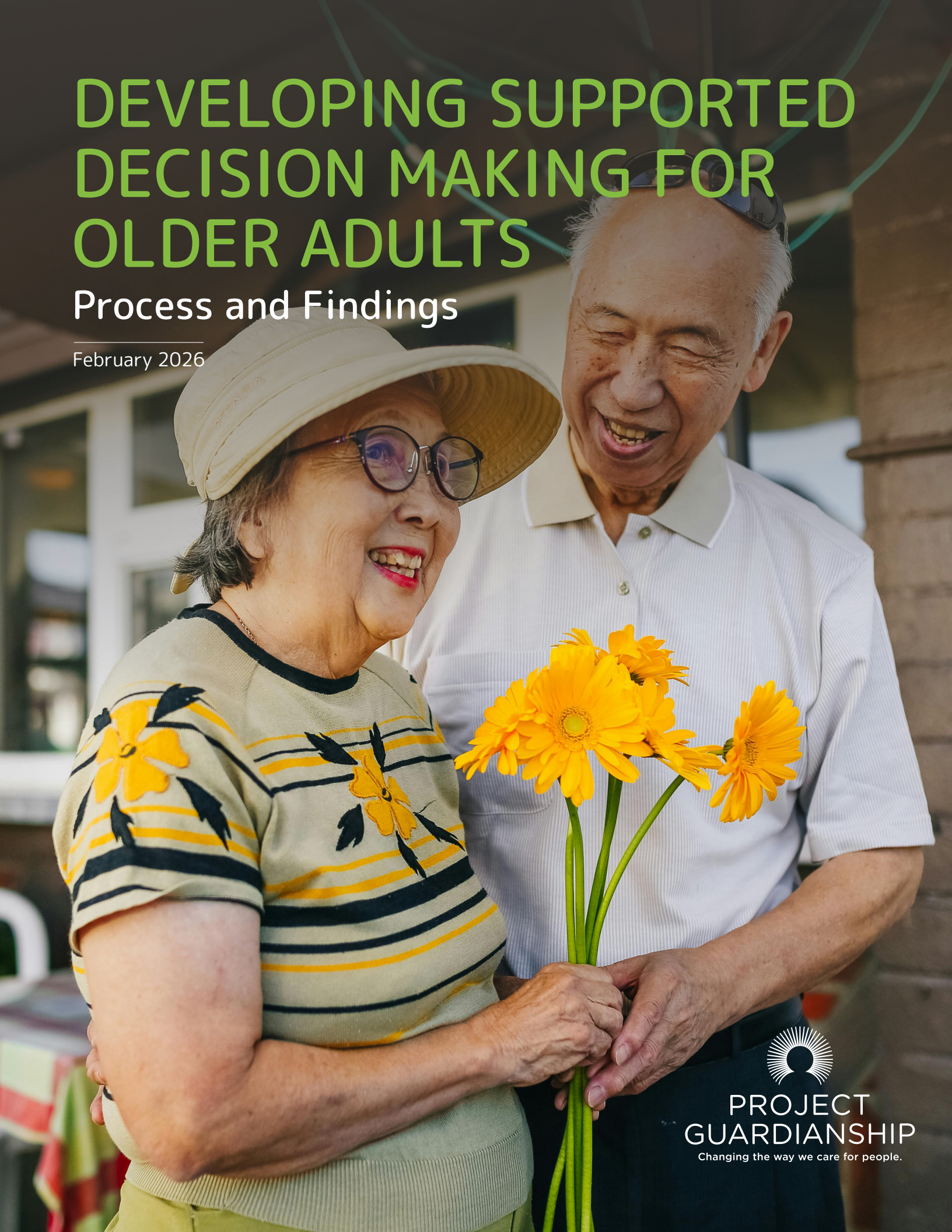


DEVELOPING SUPPORTED DECISION MAKING FOR OLDER ADULTS

Process and Findings

February 2026



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EXECUTIVE SUMMARY

As New York's population ages, more older adults are navigating complex decisions about health care, housing, finances, and daily life—sometimes in the context of cognitive change. Too frequently, guardianship becomes the default response when support is needed, even in situations where less restrictive alternatives might suffice.

Project Guardianship together with partners Rebekah Diller, Clinical Law Professor at Cardozo School of Law; Ruth Finkelstein and Mark Brennan Ing of the Brookdale Center for Healthy Aging at Hunter College, CUNY; and special advisor Hon. Kristin Booth Glen launched this initiative to explore whether and how supported decision making (SDM)—an approach that has shown promise for people with intellectual and developmental disabilities—could be meaningfully adapted for older adults. This report documents the first two phases of that work: a global environmental scan and a multi-site research effort grounded in direct engagement with older adults.

