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

Initial Report
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**Background**

In October 2021, the National Association of Councils on Developmental Disabilities (NACDD) was awarded a five-year grant from the Administration for Community Living (ACL) to establish a Community of Practice (CoP) that bridges aging and disability communities to improve supports for aging adults with intellectual and developmental disabilities (IDD) and their family caregivers. The CoP will consist of state alliance teams from approximately 15 States and Territories, selected through a competitive application process. In the first two years, seven states joined the CoP:

- Connecticut, District of Columbia, Florida, Hawaii, and New Jersey (Year 1)
- California and New Mexico (Year 2)

The purpose of this report is to identify an initial set of emerging and promising practices in order to support state teams within the CoP as they develop and implement their work plans. It provides examples that might help inform approaches in other local communities and states.

**Process to Identify Initial Set of Practices**

An environmental scan was conducted to identify potential practices. Between January and March 2023, we distributed a “Call for Information.” It was distributed widely through social media and various aging and disability organizations and networks, including:

- Administration for Community Living (ACL) Updates listserv
- The White House Disability Community newsletter
- National Association of Councils on Developmental Disabilities
We received 362 responses via a web-based Qualtrics survey and email. Individuals were asked for the following information:

- Name of practice and location
- Please describe the program or practice. Please be as specific as possible and include why you think it is a promising practice or program.
- How can we find out more about the program? Please provide links to information available online. Please provide contact information for people we can email or call to find out more about this practice or program.

While we received a large number of responses, there often was not enough information provided to assess whether there was a specific or unique practice being recommended. For example, many responses identified a provider or service agency but provided little detail about what support was provided or made it promising. In some cases, we received multiple responses referencing the same practice or a national practice in different states. We explored the links provided and followed up with contacts to obtain additional information when possible.

In addition to the “Call for Information,” project staff conducted a literature search of journal articles and grey literature on relevant topics related to aging and IDD. We met with state team leads within the current CoP during a two-day meeting in conjunction with the NACDD Annual Meeting to learn about emerging practices within their teams. We also
interviewed staff from The Lewin Group who led a similar project for the Centers for Medicare and Medicaid (CMS). The CMS project focused more on state officials of Home and Community-Based (HCBS) systems. We incorporated some practices identified from this previous work.

**Organization of Practices**

We decided to focus on a set of 18 practices for the initial report. We selected practices and policies that covered a wide range of topics and areas. We developed more detailed short summaries and descriptions, and we provided these descriptions back to the relevant contacts to help ensure accuracy. With the exception of a handful, most were considered “emerging” practices, because they were very small-scale ideas or pilots with little or no research or evaluation of their effectiveness.

We adopted the *Charting the LifeCourse “The Three Buckets” Framework* to help organize the practices into different types of support. While there is overlap between the categories, the framework generally fits well. Any practice involving peer supports was placed within “Connecting and Networking.” Some practices were more focused on policy changes at a systems level, such as the IDD service system or other systems. We placed these into the third bucket and expanded it to include policy and systems reforms.

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Ongoing Identification of Practices

Additional practices will be added on an ongoing basis, particularly as we learn from the work of state teams in the CoP. We also plan to conduct additional outreach and key informant interviews to identify additional practices. This information will be housed on the Bridging Aging and Disability CoP website.
# Emerging and Promising Practices to Support Aging Adults with IDD and Family Caregivers

## Discovery and Navigation
(Information, training, outreach and systems navigation)

<table>
<thead>
<tr>
<th>Practice</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Arc Center for Future Planning</td>
<td></td>
</tr>
<tr>
<td>Dementia Friends for Intellectual and Developmental Disabilities</td>
<td></td>
</tr>
<tr>
<td>Hawaii Addition of Disability Information to ADRC Resources*</td>
<td></td>
</tr>
<tr>
<td>Massachusetts Webinar Series Aging with IDD</td>
<td></td>
</tr>
<tr>
<td>New Jersey Aging and IDD Information and Resources</td>
<td></td>
</tr>
<tr>
<td>Person-Centered Approaches for Healthcare Decision Making</td>
<td></td>
</tr>
<tr>
<td>Skills2Care-ID</td>
<td></td>
</tr>
<tr>
<td>WE CARE</td>
<td></td>
</tr>
</tbody>
</table>

