

Services and supports for families of individuals with developmental and intellectual disabilities are dramatically changing. Many families are unaware of recent sweeping changes in Ohio law, practice, services and supports.

The Arc is a non-profit agency that serves persons with developmental and intellectual disabilities and their families. Our efforts towards systems advocacy have helped to ensure that the changes in Ohio law will enhance and not hinder the lives of persons with IDD.

We at The Arc remain independent and steadfast in our advocacy efforts. Our vision is that families should receive information about any far-reaching changes so they can be better prepared to assist their loved one with IDD. We have developed this fact sheet to inform families about these changes.

What is an advocate?

Advocacy - is this something new?

Informal advocacy has existed as long as parents have loved their children - forever! The history of formal advocacy, however, can be linked closely to the history of The Arc, "the national organization of and for people with related disabilities and their families ... devoted to promoting and improving supports and services for people with developmental and intellectual disabilities and their families."

In 1950, virtually no programs and activities existed to support families of persons with IDD or other disabilities. Children were denied day care, preschool, education, and work programs. Medical professionals urged parents to put their children in institutions. The public was afraid of, had poor opinions about, or little contact with persons with disabilities. A small group of parents and other concerned persons formed The Arc to help to change all that.

Other organizations such as UCP (a.k.a. United Cerebral Palsy) share very similar histories. From the tireless dedication of families and friends has sprung strong networks of professional advocates who are passionate about ensuring that the estimated 7.2 million Americans with IDD have the services and supports they need to grow, develop, and live in communities across the nation.

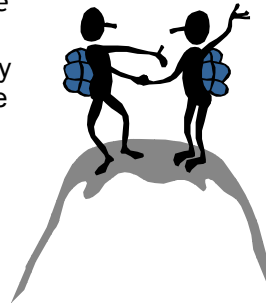
These pioneers have worked tirelessly over the years to help create legislation such as the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA) that ensure early intervention; health care; a free appropriate public education; supports for families; and equal opportunities for employment, transportation, health, and recreation.

Advocacy organizations work to protect their constituents' rights as citizens of this country - to live where and as they choose to live. But it all starts with just one person - you!

What an advocate does

An advocate

- works for change and to make things happen
- stays well informed
- helps others to make their own choices and take control of their own lives
- stands by the decisions of the person for whom he is advocating
- helps people to say what they want and makes sure that they are heard and answered
- tries to make sure that people have the opportunity to be included in their community
- enlists the support of others
- helps others to develop decision-making skills
- develops a clear vision of what needs to happen
- identifies the people who have power to make changes happen



What an advocate doesn't do

An advocate does not...

- become a referee in a dispute or argument
- take the control away from the person they are advocating
- try to change the other to his/her way of thinking
- take over the role of a Social worker or make up for gaps in services that should be provided

When should I call...

You should call an independent advocate...

- if you suspect abuse or neglect within an organization
- when a person's rights appear to be violated
- to settle disputes as an unofficial mediator between consumer, family, and provider (including the Board)
- when you need assistance with an IEP or ISP
- for disagreements regarding self-determination
- if a person is found ineligible for CCBMR/DD services and you disagree
- if people need more nurturing and support than you have time
- to act as a neutral listener not tied to funding for services
- when you can't seem to "reach" the person
- if the person plans to move out of state and needs contacts (Arc is nationwide)
- when systems advocacy is needed (letters, calls, political action)
- for simply another "ear" to brainstorm with - for yourself or for consumers
- to assist in networking process and in finding support as with Prader-Willi or Upside of Downs
- to link with community training programs like The Arc's "Making Choices; Opening Doors"
- to help an individual to be "heard"
- to develop a lifelong advocacy plan or to get links to legal or planning services

Where to go for info

Where can I get more information?

The advocates at The Arc are ready to help - call (216) 622.0755.

Here are some websites with useful information about advocacy:

The Arc of the United States is a great resource at www.thearc.org

United Cerebral Palsy www.ucp.org

Prader-Willi Syndrome Association of Ohio www.pwsaohio.org

National Down Syndrome Congress www.ndscenter.org

For local advocacy information on Down Syndrome -

www.upsideofdowns.com

Autism Society of America www.autism-society.org

Council for Exceptional Children www.cec.sped.org

Siblings are great advocates! Have them check out www.ohiosibs.org

Advocacy for family-centered health care services www.familyvoices.org

The above links are for informational purposes only. Inclusion in the above list does not constitute an endorsement by the Arc, which bears no responsibility for content of these sites.



"Recall the face of the poorest and the weakest man whom you may have seen, and ask yourself if the step you contemplate is going to be of any use to him.

Will he gain anything by it?

Will it restore him to a control over his own life and destiny?

Then you will find your doubts and yourself melting away."

Mahatma Gandhi

"Advocacy is not new. People do it everyday for themselves, for their children, for their older relatives and for their friends. Concerned individuals do it for people who are particularly vulnerable or undervalued. Advocacy gives people a stronger voice so that their wishes and needs are known."

(Source: www.advocacywestlancs.org.uk)