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Caregiving to Help Achieve an “Everyday Life”

What is an Everyday Life?

According to *Everyday Lives: Values in Action*, 2016, the Pennsylvania Department of Human Services’ Office of Developmental Programs (ODP) state that, “an everyday life is about opportunities, relationships, rights, and responsibilities. It’s about being a member of the community, having a valued role, making a contribution to society, and having one’s rights as a citizen fully respected. It is a vision that we all should be working toward together.”

What is the Role of the Caregiver?

Caregiving roles take on countless shapes and forms. Caregivers assist every day in small and big tasks. When searching for a specific definition of a caregiver and their roles you will find that there is no universal definition for the term. The Ohio Department of Aging describes caregiving as any situation in which one individual helps another with essential activities of daily living. Caregiving activities may include help with dressing and bathing, grocery shopping, managing money, providing transportation, dressing wounds, and administering medication. The definition can be further broken down into formal/informal caregivers. A caregiver who is employed by an agency or organization, or a trained individual who receives payment for the care provided is considered a “formal caregiver.” Care provided by family members and friends, most often unpaid, is considered “informal caregiving” or “family caregiving.”

Many people including individuals with disabilities need daily care, services and support to live an everyday life. All people want to live in the setting of their choice with a dignified, high quality of life. According to the Institute of Medicine, direct care workers are “the linchpin of the formal health care delivery system...this group works in a variety of settings, including private homes, and community-based residential settings such as group homes.” By 2020, the direct care workforce will be the largest occupational group in the country.

Direct support professionals can play a large role in the lives of people with developmental disabilities; not only do direct care professionals assist with the physical aspects of caring for individuals with intellectual disabilities, they can also foster stability, peace of mind, and freedom in the lives of those they support.

What Makes an Everyday Life?

ODP embraces the “Everyday Lives” concept of care and encourages caregivers to practice meaningful ways to help people with I/DD achieve an “everyday life.” “Everyday Lives” is the expression of the concept of people having a life like others in the community. People want to have self-determined lives. People with disabilities, with the support of caregivers, can decide how to live their lives. They have developed a statement called “My life, my way”. The vision statements contain the things in life that are important to them in order to have an everyday life.

EVERYDAY LIVES IN ACTION: MY LIFE, MY WAY	
STABILITY: Changes to my life are made only with my permission and input. My family, supporters, and community do “nothing about me without me.” They plan with me to meet my needs, now and for the future.	EMPLOYMENT/MEANINGFUL CONTRIBUTION: I want to work and/or have other ways to contribute to my community. My family, supporters, and community support me to find and keep a real job that I like with good wages and benefits or start and run my own business, and/or volunteer the way I want in my community.
HEALTH AND SAFETY: I am healthy and safe in all areas of my life. I, my family, supporters, and community balance health, safety, and risk according to my wants and needs.	INDIVIDUALITY: I am respected and valued for who I am and want to be. My family, supporters, and community treat me with dignity and support me in a person-centered way.
CONNECTED: I am a full member of my community with respect, dignity, and status. My family, supporters, and community know me as a person, welcome and accept me.	RELATIONSHIPS: I decide who is in my life: friends, family, partners, neighbors, pets, and others in the community. My family, supporters, and community respect the relationships I choose and support me to form new relationships.
RESPONSIBILITY: I am dependable and honor my commitments. I keep my word. My family, supporters, and community are honest and fair, do what they’re supposed to do, and keep their word.	PARTNERSHIP: I need people in my life who will honor my life’s journey. My family, supporters, and community work together with me to build bridges.
COMMUNICATION: I am listened to and understood; my input is valued. My family, supporters, and community listen to me and communicate in ways that work for me.	QUALITY: I want my life my way. I, my family, supporters, and the community make sure the services I choose are proved to be of high quality.
SUCCESS: I am the best I can be in the goals that I decide. My family, supporters, and community learn how to support me to achieve my goals.	ADVOCACY: I am the best person to let others know what I want and need. My family, supporters, and community listen to me and understand what I want and need, and assist me to be heard by others.

Everyday Lives in Action: My Life, My Way

CONTROL: I have control over all areas of my life. My family, supporters, and community know these are my decisions and work with me to achieve greater control.

