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National Task Group on Intellectual  
Disabilities and Dementia Practices

## AADMD/NTG Annual Conference Abstracts

Swissotel Chicago, Chicago, Illinois  
July 8-9, 2016

### Friday, July 8, 2016 (Afternoon)

#### A Neglected Issue in Global Aging

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**Abstract:** *Issue:* According to the World Health Organization, in 2017, the number of individuals 65 years old will outnumber 5 year olds. This is the first time in human history that this will occur and this demographic shift will continue for the next 40 years. Concurrent with an aging population is the growing incidence of Alzheimer's disease and related dementias (ADRD). Attention is being paid to this growth because of the burden of unmet needs occurring in both the health care and social care environments. Yet there is one group, individuals with Down syndrome (DS), who experience ADRD at a much earlier age, whose needs are not being addressed. As a result, the issues of prevention, early screening, early diagnosis, and ongoing intervention are often delayed or even non-existent for individuals with DS. *Positions or Findings:* There is a significant need for the primary care community to address the issues of early screening and diagnosis for persons with DS and dementia that can lead to Alzheimer's disease (AD). As individuals with DS and other intellectual and developmental disabilities are living longer, health care providers need to learn about the unique characteristics, health care needs, and clinical conditions of these adults. *Conclusions:* The presenters outline the current state of diagnosis of dementia for persons with DS and discuss the need for early screening, early diagnosis, and ongoing interventions. Community-based independent living options for persons with DS and AD, as well as family options for working with an individual (child or sibling) who has DS and AD are important, as well as consideration given to the needs at the local, state, and federal levels to provide appropriate programs for persons with DS and AD throughout the lifespan, within the context of the medical home.

**Learning Objective #1:** To understand the current state of diagnosis of dementia for persons with Down syndrome (DS).

**Learning Objective #2:** To discuss various approaches to providing community-based independent living options for persons with DS and Alzheimer's disease (AD).

**Learning Objective #3:** To understand the needs at the local, state, and federal levels to provide appropriate programs for persons with DS and AD throughout the lifespan, within the context of the medical home.

## Ontario Partnership on Aging and Developmental Disabilities

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**Abstract:** *Issue:* The Ontario Partnership on Aging and Developmental Disabilities (OPADD) have been working across sectors (health and developmental services for over 15 years. OPADD's key principle is the collaboration between the Developmental and Seniors/Long Term Care sectors to best provide the support for individuals with a developmental disability as they age. OPADD also seeks to promote inclusion of individuals with a developmental disability as seniors – to have access to services and supports as citizens of Ontario. *Position or Findings:* OPADD does not have a formal membership or structure. OPADD has always encouraged innovation “on the ground” and its projects have helped to develop and foster regional committees. Some committees were active for the duration of a project and have since disbanded; while others continued and others are just beginning. The Chairs/Co-Chairs of the regional committees connect (usually by conference call or teleconference) about twice yearly to share information. The OPADD offers an opportunity to discuss on-going projects and systemic issues, which are brought forward to the leadership of OPADD. Leadership of OPADD is vested through a group call the Collaborative. It consists of representatives from: Ontario Ministry of Community and Social Services (MCSS), Ministry of Health and Long Term Care (MOH-LTC), Ontario Agencies Supporting Individuals with Special Needs (OASIS), Ontario Non-Profit Homes and Services for Seniors (OANHSS), Ontario Long Term Care Association (OLTCA), Ontario Seniors Secretariat, Ontario Community Support Association (OCSA), Ontario Association of Community Care Access Centres (OACCAC) and the Reena Foundation. Systemic issues from the regions are brought to this group to discuss and to clarify possible actions within policy or legislative frameworks. *Conclusions:* The OPADD experience exemplifies how a regional effort, with its evolution over time, can demonstrate how to develop cross-sector relationships and projects that support individuals aging with a developmental disability.

**Learning Objective #1:** To describe how to unify disparate organizations around a common cause.

**Learning Objective #2:** To understand how service organizations can plan regionally for aging services.

**Learning Objective #3:** To provide ideas for maintain inter-agency relationships.

## Saturday, July 9, 2016 (Morning)

### Supporting adults with intellectual disabilities affected by dementia in community home settings

Panelists: Kathy Service, RN, PhD, NP, Nicole Cadovius, MBA, CAPS, FAAIDD

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National Task Group on Intellectual Disabilities and Dementia Practices

Moderator: Nancy Jokinen, MSW, PhD

**Abstract:** *Issue:* Organizations often seek assistance to develop and operationalize support services that can help adults with intellectual disabilities affected by dementia to remain living in community home settings. *Position:* In this panel presentation, service providers share their experiences of providing support services in a variety of community home settings. Additionally, a NTG working

group offers a foundation from which to develop and provide community home supports, key aspects to consider in the improvement of existing homes and a basis from which advocates can pursue continued community living options for people affected by dementia. *Conclusion:* People with and without disabilities affected by dementia can continue to live in community home settings with appropriate support. Planned, thoughtful considerations given to key aspects can pave the way for quality dementia capable community home services.

