

HEALTH AND WELLNESS AS WE AGE: A PRIMER FOR PEOPLE WITH INTELLECTUAL/DEVELOPMENTAL DISABILITIES AND THOSE WHO CARE ABOUT THEM

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SONORAN UCEDD

University Center for Excellence in Disabilities
Education, Research and Service

Expanding Possibilities – Enhancing Independence

UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES (UCEDD)

Exist in every state

**Serve as a resource for people in the areas of
education, research and service relative to the
needs of people with developmental
disabilities**

**.Are funded by the U.S. Department of Health
and Human Services, Administration on
Intellectual and Developmental Disabilities**



SONORAN UCEDD

Created by Arizona community members and the University of Arizona in spring of 2006 to address unmet needs of people with intellectual/developmental disabilities in Arizona


- Health, wellness and competent treatment issues for adults with developmental disabilities;
- Concern of aging caregivers and people with developmental disabilities as they age;
- Employment barriers for youth and young adults with developmental disabilities;
- The complex questions of supports and services in the Arizona-Mexico border region

Funded in the fall of 2006

Administered by the U of A Department of Family and Community Medicine

SONORAN UCEDD

**Health, wellness and competent treatment
issues for adults with developmental
disabilities**

- Primary Care Project for Youth and Adults with
IDD (Medical Home)**
 - Family Medicine Resident Education**
 - Medical Student Education (Medcats for
Developmental Medicine)**
- 

PRIMARY CARE PROJECT

Model coordinated primary care program

Case management

- interface with community and medical resources

- enhance availability

- record review for HCM

- flu vaccine outreach

Training for staff and providers

Physically accessible


Patient involvement (UCEDD CAC)

Uniform patient information and data

Measurement of outcomes

UCEDD- Lupita Loftus at (520) 626-0442

**Tricia Romero for Medical Home for Disabilities
at the UCEDD number above or at
triciaromero@email.arizona.edu**



THE “OVERLOOKED THREE”

Healthy Weight

Sexuality

Changes in Cognitive Function



Healthy Weight for People with Intellectual/Developmental Disability



**What do we know about people with IDD
and healthy weight?**

**Does obesity cause more illness in people
with IDD?**

**What are the barriers to healthy weight for
people with IDD?**

How can we overcome those barriers?



WHAT WE DO KNOW

People with IDD experience poorer health than the general population , including higher rates of obesity.

(Krahn, 2010, Rimmer & Yamaki, 2006).



PEOPLE WITH IDD HAVE HIGHER RATES OF OBESITY

Adults with IDD have a higher rate of obesity and morbid (severe) obesity than the general population

(Hsieh, Rimmer, Heller 2013).

Children and adults with IDD, with or without mobility limitations, are at greater risk for obesity.

(Bandini et al 2005).

OBESITY BEGINS EARLY IN PEOPLE WITH IDD

Higher rates of obesity have begun by 3 years of age,

Obesity rates remain higher in pre-adolescence and teen years

(Emerson, 2009). (Segal, et al 2016) (Maiano et al 2016)

DOES OBESITY CAUSE MORE DISEASE IN PEOPLE WITH ID?



**DOES OBESITY CAUSE MORE DISEASE IN
PEOPLE WITH ID?**

Yes.



OBESITY RELATED DISEASE IS HIGHER IN PEOPLE WITH IDD

People with IDD have higher rates of high cholesterol, and *almost twice the rate of high blood pressure* as people in the general population.

This leads to higher rates of heart attack and over three times the rate of stroke in people with IDD.

Arkansas Disability and Health Survey 2006

OBESITY RELATED DISEASE IS HIGHER IN PEOPLE WITH ID

A number of studies have shown that adults with ID and IDD have much higher rates of diabetes than the general population

**Havercamp et al 2004, Arkansas
Disability and Health Survey 2006,
Shireman, et al 2010, Balogh & Lake 2014,**

OBESITY RELATED DISEASE IN PEOPLE WITH ID BEGINS AS EARLY AS ADOLESCENCE

Adolescents with IDD have higher rates of:

- **high blood pressure,**
- **high cholesterol,**
- **diabetes,**
- **liver/ gallbladder problems,**

(Rimmer & Yamaki 2010)

WHAT ARE THE BARRIERS TO HEALTHY WEIGHT FOR PEOPLE WITH IDD?

