

HEALTH AND WELLNESS CONSIDERATIONS FOR OLDER ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: A PRIMER

University of Rochester
Geriatric Medicine Grand Rounds
February 2nd, 2022



GOLISANO INSTITUTE
for Developmental Disability Nursing

Presentation outline

1. Health status of older adults with IDD
2. Introduce HealthMatters Program
3. Introduce Healthy Brain Initiative
4. Strategies for accessing developmentally sensitive health care
5. Discuss local resources to support the education of interprofessional healthcare colleagues in the care of individuals with IDD

Health and Wellness Considerations for Older Adults with Intellectual and Developmental Disabilities: A Primer

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Department of Disability and
Human Development

HealthMatters™ Program

The Aging Population

Definitions, demographic

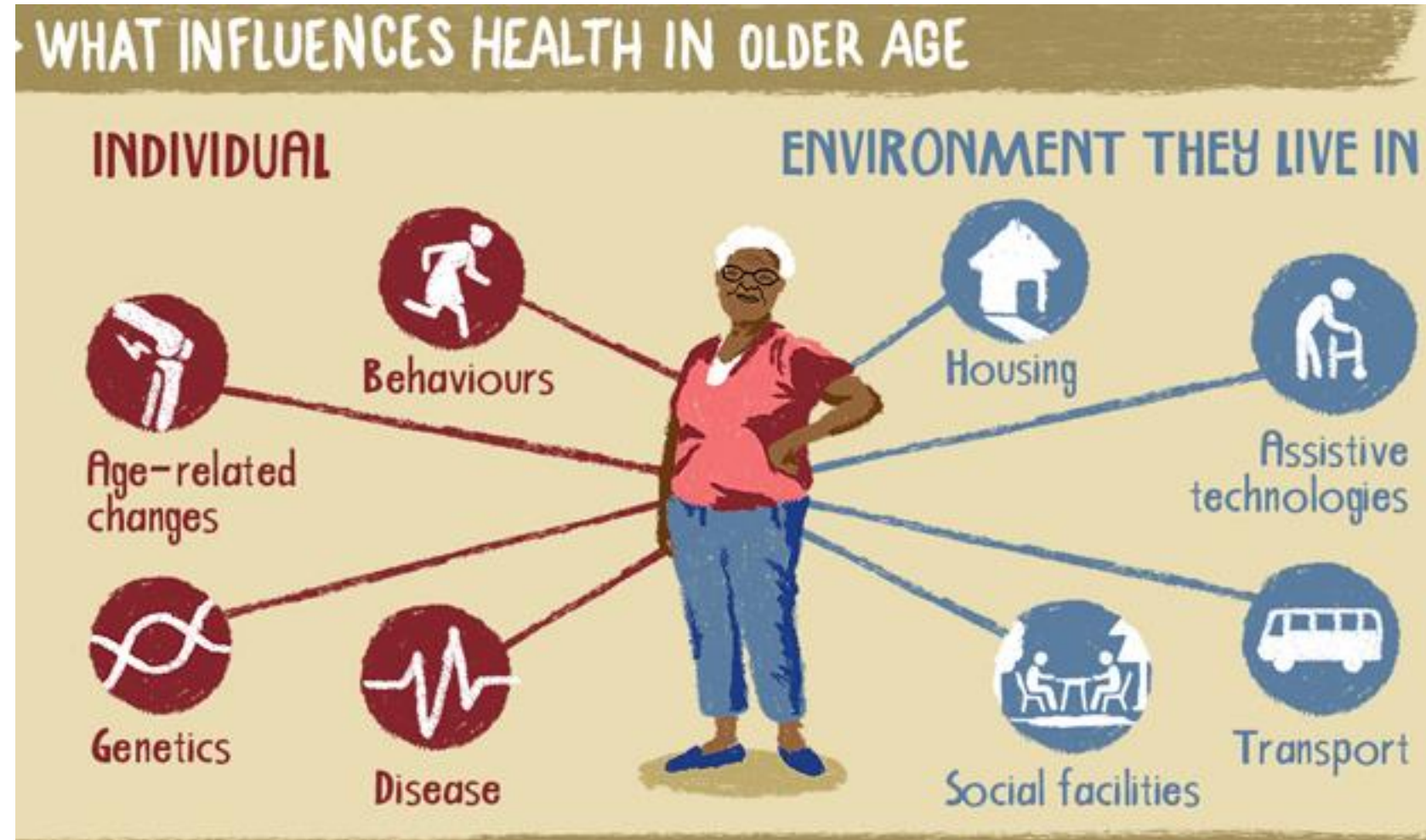
Demographic change

- Adults age 60+ with IDD
 - 850,600 (2010 US census)
 - Increase to 1.4 million by 2030 (Factor et al., 2012)



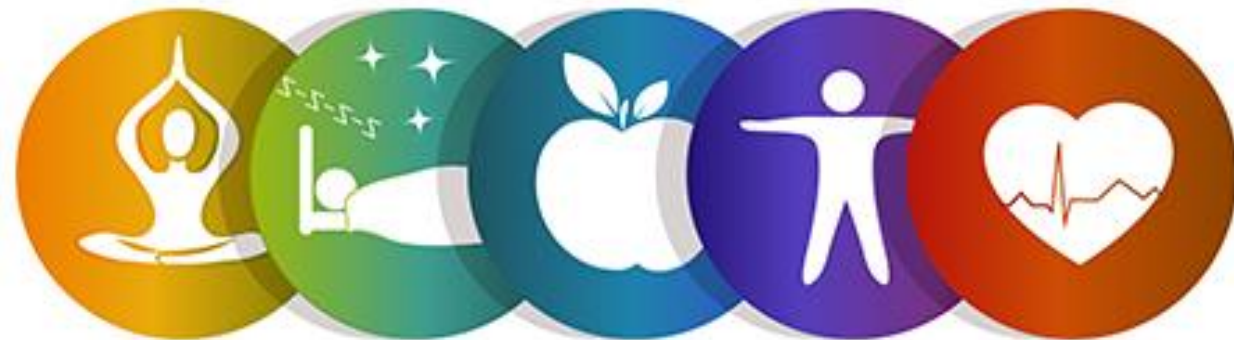
Aging and health

- Dementia
- Mental health concerns
- Cataracts
- Hearing disorders
- Diabetes
- Hypertension
- Osteoarthritis



Health of People with IDD

- More complex underlying health conditions