Supported Decision-Making has been defined as "a series of relationships, practices, arrangements, and agreements of more or less formality and intensity designed to assist an individual with a disability to make and communicate to others decisions about the individual's life."

Robert D. Dinerstein, Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making, 19 Hum. Rts. Brief 8, 10 (2012).

Phase I revealed that while a person's values remain central even amid cognitive decline, no operationalized SDM model exists for older adults. Phase II sought to understand decision-making processes of older adults by centering their voices. Across facilitated conversations, questionnaires, and focus groups involving approximately 100 participants, older adults described decision making as relational, values-driven, and highly contextual. They emphasized independence, control, trust, and not burdening others, while also naming real barriers—family dynamics, financial constraints, information gaps, and challenges inherent to imagining a hypothetical future.



"Decision-making support for older adults cannot be delivered as a one-time intervention; it is an evolving process rooted in relationships and trust."

Together, these findings suggest that decision-making support for older adults cannot be delivered effectively as a standalone tool or one-time intervention. Instead, it is a high-touch, evolving process that works best when embedded in trusted programs and ongoing relationships.

Project Guardianship will focus next on integrating lessons from this work into existing and emerging programs—supporting practitioners and organizations to engage older adults in values-based conversations over time, in ways that are sustainable, equitable, and responsive to where people are in their lives.

INTRODUCTION: WHY THIS WORK, WHY NOW

New York is experiencing a significant demographic shift. As the number of older adults grows, so too does the prevalence of cognitive impairment. While cognitive change does not automatically necessitate guardianship, the absence of planning, support, and trusted decision-making frameworks often makes guardianship the path of least resistance for courts, families, and service systems.

Guardianship is a powerful legal intervention that removes some or all decision-making authority from an individual and transfers it to another person or entity. Although it can be necessary in many circumstances, guardianship can be overused and, when it is, can lead to serious consequences, including loss of

autonomy, erosion of dignity, and associated declines in health and wellbeing.

Supported decision making offers an alternative. Rather than substituting another person's judgment, SDM seeks to preserve an individual's right to make decisions by providing appropriate supports. Existing SDM models have been developed primarily with younger adults with intellectual and developmental disabilities in mind. Whether and how those models translate to older adulthood remained an open question.

This project set out to explore that question, grounded in the belief that older adults themselves must be central to designing any approach meant to support their decision making.



PROJECT OVERVIEW AND GUIDING PRINCIPLES

Project Guardianship and its partners approached this work with several core principles:

- Autonomy and dignity are foundational. Cognitive change does not negate a person's values, preferences, or right to self-determination.
- Decision making exists along a continuum. Support needs evolve over time and vary by decision type, context, and individual circumstance.
- One size does not fit all. Any approach must be flexible, adaptable, and responsive to cultural, geographic, and relational differences.
- Relationships matter. Decision making is rarely a solitary act; it unfolds within networks of family, friends, professionals, and institutions.

The project was structured in phases to allow learning to inform direction:

- Phase I: A global environmental scan to understand the current landscape of decision-making supports for older adults.
- Phase II: Direct engagement with older adults to understand how they make decisions, what they value, and what support looks like in practice.

This report documents those two phases and the lessons they generated.



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PHASE I: ENVIRONMENTAL SCAN

Purpose and Framing

Phase I of the project focused on understanding the existing landscape of decision-making supports for older adults. The environmental scan was designed to answer three core questions:

- What models, frameworks, or practices currently exist to support decision making for older adults?
- How do law, policy, and practice address decision making when cognitive capacity changes over time?
- Where are the gaps—particularly between theory, values, and real-world implementation?

Rather than attempting to identify a single best practice, the scan sought to surface patterns, tensions, and unresolved questions across disciplines and jurisdictions.

Methods

The environmental scan was led by Rebekah Diller, Clinical Law Professor at Cardozo School of Law, in collaboration with Project Guardianship. It combined two primary methods:

Literature Review

A review of domestic and international literature spanning law, aging, disability rights,

ethics, medicine, and social services. Sources included academic research, policy reports, statutory frameworks, and guidance documents related to guardianship, supported decision making, advance planning, and substitute decision making.

Key Informant Interviews

In-depth interviews were conducted with academics, legal scholars, advocates, judges, practitioners, and service providers working at the intersection of aging, disability, and decision making. Interviewees represented diverse perspectives and roles, allowing the scan to capture both conceptual debates and on-the-ground realities.

Together, these methods provided a cross-sector view of how decision-making support is currently understood and practiced.