SUCCESS: I am the best I can be in the goals that I decide. My family, supporters, and community learn how to support me to achieve my goals.

CHOICE: I decide everything about my life. My family, supporters, and community help me learn about opportunities and together we make them happen.

EMPLOYMENT/MEANINGFUL CONTRIBUTION: I want to work and/or have other ways to contribute to my community. My family, supporters, and community support me to find and keep a real job that I like with good wages and benefits or start and run my own business, and/or volunteer the way I want in my community.

FREEDOM: I have the same rights as all other members of the community and I can fully use them. My family, supporters, and community respect my rights.

INDIVIDUALITY: I am respected and valued for who I am and want to be. My family, supporters, and community treat me with dignity and support me in a person-centered way.

STABILITY: Changes to my life are made only with my permission and input. My family, supporters, and community do “nothing about me without me.” They plan with me to meet my needs, now and for the future.

RELATIONSHIPS: I decide who is in my life: friends, family, partners, neighbors, pets, and others in the community. My family, supporters, and community respect the relationships I choose and support me to form new relationships.

HEALTH AND SAFETY: I am healthy and safe in all areas of my life. I, my family, supporters, and community balance health, safety, and risk according to my wants and needs.

PARTNERSHIP: I need people in my life who will honor my life's journey. My family, supporters, and community work together with me to build bridges.

CONNECTED: I am a full member of my community with respect, dignity, and status. My family, supporters, and community know me as a person, welcome and accept me.

QUALITY: I want my life my way. I, my family, supporters, and the community make sure the services I choose are proved to be of high quality.

RESPONSIBILITY: I am dependable and honor my commitments. I keep my word. My family, supporters, and community are honest and fair, do what they're supposed to do, and keep their word.

ADVOCACY: I am the best person to let others know what I want and need. My family, supporters, and community listen to me and understand what I want and need, and assist me to be heard by others.

COMMUNICATION: I am listened to and understood; my input is valued. My family, supporters, and community listen to me and communicate in ways that work for me.

Source: PA Department of Human Services: Office of Developmental Programs. (2016). Everyday Lives – Values in Action. Retrieved from https://s3-us-west-2.amazonaws.com/palms-awss3-repository/MyODP_Content/Everyday+Lives/EDL+booklet+proof+11-1-2016.pdf

Consider how Jessica helped James have an “everyday life” when he was recently bullied at work:

Jessica is a paid caregiver. She picked James up from his job at McDonald's and she noticed he was unusually quiet on the ride home. When they got home, she asked him what was wrong. He said that there was a group of kids at the restaurant who made fun of him today, telling him to “Go away, Down syndrome boy. You don't belong here.” Jessica listened, helped James talk about his feelings, and assisted him to make a plan to discuss what happened with his supervisor at work.

This example demonstrates Jessica's support of James in first acknowledging and addressing his feelings and the situation that occurred, but then to assist him in developing a strategy on how to handle the situation to raise awareness and prevent a similar situation from happening again at his workplace.

There are many different situations and occurrences that caregivers can make a difference in someone living their best life through determination and understanding. This edition of KEPRO CARES will offer ideas and strategies for caregivers to assist the people they serve to live an everyday life.

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Community Participation is Vital for an “Everyday Life”

What is an Everyday Life?

Community participation is a phrase often used interchangeably with social inclusion or community inclusion. The Illinois Department of Human Services defines community participation or inclusion as the opportunity to live in the community and be valued for one’s uniqueness and abilities, like everyone else. People with intellectual and developmental disabilities (I/DD) want to participate in their communities and to practice self-determination or have the ability to make their own choices.

Community participation should encompass all areas of the person’s life, including:

- Housing
- Employment
- Education
- Health status
- Leisure/recreation
- Spirituality/religion
- Citizenship and civic engagement
- Valued social roles
- Peer support
- Self-determination/advocacy

Participating in the community is vital to having an “everyday life” and is a key element to a whole life. Community inclusion provides a sense of belonging, feeling wanted, needed and capable. It enhances self-esteem by being valued for one’s ability and uniqueness, and it is most successful when those with I/DD have relationships with people who are not paid to spend time with them, they experience a variety of social roles doing things that are important to them, and they feel a sense of belonging.