Healthy Diet

Enough Exercise

Humphries, et al 2009, Barnes, et al 2013

The simple answer is that the causes are the same as for people without IDD, but at higher rates

ADULTS WITH ID ARE LESS LIKELY TO BE ACTIVE

Adults with IDD are more likely to lead sedentary lifestyles.

Adults with IDD are less likely to participate in leisure-time activity than the general population.

People with disabilities are less likely to engage in structured physical activity programs.

Adults with ID are more likely to participate in sedentary activities, such as watching television or listening to the radio.

WHAT ARE THE BARRIERS TO HEALTHY DIET AND ADEQUATE EXERCISE FOR PEOPLE WITH ID?

The majority of people with ID live in the community,

on their own, with their families or friends, or in smaller group home settings.

So they rely on community health resources and programs!



OFTEN, THE RESOURCES AREN'T THERE

“Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society.”

*U.N. Convention on the Rights of
Individuals with Disabilities*



Health care providers do not address these issues for people with ID very well

People with disabilities, including those with IDD,

- **are less likely to receive preventive care and screenings**
- **are less likely to be asked preventive health related questions**

American Association Health and Disability (March 2011) .(Caban, Nosek, Graves, Esteva, & McNeese, 2002; Courtney-Long, Armour, Frammartino, & Miller, 2011; Patja, Eero, & Iivanainen, 2001; Drum 2010)

Community-based programs that provide outreach and instruction on healthy diet and food preparation may not be accessible for people with IDD, or for their families and caregivers

Transportation

Cost

Accessibility

Not knowing about programs



People with ID have higher rates of obesity

**People with ID have higher rates of obesity
related illness.**

**People with ID experience more barriers to
healthy weight**



WHAT TO DO?

Don't let your medical provider off the hook

Change for healthy weight has to occur at the
family and community level

Don't let your community resources off the hook



AT THE MEDICAL PROVIDER LEVEL

Get a baseline

- four day food record

- four day activity record

Make changes at the "whole food" or "whole activity" level

- "High Payoff" food group changes

- Add an activity that can be inserted on most days

- Build on preferred activities (Wii, TV) or activities that have a social component

Ask to work with a nutritionist

Make weight relate to personal goals

AT THE HOME LEVEL

Change the family pantry

Activate your family time

Make healthy weight a household goal



AT THE COMMUNITY LEVEL



SPORTS PROGRAMS

Special Olympics

Team and individual sports

Unified Sports joins people with and without intellectual disabilities on the same team

Young Athletes

Associated health activities

Healthy Athletes

Healthy Leap

specialolympics.org



SPORTS PROGRAMS

KEEN (Kids Enjoy Exercise Now)

Free programs for kids with disabilities, regardless of the nature or severity of that disability.

Individualized, one-to-one, noncompetitive programming,

KEEN operates programs in the following 7 cities:

KEEN Chicago

KEEN Greater DC

KEEN Los Angeles

KEEN New York

KEEN Phoenix

KEEN San Francisco

KEEN St. Louis

keenusa.org

HEALTH CURRICULA FOR PEOPLE WITH IDD



HEALTH MATTERS PROGRAM

HealthMatters The Exercise and Nutrition Health Education Curriculum from the University of Illinois at Chicago

Published Curriculum Guide and other products can be purchased

<http://www.healthmattersprogram.org/products/>

Kentucky has used this in a statewide online based training for staff at programs, group housing, for people with IDD

In order to run successful health promotion programs at their sites

<http://www.wellness4ky.org/healthmatters-program/>

LIVING WELL WITH A DISABILITY

Ten week peer-facilitated health promotion workshop for people with disabilities.

