

Intellectual and Developmental Disabilities

National Dementia Capable Care Training: A Model Implementation and Evaluation

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Abstract

With a growing need for specialized training for direct caregivers and support staff of persons with intellectual and developmental disabilities affected by dementia, the National Task Group on Developmental Disabilities and Dementia Practices developed a comprehensive evidence-informed Dementia Capable Care Training (NTG-DCCT). To overcome the challenge of the training length and cost, and to extend its dissemination, Sonoran Center developed a shorter version of the NTG-DCCT while retaining its core components, and implemented it in seven cities in the US Southwest ($N=368$). The pre- and post-training evaluation ($n=260$) demonstrated that the short version of the NTG-DCCT is effective in significantly improving participants' knowledge and/or confidence in dementia capable care. The follow-up semi-structured interviews of participants ($n=7$) provide some insights.

Key Words:

Intellectual and Developmental Disabilities, Dementia, National Training, Evaluation, Adaptation, Caregivers, National Task Group on Developmental Disabilities and Dementia Practices, A Model Implementation

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National Dementia Capable Care Training: A Model Implementation and Evaluation

The current study provides a synopsis of the development of a national Dementia Capable Care Training for persons with intellectual and developmental disabilities (IDD) and a model implementation and evaluation of the national training in Arizona. This study offers an example of successful implementation of the national training to meet the needs of local communities and develop sustainable support capacity as well as remaining challenges within culturally diverse regions such as Arizona, which includes a high percentage of Native American and Hispanic populations who typically care for their family member at home. The details of the training program, evaluation results, successful tips, potential challenges, and future directions are discussed.

National Task Group on Intellectual Disabilities and Dementia Practices (NTG)

To address the growing need to understand and provide supports for adults with IDD affected by dementia and their caregivers, the NTG was formed in 2010 under the leadership of Seth Keller, MD and Matthew Janicki, Ph.D. as a sub-group of the American Academy of Developmental Medicine and Dentistry (Bishop et al, 2015; NTG, 2012).

The first publication of the NTG Steering Committee was ‘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 (referred to as the ‘Thinker document’ below) published in 2012 as an overview of the challenges and issues for adults with IDD and caregivers facing the risk of cognitive and functioning loss due to dementia and underlying causes (NTG, 2012). The document was named from a quote by an individual with IDD and suspected Alzheimer’s disease, who when asked about how he felt, he responded astutely, “*I don’t know but my thinker is just not working* (NTG, 2012).” Included in this

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document were the available US demographics with limited published data and studies, and recommendations for addressing the increasing needs for knowledge and supports related to IDD and dementia. Recommended priorities in the document included development of systems for family and agency advocacy at the federal and state levels, better collection of demographics and statistics related to the disease of dementia and ID, as well as funding sources for research and program development (NTG, 2012).

Development of NTG Dementia Capable Care Training (NTG-DCCT)

One of the top priorities of the NTG was creation of a training curriculum for care and support providers—NTG-DCCT. In 2011, the NTG Education and Training Committee was formed in 2011 with two co-chairs (an academician specialized in disabilities and aging, and an advocacy professional with dementia capable care background) and 70+ clinicians and advocate volunteers. Without complete evidence-based information available on dementia capable care, specific to the IDD population, debate continued throughout the writing of this curriculum and creation of a supportive resource manual to accompany the training slides as to who the curriculum should target or what information should be included (Bishop & Pears, 3/2012 – 10/2019). Of equal debate was the format to be used; academicians and some clinicians argued for short webinars or the addition of a few slides to already existing training programs on dementia capable care for the general aging population, rather than a lengthy live training option (Bishop & Pears, 3/2012 – 10/2019).

One of the most powerful arguments given by a family caregiver:

I can't wait for evidence based information. My brother and I need as much information as possible today to make today livable. I need his caregivers to know as much as possible to support him throughout the course of this debilitating disease. My family

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worked too hard to live a normal life and give him a quality of life. Now that is being taken away from us day by day. Do something NOW! (Bishop & Pears, 3/2012 – 10/2019)

After much discussion it was determined that the cost of bringing people together for a two-day training was worth it, as the outcome of networking and knowledge shared offset the costs (Bishop & Pears, 3/2012 – 10/2019). The decision was made by the majority of committee members to focus on family, Direct Support Professionals (DSPs: community, paid direct caregivers), and other paid care providers including clinicians and educators who teach DSPs.

NTG-DCCT: 2-Day Foundational Training Content

The information for the curriculum—NTG-DCCT— was gathered from participating clinicians (e.g., neurologist, primary care providers) and academicians (e.g., in human development, gerontology) based on their professional work including peer reviewed journal articles, common practice in the general aging and dementia care, and other existing publications in related topics. Contents of the NTG-DCCT are largely aligned with recently published Alzheimer’s Association Dementia Care Practice Recommendations, defining what quality of dementia care looks like (Fazio et al., 2018). The major differences were IDD systems’ policies and practices that were sometimes contradictory to those in the general community and/or were unique to the IDD community, such as detection and screening, additional health considerations, challenges associated with life-long conditions and care practices (Bishop & Pears, 3/2012 – 10/2019; Gordon, 2017; NTG, 2012).