Key Findings

Several themes emerged consistently across the literature and interviews:

Values Persist Even as Capacity Changes

The scan reaffirmed that cognitive decline does not eliminate a person's values, identity, or ability to express preferences. Even individuals with advanced impairment often continue to communicate meaning, priorities, and emotional responses—challenging assumptions that incapacity is binary.

Decision-Making Support Must Be Dynamic

Effective support cannot be static. Needs shift over time and vary by decision type, context, and risk. This reality points toward a continuum that includes independent decision making, supported decision making, and—when necessary—substitute decision making guided by known values and wishes.

Guardianship Dominates by Default

Despite growing consensus about the harms of unnecessary guardianship, legal and service systems continue to rely on it as a primary response to cognitive decline. Interviewees cited lack of alternatives, limited resources, and risk-averse institutional cultures as major drivers.

No Operationalized SDM Model Exists for Older Adults

While supported decision making is widely discussed in principle, the scan found no widely adopted, practice-ready model tailored to older adults—particularly one that accounts for fluctuating capacity, family dynamics, and the realities of aging services.

Implications for the Project

The environmental scan clarified that the challenge was not a lack of values-based frameworks writ large, but the absence of frameworks designed by and for older adults as well as practical, relational approaches that could be implemented within real systems. These findings reinforced the importance of Phase II: learning directly from older adults how decision making actually unfolds in their lives, and what kinds of support feel legitimate, helpful, and sustainable.



PHASE II: LEARNING DIRECTLY FROM OLDER ADULTS



"Person-centered research is an active, meaningful, and collaborative partnership between participants and researchers across all stages of the research process, with decisions guided by participants' lived experiences, values, and expertise."

Why Engagement Was Essential

From the outset, Project Guardianship and its partners understood that supported decision making for older adults could not be designed solely from theory or professional expertise. While Phase I clarified the gaps in existing models, it could not answer a more fundamental question: how older adults themselves understand decision making, support, and autonomy—particularly in the face of possible cognitive decline.

Phase II was therefore designed to center older adults as experts in their own lives. The goal was not to validate a pre-existing framework, but to learn directly from participants about how they currently make decisions, how they anticipate

future decision making, how values influence the process, and what kinds of support feel helpful, intrusive, or unacceptable.

Research Partnership

Project Guardianship partnered with the Brookdale Center for Healthy Aging at Hunter College, CUNY, which led the design and implementation of the research. Brookdale brought deep experience in community-engaged research with older adults, ensuring that methods were accessible, ethical, and responsive to participants' needs.

Scope and Participants

Across all research activities, the project engaged 97 older adults in New York State. Participants were recruited through community-based organizations and aging services providers and reflected a range of ages (primarily 60+), racial and ethnic identities, living situations (including living independently, with family, or in senior housing), and geographic contexts across New York State. This diversity allowed the project to surface both shared experiences and meaningful variation based on place and circumstance.

We first conducted four facilitated conversations with groups of participants in Brooklyn, Queens, and Staten Island (n=41). These conversations brought together older adults connected to community-based organizations and senior

service providers to reflect on their experiences planning for future decision-making and navigating support systems.

With a better understanding of the types of conversations we would be having, we then conducted six focus groups with participants in the Bronx and parts of Western New York, including Buffalo, Orchard Park, and Strykersville (n=56). These sessions explored participants' perspectives on decision-making, planning, and the kinds of supports older adults may need as they age.

Across the focus groups, most participants were women (77%). Nearly three-quarters identified as White (73%), though participants in the Bronx were more likely to be people of color. Education levels were relatively high, with 71% reporting at least some college education. Housing arrangements varied: half of participants lived in private homes, while 13% lived in apartments that provided services. Two-thirds owned their home or apartment. In terms of household composition, half of participants lived alone, and over one-third (36%) lived with a spouse or partner. Most participants received major federal benefits, with more than three-quarters receiving Social Security and about two-thirds enrolled in Medicare. One in five participants reported being on Medicaid, while fewer than 12% received low-income subsidies such as HEAP or SNAP.

Research Methods and Process

Phase II unfolded through a multi-step process:

Facilitated Conversations

The engagement began with group discussions held in trusted community settings such as older adult centers and community organizations.

These conversations were facilitated with questions and prompts that evolved with each group, generating an understanding of how older adults talk about making decisions and aging. The environment encouraged storytelling, reflection, and peer exchange. Facilitators used guided discussion prompts to explore topics such as:

- Preferences, wishes, values, and what brings them joy
- How participants currently make day-to-day decisions
- Who they turn to for advice or support
- The domains of life in which they anticipate making future decisions
- What worries or concerns they have about future decision making
- How they feel about planning for potential cognitive decline

Participants in the last group also completed a questionnaire about anticipated decision-making domains (e.g., health care, housing, finances), perceived supports, and personal priorities. This helped determine whether a questionnaire structure was a viable way to help people think through and document answers to these challenging questions.

