



# Active Aging I/DD

Offering Information, Strategies and Networking Resources  
To Support Older Adults with I/Developmental Disabilities

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## The Benefits of Intergenerational Programs



*The National Council on Aging defines "intergenerational programs" as "activities or programs that increase cooperation, interaction or exchange between any two generations. They involve the sharing of skills, knowledge, or experience between old and young."*

These programs purposefully bring together people of different generations in ongoing, mutually beneficial, planned activities, designed to achieve specified program goals. Through intergenerational programs people of all ages share their talents and resources, supporting each other in relationships that benefit both the individuals and the community. Successful program are based on **reciprocity**, are sustained and intentional, and involve education and preparation for all ages. Young and old are viewed as assets not problems to be solved.

This article explores the program benefits for older adults with IDD to participate in intergenerational efforts and offers program models found to be successful with this aging population.

### Benefits for the Older Adult *(Generations United Fact Sheet - gu.org)*

Studies show that active and engaged older adults remain in better health. Older adults who volunteer live longer and with better physical and mental health than their counterparts.\*

- **Enhanced Socialization:** Remaining engaged and being productive.
- **Stimulate Learning:** Learning and maintaining social and functional skills.
- **Increase Emotional Support:** Regular Participation impact quality of life.
- **Improve Health:** Older adults who regularly volunteer with children burn 20% more calories per week, experienced fewer falls, were less reliant on canes, and performed better on a memory test than their peers. Also, older adults with dementia or other cognitive impairments experience more positive effect during interactions with children than they did during non-intergenerational activities.



## Best Practice

*RRTCDD continues to provide valuable service in the area of Aging with Intellectual and Developmental Disabilities for Two Decades*



Tamara Heller, PhD  
Center Director

The Rehabilitation Research and Training Center on Developmental Disabilities and Health (RRTCDD) at the University of Illinois at Chicago (UIC) continues to provide information, research and assistance for over two decades on older adults with IDD. The Center's current goals for people with IDD are: increase understanding of health status, health access, and health behaviors; improve health and function through health promotion interventions; and, improve health care access through integrated care practices.

Initially developed to be the clearing house on information for older adults with IDD, the Center recognizes that as people with IDD are living longer and their presence in the community increases there is a growing need for information on ways to support these adults and their families. Jasmina Sisrak PhD., Associate Director of Training and Disseminations states the focus remains on adults aging with IDD

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## National Task Group on Intellectual Disabilities and Dementia Practices

The 'NTG' is a coalition of individuals and organizations working to ensure that the needs and interests of adults with intellectual and developmental disability who are affected by Alzheimer's disease and related dementias—as well as their families and friends—are taken into account.

A product of the NTG is the Early Detection Screen for Dementia (NTG-EDSD) instrument.

The National Task Group Early Detection Screen for Dementia (NTG-EDSD) is an informant-based rating tool for use with adults with intellectual and developmental disability who are suspected of having changes in thinking, behavior, and adaptive skills suggestive of mild cognitive impairment or dementia. It is considered an administrative, and not a clinical assessment, tool. The use of the NTG-EDSD provides an opportunity to review relevant information that can be used by the team and healthcare practitioner to aid in shared decision making, and planning training, services, and supports. The NTG-EDSD was not designed to diagnose dementia, but to be a help in the early identification and screening process, as well as to provide information

to begin the dialogue with health care professionals. Persons who complete this instrument are asked to indicate whether they have observed the occurrence of new problems or a worsening of problems that have previously been observed. The items are associated with changes in cognition, behavior, mood, and activities of daily living.

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.

### An invitation to affiliate with the NTG is open.

If you are interested in contributing to this effort, you can register as a contributing member or NTG friend at this site.

For questions,  
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#### UPCOMING WORKSHOPS

*Dementia Capable Care of  
Adults with ID & Dementia*



Matthew Janicki, Ph.D.  
Co-Chairman of ntg

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## Adults with Intellectual and Developmental Disabilities: A Unique Population

*Older adults with intellectual and developmental disabilities can present clinicians with unique challenges related to appropriate assessment and treatment. Providers need to develop the skills and sensitivity necessary to effectively treat these patients.*

As individuals with I/DD are living longer, geriatrics providers and care team members need to learn about the characteristics, health care needs, and common clinical issues in this population.

### Challenges

The task becomes more challenging over the individual's life span as aging-related changes impact both the person with I/DD and his or her supporting family members. Key challenges that must be addressed by communities, families, and adults aging with I/DD include improving the health and function of these adults and their families, enhancing consumer-directed and family-based care, and reducing barriers to health and community participation.

Adults with I/DD generally see primary care physicians less often in comparison with the general population. Several barriers contribute to this, including the following:

### Unique Needs

Certain conditions are strongly associated with adults with I/DD and are more prevalent among this population. For example, there is a higher incidence of dental disease, functional decline, mental illness, bowel obstruction, gastrointestinal cancer, and obesity. Additionally, hearing impairment and vision loss are common in older adults with I/DD because of preexisting undiagnosed pathologies. Adults with I/DD in their

40s may present with conditions commonly seen in the general population after the age of 70 (eg, diabetes, mental health deterioration, chronic respiratory conditions).

