

Public Comments for NAPA Council, January 22, 2024

RE: A Model Program for Training Direct Support Professionals in Dementia Capable Care

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It should be noted that the views expressed below are my own, and not necessarily the views of NTG or the other collaborating agencies mentioned in the public comments.

Direct Support Professionals (DSPs) in organizations serving people with intellectual and developmental disabilities (IDD) are the backbone of care, essential to the day-to-day care and support. In residential sites their responsibilities include nurturing the health and well-being of each person, providing meals, communicating with other shifts, and establishing routines to make sure all activities of daily living are completed before residents leave for their day activities out of the residence or when they return from day activities. If the organization is federally and state funded the activities are documented and written as plans, like plans written by teachers, that must be followed consistently as written.

Depending on the size of the organization and resources available, DSPs may be transporting individuals to the day activities, assisting with those activities, and then returning to the residence to clean, cook, schedule appointments, grocery shopping, and running errands while making sure all documentation for funding is accurately completed or attending a mandated virtual training. There may be individuals who stay home because of sickness, have multiple doctor's appointments, or have Alzheimer's disease or a related dementia (ADRD) and no longer able to tolerate day program or the car ride to the program. Most agencies have aging-in-place policies but have minimal resources to staff for those changing needs, especially after COVID-19's impact.

It is like managing your own home but for as many as five to six people who sometimes need total assistance and care as well as working with ten to fifteen clinical, Frontline Supervisors, and other DSPs. DSPs may work eight-to-twenty-four-hour shifts and be mandated to work a double shift because of call-ins, thereby needing to find care for their own family. All of this must be conducted with caring about everyone's emotional needs and expected to understand the complexity of the program plan. There are people in each residence and day program with multiple and differing needs for care. DSPs are trained, rightfully so, that each person is an individual who must be treated uniquely with full respect.

I began my career as a Pre-School Teacher in one of the largest institutions in the country, the Rome State School in upstate New York. Many of you might be familiar with the infamous television documentary by Geraldo Riveras, *Willowbrook: The Last Great Disgrace*. In it, there are scenes in the documentary from the Rome State School (in upstate New York) including an image of Robert F. Kennedy speaking in front of one of the very foreboding buildings where I taught. I learned quickly that I needed to depend on the DSPs, then called 'ward attendants,' to dress, feed, clothe, and escort my children to my class. My success in teaching was dependent on developing respectful relationships with the staff who did the work to make everything happen.

I recall driving to school one day to hear the announcement that the Rome State School was closing within the year. No staff, and certainly no ward attendants, were given any forewarning that our lives would be turned upside down within days. For a good reason, but no one included in the planning for closure who knew the individuals living in the institution or how to transfer so many people quickly with as little stress as possible. I later became an ICF Program Manager when deinstitutionalization happened, still dependent on

the same people, to conduct my plans, make sure the two community supervised residents I oversaw met all regulations including clean homes and following the elaborate plans.

Today as a gerontologist, an active member of the National Task Group with Dementia Capable Care Foundational Training and other activities, an adjunct professor at Utica University (NY), I also serve as a consultant for many organizations providing recommendations and support for older adults with IDD, health care advocacy, and dementia capable care. Though I am retired from the New York State Office for People with Developmental Disabilities (OPWDD) and the University of Rochester's School of Medicine and Dentistry, I continue to rely on the same direct support staff to carry out my plans and provide the care needed for a quality of life in later years even if there is the disease of Alzheimer's disease or a related dementia (ADRD).

For those people with IDD whose families are not able to care for their loved ones or were part of institutionalization who never met their families, they rely on the organizations to provide care with compassion and dignity of care. The organizations of care that provide residential and day program supports rely on the same DSPs with different titles but the same responsibilities with more added on. The work is accomplished by people who often make this their career even though underpaid with sometimes few benefits such as their own healthcare for the necessary work caring for and about the people they support.

These comments are not the comments I originally planned to submit to NAPA two days before the due date. I had completed the comments, decided to sleep on it for final edits, and then woke in the middle of the night to realize I had drafted an academic article with no sense of the people who performed the essential tasks of caring. I apologize if these are not the typical comments submitted to NAPA. The value of the care provided by DSPs and the need to recognize those dedicated staff are the reasons for the model collaborative project presented below.

