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NTG Track of Aging and Dementia Related Presentations
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Serial Assessment of Function in Dementia

Presenter(s): Seth M. Keller, MD, Kathryn G. Pears, MPPM, Kathy Service, RN, MS,. FNP-BC, CDDN, Adel Herge, OTD, OTR/L, Caitlin Cadematori

Abstract: *Issue:* Individuals with IDD and dementia present with behavioral and physical challenges as they progress through their disease. The support and healthcare for these individuals hold many opportunities to be able to help offset some of these complications of the disease and currently there is no consistent tool or scale which has been used to be able to provide feedback and data to help to document this disease and its many different elements. The AADMD in partnership with the Department of Occupational Therapy at Thomas Jefferson University is engaged in a project supported by the WITH Foundation to assess the validity and quality of the Serial Assessment of Function in Dementia (SAFD) tool. The SAFD is a digitalized online tool which is completed by caregivers to help provide like based information of an individual's ADL's, severity of dementia symptoms, as well as a measure on the impact to the caregiver. The presentation described the project; its goals, validity measures, and the scope and direction of that the study.

Relating Global Literature to Local Lives

Presenter: Jeanne Squires Lake, MS

Abstract: *Issues*: 1) Prevalence studies around the world are often limited by insufficient and conflicting information and data. How does this relate to area that we live in? 2) How would baseline guidelines help caregivers in recognizing disease related decline in their wards? Would one set of specific baseline guidelines work for all persons with intellectual and developmental disabilities (I/DD)? 3) What are the post diagnosis supports for caregivers and people with I/DD in local areas? How can these supports be found? *Positions and Findings:* 1) In third world countries, disabled people cope with stigmatization and lack of understanding. This same thing happens in the US. but can be changed. 2) Guidelines of cognitive function are best established in DS around age of 35, and I/DD without DS ~age 50. 3) There are websites and brochures for support networks in local areas. *Conclusions:* 1) Most insufficient and conflicting information comes from lack of understanding of conditions. Education of disabilities can help people to be more accepting of others. 2) Guidelines need to be individual in cognitive functions because each person is individual. This allows a caregiver to recognize when there is a decline in their ward, or other testing is needed to check for other problems; therefore, a specific set of baseline guidelines for all people with I/DD would not be efficient. 3) Professionals working with the individual's diagnosis should have information available for patients and caregivers support systems.

In Their Own Words: The Experience of Caregiving for Adults with Intellectual Disability and Dementia

Presenter: E. Adel Herge, OTD, OTR/L, FAOTA

Abstract: Background: There is a growing population of adults with intellectual disability (ID) and dementia. Changes in personality and behavior are often exhibited and symptoms vary from the typical population. These changes along with decline in adaptive skills and cognitive function frequently pose significant challenges to direct support personnel (DSP). Approaches for effectively supporting adults with ID and dementia demand a new set of skills that differ from those required to support a person with ID1. Evidence identifies support and training as important factors to mitigate the stress the DSP experiences when addressing needs of persons with ID and dementia2. In order to develop and implement a specialty training program for DSPs, an understanding of their experience is essential. Specific Aims: We sought to capture the daily caregiving experiences of DSPs supporting adults with ID and dementia in group homes and identify the specific language DSPs use to describe their experience. Method: A trained interviewer conducted focus groups and audio recorded and transcribed each session. Thematic analysis was conducted to identify major themes. Findings: We uncovered three themes that reflect DSP experiences: caregiver characteristics (selflessness, feeling valued), challenges and solutions (different every day; try something new), and past and current experiences (life experience; learning by doing). Discussion: These findings will be used to adapt a proven education program for family caregiver of persons with dementia for use with DSP supporting adults with ID and dementia.

A functional approach to treating challenging behaviors: Implications for individuals with ID and dementia.