<http://livingandworkingwell.ruralinstitute.umt.edu/living-well-program/>

Living Well with a Disability is offered in 46 states by over 250 Centers for Independent Living.

To find a Living or Working Well workshop in your area, send an email request and they'll respond with the contact information of a provider in your community: livingwell@ruralinstitute.umt.edu.

If there is no provider in your area, let your local Center for Independent Living know you're interested in the Living Well and Working Well workshops.

Here is a link to the ILRU nationwide directory for Centers for Independent Living: <http://www.ilru.org/projects/cil-net/cil-center-and-association-directory>

MANY YMCA'S HAVE STAFF THAT HAVE RECEIVED SPECIAL TRAINING ON INCLUSION

YMCA St Louis

Integrated Fitness Program

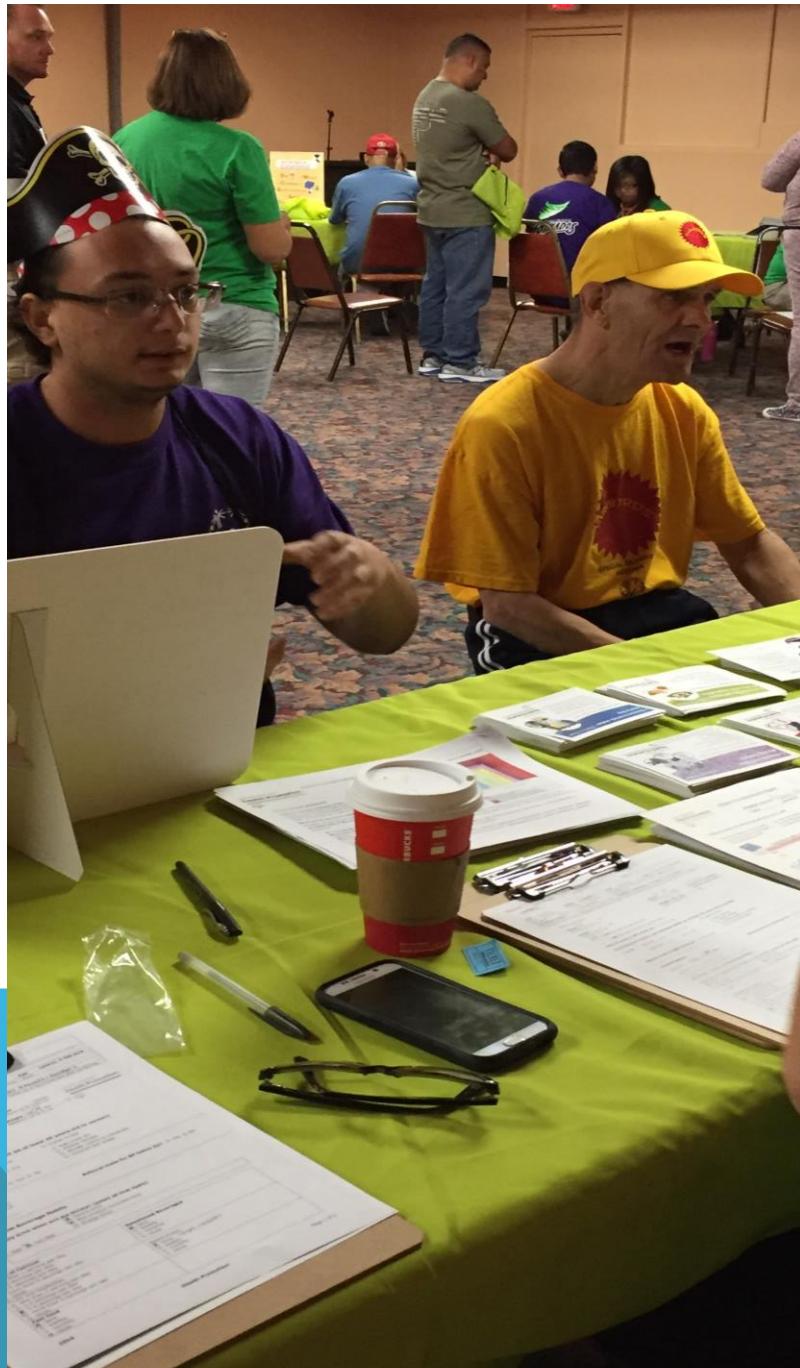
Provides opportunities for people with developmental disabilities to be engaged in a number of programs at the Y branches in St. Louis City and County.