Regularly scheduled screening and assessments (yearly or every six months, if required) is recommended along with a multidisciplinary approach to health maintenance. Key health issues that require careful examination include the following:

- **Pain and distress:** Nonverbal patients can be assessed with a caregiver's help as well as pain assessment tools adapted for adults with I/DD.
- **Polypharmacy:** It's common for the I/DD population to have numerous medications prescribed by various providers. It's important to sort out medication use, capacity to follow the medication regime, and assistance required to support medication compliance.
- **Vision and hearing:** Screen for cataracts and glaucoma (yearly for those aged 45 and older) and assess hearing, especially in light of reported changes in behavior. (Cerumen impaction may be a common cause.)
- **Dental disease:** General oral examinations may reveal the need for further investigation or closer monitoring by a dental professional.
- **Musculoskeletal disorders:** Adults with I/DD are at high risk of osteoporosis and contractures related to reduced or limited activity. Osteoporosis occurs earlier in the I/DD population compared with the general population. Osteoarthritis also is an area of concern.

### • Gastrointestinal disorders:

Screening plays an important role in the identification of gastroesophageal reflux disease. Colon cancer screening follows the same protocol used in the general population.

• **Vaccinations:** Recent research reveals that adults with I/DD do not receive vaccinations at the same rate as adults in the general population.

### Care Approach

Careful planning prior to examining an adult with I/DD will ensure good use of scheduled time and no overlooked assessments. When planning for tests and screenings, there are important questions to consider, including the following:

- What is the best way to communicate with this patient? This information can be obtained from someone who knows the patient well or directly from the caregiver.
- Will the environment hinder the flow of the appointment (eg, distracting sounds, enclosed space, proximity to other patients)?
- Are there sensory issues that may impede the appointment (eg, smells, light, white noise)?
- Does the patient require sedation to complete any tests or exams?
- Can the caregiver assist with the visit (eg, repositioning the patient, answering questions)?
- Are any other health care team members needed to complete the visit, such as nurses, audiologists, speech therapists, or dietitians?
- Does the patient use adaptive devices (eg, iPad, communication cards, voice interpreters)? It's important to consider the accommodations in terms of staffing and procedures that may need to be made during the course of the visit.

— Carolyn C. Tinglin, MSc, RN, is a health consultant working with youths and adults with dual diagnoses of intellectual and development disabilities and mental health needs.



with a life course perspective, however the emphasis is on ways to promote healthy aging.

Tamar Heller, PhD, the Center Director welcomes readers to the RRTC website (<http://rrtcdd.org>). The website is designed to provide information on the latest research, model programs, and policy issues pertaining to this population. It describes training and technical assistance opportunities, conferences, and available resources. These resources are available in various formats, including written products, videotapes, and CDs. Many of the products can be downloaded at no cost. A list serve is available to join as well.

The RRTCDD is committed to Community Based Participatory Research (CBPR)- an approach that ensures resulting activities and products are relevant to stakeholders and are responsive to culturally diverse populations. Key to this process are the RRTCDD's consumer and family advisors and the Center's National Advisory Board of major disability, aging, and advocacy organizations.

**How can the Center help professionals, families and persons with disabilities? Dr. Sisirak explained that the Center has several experts on aging and provides assistance and resources to individuals, caregivers and providers related to dementia care, health and long-term support services, health promotion activities, developing health promotion programs, sibling leadership and advocacy.**

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Can these benefits be transferred and available to the older adult with IDD? Let's look at the impact that the below program models have had on older adults with IDD.

### Program Models and Efforts

- ◆ **Community Housing:** Allied Continuing Care/AdaKevall, Southfield Michigan, operates group homes for individuals with developmental disabilities. In 2012, an Intergenerational group home was opened to serve individuals from the age of 18 to 67 years old. Three women in their 60's and 5 other residents between the ages of 18-40 (4 males, 1 female). The older adults were a calming presence to the younger and highly energized younger males and often assumed a grandparent role to them, while the younger population offered increased socialization and stimulation to the older adults. Both age groups were aware of the affect each other had on them and expressed high satisfaction.
- ◆ **Adopt a Family:** Adult Services Program, Stark County DD, Canton, Ohio. Since 1977, older adults with IDD have been served in community and facility based programs. Adopt a Family is a community project for families needing help during the holidays. Many families are not able to provide a Christmas to their children. The older adults with IDD in the program are given a family with ages, gender and wishes. The Older Adults plan and run fundraises to raise money for the wishes of each child. They select and purchase the gifts, as well as, wrap and send the gifts off to the family. Even though no direct contact is made, the experience is positive and beneficial. Reciprocity is the greatest value learned. The older adult w IDD now have an opportunity to give back and experience the satisfaction of giving and helping others.
- ◆ **Intergenerational Caregiving:** Many adult individuals with IDD still live with their parents and / or siblings. It is estimated that 75 % of these adults remain with their families. (Fujiura and Park, 2003). Toni Hill PhD explored intergenerational familial relationships in the community blog titled 'Intergenerational caregiving impacting relative relationships' (NCFR 2011). The reality of persons with IDD remaining in the home with their parents and siblings offer unique intergenerational experiences that do not have to be stressful but ones that can be filled with potential to share, learn, support and socialize.
- ◆ **"ONE GENERATION INTERGENERATIONAL DAYCARE" PROGRAM:** An intergenerational program that provides shared site senior care to include developmental disabilities and child care activities in Van Nuys, California. The Program has helped enrich the lives of seniors, children, and their families through an intergenerational community to create a bond between generations. The ONE Generation" Program is a pioneer and national model with national accreditation for intergenerational care. The program also promotes healthy aging and child development through intergenerational relationships. Intergenerational activities help to engage seniors, adults, children and youth. For example, older adults can assist young people providing one-on-one attention and young people make seniors more comfortable with new technologies.

***If these models are any indication of the positive impact upon the older adult IDD than Intergenerational programs can be a significant factor in the overall quality of life for them.***