A Brief Review...

- **Intellectual disability** refers to a group of disorders characterized by:
  - Origination before the age of 18
  - Possible causes
    - infection, chromosomal, metabolic, environmental, nutritional, toxicity, trauma
  - A limited mental capacity that affects:
    - Reasoning
    - Learning and problem solving
    - Results in difficulty with adaptive behaviors, a collection of conceptual, social and practical skills

- **Developmental disability** is an umbrella term that refers to severe, long term disability that can affect cognitive ability, physical functioning, or both.
  - These disabilities appear before age 22 and are likely to be life-long.
  - The term “developmental disability” encompasses intellectual disability but also includes physical disabilities

- Some developmental disabilities may be solely physical, such as blindness from birth, cerebral palsy, epilepsy etc.

- Others involve both physical and intellectual disabilities stemming from genetic or other causes
  - such as Down syndrome and fetal alcohol syndrome
Facts of Life
For Many People with an Intellectual and/or Developmental Disability

*Putting the challenge into perspective...*
There are frequently multiple co-occurring conditions which translates into...

Joel
Diagnosing Alzheimer’s disease or related dementia... a formidable challenge

Lucy and Sarah
The risks of Diagnostic Overshadowing...

“That means once a diagnosis is made of a major condition there is a tendency to attribute all other problems to that diagnosis, thereby leaving other co-existing conditions undiagnosed”.*

*Jim Blair, Associate Professor of LD, Kingston and St. George’s University, British Journal of Family Medicine, Jan/Feb. 2017
“You matter because you are you and you matter to the last moment of your life. We will do all we can to help you, not only to die peacefully but to live until you die.”

Dame Cicely Saunders, 1976
Nadou’s Story

Receiving palliative care of course does not change the presently inevitable course of Alzheimer’s disease; but it provides much-needed relief and comfort to the caretaker, who is no longer totally alone.

Information about the process of Alzheimer’s disease is lovingly dispensed; and you are able to recover some of the energy required to go on and be totally there to comfort your child or sibling.

You feel some of your fatigue, grief and depression lifting, grateful for the welcome help...this service tends to create a healing energy felt by all.
WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
WHO Definition of Palliative Care (continued)

Palliative care:
✧ provides relief from pain and other distressing symptoms
✧ affirms life and regards dying as a normal process
✧ intends neither to hasten nor postpone death
✧ integrates the psychological and spiritual aspects of patient care
✧ offers a support system to help patients live as actively as possible until death
✧ offers a support system to help the family cope during the patients illness and in their own bereavement
✧ uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated
✧ will enhance quality of life, and may also positively influence the course of illness
✧ is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy
✧ includes those investigations needed to better understand and manage distressing clinical complications
International Summit on Intellectual Disability and Dementia
Glasgow, Scotland - October 13-14, 2016
University of Stirling and National Task Group on Intellectual Disabilities and Dementia Practices (NTG)
Dementia and Advanced Dementia in Persons with Intellectual and Developmental Disabilities

Prevalence of Dementia in People with Down syndrome and in People with Other Intellectual Disabilities

People with Down syndrome (8%, 55%, 75%) are shown in red.
People with Other Intellectual Disabilities (15%, 23%, 70%) are shown in blue.

Lai, F. Williams, R. 1989 Archives of Neurology; Cooper, SA. 1997 JIDR
Advanced Dementia
• Profound memory deficits (e.g., inability to recognize family)
• More extremely limited verbal communication
• Greater loss of ambulatory abilities
• Increased inability to perform activities of daily living
• Noticeable loss of muscular control
• Late onset seizures particularly in Down syndrome
• Urinary and fecal incontinence

Frequent and severe seizures more prevalent in advanced dementia among people with an intellectual disability
Recommendation for Defining Advanced Dementia

**FAST Stage 7 - Severe Alzheimer’s disease**

Speech ability declines to about a half-dozen intelligible words. Progressive loss of abilities to walk, sit up, smile, and hold head up. (Reisberg, et al., 1988)

- **7A** - In a course of an average day or an intensive interview, no consistently meaningful verbal communication, only stereotypical phrases, or ability is speak is limited to 6 or fewer intelligible words.

