

Aging of Individuals with Intellectual and Developmental Disabilities (IDD)

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SCIENCES**



Agenda

- Introduction to Aging with IDD
- Aging Challenges and Supports
- Questions

Common Thread

- Focus on creating positive and meaningful aging experience
- Application of life course perspective to aging/IDD
- Interventions informed by experiences of aging adults with IDD

Introduction to Aging with I/DD

Understanding aging

Biological, psychological, social, political,
legal

Multiple indicators of age (Dannefer & Settersten Jr., 2010)

Lifelong (Elder Jr. et al., 2004)

Cumulative (dis)advantage (Dannefer, 2003)

Aging with disability

More people 'aging with disability' than ever before (Sheets, 2011)

Lifelong (early onset) v. late onset disability (Putnam, 2007)

12 million Americans with lifelong disabilities are aging (Sheets, 2011)

Aging with lifelong disability recent phenomenon (Mosqueda, 2004)

Little is known about disabled people's lives over time (Heller & van Heumen, 2013)

Population of older adults with I/DD

Largest group of people aging with lifelong disability (Bigby, 2004)

Increasing life expectancy

- 641,000 people with developmental disability over age 60 in US.
- Numbers to double and potentially triple by 2030 (Heller, 2013)

Population of older adults with I/DD (II)

Life expectancy similar unless

- severe intellectual disability
- Down syndrome
- cerebral palsy
- multiple disabilities (Haveman et al., 2009)

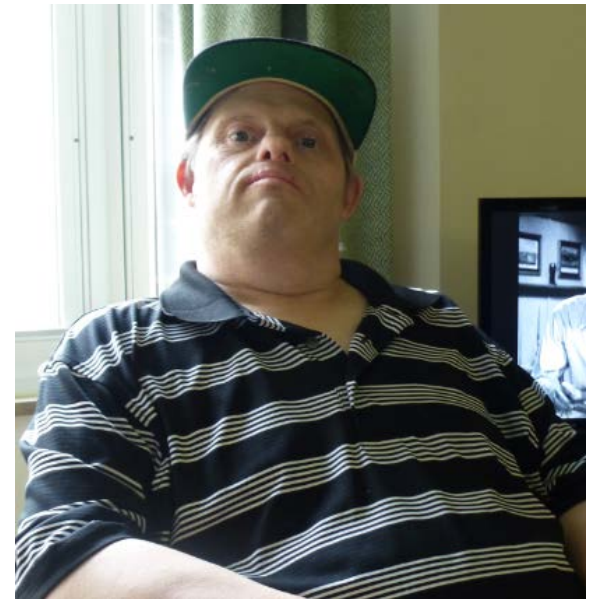
Aging in people with Down Syndrome

Alzheimer's disease 15-20 years earlier

Earlier menopause (age 47 versus 52)

Earlier sensory, adaptive behaviors & cognitive losses

At greater risk for joint problems, seizures, tumors and heart disease (Haveman et al., 2009)



Transitions

Addressing chronic health conditions



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graph TD; A[Addressing chronic health conditions] --> B[Addressing long term services and supports]; B --> C[Retiring from employment]; C --> D[Addressing end-of-life care];
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Addressing long term services and supports

