



Emerging and Promising Practices to Support Aging Adults with Intellectual and Developmental Disabilities (IDD) and Family Caregivers

Initial Report: Plain Language Version
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Background

- The National Association of Councils on Developmental Disabilities (NACDD) is working with states to support people with individual and developmental disabilities (IDD) and their families who are getting older.
- Many times, agencies that provide services and support to people with IDD do not talk with agencies that provide support to older adults. Getting these groups to work together can make supports better. This is called “bridging” aging and disability.
- NACDD is working with state teams in 7 states to bridge aging and disability. They are learning from each other. This is called a “Community of Practice.” We will work with more states next year.

Why We Did this Report

- We want to highlight state examples where aging and disability groups have worked together.

What We Did

- We put out a “Call for Information.” This asked people to give us examples they know of where aging and disability groups worked together to support people with IDD and their families.
- We sent the “Call for Information” across the country to all states. Groups that helped send it out included:
 - Administration for Community Living
 - The White House

- Association for University Centers on Disabilities
- The Arc of the United States
- Advancing States (they represent state aging and disability services)
- We also shared on Twitter and Facebook
- Over 360 people shared information with us about examples they knew about where aging and disability communities worked together. We also looked on the internet and talked with other people to find other examples.
- We picked 18 examples to share in this report.
 - Most of the examples are still new. These are called “emerging practices.”
 - A few examples have been around longer. Some have research and evaluations that show they work. These are called “promising practices.”

Kind of Examples We Found

- We put the examples into three “buckets” based on the kind of support they provide.



Discovery and Navigation

- Information, training, and tools
- Help finding services and supports



Connecting and Networking

- Peer support



Services and Policies

- Goods, services and supports
- Policies

What Is Next?

- We list the examples of 18 practices on the next pages. We explain:
 - What they are
 - Where they are
 - How to find out more
- This is just a start. We are going to talk to more people and states to find more examples. We will add these to the list and put them on the NACDD website.

Who Supported this Project?

- The Administration for Community Living provided support for this project.
- However, views in the report are those of the authors. These may or may not be the same views as the Federal Government.

Discovery and Navigation

The Arc Center for Future Planning

What It Is?

This is an online resource to help people with intellectual and developmental disabilities (IDD) and family caregivers make plans for the future. It has tools and videos by self-advocates. It includes things like wishes for the future, deciding where to live and work, and making friends and having good relationships. It includes a tool to write down plans and share with other family members.

Where Is It?

National

How to Learn More?

<https://futureplanning.thearc.org/>

Dementia Friends for Intellectual and Developmental Disabilities

What It Is?

This is an online resource where people can learn about the experiences of people living with dementia. It includes online videos and training lessons. They also did sessions on supporting people with intellectual disabilities with dementia. These lessons can help you learn more about supporting people with dementia.

Where Is It?

Ohio and National (they have chapters in states)

How to Learn More?

<https://dementiafriendsusa.org/>

Hawaii Addition of Disability Information to Aging and Disability Resource Center (ADRC)

What It Is?

Aging and Disability Resource Centers (ADRCs) are a place where people can get information about Home and Community-Based Services. They are sometimes called “No Wrong Door” because they provide information to all individuals regardless of their type of disability or age. However, some ADRCs do not provide good enough information about services and supports for people with intellectual and developmental disabilities (IDD). The Hawaii Developmental Disabilities Council helped change that by adding more information about disability services to the ADRC list of resources. They also developed a refrigerator magnet with the number and website of the ADRC. They passed these out at local fairs to help reach people who are not being served.

Where Is It?

Hawaii

How to Learn More?

<https://www.hawaiiadrc.org/>

Massachusetts Webinar Series Aging with IDD

What It Is?

The Massachusetts Department of Developmental Services offers webinars focused on aging with IDD. They include many topics such as planning for the

future, legal issues, staying health as you age, and honoring cultural values and preferences. They help people learn about aging and planning for the future.

Where Is It?

Massachusetts

How to Learn More?

https://shriver.umassmed.edu/programs/cdder/aging_idd_education/general-aging/

<https://www.mass.gov/orgs/department-of-developmental-services>

New Jersey Aging and IDD Information and Resources

What It Is?