Presenter: SungWoo Kahng, Ph.D., BCBA-D

Abstract: Clinical Aim: There is a paucity of research examining behavioral interventions for challenging behaviors exhibited by individuals with intellectual disabilities (ID) and dementia. The aim of this clinical research project is to demonstrate the applicability of an applied behavior analytical approach to treating these problem behaviors in this population. *Patients/Subjects*: Individuals with ID and dementia who exhibit challenging behaviors such as self-injurious behaviors, aggressions, and disruptive behaviors. *Intervention:* Treatment based on applied behavior analysis (ABA) has been demonstrated to be an evidenced-based intervention for challenging behaviors exhibited by individuals with intellectual and developmental disabilities. However, there is little clinical research on how dementia can impact ABA treatment efficacy. *Conclusion:* Discussed was how ABA-based interventions, which include accommodations for dementia, can be effective for this populations.

Relationships: Fundamental to the Provision of Quality Dementia Capable Care

Presenters: Nancy Jokinen, MSW, PhD. & Kathryn Service, MSN

Abstract: *Issue*: A person-centered approach has long been championed in the field of intellectual disabilities (ID) as an underlying tenet in providing service supports. It is also promoted in general gerontological practice, particularly in supporting people affected by dementia. While certainly a person-centered approach is important, the relationships people have with family, friends, members of the wider community, staff and agencies providing service may be fundamental to achieving person-centered care that enhances quality of life. This presentation discusses the role of relationships within the context of providing dementia capable care. *Position:* A person-centered approach needs to be balanced with a relationship centered approach. They are not mutually opposed concepts rather viewed as working in unison. The nature and quality of relationships between individuals are a major influence in providing person-centered care. We question if in fact quality person-centered care can occur in the absence of positive relations. Factors influencing various relationships are highlighted and discussed. The presentation also considers what constitutes ideal relationships and engages the audience in a dialogue on how we might work more consciously towards those ideal relations - with the individual, their families as well as staff and their agencies. *Conclusion:* Clinical and personal struggles occur in providing dementia capable care to persons over the course of the disease. Taking a deliberate stance to incorporate a relationship centered approach balanced with a person-centered approach may pave the way to achieve quality dementia capable care.

Open NTG Conversation on Responses to RFI RE: 2nd National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers

Presenters: Matthew P. Janicki PhD & Seth M. Keller MD

Abstract: The National Institute on Aging has issued a Request for Information (RFI) inviting comments and suggestions for the 2nd National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers, set to occur on March 24 & 25, 2020. The National Institute on Aging, in conjunction with the Department of Health and Human Services as part of the National Alzheimer's Project Act (NAPA), is seeking input on topics of consideration from its stakeholders, including persons living with dementia, caregivers, members of the scientific community, academic institutions, the private sector, health professionals, professional societies, advocacy groups, patient communities, as well as other interested members of the public. This session invited conference attendees to raise and explore a range of issues related to dementia caregiving and services research and intellectual disability and solicits recommendations that could be passed along to the NIA.

The HealthE6 Lifestyle Model for Adults with Intellectual and Developmental Disabilities

Presenters: Alyce Sherwood MA CCC/SLP, & Sara Budde

Abstract: *Issues*: Given the longer life expectancy of adults with intellectual and developmental disabilities (IDD), it is critical to develop lifestyle approaches to meet the unique challenges of this population. Models of care to support adults aging with IDD and other complex disorders are significantly limited. The Adult Program at The Center for Discovery features a continuum of residential opportunities for 168 adults, from 21 to senior citizens with complex disabilities including those with a variety of aging issues. The program is designed to accommodate varying levels of independence with a focus on personal progression and individual preferences. *Positions or Findings*: The HealthE6 Lifestyle Model is the basis for adult program development at The Center for Discovery. The dimensions in the HealthE6 are designed as a foundational intervention to optimize health and functioning. The first four of the six primary components, each with their own essential elements, are the environment, energy regulation, eating and nutrition and emotional regulation. The two remaining elements, education and evidence based ensure the integrity of the model. A forty-hour training course for direct care providers based on the model has also been developed. This model of care has been successfully implemented within the adult residential and day program for adults with IDD and complex disorders.