## Connecting and Networking
(Peer supports)

<table>
<thead>
<tr>
<th>Practice</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Future is Now</td>
<td></td>
</tr>
<tr>
<td>Planning Forward</td>
<td></td>
</tr>
<tr>
<td>MI-OCEAN Family Support Project</td>
<td></td>
</tr>
<tr>
<td>Sib2Sib Mentoring Program</td>
<td></td>
</tr>
</tbody>
</table>

## Goods and Services
(Services and supports, policy and systems reforms)

<table>
<thead>
<tr>
<th>Practice</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bridging Aging and Disability in Hawaii Disaster Response*</td>
<td></td>
</tr>
<tr>
<td>District of Columbia Disability Services Reform Amendment Act of 2018</td>
<td></td>
</tr>
<tr>
<td>District of Columbia Modified Intake Form for Aging System Entry*</td>
<td></td>
</tr>
<tr>
<td>Hawaii Direct Support Professional Internship Program*</td>
<td></td>
</tr>
<tr>
<td>Lifespan Respite Care Program</td>
<td></td>
</tr>
<tr>
<td>Pennsylvania Prioritization of Urgency of Need for Services</td>
<td></td>
</tr>
</tbody>
</table>

* Practices from the ACL Bridging Aging and Disability Community of Practice
The Arc Center for Future Planning

**Primary Practice:**
Online resources and tools to support future planning

**Location:**
National

**Description:**
The Arc of the United States established the Center for Future Planning in 2014 to support and encourage adults with IDD and their families to plan for the future, particularly aging caregivers of adults with IDD. The Center provides reliable information and practical assistance to individuals with IDD, their family members and friends, professionals who support them, and other members of the community on areas such as person-centered planning, decision-making, housing options, and financial planning. The Arc’s Center for Future Planning hosts an interactive and user-friendly tool (*Build Your Plan*) designed to assist families with building a plan for the future. The tool includes the following areas: 1) Expressing wishes for the future in writing; 2) Deciding where to live and how much support is needed; 3) Paying for basic and other needs; 4) Getting a job and other daily activities; 5) Making daily and major life decisions; and 6) Making friends and having good relationships. The plan is a living document that can be updated and shared with other family members. Alongside the *Build Your Plan* tool, there is a resource directory to find additional resources across various states. This directory includes an extensive video gallery providing overviews and example summaries from self-advocates with IDD of how they have approached their own future planning.

**For More Information:**
[https://futureplanning.thearc.org/](https://futureplanning.thearc.org/)
Dementia Friends for Intellectual and Developmental Disabilities

**Primary Practice:**
Resources and training on Dementia

**Location:**
Ohio and national

**Description:**
Originating from the United Kingdom’s Alzheimer’s Society, Dementia Friends USA Initiative is an American organization striving to educate people about dementia. People can view a series of online videos or attend live sessions to learn about the experiences of people with dementia. They can also turn this understanding into action by becoming a Dementia Friend. Dementia Friends for Intellectual and Developmental Disabilities (IDD) was adapted from Dementia Friends, with support from three Ohio-based grants from the Administration for Community Living (ACL) and the US Department of Health and Human Services. The goal of this program is to improve the quality of life for people with IDD who are living with dementia and their caregivers. Dementia Friends for Intellectual and Developmental Disabilities provides educational materials on dementia risk factors, signs, and symptoms, as well as engagement tips and community resources. Dementia Friends for Individuals with Intellectual and Developmental Disabilities strives recognize and support both aging caregivers and people with IDD living with dementia. These efforts have been shared beyond Ohio, with other states looking to expand programs.

**For More Information:**
[https://dementiafriendsusa.org/](https://dementiafriendsusa.org/)
Hawaii Addition of Disability Information to ADRC Resources