 - Mental health concerns
 - Lower cancer screenings and preventive services
 - Limited access to health care services
- Poorly managed multiple chronic conditions (MCCs)
 - high cholesterol
 - Hypertension
 - Cardiovascular disease
 - Obesity
- Poor health outcomes



Physical Activity and People with IDD

- Not as active as the general population.
- Adults with IDD continue to lead a sedentary lifestyle with higher rates of overweight and obesity.
- 67% of the time (495 min) being sedentary.
- 2016 study found 9% of 3159 adults with ID met the minimum Physical Activity Guidelines.
- Adults in a 2018 Hong Kong study averaged 2% of their daily time (or 10 min) engaged in moderate-to-vigorous PA (MVPA).

Dairo, Y.M., Collett, J., Dawes, H, & Oskrochib, G.R. (2016); Chow, Choi, Huang (2018)

Nutrition

93% adults with IDD in the community have a high fat diet.¹

63-69% do not consume enough fruits and vegetables.²

People consumed about 2 servings of F&V.²

People with higher F&V intake had lower BMI.²

People living on their own, group home, or with family ate less F&V than people larger residences.²

Healthy Eating Index (HEI-2005) score of 45.6 (poor diet quality)³



¹ Draheim, et al. (2002); ² Sisirak et al. (2008); ³ Ptomey et al. (2013)