The public comments today are intended to increase awareness of a model program for Direct Support Professionals (DSPs) through the extensive NAPA outreach. DSPs are the backbone for providing day to day care and support to people with IDD. With the increased percentage of adults aging closer to the life expectancy of adults in the general population, there is a greater incidence of adults diagnosed with Alzheimer's disease or a related dementia (ADRDs).

Thus, training and understanding of dementia capable care for adults challenged by this disease or suspected to have the disease without a thorough diagnostic process including a differential diagnosis is essential for organizations and families supporting older adults with IDD. The model presented today is an approach for training to DSPs developed by three collaborating agencies: The NTG, The National Alliance for Direct Support Professionals (NADSP), and the Merakey Organization in Pennsylvania. Collaboratively, the representatives from the three organizations created the model and worked together to implement the model through a grant from the Pennsylvania Office of Developmental Programs.

The NTG is a 501©3 not-for-profit organization incorporated in Maine in 2020 after ten years as a voluntary organization under the auspices of the American Academy of Developmental Medicine and Dentistry (AADMD). The National Task Group on ID and Dementia Practices (NTG) began in 2010 with a small group of clinicians, family members, and academics who were concerned about the lack of resources, research, and funding to support programs and services for older adults with IDD challenged by dementia, their families, caregivers, advocates, and self-advocates. One of the primary objectives for NTG at the beginning and today is to ensure that the interests of adults with IDD who are affected by dementia are considered as part of the National Plan to Address Alzheimer's Disease (NAPA).

As one of the lead creators of the NTG Dementia Capable Care Foundational 2-day training, a lead trainer and Master Trainer who with other NTG colleagues, NTG has trained over four thousand plus individuals in this curriculum with approximately nine hundred attending the Third Day Train-the-Trainer to become part of the NTG network providing resources to their states or regions as NTG Affiliated Regional Trainers (NTG ARTs).

The second collaborative organization is the National Alliance for Direct Support Professionals (NADSP). The NADSP was founded in 1996 by a small and dedicated group of visionary professionals, committed to the provision of quality services for people with disabilities. The group's best-known visionary was John F. Kennedy, Jr., who was the President of Reaching Up and working closely with the City University of New York. The founders shared a vision of improving outcomes for individuals with disabilities by improving the support, training, conditions, and level of expectation for the direct service professionals, who work with individuals with IDD daily. These workers require an ethical standard, proficiency, and professional support to effectively care for people as they strive for lives of full inclusion in their communities.

The NADSP launched the NADSP E-Badge Academy to address the need for the training and development in DSPs and their Frontline Supervisors who are also significant contributors for the day-to-day delivery of competent and knowledgeable care. Through the E-Badge Academy participants, supported by their organizations as paid members of the academy, can earn national certification through “stackable electronic badges. The badges demonstrate the knowledge, skills, and values that these professionals utilize every day and meant to recognize the importance of providing practical and easily accessible training to promote the professional development which might otherwise go unacknowledged.

E-Badge participants submit specific examples, experience, and education highlighting their contributions to human services. The electronic platform has multiple options of E-Badges that are skills most often used by DSPs. The E-Badges are all completed virtually (on-line) with agencies providing the technical support. DSP users upload their testimonials summarizing how they meet the requirements for understanding the skill for review by NADSP reviewers for approval or to send back for adjustments. DSPs accumulate E-Badges towards the required number for the completion of the specific E-Badge. Upon completion of reach required to submit to complete the recognized nationally recognized certifications.

The Merakey Organization is the third Collaborator in the model E-Badge program to develop DSPs in dementia capable care skills. Merakey is a leading developmental, behavioral health and education provider of integrated services including people with IDD in twelve states. Merakey/Pennsylvania was the collaborating chapter located throughout the state of Pennsylvania. As with other organizations around the country the mean age of the individuals with IDD served by the Merakey Organization continues to increase, thus increasing the organizational needs for specialized training related to aging and dementia.

A long-time partner with NTG and the NADSP, it was a natural fit to work together to create a program to increase the dementia capable care competency of DSPs. The organizations developed the E-Badge competency skills and the process for completion of the E-Badge series of E-Badge competency-based ‘Dementia Capable Care’ option developed by the three collaborators.

The Merakey Education and Training Administrator worked with her staff to respond to an RFP for funding or a pilot program for DSPs utilizing the newly created E-Badge series. Unique to this collaborative E-Badge program and grant was the concept of DSPs attending the NTG 2-day Dementia Capable Care Training along with their Frontline Supervisors and the Merakey Training department who will train a condensed version of this training after the completion of the 18-month grant. This is the only badge that includes formal training. It was felt the training for DSPs was essential for thorough understanding. Three sessions were held, one each in Pittsburg, Philadelphia, and Harrisburg.

