



We must persevere through courage, seek common ground in alliance, and embody values of dignity, inclusivity, integrity, and respect. If so, we can together invest in better lives for people impacted by neurodegenerative diseases and preserve their *time, money, energy, confidence, and relationships.*

Blueprint for Action

Executive Summary

Collective action is any form of organized acts carried about by a group of people in order to address their needs. If multiple populations impacted by neurodegenerative diseases work together as one, we can improve lives. People need better services now. “Patient-centered” care is losing its meaning. The person in this proverbial “center”, by definition, sits passively with services offered to them. Sadly, rarely designed “with” them. Care, therefore, calcifies into top-down silos driven from the system point-of-view.

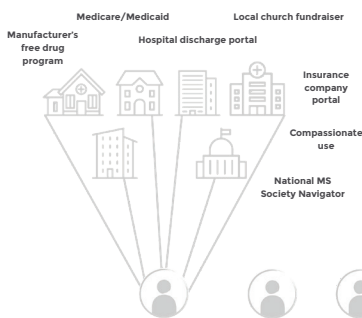
Those that need complex care, like those with neurodegenerative diseases, might need to find, receive, maintain, and juggle ten or fifteen “person-centered” programs. Each sitting in its own silo. More durable change finds root, however, when care is not only centered around **but also driven by the people most impacted, those living with disease and their care partners**. The aim: to build bridges across silos.

Adira Foundation has labored mightily to find, champion, and build better help driven by people most impacted by neurodegenerative diseases. **To prove the concept, Adira Foundation (Adira) focused principally, though not exclusively, on five populations: those living with ALS, Alzheimer’s and related dementias, Huntington’s disease, multiple sclerosis, and Parkinson’s disease-- as well as their care partners.**

Turning the Vertical Health Care Model on its Side

Problem

Asking for help feels like climbing a rope alone.



- ▶ Some very good help for sick people already exists. But typically a person needing health care must find goods or services from one provider at a time. This vertical—or top down—model of health care is often referred to as siloed—which is inherently a power imbalance.
- ▶ But it is good help. It comes from well-intentioned good people and entities.
- ▶ Very sick people may need dozens of goods and services. Pressure to find them increases and stakes become higher. Asking for help feels like climbing a rope.

Solution

Addressing the urgent, common needs of five populations as one.

- ▶ We gather and assemble voices from five populations as one—focusing on their many urgent common needs.
- ▶ Together, this group is 10+ million and can act with more equal footing to providers.

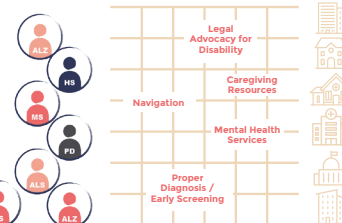
Common needs of the five populations:

- Navigation
- Mental health
- Caregiver burnout
- Stigma
- More collaboration
- Clinical trials

Adira's Result

To bridge across silos!

People impacted drive solutions built from equal standing with services providers. The result is inventive programs that address common problems:



We turn the model on its side to help supplement this help

- ▶ We ask people what they still urgently need but aren't getting, then name the top 3-4 together.
- ▶ We also ask what help would look like. We bring a constituency of lived experts in that is just as diverse and formidable as the well-intentioned providers who help them.
- ▶ We join the constituency in congress with those providers to transform care by leveraging new funding to build bridged programs that preserve siloed funding dollars.

We offer a blueprint for action summarizing what we learned.

Blueprint for Action for “Person-Driven” Care

Adira’s mission and vision – to find new solutions for patient needs across five complex disease communities – has been ambitious. Many organizations work on goals they alone can wrap their arms around. At Adira, we know **the only way for us to wrap our arms around the shared needs of five populations at once would be to link arms with others.**

Our model compels collaboration. After funding 20 competitive grants and five innovative projects, publishing three research reports, and building a chorus of conversation through the Sounding Board, we found great pride in our Neurodegenerative Disease (ND) Congress series.

