbreviation, St. Louis A.R.C.

In the 1990s, organizations like the St. Louis Arc and individuals, like the people we support, became more concerned with how the language used to describe people with disabilities affected the way they were treated by society. Because of the philosophy of people-first language and also to more closely identify its affiliation with The Arc of the United States, the St. Louis Association for Retarded Citizens officially changed its name to St. Louis Arc. "Arc" in our name is considered a word in itself, not an acronym referring to any specific type of disability, outdated diagnostic term or medical condition. It symbolizes the breadth of services we provide to people and families throughout their lifetimes.

How can I help people who have developmental disabilities?

People who have developmental disabilities, like all people, deserve our respect and care. They have the right to live as they want to live and to take advantage of all of the opportunities of our free society. They may use support to participate fully in our community. You can help by treating people with disabilities as individuals and welcoming each person's participation and unique contributions. By being open to and cognizant of peoples' differences you can do much to help a person with disabilities achieve his or her personal goals.

How can I get involved with the St. Louis Arc to help people and families achieve their goals?

There are many ways you can get involved with the St. Louis Arc.

- Volunteer with us
- Work with the St. Louis Arc
- Support our organization through special events or financial contributions
- Hire people who have developmental disabilities