Plain Language Summary of the

2022 Joint Position Statement of AAIDD and The Arc on

Advocacy

Advocacy is what you do when you:

- Work to fix an issue.
- Get the support or service you need, or
- Support a change in what the government, businesses, or groups do or say.

People, families, and groups can all advocate. This includes people with intellectual and developmental disabilities (IDD), who are **self-advocates**. It is critical to promoting and protecting people's **civil and human rights**.

Advocacy by, about, or with people with IDD must be based on what self-advocate leaders say and think. Self-advocates are people who have the lived experience of having IDD. They should be leaders in the advocacy movement.

ISSUE

People with IDD often do not get the chance or help they need to protect their civil and human rights. We need strong advocacy to make sure people with IDD are fully included in society. It is also critical to prevent and confront abuse, neglect, **discrimination**, injustice, **bias**, and **exploitation**.

POSITION

Advocates must be able to meet and communicate directly with people and groups who make rules and decisions about their lives.

People with IDD and families need:

- Tools and information to understand the political, legal, and disability services systems.
- Education and resources to become powerful advocates.
- Support to navigate the disability service system.
- To have the support they need when they ask for it.

Any advocacy organization should be inclusive and accessible. They must:

- Understand the issues that people with IDD face and know the people they are advocating for or with
- Create opportunities and support people with IDD to advocate for themselves.
- Respond to self-advocate needs and provide education.

People should not be threatened or punished because of their advocacy.

Advocacy efforts should involve whole communities, not just people with IDD.

Advocacy is not always about helping one person. It is about making better laws and systems for people.

Advocacy helps make sure people with IDD can access and use all their civil and human rights.

It makes sure people who have been treated unfairly have access to services that are responsive to them.

Advocacy can happen in many ways:

- Educating and training
- Sending letters or social media posts
- Going to meetings
- Testifying to government agencies or leaders
- Filing court cases

Sometimes, people with IDD need legal advocacy.

Protection and Advocacy (P&A) systems operate in each state to help people with IDD. They advocate for and protect the rights of people with disabilities. They offer legal assistance to people with disabilities.

Any public legal assistance must be available and accessible to people with IDD. It must:

- Be independent of anything that could unfairly influence the quality of services, like a conflict of interest or government control.
- Have enough funding and staff to do their work well.
- Provide advocacy for people of all ages, even when no one has made a formal complaint.
- Be able to provide information and resources, legal action and solutions, legislative and regulatory fixes.

DEFINITIONS OF WORDS USED IN THIS DOCUMENT

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.

BIAS: Unfair opinions or ideas of people based on something they cannot change.

CIVIL RIGHTS: Rights we have in the United States of America.

DISCRIMINATION: When someone treats you unfairly because of who you are or how you express yourself.

EXPLOITATION: When someone takes unfair advantage of a person or a situation.

HUMAN RIGHTS: Rights we all have because we are human.

SELF-ADVOCATES: People who have a lived experience of having intellectual and developmental disabilities (IDD).