Retiring from employment

Addressing end-of-life care

Aging well for adults with I/DD

Living on your own terms

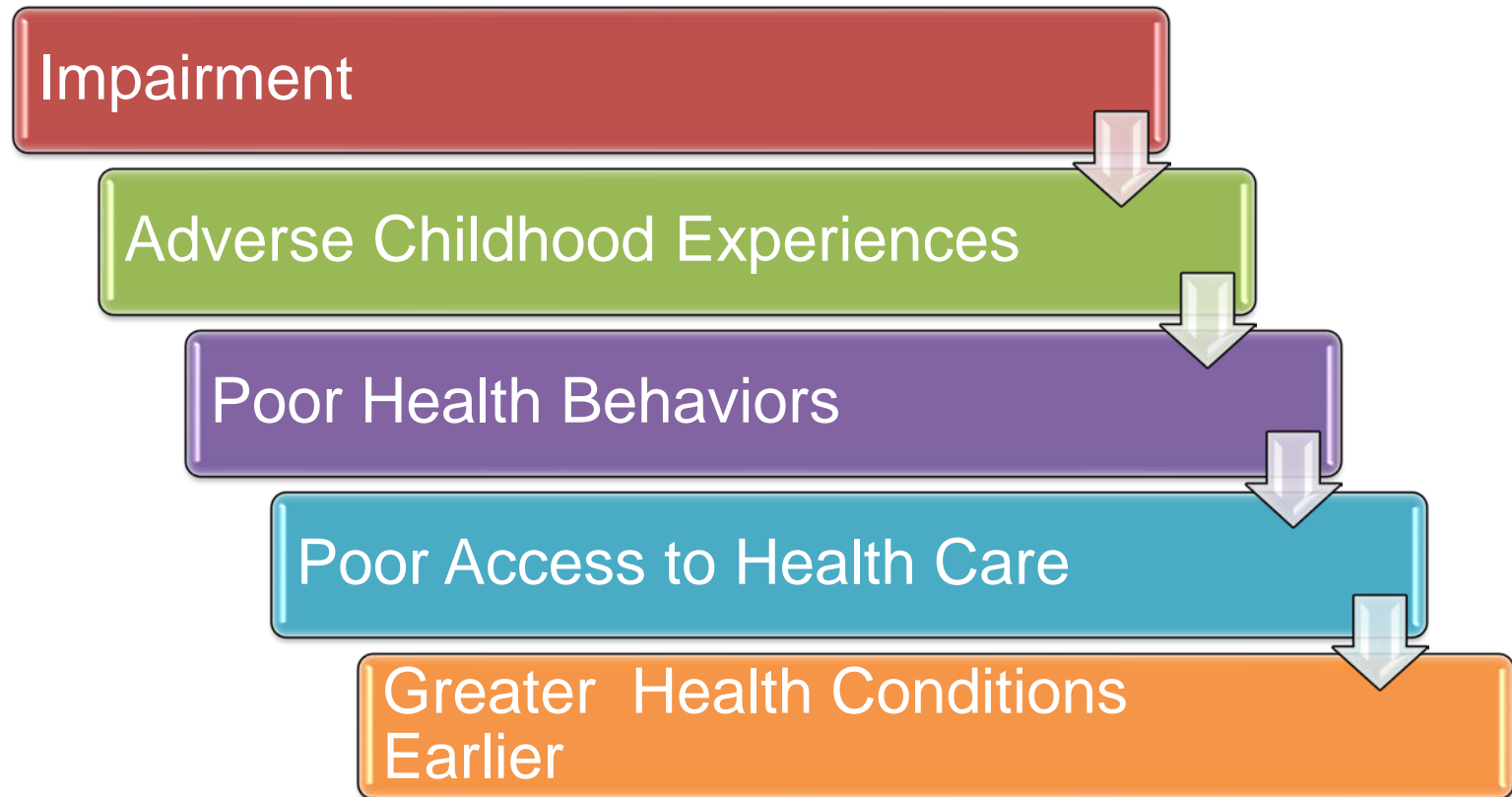
Adding value to society, family or friends

Maintaining health and cognitive function, maximizing mobility, retaining function, and reducing the impact of chronic disease/dysfunction (Heller, 2004)

Challenges and supports

Health

Cascade of health disparities



(Krahn, Hammond & Turner, 2006)

Health of older adults with I/DD (I)