The Boggs Center is New Jersey’s University Center for Excellence in Developmental Disabilities (UCEDD). They have a project that helps provide information to families and professionals about aging with intellectual and developmental disabilities (IDD). The project gives information, resources, and trainings online and in-person. Trainings include topics such as staying health as you age, decision making, and end of life planning.

Where Is It?

New Jersey

How to Learn More?

<https://boggscenterstage.rwjms.rutgers.edu/training-and-consultation/aging>

<https://boggscenterregistration.rwjms.rutgers.edu/index.php/event/training>

Person-Centered Approaches for Healthcare Decision Making

What It Is?

This is an online training course that teaches people about how to support people with intellectual and developmental disabilities (IDD) in advanced care planning. Advanced care planning is about discussing and preparing for future decisions about your health care in case you become unable to make decisions. This is important for people of all ages, but it is really important when people are nearing the end of life.

Where Is It ?

National, multiple states

How to Learn More?

<https://tlcpcp.com/md-profile/leigh-ann-kingsbury/>

[https://ncapps.acl.gov/docs/Webinars/2022/Feb/NCAPPS Webinar PL Summary 220222.pdf](https://ncapps.acl.gov/docs/Webinars/2022/Feb/NCAPPS_Webinar_PL_Summary_220222.pdf)

Skills2Care-ID

What It Is?

This is a program that assists family caregivers of individuals with intellectual and developmental disabilities (IDD) who also have dementia. Professionals (Occupational Therapists) come to the home. They provide one-on-one education and training to the family caregivers on how best to support the person with dementia. Research on the program has shown that it helps caregivers on individuals with dementia.

Where Is It

Multiple states

How to Learn More?

<https://www.dementiacollaborative.com/pages/skills2care-certification>

WE CARE (Wellness, Education, Confidence, Assessment & Recognizing Emergencies)

What It Is?

This is a project by the Missouri Developmental Disabilities Council that trains people with intellectual and developmental disabilities (IDD) on how to be caregivers for their aging family members. As parents and other family members age, people with IDD often become caregivers. They often do not receive any formal training or resources. WE CARE is a project that helps teach people with IDD skills about recognizing and responding to basic needs and home safety. The goal is to increase the ability of people with IDD and aging family members to support each other as they age.

Where Is It?

Missouri

How to Learn More?

<https://moddcouncil.org/>

Connecting and Networking

The Future is Now

What It Is?

This is a training to help families make future plans and take action on those plans. People with disabilities and their family members, including siblings, participate in the training together. They meet in five sessions that are co-led by peers who are other family members and self-advocates with disabilities. They discuss dreams for the future, relationships and support networks, where

individuals with IDD want to live and where to work in the future. The family writes down plans and sets goals to take action. Research has shown that the in-person training with peers results in families taking action, decreases worries about the future, and includes people with IDD. An online version is being tested now. The hope is that it can make it easier for more families to take part in the training.

Where Is It?

National, international, multiple states

How to Learn More?

<https://ahs.uic.edu/disability-human-development/lifespan-health-community-living-and-intellectual-developmental-disabilities-research-and-training-programs/virtual-future-is-now/>

Planning Forward

What It Is?

This is a training done by the Arc in Saint Louis, Missouri to assist families in planning for the future. It is an eight-week series that provides peer group learning. The project used the resources from The Arc of the United States, Charting the Lifecourse training through the University of Missouri-Kansas City, and resources on financial planning through the National Disability Institute (NDI). After the training with peers is finished, people can get more information and help that is just for them and their families, separate from the group.

Where Is It?

Missouri

How to Learn More?

<https://www.slarc.org/programs/family-support/support-groups/>

MI-OCEAN Family Support Project

What It Is?

This is a program for people with IDD and their family caregivers that are getting older who are not connected to services. The program pairs aging caregivers (peer navigators) with other people who have similar experiences to learn from and help each other learn about the system and how to get services. The program was tested in Michigan through Wayne State University which is the University Center for Excellence in Developmental Disabilities (UCEDD). It was successful. However, they have not yet found a way to expand it and keep it going.

Where Is It?

Michigan

How to Learn More?

<https://ddi.wayne.edu/miocean>

<https://ddi.wayne.edu/fsnresources>

Sib2Sib Mentoring Program

What It Is?

