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The Role of Aging and Disability Resource Centers in Serving Adults Aging with Intellectual Disabilities and Their Families: Findings from Seven States

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Abstract

For the first time, adults with intellectual and developmental disabilities (I/DD) are living to experience old age. The purpose of this project was to assess the activities of Aging and Disability Resource Centers (ADRCs) as they seek to serve older adults with intellectual disabilities and their family caregivers. Data come from 21 in-depth qualitative interviews with ADRC staff in seven states. Results of this qualitative analysis indicate that ADRCs are not focusing explicitly on adults aging with intellectual and developmental disabilities and their family caregivers, but meeting the needs of this population is a future goal of ADRCs. Challenges related to accessing and providing information and referral services for adults aging with intellectual and developmental disabilities were described, which highlight existing unmet needs of this population. Supporting adults who simultaneously require aging and disability services requires true coordination of aging and disability service systems.

Keywords

community living; disability; intellectual disability; long-term services and supports (LTSS); state policy

Background

Due to dramatic increases in life expectancy, the population of adults with intellectual and developmental disabilities (I/DD)—such as Down syndrome, autism, and other life-long conditions that impact intellectual functioning—is increasing. As these individuals age, new

needs for support with aging-related challenges, such as frailty or dementia, are added to life-long needs for assistance, much of which has been met by family members. Yet these family support networks, including both parent and sibling caregivers, are also aging. This shift in the composition of the population brings with it a number of important questions about how older adults with I/DD and their caregivers interact with the matrix of long-term services and supports (LTSS) which has been noted as being complex, often disjointed, and difficult-to-manage (Kane, Priester, & Neumann, 2007; Leuning & Certo, 2003).

This is particularly relevant at this time given the significant policy changes being made in the provision of LTSS. In response to the Supreme Court's *Olmstead v. LC* ruling (*Olmstead v LC*, 1999), the institutional bias in Medicaid-financed LTSS services has been reduced through “rebalancing” efforts (Kassner et al., 2008), which has spurred growth in the home and community-based care sector and increased the care options it provides for older adults and people with disabilities (Mollica & Gillepsie, 2003; Doty, 2010). As part of this effort, The Administration on Aging, within the Administration for Community Living (ACL), established the Aging and Disability Resource Center (ADRC) program in 2003. The intention of ADRCs is to facilitate the integration of information and referral services across the LTSS system, provide benefits and options counseling about LTSS to support informed decision making by consumers, and to streamline access to publicly and privately financed long-term services and benefits through coordinated and/or unified benefit eligibility and assessments for older adults, individuals with disabilities, and their families and caregivers (O'Shaughnessy, 2010).

Currently, an ADRC exists in every state as well as several territories of the United States (Administration for Community Living, 2013). All ADRCs were charged initially with serving both older adults and at least one other target population, such as adults with physical disabilities, intellectual or developmental disabilities, or mental illness. Despite the large number of ADRCs that partner with a developmental disability organization (O'Shaughnessy, 2010), the capacity of ADRCs to support persons aging with I/DD is relatively underexplored (Putnam, 2014), and the extent to which appropriate and targeted services and supports actually exist is unknown.

Specifically, LTSS needs of older adults with I/DD can differ from those of older adults without I/DD and may require more specialized knowledge within the LTSS system—including ADRCs. For example, our previous research suggests that older adults with I/DD and their family caregivers may require unique delivery of services and supports, and that challenges navigating the service system are common in this population (Coyle, Kramer & Mutchler, 2014). Indeed, LTSS services designed to support families caring for individuals with I/DD are not necessarily prepared to address their aging-related needs; similarly, LTSS services designed for older adults may be limited in their capacity to meet the unique needs of those with I/DD (Factor, Heller, & Janicki, 2012; Putnam, 2011). Given ACL's mission for ADRCs, these structures may be a promising entity by which persons aging with I/DD and their families are supported.

Thus, the purpose of this research is to develop an understanding of how ADRCs administer resources and support to the population of adults aging with I/DD and their family

caregivers. Specifically, four primary objectives are pursued: 1) describe the goals expressed by ADRCs with respect to serving the population of older adults with I/DD and their families; 2) determine how these older adults and their families are referred to both aging and to disability resources; 3) understand the range of program activity geared towards serving adults with older adults with I/DD and their families; and 4) identify gaps in resources and services for older adults with I/DD and their families. We present results related to each of the corresponding objectives and then discuss them within the context of recommendations for building future research and policy to support the LTSS needs of older adults with I/DD and their caregivers.