Successful aging for people with IDD

Recommendations, resources



Key indicators

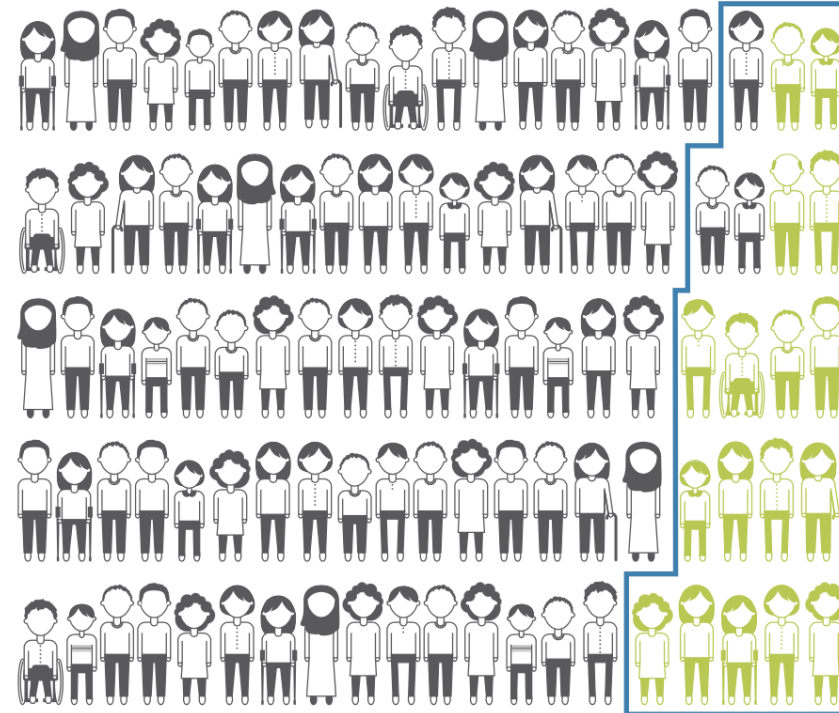
- good physical and mental health,
- healthy lifestyles and behaviors
- social interaction and productivity,
- life satisfaction,
- access to quality healthcare.

Health promotion and primary care

- Basic building blocks of public health.
- Individual level (screening for risk factors and disease, early treatment, advice, counseling, and referral).
- Organizational, community, and government levels.



7.38 million people in the United States had Intellectual or Developmental Disabilities (IDD) in 2017



20% 1.48 million people with IDD were known to or served by state IDD agencies

17% 1.28 million people with IDD received long-term supports or services through state IDD agencies

- Residential Information Systems Project (2020). How many people with intellectual or developmental disabilities live in the United States? Minneapolis: University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from: <https://risp.umn.edu>



