

## COMMUNITY-BASED SUPPORTS FOR ADULTS AGING WITH I/DD: A PLACE FOR TRUE PARTNERSHIP

By Caitlin E. Coyle, John Kramer, Jan Mutchler, and Michelle Putnam

**Suggested audience for this brief:** Researchers and Service Professionals

For the first time, adults with intellectual and developmental disabilities (I/DD) are living into old age, raising questions about how service systems will respond to this emerging demographic. New needs for support with aging-related challenges, such as frailty or dementia, are added to life-long needs for assistance, many of which have been met by family members. Yet these family support networks, including both parent and sibling caregivers, are also aging.

Aging and Disability Resource Centers (ADRCs) offer some promising possibilities for supporting people with I/DD as they transition to old age. An ADRC exists in every state, as well as in several U.S. territories.

### THE ROLE OF ADRCs

ADRCs integrate information and referral services across the long-term services and supports (LTSS) system. This means that they provide benefits and options counseling about LTSS to support informed decision-making by consumers with I/DD and their families. ADRCs also streamline access to publicly and privately financed long-term services and benefits.

ADRCs operate from a “no wrong door” philosophy. This means that wherever consumers come from, and whatever services they’re seeking, ADRCs offer a single point of access to information, referrals, and in some cases service provision. The main population that ADRCs serve is adults with I/DD, including the growing population of adults over 60 with I/DD.

In this brief, we’ll draw on the experiences of seven high-functioning ADRC systems to generate an agenda for policymakers to begin addressing the question of how adults aging with I/DD and their caregivers navigate the complex system of LTSS in this country.

### WHAT WE DID

During the summer of 2014, we contacted ADRC program coordinators from eight states (CT, MA, MD, NH, OR, VT, WA, and WI) by email to solicit their participation in 60-minute in-depth telephone interviews. We explained that the interviews would focus on the services their Enhanced Options Counseling programs provide to adults aging with I/DD or their family caregivers.

Seven out the eight state ADRC coordinators agreed to participate. In addition, we interviewed staff from two local ADRCs within each of the seven states, bringing the total interviews to N=21.

### OUR FINDINGS

Each interview followed a standard protocol developed by the research team. Here are some of the primary themes and sub-themes that emerged from our qualitative analysis of these interviews.

#### **ADRC STAFF SEE ADULTS AGING WITH I/DD AS A PRIORITY.**

Adults aging with I/DD and their family caregivers are considered a focus of the ADRCs’ work, although this population is not addressed specifically in ADRCs’ mission. ADRC employees often mentioned this service population in the context of their future ADRC goals.

Staff felt that improved partnerships across aging and I/DD service systems could increase the ability of ADRC staff to work with adults aging with I/DD and their families.

#### **UNIQUE CHALLENGES EXIST IN PROVIDING INFORMATION AND REFERRAL SERVICES TO THIS POPULATION.**

ADRC staff mentioned a lack of prior connection to formal services and supports among people aging with I/DD and their families. This population is often not aware of ADRCs, or don’t identify as being part of the ADRC service group. The simultaneous need for service across aging and I/DD systems also creates challenges for information and referral.

Interviewees mentioned that eligibility requirements create gaps in service for people aging with I/DD. These gaps were also attributed to a general lack of programs or resources targeting this population.

*“Agencies are looking [for] opportunities for working together...the population that is aging [with I/DD] has been an area in which everybody agreed could be [an] opportunity to collaborate.”*

## **THE NEEDS OF THIS POPULATION ARE PARALLEL TO THOSE OF THE BROADER AGING ADULT POPULATION, AND ACCESSIBLE PROGRAMS AND SUPPORTS ARE LIMITED.**

Cross-training with staff is one mechanism by which ADRCs aim to support this population. Although few in number, programs specifically developed to include this population were described by the ADRC staff we interviewed.

*“[Understanding] the physical, cognitive, mental and social changes that they’re going through...how to approach that as a professional, how to connect them to resources--that would be important training.”*

—Local ADRC staff

## **OUR POLICY RECOMMENDATIONS**

Our findings suggest that ADRC staff are aware of the need to allocate greater attention to adults aging with I/DD and their families. This need has been recognized by national I/DD advocacy organizations and scholars working in this area, but also requires investment in identifying and constructing the right infrastructure.

We propose the following recommendations for continuing to raise awareness about the community-based LTSS needs of adults aging with I/DD and their caregivers:

- ▶ Identify specific aging-related needs of adults aging with I/DD and their caregivers, and best practices for service delivery, through investment in research and evaluation efforts. This work should focus on identifying areas of overlap between aging and I/DD service systems, as well as the identification of areas in which unique needs exist.
- » Federal agencies should provide support for comprehensive research and evaluation projects to guide the improvement of existing programs. This will help to address the needs of adults aging with I/DD, as well as to identify areas where new programs must be designed.
- » Adults aging with I/DD and their caregivers should be incorporated into program implementation and evaluation efforts at the state and federal levels.
- ▶ Create more coordinated, responsive, and functional state-based information and referral systems.
- » Developing stronger partnerships among public units and private organizations engaged in the LTSS enterprise through state- and national-level workgroups or commissions is needed to guide this policy work.

- ▶ Build the professional capacity of the LTSS system to support individuals aging with disability through the ADRCs.
  - » National guidelines for cross-training across I/DD and aging staff is needed, both to address systemic misconceptions about aging with I/DD and to learn about the unique needs of this population.

Adults aging with I/DD exist at the nexus of two historically distinct LTSS systems. A focus on this population and their support networks provides an opportunity for learning and growth relative to systems integration across aging and disability systems.

This project is a collaboration between the Institute for Community Inclusion (ICI) and the Gerontology Institute at UMass Boston. This collaboration is focused on the intersections of aging, intellectual disability, caregiving, and long-term services and support systems.

The ICI promotes the full inclusion of people with disabilities in every aspect of society. We do this through training, research, consultation, and clinical and employment services. Our projects increase disability inclusion throughout New England, across the United States, and internationally.

The Gerontology Institute is located in the McCormack School and carries out basic and applied social and economic research on aging. The Institute engages in public education on aging policy issues, with an emphasis on long-term services and supports, health and health care, income security, productive aging, and basic social and demographic research on aging.

### **For more information**

John Kramer

Institute for Community Inclusion (ICI) | UMass Boston

Phone: 617.287.4369 | john.kramer@umb.edu

### **About the Authors**

Caitlin E. Coyle, PhD, is a research fellow at the Yale School of Public Health in New Haven, CT.

John Kramer, PhD, is a research associate at the Institute for Community Inclusion at the University of Massachusetts Boston.

Jan Mutchler, PhD, is a professor of gerontology at the University of Massachusetts Boston.

Michelle Putnam, PhD, is a professor of social work at Simmons College in Boston, MA.

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