In 2014, the 2-day foundational training content, with a 200-page power point presentation, was finalized through three pilot trainings.

Day-1 focuses on:

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- Distinguishing normal aging from the significant changes associated with dementia
- Common types of dementia, including Alzheimer's type
- Importance of appropriate diagnosis (differential diagnosis) and interventions
- An early dementia screening tool for people with IDD—Early Detection Screening for Dementia (EDSD)—developed by a separate NTG workgroup

Day-2 focuses on:

- System issues including lack of caregiver training on aging or dementia in the IDD field
- Sensory, functional and behavioral changes associated with dementia
- Practical communication and care tips
- An overview of expected stages and progression of the disease process

(Bishop & Pears, 3/2012 – 10/2019; Bishop et al, 2015; Gordon, 2017; NTG, 2012).

Trainees are clearly informed that the information presented throughout the 2-day foundational training is evidence-informed, based largely on commonly accepted dementia capable care practices and research in the general population, but not fully examined in the adults population with IDD and dementia (Bishop & Pears, 3/2012 – 10/2019; Bishop et al, 2015; Bishop, 2017; Gordon, 2017; Moran et al, 2013; NTG, 2012).

NTG-DCCT: Day 3, Affiliated Regional Trainer

The third day was created to bring together a selected group from the 2-day foundational training attendees, as NTG Affiliated Regional Trainers, to develop further expertise and create sustainability of the knowledge and practices in their regions of the country. Becoming the NTG Regional Trainer provides opportunities for continued trainings through webinars, access to extensive digital training modules and additional resources, and the NTG regional trainer web-meetings, as well as connections to expertise within the NTG network (other NTG work groups

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and members), such as the NTG Family Support Group. Becoming part of this network also expands the capacity for regions to develop their own resources, and provide local trainings, but often requires external funding to develop enough local infrastructure. A goal of the NTG is to work with each regional organization in the development of their specific capacities as each region and locality is unique while sharing some common needs (Bishop & Pears, 3/2012 – 10/2019; Bishop et al, 2015; NTG, 2012).

Implementation of NTG-DCCT

At the time of the writing of this article, 58 two-day foundational trainings, with the third day following for development of the NTG Affiliated Regional Trainers, have been provided in 25 states. Three thousand attendees have attended the first 2-day foundational training, and over 700 of those, completing the 2-day along with the third day, are recognized as NTG affiliated Regional Trainers. The federal, state, and community grants received, as well as the enthusiastic support and numbers of trainees staying connected to the NTG while providing local training and expertise, are testaments to the success in achieving knowledge dissemination of the NTG-DCCT (Bishop & Pears, 3/2012 – 10/2019; NTG SC Meeting Minutes, 2019).

However, with success, the NTG-DCCT also brought challenges in the implementation. Though a majority of the training is supported through grants and agency funds, the financial and physical costs of the 3-day training continues to make the training less accessible for direct caregivers who have the daily interactions with individuals with IDD and dementia, including families and DSPs. Since majority of family members, who are full-time caregivers, also have a half to full-time job (Anderson, 2018), their care-recipients' Medicaid supported IDD services could be easily used up to fill the gaps between these responsibilities (e.g., Home and Community Base Services: attendant care, habilitation support). Although community care

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providers recognize the need for the training, securing financial and work coverage for the DSPs can prevent them attending the 2-3 day training especially if not grant funded (non-reimbursable training and work time: Bishop & Pears, 3/2012 – 10/2019, Shirai & Kushner, 10/2016 – 10/2019).

A Model Implementation and Evaluation of the NTG-DCCT in Arizona

To overcome the challenge of the NTG-DCCT training length and cost, and to extend its dissemination in Arizona, the Sonoran Center for Excellence in Disabilities (a federally designated University Center for Excellence in Developmental Disabilities; UCEDD) contacted the NTG for assistance with a state grant application for adapting and implementing the NTG-DCCT. The evaluation of the Arizona NTG-DCCT Implementation Model, which was tailored to direct caregivers, is presented below.

In Arizona, it is estimated that there were 157,550 individuals with IDD in 2016 (Larson et al., 2018). Of these, 55,143 (35%) were in the adult and aging group (22 years and older), only 37,605 (23.8%) of individuals with IDD were served by the Arizona State Division of Developmental Disabilities (DDD) agencies and received long-term support and services (e.g., residential, attendant care, habilitation services: Larson et al., 2018). Arizona has an uncommon residential arrangement; compared to the U.S. average of 58 %, 87% (32,706) of individuals who receive the state DDD support were living in family homes, which is the highest estimate in the nation, while a small percentage (13%) received varied residential services (Larson et al., 2018). Those family caregivers who support individuals with IDD at their homes are most likely involved with the care of an individual who develops dementia or aging related declines. As family caregivers age out from their primary caregiving role, community providers take over their responsibilities. It is critical to provide the dementia capable care training to not only family

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members, but also DSPs.

