

Fall 2021 Pervasive Needs Grants – FAQ

Eligibility Criteria

My organization serves diagnoses beyond ALS, Alzheimer’s disease and related dementias (ADRD), Huntington’s disease (HD), multiple sclerosis (MS), or Parkinson’s disease. Can we still apply?

You can apply, but any funds granted must go exclusively to people living with ADRD, ALS, HD, MS, Parkinson’s, or their caregivers.

If applying, please include answers to these questions in the description of who the project will reach:

- How many people living with ADRD, ALS, HD, MS, Parkinson’s, or their caregivers will the project serve?
- How do you identify and track this information?
- What financial processes are in place to ensure funds awarded by Adira are directed toward people living with ADRD, ALS, HD, MS, Parkinson’s, or their caregivers?

What are some examples of projects that would fit into the granting priority, “Simplifying Clinical Research”?

- Creating a tool that simplifies the way people living with neurodegenerative diseases (ND) or their caregivers find, understand and apply to participate in research.
- Providing education and information about clinical research to populations typically underrepresented in research to build trust and increase participation.
- Offering direct support to people living with ND or their caregivers to help them meet research participation criteria or remove other barriers to participation, like technology, transportation, etc.

These examples should not limit you. We are seeking any project that meets the spirit of “Simplifying Clinical Research” described in the funding announcement.

What are some examples of projects that would fit into the granting priority, “Preparing for Future Threats to Livelihood”?

- Providing legal services that ensure people living with ND and their caregivers have the benefits, resources and documents necessary to address short- and long-term needs.

- Creating a skill-building curriculum that trains people living with ND on how to be an effective patient and ND caregivers how to be an effective caregiver.
- Offering family planning services to people living with ND so they have information and resources to make informed decisions that best fit their family's needs.

These examples should not limit you. We are seeking any project that meets the spirit of 'Preparing for Future Threats to Livelihood' described in the funding announcement.

What are some examples of projects that would fit into the granting priority, "Thriving Again in Common Pursuits"?

- Providing the tools, equipment or resources needed to give people living with ND the ability to participate in their preferred community hobbies.
- Educating community institutions about the specific needs of people living with ND and caregivers to support the implementation of practices that remove participation barriers and reduce stigma.
- Delivering direct social or recreational programs to people living with ND or their caregivers to connect people to their favored forms of interaction in the community.

These examples should not limit you. We are seeking any project that meets the spirit of 'Thriving Again in Common Pursuits' described in the funding announcement.

"Preferred Eligibility" Criteria

Can you clarify what "aggregating" eligibility requires?

Aggregating refers to combining service(s) for two or more of the following populations: ALS, Alzheimer's and related dementias (ADRD), Huntington's disease (HD), multiple sclerosis (MS) and Parkinson's disease.

People served can be those living with one of the above diagnoses or their caregivers.

Examples of **aggregating**:

- Under Adira's Round 2, Fall 2020 Pervasive Needs Grants program, Family Caregiver Alliance designed and delivered services specifically for caregivers of people living with ADRD, ALS, HD, MS and Parkinson's.
- And the Chronic Care Collaborative launched a statewide navigation service in Colorado to offer information and relevant resources to people living with ADRD, ALS, HD, MS, Parkinson's and their caregivers.

Can you clarify what "convening" eligibility requires?

Convening refers to seeking the input of people impacted by ALS, Alzheimer's and related dementias (ADRD), Huntington's disease (HD), multiple sclerosis (MS) or

Parkinson's disease and applying it to the design, delivery, or measurement processes of programs that serve them.

Convenings may include:

- People living with ADRD, ALS, HD, MS or Parkinson's.
- Caregivers for people living with ADRD, ALS, HD, MS or Parkinson's.
- Professionals who serve them (advocates, health care providers, case managers, insurers, counselors, respite providers, policy makers, etc.).

Convenings can be held virtually or in-person. It is most important to provide a space where a diverse set of people can participate comfortably and with peace of mind for their safety and the safety of those around them.