Benefits of Community Participation for Individuals with I/DD:

- Increases potential for employment (to earn their own living)
- Increases independence
- Builds natural supports
- Enhances life experiences
- Provides an opportunity to engage with others and form social relationships
- Provides an opportunity to share talents and gifts with the community through working towards achieving dreams and desires
- Improves feelings of well-being and self-esteem

Caregivers for people with disabilities should promote community inclusion because it is the right of all people. Specific legislation protecting these rights for people with disabilities include the Americans with Disabilities Act (ADA) (1990), the ADA Amendments Act (ADAAA) (2008), the Supreme Court “Olmstead” decision (1999), and the Disability Inclusion Act 2014.

Despite moving from residential institutional settings to community settings, people with I/DD continue to experience high rates of social isolation. This may be due to barriers from both societal attitudes and society’s perception that the person with a disability has nothing to offer. Society may not be welcoming to the person because they are not sure how to interact with him or her, and may not take the time necessary to learn what is needed to include the person. Individuals with I/DD may require caregiver support to identify opportunities for participation in the community, and to work through barriers to inclusion. Caregivers who understand these barriers and work to promote the person’s gifts and strengths can assist the person with I/DD to achieve greater community participation.

For example, consider how Trisha helped Joe become an active member of the local senior center.

Joe’s Story

Joe told his caregivers at his annual ISP meeting that now that he is retired he wants to spend time at the local senior center and “get their good lunch” every day. The team agreed that this was something they could help Joe pursue, but they knew there would be some challenges in making this happen. Trisha, Joe’s primary caregiver, decided it would be a good idea to talk with the people at the senior center to learn of their concerns with accepting Joe into the group. She also knew eating the hot lunch served daily at the center was very important to Joe, but she did not know if they could accommodate his diet.

Trisha contacted the center’s director and she learned that people there had never interacted with an individual with I/DD and really didn’t understand that Joe was more like them than not. They were afraid Joe would require special skills they were not trained to provide, and they said they wouldn’t know how to talk to him. The caregiver understood that these concerns could be easily addressed if she shared basic information about people with intellectual disabilities and provided tips on how to communicate with them. She put together a communication tip sheet for them and asked to meet with them. Here is the tip sheet she made for them:

- Call the person’s name before speaking and assure he knows you are talking to him.
- Speak clearly and simply, to the person with an intellectual disability, using common words and phrases. Avoid jargon and slang language.
- Speak in a normal tone of voice unless you are sure the person is hard of hearing.
- Allow at least 18 seconds for the person to respond.
- Treat everyone as an individual and provide them the same respect and dignity you would like yourself; adults with I/DD are not children; interact with them as you would anyone else.
- Talk about the same subjects you would with anyone – the weather, current events, plans for the weekend or vacation, for example.

- Don't be offended by behaviors that are difficult to manage; the person may not be aware that the behavior is offensive.
- Avoid pretending to understand if you do not; it is OK to ask the person to repeat the information or act out what they are saying.
- Ask for permission before assisting the person and don't insist on offering help if your request is turned down.

With Joe's permission, she shared some interesting information about him and helped the center participants understand that Joe was very similar to them. At the end of her talk, everyone agreed they were willing to meet Joe. It was decided that Joe would join them for lunch the next week. Trisha knew that Joe was at his best when eating good food and talking about his job.

Joe had some really interesting and funny stories to tell from his work days! Trisha worked with Joe to identify what stories would be good to share. She also talked with the center's director and told him that Joe was really looking forward to eating lunch at the center, but he was on a special diet. She learned that they were able to accommodate Joe's special diet. She arranged for the lunch meeting and told Joe, "Just be yourself."

On the day Joe met the group at the senior center he had them laughing hysterically as he told stories of funny animal antics he saw when he worked at the zoo. Trisha saw that the senior center group members relaxed and talked with Joe without reservations of any kind. On the drive home from that meeting, Joe told Trisha what a good time he had, and said he could not wait to go back the next week. Trisha knew that the preparation she did with Joe and the group at the senior center made a difference and she helped Joe to have an "everyday life" with this experience.

This is a great example of how to practice community inclusion for people with I/DD. Astute caregivers know that there will be some barriers to inclusion, and they work to identify and remove the barrier, just as Trisha did for Joe. Community inclusion is best done on an individualized basis, where the person's talents and gifts are shared with the community, in an activity chosen by the person.