Offers trained staff to assist and ensure that each person is able to become familiar and comfortable with the programs and equipment, including aerobics, aquatics, lap swimming, strength training and a variety of other activities.

Child Care and Summer Camp

YMCA Adult Habilitation Day Program











HEALTHY SEXUALITY



SEXUAL EXPRESSION

SEXUAL FEELINGS

SEXUAL THOUGHTS/FANTASIES

MASTURBATION

OBJECT ATTACHMENT

SOCIAL (DATING)

SEXUAL ACTIVITY WITH ANOTHER PERSON



SEXUAL RIGHTS

RESTRICTION OF SOCIAL ACTIVITY (DATING)

RESTRICTION OF SEXUAL ACTIVITY

MASTURBATION

ACTIVITY WITH OTHERS

RIGHTS TO SOCIAL ACTIVITY (DATING)

SUPPORT OF SOCIAL ACTIVITY (DATING)

RIGHTS TO SEXUAL ACTIVITY

PRIVACY

CONTRACEPTION IF NEEDED

ACTIVE SUPPORT OF SEXUAL ACTIVITY

EMOTIONAL

PHYSICAL

SEXUAL OPPORTUNITIES

SOCIAL OPPORTUNITIES

SOCIAL SKILLS

SEXUAL KNOWLEDGE

CAPACITY TO CONSENT

RISK OF ABUSE/EXPLOITATION

LEGAL ISSUES

PEOPLE WITH IDD AND THE LEGAL SYSTEM

**PREVENTION OF ABUSE VS ALLOWING CONSENTING
RELATIONSHIPS**

HEALTH CARE OPPORTUNITIES

Health Care Providers ask people with disabilities:

--More questions about pain, depression, stress

--Less questions about smoking, blood pressure, mammograms, sexual activity, cholesterol.

Drum, (2010)

CAREGIVER/FAMILY ATTITUDES

**Intellectual disability, sexuality and sexual abuse
prevention**

**A study of family members and support workers in
Australia**

AFP

Volume 41, No.3, March 2012 Pages 135-139



CAREGIVER/FAMILY ATTITUDES

Support needs and rights to form healthy, mutual sexual relationships.

Actual relationship experiences of those they cared for in strongly negative terms.

- lonely,

- limited social circles and few opportunities

- examples of sexual abuse and exploitation

Real-life mutual relationships

- considerable discomfort

- strong concern from family members about folks having a child they could not raise.

CAREGIVER/FAMILY ATTITUDES

Complexities regarding capacity to consent

**Vulnerability to exploitation increased by
new technologies**

**Concern about involvement in the sex
industry.**



CAREGIVER/FAMILY ATTITUDES

Participants described glaring holes in sexual knowledge, relationship skills and self-protection skills,

Knowledge was important but not sufficient.

Need for comprehensive, ongoing support

Education

Contraception

Assistance in self-protection.



PEOPLE WITH IDD NEED:

A child's sexuality education comes from a range of sources, including their parents, teachers and friends.

People with intellectual disability also require sexuality education that:

covers age-appropriate sexual issues that may be associated with their particular disability

explains social rules, such as telling the difference between private and public behaviours

is delivered in a way that a person with intellectual disability can understand.

It is important for parents to have access to the information they need to support their child in dealing with particular challenges they may face.

