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Module 7 Health Care Advocacy




National Task Group
on Intellectual Disabilities
and Dementia Practices

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Section Objectives

Participants will be able to:

- List steps of health care advocacy.
- Identify the process of conducting observations for health care advocacy.
- Utilize this information to inform situations in their work and make appropriate recommendations for advocacy and follow-up.
- Recognize that while caregivers are not responsible for assessment and diagnosis, their input is essential for an accurate and helpful diagnosis/intervention
- Define reportable health information (HIPPA and state regulations)

Proficiency: Understanding health and aging



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Health Care Advocacy



Health care advocate - a person who is not a health care professional, but can assist a patient in obtaining high-quality health care.

An advocate may be a counselor at a service organization, a relative, or a friend of the 'patient'.


www.communityhealthadvocates.org/advocates-guide/appendix/glossary

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Dementia and Health Advocacy


• Dementia-related health advocacy is:

- Speaking for the adult affected by dementia
- Looking after his/her interests during health interviews and visits
- Ensuring that concurrent conditions are diagnosed and treated
- Tracking the rate and course of dementia and helping the health practitioner better understand the changes occurring
- Coordinating care when various providers are involved
- Arranging for appropriate care and supports

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You may be in a position to be a health advocate...

- You are given the responsibility to look after the welfare of the adults that are in your program
- You are a care manager
- You work along with health personnel
- You are a relative or family member
- You are a friend or mate
- You are involved in way that the health of adults you work with can be your concern
- You are engaged in some other capacity that gives you access to the health practitioners

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Importance of Health Care Advocacy

There are often interventions that can make a difference in quality of life and health.

➔

Staff and family are the experts about individuals with ID.

- To recognize current changes and symptoms, knowing the person across the lifespan is the best resource.

➔

Health care is an art, not a science!

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Why is **Dementia** Health Care Advocacy Needed?

- Helping to speak for an adult with dementia when his or her cognitive impairment becomes a barrier to self-advocacy.
- *Ageism* (prejudice or discrimination on the basis of a person's age) by health care providers.
- Assumption of automatic loss and decline as part of aging.
 - Untrue but commonly believed.
- Assumption that all changes are due to dementia.
 - Especially in persons with Down syndrome.
- "Giving voice" on behalf of those who cannot.

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Four steps of health advocacy

#1 Observe

#2 Report

#3 Prepare for the health appointment

#4 Follow-up after the appointment

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Step #1 of Health Care Advocacy

#1. Observe

- Recognize that the functional and behavioral changes you observe are a form of communication.
- Screening as a tool for observation (NTG-EDSD)

Look for changes in the person such as:

- Behavior
- Personality
- Activity level
- Unintended weight loss or gain (10%)
- Changes in wake/sleep patterns
- Diarrhea/constipation





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Step #2 of Health Care Advocacy

#2. Report

- Document your observations
- Be accurate and specific
- To the right person
- Use correct forms and processes



Important components of reporting:

- Time of the day, who is present, where did it happen?
- How often do you observe this symptom?
- What was happening before? After?
- Making sure there is a system/process for reporting to the right person!




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Step #3 of Health Care Advocacy

#3. Prepare for the health care appointment

- Hold a team meeting (residential/family/program/individual advocates).
- Meet with caregivers to bring together symptoms observed.
- Prioritize symptoms and concerns to be addressed.
- Checklist or form for the attending caregiver to bring to the appointment
- Gather all pertinent information in an organized format so that the information can be provided in a brief and concise manner.
- Make sure the person who goes with the individual is:
 - Included in the meeting
 - Able to communicate symptoms
 - Has some health care advocacy skills





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Cultural considerations in health advocacy

- Adults with ID come from many different backgrounds and cultures.
- When an adult with ID exhibits signs and symptoms of dementia, seeking help, assessment, and treatment will be directly impacted by the culture of the adult and the adult's caregivers.
- Ethnically diverse communities define ID and dementia differently depending on the culture and the cultural belief systems' definition of disability and disease.



Challenges

- Recognize genetically related clinical differences among ethnic and 'racial' groups.
- Know how the adult best communicates.
- Respect others' belief systems.
- Build trust through honesty, respect, and acceptance of other points of view, traditions, and needs.
 - If language is a barrier, use an interpreter (not a family member).
 - Avoid slang; use visuals.
 - Be careful using nonverbal gestures such as touch, eye movement, facial expression, body posture – as these may convey messages that members of certain cultures may find insulting, disrespectful, or make them uncomfortable.