Attention to detail about the person and about what skills are needed to achieve a goal help to focus a community inclusion plan. Here are some considerations as you think about increasing community inclusion for the people in your care:

- Identify the person's interests and skills. Ask the person what he or she wants/likes to do. A sample Social Skills form is available from the HCQU to assist caregivers to identify the person's interests, strengths, abilities, and comfort levels in specific situations within the community.
- Listen to what the person says regarding community activities.
- Think about what supports the person will need to achieve the goal, and make a plan to provide these supports.
 - » Think about the skills required for the person to function successfully in the desired goal and make a plan to assist the person to gain/improve the skills if they do not already exist.
 - » Look at the person's physical capabilities and determine if the desired activity meets the person's needs. If there are barriers, can adjustments or accommodations be made to achieve the goal?

Another way to enhance community participation is to encourage individuals with I/DD to have self-determination and self-advocacy. Self-determination is defined as people having the degree of control they desire over those aspects of life that are important to them. Caregivers can assist those with I/DD to achieve self-determination by listening to what they say and developing a plan to help them reach their goals. Sarah achieved self-determination with the help of her caregivers.

Sarah's Story

Sarah is a 62-year-old female with cerebral palsy and lives in a group home in the country. Sarah uses a wheelchair for mobility. During the holidays, Sarah enjoys working at her craft table creating holiday cards for her family, friends and staff.

During the past year, Sarah has had several infections of her lower legs from cellulitis. Sarah told her caregivers she doesn't want to do any exercises recommended by physical therapy to increase circulation of her lower extremities because she is depressed and doesn't feel like doing anything.

One day Sarah stated, "What's the use, nothing is going to change anyway." Caregivers asked Sarah what things made her happy and what things made her unhappy. Sarah replied, "I don't like living in the country – it's lonely. I like the city like where I grew up, with lots of people. I wish I could have my own business. I'd like to be my own boss and earn my own money."

Sarah's caregivers talked with their agency and arranged for Sarah to have a visit with another individual, Mary, who lives independently in a city setting. Sarah and Mary became best friends and visited each other once a week and talked every evening on the phone. Sarah started to do the exercises recommended by physical therapy, and she did not have any more infections in her legs.

Eventually the agency was able to arrange for Mary and Sarah to move in together. Caregivers then talked with a local church who ran a craft shop in the neighborhood. Sarah met with the church and she showed them the beautiful cards she made. Sarah began selling her cards and is volunteering to help run the craft shop. At her last ISP meeting Sarah thanked her caregivers for helping her to live her dream.

"A person who is severely impaired never knows his hidden sources of strength until he is treated like a normal human being and encouraged to shape his own life."

(Helen Keller, 1955)

Caregivers can assist people with I/DD to be active members of their communities, doing things that interest them and hold meaning for them. The first step is to listen to what the person wants, and then use resources, thought, and creativity to make it a reality for the person. In doing so there will be benefits both to the community and to the person.

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Is Simply Participating in Activities Enough to Help People Feel Better?

Erin Sass, Behavioral Clinical Educator

Mary lives in a group home and often complains of boredom. When her caregivers suggest doing an activity, Mary resists. When her caregivers suggest a favorite TV show, Mary says, “I’m tired of watching TV.” Mary’s caregivers have become concerned about her behavior and decided to hold a team meeting to figure out how to help. They wondered if the activities being suggested no longer have purpose or meaning for Mary.

In the past, you may have made suggestions for someone to find a hobby, go for a walk, listen to music, or work on a puzzle. Most of us believe that keeping busy or participating in an activity will help someone feel better. The suggestions are well intended, but is it meaningful enough to help someone feel better? Or, when it comes to activities, is there a specific ingredient needed?

People find meaning in their lives through their relationships, spirituality, careers and hobbies. Meaning also comes from connections with others. According to social researcher Brene’ Brown, Ph.D., connection is defined as “the energy that exists between people when they feel seen, heard and valued; when they can give and receive without judgment; and when they derive sustenance and strength from the relationship.” (Brene’ Brown, 2010)

This may be especially true for people whose lives are led by others who make life decisions for them, or who don’t feel they belong. As a result, some people use unhealthy strategies that may result in behavioral challenges to feel connected with others. None of this happens intentionally, but it happens.

