

Strategic Partnerships:

Building a Relationship with DD Network Partners



Self-advocates can create change on many levels and through many channels. Common levels advocates talk about making change are the federal level, state level, and local level. Common channels are through policy, litigation (taking legal action), media, direct action (protesting), education, and community building.

At all of these levels and through all of these channels, there are many groups and organizations that make natural allies for self advocates.

When deciding who to partner with, it is important to ask yourself five questions:

- who are people that have similar goals?
- who are people that have similar values?
- who are people that have something of use to your group?
- what can I offer in a partnership?
- who are people that need something I can offer?

For example, there may be a parent group that has similar goals and values as you, but are the same size as your group and have the same resources as you. You might get friendships and support by working with them, but strategy wise, you might also want to find groups that can lend you meeting space or give you a grant. That doesn't mean not to work with the parent group — it just means to keep meeting people!

Another example might be that you are considering partnering with a large service organization. They might have a lot of resources, but if they don't share values with you, it might be a less strategic partnership.

The DD Network

The Administration on Intellectual and Developmental Disabilities (AIDD) is a federal agency that works to ensure people with developmental disabilities can participate in their communities. AIDD falls under the Administration on Community Living. AIDD allocates (distributes or gives away) funds created through the Developmental Disabilities Assistance and Bill of Rights Act (DD Act).



The DD Act funds:

- State Councils on Developmental Disabilities (“DDC”)— a council in each state that creates a state plan to support citizens with developmental disabilities and gives away money based on that plan
- State Protection and Advocacy Agency (“P&A”, pronounced “P and A”)— an agency in each state that provides legal support and advocacy to support citizens with disabilities. Sometimes the P&A might have to take action against the state, even if it is a part of the state’s government.
- University Centers for Excellence in Developmental Disabilities Education, Research, and Service (“UCEDD”, pronounced “you-said”)— centers at various universities that conduct research, educate students, and provide services. There are currently 68 in the United State.
- Projects of National Significance (“PNS”)— AIDD has a small pot of money that they can spend based on their priorities. Often times, Congress cuts this budget before other projects so it is hard to know how much funding will be available. When there is funding available, AIDD will announce it and allow agencies to apply to do certain projects.
- President’s Committee for People with Intellectual Disabilities (“PCPID”) is a committee that makes recommendations to the President and Secretary of Health and Human Services. Recommendations are about how to improve the quality of life for people with intellectual disabilities.

The State Council, the Protection and Advocacy Agency, the University Centers, and any Projects of National Significance in a particular state are supposed to work together. This group of agencies is called the Developmental Disabilities (DD) Network. The agencies were created with overlapping goals that promote collaboration. Together they are supposed to promote the values of the DD Act: self-determination, independence, productivity, integration and inclusion.

The DD Network and Self Advocacy

The DD Network is supposed to work with self advocates. Some states are better at it than others.

DD Councils: In the past, it was extremely common for DD Councils to fund self advocacy organizations. The DD Council was often the main funder for the self advocacy organization. Many DD Councils still do fund self advocacy groups, but have created higher



standards for how they expect self advocacy organizations to use the funding. If you are interested in seeing if you can receive funding for the self advocacy work you are doing, try to get a copy of the DD Council's state plan. It can usually be found on their website. See if they have identified self advocacy as a funding priority, and if so what kind of work they are funding. It can be helpful to ask an ally that knows about the DD Council's activities what they think. See ASAN's website pacific-alliance.org for to find a webinar and resource guide on how to ask for money for more information.

Even if the DD Council doesn't have funding for your organization, it is a good idea to still connect with them. They often have a staff person who coordinates collaboration between self advocacy efforts. That person might be able to connect you to other resources. DD Councils often also lend meeting space, facilitation support, and printing when asked. If you are hosting an event, it can be a good idea to let the DD Council know, and to ask them to help promote it. They usually have a wide network of people they know.



P&As: Protection and Advocacy Agencies mostly provide legal services, but include self advocates in advisory roles and sometimes on their staff. They typically don't have funding they can give to self advocates, but can be great allies. P&As often help promote self advocacy events, connect self advocates to other allies, and share non-financial resources (e.g. meeting or office space).

UCEDDs: UCEDDs don't typically have funding to give to self advocates, but often apply for grants where they can write in self advocacy groups as partners if they choose. It can be helpful to network with your local UCEDD. Often times, to build a relationship, you might support them in a research or service project. UCEDDs must have a Consumer Advisory Council, which is a great opportunity for self advocates to serve, have their voices heard, and build their leadership skills.



Tips for Communicating with DD Network Partners:



If you don't know your DD Network partners, reach out to them! One way to do this is to contact them, let them know you are a self advocate, and ask how you can get involved. If you have self advocacy leadership experience, it can be good to include that so they know what kind of opportunities might be a good fit for you.

Have 1-2 communication lines that you check regularly. For example, if you share with them an email address, check it every 2-3 days in case they contact you. If you don't use email, that's completely fine, but communicate to them that you prefer to be contacted via phone.

Note: If you choose to communicate via email, it is often a good idea to create a professional email address. Some examples are: john.Doe@yahoo.com, jdoe@gmail.com, or doej@hotmail.com.

When in-person, think of a conversation like a basketball game. In basketball, players dribble the ball so that it keeps bouncing. You want to keep a conversation going the same way. One way to do this is by asking the person a question, or if they tell you a story, finding something that you can share or ask related to what they just said.

Try your best to remember details of people's lives. (For example, try to remember if the person you are talking to has kids, traveled recently, has a hobby you like, too, etc.) Next time you see them, you can ask them about it and they will be happy you remembered.

If you have something you want to get from the conversation, direct the conversation towards what you want to ask. As an example, let's say you want to ask the DD Council director if they will fund your youth program. One way to start is by asking what the Council is doing to support youth leadership. If what they share is something you want to get involved in, you can ask if they would be open to talking about collaboration opportunities for your youth program and the Council.



For questions about this resource guide, please contact the Autistic Self Advocacy Network (ASAN) at info@autisticadvocacy.org

This Resource Guide was developed for ASAN's Pacific Alliance on Disability Self-Advocacy project.

***Pacific Alliance** was a project funded by the Administration on Intellectual and Developmental Disabilities to support self advocacy groups with technical assistance.*

For more about ASAN, visit us at
www.autisticadvocacy.org.