<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/intellectual-disability-and-sexuality>

BOOKS ON SEXUALITY EDUCATION- INTELLECTUAL DISABILITIES

Your Sons and Daughters with Intellectual Disabilities

by Karin Melberg Schwier & Dave Hingsburger, M.Ed. Brookes, 2000

The Facts of Life...and More: Sexuality and Intimacy for People with Intellectual
Disabilities

Edited by Leslie Walker-Hirsch, M.Ed., FAAMR, Publisher Paul H Brooks

Book written to help professionals and teachers..

Teaching Children with Down Syndrome about their Bodies, Boundaries and
Sexuality

by Terri Couwenhoven, MS, Woodbine House, 2007

This book, written by and for the parents of a child with a disability, covers topics such as anatomy, dating, boundaries, emotional development, friendships and abuse prevention.

SEXUALITY EDUCATION FOR PEOPLE WITH DISABILITIES

<http://www.siecus.org/>

A 40-page comprehensive news digest on sexuality education for children and youth with disabilities written for parents. It addresses issues of concern for parents of children with disabilities around sexuality and the meaning of relationships.




SEXUALITY EDUCATION FOR CHILDREN & ADOLESCENTS W/ DEVELOPMENTAL DISABILITIES

<http://ceacw.org/docs/parentworkbook.pdf>

A free downloadable, 81-page 'parent as educator' workbook.

It contains learning activities and lots of pictures covering information for grades K-12 on topics such as: helpful hints for parents, body changes, social skills and dating.



GRADES K THROUGH 5

Knowledge and understanding:

Identifying body parts; includes being able to recognize and use correct terms

Identifying the ways all people are alike and different Attitudes and values:

Demonstrating an appreciation of people with different attributes

Self-management skills:

Observing differences and similarities between themselves and others

Interpersonal skills: important in family and social situations

Practicing taking turns when speaking and listening

Sharing

Listening carefully and clearly expressing oneself

Following rules

GRADES K THROUGH 5-METHODS

Anatomically correct dolls

Skeleton

Mirrors

Dress up area

Scissors

A display of posters of anatomically correct bodies

Books and stories about the human body (see Resource Guide)

Create an activity/collage table. Include butcher's paper, art paper, card, pencils, felt, pens, crayons, paints, brushes, textiles, wool materials, clay and glue

Prepare a learning corner

- Dolls (anatomically correct, multicultural, a boy and a girl)
- Puzzles with correct body part labels

Dress up clothes for male and female

Cut out two paper dolls with exactly the same paper clothes on

Create an example board that has pictorial examples of all terms being addressed in the lesson.

GRADES 4 THROUGH EIGHT

Knowledge and understanding:

Identifying body parts; includes being able to recognize and use correct terms

Identifying that all people are alike and different

Understanding the difference between male and female

Understanding the changes in their emotions

Attitudes and values:

Valuing their own bodies and understanding that the changes in their bodies and emotions are important and natural

Self-management skills:

Observing differences and similarities between themselves and others

Interpersonal skills:

Learning how females differ from males

Understanding and exhibiting appropriate behavior

Learning how to express feelings regarding emotions

GRADES 4 THROUGH EIGHT-METHODS

Anatomically correct dolls

Diagrams provided

Picture board

Scissors

A display of posters of anatomically correct bodies

Books and stories about the human body (see Resource Guide)

Samples of sanitary napkins (pads) or tampons (if plan to use these)
to show

An example board that has pictorial examples of all terms being
addressed in the lesson.



GRADES 9 THROUGH 12

Becoming an adult

Identifying body parts; includes being able to recognize and use correct terms

Understanding the importance of personal hygiene (self-care)

Understanding the difference between male and female

Understanding the changes in their emotions

How to talk about masturbation

Having a positive self-esteem

Understanding the development of a baby

GRADES 9 THROUGH 12

Attitudes and values:

Valuing their own bodies and the importance and naturalness of the changes in their bodies and emotions

Self-management skills:

Observing appropriate sexual behaviors

Interpersonal skills:

Learning how to respect other individuals

Understanding appropriate behavior

Masturbation

Intercourse

MORE INSTRUCTIONAL MATERIALS ON SEXUALITY AND RELATIONSHIPS

Attainment Company

<http://www.attainmentcompany.com/xcart/home.php>

A for-profit book company specializing in students with developmental disabilities.