Mary's caregivers tried something different. They began asking Mary if she would like to do an activity together. Mary's caregivers sat with her, paid attention to her, listened to her, and showed her that they valued their time with her. Because Mary's caregivers began connecting with her through activities, she happily participated in activities. The connection she felt with another person made the activity meaningful for her.

“Connection is why we’re here; it is what gives purpose and meaning to our lives.”

(Brene’ Brown, 2012)

Most of us can agree that it feels good to feel connected to others. Research has linked social connections to happiness, health, and a longer life. In one study it was suggested that feeling connected with others inspires people to want to do well. When participants in a study felt connected, researchers found that they were more willing to volunteer and/or help others.

Strengthening connections with people you support will not happen without effort. Connecting with others is a skill and, like most skills, requires daily practice. Connections occur when a person feels seen, heard and valued.

- **To see a person** one must embrace the person for who he/she is rather than who they are supposed to be. Let go of inner assumptions about what this person should be doing or what this person needs to do.
- **To hear a person** one must listen actively and not judge or offer advice. Put aside personal agendas so there is full attention on the person.
- **To value a person** show empathy. Try to see the world as this person sees it; try to understand how they might be feeling. Use their perspective when looking for ways to comment and respond. Make an effort to understand how another person is feeling and show them their feelings matter.
- Try these practices every day to help others feel seen, heard and valued:
 - Offer to engage in activities together
 - Give the person your full attention
 - Smile at the person
 - Avoid critiquing how the person is doing, i.e., “Why are you doing it that way?”
 - Ask the person questions about their interests, family, likes and dislikes
 - Be the best listener you can be; listen to hear what is said rather than listen to formulate a response
 - Sometimes, simply being present is enough
 - Help people feel appreciated
 - Avoid offering advice that the person doesn’t ask for
 - Show empathy by asking the person questions about their experiences and what it feels like, (i.e., “When that happened to you, were you upset?”)
 - Validate the person, (i.e., “Feeling sad sometimes is okay. Would you like to talk more about it?”)

We find meaning in many things and often what is most meaningful is the connection that is felt with another person. It is through such connections that people will lead more meaningful lives and be more open to change and growth.

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Health Literacy:

Facilitating the Understanding of Health Information

Margie Grieser, RN, CDDN

Health Literacy is the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed in order to make appropriate health decisions, (Center for Health Care Strategies, Inc. 2013). People with I/DD may require assistance from caregivers to achieve health literacy. The person's ability to read, write, effectively communicate and understand information are essential elements to consider. When a person can understand their health, they are better able to participate in their own health care.

The first article in this series appeared in the fall 2016 edition of this newsletter. The focus was on the barriers for the caregiver in helping the individual to become health literate. The second in a series of three, this article discusses the possible challenges affecting the person, which may make it difficult for them to understand and respond to their health needs. It also offers caregivers strategies to overcome these concerns. Understanding the person and using strategies that can overcome challenges, can provide caregivers with the tools needed to help an individual live an everyday life.

Limitations in Executive Function

Individuals with I/DD may experience limitations in cognitive processes that enable a person to plan, focus attention, remember, and problem solve. Visual and auditory processing, the two most common areas of processing limitations, is how the brain recognizes and interprets information that has been taken in through vision and hearing, (National Center for Learning Disabilities).

Individuals with I/DD may experience the following information processing deficits:

- **Slower processing speed.** Individuals with I/DD may require more time to process what is heard or seen and to formulate a response.
 - **How to Help:**
 - Talk about the information in a quiet place at a time when the individual is ready to learn.
 - Allow for the "18 second rule". It can take 18 seconds or longer for an individual with I/DD to process the information received. When urged to process information more quickly, frustration and anxiety may result due to individual's lack of an "instant" ability to make sense of the information. This behavior can be misinterpreted. Be careful not to interpret a processing delay as a lack of interest or an unwillingness to learn.
 - Use pictures in creative ways to enhance learning. Pictures should be age appropriate and clearly convey the intended message.
 - Repeat the information often.
 - Discover what the individual wants to know and focus only on those questions or comments.
 - Do not overload the person with too much information.
- **Limited ability to understand abstract ideas, time, and complicated language.** People with I/DD think in concrete terms, which means they have difficulty understanding abstract ideas, jargon, slang and many medical terms.