The goal of the series was to co-design better help— grants to nonprofits – from the ground up, driven by those with lived expertise and leavened by the experience of professional expertise. Coming out of this Congress series is a Final ND Congress report as well as a Blueprint for Future Action. **Enacting this blueprint requires courage to collaborate.**



1. Grow and sustain vision around the common good

People impacted by ALS, Alzheimer’s and other dementias, Huntington’s, multiple sclerosis, and Parkinson’s share far more in common than not. Building alliances around a shared vision can fortify existing good work. This is an approach we’ve seen taken around the need for collaborative research, but research is for the future. People need help here in the present. We believe it vital that alliances form around designing and financing better services now. Such collaborations can learn from successful alliances on advocacy as well as on research to create better help for common needs.

Examples: Caregiving, navigation, earlier detection, depression, fatigue, mobility, loss of income, loneliness, Social Security Disability, cognition, anxiety, and stigma are some of the chronically under-funded issues common across neurodegenerative populations. Learn more about [what we’ve done](#) and why.

One disease may be considered “niche”; five are not. Almost everyone is personally affected by one or more neurodegenerative diseases. Incidence and prevalence are growing alarmingly quickly. Costs to both individuals but also to systems are climbing unsustainably. We can inspire new financing by stretching beyond traditional donors, to those with health-adjacent missions or transformational visions. Thus, new funding for common needs must complement, not compete with, existing good help for unique needs of specific diagnoses.



Examples: Some of our published reports on Quality-of-Life tools, on multilateral models, engaging more persons of color, and others can be found [here](#).

2. Start small, specific, and immediately

The enormity of need means finding the courage to simply start somewhere. Through our ND Congress series, we asked a representative cross-section of people across five diseases, throughout the U.S., both the diagnosed and care partners, transcending age, ethnicity, and geography, to name urgent issues, prioritize among them, imagine better help in response, and suggest ideas for projects that would be appealing, viable, and sustainable.

Examples: Over 2022, our assembly of people most impacted named problems most urgently under-addressed then divided into workgroups called Teams to refine the details of what solutions in response might look like.

To learn how they identified their top 12 solutions, narrowed them to six, then ultimately prioritized three in a fully developed grant proposal, including specifics on equity, metrics, and evaluation, [click here](#).

ND Congress Series Timeline

LISTEN

Pilot
Virtual | 1/20 - 1/21
Discover Needs

LEARN

Extended Pilot
Denver, CO | 6/16 - 6/17
Finalize Solutions

ACT

ND Congress
Virtual | 11/3 - 11/4
Implement Solutions

Teams Form | February - June
Teams create viable grants

- Build teams to volley potential solutions and use evidence to build and grow these informed solutions
- Invite and recruit an evergreen alliance of people living with ND, caregivers and professionals to participate in part two of the ND Congress series and beyond

Teams Advance | June - November
Teams finalize grants and impact metrics

- Prioritize between three and five programmatic ideas for funding
- Set markers and metrics to best monitor and evaluate impact
- Ask people to bring forth their best strengths to see this plan of action through

3. Measure success through Quality, as described by individuals - not just Quantity

Typically help is provided in what people can count. “Quantity” is good but insufficient. The life improvement that people individually experience – “Quality” – needs to be recorded, described in language and terms set by people most impacted.

Examples: Adira offered five quality-measures as a place to start. We simply encouraged programs that preserve five precious resources for people: Time, money, energy, confidence, and relationships. We have worked with people to further define and edit these terms over time. See here.

Measure	Description
Time	More time to do the things you enjoy
Money	More money to feel financially secure
Energy	More physical and mental energy
Confidence	More confidence to make informed choices
Relationships	More connection to others and community

4. Build trust through continual conversation, speaking side-by-side, with respect and inclusion

To build bridges across silos, we see trust and respect being built over time by valuing the expertise and points-of-view of others. This needs to be a respectful “alongside” approach rather than historically hierarchical approaches, like “top-down” to consultation. Participants with lived experience should also receive fair payment, in the form of stipends or similar compensation, for contributing their expertise, time, and energy. Care partners respected similarly to patients. People dealing with rare neurodegenerative diseases respected equally to those dealing with more common diagnoses. Lived expertise valued equally to career expertise.