Look

for the “Learn about Life” curriculum - an illustrated sex education and social skills program covering puberty, dating, pregnancy, STDs and more.

Circles Curriculum

<http://www.stanfield.com/circles-main.html>

Teaches relationship boundaries and relationship-specific behaviors, using a simple multi-layer circle diagram to demonstrate the different relationship levels students will encounter in daily life. Website also has other curricula for special education students.

Educational Resource Information Center (ERIC)

<http://www.hoagiesgifted.org/eric/faq/sex-ed.html>

Information on providing sex education to students with developmental disabilities, including links to discussion groups, assessment tools and tools for instructors.

AND MORE...

-<http://www.kingcounty.gov/healthservices/health/personal/famplan/educators/flash.aspx>

The Family Life and Sexual Health curriculum (F.L.A.S.H.) is a comprehensive sexuality education curriculum first developed by Public Health - Seattle & King County. The lesson plans, including separate ones for Special Education Students can be downloaded free at this site.

Fostering Friendship Skills for Students with Disabilities

<http://www.cec.sped.org/AM/Template.cfm?Section=Home&TEMPLATE=/CM/ContentDisplay.cfm&CONTENTID=6265>

by Sharon Maroney at the Council for Exceptional Children website.

RECAPP - Resource Center for Adolescent Pregnancy Prevention

<http://www.etr.org/recapp/index.cfm?fuseaction=pages.EducatorSkillsDetail&PageID=96>

Provides a brief overview of the basics of teaching sexual education to students with developmental disabilities. The site emphasizes teen pregnancy but has great information for sexuality education.

AGING AND COGNITIVE DECLINE



DEMENTIA

Alzheimer disease 70%

Vascular dementia 17%

Others 13%

- Lewy body

- Parkinson-related

- Alcoholic

- Frontotemporal Dementia (FTD or Pick's disease)

Other causes cognitive change

- B12

- Tertiary syphilis

- Hypothyroidism

- Depression (pseudo-dementia)

ALZHEIMER'S DISEASE

After 65 years of age, the lifetime risk is 17 to 20 percent;

71 to 79 years of age, prevalence 5 percent,

Older than 90 years of age, prevalence 37 percent

Other risk factors:

- family history

- apolipoprotein E4 genotype (increase risk two to tenfold)

- cardiovascular comorbidities,

- chronic anticholinergic use (HR1.65)

- lower educational level. (college education delays onset by 2 years)

Mild cognitive impairment, which is defined as memory impairment without meeting criteria for dementia.

Each year, 10 to 15 percent of patients with mild cognitive impairment develop Alzheimer disease.

DEMENTIA IN PEOPLE WITH IDD

With the exception of Down Syndrome,
Alzheimer's Disease prevalence may be
equivalent to the general population

Poor data though



ALZHEIMER'S DISEASE AND DOWN SYNDROME

Chromosome 21 carries the apoprotein precursor protein gene (APP), also other regulatory genes which are associated with AD

By age 40, all adults with DS will have some degree of neuropathological changes characteristic of AD

Prevalence is 50% in ages 60 years and older

Earlier onset- age 40

More rapid progression



RISK OF DIAGNOSTIC OVERSHADOWING FOR ADULTS WITH IDD

Definition: Blaming decline of abilities and changes in behavior on a pre-existing diagnosis.

- Example – Decline assumed to be a result of intellectual disability rather than disease process

DIAGNOSIS BY NEUROPSYCHOLOGICAL EVALUATION

AD may present differently in people with DS

More “prefrontal lobe” symptoms

indifference, uncooperativeness, apathy, depression,
socially deficient communication, impaired adaptive
functioning in general.