Methods

I-AADAPT Training Description

In September 2016, as there were no organizations or individuals who could provide NTG-DCCT in Arizona, the Sonoran UCEDD formed Project Identify and Address Alzheimer's and Dementia in Adults through Prevention and Training (I-AADAPT), with a funding support from the Arizona General Attorney's Office.

I-AADAPT team. In order to effectively adapt a mixture of clinical and practical NTG-DCCT contents for targeted audiences of families, and care and support providers, the I-AADAPT project team members were selected from the Sonoran UCEDD, Aging and Transition Project committee to represent varied backgrounds and experiences. Three were affiliated with the University of Arizona College of Medicine (a physician, a gerontologist/social worker, a social behavioral scientist), and four included a staff program coordinator, a clinical care coordinator, a family advocate, and the director of the regional Alzheimer's Association.

Curriculum adaptation. Prior to the curriculum adaptation, all team members were certified as the NTG Affiliated Regional Trainers by completing the NTG-DCCT 3-day trainer trainings, offered in other states. During the curriculum adaption, the I-AADAPT team closely worked with the co-chairs of the NTG Education and Training Committee, for review, feedback, and approval. After the I-AADAPT team reviewed all the original NTG-DCCT materials, the team unanimously agreed to keep all the original training contents, but to reduce the training time to a maximum of one day (8 hours) by adjusting the training delivery strategies. In order to reach as many family members and DSPs as possible across Arizona, the team also decided to provide trainings for free with the current project funds and additional sponsorships (Shirai & Kushner,

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9/2016 – 10/2019).

To efficiently and effectively deliver the training contents, the team developed an outline of key points for each slide. We also obtained permission to insert short segments of an educational video into several clinical content slides, which were developed by a neurologist, as well as other publically available videos for caregiving tips and family perspectives. The addition of those videos helped instructors to accurately deliver information with clear descriptions and visual supplements within our limited training time (Shirai & Kushner, 9/2016 – 10/2019). The class videos are listed in Table 1.

After we adapted the NTG-DCCT 2-day training materials to a 1-day, 8-hour training, we further revised the training contents for different audiences, including:

- DDD and Community Service Support Staff Module (6-hour) for individuals with limited hands-on interaction with individuals with IDD (e.g., weekly or monthly basis), and eliminated some of the detailed caregiver related materials.
- Family and DSP Module (8-hour: 4-hour x 2 days) for individuals with daily direct contact with individuals with IDD so the participants could use the tools between the classes, and share and discuss their experiences at their second class.
- Combined Audience Module (7-hour) for rural locations with a mixed audience.

To increase participants' engagement and application opportunities, we added a few short individual and group activities integrated into the trainings, in which participants shared their background and reflected on the class content in their personal experiences (e.g., cultural influence on participant's own as well as care recipients' care preferences and potential barriers, exploration of care strategies on given scenarios and situations). We also provided several hard copies of tools and resources, including a summary of caregiver approaches/communication tips,

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and the NTG Early Detection Screen for Dementia (NTG: ESDS). See the list of provided tools and resources in Table 2.

Implementation. The I-AADAPT DCCT implementation was targeted for family members, DSPs, community service support staff (administrative staff and supervisors), and DDD staff who coordinate and/or provide support for individuals with IDD in Arizona. The training participants were recruited through training flyers sent out by the Sonoran UCEDD listserv with community partners and organizations, and through the Arizona DDD announcements. The team closely worked with the local regional office of the Alzheimer’s Association and the DDD training unit, selecting seven cities in Arizona, including Phoenix, Tucson, Yuma, Safford, Sierra Vista, Flagstaff, and Coolidge, where they had already established local partners who can assist us in the recruitment and securing free training spaces. Between June 2017 and June 2018, two I-AADAPT instructors (the project director and the coordinator) implemented the following training modules to a total of 368 participants:

- 11, DDD and Community Service Support Staff Module (1-day, 6 hours; $n = 200$),
- 8, Family and DSP Module (2-day, 4 hours each day; $n = 97$), and
- 4, Combined Audience Module (1-day, 7 hours; $n = 71$).

For 80% of our trainings, an Alzheimer’s Association representative(s) was also present at the training sites to host an information table and to answer participants’ questions specific to local support, programs, and additional dementia care related resources.

Evaluation Procedure

In order to evaluate the I-AADAPT training efficacy for improving the participants’ *Knowledge & Confidence in Dementia Capable Care*, pre- and post-workshop evaluation surveys were employed, and follow-up semi-structured phone interviews were conducted with volunteer

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participants. All I-AADAPT training participants ($N = 368$) from Family and DSP, DDD and Community Service Provider Support Staff, and Combined Audience trainings were eligible to participate. The current research procedure, including recruitment, consent, survey, and interview related protocols and instruments, was approved by the University of Arizona Institutional Review Board for the Protection of Human Subjects.