This is a program to help brothers and sisters of people with IDD. This program matches people together and gives information and community so that they can learn how to best support their siblings with IDD.

Where Is It?

National, multiple states

How to Learn More?

<https://siblingleadership.org/2021/12/23/sib2sib-adult-sibling-mentoring-program/>

Services and Policies

Bridging Aging and Disability in Hawaii Disaster Response

What It Is

In August 2023, there were wildfires in Maui that caused a lot of damage and pain. Certain groups of people, like older people and people with disabilities are more likely to be hurt during situations like wildfires. Because of the National Association of Councils on Developmental Disabilities (NACDD) grant on bridging aging and disability, Hawaii already had a state of aging and disability organizations in place that were working together. They used this state team to respond to the disaster. They worked together to make sure that people who were older and people with IDD were found and helped during this scary time.

Where Is It

Hawaii

How to Learn More?

<https://www.mauinuistrong.info/resource-categories/agingdisabilities>

District of Columbia Disability Services Reform Amendment Act of 2018

What It Is?

This is an example of a policy that helped protect the rights of people with intellectual and developmental disabilities (IDD) to make their own decisions

with supports. Some people with IDD have guardians who do not need them. When a guardian passes away, a new guardian is appointed. The law passed in the District of Columbia (CD) requires the court to consider less restrictive alternatives to guardianship.

Where Is It?

District of Columbia

How to Learn More?

<https://dds.dc.gov/sites/default/files/dc/sites/dds/publication/attachments/DSRAA%20CIDCRRRA%201-10-2018%20Plain%20Language%20Fact%20Sheet.pdf>

<https://dds.dc.gov/page/dds-decision-making-rights-people-disabilities>

District of Columbia Modified Intake Form for Aging System Entry

What It Is?

When people need to get services from Aging Systems, they fill out a form. The District of Columbia made sure to add a question in their form that asks, “are you caring for someone else and are they an adult with disabilities?” If the answer to this question is ‘Yes,’ people are also sent to the Developmental Disabilities System to make sure that people with IDD are also getting the help they need in addition to their caregivers.

Where Is It?

District of Columbia

How to Find Out More?

<https://ddc.dc.gov/>

Hawaii Direct Support Professional Internship Program

What It Is?

High school students in Hawaii are required to do an internship. The Hawaii Developmental Disabilities Council created an internship program for students to give them experiences supporting people with intellectual and developmental disabilities (IDD). They receive training and support. They hope that this will help recruit new direct support professionals to the field and make it easier for people with IDD, their families, and agencies to find workers.

Where Is It?

Hawaii

How to Find Out More?

<https://www.hawaiidrc.org/>

<https://hiddcouncil.org/internship-opportunities/>

Lifespan Respite Care Program**What It Is?**

The Lifespan Respite Care Program is a national program that helps provide respite to family caregivers. Respite provides a break from caregiving so that caregivers can recharge and not get burned out. Unfortunately, respite is not always available to families who need it. Many families do not qualify for respite services because their family member doesn't have a certain type of disability or is not the right age. This program gives grants to states to help serve everyone, regardless of their type of disability or age.

Where Is It?

National, multiple states

How to Find Out More?

<https://archrespice.org/ta-center-for-respice/>

<https://acl.gov/programs/support-caregivers/lifespan-respice-care-program#:~:text=Lifespan%20Respice%20Care%20programs%20are,disabilities%20and%20For%20chronic%20conditions.>

Pennsylvania Priority to People on the Waiting List Living with Aging Caregivers

What It Is?

The Pennsylvania Developmental Disabilities Services System uses a system that collects information about people on the waiting list for services. They use this system to identify people with intellectual and developmental disabilities (IDD) who are living at home with older family caregivers. People living with an aging caregiver may face emergencies when their caregiver can no longer provide care or passes away. Pennsylvania and many other states have used this information to serve people who are in the most need of services and support.

Where Is It?

Pennsylvania

How to Find Out More?

https://palms-awss3-repository.s3.us-west-2.amazonaws.com/MyODP_Content/Everyday+Lives/ODP+Annual+Waiting+List+Report+2022.pdf [Prioritization of Urgency of Need for Services \(PUNS\) Manual](#)
https://www.medicaid.gov/sites/default/files/2023-05/3.1_State_Agencies-508%5B22%5D.pdf