Primary Practice:
Information and resources on disability services and supports

Location:
Hawaii

Description:
Aging and Disability Resource Centers (ADRCs) serve as single points of entry into the long-term services and supports (LTSS) system for older adults, people with disabilities, veterans, and family caregivers. Some states refer to ADRCs as “No Wrong Door” systems. ADRCs provide unbiased, reliable information, and counseling to individuals with all levels of income. Since 2003, support for ADRCs/No Wrong Door Systems has been provided through various opportunities funded by the Administration for Community Living (ACL), Administration on Aging (AoA), Centers for Medicare and Medicaid Services (CMS), and Veterans Health Administration (VHA). However, federal funding has not been consistent. States rely on state funding to support systems and functioning of ADRCs/No Wrong Door Systems varies from state to state. While aging and disability partnerships have improved, disability advocates in many states have expressed concerns that ADRCs do not serve the disability communities well, particularly the intellectual and developmental disabilities (IDD) population. Through the ACL funded Bridging Aging and Disabilities Community of Practice, the Hawaii DD Council developed a partnership with the Hawaii ADRC. They reviewed ADRC resources and found gaps in information and resources for individuals with IDD and their families. They worked together to develop and add a list of relevant resources such as agency providers, advocacy groups (i.e., Hawaii Disability Rights Center), and community supports. Additionally, the Hawaii ADRC worked to further expand its outreach by designing and distributing fridge magnets with a logo created by a self-advocate, which advertised “Kapuna and Disability Resources.” The fridge magnets were distributed at community events and fairs.

For More Information:
https://www.hawaiiadrc.org/
Massachusetts Webinar Series on Aging with IDD

Primary Practice:
Webinar series focused on aging with IDD

Location:
Massachusetts

Description:
The Massachusetts Department of Developmental Services offers webinars focused on aging with IDD that were funded by the Massachusetts State Legislature. The intended audience for these webinars includes caregivers, families, direct service workers, residential managers, and case managers. Webinar training consists of several modules with person-centered planning topics including health, adapting to age-related changes in the home, dementia and IDD, and honoring cultural practices and individual preferences. Additionally, there are also separate resources regarding more legal-related topics such as life-sustaining treatment policy, guardianship, and Five Wishes. In addition, the Massachusetts Department of Developmental Services is conducting research and interviews as part of a needs assessment for aging caregivers and has an aging and caregiver workgroup to better support caregivers. These webinar resources and information (i.e., total general aging and dementia trainings, end-of-life trainings, etc.) are available to the public on their website.

For More information:
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

Primary Practice:
Information and resources related to aging with IDD

Location:
New Jersey

Description:
The Boggs Center is New Jersey’s federally designated University Center for Excellence in Developmental Disabilities (UCEDD) and part of Rutgers’ Robert Wood Johnson Medical School, Department of Pediatrics. The Center has emphasized a community-based, lifespan approach to meeting the needs of individuals with developmental disabilities and their families. Under the Training and Consultation tab, there are several resources regarding education, employment, and more, including the Aging Project in collaboration with the Division of Developmental Disabilities. This project focuses on both the experiences of aging people with (IDD) and those of their caregivers. The project seeks to provide professionals and families with information and resources to effectively support healthy aging, person-and family-centered health care decision-making, and considerations for end-of-life planning through in-person and virtual training.

For More information:
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

Primary Practice:
Training course on advance care planning and future planning

Location:
National, multiple states

Description:
The Person-Centered Approaches for Healthcare Decision Making is an 18-hour virtual course that teaches skills needed to facilitate advance care planning and future planning with people with IDD and other disabilities. Participants leave the training more informed on how to complete advanced care directives and support others with such future plans. This is a new training led by Leigh Ann Kingsbury, a consultant and gerontologist who has supported people with complex healthcare and disabilities for more than thirty years. She is the author of the American Association on Intellectual and Developmental Disabilities (AAIDD)’s People Planning Ahead: A Guide to Communicating Healthcare and End of Life Wishes. The course is relatively new and has been run twice with participants from several states (California, Indiana, Minnesota, New Jersey, Virginia, Ohio, Maryland, Oklahoma, and South Carolina).

For More information:
https://tlcpcp.com/md-profile/leigh-ann-kingsbury/

https://ncapps.acl.gov/docs/Webinars/2022/Feb/NCAPPS_Webinar_PL_Summary_220222.pdf
**Skills2Care - Intellectual Disabilities (ID)**

**Primary Practice:**
Intervention to support family members and caregivers of individuals with dementia and intellectual disabilities

**Location:**
Multiple States

**Description:**
Skills2Care is an evidence-based intervention designed to support family members and caregivers of individuals with dementia to equip themselves with skills and information that enable them to modify living spaces and provide the best care and support they can. This intervention involves five 90-minute home visits by an occupational therapist who observes the living space and caregivers. These professionals provide education and strategies on how to provide the best care and cope with challenges in providing such care to their loved ones with dementia. Early analyses of the original Skills2Care program data revealed that family caregivers of people with ID and dementia had different needs that the program did not capture. As a result, the adapted Skills2Care ID program was developed to directly address the needs of caregivers of adults with both intellectual disability and dementia. Skills2Care ID program was launched in 2018, and has trained seven occupational therapy students and one clinician, in addition to developing a training for occupational therapists certified in Skills2Care to expand their services to the ID population. This program has been delivered in three states (PA, NY, and CT) in shared living and day program settings.