Worse health and more unmet health care needs

More secondary conditions

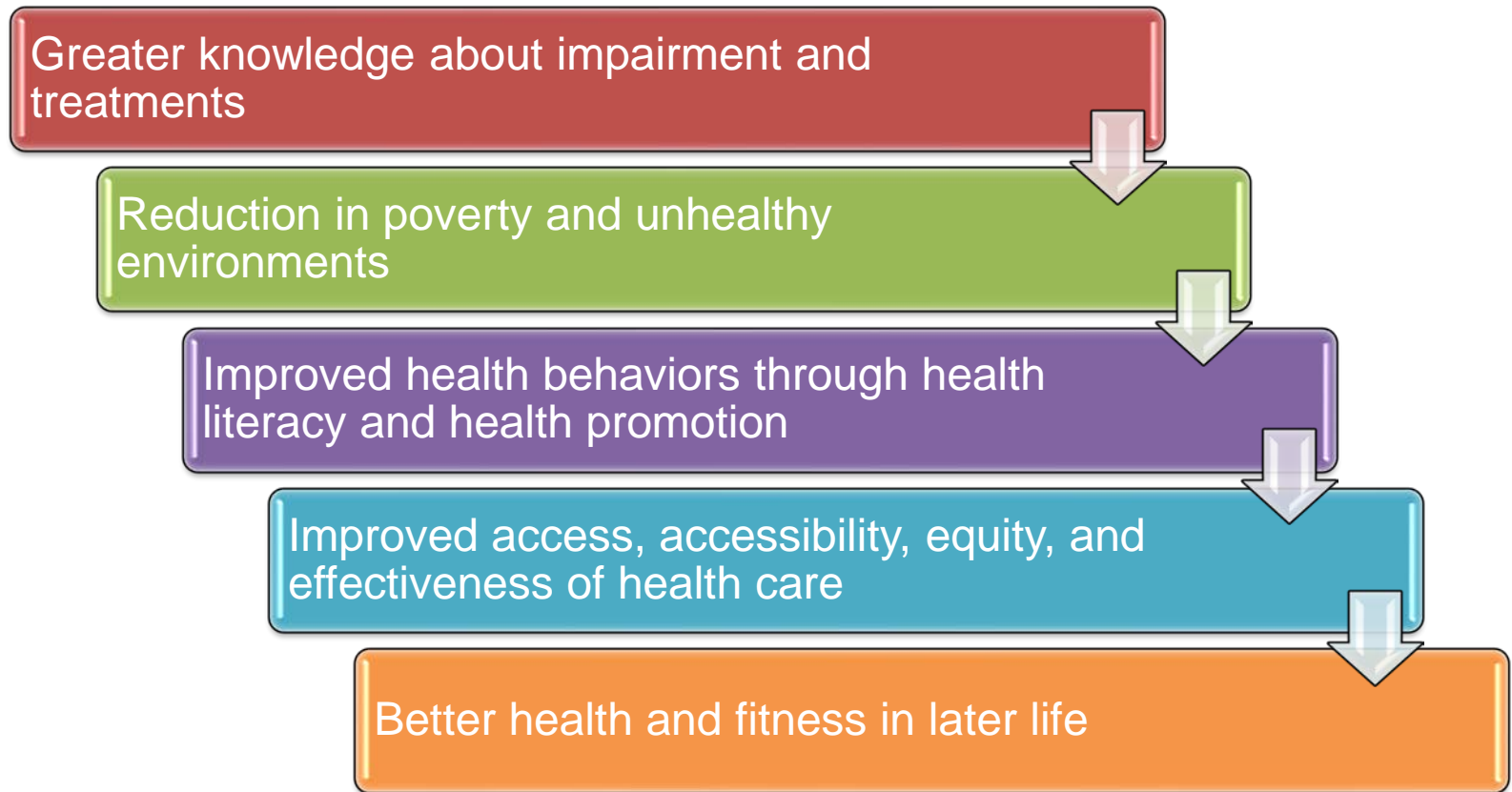
- Obesity
- Constipation
- Poor dental hygiene
- Skin problems
- Osteoporosis and fractures
- Diabetes
- Incontinence
- High blood pressure
- Dementia
- Depression and other psychiatric issues