- **How to Help:**

- Use the person's preferred words for body parts and body processes.
- Keep the information as simple as possible.
- Use the simplest words to describe what will happen. For example, instead of skin biopsy use the words skin sample; instead of echocardiogram use the words picture of your heart.
- Avoid slang and jargon words and phrases. Instead of, "Put your John Hancock on the line," say, "Sign the form." Instead of, "Barium slurry they give you", say "Drink the white liquid they give you."

- **Coping strategies.** Too much information or stimulation can cause behaviors that serve as coping strategies for the person. These behaviors may be mistaken as an unwillingness to learn.

- **How to Help:**

- Keep the topic limited to two or three main points.
- Watch for clues that the person may need a break, such as getting up and moving around, or lack of focus on the task at hand.
- Learn and know the signals that the person may be anxious and/or overstimulated. End the learning session if these are noted.

Other Techniques to Enhance Learning and Processing

Reflection and Observation

Reflective practices summarize the two or three main points of the health teaching. Individuals process information more efficiently when repeated. Summarizing helps to put the pieces in place and keeps the information clear. Summarizing will offer the opportunity to engage the individual in continued conversation about the specific health topic.

Observational practices include watching the person demonstrate the information taught or repeat a demonstration if one was given. Caregivers can also observe how the person thinks about information provided. When reflection and observation are used in combination, they help the caregiver to assess the individual's ability to process and understand health information.

When assisting the person to reflect on what was learned the caregiver may decide to:

- Talk more slowly.
- Adapt the time for the attention span of the individual.
- Reflect by summarizing the two or three main points.
- Ask the individual to teach back the main points of information

When summarizing the health care topic, the individual may ask questions. Take one question at a time and answer only the question. Do not try to explain every detail, just the question. If Ron asks, "Why do I have to have a skin biopsy?" The caregiver can answer, "The doctor wants to be sure that little mole is not cancerous." Then listen to the next question, reflect and observe.

If the observations by the caregiver during the teaching session are not the desired response for health literacy, and reflective techniques offer little indication of successful information processing, try, try again! Persistence and patience are two essential qualities of a caregiver, when trying to achieve health literacy.

Reflective practice and observational skills should be used often when assisting an individual with I/DD to learn and grow. The reflective process should not be presented as a quiz or a "fill in the blank" session.

Create a Story

Create a story to help the person understand the information. Make the person the main focus of the story. It lets the person know that this information is important to him or her, since they are the star of the story.

Having the person participate, if they are able, in developing the story provides an opportunity for the person to have “buy-in” of the information provided through the story. The most favorable outcome might be a complete understanding of the health concern as the story allows the caregiver and the individual to review the material multiple times.

There are several tips to putting together an effective story:

- Keep the information in the story positive and upbeat.
- Use simple age appropriate pictures that portray one idea at a time

Rehearsal guides that include pictures and simplified information to convey health care procedures are available at www.hqcu.kepro.com. The guides can be individualized as necessary.

Helpful Apps for Smart Phones, iPads and Tablets

There are applications for smart phones, iPads and tablets that can enhance learning for people with I/DD. Many of these apps are free and can easily be downloaded. An individual who has limited verbalization skills and/or limitations in physical movement abilities may benefit greatly from this approach.

This approach can increase success in making choices and sharing comments and feelings, which will facilitate effective information processing. Motivation to use the app may come from a natural curiosity about it, and those who learn by watching others may learn to use the application themselves after demonstration. These factors may ultimately increase the person’s ability to process health care information.

Search for these applications in the “app store” using the category of special education or medical education. Many applications can be trialed at no cost.

Apps to Consider:

- **Cough Drop** – show medical pictures and has a voice/speaker option
- **Know Your Body** – Is set up as questions and answers or a quiz style format which may suit the direct caregiver
- **SmartEDApp** – Is not specific to health care or health issues but, it does address social interactions
- **Social Stories** – has information on coughing/sneezing etiquette
- **iCommunicate** – use the medical category
- **My Talk Tools** – has a workspace to upload pictures and create communication boards

A processing delay may be challenging to identify and overcome but many adults with I/DD can achieve health care knowledge and be an active participant in their care. Understanding and applying a few basic strategies and tools helps people achieve an everyday life.

