

**Aging Services Report:**

**Current Services and Needs for Aging Consumers  
and their Families in St. Louis County**

Productive Living Board

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## **Executive Summary**

Individuals with developmental disabilities are aging at a greater rate than ever before. The Productive Living Board (PLB) recognizes this shift in demographics and the ever-increasing need for streamlined services for individuals with developmental disabilities who are aging and their families. In 2012, the PLB contracted with Michelle Putnam, Ph.D. to conduct a research study of the St. Louis area generic aging service providers to determine their preparedness and willingness to support individuals with developmental disabilities who are aging. The Aging Service Study found that generic aging services are willing to support individuals with developmental disabilities, but don't feel like they have the appropriate knowledge or tools to do so effectively.

In November 2013, the PLB produced and distributed an online Aging Services Survey to all PLB funded agencies to build on the information from the initial 2012 study. Sixteen PLB funded agencies responded to the Aging Service Survey. Interviews were performed with local generic aging service providers and online research was done to identify trends in aging and developmental disabilities. This report examines information from the 2012 study along side newly gathered information to make recommendations for next steps that the PLB may consider to better support individuals with developmental disabilities who are aging.

### **Funded Agency Survey Trends:**

- The greatest identified needs for families include respite, caregiver education, financial planning support and planning for care after the loss of an aging parent.
- Few PLB funded agencies provide specialized services for aging consumers, but many indicate that individuals in their general programs are aging.
- Identified challenges in providing supports to aging consumers include transition to retirement, support in maintaining an active lifestyle and age related health changes.
- Funded agencies make referrals to generic aging service providers, but it is unclear how and to what extent.

### **Generic Aging Services Interview Trends:**

- There is interest in serving individuals with developmental disabilities and their families.
- Few individuals with developmental disabilities and their families are reaching out or being referred for services.
- Training is needed to help aging providers feel better equipped to serve individuals with developmental disabilities and their families.

### **Recommendation:**

- Host a facilitated discussion with aging and developmental disability service providers to encourage collaboration.
  - Identify a neutral facilitator with expertise in aging and developmental disability collaboration.
  - Facilitate the brainstorming of collaborative ideas and resource sharing.

- Develop a plan to address unmet needs for individuals with developmental disabilities and their families.

## Introduction

Baby boomers are reaching age 65 at a rate of approximately 8,000 per day. Many individuals with developmental disabilities fall into the category of baby boomers and are no exception to the rapid aging of our society. Based on the 2010 Census, there were more than 800,000 individuals with developmental disabilities age 60 and over in the United States. By the year 2030, this number is expected to grow to 1.4 million individuals. An estimated 75% of individuals with developmental disabilities live at home with family members, who are also aging at this rapid rate. Approximately 25% of current family caregivers for a person with a developmental disability are over the age of 60. 2009 data indicate that over 15,000 Missourians with developmental disabilities lived with an aging caregiver (Braddock, et al., 2012).

As people age, whether or not they have a developmental disability, they are at increased risk for health issues and physical disability. For adults with a developmental disability, there is an even greater risk of developing chronic health conditions due to biological factors, lifestyle and environment. In addition to health concerns, a person aging with a developmental disability needs supports to transition to retirement, access and participate in community activities and ensure continued support for those living with an aging family member.

The Productive Living Board (PLB) recognizes the increasing number of individuals aging with a developmental disability and the growing need for streamlined services for this group. For fiscal year 2013, the PLB provided funds that supported 4,282 individuals with developmental disabilities in St. Louis County. 619 of those were age 50 and over, representing nearly 15% of the total number of individuals receiving services.

In 2012, the PLB contracted with Michelle Putnam, Ph. D. to conduct an Aging Service Study that examined generic aging services in St. Louis County and their preparedness and willingness to support individuals with developmental disabilities who are aging. This research found that generic aging service providers are willing to support individuals aging with a developmental disability and their families, but many don't feel that they have the appropriate knowledge or tools to do so effectively. In November 2013, the PLB sought to build on information from the initial study by surveying funded agencies on what they are doing to support individuals with developmental disabilities who are aging. A few PLB funded agencies indicated that they either currently support individuals who are aging, or that they anticipate doing so in the near future. PLB funded agencies also report that they refer individuals to generic aging services in the St. Louis area, but it is unclear how often these referrals are made. Results indicate that there needs to be more communication and collaboration between the two service sectors in St. Louis County.