Health of older adults with I/DD (II)

- Higher rate of falls
 - higher risk if female, have arthritis, seizures, polypharmacy, use walking aids, difficulty lifting/carrying ≥ 10 lbs
- Cardiovascular disease one of the most common causes of death
- Poorer health behaviors
 - Sedentary behavior
 - Fewer fruits and vegetables

(Hahn et al., 2016; Haveman et al., 2009; Hsieh, Rimmer & Heller, 2012)

Strategies to reduce disparities



(Krahn, Hammond & Turner, 2006)

Promoting health

Develop health care advocacy skills

Incorporate exercise into the daily routine

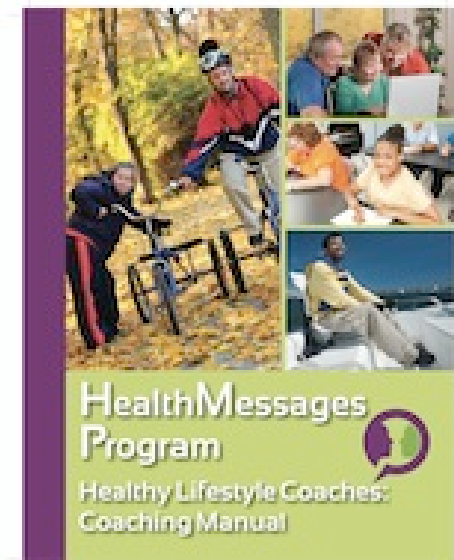
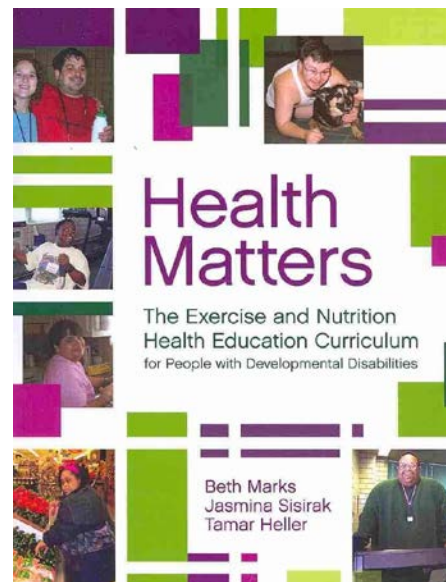
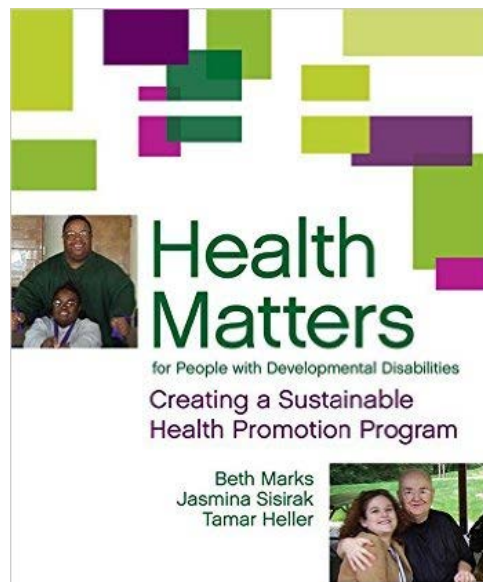
Encourage proper nutrition

Reinforce participation

Educate individuals, staff, & families

Health Matters

Creating a health promotion program
Health education program
Peer to peer program



My Health Passport: A Journey to Better Healthcare



! If you are a *health care professional* who will be helping me, **PLEASE READ THIS** **!**
before you try to help me with my care or treatment.

<p>My full name is: _____</p> <p>I like to be called: _____</p> <p>Date of birth: ____ / ____ / ____</p> <p>My primary care physician: _____</p> <p>Physician's phone number: _____</p>	<p>Attach your picture here!</p>
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This passport has important information so you can better support me when I visit/stay in your hospital or clinic.

