



Peer 2 Peer

Self-Advocacy Efforts

Three self-advocacy activities are required annually. Basic information is below.

- 1) Establish or strengthen a program for the direct funding of a state self-advocacy organization LED by people with intellectual disabilities (ID) or developmental disabilities (DD) ID/DD.**

An important piece of this requirement is the self-advocacy organization must be LED by people with intellectual and developmental disabilities (not parents, not siblings, not caregivers, but people with ID/DD).

Lots of people ask about the wording “for the direct funding of”. This means the Council must invest time, money, or other resources so a self-advocacy organization operating in your State or Territory can work towards their own direct funding.

The activity is centered on ESTABLISH or STRENGTHEN....

- 2) Support opportunities for people with ID/DD who are considered leaders to train other people with ID/DD who may become leaders.**

The Council must support opportunities for leaders with intellectual and developmental disabilities to provide training to other people with ID/DD who may become leaders.

Sometimes Councils report activities where self-advocates are getting training from people without ID/DD. That type of activity may make sense in other areas of your 5-year plan but would not meet this self-advocacy requirement of the DD Act.

The activity is centered on SUPPORT OPPORTUNITIES...

- 3) Support and expand participation of people with ID/DD in cross-disability, culturally diverse leadership coalitions.**

A **CROSS-DISABILITY COALITION** is an alliance or group made up of individuals, organizations, or advocacy groups that represent and advocate for the rights and needs of people with various types of disabilities. A **CULTURALLY DIVERSE LEADERSHIP**

COALITION is a group of leaders from various cultural, ethnic, and social backgrounds who come together to work on common goals or initiatives. A **COALITION** is a group or alliance formed by individuals, organizations, or entities that come together to achieve a common goal or to address a shared concern.

The activity is centered on SUPPORT and EXPAND participation...

Below are some ideas to meet each activity with “activity snapshots” from Council PPRs.

Required Activity #1 - Ideas on HOW to establish or strengthen

For an organization that is established, consider supporting a needs assessment, developing a funding strategy with sources and information on diversifying funding streams. Support a way to evaluate the success of the self-advocacy organization, ways to communicate impact, and a plan for sustainability moving forward.

Establishing a self-advocacy organization in the state or territory involves planning, collaboration, and understanding the ID/DD community’s needs. The Council can support research and planning efforts to include, but are not limited to, recruiting a core team, creating a legal entity, and developing organizational documents. Consider support for developing a budget, identifying funding sources and in-kind donations! Support the organization to engage the community, launch programs and/or services (i.e., advocacy training, awareness campaigns), strategic planning, leadership development and public awareness about the organization’s mission, activities, and successes.

Activity snapshot (from 2023 PPRs)

Providing funding was most common. Often funding was tied to specific activities such as:

- Annual self-advocacy summit.
- State conference and an advocacy day in the capital.
- Strengthening local self-advocacy groups, providing training and technical assistance on goal planning, bylaws development, effective use of social media, and membership and coalition building.
- Expanding chapters across the state.
- Increasing the number of advocates involved.
- Increasing participation in local groups led by people with ID/DD.
- Council staff expertise and financial support for statewide and local self-advocacy group development.

REPORTING TIPS

When reporting, include information about how your efforts to establish or strengthen a self-advocacy organization are supporting them to work towards their own direct funding.

Double check to make sure you are reporting about organizations that are LED by people with ID/DD.

Required Activity #2 – Ideas about HOW to provide opportunities for leaders with ID/DD to train other people with ID/DD to become leaders.

Peer Leadership Training Programs

Design Peer-Led Workshops. Create opportunities where the curriculum is co-designed and led by people with ID/DD who have already received leadership training. This can help ensure the content is relatable and accessible.

Certification Programs. Consider offering certification for people who complete training. This can enhance their resumes and gain recognition as leaders within their communities.

Mentorship Programs

Peer-to-Peer Mentorship. People with ID/DD who are experienced in leadership roles mentor others who are interested in becoming leaders. A formal process can include regular meetings, goal setting, and progress tracking.

Reverse Mentorship. People with ID/DD who are newer to leadership roles share their fresh perspectives with more experienced leaders and can foster mutual learning.

Train the Trainer Programs

Customized Training Modules. Create a program where people with ID/DD learn how to teach leadership skills to their peers. Topics could include public speaking, decision-making, advocacy, and teamwork.

Offer Practical Experience. Provide opportunities for trainers to practice teaching in small groups before leading larger workshops or seminars.