Methods

Sample

The sample for this study comes from eight states (CT, MA, MD, OR, NH, VT, WA, WI) that were competitively awarded funds in 2012 to implement the ADRC Enhanced Options Counseling (EOC) Program by ACL. Options Counseling is an ADRC information and referral program with a person-centered focus. The intention of funding these eight states to develop EOC programs was to accelerate the development of mechanisms within existing programs to streamline the intake and eligibility determination processes for older adults and at least one younger consumer group with disabilities in accessing LTSS (Administration for Community Living, 2012).

Each state ADRC program coordinator was recruited by email to participate in a 60-minute in-depth telephone interview focusing on the services their EOC program provides to adults aging with I/DD or their family caregivers. Seven out of the eight state ADRC coordinators agreed to participate. Each interview followed a standard protocol developed by the research team. To ensure consistency across interviews, each participant was read a definition of adults aging with I/DD: *“When I refer to an adult aging with I/DD, what I mean is an individual who had onset of a cognitive impairment before the age of 22 and who is now age 50 or older. An example might be an individual with Down syndrome or cerebral palsy.”* In addition to a description of their roles and duties within the state's ADRC system, participants were asked a series of semi-structured questions that inquired about 1) the extent to which adults aging with I/DD are considered a focus of their state's ADRC's work, 2) existing challenges and opportunities related to supporting adults aging with I/DD through their state's ADRC options counseling program, 3) the roles of state-level partnerships with I/DD organizations and other collaborations in helping serve the I/DD population, and 4) future goals of the state relative to serving the aging I/DD population. At the end of each state ADRC coordinator's interview, he or she was asked to recommend three local ADRC program staff in the state to participate in a second tier of interviews focused on how individual ADRCs are working with adults aging with I/DD.

To obtain the local program staff sample, each nominated local ADRC contact person was recruited via email to participate in a 60-minute semi-structured telephone interview with the same member of the research team who interviewed the state ADRC program coordinators. Out of the 21 recommended local ADRC contacts (three in each of the seven states), 14 agreed to participate; two local-level interviews were conducted within each of seven states.

The interview guides predominately mirrored the state-level interviews with the addition of questions related to how the local ADRCs serve adults aging with I/DD, including how often they provide Options Counseling to this population and their family members, the types of services or support these individuals or families typically seek, and if they rely on any local I/DD partnering organizations to help serve this population.

The total sample size for this study is N=21. All parts of this procedure were reviewed and approved by the Institutional Review Board at the University of Massachusetts Boston (protocol #FWA00004634) and Simmons College (protocol #14-025). Due to the public position these ADRCs play in their states and communities, study participants were informed in the consent process that their confidentiality could not be ensured. Researchers, however, indicated that data would be aggregated across all states and individual state-level analysis would not be reported as a means of providing some level of protection against direct linkage of interview data to program staff. ACL was made aware of this study and provided verbal support for it; however, the ACL has no formal affiliation with the study or access to study data.

Analysis

A constant comparative process was used to generate primary and secondary themes from the data (Taylor & Bogdan, 1998). All interviews were audio recorded and transcribed verbatim. Two members of the research team conducted the primary coding. Each researcher open coded data for half of the state-level transcripts and the two corresponding local-level transcripts. For example, one researcher coded nine transcripts, and the other coded twelve transcripts. The two researchers then compared their independently derived codes and verified the list of primary codes to address any discrepancies. The final coding structure and excerpts of sample data were then presented and discussed with the full research team to reach agreement on analysis. After this corroboration of codes, the same two members of the research team conducted a more refined analysis of the sub-themes within each primary code. All individual interviews were treated as distinct data sources. Data presented are aggregated and represent the general perceptions of program staff working in seven of the eight ADRCs awarded Enhanced Option Counseling Program funds. Verbatim quotes are used to illustrate themes, and these quotes are anonymously attributed to either state or local ADRC staff responses.