Please keep this with my other notes, and where it may be easily referenced.

My signature: _____ Date completed: ____ / ____ / ____

You can talk to this person about my health: _____

Phone number: _____ Relationship: _____

<p>I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/support is needed)</p> <p>_____</p> <p>_____</p>

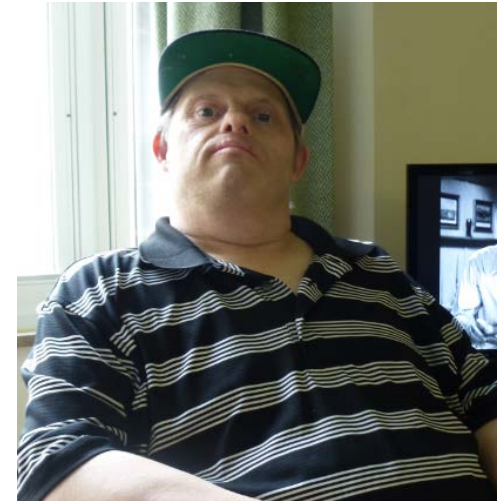
Dementia

Prevalence dementia in adults with I/DD

Higher prevalence in Down Syndrome

- 22 % of people 40 years and older
- 56 % of people 60 years and older

Prevalence in people with other types of ID over age 60 similar to general population (Strydom et al., 2009, NTG, 2012)



Presentation dementia in adults with I/DD

Earlier onset

- Mean age in Down Syndrome: 52.8 years
- Mean age other ID types: 67.2 years

Early symptoms not as noticeable

Faster disease progression in Down Syndrome

- 2-7 years
- < 2 years in aggressive Alzheimer's disease

(Strydom et al., 2009; NTG, 2012)

Signs of dementia in adults with I/DD

- Forgetfulness
- Loss of skills
- Personality changes
- Sleep disturbances
- Wandering
- Aggressiveness
- Verbal outbursts
- Argumentative
- Incontinence
- Hoarding
- Late-onset seizures (Jamieson-Craig et al., 2010; Menendez, 2005)

Challenges with identifying dementia

- Individuals with I/DD might be unable to report symptoms
- Norms and tools general population not useful
- No average premorbid level of functioning
- Diagnostic overshadowing and underrepresentation (Strydom et al., 2009)

Current state of affairs

Limited recognition of dementia in I/DD

Limited experience with specific
presentation

Limited screening and assessment



No diagnosis, misdiagnosis, misdirected
course of treatment (NTG, 2012)

Diagnostic process

Conduct early and regular screening

- Establish baseline of optimal functioning
- Create comparative data to determine decline

(NTG, 2012)

If screening positive, refer for clinical assessment

If assessment positive, refer for full diagnostic evaluation

National Task Group

Early Detection Screen for Dementia

<http://aadmd.org/ntg>



NTG-EDSD

v.1/2013.2

The NTG-Early Detection Screen for Dementia, adapted from the DSQID[®], can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.6 of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/screening).

⁽¹⁾ File #: _____ ⁽²⁾ Date: _____

Name of person: ⁽³⁾ First _____ ⁽⁴⁾ Last: _____

⁽⁵⁾ Date of birth: _____ ⁽⁶⁾ Age: _____

⁽⁷⁾ Sex:

Female
Male

Instructions:
For each question block, check the item that **best applies** to the individual or situation.