- **7B** - In a course of an average day or an intensive interview, ability to speak is limited to the use of a single intelligible word which the patient may repeat over and over.

- **7C** - Ability to ambulate without personal assistance is lost.

- **7D** - Cannot sit up without assistance (patient will fall over if there are no lateral arm rests on the chair).

- **7E** - Loss of ability to smile.

- **7F** - Loss of ability to hold head up independently.
Recommendation for Defining Advanced Dementia (continued)

Meeting FAST criteria AND

- Multiple hospitalizations

- Recurrent infections (e.g., urinary tract infections)

- Aspiration pneumonia (resulting from choking on food or fluids)
What’s Still Needed

Collaboration to create universal practice guidelines on end–stage care and support practices for persons with intellectual disability and advanced dementia.

Understanding that caring roles may be lifelong.

‘Home’ may be with family members or friends with own health or social care needs, or an out-of-home setting.

More valid/reliable instruments to assess advanced dementia-related cognitive and physical deterioration in adults with intellectual disability/Down syndrome.

Practice guidelines, training and education to support quality care when adults with an intellectual disability have advanced dementia.
Integrating Intellectual Disability and Specialist Palliative Care Services Philosophies and Expertise

- Knowledge and skills for intellectual disability services workers in recognizing and managing symptoms of pain, constipation, fevers, and nutrition and hydration concerns.

- Staff in specialist palliative care need training in and sensitivity to
  - communication challenges
  - facilitating grief and loss discussion
  - addressing disenfranchised grief among staff and peers as well as family members

- Inclusion of values, needs, and preferences already expressed in existing person-centered plans for the person with an intellectual disability.
Involvement in Palliative and End of Life Care Decision-making

- Draw upon statements of values in person-centered plans, where available

- Encourage practitioners and family to ascertain and honor the person’s desires
Key Aspects of Advance Planning

- Advance planning should be encouraged
  - Guided by legal and/or accepted practice frameworks
  - Protocols in place to ensure that people with an intellectual disability have the same opportunities to express their desires in a formal manner.
  - Educational materials and interventions to support both the individual with intellectual disability and their carers, family, peers, and staff.
Summit Publications: Information at http://www.aadmd.org/ntg

- International Summit Consensus Statement: Intellectual Disability Inclusion in National Dementia Plans
- Consensus Statement of the International Summit on Intellectual Disability and Dementia Related to End-of-life Care in Advanced Dementia
- Consensus Statement of the International Summit on Intellectual Disability and Dementia Related to Nomenclature
- Consensus Statement of the International Summit on Intellectual Disability and Dementia Related to Post-Diagnostic Support
- Consensus Statement of the International Summit on Intellectual Disability and Dementia on Valuing the Perspectives of Persons with Intellectual Disability
- Consensus Statement of the International Summit on Intellectual Disability and Dementia on Defining Quality Care for People with Intellectual Disability and Advanced Dementia
- Perspectives on Family Caregiving of Ageing People with Intellectual Disability Affected by Dementia: Commentary from the International Summit on Intellectual Disability and Dementia
Additional Resources

*Thinking Ahead: My Way, My Choice, My Life at the End*
- Workbook and video created by California advocates with developmental disabilities [http://www.dds.ca.gov/ConsumerCorner/ThinkingAhead.cfm](http://www.dds.ca.gov/ConsumerCorner/ThinkingAhead.cfm)

- A two-volume guide for supporting older people with intellectual disabilities and their families. To order, 518-439-8311; info@nysarc.org

*NYSARC, Inc. Advocacy Monograph Number 4*
- A collaboration of NYSARC, Inc.; Hospice and Palliative Care of New York State; and OPWDD. Cross-systems training for staff in developmental disabilities agencies and staff in hospice and palliative care agencies to understand each other's systems. To order 518-439-8311; info@nysarc.org
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