



Researching Causes of Intellectual and Developmental Disabilities to Improve Policies, Practices, and Quality of Life

People with intellectual and developmental disabilities (IDD) are valuable members of society.

The DD Act notes that “disability is a natural part of the human experience.”

Understanding more about the causes of IDD can be used to make policies and practices that better support people with IDD to live the lives they want.

ISSUE

There are many causes of IDD. There may be one or more causes for a person’s IDD.

The causes of IDD can be grouped into four types or areas:

- Not enough chances to learn and develop important skills during childhood.
- Not enough attention or support during childhood.
- Genetic, medical, or nutritional situations before a person is born or during their childhood.
- Seriously harmful treatment in health, education, or other life areas during childhood.

POSITION

People with IDD are valuable members of society.

Understanding more about the causes of IDD can be used to make policies and practices that better support people with IDD to live the lives they want.

People with IDD and their families should be included in:

- Learning more about the four causes of IDD.
- Creating policies that affect people with IDD.
- Providing person-centered supports for people with IDD.

Priorities for removing barriers to high-quality research, policies, and practices that help people with IDD are:

1. Learning more about the causes of IDD

- Learn more about the four causes and the number of people with IDD.
- Understand how to improve the quality of life of people with IDD.
- Include people with IDD in all parts of doing research and sharing findings.
- Make sure that study teams reflect diversity, equity, and inclusion.
- Make sure that there are enough funds to support IDD research that could benefit people with IDD.

2. Creating policies that affect people with IDD

- Promote policies that increase quality of life by addressing the four causes of IDD.
- Promote policies that are person-centered.
- Promote policies that include new ways of supporting people in achieving their goals.
- Make sure that policies are informed by people with IDD and their families.

3. Providing person-centered supports for people with IDD

- Promote supports and interventions that increase quality of life by addressing the four causes of IDD.
- Promote access to supports to improve the functioning of people with IDD.
- Promote family supports that recognize that caregiver needs change with age.
- Make sure that there are enough funds to pay for the supports that people with IDD need.
- Make sure that there are enough funds to pay support staff fairly.

People with IDD and their families must be included in activities for understanding the causes of IDD, creating policies that affect their lives, and removing barriers to high quality IDD research, policy, and practices.

Definitions used in this document:

Accessible: Made so people with IDD can understand, engage, and fully participate.

Advocacy: Ways to work alone or with others to fix an issue, get services or supports, or make changes in what the government, businesses, or groups do or say.

Diverse or Diversity: Seeking out and valuing different views. People have different views related to their lived experiences with things like their race, age, gender, faith, culture, sexuality, and disability.

Equity: Reaching the goal of fairness by giving each person what they need to succeed.

Genetic: The most basic cause of things like a person's eye color or the shape of their ears.

Inclusion: People feel and are treated like they belong.

Nutritional: How well the foods a person eats can help them grow or be healthy.

Person-Centered: The person with IDD has a central role in choosing the supports that match their needs.

Policies: Rules, regulations, or laws.

Practices: The ways that services, supports, and programs are provided.