**For More Information:**
WE CARE (Wellness, Education, Confidence, Assessment & Recognizing Emergencies)

Primary Practice:
Intervention/training for people with IDD to support aging family caregivers

Location:
Missouri

Description:
The Missouri Developmental Disabilities Council (MODDC) has a project with the Association on Aging with Developmental Disabilities (AADD) called WE CARE (Wellness, Education, Confidence, Assessment & Recognizing Emergencies). As caregivers age, their needs also change. This can result in the family member with IDD taking on additional tasks to support their caregiver. These supports and tasks performed by family members with IDD often occur with little to no formal training or guidance. WE CARE is a project developed to support aging caregivers and their family members with IDD by teaching people with IDD the skills necessary to recognize and respond to their loved one’s basic care and home safety needs. The long-term goal of this project is to increase the ability of both family members to support each other and prolong the mutual caregivers’ abilities to age-in-place in the family home. The project is based on Bromley Mencap’s Mutual Caring Project, which was implemented in the early-to-mid 2000’s in the United Kingdom. This project is just in its second quarter and will end in April 2024.

For More Information:
Contact the Missouri DD Council: https://moddcouncil.org/
The Future Is Now

**Primary Practice:**
Peer support, person-centered future planning intervention/training for individuals with IDD and aging family caregivers

**Location:**
National, International, multiple States

**Description:**
The Future is Now was developed by the University of Illinois at Chicago. The program is designed to assist aging family caregivers and adults with intellectual and developmental disabilities (IDD) to plan for the future when aging caregivers pass away or are no longer able to provide care. Workshops include family members as well as their relatives with IDD. These workshops consist of five 2.5-hour sessions, including breakout sessions for family members and individuals with IDD. Groups are co-facilitated by a professional and a peer mentors (family members who have done future planning and self-advocates with IDD). Sessions include: 1) Dreams for the future; 2) Expanding support networks; 3) Future living arrangements; 4) Work, education, and retirement; and 5) Safeguards to ensure their future plan will be implemented. Families also receive training in legal and financial aspects of planning. Families set individual planning goals and work towards achieving them. The Future Is Now was tested using a randomized pre-test and one-year post-test design. It contributed to outcomes of families taking concrete steps in planning, decreased caregiver burden, and increased involvement and choice-making of adults with IDD in future planning. It has been implemented in many states across the US and in other countries. The virtual version, The Virtual Future Is Now (V-FIN) is currently being adapted and pilot tested. The virtual version will allow more families who are unable to attend in-person groups or prefer virtual sessions to participate.

**For More information:**
Planning Forward

Primary Practice:
Information and resources related to aging and future planning with IDD

Location:
Missouri

Description:
Planning Forward is a project offered by the St. Louis, Missouri Arc focused on educating aging individuals and their families on future planning. In addition, Planning Forward is testing an enhanced training plan for improving the quality of care for aging individuals with IDD from their direct support caregivers. Planning Forward is an eight-week series designed to develop and provide peer group learning opportunities about future planning and provides consultation to interested families who have completed the group sessions. This project utilized resources such as Future Planning training through The Arc of the United States, LifeCourse Ambassador Training through the University of Missouri – Kansas City, and financial resource training through the National Disability Institute (NDI).