Results

Emergent themes across all participant responses were summarized into three major findings. These three findings are presented individually and include the presentation of primary themes that support them.

No Explicit Focus on Adults Aging with I/DD and Their Families in the ADRC's Work

Across all states included in this analysis, ADRC staff indicated that adults aging with I/DD were not considered a *specific* focus population for their ADRC. However, ADRC staff were aware of this population and, based on their discussions, three main perspectives of how this population fits into the overall work of their ADRCs emerged. First, the ADRC staff

interviewed felt that adults aging with I/DD and their families did not have any special needs that would segment them from the broader service population and thus require a specific focus within ADRC programs:

“...they're not specifically called out in this work, but they fall within the consumers in the populations that we're hoping to reach, which are aging and people with disabilities across the lifespan. So they fall into that category.”

—State ADRC

Staff of these particular ADRCs recognized adults aging with I/DD as an important group to think about targeting in the future in terms of unique needs, but noted that they were not yet a specific focus of their own ADRC's work. These staff members often included a reference to the growth of this population in their comments and the crisis-oriented circumstances that tend to lead their caregivers to contact the ADRC as indicators of this need:

“We're always saying that ... this is an issue -- as people are living longer and parents pass away, but we haven't necessarily carved them out yet. And it comes up in every single discussion, particularly the area agencies on aging have their laser focus on it. To my knowledge, this is a new population.”

—State ADRC

Finally, another segment of ADRC staff discussed the need to improve partnerships across aging and I/DD service systems in the future in order to create greater capacity for ADRCs to work with adults aging with I/DD or their families. Multiple participants described efforts to further partnerships in order to better serve the population of adults aging with I/DD and their families through their ADRCs and articulated expectations of continued future progress in this area:

“...We've gotten the different agencies together regionally, sometimes there's ... this quietness amongst them because they're looking...[for] opportunities for working together... that population that is aging [with I/DD] has been an area in which everybody has sort of agreed without hesitation that could be [an] opportunity to collaborate with each other.”

—State ADRC

Unique Challenges in Providing Information and Referral Services, Resulting in Difficult Complexities and Gaps in Services

The second major finding was that ADRC staff across states articulated unique challenges related to accessing and providing information and referral services for the population of adults aging with I/DD. As ADRC staff described these challenges, they also identified service gaps important to adequately supporting this group of clients. Three common challenges were described across states: 1) It is common that adults aging with I/DD or those who assist them often contact the ADRC in times of crisis due to a lack of connection to any formal service system; 2) ADRC staff report that their community outreach efforts may not resonate with this population of older adults or their families, which limits their capacity to support them at all; and 3) specific differences in needs for service delivery were described, which make providing information and referral services to adults aging with I/DD

and their families more challenging to a system historically providing supports to older adults without I/DD.

Perhaps the most relevant for ADRCs is the lack of prior connection of the adult aging with I/DD to formal services/supports. Family members frequently contact the ADRC during a crisis situation, and it is learned that the adult with I/DD has no history of receiving supports and services of any kind. This often urgent need for formal LTSS can be challenging for ADRCs because it consumes substantial staff time and resources. Often, this means that ADRC staff are starting at the beginning in terms of determining eligibility and getting access to programs and other supports for these adults. This is described as challenging in terms of paperwork but also because of a qualitative difference in adults who have remained largely unconnected from services their entire life versus those who have been more strongly linked to the I/DD system. These challenges make it more difficult to provide information and referral services:

“...As they come to me and they're older, and they have not had the opportunity over the last 20 or 30 years to leave their family's home ... it's more challenging. I maybe can get them...working a few days at a sheltered workshop, but they've lost many valuable years in terms of life skills and being independent. That's real hard. I'm really worried what happens after their parents pass away. Are they going to end up in a group home or institution? Very possible.”

—Local ADRC

This finding also highlights a point made by many ADRC staff that within these crisis situations, it is not only the adult with I/DD who needs immediate support but often an aging parent or family caregiver who is also in need. This adds complexity to the information and referral process:

“... their parents...they're just like... 'we're not going to utilize the services, agencies. We'll just take care of this individual as a member of our family'...so they're not in the system...they're just not visible...as the parents are aging... there hasn't been any systems or support in place along the way. So it becomes a bigger and bigger chasm to cross...if the parent falls, breaks a hip, is in rehab. Now what? ...It becomes a crisis.”