⁽⁸⁾ Best description of level of intellectual disability

No discernible intellectual disability
Borderline (IQ 70-75)
Mild ID (IQ 55-69)
Moderate ID (IQ 40-54)
Severe ID (IQ 25-39)
Profound ID (IQ 24 and below)
Unknown

⁽⁹⁾ Diagnosed condition (check all that apply)

Autism
Cerebral palsy
Down syndrome
Fragile X syndrome
Intellectual disability
Prader-Willi syndrome
Other:

Current living arrangement of person:

- Lives alone
- Lives with spouse or friends
- Lives with parents or other family members
- Lives with paid caregiver
- Lives in community group home, apartment, supervised housing, etc.
- Lives in senior housing
- Lives in congregate residential setting
- Lives in long term care facility
- Lives in other: _____

Practice guidelines NTG

Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia

Practice Guidelines for the Evaluation and Management of Dementia in Adults with Intellectual Disabilities

Guidelines for Dementia-Related Health Advocacy for Adults With Intellectual Disability and Dementia

Resources National Down Syndrome Society

- Aging and Down Syndrome. A Health and Well-Being Guidebook

<http://www.ndss.org/wp-content/uploads/2017/11/Aging-and-Down-Syndrome.pdf>

- Alzheimer's Disease and Down Syndrome: A Practical Guidebook for Caregivers

https://www.ndss.org/wp-content/uploads/2018/12/NDSS_Guidebook_FINAL.pdf

Environmental modifications

Simplification of the environment

Way finding and orientation

Furniture

Noise

Illumination

Color

Flooring

Bathroom management

Kitchen safety

Supports for wandering

Assistive Technology

Social Relations

Social relations

Supportive networks evolve across the life course

Social networks are important for older people

(Cavanaugh, 1999)

Supports and opportunities are needed to develop and maintain a supportive social network to age with

Inclusion requires connection to others (Bigby, 2005)