For More information:
https://www.slarc.org/programs/family-support/support-groups/
Michigan Older Caregivers of Emerging Adults with Autism and Other Neurodevelopmental Disabilities (MI-OCEAN) Family Support Project

Primary Practice:
Peer navigators to support aging caregivers

Location:
Michigan

Description:
Michigan Older Caregivers of Emerging Adults with Autism and Other Neurodevelopmental Disabilities (MI-OCEAN) Family Support Project is a statewide initiative piloted with aging family caregivers (55+ years) of ‘emerging’ adults (age 22 and older) with autism spectrum disorder and other neurodevelopmental disabilities across Michigan. MI-OCEAN uses a peer support model to match aging caregivers with Family Support Navigators (FSN) to improve health outcomes and quality of life. Thirteen peer family support navigators (FSN) were recruited from across Michigan and participated in a 2-day online training. One hundred and three aging caregivers from across the state were enrolled and paired with an FSN in their geographic area. 32 caregivers have completed the program and 81 additional people also participated in the program. Pre- and post-survey data was collected related to caregiver health and quality of life. The project was funded with a two-year grant from the Michigan Health Endowment Fund, and extended for an additional six months due to the Covid-19 pandemic. While successful, the MI-OCEAN project was unable to be continued as grant money ended and the program was not sustained through other funding streams. Lessons learned from the study have informed a new project with different funding sources that similarly will focus on aging caregivers, health disparities, and the intersectionality of race starting in January of 2024.

For More information:
https://ddi.wayne.edu/miocean

https://ddi.wayne.edu/fsnresources
Sib2Sib Mentoring Program

Primary Practice:
Peer mentoring for siblings

Location:
National, across multiple states

Description:
The Sibling Leadership Network (SLN) serves as a network to support the siblings of individuals with IDD by providing tools and connections to social and structural supports across the lifespan, which enables them to be effective advocates with their brothers and sisters. The Sib2Sib Mentor Program is specifically for adult siblings of people with disabilities where adult siblings (18 and older) are matched with each other to share their experiences. This is important because siblings often have the longest relationships with their brother or sister with disabilities, yet they are often overlooked in receiving supports or training for this role. Sib2Sib mentors connect virtually through phone, email, and zoom for a 3-month period to provide peer support and connections. The SLN spent two years creating a Sib2Sib mentor matching model through collaboration with Parent2Parent USA and three of their state chapters. Recently, a small Sib2Sib mentoring program was piloted where 24 siblings were matched to create 12 Sib2Sib Mentor matches. A post-program survey was also distributed that was completed by 22 of the 24 mentors. The self-report of the mentors illustrated that adult siblings were most likely to discuss the topics of future planning, navigating family dynamics, and how to navigate the disability service system.

For More Information:
https://siblingleadership.org/2021/12/23/sib2sib-adult-sibling-mentoring-program/
Bridging Aging and Disability in Hawaii Disaster Response

**Primary Practice:**
Aging and disability collaboration in disaster response

**Location:**
Hawaii

**Description:**
Through participation in the ACL Bridging Aging and Disability Community of Practice, Hawaii established a Hawaii State Alliance Team (SAT) comprised of eight different agencies to improve collaboration across aging and disability networks. This established a forum for regular communications that previously did not exist within the state. In August 2023, wildfires in Maui caused widespread damage and destruction. Often, when disasters strike, people with disabilities and older adults are more impacted and less accommodated in states’ approaches to disaster relief. Hawaii was able to quickly leverage the SAT forum to coordinate disaster response across aging and disability systems. Within 48 hours of the Maui fires beginning, the Hawaii SAT had worked to identify the locations of every impacted individual with IDD supported by its agencies, and representatives traveled to the respective shelters to ensure that the needs and resources of the disability population were being met. Those with IDD who were not receiving supports were also identified and outreach was conducted.

**For More Information:**
[https://www.mauinuistrong.info/resource-categories/agingdisabilities](https://www.mauinuistrong.info/resource-categories/agingdisabilities)
District of Columbia Disability Services Reform Act of 2018

**Primary Practice:**
Legislation protecting the decision-making rights of individuals with IDD

**Location:**
District of Columbia

**Description:**
The District of Columbia established legislation for Supported Decision Making (SDM) as an alternative to guardianship. When guardians or parents, who sometimes serve as legal guardians to adult children over age 18, are no longer able to provide care, adults with IDD are at risk of having a court-appointed guardian with no personal relationship or knowledge of the individual’s needs or preferences. With the passage of the *District of Columbia Disability Services Reform Act*, individuals with disabilities identify supporters for key areas in their lives (e.g., health care decisions, purchases, moves), and include them in the decision-making process. Supporters help the individual gather information and assist them through the decision-making process.