Insights from the early facilitated conversations informed the development of a more standardized research protocol, which was subsequently reviewed and approved by the Institutional Review Board (IRB).

Focus Groups

The team used structured prompts, plain-language scenarios, handouts, and a conversation guide to conduct focus groups in New York City and Western New York. The groups were designed to help participants imagine what decisions they might make as they age, what processes they might use to make those decisions, to whom they might turn for support, and how personal values play a role. Participants also reflected on how they think others should make decisions, using a fictitious story of a widow facing serious health problems.

An optional survey was administered to collect demographic information, including whether a participant had advance directives, owned property, received public benefits, and more.

Ethical and Trauma-Informed Approach

Throughout Phase II, the research team prioritized a trauma-informed and respectful approach. Conversations about aging, decline, and loss can be emotionally charged, and facilitators were prepared to recognize discomfort, allow participants to opt out of discussions, and keep engagement voluntary and participant-led. Importantly, the research design treated moments of resistance, avoidance, or discomfort not as failures of engagement, but as data—signals about how older adults experience conversations about decision making and what conditions make such conversations possible.



"Moments of resistance, avoidance, or discomfort were not failures of engagement, but signals about how older adults experience conversations about decision making."

WHAT WE HEARD: KEY THEMES AND FINDINGS

Phase II generated a body of primarily qualitative findings, supplemented by descriptive demographic and survey data. Focus group conversations were recorded, transcribed, and analyzed. While participant experiences varied, several themes emerged that shed light on how older adults understand decision making, where they experience support or constraint, and what matters most as they anticipate future change.

Decision Making as Relational and Contextual

Older adults rarely described decision making as an individual or purely cognitive act. Instead, decisions were embedded in relationships and shaped by context. A person's network of support and the quality and history of those relationships influenced when decisions arose and how they unfolded. While some participants initiated decisions by anticipating future needs, many described decision making as emerging in response to life events such as changes in health, the death of a partner, financial pressures, retirement, or observing the experiences of peers. These moments often acted as prompts that brought decisions into focus.

Decision making was frequently described as a process of consultation and deliberation rather than solitary choice. Family members and friends often played central roles by sharing information, raising concerns, helping weigh options, or simply initiating conversations. At

the same time, decision pathways were shaped by relationship dynamics, including geographic distance, family conflict, or relatives' capacity and willingness to help.

Participants identified a wide circle of potential supports: spouses or partners, adult children, extended family members, friends, neighbors, faith communities, and professionals such as doctors, lawyers, and social workers. Many described drawing on multiple sources simultaneously when making important decisions. Trust—built through longstanding relationships and prior experience—often mattered more than formal authority. Community-based organizations and professionals were most influential when relationships already existed and credibility had been established.

Support took many forms, including informal conversations, shared problem-solving, emotional support, and practical assistance. Participants also described gathering information from a range of sources, including peers with lived experience, community organizations, service providers, and online resources. Access to reliable information and the ability to compare options were seen as essential to feeling confident in decisions.

Importantly, participants distinguished between support that they experienced as collaborative and support that felt controlling or dismissive. Decision-making support

existed along a continuum from collaborative decision making with a spouse, to family members recommending specific actions, to situations in which others assumed control without meaningfully incorporating the older adult's wishes. While collaboration was valued, maintaining agency remained essential.

Participants also emphasized that decision-making support often evolved over time. Individuals might begin by making decisions independently, then shift toward consultation and shared deliberation as circumstances changed. This gradual adjustment allowed them to preserve autonomy while accepting assistance when needed.

These findings also highlight a key distinction between supported decision making for older adults and models developed for people with intellectual and developmental disabilities (I/DD). SDM for the I/DD population often relies on structured tools designed to help individuals build decision-making skills. By contrast, most older adults have spent a lifetime making decisions independently and are focused on preserving that independence. For many, supported decision making can feel less like gaining autonomy and more like confronting the possibility of losing it. This distinction underscores the need for approaches that honor lived experience and prior autonomy while supporting decision making within trusted relationships.

Domains of Anticipated Decisions

Participants anticipated needing support across several domains:

- Health and health care, including medical decision making, treatment preferences, and navigating providers
- Housing, particularly decisions about aging in place, downsizing, or moving to supportive settings
- Transportation, especially driving cessation and access to alternatives
- Finances, including budgeting, bill payment, and asset management
- Advance directives and end-of-life planning

The salience of these domains varied by geography. Participants in suburban and rural areas more frequently emphasized housing, transportation, and financial decisions, reflecting differences in infrastructure and service access.