Examples: Vehicles such as Adira’s Sounding Board, our [listening and learning convenings](#) and [ND Congress Teams](#) invited our full community to join and participate in the ways most important and accessible to them. Adira insisted upon an ongoing feedback conversation. Many from those vehicles stay in touch with each other.

- Life sciences
- Foundations
- Government
- Private payers
- Patient organizations
- Clinicians
- Hospital systems
- Other nonprofits

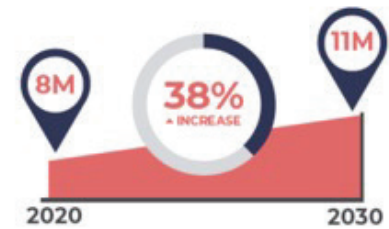
51%

or more of attendees are people with 1 of the 5 target diseases and/or their caregivers

5. Stretch to reach those outside care for transformational outcomes

Traditional systems like healthcare institutions and social services are difficult to navigate for most people. For those experiencing mental health problems, decline in their cognitive ability, depression and apathy, or burnout from managing the complexities of a chronic disease, these systems are even more confusing, frustrating, and inaccessible. Add to that other concerns people face - financial insecurity, disability, isolation, stigma, language barriers, mistrust, family care duties, etc. – and navigating becomes near impossible. With these factors in play, **those most in need of help are unable to reach out.**

As the number of people directly impacted by neurodegenerative diseases climbs rapidly, it is the responsibility of the systems meant to serve them to adapt and begin to reach out further, into their communities, and into those spaces where people are living their day-to-day lives and feeling their best - to find and wrap their arms around them, lead them in and guide them through. Otherwise, more and more of those most vulnerable will find themselves excluded.

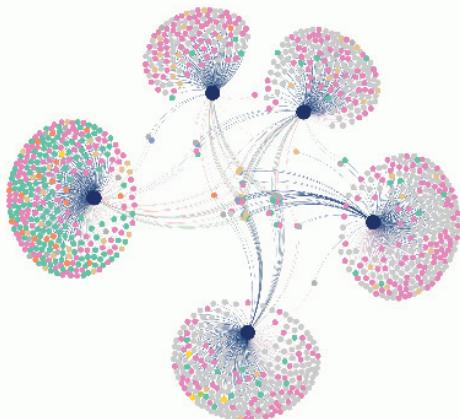


The total who live with these five diseases is expected to grow from 8 million to 11 million by 2030, a 38% increase.

6. See the loneliness and isolation, not just of people with ND, but also those entities who serve them, then fill the space in-between

