Context

• The nexus of aging and disability, characterized by the phenomena of **aging WITH a disability**, will become more visible as our population ages and the number of people with disabilities surviving to midlife increases.
**Purpose**

Address 3 issues critical to aging WITH a disability:

- **increasing demand** for community-based long-term services and supports;
- **paucity of evidence-based programs** demonstrating effectiveness in facilitating independence for those aging with a disability;
- **lack of a federal infrastructure** to support coordinated investments in “research-to-practice” for this population.
BACKGROUND
• The term “aging with a disability” refers to the increasing trend for people aged 65 years and younger with early onset of disabilities to survive into mid- and later life.

• Because of advances in medical science, they are reaping the benefits and hazards of greater longevity.

• However, they are also at risk for onset of age-related impairments and chronic conditions which threaten health, independence, and the ability to live independently in the community.
Percentage of Total Non-Institutionalized U.S. Population with Disabilities by Age and Type of Disability

(Source: U.S. Census Bureau 2008 American Community Survey)
Percentage of Earliest Age of Onset of Disability by Age and Type of Disability

- ADL: Personal Care Activities
- IADL: Household Management
- PLIM: Physical Tasks
Background

Policy & legislative initiatives have begun to target both older adults and younger persons with disabilities:

- 2001 New Freedom Initiative
- 2009 Community Living Initiative
- 2010 Patient Protection and Affordable Care Act
Why?

1. Theory development, research, and practices translated from the evidence base at the nexus of aging and disability have lagged behind policy advances.
   
   - No systematic national surveys on aging & disability that collect age of initial onset, total duration of time spent living with a disability (Putnam, 2007)

2. Not knowing the scope of the phenomena, we also do not know what demand for services will be, which evidence-based interventions have proven outcomes, or how best to provide services to this population
MISSION:
To help elderly individuals maintain their health and independence in their homes and communities through comprehensive, coordinated, and cost effective systems of long-term care, and livable communities across the United States.

PRIMARY AUTHORITY: Older Americans Act of 1965
Our Priority: Aging In Place

Helping Seniors Age In Place Through Three Key Strategies

- **Invest** in Core Services that Help Seniors Stay in their Communities
- **Build** Partnerships that Leverage Additional Public & Private Resources
- **Promote** Evidence-Based Research Translation & Innovations to Ensure Effective Outcomes
Aging Network and Services

56 State Units, 629 Area Agencies & 246 Tribal Organizations

20,000 Service Providers & 500,000 Volunteers

Provides Services and Supports to 1 in 5 Seniors

- 241 million meals
- 28 million rides
- 29 million hours of personal care
- 69,000 caregivers trained
- 4 million hours of case management
- 855,000 caregivers assisted
- 6.4 million hours of respite care
- 483,000 ombudsman consultations
Who Is Served

- **10.5 Million** Elderly 60 & Over
- Of which **3 Million** Rely on the Aging Network for Intensive Services
- Nearly **700,000** Caregivers
LOCAL PARTNERS & SERVICES

Area Agencies on Aging / Partners

- Senior Centers
- Home Care Agencies
- Aging in Place Community Groups
- Community Health Centers/Health Depts.
- Medicaid/dual eligibles (CMS)
- Assisted Living
- Social Security
- HUD Public Housing
- Alzheimer’s chapters
- Hospitals for discharge planning
- Veterans Affairs
- Adult Protective Services
- Many other partners...

Services Available

- Information & Referral
- Adult Day Care
- Respite Care
- Transportation
- Home Delivered Meals
- Congregate Meals
- Grocery shopping/meal preparation
- Chronic Disease Self-Management
- Personal Care
- Home Health Aide
- Socialization/Senior Centers
- Financial Planning/Management
- Benefits Counseling
- Legal Assistance
- Many other services....
Mission

At the individual level:
- To generate new knowledge and to promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community; and

At the systems level:
- To expand society’s capacity to provide full opportunities and accommodation for its citizens with disabilities.
Office of Special Education and Rehabilitative Services (OSERS):
- The Rehabilitation Services Administration (RSA)
- The Office of Special Education Programs (OSEP)
- The National Institute on Disability and Rehabilitation Research (NIDRR)

AUTHORITY: Title II, Rehabilitation Act of 1973, as amended
**Scope of NIDRR Mandate**

**Cross-disability Work**
- Physical and mobility impairments;
- Sensory impairments; and
- Cognitive impairments and psychiatric disability.

**Cross Life-span Work**
- Children and youth;
- Working-age adults; and
- Individuals “aging with” lifelong and early-onset disabilities, and those “aging into” disability in mid- to later life.
What NIDRR FUNDS

• **Research and Development grants** – aimed at generating discoveries, products, best practices and evidenced-based solutions to advance NIDRR’s mission.