Core Values Shaping Decisions

Across all research activities, participants articulated values that guided how they wanted decisions to be made:

- Independence and control over daily life
- Trust and security, particularly trust in the people providing support
- Quality of life, sometimes prioritized over safety or longevity
- Not being a burden on family members

These values shaped not only participants' preferences, but also their openness to support. Many older adults expressed strong interest in gaining information—about services, benefits, and options—even when they were reluctant to engage in formal planning for decline. Information-gathering was often perceived as empowering, whereas planning for diminished capacity felt threatening or premature.

Barriers, Tensions, and Limits of Formalization

Participants identified multiple barriers to effective decision-making support, including:

- Complex or strained family relationships
- Financial constraints and fear of losing resources
- Limited access to clear, trustworthy information
- Social isolation and shrinking support networks
- Difficulty imagining potential future decline



Many participants believed that they would remain fully independent until the end of their lives, a form of wishful thinking that delayed planning even when risks were apparent. Participants spoke more easily about the major decisions faced by others.

At the same time, the research affirmed the value of conversation itself. Participants were often willing—and even eager—to talk about their values, priorities, and concerns when discussions were framed around independence, choice, and access to information rather than decline. These findings point toward programming that leans into older adults' desire for autonomy while creating opportunities to learn what they may not know and connect to resources.

Finally, while participants emphasized the importance of embedding decision-making support within trusted community settings, the research also highlighted the need for intentional outreach to more isolated older adults. Many participants mentioned how people don't know what they don't know. This was especially evident in urban environments, where norms of self-reliance are strong, but informal safety nets may be thinner. Any future approach must balance integration within existing programs with strategies to reach those who are least connected.

WHAT DIDN'T WORK— AND WHAT WE LEARNED

Equally important were the challenges encountered during engagement. Some participants struggled to articulate values or preferences in abstract terms, while others resisted conversations about cognitive decline altogether. Conversations sometimes shifted toward more immediate concerns.

These moments revealed how emotionally charged and identity-threatening future-focused planning can feel. The research underscored that willingness to engage is highly situational and dependent on trust, timing, and framing.

This learning reshaped the project's direction. It suggested that supported decision making for older adults cannot be rushed, standardized, or separated from the relationships in which it unfolds.



IMPLICATIONS FOR PRACTICE, RESEARCH, AND SYSTEMS

The findings from Phases I and II point to several implications:

For Practice

- Decision-making support should be embedded within ongoing service relationships, not delivered as a one-time intervention.
- Conversations about values and preferences are most effective when they occur incrementally and in familiar settings.
- Informal supporters such as family, friends, and trusted community members must be engaged alongside professionals.

For Research

- Future research should prioritize longitudinal approaches that track how preferences and support needs evolve.
- Researchers should focus on engaging diverse samples.
- Methods must account for participant resistance and varied comfort levels when it comes to talking about future needs.

For Systems and Policy

- Overreliance on guardianship reflects systemic gaps, not individual failure.
- Aging and legal systems need practical alternatives that are flexible, relational, and adequately resourced.
- Equity concerns—including disparities in access to advance directives and planning supports—must be addressed explicitly.

WHAT COMES NEXT: FROM STANDALONE TOOLS TO PROGRAMMATIC INTEGRATION

Decision-making support for older adults is a high-touch, relational process that unfolds over time. Participants were most willing to engage when conversations occurred within programs they already trusted and when support was integrated into services they were already receiving.

As a result, Project Guardianship will focus next on infusing lessons from this work into existing and emerging programs, rather than pursuing a standalone supported decision making model. This includes:

- Supporting programs to learn about clients' values, wishes, and preferences over time
- Embedding decision-making conversations into case management and service delivery
- Advancing approaches that meet older adults where they are emotionally and practically
- Exploring program-based models as a path toward sustainability, given the intensive nature of decision-making support

By centering older adults' voices and documenting both successes and challenges, Project Guardianship and its partners offers a grounded path forward: one that treats supported decision making for older adults not as a technical fix, but as an ongoing practice rooted in conversations about values and beliefs.



"Supported decision making for older adults is not a technical fix, but an ongoing practice rooted in conversations about values and beliefs."

Project Guardianship is a 501(c)(3) nonprofit organization that uses direct services, training and education, and budget and policy advocacy to advance person-centered guardianship, promote less-restrictive alternatives, and realize a fairer, more accessible guardianship system in New York. Learn more about our work at projectguardianship.org.