Convenings can include participants from one ND community (ADRD, ALS, HD, MS or Parkinson's) or from two or more communities.

Convenings should include a plan to report on what you learned that answers:

- What was the purpose of the convening?
- Who participated?
- What insights did they provide?
- How will you apply those insights to the design, delivery, or measurement of your program?
- How will you follow up with participants to close the feedback loop?

Can you clarify what “health equity” eligibility requires?

Health equity refers to delivering services that provide a solution to an identified health disparity or health inequity within the target ND population(s).

- A health disparity is a *difference in health and well-being outcomes among groups of people*. For example:
 - Risk behaviors influenced by individual health knowledge like smoking, nutrition or physical activity.
 - Disease and injury rates influenced by health care access and genetics, like infectious disease, chronic disease or intentional/unintentional injury.
 - Mortality rates influenced by overall health status like infant mortality and life expectancy.
- A health inequity is a *difference in health and well-being outcomes that is avoidable, unfair, and unjust*. For example:
 - Social conditions like oppression based on race, ethnicity, class, gender, sexual orientation, immigration status, etc.
 - Economic conditions perpetuated by institutions of authority such as governments, churches, corporations or schools that create unequal opportunities among groups of people.

- Environmental conditions like neighborhoods with poor infrastructure, access, air quality, water quality, etc.

Health equity services should clearly identify the group being served and the specific health disparity or health inequity addressed.

Health equity services should include a plan to effectively reach the target group:

- How will you identify people living with ND or their caregivers as members of a group historically experiencing less power and privilege based on their race, ethnicity, class, gender, sexual orientation, immigration status, etc.?
- How will you increase or tailor outreach and program recruitment activities to ensure your messaging reaches and resonates with people in the target group?
- How will services be uniquely designed to meet the needs of people in the target group?

Outcomes and Impact

Can you clarify the quality-of-life (QOL) measures identified as time, money, energy, confidence and connection?

Adira wants to improve quality of life for people with ND and through research identified five metrics that we will use to measure impact in all our work.

We have seen that, despite our personal complexities and existence as unique individuals, we all ultimately need and desire the same things to live full, rich lives—**more time, more money, more energy, more confidence and more connection.**

We seek to support projects that give people most impacted by ND more:

- **Time** to spend doing the things they enjoy:
 - Accessibility for preferred hobbies.
 - Less time spent dealing with symptoms/consequences of disease.
 - Improved longevity.
- **Money** in their pockets:
 - Access to important benefits.
 - Less money spent dealing with symptoms/consequences of disease.
 - Accessible employment opportunities.
- Physical and mental **energy**:
 - Reduced physical symptoms like pain, difficulty swallowing, etc.
 - Improved physical symptoms like mobility, strength, etc.

- Reduced mental symptoms like depression, anxiety, etc.
- Improved mental symptoms like cognition, focus, etc.
- **Confidence** to navigate systems and make informed decisions:
 - Accessible and comprehensive navigation tools or resources.
 - Disease and disease management education.
 - Skill-building opportunities that improve access, understanding, safety, etc.
- **Connection** to people and communities:
 - Reduce isolation and loneliness.
 - Reduce stigma.
 - Improve community accessibility.
 - Provide community-building opportunities.

Is there a particular evaluation method or tool Adira requires to assess QOL outcomes related to time, money, energy, confidence or connection?

Adira does not require the use of a particular evaluation tool.

A tool library is available on our website at adirafoundation.org/inform-qol/. It analyzes 50 tools commonly used to evaluate quality-of-life outcomes in general and ND-specific populations. This library aligns each tool's existing measures with the five QOL areas Adira is interested in impacting: time, money, energy, confidence, connection.

The library can act as a resource for projects that have not yet identified an evaluation tool.

Projects selected for funding will be required to submit an evaluation plan. Adira will work together with grantees to align project outcomes with the five QOL areas Adira is interested in impacting: time, money, energy, confidence, connection.