—Local ADRC

An additional challenge identified was that adults aging with I/DD and their caregivers may not be aware of ADRCs or they do not identify as being part of the ADRC service population and therefore do not contact the ADRC for assistance to get the help they need:

“Aging and Disability Resource Center? I'm not sure everybody in that particular age group, or their informal [care provider]...necessarily sees us in the phone book, or sees the ad on TV, or talks to the neighbor who says 'oh these people could help me.' I'm not sure they necessarily would identify with us. So it's a work in progress.”

—Local ADRC

In either case, ADRC staff described challenges in working across aging and I/DD systems to provide appropriate information and referral services. For example, they suggested that the level of knowledge and flexibility of staff working across the two systems can influence the provision, quality and continuity of care for adults aging with I/DD. Additionally, they commented on the capacity of the aging system to provide care to this population, suggesting that standard services provided to older adults may not fit the needs of adults aging with I/DD, but it may not be possible to address this in the siloed systems of aging and disability services:

“If we ...use our standard homemaker services, personal care – people to do bathing, and dressing, and that kind of thing. [There] are very likely to be more physical mobility challenges in addition to I/DD.... so it gets more complex.”

—Local ADRC

Moreover, ADRC staff described differences in the need for service delivery, which can make the provision of information and referral cumbersome for ADRC staff. For example, participants from this study reported that family caregivers are often the first points of contact for adults aging with I/DD. As a result, coordination between the caregiver, adult aging with I/DD, and the appropriate referral agencies can make streamlining services across aging and disability systems difficult:

“One of the challenges in serving this population... is that we place a very high priority on getting the primary guidance [from] the person with the disability. [For example] we cannot provide advocacy related to benefits...unless we are talking directly with the person who has the disability or their legal representative. And so if you have a sibling or a friend who isn't in that position of having the legal representation...calling ...we can't just dive straight into solving the problem. That could definitely be a barrier.”

—Local ADRC

As participants discussed service challenges for this population, they highlighted two types of existing gaps in service for this population, which in turn make providing adequate information and referral more difficult. First, some gaps in service exist as a result of eligibility requirements based on chronological age that may not match well to the accelerated aging of a sizable proportion of the I/DD population. This seemed to be particularly true of direct services. One participant explains:

“...the challenge is, that our Area Agency on Aging partners received the majority of their funding from the Older Americans Act (OAA). If you are in that population [age 60+] and have I/DD, theoretically you can receive unbiased information assistance, Meals on Wheels [and] a number of other services... But if you were to show up at their door, and you're age 45, there is a very limited scope of services that our Area Agency can provide. And it's certainly is not in the realm of direct services...”

—State ADRC

Second, gaps in service reflect the general lack in programs, resources, and training tailored to meet the different needs of this population. Participants noted that existing supports and

services are not adequate to meet the growing needs of the general population of ADRC consumers let alone the growing population of adults who are aging with I/DD and their families:

“I think we, as a state, need to look creatively [at]... How do we best support the family caregivers that are already out there? How do we expand that paid caregiver pool? Because the need is just going to exponentially increase. ...you have to have the folks in place to help them with the skill sets in place [to care for adults aging with I/DD]”

—State ADRC

LTSS needs of adults aging with I/DD perceived as parallel to those older adults without I/DD, but appropriate tailoring or delivery models are lacking

The third major finding from this study is that ADRC staff perceived the LTSS needs of the population of adults aging with I/DD generally to parallel those of the broader older adult population. For example, opportunities for productive and successful aging and services to promote safe community-living are named as commonly requested supports by adults aging with I/DD and their families. However the ADRC staff interviewed indicated that most programs and supports are not designed to include this population, leaving ADRCs at a loss for referring families to appropriate information sources or community supports. In explaining this, ADRC staff indicated that in some cases, there are existing LTSS programs that could meet the needs of adults aging with I/DD but either due to eligibility criteria tied to funding sources or other reasons they are not open to adults with I/DD. In sum, ADRC staff reported the types of LTSS are generally parallel, but there is an absence of appropriately tailored programs to meet the unique LTSS delivery needs of adults aging with I/DD:

“I think everybody needs to feel valued...we need to continue to...create employment opportunities, or volunteering opportunities...purposeful, meaningful things that people can do for as long as possible...[For example, a consumer with I/DD] says she's going to school... we have her going to classes at the Senior Center, which she considers school.”