Knowledge & Confidence in Dementia Capable Care Survey

In the surveys, participants were asked to voluntarily report on ten items regarding their *Knowledge & Confidence in Dementia Capable Care* at the beginning and at the end of the training. Please see Appendix A for the survey. The survey included questions about warning signs of dementia, functional changes, challenging behaviors, other conditions that could mimic dementia, the NTG dementia screening tool, health care advocacy, quality care tips, communication tips, environmental tips, and care planning. For each item, participants indicated their level of confidence, “*how comfortable/confident are you in ...*” and knowledge with, “*how familiar are you with...*” on a 4-point scale with choices ranging from 0 (not at all) through 4 (very much). Scores reflected the sum of all items and therefore could range from 0 through 40.

Follow-Up Semi-Structured Interviews

Following the I-AADAPT training, all participants received an email regarding the follow up interview; if they showed interest, the interviews were conducted 1- 4 months after the workshop. The follow-up semi-structured interviews asked how and whether the training participants actually applied their newly gained knowledge, strategies and tools in their daily practices. Based on open-ended questions regarding training related contents, two research assistants conducted the interviews, and participants were asked to elaborate on the topic based on their experiences. The research assistants documented participants’ comments in quotations

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and summary notes for each question for content analyses.

Analysis Strategies

To evaluate overall, as well as content specific improvement in participants' *Knowledge & Confidence regarding Dementia Capable Care*, we conducted a series of Wilcoxon signed-rank tests, comparing pre- and post-workshop survey scores by using statistical software (IBM SPSS Statistics—version 26). To determine the magnitude of improvements, we calculated the effect sizes (Fritz et al., 2012). To explore and understand the potential extended effect of training on the participants' daily caregiving practices, three research team members conducted a content analysis on the follow-up interview notes taken by the research team during the interviews (Assarroudi et al., 2018; Elo & Kyngäs, 2008).

Results

Participants

Of the 368 I-AADAPT workshop participants, 260 (71%) voluntarily completed the pre- and post-training evaluation surveys. Of those 260 survey participants, 74 (28%) were DDD Support Coordinators, 59 (23%) were DSPs, 46 (18%) were community provider supervisors, 26 (10%) were family members, seven (3%) were aging agency/provider staff, five (2%) were DDD administrative staff, and five (2%) were nurses. Twenty-one participants (8%) marked other or N/A, but did not report their specific roles. Seventeen (7%) reported that they also function in more than one capacity, but they did not provide specifics. For the follow-up interview, seven I-AADAPT training participants responded to the recruitment email and participated; these include four community DSPs, two family members, and one community nurse.

Analyses Results

Table 3 shows mean scores and standard deviations of the participants' self-reported

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Knowledge & Confidence in Dementia Capable Care total, as well as item level, at the pre- and the post-training, and the summary of Wilcoxon signed-rank test results. Before the I-AADAPT training, 62% of the participant reported a range of “not at all” to “little” knowledge and confidence in dementia capable care, whereas after the training, 82% of the participants reported a range of “somewhat” to “very much”; the participants’ mean total score increased from 18.79 ($SD = 10.57$) to 33.75 ($SD = 6.48$), improving an average of 14.96 points. Regarding trainee group differences, DDD support coordinators improved an average of 18.2 points, family caregivers improved an average of 17.25 points, direct caregivers improved an average of 16.43 points, community provider/DDD support staff improved an average of 13.4 points and others (combination of e.g., nurse, EMT, aging care provider) improved an average of 10.7 points. The Wilcoxon signed-rank test results demonstrated that the improvement in the participants’ total score was statistically significant as a whole, $Z = -12.20$, $p < .001$, with a large effect size, $r = .59$, and the post-hoc analysis indicated that there were no significant group differences.

The reported item level mean scores ranged from 1.01 to 2.28 at the pre-training and from 3.33 to 3.56 at the post-training. Before the training, the participants reported that they had least knowledge or confidence in “NTG Early Detection Screening for Dementia” ($M = 1.01$), and “knowing conditions that could mimic dementia” ($M = 1.48$). After the training, all item level mean scores were significantly increased ($p < .001$) with large effect sizes ($r = 0.49$ to 0.57). In the following, we present several key *Knowledge & Confidence in Dementia Capable Care* items with quantitative analyses results and provide supplemental qualitative responses from seven volunteered follow-up interview participants.

NTG Early Detection Screen for Dementia Tool (NTG-EDSD). The participants’ confidence in using the NTG-EDSD was the most improved training item, increasing the mean

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score from 1.01 at the pre-training to 3.34 at the post-training ($p < .001$; $r = .57$). According to the follow-up interview, some participants not only improved their self-reported knowledge, but also improved their competence in actually using the NTG-EDSD tool in their daily practices. They reported that the tool was user-friendly and practical enough for them to implement right away. “I used the NTG tool on my members who are Down Syndrome and over the age 50, and identified [potential memory related changes] over 30 of them ...” (Interview Participant: IP #1); “Yes [I used the NTG-EDSD], did not have any problems with it” (IP #7). Some indicated that they also shared this tool with other people and/or groups: “Began to distribute the tool to different groups...will use it as a baseline and track [the changes]” (IP #3).

