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Section Objectives

Participants will be able to:

- •List steps of health care advocacy.
- \bullet 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. $% \label{eq:controlled}$

- •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 on Dementia and I/DD.

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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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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 selfadvocacy.
- 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.











Step #3 or	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

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.

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Case Study: Preparing for the health care appointment

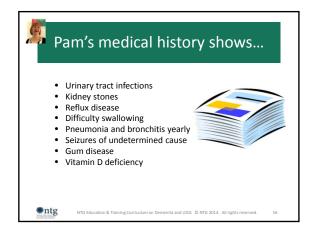
Primary diagnosis

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







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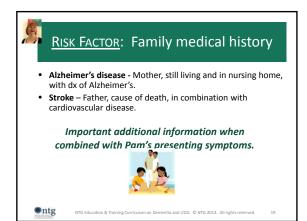
RISK FACTOR: Pre-existing neurological condition (cerebral palsy)

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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#4. Follow-up after the appointment **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Curriculum on Dementia and I/DD. © NTO 2014. Mirghts reserved. **To Education & Training Cur



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



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 www.aadmd.org/ntg/curriculum