CHALLENGES AT MEDICAL PROVIDER VISITS

Lack of knowledge of medical history due to the following:

- **Staff turnover**
- **Family not available for information, historical documentation unavailable**
- **Health care provider turn over**
- **Information provided for the appointment may not include all pertinent information**
- **Staff/family attending health care appointments may not be the most knowledgeable about the symptoms.**

Providers not understanding baseline functioning of the presenting older adult with ID

EARLY DETECTION/SCREENING

Looking for and recognizing symptoms.

- Family and caregivers should be aware of patients baseline for early detection.

Family, caregivers and staff should work together with the provider to share information about observed changes.

Use of a screening tool to note changes in adaptive skills, behavior, and cognition is recommended.

National Task Group Early Detection Screen for Dementia (NTG-EDSD)

NTG EARLY DETECTION SCREEN FOR DEMENTIA (EDSD)

Adapted from:

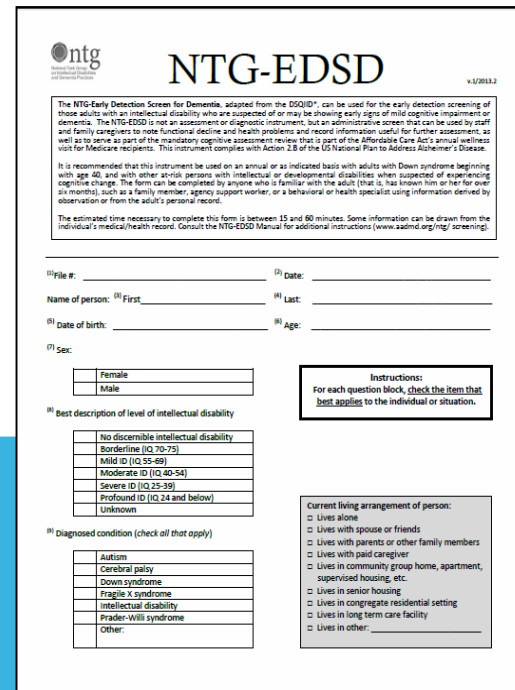
- Dementia Screening Questionnaire for Individuals with Intellectual Disabilities
- Dementia Screening Tool (adapted by Philadelphia Coordinated Health Care Group)

Down Syndrome begin at age 40

Non-DS begin at age 50

EDSD available in 9 different languages

Caregiver or staff should know patient for more than 6 months before using the EDSD.

The image shows the NTG-EDSD form, which is a screening tool for dementia. It includes a header with the NTG logo and the title "NTG-EDSD". Below the header, there is a paragraph explaining the purpose of the form and its use. The form is divided into several sections: (1) File #: (2) Date: (3) Name of person: (4) First: (5) Last: (6) Date of birth: (7) Age: (8) Sex: (9) Best description of level of intellectual disability: (10) Diagnosed condition (check all that apply): (11) Current living arrangement of person: The form is designed to be filled out by a caregiver or staff member who knows the individual well. It includes checkboxes for various conditions and living arrangements, and a section for the best description of the individual's intellectual disability. The form is available in 9 different languages.

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.B 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 30 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: _____

(8) Best description of level of intellectual disability

<input type="checkbox"/> No discernible intellectual disability
<input type="checkbox"/> Borderline (IQ 70-75)
<input type="checkbox"/> Mild ID (IQ 55-69)
<input type="checkbox"/> Moderate ID (IQ 40-54)
<input type="checkbox"/> Severe ID (IQ 25-39)
<input type="checkbox"/> Profound ID (IQ 24 and below)
<input type="checkbox"/> Unknown

(9) Diagnosed condition (check all that apply)

<input type="checkbox"/> Autism
<input type="checkbox"/> Cerebral palsy
<input type="checkbox"/> Down syndrome
<input type="checkbox"/> Fragile X syndrome
<input type="checkbox"/> Intellectual disability
<input type="checkbox"/> Prader-Willi syndrome
<input type="checkbox"/> Other: _____