Knowing other conditions that could mimic dementia. The participants’ self-reported knowledge in other conditions that could mimic dementia was the second most improved item, increasing the mean score from 1.48 at the pre-training to 3.32 at the post-training ($p < .001$; $r = .56$). According to the follow-up interviews, some participants were surprised by other potential conditions, and that investigating the cause could be critical for proper treatment, especially for treatable conditions: “how many other diagnoses can cause the same symptoms” (IP #5), and recognized the importance of having this knowledge: “Yes, I have shared it [a list of conditions that mimic dementia] in every class I’ve taught since I received it” (IP #4).

Communication and environment tips. The participants’ self-reported knowledge and confidence in effective communication and environmental strategies were the third most improved items, increasing the mean scores from 1.84 (communication) and 1.82 (environment) at the pre-training to 3.53 (communication) and 3.56 (environment) at the post-training ($p < .001$; $r = .55$). In the follow-up interviews, several participants reported an immediate implementation of some strategies: “One person in the day program is somewhat ‘borderline’ [exhibiting some

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symptoms] and I've been thinking about what else in the environment could be causing the symptoms" (IP #6); "I [now] give him choices on how he wants to spend his time" (IP #3); "Tried the music technique from workshop to stimulate memory and found it to be effective" (IP #1); and "used it to plan a design for a room at the day program" (IP #5). The participant's response further demonstrated extended positive effects from changes in caregiver strategies on care-recipient's behaviors: "We [caregivers] are modeling a different behavior and they [care recipients] see that difference" (IP #1); "minimized challenging behaviors using de-escalation technique from the workshop" (IP #2); and "reduced how long tantrum and behavior lasted" (IP #2). A few participants, however, noted that the strategies from the training do not necessarily provide a universal solution for all situations: "Remember lessons from the workshop but don't see it as applicable to every behavior or problems I encounter" (IP #2).

Care planning need. The care planning need was also the third most improved item, increasing the mean score from 1.67 at the pre-training to 3.46 at the post-training ($p < .001$; $r = .55$). According to the interviews, some participants understood the progressive nature of the disease process and the importance of on-going planning for securing the quality of care for an individual with Alzheimer's disease or related-dementia. One family caregiver took immediate action: "re-evaluates previous care and skill development plan ...take it back to more simple & maintain" (IP #3); and "I am in the process of making a future plan for [him], I am now communicating with the home nurse. In the future, I might need more help taking care of him" (IP #3).

Additional Themes from the Follow-Up Interviews.

Although we had a limited number of follow-up interview participants, the interview participants' narratives provided further additional insights, worth noting beyond the survey

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items. With improved knowledge and/or confidence, some participants reported that they gained several key skills to provide quality dementia care:

(a) Ability to pay attention and identify changes in behaviors and symptoms: “I came to the workshop because some of our clients were showing signs of Alzheimer’s. Since then, have identified individuals who would be in the at-risk category” (IP #1); and “Noticing more behavioral changes after the workshop” (IP #2).

(b) Confidence in their own ability as well as acceptance in their situations: “[I have now] confidence in handling future progression and acceptance with negative feeling with caregiving” (IP #3); “After the workshop, I don’t worry as much” (IP #1); and “Begin to understand why [Care-recipient] may be showing particular behaviors and be able to identify why” (IP #2).

(c) Skills to be better health care advocates by disseminating dementia care related information, tips and tools: “I implemented new practice involving other colleagues” (IP #1); addressing patients’ needs: “Patients can’t tell you if or when/where they are in pain. You need to observe behavior-what happened, what happened before, who was there, where did it happen—and help them to pinpoint where the pain is” (IP #4); sharing key information with the care team and health care professionals: “show families the progression of symptoms... to have nurses take a look” (IP #1); and encouraging care planning: “Most who attend my class don’t have a care plan. I encourage them to develop the life plan and care plan” (IP #4).

Some participants’ comments have also shed light on potential challenges and the complexity of providing support within a large care team for individuals with IDD. Each member has limited influence beyond his/her own work territory and buy-in from the team members can be challenging. For instance, a few participants reported that they shared their knowledge with the care team, but struggled with the implementation: “No, it happens at home. Those who are

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involved in the planning know that this tool exists and can be used but it's been difficult to implement" (IP #1); "gave many of the care tips and communication strategies but nobody followed through..." (IP #4); and "received resistance from family in completing [the screening] forms" (IP #1). Although some expressed their frustration, they also understood what they can do in their role: "I do what I can when I'm there and that's all I can do" (IP #4).