HealthMatters™ Program

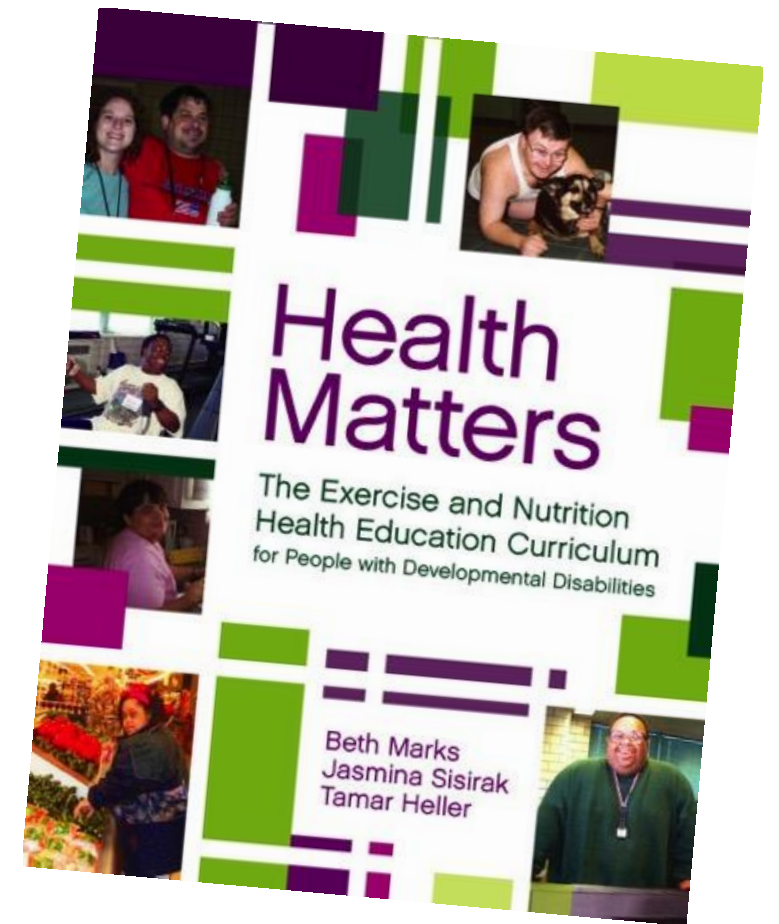
Components, studies, reach

Components

1. HealthMatters™ Program: Certified Instructor Workshop Webinar (6 hours, 90 minutes over 3 days, 90 minutes offline work)
2. Health Matters: The Exercise and Nutrition Health Education Curriculum for People with Developmental Disabilities (Curriculum)
3. 12-Week HealthMatters™ Program (12-Week-HMP) – three 1.5-2h sessions per week for 12 weeks, total 36 lessons
4. Virtual Coach: HealthMatters Program Classroom

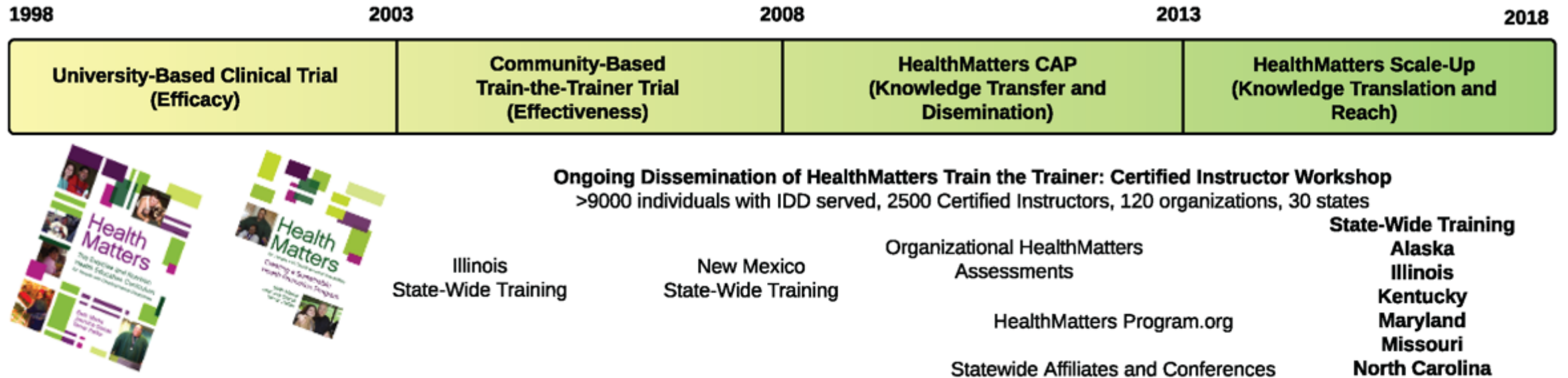
Health Matters: Exercise and Nutrition Health Education Curriculum

- Evidenced-Based Curriculum for people with IDD
- 36 interactive lessons with 23 additional lifelong learning lessons
 1. Understand attitudes toward health, exercise & nutrition.
 2. Identify current behaviors.
 3. Develop clear exercise and nutrition goals and stick to them.
 4. Gain skills and knowledge about exercising & eating nutritious foods.
 5. Support each other during class



Over 2 decades of research to practice...

HealthMatters™ Program



HealthMatters Program Reach 2008-2020

10,000

PEOPLE WITH IDD

2,650

CERTIFIED
INSTRUCTORS

210

COMMUNITY BASED
ORGANIZATIONS

35

STATES

8

COUNTRIES

HealthMatters™ Program and all its components is an evidence-based Administration on Community Living (ACL) approved health promotion program designed specifically for and by the people with intellectual and developmental disabilities.