**For More information:**

District of Columbia Modified Intake Form

**Primary Practice:**
Modification of aging system intake forms to identify aging caregivers and adults with IDD

**Location:**
District of Columbia

**Description:**
The District of Columbia modified its intake form for the Aging Systems entry by including questions that ask, “are you caring for someone else and are they an adult with disabilities?” If the answer to this question is ‘Yes,’ individuals are also automatically referred to the Developmental Disabilities System to ensure that the individuals with intellectual and developmental disabilities (IDD) also receive necessary services in addition to their caregivers. This promising practice is an example of a simple implementation that supports the bridging between aging and disabled populations. Modifying intake forms can result in more referrals across aging and disability service systems, where individuals often fall through cracks based on eligibility.

**For More information:**
https://ddc.dc.gov/
Hawaii Direct Support Professional Internship Program

**Primary Practice:**
Internship program for high school students to become direct support professionals

**Location:**
Hawaii

**Description:**
The Hawaii State Council on Developmental Disabilities (DD Council) has begun implementing an internship program that consists of recruiting high school-aged students through an online application process to work in Adult Day Health Centers. These centers include The Arc of Maui, Ka Lima O Maui, and Easterseals Waimea on Kaua‘i. It is an opportunity for students who are interested in pursuing an array of careers in nursing, education, psychology, social work or the medical field to gain valuable skills and experiences working with people with IDD. The project is responding to the critical shortage of direct support professionals. This pilot program is also partnering with the Department of Aging and could eventually be extended more broadly to Adult Day Health Centers with older populations. Students will undergo 4.5 hours of online modules in preparation of 20-60 hours of work where they will receive additional hands-on experience and training to learn how to best support aging and disabled individuals.

**For More information:**
[https://www.hawaiiadrc.org/](https://www.hawaiiadrc.org/)
[https://hiddcouncil.org/internship-opportunities/](https://hiddcouncil.org/internship-opportunities/)
**Lifespan Respite Care Program**

**Primary Practice:**
Respite systems that serve individuals across the lifespan

**Location:**
National, multiple States

**Description:**
The Lifespan Respite Care Program was authorized by Congress in 2006 and is implemented by the Administration for Community Living (ACL). Lifespan Respite Care programs are coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with disabilities and/or chronic conditions. They bridge aging and disability networks to remove silos and gaps in access to respite based on eligibility criteria often tied to funding streams. Such programs reduces inefficiencies and assist in the development of respite care infrastructures at the state and local levels. Lifespan Respite Care programs work to improve the delivery and quality of respite services available through the following objectives: 1) Expand and enhance respite services in the states; 2) Improve coordination and dissemination of respite services; 3) Streamline access to programs; 4) Fill gaps in service where necessary; and 5) Improve the overall quality of the respite services currently available. Since the program was first funded in 2009, thirty-nine states and the District of Columbia have received grants to establish or enhance Statewide Lifespan Respite systems. The ARCH National Network and Resource Center serves as the national Technical Assistance (TA) Center for the Lifespan Respite Program. The ARCH website provides details about current and previous grantees and state Lifespan Respite programs as well as many other resources related to respite and exemplary respite programs.

**For More information:**
https://archrespite.org/ta-center-for-respite/

https://acl.gov/programs/support-caregivers/lifespan-respite-care-program#:~:text=Lifespan%20Respite%20Care%20programs%20are,disabilities%20and%20chronic%20conditions.
Pennsylvania’s Prioritization of Urgency of Needs for Services (PUNS)

**Primary Practice:**
Prioritizing individuals with IDD living at home with aging caregivers for IDD services

**Location:**
Pennsylvania

**Description:**
The Pennsylvania Prioritization of Urgency of Needs for Services (PUNS) was developed to identify individuals and their particular service needs as they are waiting for access to services and supports from the state Intellectual and Developmental Disabilities Service System. The PUNS system organizes the need for services into three areas: 1) Emergency Need: the service need will occur within six months. 2) Critical Need: the service need is anticipated to occur after six months but within two years. 3) Planning for Need: the service need is anticipated to occur more than two years away but less than five years away. Data is collected on individuals residing at home with aging family caregivers (60 and over). The data from this system is then used in predicting the need of what supports are most needed and how to fund such requests, planning strategies, and service adaptations. The data from PUNS has been used to approach policy throughout Pennsylvania to center and meet the needs of individuals with aging caregivers’ access to services and supports.

**For More information:**
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
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