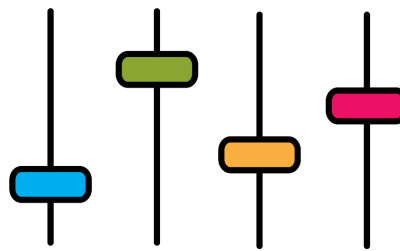


>> SLIDE 1

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>> SLIDE 2

Collaboration Across the Aging and Disability Networks to Meet the Need of Americans Aging with Long-term Disabilities: Examples of Success and Future Possibilities

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Background

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Shifting Demographics

- People age 65 and older are expected to represent approximately 22% of the population by 2040.¹
- The estimated population of 12 to 15 million Americans aging with disabilities (AwD) is expected to grow,² reflecting general population aging trends and for some conditions, medical advances.³

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Supporting Adults AwD

- Maintaining independence is key for many adult AwD who experienced the onset of their disability at birth, in early childhood, or before middle age.^{2,4,5,6}
- Although services and supports for older adults and people with disabilities often overlap, adults aging with disabilities experience unique needs.

>> SLIDE 7 AwD Project Description

- Project Purpose

- Provide ACL with a better understanding of how the aging and disability networks provide supports and work together to help people aging with disabilities remain living safely in their homes and communities.

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AwD Project Description (continued)

Research Questions

1. How does the literature describe the community-based supports and services available to meet the needs of aging adults with disabilities?
2. To what extent do the ACL-funded aging and disability networks capture systems-level data or metrics related to service eligibility, needs, and use of this population?

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AwD Project Description (continued)

3. What, if any, improvements to the ACL-funded aging and disability networks are required to ensure that adults aging with disabilities are receiving the services and supports they need to stay independent at home?
4. What examples exist of successful collaboration among the ACL-funded aging and disability networks?
5. What are the barriers and facilitators to positive and long-term engagement in the ACL-funded aging and disability networks for adults aging with a disability?

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Project Activities

Phase 1

- Conduct scoping review
- Select sites and prepare for site visits

Phase 2

- Collect and analyze data from site visits (six sites, an average of 11 interviews per site)

>> SLIDE 11

Study Methods

>> SLIDE 12

Study Methods Phase 1

Scoping Review

- Reviewed peer-reviewed and grey literature
- Screened titles, abstracts, and full texts
- Included 38 publications

Site Selection and Preparation

- Conducted Site Selection
 - Used ACS Aging Data (2017-2021) & AAA/CIL lists
 - Randomly selected six sites via Census region stratification
- Prepared for Site Visits
 - Conducted website & policy reviews
 - Developed protocols
 - Coordinated visits with CIL/AAA points of contact

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Study Methods Phase 2

Site Visits

- Recruitment supported by AoA and AoD via email/phone
- 64 semistructured interviews across six sites
- Interviewees included CIL/AAA program staff and partners
- Site visits spanned 2-3 days

Data Analysis

- Interviews recorded and transcribed
- Transcripts coded in NVivo 12
- 20% of transcripts double-coded (IRR>80%)
- RTI-developed tool used to document themes and extract supporting quotes
- Themes reviewed & refined through team consensus and quality checked with AI

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Site Visit Findings and Promising Practices

>> SLIDE 15

Data Collection and Sharing Findings

- Aging and disability networks are collecting data on program eligibility, service needs, and usage.
- Disability date of onset or duration data were more often reported to be collected by CILs than AAAs unless needed for program eligibility.
 - Disability onset or duration data collected were not used to identify individuals on the cusp of eligibility for aging services and supports.
- Cross-network data sharing approaches and frequencies varied.

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Promising Practices in Data Collection and Sharing

- Among the six participating sites, three reported using a data system to support cross-network collaboration. These systems facilitate referrals, track service provision, and ensure coordination among service providers.
 - One site's data network connects a range of community providers, including aging and disability network providers, and behavioral and social services, to streamline referrals, enhance case management, prevent duplication, and improve service tracking. Network participants select a tier of participation in the system; some function solely as referral receivers, while others can both send and receive referrals. Both the CIL and AAA participate in the data network.