(2019) Approved to meet the Administration for Community Living's (ACL) criteria for evidence-based programs under Title III-D Highest Tier Evidence-Based Health Promotion/Disease Prevention Programs (<https://www.ncoa.org/article/evidence-based-program-healthmatters-program>)

AK, IA, AZ, CA, CO, CT, DE, FL, IL, KY, LA, ME, MD, MA, MI, MS, MO, NE, NJ, NM, NY, NC, SC, OH, OK, OR, PA, TN, TX, UT, VA, WA, WI, Washington DC

Sweden
Australia, Belgium Canada
UK
Kenya
Malawi Netherlands

Virtual Coach: HealthMatters Program reach since November 2020

75

participating
community-based organizations



27

States in the USA, including two
countries, the Netherlands and Portugal



204

trained staff members



1700

participants with intellectual
and developmental disabilities
reached





**HEALTHYBRAIN
INITIATIVE**

HealthMatters™ Program

HEALTHY BRAIN INITIATIVE

People with Intellectual and Developmental Disabilities

Partner focus,



Dementia is NOT a natural course for people with IDD

- ~ 11,000 (6%) of the 180,000 older people with IDD will experience a form of Alzheimer's disease and related dementias (ARD) after age 60 (increases with age).
- 6 Pillars of Brain Health
 - Physical Exercise
 - Food & Nutrition
 - Medical Health
 - Sleep & Relaxation
 - Mental Fitness
 - Social Interaction



Goal

Support *“populations with a high burden of Alzheimer’s disease and other dementias”*

- **Education and training program and resources** for healthcare and public health professionals and caregivers to provide person-centered care for PwIDD and their supports
- **Workforce development** to expand and scale-up Healthy Brain Initiative Road Map Series (2018-2023) for people with IDD and their supports
- **Policies and partnerships to implement public health strategies to promote brain health**

National Healthy Brain Initiative Collaborative

Partnership

- **HealthMatters Program, University of Illinois at Chicago**
(Beth Marks, PhD, RN, FAAN and Jasmina Sisirak, PhD, MPH)
- **National Task Group on Intellectual Disabilities and Dementia Practices (NTG)**
(Matthew Janicki, PhD and Kathryn Service, RN)
- **ENGAGE-IL HRSA Geriatrics Workforce Enhancement Program (GWEP)** (Valerie Gruss, PhD, APN, CNP-BC, FAAN)

Healthy Brain Initiative Activities



Brain Health
You Can Make a Difference!

- Interactive **HealthMatters website** + Healthy Brain **Messaging** and **Webinar Series** + Virtual Coach **HealthMatters Program**
- ENGAGE-IL **CEU Modules** + *Dementia Guide Expert* App
- NTG **Dementia Capable Care** of Adults with IDD + **Healthy Brain Curriculum**
 1. Dementia **Information Package** for people with IDD
 2. Nutritional and **Dietary Guidelines**
 3. Memory Care **Home Solutions**
 4. Project SEARCH's **Employment Transition with Health**
 5. Brain **Health Screenings**
 6. Education and **Advocacy Package**

Educate Interprofessional Healthcare Workforce with Online Technology and Student Fellowships

Online Accredited Learning in Interprofessional Geriatrics (OALIG)TM



- Library of 27 Online geriatric training modules
- Our website (engageil.com) serves as a portal to our online program
- Modules offer Free continuing education credits to licensed professionals

IMPACT

- Total number of modules completed: **21,258**
- Total number of learner profiles: **5,956**

Create Age-Friendly Communities Transforming the Alzheimer experience with a **Mobile App**

Dementia Guide Expert™



Guia Experta Sobre La Demencia

치매 안내 전문가

FREE App Download!!

Available for iOS on Apple iTunes and for
Android on Google Play

IMPACT:

App downloads/views: > 66,211

12 Countries: Australia, Brazil, Canada, China, Germany, Japan, Korea,
New Zealand, Spain, Taiwan, U.K., U.S.





National Task Group
on Intellectual Disabilities
and Dementia Practices

www.the-ntg.org

The National Task Group is a national non-profit organization with a charter to 'advocate, provide technical and clinical assistance, disseminate information, aid with research, and create and provide educational and technical matter related to dementia among adults with intellectual disability'

Key Activities...

