

Aging Service Study: Building Capacity to Serve People with Developmental Disabilities in St. Louis County

Executive Summary

Prepared for: The Productive Living Board for St. Louis
County Citizens with Developmental Disabilities

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A. Introduction

The Aging Service Study had one over-arching intention – to understand current capacity of generic aging service providers to meet the needs of persons aging with developmental and/or intellectual disabilities (DD/ID). The Study was completed in three phases:

- **Phase 1: Development of the Index of Aging Service Providers.**

The aim of the Index was to create a consolidated listing of generic aging service providers serving St. Louis County for both informational purposes and to generate the sample for the Aging Service Provider Survey. The Index was created using existing print and electronic resources and completed over a period of three months. A total of 670 generic aging service-providing organizations with unique addresses were identified. Twenty-one categories of services were identified. The 670 organizations were narrowed to 537 for the survey sample based on removal of duplicate contact names. Some provider organizations have multiple locations but a single professional listed as the contact across locations.

- **Phase 2: Completion of the Aging Service Provider Survey.**

The intent of the Survey was to determine current capacity among generic aging service providers to support older adults aging with DD/ID and their families as well as interest in gaining more education and training related to aging with DD/ID. The final survey contained 57 questions and included a query sheet to obtain information on current best practices. Two mailings of the paper survey materials were sent out between February 7th and March 31st, 2012. A third mailing was sent in the last weeks of data collection offering an online completion option. Sixty-two surveys were completed, resulting in a return rate of 12%. Collected data was compiled in Excel and analyzed using SPSS statistical software. Overall findings from the survey indicate that currently few generic aging service provider organizations have specialized training or knowledge in aging with DD/ID, however there is substantial interest in obtaining information and new skills related to the aging with DD/ID population. Barriers cited to providing specialized programs and services for persons aging with DD/ID included staff time and program funds. Respondents suggested a “go to”

organization to provide assistance in working with older adults with DD/ID and their families would be useful.

- **Phase 3: Creation of a Best Practices Resource Guide.**

The Best Practices review was intended to provide information on current practices that relate to the areas of programmatic, education and training interests of generic aging service providers in St. Louis County. To complete the guide, a broad search of existing scientific and practice literature was obtained and reviewed and an extensive on-line search for program and practice materials was conducted. Findings from the reviews indicate that in this new area of practice, there are few examples of best practices to draw from. However, several resources were identified that may be useful to the PLB going forward particularly in the areas of training of professional staff and informational resources for consumers and their families. A principal take-away message from the Best Practices review was that there is real potential for the PLB to provide leadership in developing best practices for supports and services related to aging with DD/ID.

These three Study components built on one another to create an assessment of the capacity of current generic aging service providers in St. Louis County and to make recommendations to the PLB for next steps based on these findings.

B. Overall Findings of the Study

The three phases of the Aging Service Study were successfully completed and specific results and findings are presented in the products that accompany this report. When reviewed collectively, themes emerge as overall Study findings:

Finding 1: It is likely that limited specific aging with DD/ID knowledge and programming exists among the generic aging service provider population.

This finding is based on the results of the Index of Aging Service Providers and the Aging Service Provider Survey. The first piece of evidence that this is the case is the failure of the interview portion of the Index of Aging Service Providers. The methodology assumed it would be fairly easy to contact generic aging service providers and inquire about whether or not they have special programs for older adults with DD/ID. It was understood that asking if they provided services to persons with DD/ID was not ethical, given that a “no” answer would not be legal under the provisions with the Americans with Disabilities Act – so that question was not asked. However, the telephone survey was terminated after nearly 30 calls. The research assistant undertaking this component was spending an inordinate amount of time per aging service provider organization trying to obtain the information requested by

the Study protocol. This was due to: a low “hit” rate of talking to a live person, not having voice mail messages returned, and having poor quality exchanges with individuals she was able to speak to in person. To pursue this aspect of creating the Index the substitute approach involved reviewing available websites to obtain a contact name for the providers listed in the Index of Aging Service Providers and using a name listed in the resource directories used to create the Index when that was not possible.

The research assistant’s experience was notable as it mirrored a consumer attempting to obtain the same information for someone in need of services (i.e. if the provider had special programs, staff, knowledge of DD/ID, what insurance was accepted, and/or if the provider served citizens of St. Louis County). The lesson learned was that a cold-call to generic aging service providers might result in frustration by consumers. A summary report based on the calls that were made is presented in Appendix A. While this is only anecdotal experience, the Aging Service Provider Survey confirmed a general finding that among respondents a sizable percentage of generic aging service provider organizations currently have clients with DD/ID. There is general absence of specific programming designed to meet possible unique needs of people aging with DD/ID and their families. Additionally, survey respondents indicated a strong need for additional education and training in key areas of service provision to this population.