**Learning Objective #1:** To better understand the successes and challenges experienced by service providers in providing community dementia capable supports in home settings.

**Learning Objective #2:** To learn various options to maintain community living for persons with ID affected by dementia.

**Learning Objective #3:** To learn key aspects to develop and operationalize home supports.

## Saturday, July 9, 2016 (Afternoon)

### Meeting the Needs of Adults with ID/Dementia Through an Evidence-based Program: Outcomes and Future Directions

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**Abstract:** *Clinical Aim:* The changes in personality and behaviors associated with dementia frequently pose significant challenges to the staff, especially when the desired goal is to support the person remaining in the home. The skill set for effective caregiving for a person with ID/dementia varies significantly from that required to care for an adult with ID. Skills2Care®, a home-based program for family caregivers of people with dementia is effective in reducing dementia-related behaviors, promoting function and reducing caregiver stress. Our clinical aim was to translate this program into group homes. The program was provided to 22 adults with ID/dementia and their staff across 20 group homes. The mean age of the adults was 63 years. There was an equal number of male and female adults. *Intervention:* Skills2Care® is delivered by certified occupational therapists (OT) in the group home. The OT and the staff member collaborate to develop customized strategies to address the needs of the person with ID/dementia. Strategies focus on issues such as helping the staff manage challenging behaviors, adapting the group home environment to make it safer, engaging the person with ID/dementia in meaningful activities and reducing behavioral upset and staff stress. *Outcomes:* Descriptive statistics show changes in three outcomes: staff ability to identify and resolve problems, staff readiness to implement strategies, and client goal achievement. A thematic analysis illustrates the types of problems and goals that were addressed during the program.

**Learning Objective #1:** Describe the effectiveness of an evidence-based program that addresses the needs of adults with ID/dementia and their staff.

**Learning Objective #2:** Appreciate the distinct contribution of occupational therapy in expanding the skills of staff to enhance the function and well-being of persons with ID/dementia.

**Learning Objective #3:** Discuss the recommendations for ongoing implementation of Skills2Care to better meet the needs of adults with ID/dementia and their staff.

## The Experience of Living with Intellectual Disability and Dementia: A Literature Review and Implications for Practitioners and Research

Alisa Jordan Sheth, MS, OTR/L, & Lieke van Heumen, PhD.

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**Abstract:** *Issues:* With the continuing “greying” of the intellectual disability (ID) population and increased recognition that the phenomenon of aging with ID and dementia deserves academic and clinical examination, recent years have seen a significant increase in related research detailing neuropathology, surveillance data and other quantitative explorations. Notably absent is an understanding of ID and dementia, particularly within the intersections between the two, from different perspectives, particularly a more social model of disability. Using the social model as a framework grounded in the experiences and actions of people with ID for research has the potential to identify and work towards eliminating barriers that cause disablement beyond individual diagnosis and has been increasingly acknowledged in some fields as an important priority for ID research. A literature review was undertaken to study the existing body of research on the experience of living with ID and dementia. *Findings:* While there has been an expanding body of literature that examines the experiences of aging with ID and dementia and recommendations that adults with ID be included in research, a majority of this knowledge focuses on the viewpoints of professional service providers, policy makers, and family or paid caregivers. Some of this research also attempts to capture elements of the experiences of care recipients with ID and dementia, although from the input and perspectives of their caregivers. Minimal research has been found that explores living with ID and dementia directly from this population’s point of view. *Conclusions:* This presentation will explore how results from the current state of the literature on the experience or perceptions of living with ID and dementia can inform service provision and care systems, as well as what gaps exist in current knowledge to inform directions for future research. Issues such as best practices, inclusivity, and accessibility will be addressed.

**Learning Objective #1:** Participants will be able to identify dominant and alternative frames of reference used in research on intellectual disability and dementia.

**Learning Objective #2:** Participants will be able to summarize the current state of research on the experience of living with intellectual disability and dementia and its implications for practice in the field.

**Learning Objective #3:** Participants will be able to describe gaps in the literature related to the experience of living with intellectual disability and dementia and future directions for research.