—Local ADRC

One exception was in the area of housing and home modifications supports where provision of more universal supports was seemingly less challenging:

“...things like ramp and bathroom modification...a lot of issues around housing, finding housing...working with people on that process of independently facilitating a support person...That's been a big part of what we do for this population”

—Local ADRC

As ADRC staff discussed future goals related to addressing these challenges and better serving the population of adults aging with I/DD and their families, they most commonly identified additional cross-training with staff as one mechanism by which this could be accomplished. Although some cross-training does exist that educates ADRC professionals about LTSS in the aging and disability systems in their states, no interview participants

reported training opportunities related specifically to learning more about adults aging with I/DD and their families:

“...the physical, cognitive, and mental/social changes that they're going through because they age like everyone else but they age a lot faster. They don't have the same social networking that an average older adult has. And I think [knowing] how to approach that as a professional, how to connect them to resources and navigate the system – that would be important in a training.”

—Local ADRC

Another goal ADRC staff identified was the development of programs specifically for adults aging with I/DD. A few described what they thought were very rare cases where a program was established in response to the needs of adults aging with I/DD. However, more often they noted that existing services were expanded to include this population. Both actions were viewed as positive. Challenges related to sustaining these programs were described as being both financial and functional:

“...we have opened up our [Senior Center] classes for adults with I/DD, but ...they don't like to participate here...they view us as a Senior Center... trying to balance the seniors with people with developmental disabilities sometimes is a stress to be perfectly honest. But we do it. And we get some push back on that.”

—Local ADRC

Overall, ADRC staff did not identify extensive goals their ADRCs had for meeting the needs of adults aging with I/DD and their families. We conclude that insufficient information about the LTSS needs, both in content and delivery mechanism, has prohibited the growth of ADRC's capacity for serving this population of families.

Study Limitations

Limitations of this study include the selective sampling of states ADRC systems to participate in the study. Although ACL identified these state ADRCs as being among the best performing in the nation in terms of meeting demonstration program goals, they are not necessarily representative of all ADRCs. There may be other ADRCs that are more directly working to meet the needs of the population of adults aging with I/DD and their families. Another limitation is the lack of confidentiality provided to study participants. It is possible that some study participants' comments were biased to present the ADRC program in a positive light and/or to not disclose more negative perspectives.

Discussion

The results of this study suggest that 12 years after the ADRC program demonstration began, the top-performing ADRCs still face challenges in meeting the needs of adults aging with I/DD and their families. The lack of integration of this population into the focus of ADRC work is problematic given the growing awareness of the complex situations and circumstances experienced by adults aging with I/DD and their families as they transition from mid to later life as individuals and as family units (Innes, McCabe, & Watchman, 2012). It must be noted that although the ADRC demonstration program has evolved and

expanded over time, it has not focused on integrating traditional aging and disability LTSS clients, but rather on streamlining access to LTSS through stronger integration of information technology, greater collaboration across historically fragmented service networks, and the development of stronger partnerships among public units and private organizations engaged in the LTSS enterprise. The difference is an important one because the emphasis is on improving the operational performance of the home and community-based LTSS system in particular, but not on building professional or program capacity to serve emergent populations like adults aging with I/DD.

Given the very modest amount of funding the ADRC program has allocated over its lifetime to its more than 54 state and territory awardees—slightly over \$100 million (O'Shaughnessy, 2010)—this focus on infrastructure improvement is not surprising. Calls to improve the fragmented LTSS system have been voiced for decades. Arguably, the series of competitive grants awarded to states to develop ADRC structures have made substantial progress in creating more coordinated, responsive, and operational state-based information and referral systems. This is impressive work and has relied mainly on highly motivated professionals who staff ADRCs at the state and local levels. That said, our findings suggest that ADRC staff are aware of the need to allocate greater attention to meeting the needs of adults aging with I/DD and their families, a need that has been recognized by national I/DD advocacy organizations and scholars working in this area (Factor, Heller & Janicki, 2012)