This report examines the results of the Aging Services Survey, how local generic aging services support individuals aging with a developmental disability and their families and trends in research. Recommendations are made for next steps that the PLB may consider to better support this ever-growing group of individuals. For the purpose of this report, "funded agencies" refers to developmental disability service providers funded by the PLB and "aging service providers" refers to generic aging service providers in St. Louis County.

## **Methodology**

The Productive Living Board produced and distributed an online survey through Survey Monkey on November 18, 2013. The survey link was sent via e-mail to representatives from each of the 35 PLB funded agencies. The survey was available online for 4 full weeks until Friday, December 13 at 5:00 pm. Agency representatives were sent two reminder e-mails at 10 days prior and again at one day prior to the close date of the survey. Sixteen agencies responded to the Aging Services Survey, representing approximately 46% of funded agencies. A list of survey respondents can be found in Appendix A. In addition to the survey, informal interviews were conducted with local aging service providers and research trends were examined.

## **Survey Results**

### **Current Services for Aging Family Members**

The Aging Services Survey asked agencies to identify services they provide to support both parents and siblings of individuals who are aging with a developmental disability. Seven out of the sixteen respondents indicated that they provide some level of support to these family members. Five agencies provide caregiver education on aging issues. Four agencies provide caregiver support programs. Three agencies provide some level of in-home or residential support or personal care support for consumers as respite for aging caregivers. Two agencies responded that they provide families with resources for guardianship, estate and financial planning. St. Louis Arc and Association on Aging with Developmental Disabilities (AADD) both provide all of the above stated services for both parents and siblings of individuals who are aging.

### **Greatest Need for Aging Family Members**

Funded agencies were asked to rate the greatest needs for aging parents and siblings. Most agencies rated service needs the same for both of these groups, with the following being the highest rated service needs:

- In-home or personal care support for the consumer (respite)
- Caregiver education
- Financial Planning
- Transition planning for both consumer's retirement and for transition once the family member can no longer provide care due to disability or death

### **Current Services for Aging Consumers**

Funded agencies were asked to identify any services they provide that are uniquely designed to address the needs of individuals who are age 55 or greater. Four out of sixteen agencies reported specialized programs.

- The Center for Specialized Services provides an adult day program for five older adults.
- Mercy mentioned their volunteer program, currently serving two individuals age 55 and over.
- St. Louis Arc provides support groups for 20 aging consumer and leisure services for 32 aging consumers.

- AADD provides a variety of aging programs including retirement support, education and support services, supported living and community supports. PLB funds post-employment services at AADD for close to 50 consumers. AADD reported that they serve 111 adults with retirement supports across their service territory.
- OASIS provided post-employment services to 23 consumers in fiscal year 2013. The OASIS FRIENDS program partners older adults with developmental disabilities with volunteers to experience community education programs and events.

### **Identified Challenges in Providing Services to Aging Individuals**

Funded agencies were asked to identify challenges they encounter in providing services for individuals with developmental disabilities who are aging. The following challenges were identified:

- Age-related health issues including dementia
- Balancing medical supports with quality of life supports.
- Isolation due to lack of transportation and age appropriate activities
- Transitioning individuals from work to retirement
- Lack of training for direct support staff on age-related issues

### **Referrals to Generic Aging Services**

7 out of 16 funded agencies indicated that they refer consumers to generic aging services in the community. The services most commonly referred to include:

- Senior Centers
- Adult Day Services
- Alzheimer's Education and Support
- Adult Education (OASIS)
- Senior In-Home Care Services

## **Generic Aging Services**

In order to get a full picture of services provided to individuals with developmental disabilities and families who are aging in St. Louis County, informal interviews were held with various generic aging service providers. Trends from these interviews along with a review of data from the 2012 PLB Aging Services Study is included below.

### **Lack of referrals to services**

Aging service providers indicated that they do not provide services to many individuals aging with developmental disabilities or their families. It was stated in interviews and through the 2012 PLB Aging Services Study that there is interest in providing supports to this constituency, but there are not many who are seeking their services and they do not actively market to this group. PLB funded agencies indicated through the Aging Services Survey that they do provide referrals to generic aging service providers, but it was not indicated how often or under what conditions these referrals are made. Aging service providers such as Mid-East Area Agency on Aging (MEAAA) and County Older Residents Program (CORP) offer a variety of programs and resources that could positively impact quality of life for individuals aging with a developmental disability and their families, including:

- free or reduced-cost meals delivered to home or at congregate meal centers
- free or low-cost transportation
- aging resource referral
- classes and counseling around aging issues
- social opportunities

### **Older parents don't seek help**

Conversations with aging service providers indicated that older adults who are supporting an adult child with a developmental disability are often resistant to support. The local Social Security Administration representative stated that these parents will often forego social security benefits, which can leave a challenge for family after they die and a sibling or other family member must take over support for the adult. MEAAA indicated that there is a need to provide better training to case workers and better outreach to find these families who are falling under the radar of both developmental disability and aging services.