Finding 1 Recommendation: Consider implementation of a general education and awareness campaign about aging with DD/ID that can build a base level of knowledge among generic aging service providers about this population.

Finding 2: There is significant interest in building capacity to better serve older adults aging with DD/ID and their families among generic aging service providers serving St. Louis County.

Perhaps the most significant summary finding of the Aging Service Provider Survey is that there is identified need – and interest – in developing greater professional capacity to better serve older adults aging with DD/ID. This is true across most areas queried about and among most categories of aging-related service delivered. While survey respondents did indicate some concern about available resources (including fiscal and staff) to increase capacity, there was substantial agreement that building capacity was within the mission of their organizations. Additionally, the majority of respondents indicated that it was both the responsibility of aging and disability organizations to build capacity to serve older adults aging with DD/ID and agreed that professionally they thought it was important to do so themselves.

Overall, survey findings suggest that there is a willingness among generic aging service providers to build their capacity to serve older adults aging with developmental and intellectual disabilities and their families. Additionally, the survey identifies specific areas of training, organizational need, and possible areas to invest development efforts in.

Recommendations for next steps include:

- Facilitating education and training efforts in areas identified as needed by generic aging service providers in this survey.
- Facilitating the development of formal cross-sector (aging and disability) collaborative efforts as identified by survey respondents (e.g. “go-to” organization, integrated intake tools).
- Furthering a larger, more representative, discussion among generic aging service providers about capacity building and/or more targeted discussions around specific substantive issues (e.g. end of life, socialization) to determine how to proceed with capacity building efforts. (See Finding 3 below.)

Finding 2 Recommendation: Begin dedicated efforts to increase education and training opportunities that focus on substantive areas of practice or issues to measurably build capacity among generic aging service providers to meet the aging-related needs of older adults aging with DD/ID and their families.

Finding 3: There is reasonable interest among generic aging service providers in building collaborations with disability organizations.

Findings from the Aging Service Provider Survey indicate that most respondents felt a “go-to” organization to consult with on aging with DD/ID issues would be a helpful resource to them. A fair percentage of respondents indicated their organizations had formal and informal relationships with disability organizations already. Time, staff, and resources to support collaborative activities are noted as key barriers to collaboration potential.

Finding 3 Recommendation: Review successful models of sustained collaboration between aging and disability organizations to consider if and what models may be worth pursuing as part of the PLB’s future work in the area of capacity building.

Finding 4: There are some existing resources related to aging with DD/ID, but few best practices – including programs or trainings – to draw from to facilitate capacity building among generic aging service providers.

Despite a thorough literature review, consultation with a set of leading experts in the field, and an online search for capacity building resources – programs, trainings, or other items – the best practices review turned up a very small number of resources. This was disappointing, but as discovered through the process of doing the work, not necessarily unexpected given the state of development within this field of practice and research. Although there has been some federal and state funding related to aging with DD/ID for more than four decades, it has not been consistent in amount or provision over time. Additionally, many of the research centers and leading experts in the field have not changed over this time period (i.e. the field has not grown substantially). That is, the work that does exist reflects sustained efforts by a small pool of scholars and practice professionals over their careers. While there is sizable literature describing the experience of aging with DD/ID for individuals and families, there is a very small set of programs or training found within that literature that have actually been developed and implemented as practices. This left the best practices review with a rather slim set of items to choose from and resulted in the presentation of a set of what are perhaps more appropriately thought of as “current” practices rather than best practices. Moreover it made identifying gaps in best practices seem akin to describing an ocean – thus instead we highlighted the few small ships braving the ocean. The downside of this finding is that there are few resources to draw on going forward. The upside is that PLB can be a national leader in the field with its future work.

Finding 4 Recommendation: Review the best practice resources, which is divided by audience because of the small amount of resources found, and to determine if there are educational materials, trainings, or programs that the PLB would like to use to pilot-test capacity building among St. Louis County generic aging service providers.

C. General lessons learned from conducting the Study

Lesson 1: The PLB is on the leading edge of interest in capacity building work nationally.

The approach that the PLB is taking is a unique tact nationally in considering how to build capacity to serve older adults aging with DD/ID. Both the best practices review and current national conferences, meetings, and initiatives demonstrate a preference for building aging-related capacity inside the DD/ID service network and service provider pool instead of building capacity among generic aging service providers.