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

Current living arrangement of person:

<input type="checkbox"/> Lives alone
<input type="checkbox"/> Lives with spouse or friends
<input type="checkbox"/> Lives with parents or other family members
<input type="checkbox"/> Lives with paid caregiver
<input type="checkbox"/> Lives in community group home, apartment, supervised housing, etc.
<input type="checkbox"/> Lives in senior housing
<input type="checkbox"/> Lives in congregate residential setting
<input type="checkbox"/> Lives in long term care facility
<input type="checkbox"/> Lives in other: _____

CONTINUED

Can be used by families, caregivers and support staff

Notes the presence of key behaviors associated with dementia

Picks up on health status, ADL's, behavior and self reported problems

NTG-EDSD - page 3

NTG-EDSD - page 2

NTG-EDSD - page 5

[Check column option as appropriate]

[Check column option as appropriate]

[Check column option as appropriate]

Recent condition (past year)

Condition diagnosed in last 5 years

Lifelong condition

Condition not present

Death of someone close

Changes in living arrangement, work, or day program

Changes in staff close to the person

New roommate/housemate

Illness or impairment due to accident

Adverse reaction to medication or over-medication

Interpersonal conflicts

Victimization / abuse

Other

Seizures

Recent onset seizures

Long term occurrence of seizures

Seizures in childhood, not occurring in adulthood

No history of seizures

Diagnosis by:

☐ Geriatrician

☐ Neurologist

☐ Physician

☐ Psychiatrist

☐ Psychologist

☐ Other

Reported date of onset of MCI/dementia

(When suspicion of dementia first arose)

Note approximate year and month

Comments / explanations about dementia suspicions:

Pages 1 & 2 Focus on Basic Information

Pages 3 & 4 Focus on function and indicators of problem areas associated with dementia

Page 5 Chronic Health Conditions

Page 6 Medications & Comments

NTG-EDSD: 4 KEY SECTIONS

Demographics

Ratings of health, mental health and life stressors

Review of multiple domains

- Activities of daily living
- Language and Communication
- Sleep – Wake Patterns
- Ambulation
- Memory
- Behavior & Affect

Chronic health conditions

NTG - CAPABLE CARE OF ADULTS WITH INTELLECTUAL DISABILITY AND DEMENTIA

**Sonoran UCEDD is offering training for families,
caregivers and staff.**

**This training covers various topics and provides
families/caregivers education and tools necessary
when caring for an individual with ID and
dementia.**

UCEDD- Lupita Loftus at (520) 626-0442

IF YOU HAVE A POSITIVE SCREEN, WHAT NEXT?



GENERAL WORKUP FOR COGNITIVE CHANGE

LABS

Calcium

B12*

TSH*

Chem Panel

CBC

Folate

Head imaging (5% yield)

OTHER

HIV

RPR

Lyme titre

CSF analysis

AGS

* AAN

OTHER CAUSES OF COGNITIVE CHANGE (IMPORTANT IN PEOPLE WITH IDD)

Medications

anticholinergic (Diphenhydramine Hydroxyzine Promethazine)

bladder medications

seizure medications

psychiatric medications (benzodiazepines, TCA's, some antipsychotics)

Depression

Pain

Sensory Disturbance

Sleep disorders (OSA)

Hx of CVD, head injury

Environmental changes

TREATMENT

Medication adjustment

Trial of antidepressant

Medications:

Raise acetylcholine (Donepezil, Rivastigmine,
Galantamine)

Block glutamate (Memantine)



TREATMENTS IN PEOPLE WITH DS

Raise acetylcholine (Donepezil, Rivastigmine, Galantamine)

six studies with and without dementia

- 2 case reports (improvement)

- 2 case control (improvement NS, improvement sig)

- 2 RCT (improvement NS)



TREATMENTS IN PEOPLE WITH DS

Block glutamate (Memantine)

One RCT, no sig improvement