- 'Thinker' report
 - national plan for dementia and ID
- Early detection-screening instrument
 - NTG-EDSD
 - SAFD
- Practice guidelines
 - Community supports
 - Health advocacy
 - Assessment
- Training and education activities
 - National education curriculum on dementia and ID
 - Training workshops and webinars
- Family supports
 - Informational matter
 - Support group
- Participation
 - Federal NAPA Council
 - DS-Consortium (NICHD)

HealthMatters™ Program

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www.HealthMattersProgram.org

Join our email list: <https://machform.healthmattersprogram.org/view.php?id=7>



**APPLIED HEALTH
SCIENCES**

Department of Disability and
Human Development

CLINICAL PEARLS WORKING WITH

**INDIVIDUALS WITH IDD AND
AGING**

SHIRLEY MCMILLAN CLINICAL NURSE SPECIALIST IN THE ADULT PROGRAM

Surrey Place Toronto Canada

www.surreyplace.ca

Snap shot of Surrey Place

- Interdisciplinary agency that serves individuals with intellectual disabilities and/or Autism through lifespan
- Consultative family physicians, developmental pediatricians and psychiatrists
- Audiologists; Behaviour Analysts; Speech Language; Psychology; Nursing; Service Coordinators and Intake Coordinators

GLOBAL ACTION

- 20 to 30 years ago individuals with IDD returned to the community
- Our knowledge has increased in this time with research and education
- Many of these individuals now are elderly
- Now more are “aging in space” as opposed to be sent to long term care facilities
- Elderly group homes are being created
- Challenge has been to find a balance of quality of life



Difference in how aging looks from general population

- May demonstrate first signs of aging much earlier
- Normal signs of aging include declining; slowing down; forgetting little things; searching for words; losing things or confusion
- Signs are no different with individual with IDD than the general population