Discussion

The evaluation of the Arizona NTG-DCCT implementation revealed several gaps in families and community care providers that there is a clear and low baseline of knowledge regarding basic facts about dementia and low confidence in providing proper and quality support among families and community care providers of individuals with IDD. The quantitative results demonstrated that an adapted shorter version of the NTG-DCCT training—I-AADAPT—is a sufficient and effective format to improve training participants' *Knowledge & Confidence in Dementia Capable Care* in all 10 training domains. The results also highlighted key domains that can play critical roles in practicing the Alzheimer's Association Dementia Care Practice Recommendations (Fazio et al., 2018), specifically for the IDD population.

Noticeably, the most improved training domains are the NTG-EDSD tool and Knowing Other Conditions that could Mimic Dementia. Prior to the training, the participants were not informed or aware about the NTG-EDSD and conditions that could mimic dementia. As adult and aging individuals with IDD may have difficulty articulating health and functional changes as they age, it is critical to have a care team that understands common conditions and signs of aging and dementia, as well as how those signs can be varied or modified by their life-long conditions. The NTG-EDSD, as a person-centered screening tool, can set an individual's functional, cognitive, health, and behavioral baselines, track changes, and share information

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among the care team (e.g., families, DSPs, and health care providers: Esralew et al., 2017). Having both the NTG-EDSD and knowledge regarding common conditions help the care team to not only identify conditions, but also to properly arrange medical appointments and treatment at an early stage, possibly minimizing complications. The evaluation results also demonstrated improved participants' knowledge and confidence in effective communication and environmental strategies. These strategies, especially for individuals with memory loss, help the care team to meet changing care demands with increased behavioral and psychological symptoms while optimally dignifying remaining skills and functions throughout the course of the disease (Fazio et al., 2018; Scales et al., 2018).

Person-centered care planning is a critical tool to gather information regarding individuals' preferences and identify care and/or treatment goals, strategies, and settings to maintain the individual's quality of life (Fazio et al., 2018; Molony et al., 2018). This is also one of the third most improved training domains in our study. Person-centered planning has been a commonly utilized tool for the IDD community for decades, particularly for living in and being part of their community; more recently, it became a common practice to support youth transitions from school to young adulthood. However, as individuals with IDD often live beyond their parents, late life, end of life, and advance planning should be encouraged to promote the quality of life across their lifespan (Heller et al., 2000; McCallion et al., 2017). Although many family members and DSPs may have good fundamental knowledge in setting support goals and strategies to improve the skills and functions of younger individuals with IDDs who continue to learn and grow, they have little training in how to adapt these when/if individuals develop dementia and/or declining conditions as they age.

Successes

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There were several key factors in our successful implementation. First, the NTG network with evidence-informed training materials and resources provided the foundation of this project (Bishop & Pears, 3/2012 – 10/2019). Through the generous sharing and collaboration of the NTG-DCCT master trainers, we were able to pursue the Arizona implementation project by focusing on the training implementation with minimum time spent for training curriculum and material development. Second, the funding from the Arizona General Attorney's Office enabled us to form the I-AADAPT team with different areas of expertise and thoroughly execute the statewide training implementation. The funding also enabled us to provide free training statewide, which maximized participation, and thus helped us to develop a broader network across Arizona. Third, developing a local partnership with community organizations and DDD agencies, who share a common mission, was the critical and necessary first step of this project. Utilizing existing partner networks such as the Arizona DDD, Arizona Developmental Disabilities Planning Council, Arizona Health Department, the ARC of Arizona, and the Alzheimer's Association's Local Office, have provided a great platform to disseminate training fliers through already established networks, and selecting and securing training spaces at minimum cost. Fourth, partners beyond the DDD network, such as the Alzheimer's Association, hospices, and aging care providers, provided critical feedback on our project implementation strategies and expanded potential local resources for training participants who otherwise had no awareness of these additional resources.

Finally, developing the local training capacity and a coalition were essential for future training implementation and regional trainer support beyond the funding period. At the end of the two-year I-AADAPT training implementation, we hosted the NTG-DCCT 2-3 day training provided by the NTG master trainers in Phoenix which produced 29 additional NTG Affiliated

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Regional Trainers throughout Arizona. With these newly trained trainers and additional stakeholders, we developed a statewide task force in which members can share resources, identify and address local needs/issues, develop additional tools, and provide mutual support.

Challenges/Limitations/Future Directions

Although the Arizona NTG-DCCT implementation was successful in expanding local training capacity, and reaching out to a significant number of caregivers in multiple communities in Arizona, the study results should be understood within the given challenges and barriers. A large proportion of the I-AADAPT training participants were community DSPs, whereas a smaller proportion were family caregivers despite our efforts to reach out to both direct caregiver groups. It is possible that family members, having dual roles (e.g., a professional and a family caregiver), might find taking any extra training time during weekdays to be challenging. Some families might be hesitant to face potential future challenges, such as getting early aging related symptoms and learning about their own limitations as a life-long caregiver; and/or others might simply not consider that they were qualified because their loved ones are in their youth or middle aged (not old). For future efforts, we should closely examine potential barriers of family caregivers and explore better recruitment strategies.