• **Knowledge Translation and Technical Assistance grants** — aimed at promoting the dissemination and use of NIDRR funded R&D outputs and providing information and referral services to the public.

• **Capacity Building grants** – aimed at training researchers and building capacity to conduct rehabilitation and disability research.
Research Domains

Focus on outcomes in five major domains:

1. Employment
2. Participation & community living
3. Health & function
4. Technology for access & function
5. Disability demographics
EVIDENCE-BASED INVESTMENTS
AOA’s Evidence Based Investments

Example #1
“Health, Prevention, and Wellness” programs

- Core Activities:
  - Chronic Disease Self-Management Program” (CDSMP)
  - Evidence-Based Disease and Disability Prevention Program
AOA’s Evidence Based Investments

Example #2
Diabetes Self Management Training Initiative

Example #3
Alzheimer’s Disease Supportive Services Program
NIDRR’s Evidence Based Investments

1. Rehabilitation Research and Training Centers (RRTCs)
   • Conduct coordinated and advanced programs of research, training, and information dissemination

2. Rehabilitation Engineering Research Centers (RERCs)
   • Conduct coordinated programs of engineering and technological research to design, develop, and test equipment, technologies, assistive devices, and methods that will remove environmental barriers, promote participation and community living, and provide innovative models for rehabilitation technology service delivery
NIDRR’s Evidence Based Investments

Approximate # R&D centers addressing aging-related issues:

• 8 out of 32 Rehabilitation Research and Training Centers (RRTCs) funded at average of $850K/year for 5 years; and

• 13 out of 23 Rehabilitation Engineering Research Centers (RERCs) funded at average of $1M/year for 5 years.
NIDRR Investments: 
Technical Assistance and Informational Resources

National Rehabilitation Information Center (NARIC)

- **Type of Resource:** Comprehensive information and dissemination source.

- **Description:** maintains a database of more than 65,000 documents on disability and rehabilitation; responds to information requests; provides database searches and document delivery; and disseminates information and products from NIDRR projects, other federal programs, and from journals, periodicals, newsletters, films, and videotapes.

- **Toll-Free Number:** 800/346-2742
- **Website:** [http://www.naric.com](http://www.naric.com)
NIDRR Investments: Technical Assistance and Informational Resources

ABLEDATA

- **Type of Resource:** Online database of more than 34,000 commercially produced and custom-made assistive devices.

- **Description:** Maintains the ABLEDATA product database; provides I&R services on the technology product needs of consumers and professionals, and supplies data to ensure wide distribution and availability of information to all who need it. Requests are answered via phone, mail, electronic communications, or in person.

- **Toll-Free Number:** 800-227-0216
- **Website:** [http://www.abledata.com](http://www.abledata.com)
WHAT NEEDS TO BE DONE?
Translating Research Into Practice

• No structures for systematic translation of research into practice and dissemination of innovation have been created at the Federal level in “Aging WITH a Disability”

• This lack of coordination between structures that support research, its translation into practice, and the adoption of research-based innovations is one of the major barriers to closing the gap between knowledge and application.
HOW: Federal “Levers”

• Starts with agencies that fund basic and/or applied scientific research (e.g. NIDRR): continue to invest in basic research as well as new efforts to translate findings

• Translation ideally occurs in collaboration with the agencies that fund service provision (e.g. AoA)

FOR THOUGHT: Could research infrastructure could also serve community operations?
HOW: Federal “Levers”

• Service-provision agencies take the lead in propagating the practices and facilitating widespread dissemination.

FOR THOUGHT: Opportunity to assist with this phase would be to evaluate existing delivery mechanisms (e.g. AAAs, ADRCs, ADA National Network Centers) on how well putting research into practice is currently going?
How key stakeholders—specifically research partners and community-level partners—relate to one another cannot be ignored.

If relationships between research and community partners are not nurtured and communication channels are not promoted and developed, widespread adoption of evidence-based practice will not be achieved.

Explicit roles should be defined for each; however, all must come to the partnership on equal footing.
**CLOSING**

- “Aging with a disability” requires attention not yet afforded from either the aging or disability fields;

- Increasing demand for, and a paucity of community-based LTSS tailored to individuals at the nexus of aging and disability is apparent;

- Translating research is a critical step in bringing evidence-based results on “what works” out of the clinical setting and into community-based demonstration programs, where most social work research takes place.

- To occur on a large scale, a coordinated federal infrastructure supporting translation of research into practice initiatives in this area must be created.
Questions?

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