Primary Care of Adults with Intellectual and Developmental Disabilities

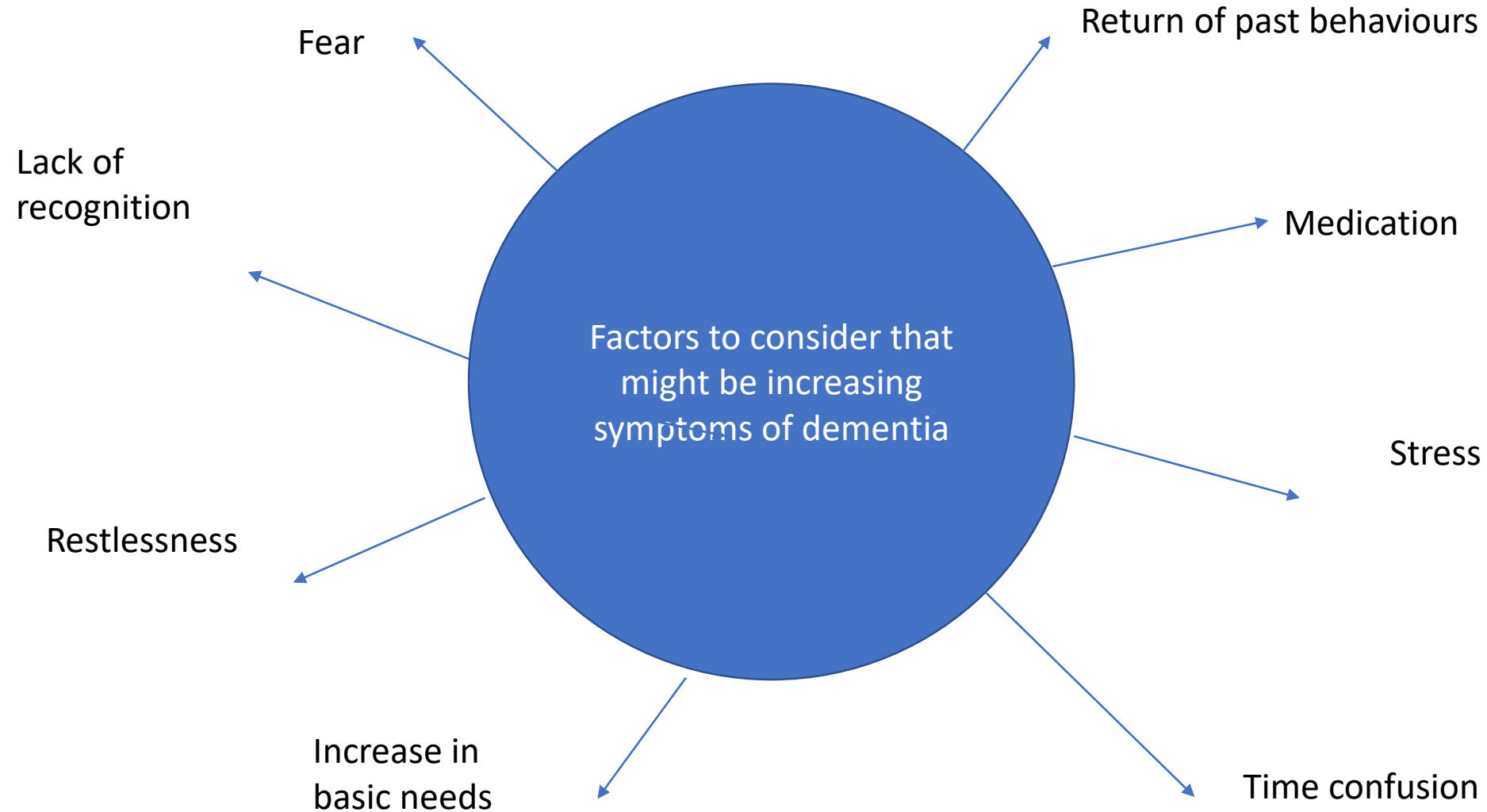


This is one of the two special issues on primary care of adults with intellectual and developmental disabilities

What can mimic symptoms of dementia

- Abnormal thyroid function
 - Infections
 - Pernicious anemia
 - Adverse drug reactions
 - Acute physical illness
 - Diabetes
 - Cardiac abnormalities
 - Sleep apnea
- Depression
Constipation
Hearing/vision loss
Multiple strokes
Recent bereavement

Factors to Consider That Might be Increasing Symptoms



Risk Factors

- Down Syndrome

- Ages

- 40 to 49 11%
 - 50 to 59 70%
 - 60 to 69 90%
 - Over 70 100%

Family History

Age

Some Typical Challenging Behaviours

View behaviours as a form of communication and not always a problem- a problem for whom the person or the carer

- Sundowning and shadowing
 - Agitation
 - Anger
 - Catastrophic reaction
 - Confusion
 - Paranoia
 - Depression
 - Eating
- Forgetfulness
 - Hoarding
 - Hygiene/Bathing
 - Incontinence
 - Dehydration
 - Repetitive questioning
 - Wandering

HELP with Emotional and Behavioural Concerns in Adults with Intellectual and Developmental Disabilities

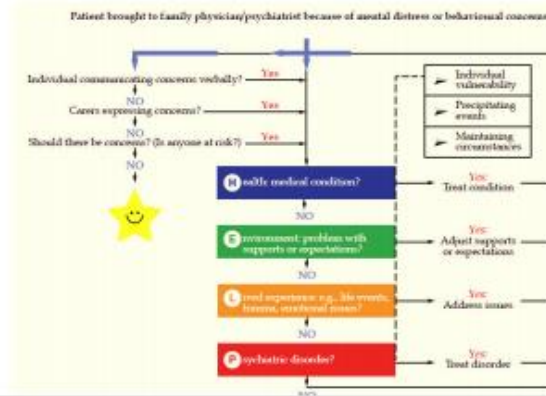
Introduction

This tool helps primary care providers and others supporting adults with intellectual and developmental disabilities (IDD) to conceptualize aetiological contributors when these adults present with emotional distress and behavioural concerns. Clinical presentation of mental distress in patients with IDD, while often seeming to be 'psychiatric', might turn out to be associated with undiagnosed medical conditions, unrecognized support issues, or related to past adversity and trauma.¹ This tool provides a systematic and sequential exploration of four areas (see Figure 1) relating to biopsychosocial circumstances that might underlie or be contributing to emotional distress and behaviours of concern, including behaviours that challenge*: Health, Environment, Lived Experiences, and Psychiatric Disorders (HELP). Apply this tool with careful scrutiny, repeated as necessary over time.