The findings from this study also suggest that ADRC staff is receptive to working with the broad population of older adults, including adults aging with I/DD. Their primary concerns include having the resources and knowledge to provide adequate information and referral and having a receptive and supportive set of programs and services to which staff can refer individuals and their families. This was evidenced by our finding that ADRC staff perceived commonalities among the needs of adults aging with I/DD and the broader population of older adults, while simultaneously recognizing there may be important differences needed in the information and referral process to LTSS. An example from study data may be the recognition by ADRC staff that the initial contact with an ADRC regarding LTSS for an adult aging with I/DD may come from an individual who has no historical contact with a disability service system. Finding the right LTSS takes time and training that ADRC staff may not have. Another example is the dual-client situation of an initial ADRC contact being made by an aging family caregiver such as a parent, who is in need of services and supports as well as the adult aging with I/DD. These findings support the overall need for greater professional and organizational capacity to support individuals aging with disabilities within the ADRC system (Putnam, 2011).

Our findings also suggest that there are likely inherent difficulties in streamlining information and referral services and improving access to LTSS, two primary aims of the ADRC program, for the population of adults aging with I/DD. Based on our findings, ADRC staff report a lack of programs and services that are either open to adults aging with disabilities, through inclusive eligibility requirements, or modified for this population through integration activities. In short, for this population, the ADRC systems in these seven states with Enhanced Options Counseling programs are not able to help adults aging with I/DD access adequate and appropriate LTSS. Our study participants indicated that, in large

part, this was because appropriate resources do not exist. Thus, there are important LTSS service gaps for adults aging with I/DD and their families that are recognized by ADRC staff.

For ADRCs to fulfill their mission, they must be inclusive of the wide range of LTSS consumers in the aging population. Adults aging with I/DD are one important segment of this population. Closing gaps in the LTSS system and development of specific programs, supports, and services may be outside of the scope of the ADRC mission. However, it is not outside of the mission of the OAA, which forms the aging network onto which most ADRC systems are mapped. It is also not outside the scope of the mission of Centers for Independent Living, agencies for developmental disability, and the wide range of non-profit LTSS service providers. There is great opportunity to develop LTSS options that do meet the needs of adults aging with I/DD and their families by leveraging the expertise and existing resources of these two systems. Our study participants articulated the importance of building these supports for the carrying out of their own work.

We acknowledge that the OAA is, and historically has been, under-funded given its broad mandate (Napili & Colello, 2013). Given the current fiscal struggles of the federal and state governments, an infusion of new funds to support OAA programs seems unlikely. That said, the aging network is the most extensive community-based infrastructure available, an asset the ACL is leveraging as it links ADRC's to LTSS-related programs funded by Medicaid, Medicare, the Veteran's Administration, the Affordable Care Act and others.

This move to grow and fiscally support ADRCs through their attachment to other programs and policies—by contractual or through administrative guidelines—is impressive as it suggests a business savvy among ACL staff and strategic planning based on acute awareness that OAA budgets will continue to be flat despite the growing size of the aging population while other program budgets will grow (or are already quite large). Arguably, this collation and coordination of programs will reduce the fragmentation found within the LTSS system for all persons including persons aging with I/DD and their families and help ADRCs meet their mission. Using the leveraging approach, we believe there is potential for ACL to help forward LTSS policy and program advancements for persons aging with I/DD within the aging and disability networks. Based on these findings, a purposeful approach to planning for and evaluating inclusion will be required to ensure that persons aging with I/DD are recognized as a population with potentially unique service needs.

Future Research

Developing detailed models of service gaps as a means of understanding where new programming is required or where improved integration of aging/IDD systems to better serve the population of adults aging with I/DD and their families is a useful avenue for future research. To that end, asset mapping is one promising avenue of community-based research in this area (Beaulieu, 2002). This translational work could serve both ADRCs and the wider community of potential service users by providing a comprehensive compilation of available LTSS with capacity to support adults aging with lifelong disability as well as by highlighting gaps in services. Simultaneously, this work could provide researchers with knowledge about the context within which adults with I/DD are aging in their communities.

Efforts to develop education and training for ADRC staff, and LTSS service providers in general, about the needs of adults aging with I/DD and their families are also called for given the findings from this study.

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