Some feedback from training and interview participants revealed a few limitations of the I-AADAPT training that should be addressed in further studies; although the I-AADAPT training provides the foundation of Dementia Capable Care, it does not address all potential situations and universal strategies that work for all. First, some participants faced challenges of implementing the Dementia Capable Care strategies within a team environment. It is important to have a buy-in from all team members as well as decision makers, such as guardians and supervisors, who understand the value of Dementia Capable Care. Although our statewide

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implementation focused on family and direct care providers, making a shorter version of training for administrative and supervising staff may be beneficial in our effort to promote a coordinated Dementia Capable Care implementation within, as well as across, systems. Second, the I-AADAPT training is not necessarily developed for a community with a diverse and unique cultural and geographical background. A few participants from the Native American communities provided feedback that some of the training concepts and related terms, as well as the format, may not be appropriate for their communities. We also learned about the barriers in rural communities where they have limited health care provider choices and cannot find specialists who could provide proper support for individuals with IDD. These barriers highlight the importance of Dementia Capable Care knowledge and practice dissemination across the health care services sphere, including family, community DSPs, state agencies, and health care providers. We should have continued effort in addressing unique and specific challenges of diverse communities for all stakeholders (Shirai & Kushner, 9/2016 – 10/2019).

Finally, the current study evaluated participant's knowledge and confidence in Dementia Capable Care via self-reported surveys, and explored possible change in participants' behavior in how they may have integrated knowledge gained from the training into their day-to-day practices via the follow-up surveys. However, with the limited numbers of survey participants, the results should be cautiously interpreted and generalized. Self-reported knowledge and confidence is a subjective evaluation which may differ from an objective evaluation. In future research, different levels of training evaluation, such as participants' behavior changes, organizational/system changes, and direct benefits and/or changes in care-recipients (Morrison, 2003), should be thoroughly explored.

Conclusion

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It is estimated that family caregivers of IDD provide an average of 57.4 hours per week in varied types of support (e.g., personal care, financial, service/system support); as the majority of caregivers are over 50, there is a critical need for care planning education and training for their near future (Anderson et al., 2018; NDSS, 2019). Coupled with the aging of family caregivers and the significant staffing shortage for DSPs, quality dementia capable care for older adults with IDD will become increasingly difficult to provide (Optimize, September 30, 2018). The NTG in their first publication *The Thinker Document* presented this challenge with recommendations to develop a national training curriculum to help increase the quality and efficiency of caregivers and DSPs (NDSS, 2019; NTG, 2012).

Training provided by a national advocacy group, such as the NTG, alone cannot solve the problem for all. It is necessary for partnerships with organizations like the Arizona I-AADPT Project to adapt the curriculum materials to meet regional and caregiver needs, as well as evaluate the effectiveness of the training. The evaluation must, as does the I-AADPT Project, include what difference this makes for caregivers on a day-to-day basis (Bishop et al, 2015; NTG, 2012). The partnership between the NTG and Arizona I-AADPT has been successful at promoting effective outcomes. It is only through such collaboration that the ultimate goal of the NTG to support and provide resources to family and DSPs can be achieved. This project serves as a reminder that it is essential for teams of caring people to work together to combine their knowledge and expertise to make a difference at the day-to-day level. It is also a model that demonstrates a small group of enthusiastic people from diverse backgrounds can work successfully to make a very positive impact on communities (Bishop et al, 2015; NDSS, 2019; NTG, 2012).

The challenge ahead is to assist other diverse communities to use such models to affect

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positive changes and supports at the local level. Models provide a framework, however, each community needs to apply knowledge gleaned to be respectful of the diverse needs of each community. A maximum effect can be accomplished with efficient effort in the application of existing curriculums modified to meet the needs of the local community of care providers (NTG, 2012).

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Table 1. Video Used in the Training

Trainig Content	Source of Video
<p>1) Clinical Content by Dr. Sanjay P. Singh, MD, Chairman & Professor of Department of Neurology at Creighton University School of Medicine</p> <ul style="list-style-type: none"> ▪ The most common types of dementia and symptoms ▪ The connection between Down syndrome and Alzheimer’s Disease ▪ The area of the brain affected by Down syndrome and how brains process memory <p>2) Perspective/Experience of Parent/Caregiver: Interview with a parent/caregiver of 38 year old daughter with Down syndrome and Alzheimer’s Disease</p>	<p>“Now What? Alzheimer’s, Down Syndrome & Other Disorders” by Nebraska Public media</p> <p>http://netnebraska.org/basic-page/television/now-what-alzheimers-down-syndrome-other-disorders</p>
<p>3) Perspective of Individual with Dementia A role play documentary of an individual with dementia going out for errands in her community.</p>	<p>“Small Changes Help Make a Dementia Friendly Community” by Alzheimer’s Society in United Kingdom</p> <p>https://www.youtube.com/watch?v=Fz8ACEu7Lho</p>
<p>4) Importance of Personal-Centered Care: Personal Story A documentary of an old man in a nursing home suddenly engaging and sharing his story when he hear music from his era.</p>	<p>“Old Man In Nursing Home Reacts To Hearing Music From His Era” an excerpt from a documentary film “Alive Inside” by Rossato-Bennett M.</p> <p>https://www.youtube.com/watch?v=NKDXuCE7LeQ&spfreload=5</p>