Important to future work will be an awareness of this unique tact – and that it has significant implications for finding like or similar work/initiatives – mainly because the field of DD/ID is bending in the other direction. That said, the approach the PLB is taking seems more consistent with the likely direction that funding for programs and services will head in as they expand to include the population of older adults aging with DD/ID. This assessment is made because the Older Americans Act (OAA), which is implemented in the St. Louis region by the St. Louis City Area Agency on Aging and the Mid-East Area Agency on Aging (serving St. Louis County), has a single eligibility criteria of being age 60 and older. Thus all persons, regardless of disability status, are eligible for services under this federal program and OAA programs and services cannot be discriminately denied or inadequately provided to older adults with DD/ID based on the Americans with Disabilities Act. Moreover, many initiatives such as Aging and Disability Resource Centers, Care-Coordination programs, and Community Living Initiatives are attempting to bridge both aging and disability service systems. Currently building professional capacity among generic aging service providers to assist persons aging with DD/ID is not an expressed goal within these initiatives, but development of capacity within the aging network to help older adults with lifelong disabilities is an issue of concern being raised with federal and state administrators. In sum, it appears that the PLB is on the leading edge of this work at the local and national level.

Lesson 2: There is likely utility in understanding capacity with the DD/ID network to address aging issues.

While this Study focused on generic aging service providers, the question remains about the capacity of DD/ID service providers to address aging issues given that this capacity is only emerging within the aging service network. This information is important for understanding the general level of capacity persons aging with DD/ID and their families may find generally among service providers in St. Louis County. If, for example, the need to build capacity is also identified among DD/ID service providers, this may guide potential collaborative efforts and create more equitable investment across service networks in capacity building (which was noted in the survey findings to be believed to be a shared responsibility across aging and DD/ID networks). As the PLB shares study findings with both generic aging service providers and agencies providing services to adults with developmental disabilities who are aging, it is probable that the conversation about understanding capacity across aging and disability providers will unfold in a way that provides greater direction towards assessing capacity across service networks.

Lesson 3: Alternate methodologies should be considered in future research.

Due to the limited level of knowledge and awareness of aging with DD/ID, in future research it may be advisable to consider alternate methodology for obtaining the desired information. Although a survey is comprehensive and in this case permitted an optimal format for gathering a range of information, it did not attract substantial interest from the generic aging service provider community serving St. Louis County. It is not clear whether it was the survey itself or if the topic was not compelling enough to elicit response. In either case, the methodology fell short on producing the desired level of rigor in the research. It may be useful in the future to use focus groups or key informant interviews in addition to or in place of a survey format to target research efforts related to capacity building activities such as training, education, and possibly collaborative activities.

D. Summary Conclusions

The Aging Services Study provides background information and knowledge that can serve as a launch point for future work by the PLB in the area of aging. The field of practice in aging service provision to older adults with DD/ID and their families is very young, so the PLB will likely need to be comfortable with its pioneering position. That said, there are experts in this field, who are well known and established and who can offer good consultation and advice should it be desired. These include experts from the Rehabilitation and Research Training Center on Aging with Developmental Disability at the University of Illinois, Chicago (Dr. Tamar Heller and Dr. Alan Factor), the Center for Aging at the Virginia Commonwealth University (Dr. Edward Ansello), and the Center for Excellence in Aging Services at the University of New York, Albany (Dr. Philip McCallion). All of these experts were consulted for this Study regarding best practices in the field.

While there are no known dedicated funding sources for this work, it may be possible to use existing funding channels in aging or disability to support more focused capacity building efforts. Locally, it seems possible given the interest of the service providers responding to the survey to begin to build a network of aging and disability professionals focused on aging with disability – however how to develop and sustain that is a separate concern from this Study, but one perhaps worth pursuing. Anneliese Stoeber, MSW, at the St. Louis City Area Agency on Aging is currently engaged in efforts supportive to this goal and may be an important professional partner in this work going forward.

That the Aging Service Study seems to have uncovered an interest in building capacity among generic aging service providers to help older adults aging with developmental and/or intellectual disability have a positive aging experience is in itself a successful outcome for the

Study. It demonstrates potential for creating increased capacity among service providers. There are many next steps from interest to measured capacity, however, it seems this work will require strong and smart investment of resources as there are few existing best or current practices to draw on. The findings from the Study do give some direction of how to move down this pathway and suggest that future work will be positively received among the generic aging service provider community.