*Behaviours that challenge are behaviours that put the patient or others at risk of harm.^{2,3}

How to use this tool

When a patient with IDD presents with mental distress or behavioural concerns, follow the HELP diagnostic framework as in figure 1.





1



2



Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities:

Promoting Capabilities

Introduction

This tool is for healthcare providers who assess legal capacity of adults with intellectual and developmental disabilities (IDD). In light of the United Nations' *Convention on the Rights of Persons with Disabilities*¹⁴, it offers a person-centred approach that considers the rights of persons to be accommodated to demonstrate their capacity to make a certain healthcare decision. Such accommodations can include the help of decision-making supporters who know the patient well. Laws recognize decision-making supporters in British Columbia, Alberta, Manitoba, and The Yukon. In Ontario, and elsewhere in Canada where the law does not yet recognize decision-making supporters, these individuals can and should be included as much as possible within existing legal structures to help the patient, as much as needed, to respond to the healthcare provider who is performing the assessment.

How To Use This Tool

SECTIONS 1 AND 2: Complete information about your patient before the visit.¹⁴

SECTION 3: Plan how to accommodate your patient, guided by the patient and patient's caregivers if you are unfamiliar with the patient or uncertain how to accommodate.^{14,15} Consistent with Ontario's human rights laws, healthcare providers should consider what accommodations people with disabilities need, and should comply with their duty to accommodate them to the point of undue hardship.¹⁴

SECTIONS 4 AND 5: Determine the patient's capacity, including the patient's need for someone to help them respond to assessment questions (Table 1). Laws vary across Canada regarding the legal role of decision-making supporters (see Table 2 and Supporting Materials).¹⁴

Decision making and advanced planning

- Can be a difficult subject but must talk about – so necessary and may take several appt like a CPx to complete
- Is there a substitute decision maker? Needs to be part of the conversation.
- What is the level of cognition to determine ability to make decisions
- Should be included in the end-of-life discussion

Other

- Tend to arrange a baseline psychological assessment especially for individuals with Down Syndrome around the age of 25 to 30 years
- To have to compare when there is reports of decline
- National Taskforce Group on IDD and Dementia Practices (NTG)

Resources

- <https://ddprimarycare.surreyplace>
- NTG- <https://ntg.wildapricot.org>
- Canadian Family Physician (2019) Vol 65
- Guidelines for community practitioners –Massachusetts Department of Developmental Services
- https://shriver.umassmed.edu/cdder/aging_idd
- Journal of Applied Research in Intellectual Disabilities- How to best support individuals with IDD as they become frail. Ouellette-Kuntz et al (2018).

LOCAL RESOURCES

Office of People with Developmental Disabilities Article 16 Clinic:

Community Based Organizations:

- Arc of Monroe: Day Habilitation Services at Ballantyne
 - Specific for older adults with IDD, including those with dementia and Alzheimer's
- Lifespan
- Alzheimer's Association

GOLISANO INSTITUTE FOR DEVELOPMENTAL DISABILITY NURSING

Mission

To generate an international cadre of health care professionals prepared with the knowledge, skills and competencies to effectively support individuals diagnosed with IDD throughout the life span and across settings

GOLISANO INSTITUTE FOR DEVELOPMENTAL DISABILITY NURSING

Vision

Improving the health care experience and outcomes for individuals diagnosed with IDD through the provision of reliable, high quality nursing care that promotes an individual's well being, respects their agency, uniqueness and possibility through: (higher) education, partnerships, leadership, advocacy and health policy

FINAL THOUGHTS

- Older adults with IDD have more in common with their typically aging counterparts as it relates to health and wellness
 - Regular screening
 - Understand baseline functioning as a point of comparison in early adulthood and monitor for changes in status
 - Promote wellness
- Resources
 - Impact of COVID– establishing and/or updating a resource list for older adults

THANK YOU FOR THE PRIVILEGE OF YOUR TIME

Questions?

Contact: hbrown@sjfc.edu



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