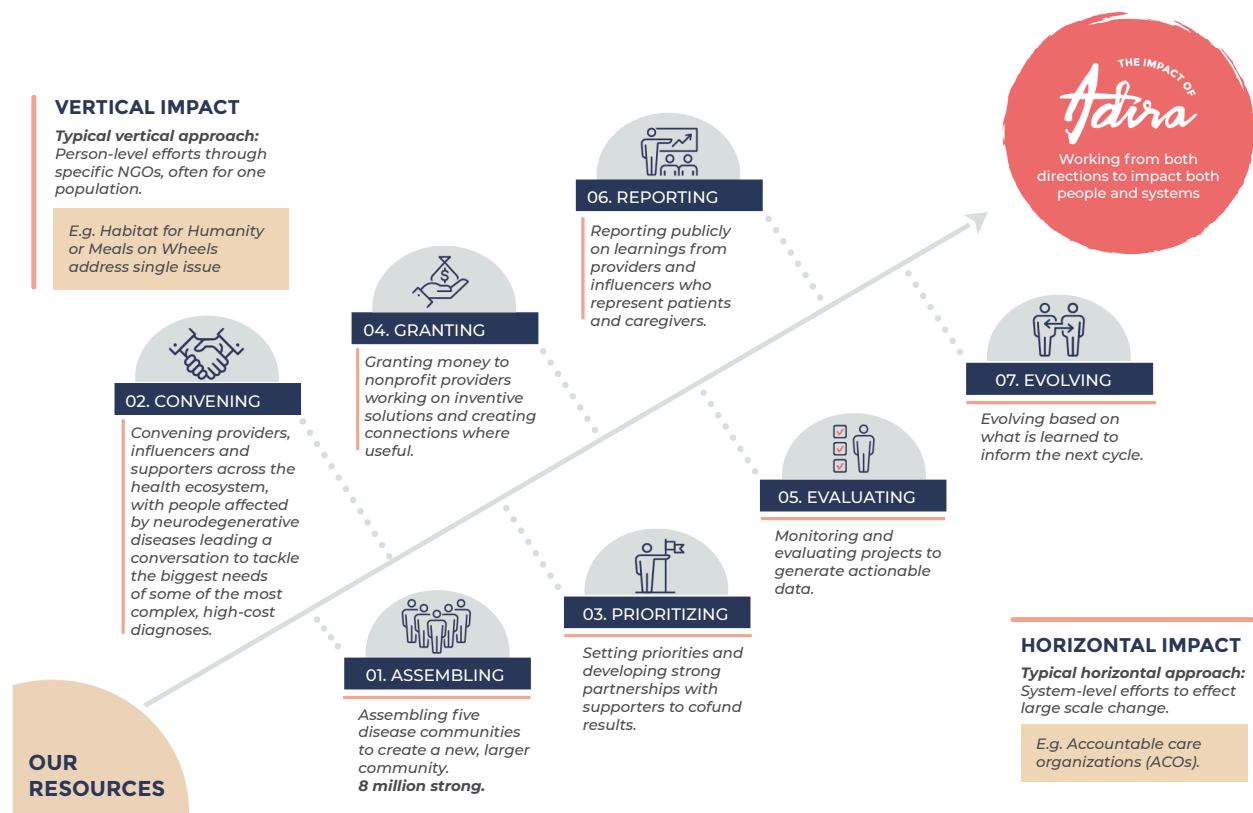
Like the five petals of a flower, individual disease communities form mighty but often lonely communities. Nonprofits that help them can be as anxious and overwhelmed as the communities they serve and private sector and public sector entities are often asked to be saviors beyond their capacity. By working together on the space between existing good help, we can layer on additional services centered around common needs.

Examples: Adira gathered voices to listen for common needs - themes identified not only by people in need but by those who help them. Activities ranged from story collection with [Story Corps](#), to convening grantees, to mutual feedback sessions with nonprofits. Click [here](#) or [here](#) to explore prototypes for how we in 2021 proposed *mapping networks* of neurodegenerative disease resources.



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Thank You



Adira Foundation, our visionary funding partners and our 25 non-profit grantees throughout the country made much progress over the past three years. The board and staff are proud of these accomplishments and are deeply grateful for the collaborations with innumerable partners. While we are confident that the collaborations and the successes will live on, the Adira Foundation Board concluded that the onset of the COVID pandemic immediately following Adira's launch caused insurmountable challenges in creating the necessary momentum – relationship development, brand recognition and fundraising – to sustain an ambitious, new, systems-change endeavor. After several months of scenario planning, the board voted to dissolve Adira Foundation as an independent entity.

We are hopeful that this summary of lessons-learned exemplifies Adira Foundation's legacy and serves as a call to **Collaborative Action** among individuals living with neurodegenerative diseases, their care partners, service providers and cross-sector funding partners. Together, breaking down silos, we will always be stronger in voice, action and impact.

December 2022

Greg Smiley
CEO & Founder