A greater focus is needed in practice

Promoting social networks

Persons with ID need ongoing support to develop social networks

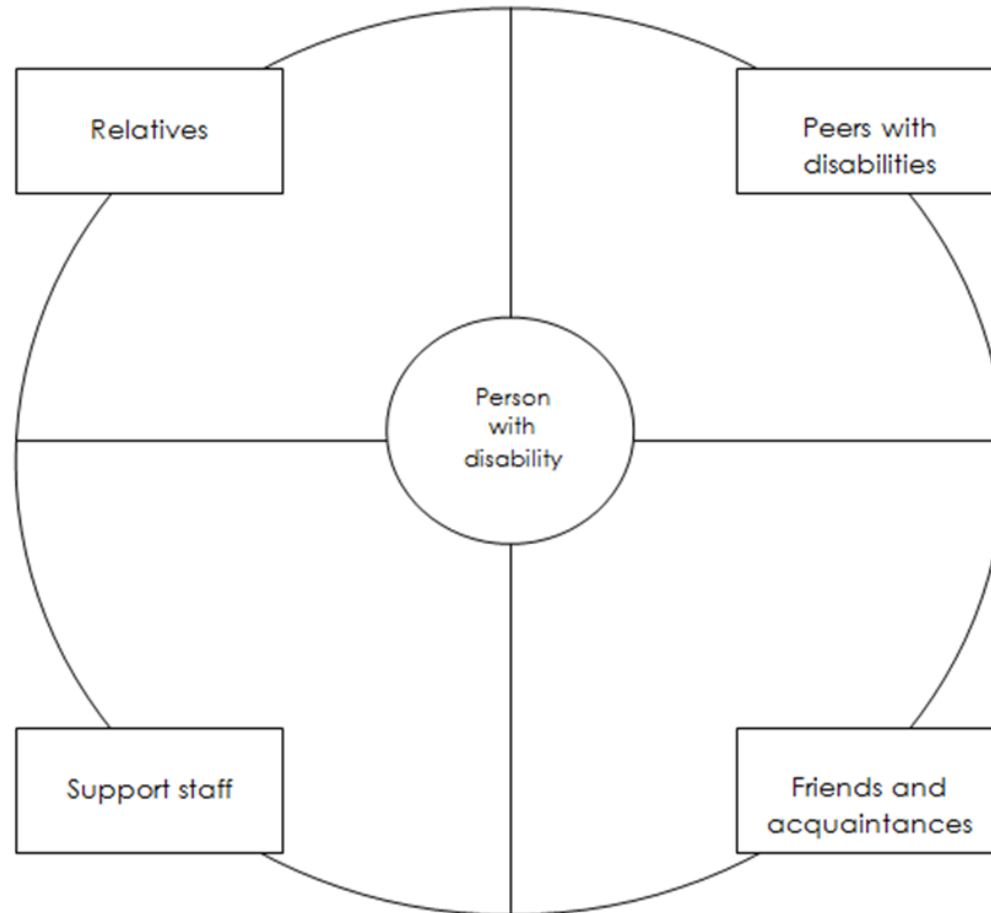
Acknowledge and maintain informal ties

Encourage and help build informal networks

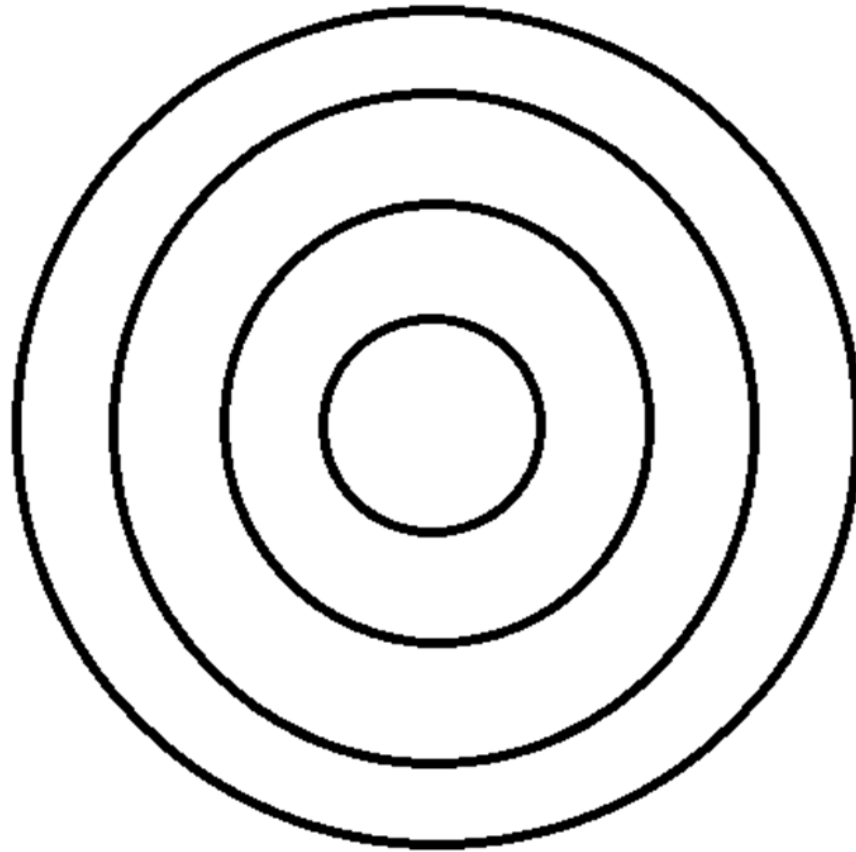
Skilled inclusion/relationship worker

Continuous social network mapping (Bigby, 2008)

Social network mapping (I)



Social network mapping (II)



Death and Dying

Engage with loss, grieving and end-of-life

Appropriate death education and bereavement counseling lacking (Blackman, 2003; Botsford, 2000)

People with ID need assistance in expressing loss and grieving

Need for involving adults with IDD in planning (Ronneberg et al., 2015; Watchman, 2005)

Resources

- Resources in IDD and Coping with Grief, Death and Dying:

http://rwjms.rutgers.edu/departments_institutes/boggscenter/projects/documents/EndofLifeResources11.11.11.pdf

Life story work

Use life story work to inform everyday support (Meininger, 2005)

Create life book

- Family
- Residential history
- Childhood
- Disability experience
- The present
- Future wishes
- End of life planning

Questions

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