Inclusive Leadership Conferences and Workshops

ID/DD-Led Sessions. Host leadership conferences or workshops that feature sessions led entirely by people with ID/DD. Encourage topics such as advocacy, community engagement, and leadership development.

Panel Discussions. Organize panel discussions where leaders with ID/DD share experiences, challenges, and successes. Panels can serve as a platform for networking and inspiration for future leaders.

Provide ongoing support, such as coaching to help new leaders navigate challenges and continue to develop their skills. Ensure all training materials are accessible so that content is understandable to a wide range of abilities. Celebrate the achievements of people who take on leadership roles. Consider public acknowledgement or highlighting their work in newsletters or social media. Share success stories of leaders with ID/DD who train others and serve as a role model for aspiring leaders.

Activity snapshot (from 2023 PPRs)

- The Fellows Leadership Program. Self-advocate leaders serve as Fellows who then train other people with ID/DD to become leaders.
- Self-Advocate Leadership Academy designed to strengthen advocacy skills.
- People with ID/DD became certified trainers to provide training to other people with ID/DD on Healthy Relationships.
- Peer to Peer training on Charting the Life Course is conducted by a self-advocacy organization.
- Self-advocate leaders are trained to teach Healthy Relationships and Sexual Health for All curriculum.
- Peer trainers implement Self-Advocacy Leadership Series Trainings.

REPORTING TIPS

When reporting, focus on training to develop other people with ID/DD to become leaders.

Most Councils include information about people with ID/DD providing training. However, there is a lack of, or no information about who received the training. For this required activity, it is important you include information that leaders with ID/DD are training other people with ID/DD who may become leaders. (We noted information being provided about training by people with ID/DD to others (family members, parents, professionals) and know this is important work too! Please continue to highlight. When reporting to demonstrate compliance with this requirement, focus on training efforts by people with ID/DD to people with ID/DD.

Required Activity #3 – Ideas to support and expand participation of people with intellectual and developmental disabilities in cross-disability, culturally diverse leadership coalitions.

This required activity has several important aspects and include cross-disability, culturally diverse, and coalition. See the information on page 1 for details.

This activity is essential for fostering inclusivity and ensuring people with ID/DD have their voices heard in decision-making processes. Here are a few ideas to help achieve this:

Accessible Communication such as plain language, visual aids including symbols, pictograms to help convey information more clearly, language access such as sign language, language interpreters, and captioning during meetings and events.

Training and Capacity Building such as skills training to build self-advocacy, communication, and leadership skills, pairing individuals with ID/DD with experienced mentors to help guide them through participation in coalition activities and pre-meeting briefings to go over the agenda, talk about key points to help all participants understand and prepare for the meeting.

Representation and Leadership such as promoting people with ID/DD to ask for representation on a coalition's board or steering committee, encourage and support people with ID/DD to take on leadership roles within the coalition, promote and support the establishment of advisory groups made up of people with ID/DD to provide input on coalition activities and decisions.

Customized Participation Opportunities such as identifying and promoting engagement strategies that are tailored to the individual preferences and abilities of people with ID/DD, allowing for varying levels of involvement.

Accessible Technology such as providing technical support to help people with ID/DD use digital tools effectively during coalition activities.

Resources such as funding for transportation, direct support needs to help people participate.

Activity snapshot (from 2023 PPRs)

- Provided support to self-advocates such as scheduling, processing information, preparing for meetings, sharing information.
- Provided technical assistance to coalitions and committees related to recruiting people with DD (focus on plain language materials used to recruit people with I/DD), supported collaborations between the statewide self-advocacy organization and cross-disability organizations.
- Council members and staff identify people with ID/DD who are interested in serving on other boards and commissions and make recommendations to organizations or the Governors Appointments staff for consideration.

REPORTING TIPS

WHEN reporting, include information about HOW or WHAT your Council is doing to support and expand participation of people with ID/DD to participate in cross-disability leadership coalitions.

Often, PPR information focuses on where people are participating by naming the groups or coalition without describing HOW the Council is supporting and expanding participation of people with ID/DD in cross-disability, culturally diverse leadership coalitions.

Double-check to make sure you are reporting about participation in coalitions rather than conference attendance for this required activity.

Understanding the difference between a conference and a coalition is critical to reporting.

A **conference** is a short-term event focused on discussion, knowledge-sharing, and networking.

A **coalition** is a partnership or alliance formed to achieve a specific goal or address an issue through coordinated efforts.

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This document is intended for Council staff. Readability level is 13.