Over 150 participants attended, the majority DSPs, the others future trainers that became NTG Affiliated Regional Trainers (ARTs) and the DSPs' Frontline Supervisors. Completion of the two-day training awarded each DSP the first E-badge in the Dementia Capable Care E-Badge competency. For successful completion of the Dementia Capable E-Badge DSPs need to complete a total of five E-Badges in the series. Once each successfully completes the required five, as part of the pilot grant-funded program each will receive fifty cents an hour raises and the title of Dementia Capable Care Specialist along with their DSP title. As a result of the implementation of this pilot, Merakey, the supporting organization, will more likely retain the Specialists as DSP longer and the organization gains greater understanding of dementia capable care. The Education and Training Administrator, who is an NTG ART and a Master Trainer as one of the participants in developing the 2-day curriculum will work with NTG and NADSP to expand this pilot program to other organizations including other national Merakey sites.

In the *2023 Alzheimer's Association Facts and Figures Report*, the link available below, the need for training of those who provide the daily care is essential to attract and retain workers. It was also noted in the report that the health care workforce, including in human services, were integral to diagnosing, treating, and caring for people with dementia. While not mentioned directly in this report it is even more essential for DSPs to provide support to adults with IDD who often cannot report symptoms of functional and cognitive loss or pain and discomfort.

DSPs who participate in this E-Badge series are trained in Health Care Advocacy including skills of observation and reporting that can provide essential information to the Health Care Provider (HCP) in conducting a differential diagnosis. In many organizations supporting people with IDD, DSPs accompany individuals on their Health Care Appointments and are expected to provide helpful information to HCPs who often are unfamiliar with older adults with IDD. In other organizations it is the DSPs who provide the information to family or clinicians who go on the appointments. The information they provide is essential for screening, assessment, and appropriate interventions if indicated. For the DSPs who complete the E-Badge series they are better prepared to provide the relevant information.

The *2023 Alzheimer's Association Facts and Figures Report* also indicates that approximately 30% of people who were diagnosed with a ADRD did not demonstrate the typical pathology expected to be found during autopsy after death. The Report mentions that there may have been other underlying causes for the symptoms of loss and changes observed. Adults with IDD, especially adults with Down syndrome, are more likely to not receive a differential diagnosis, the standard for diagnosis of ADRDs.

Adults with Down syndrome are known to have a higher risk for Alzheimer's and other dementias (ADRD) than the general population. Trained DSPs are more likely to report changes and symptoms that may help HCPs make diagnostic decisions and encourage HCPs to conduct more thorough ruling in or out possible other causes for decline.

Additional information given in the NTG Foundational Training includes understanding normal aging versus disease process in adults with IDD, further health care advocacy skills, environmental awareness, and practical modifications to address needs as people lose capacity to perform previous skills or participate in former interests, and general therapies such as "Therapeutic Fiblets." Therapeutic Fiblets are techniques of distracting, and validating the emotion and reality of each person, a therapy researched as effective strategy for many with an ADRD. This strategy is often the opposite of historical training for care of people with IDD, who are usually encouraged to be in the reality of the moment rather than memories of the past.

I have tried to provide sufficient information that can help the reader understand the issues and the value of the collaborative E-Badge program in developing DSPs. Below is an abbreviated resource list for further information.

It has been an honor to present these public comments to the NAPA Council. Funding for such programs as this model collaborative EBadge program or other programs to support DSP development through grants and other sources is needed and would be well spent to make a difference for individuals with IDD challenged by dementia, family and paid caregivers, and the communities/organizations that provide the supports. Thank you for your time. I am available through my email address above to answer any follow-up questions the Council may have.

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Abbreviated List of References for Public Comment to NAPA, January 22, 2024

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Merakey website: www.merakey.org

National Alliance for Direct Support Professionals website: <https://nadsp.org>

National Task Group on Intellectual Disabilities and Dementia Practice website: <https://nadsp.org>; Please see Education and Training for further information on the 2-day Dementia Capable Care Foundational Training and the Third Day Train the Trainer to become NTG Affiliated Regional Trainers.

National Task Group on Intellectual Disabilities and Dementia Practice. (2012). *My Thinker's Not Working': A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports*. <http://ntg.org/ntg/thinker>

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