Table 2. Training Handouts

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- 1) National Task Group on Developmental Disabilities and Dementia Practices (NTG) related handouts
 - Early Detection Screen for Dementia (NTG: EDSD) – Dementia Screening Tool for people with intellectual and developmental disabilities: <http://aadmd.org/ntg/screening>
 - *Guidelines for Structuring Community Care and Supports for People With Intellectual Disabilities Affected By Dementia*: <http://aadmd.org/sites/default/files/NTG-communitycareguidelines-Final.pdf>
 - Alzheimer’s Stages Chart – exerted information into an infographic
 - Communication Tips and Key Concepts in Dementia Care – infographic exerted from the original NTG Dementia Capable Care Training (NTG-DCCT) material
- 2) Dis DAT – Disability Distress Assessment Tool by Northumberland Tyne & Wear NHS Trust and St. Oswald's Hospice: <https://www.choiceforum.org/docs/asst.pdf>
- 3) PAINAD – Pain Assessment in Advanced Dementia Scale by Warden V, Hurley AC, Volicer L: <http://dementiapathways.ie/filecache/04a/ddd/98-painad.pdf>
- 4) Behavior Communication Chart from the Leaning Community of Essential Lifestyle Planning (<https://dhs.sd.gov/developmentaldisabilities/docs/PCTResourceGuide07-27-05.pdf>)
- 5) My Life, My Wishes, Sharing My Journey – End of life planning tool for individuals with intellectual and developmental disabilities by Sonoran Center for Excellence in Disabilities, Tomasa, L. <https://sonoranucedd.fcm.arizona.edu/publications/1275>
- 6) Care Partner Tip Sheets by Arizona Center on Aging: <https://www.uofazcenteronaging.com/care-partners>
- 7) List of Web-based and Local Resources: https://sonoranucedd.fcm.arizona.edu/Project_I-AADAPT
- 8) PowerPoint Class Notes with Glossary for terms covered in training

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Table 3. Mean Scores and Standard Deviations of Participants' Knowledge and Confidence in Dementia Capable Care Measured in 10 items, and Wilcoxon Signed-Rank Test Results, Comparing Pre- and Post-Workshop Scores.

	Pre-Workshop		Post-Workshop	
	Range [0-4]		Range [0-4]	
	<i>M (SD)</i>	<i>M (SD)</i>	<i>Z</i>	<i>r</i>
1 Warning signs	2.14 (1.18)	3.54 (0.55)	-12.20**	-0.53
2 Other conditions	1.48 (1.25)	3.33 (0.70)	-12.68**	-0.56
3 NTG screening tool	1.01 (1.27)	3.34 (0.80)	-12.81**	-0.57
4 Health care advocacy	2.12 (1.40)	3.55 (0.68)	-11.29**	-0.50
5 Tips for quality care	2.11 (1.36)	3.49 (0.69)	-10.50**	-0.49
6 Impact on functions	2.28 (1.23)	3.55 (0.68)	-11.46**	-0.51
7 Tips for communication	1.84 (1.26)	3.53 (0.70)	-12.44**	-0.55
8 Tips for environment	1.82 (1.29)	3.56 (0.63)	-12.38**	-0.55
9 Challenging behaviors	2.01 (1.28)	3.50 (0.66)	-12.12**	-0.54
10 Care planning	1.67 (1.29)	3.46 (0.63)	-12.48**	-0.55
Total Score: Range [0-40]	18.79 (10.57)	33.75 (6.48)	-10.29**	-0.59

** $p < .001$.

Note. *M* = Mean, *SD* = Standard Deviation, *r* = effect size ($> \pm .05$: large).

Appendix A

Knowledge & Confidence in Dementia Capable Care

Participant's pre- and post-training survey

[0 = not at all; 1 = very little; 2 = little; 3 = somewhat; 4 = very much]

How comfortable/confident are you in:

- a) Knowing the warning signs of Dementia?
- b) Knowing conditions that could mimic dementia?
- c) Tracking cognitive and functional symptoms of individuals with IDD using the National Task Group of Disabilities and Dementia Practices Early Detection Screening for Dementia?
- d) Advocating (communicating on behalf of) individuals with intellectual and developmental disabilities (IDD) to his/her health care provider regarding dementia related changes and treatment?
- e) Providing quality care for individuals with IDD who are experiencing Alzheimer's or Dementia?

How familiar are you with:

- f) Potential impact of Dementia in individuals' abilities and functions?
- g) Communication strategies that would work well for individuals with Dementia?
- h) Adaptive strategies to make a dementia friendly environment?
- i) Adaptive strategies to deal with challenging behaviors?
- j) Care planning needs as dementia symptoms progress?