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Cross-network Collaboration Findings

- Collaboration is happening through the provision of I&A/I&R, coordinated service delivery, and staff networking, but it is often inconsistent and informal.
- Organizations have many examples of successful collaborations that provide important insight.
- Organizations are not located near one another, creating physical separation and potentially introducing additional access barriers for individuals.

>> SLIDE 18 Promising Practices in Cross-network Collaboration

- Collaborative Advocacy
 - At one site, the CIL, AAA, and an aging network partner worked together to encourage an expansion of the city's requirements to allow for home modifications (i.e., ramps) under the city's home repair program.
- Sharing Programs or Funding
 - One site described blending funding to meet consumer needs. For example, the AAA has flexibility in defining home modifications, but the program only allows up to \$300 per person and this amount hasn't increased in years and is often insufficient. If the funds are insufficient, the AAA will combine funds with resources from other organizations, including the CIL, to support the consumer.

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Promising Practices in Cross-network Collaboration (continued)

- Collaboration/coordination for complicated cases
 - At one site, the AAA described working across the networks to assist a client find services for his mother who was transitioning out of a nursing home. The case was complicated because it involved APS as well. The AAA collaborated with the social worker at the facility, the senior center, and the CIL. The partners worked together to get the client educated on how to care for his mother, access transportation to and from specialist appointments, and get their house more wheelchair friendly. “It was awesome coming together and working to get this lady back in her home with her son like she wanted.”

>> SLIDE 20 **Barriers and Facilitators Findings**

- Network- and individual-level barriers and facilitators can significantly impede or improve access to supports and services.
 - Barrier examples:
 - Complexity accessing available supports and services
 - Transportation
 - Organizational silos
 - Funding shortages
 - Facilitator examples:
 - Collaboration of the aging and disability networks
 - Awareness of available supports and services
 - Simplified self-referral and application processes

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Promising Practices in Overcoming a Barrier

- Complexity accessing available supports and services
 - At one site, through a joint decision of best fit, the Long-Term Care Ombudsman program was relocated from the AAA to the CIL (where it is currently housed). Since the program's relocation, the Ombudsman staff have been able to easily refer Money Follows the Person participants to the CIL for assistance with Medicaid applications, which has resulted in timely and accurately completed applications.

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Possibilities

>> SLIDE 23 Possibilities for AAAs & CILs

- Data Collection and Sharing:
 - Consistently collecting date of disability onset or duration and sharing across networks.
 - Sharing data/referral systems and interoperable tools.

>> SLIDE 24 Possibilities for AAAs & CILs

- Cross-network Collaboration:
 - Setting aside organizational operating resources to better align AAAs' and CILs' goals, service objectives, and staff for selected target population.
 - Looking for opportunities for co-location (e.g., when leases are up).
 - Offering frequent opportunities for staff to collect, review, and disseminate successful local innovations.

>> SLIDE 25 Possibilities for AAAs and CILs

- Cross-network Collaboration (Continued):
 - Holding local cross-system discussions and routine check-ins.
 - Cross-training staff and ensuring frontline staff are familiar with cross-network resources.
 - Sharing referral protocols and co-enrollment strategies to reduce duplication and improve client/consumer pathways across networks.

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Possibilities for AAAs & CILs

- Overcoming Some Barriers:
 - Identifying a point of contact to help individuals aging with disabilities navigate supports and services across networks, apply for supports and services, and understand eligibility.
 - Looking for ways for the networks to collaborate, such as universal design in local housing initiatives.
 - Supporting mobile and virtual service delivery models, especially in rural areas.

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Conclusions and Study Limitations

>> SLIDE 28 Conclusions

- This study provides a useful snapshot of current approaches to supporting adults aging with long-term disabilities.
- The networks aim to serve all older adults and people with disabilities—but gaps exist in efforts targeting adults aging with disabilities.
- The aging and disability networks may benefit from opportunities to learn from their peers on ways to better support adults aging with disabilities.

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Study Limitations

- Interview data are not generalizable. The experiences of those who participated in our study are specific to those individuals and site and may not reflect all aging and disability networks.
- These findings also only reflect participants' experiences during a snapshot in time.

>> SLIDE 30 **References**

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Questions?