Case Study: Preparing for the health care appointment

Primary diagnosis


Severe cerebral palsy (non-ambulatory)

Reason for referral


- Changes in level of ADL skills (eating and toileting)
- Ongoing weight loss (any time 10% or more is lost it is a major concern)
- Avoids group activities, especially going to program in morning on the bus. Will agree to go later if driven by staff.
- Cries and screams, refuses to eat or get dressed.
- Staff suspicion of possible dementia





Pam

 **Pam's medical history shows...**

- Urinary tract infections
- Kidney stones
- Reflux disease
- Difficulty swallowing
- Pneumonia and bronchitis yearly
- Seizures of undetermined cause
- Gum disease
- Vitamin D deficiency





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 **RISK FACTOR: Previous medical conditions**

History of:


- Urinary Tract infections and kidney stones.
 - Dual risk due to lifelong cerebral palsy
- Increase in fractures and pain from osteoporosis in combination with arthritis.
 - Dual risk due to cerebral palsy
- Significant pain and discomfort from ulcers & GI reflux.
 - Dual risk
- Gum disease.
 - Dual risk due to lifelong use of medications and poor oral health


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 **RISK FACTOR: Pre-existing neurological condition (cerebral palsy)**

Having lifelong neurological limitations, places Pam at increased risk of earlier onset and aggravated:

- **Arthritis** – significant pain (observe movement, times of day)
- **Osteoporosis** (due to seizures and medication as well as lack of weight bearing exercise & lack of exposure to sunlight)
- **Eating and swallowing disorders** (indicated by weight loss)
- **Urinary tract infections**



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RISK FACTOR: Family medical history

- **Alzheimer's disease** - Mother, still living and in nursing home, with dx of Alzheimer's.
- **Stroke** – Father, cause of death, in combination with cardiovascular disease.

Important additional information when combined with Pam's presenting symptoms.

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Possible causes for changes observed in Pam

SYMPTOMS WITH THE HIGHEST RISK:

Reflux/eating swallowing disorders

- Weight loss, such as the 10% noted loss for Pam, should be immediately followed up with appropriate interventions.

Urinary tract



- Dual risk

Pain due to: fractures/osteoporosis/arthritis

- Dual risk, highly likely at least one of the causes for changes noted in behavior.

Medication side effects

- Especially if medications are blocking absorption of vitamins and minerals.



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Step #4 of Health Care Advocacy


#4.

Follow-up after the appointment

- Follow-up recommendations with all caregivers
- Make sure recommendations are understood.
- Are there any follow-up questions?
- Continue observing and reporting.
- Don't give up!
- You may have to search out a new provider
- Be as prepared for the follow-up as for the first appointment

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Follow-up for Pam

Communicate recommendations from the health care provider to all staff:


- Follow-up all recommendations (including making appointments to specialists).
- Monitor and report any changes or decline.
- Ongoing consistent follow-up and monitoring.

If the health care provider ignores symptoms or doesn't feel they are important enough to address:

- Make another appointment quickly; send the nurse.
- Find another provider willing to partner with caregivers to figure out underlying causes.




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Let's talk about Pam ...

- What are the areas you would focus on?
- What would you bring to the health practitioner if you were to accompany Pam?
- Who should be notified of the outcome of the health visit afterwards?
- What kind of follow-up could you do?




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Tips for health care advocacy

- *Be aware of myths and stereotypes about aging in persons with ID.*
- Know the possible side effects and interactions for medications used by the individual.
 - Beers List
www.americangeriatrics.org/files/documents/beers/PrintableBeersPocketCard.pdf
 - Physician's Desk Reference
www.pdr.net/browse-by-drug-name
- Never assume the changes you see are always the result of aging or Alzheimer's disease!

Be persistent! Be an advocate!



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To be an effective advocate you must use your knowledge about the individual

Typical behaviors over the lifespan:

- Has the adult exhibited similar behaviors in the past to those recently observed ?
- Has the frequency of past behaviors changed, increased or decreased significantly?
- When the behavior(s) were observed in the past was there diagnosis of an illness, pain, or discomfort?

Personality patterns

Medical history

Family medical history (if known)

Prioritize based on likely relationship to current behavior, history, invasiveness and expense/ease of completing assessment.



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Understand the risks for specific syndromes and conditions

Use your knowledge of general aging and aging in persons with pre-existing disabilities:

- Risk for specific age-related diseases and conditions?
 - Examples include higher risk for visual and hearing impairments related to older age
- How common in older adults?
 - Know that cataracts are one of the most frequent causes for visual impairment in older adults.
- Disability specific risk factors?
 - Adults with Down syndrome are at a higher risk for hearing impairment from birth and increasing risk at a younger age than the general population.



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Health Care Advocacy Summary



Be aware of myths and stereotypes about aging in persons with ID.



Know the possible side effects and interactions for medications used by the individual.



Never assume the changes you see are the result of existing disability, aging, or dementia!



Observe...Assess...Report...Prepare...Communicate



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For guidance...



'Guidelines for Dementia-related Health Advocacy for Adults with Intellectual Disabilities and Dementia of the National Task Group on Intellectual Disabilities and Dementia Practices'

- NTG Guidelines and recommendations for dementia-related health advocacy preparation and assistance that can be undertaken by provider and advocacy organizations.
- The guidelines help caregivers recognize and communicate symptoms, as well as find appropriate practitioners familiar with the medical issues presented by aging adults with lifelong disabilities.

www.aadmd.org/ntg


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Take-away points

- Many adults with age-related decline or dementia also may have secondary health problems and these warrant as much attention as the adults' primary problems.
- Health advocacy can help the adult with ID get the right kind of medical attention.
- To be an effective health advocate, you need to sharpen your observation skills, don't be afraid to speak up, and trust your instincts about the health needs of the adult with ID.

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Thanks to all of the NTG volunteers who contributed to this curriculum



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