## Using Telehealth Technology to Deliver Specialized ID and Dementia Consultations to Community Providers in Rural and Underserved Areas

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National Task Group on Intellectual Disabilities and Dementia Practices

**Abstract:** *Issues:* Community service providers are facing a ‘graying’ of their population, many of whom are affected by cognitive decline and dementia. A lack of access to specialists skilled in diagnosing and managing dementia in an adult with ID increases costs to the system and jeopardizes quality of life for the individual with dementia, their families and their caregivers. *Positions or Findings:* Project ECHO® ID and Dementia was a pilot program funded by a grant from the Special

Hope Foundation. The project goal was to develop, implement and evaluate a pilot telehealth program to address assessment, differential diagnosis, complex case consultation, care management and care planning and training issues influencing quality of care for people with DD and dementia. This session's purpose is to provide an overview of the Project ECHO® ID and Dementia project and how its guided-practice model can increase workforce capacity to provide best-practice ID and dementia care and reduce health disparities for adults with ID and dementia. *Conclusions:* The session content presents the ECHO® model and explains how the teleECHO™ clinic's knowledge-sharing hub and spoke model, led by expert teams who use multi-point videoconferencing to conduct virtual clinics with community providers, can improve access to specialty consultation services for adults with ID and dementia, especially in rural and under-served areas.

**Learning Objective #1:** Understand the distinction between telehealth and telemedicine.

**Learning Objective #2:** Understand the unique challenges community providers face in caring for aging clients at risk for or who have been diagnosed with dementia and how the ECHO® model can address these challenges.

**Learning Objective #3:** Explain how ECHO® creates ongoing learning communities where community providers and clinicians receive support and develop the skills they need to manage the care of adults with ID and dementia and become local experts.

## "Aging in Place" - A Comprehensive Memory Care Program for Individuals with Intellectual Disabilities

*Carol G. Erzen, M.Ed.*

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**Abstract:** *Issue:* "Aging in place" becomes significantly more challenging when Alzheimer's disease or another form of dementia strikes. Now that individuals with intellectual and developmental disabilities are living longer, we are seeing more cases of Alzheimer's disease and dementia.

Concerned with the impact on the individuals we serve, their families and employees who provide care NHS/Allegheny Valley School secured a grant to develop a Memory Care Demonstration Project.

*Intervention:* The project consisted of the design of a Memory Care home with enhanced features to meet the needs of individuals during the changing stages of Alzheimer's and dementia. Development of specially designed programming and training for caregivers and family members was also part of the demonstration project. The Memory Care home was opened in 2014, with a mission to share "lessons learned" throughout the demonstration to include the successes and challenges experienced along the way and look at ways to expand the Memory Care program moving forward.

*Conclusion:* Staff and family members who were surveyed throughout the demonstration process noted efforts to validate the success of the program.

**Learning Objective #1:** Examine the design of a Memory Care home that has many features intended to enhance quality of life and a sense of well-being for individuals with intellectual and developmental disabilities that now live in the home.

**Learning Objective #2:** Discuss specialized programming provided in the Memory Care home including, two sensory based curriculums developed at NHS/Allegheny Valley School.

**Learning Objective #3:** Describe mechanisms to help families cope as their loved one's health declines, including a family discussion group and newsletter.

## How You Too Can Provide Quantitative Proof of Treatments that Facilitate Neuroplasticity in the Brains of People with Dementia

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**Abstract:** *Issue:* The challenges of quantifying thematically coded qualitative data to show the nonlinear neurodynamical systems changes associated with treatments that facilitate neuroplasticity in people with dementia, with or without previous intellectual disabilities, has slowed progress in proving the superior benefits and cost-effectiveness of these treatments. *Positions or Findings:* A therapist who treats people with and without intellectual disabilities who are developing or have developed dementia, will explain and demonstrate how to convert thematically coded categories of data into quantitative data sets. The session's purpose is to show how this sophisticated data analysis process can be used to prove that a high standard of therapeutic care and treatment that facilitates neuroplasticity in the brains of people with dementia is now possible and will improve the cost-effectiveness of care and treatment over time. *Conclusions:* Current advances in treatment of dementia in people with and without intellectual disabilities can now be proven by turning thematically coded qualitative data into quantitative data using nonlinear data analysis processes such as the one that will be introduced and demonstrated in this presentation. A case example of the use of this process to analyze a thematically coded treatment video will be examined. The data analysis program, called Orbital Decomposition, will be used to show that over the course of five, 30-minute treatment sessions, a client who was receiving hospice services for advanced dementia demonstrated a dramatic and sustained increase in self-in-environment awareness and purposeful occupational engagement.

**Learning Objective #1:** To evaluate the benefits of using nonlinear analysis to convert qualitative to quantitative data sets that may prove the benefits and cost-effectiveness of providing a high level of care and treatment for people with dementia.

**Learning Objective #2:** To analyze videotapes such as one that will be introduced and demonstrated in this case study that are promising for proving the benefits and cost-effectiveness of treatments that facilitate neuroplasticity in the brains of people with dementia.

**Learning Objective #3:** To create a network of health care professionals with the shared goal of demonstrating the benefits and cost-effectiveness of treatments that actually facilitate neuroplasticity in the brains of people with dementia.