### **Training needs**

While the interest exists to support individuals with developmental disabilities and their families, the 2011 study and recent conversations with aging service providers indicate a training gap. Aging services generally do not feel that they have the proper training or expertise to provide the needed services to individuals with developmental disabilities and their families. A representative from MEAAA suggested that this expertise could be gained through diversification of boards of directors. The suggestion was for aging service providers to have an expert in developmental disability needs and services on their board to help direct appropriate service and training. Likewise, developmental disability agencies could do the same to increase their knowledge on aging issues.

## Conclusion

Individuals with developmental disabilities are reaching advanced age at rates unlike ever before and the rate of older adults will continue to grow exponentially in the coming years. Survey data, discussions with service providers and current research trends indicate that both individuals with developmental disabilities and their aging family members are in need of increased support to remain healthy and enhance quality of life.

Funded agencies responding to the PLB Aging Services Survey indicated that they do not feel prepared to support consumers as they approach advanced age. Discussions with aging service providers indicate that individuals aging with a developmental disability and their families could benefit from the many services and benefits offered through aging programs, but these individuals and families rarely access these programs.

Based on the results from this review, it is apparent that more needs to be done to encourage collaboration between PLB funded agencies and generic aging service providers. This collaboration could provide more streamlined services to better support the complex needs of individuals aging with a developmental disability and their families. The Productive Living Board is uniquely positioned to facilitate discussions between these service sectors as we strive for best practices to serve residents of St. Louis County. A better understanding of available resources will help service providers in both sectors improve quality in serving individuals with developmental disabilities and their families.

### Recommendation:

- Host a facilitated discussion with aging and developmental disability service providers in Fiscal Year 2015 to encourage collaboration.
  - Identify a neutral facilitator with expertise in aging and developmental disability collaboration.
  - Facilitate the brainstorming of collaborative ideas and resource sharing.
  - Develop a plan to address unmet needs for individuals with developmental disabilities and their families.

### Other Options for Consideration:

- Encourage diversification of agency Boards of Directors.
  - Following a recommendation from MEAAA, having an aging expert on developmental disability boards and vice versa could help service providers better facilitate change.
- Establish a plan to identify individuals aging with a developmental disability who are not currently receiving services or benefits.
- Create a resource guide to help individuals aging with a developmental disability and their families understand various services and benefits through Aging and developmental disability providers.
  - Identify how aging and developmental disability services and benefits overlap.
  - Consider utilizing an existing resource, such as St. Louis Times Senior Resource Guide.

## **Appendix A: Survey and Interview Participants**

### **Aging Services Survey Respondents:**

- Chris Camene, Paraquad, Inc.
- Emily Dilthey, Heartland Industries, Inc.
- Judy Grainger, The Center for Specialized Services
- Nicole Johnson, Life Skills
- Barbara Mayer-Douglas, Canterbury Enterprises, Inc.
- Pamela Merkle, Association on Aging with Developmental Disabilities
- Claudine Miller, Provident, Inc.
- Sheri Morrison, Great Circle
- Jessica Naslund, YWCA Metropolitan St. Louis
- Karen Nolte, The Children's Home Society of Missouri
- Jasmine Rangel, Jewish Community Center
- Carrie Sheahan-Pernsley, MERS/Missouri Goodwill Industries
- Sharon Spurlock, St. Louis Arc, Inc.
- Kelly Tiefenbrun, Bridges Community Support Services, Inc.
- Barbara Toulster, SSM Health Care
- Kim Uhlmansiek, Mercy Hospital St. Louis

### **Generic Aging Services Interviewees:**

- Sharon Byrd, Social Security Administration
- Tina Grosso, Lindenwood University Gerontology Program
- Terri Hirsch, Mid-East Area Agency on Aging
- Lisa Knoll, Mid-East Area Agency on Aging
- Mike Nickel, County Older Residents Program
- Kelli Wright, University of Missouri - Kansas City Center for Aging in Community

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