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Supporting People with I/DD

As They Age

Cheryl Pursley, RN, CDDN

Recent studies report that the number of adults with I/DD aged 60 and older will likely double from 641,860 in 2000 to 1.2 million by 2030. Due to biological factors, lifestyle choices, and limited access to quality health care, this population is more likely to develop chronic health conditions at a younger age than other adults are. The good news is that health care providers, agencies supporting people with I/DD, and families are increasingly aware of the specialized health care this population requires to support them as they age, (Tinglin, MSc, RN, C.).

It is important to remember that aging does not cause illness or disease; but the effects of aging on the body with genetic predisposition for disease, poor general health, and unhealthy lifestyle choices can contribute to developing a disease.

Listed below are the normal changes that occur from aging and tips to support the person with I/DD to maintain function, independence and quality of life despite the changes.

Vision Changes

- Images are less clear as the lens of the eye becomes denser and cloudier
- Less able to focus on close items as the lens becomes more rigid
- Cataracts may distort color perception
- More difficult to adapt to and see in the dark
- Less able to adapt to glare
- Dry eyes and inflammation or infection of eyelids may impair vision
- Age-related eye diseases such as the loss of central vision, loss of peripheral vision, the thinning of the cornea, and cataracts can effect vision
- Many older people develop diabetes, which can cause a loss of vision.

Tips for Caregivers

- Look for behaviors indicating vision problems such as: squinting, confusion, rubbing the eye, shutting/covering one eye, tilting the head, holding objects closer. Many vision changes occur gradually and individuals may have difficulty recognizing or communicating the changes.
- Provide periodic eye exams
- Use bright and contrasting colors such as yellow, orange, red
- Use contrasting colors or different textures at stairs and other places to assist with decline in depth perception
- Increase lighting levels and arrange lights to focus on individual tasks
- Provide nightlights and large print books.
- Pause and allow time for a person to adjust to changes in light
- Reduce glare by using dull instead of highly polished finishes on furniture and floors

Hearing Changes

- High-pitched tones become harder to hear, which often occurs around 55 and worsens with age, this makes it harder to filter out background noise
- Progressive loss of hearing
- Increase in wax and hair growth in ear canals

Tips for Caregivers

- Look for signs of hearing loss such as turning up the television volume, speaking loudly, retreating from social situations and conversations.
- Check for cerumen (wax) in the ears
- Hearing loss may be correctable with a hearing aid
- To communicate:
 - » Look directly at person when speaking
 - » Speak clearly and slowly in deeper tones
 - » Converse in a quiet place with low background noise
 - » Allow person time to understand what has been heard

Changes in Taste and Smell

- Decreased sensitivity of taste buds so sense of taste declines
- Sense of smell may weaken
- The thirst mechanism may be reduced which can cause dehydration.

Tips for Caregivers

- Look for signs of lack of appetite and weight loss.
- Add more seasoning in foods, but avoid salt.
- Ensure adequate fluid intake to prevent dehydration.

Tips to Enhance Taste and Smell

- Add more seasoning in foods, avoid salt.
- Ensure adequate fluid intake to prevent dehydration.

Changes in the Skin

- Skin becomes thinner, dryer and wrinkles develop
- Loss of the layer of fat under the skin decreases ability to stay warm in cool temperatures
- Sweat glands lose ability to cool body in hotter temperatures
- Brown discoloration (aging spots) increase
- Skin loses sensation to feel pain and a light touch

Tips for Caregivers

- Check for dry, scaly skin, pressure injuries, cuts, and burns.
- Provide good skin care by gently rinsing soap to prevent dry and flaky skin
- Gently dry the skin and apply moisturizing lotion after bathing
- Frequently reposition people unable to move or position themselves to prevent pressure injuries
- Monitor bath water and heating pad temperatures to prevent burning

Changes in Muscles and Bones

- Muscles lose their strength and tone as muscle mass slowly decreases
- Muscles, tendons, ligaments become less flexible
- Bones become less dense and break easier
- Women have higher risk for osteoporosis due to menopause
- People taking certain medications long term, such as some anti-seizure medications, are at greater risk of osteoporosis
- Arthritis becomes more common
- May experience difficulty swallowing due to a loss of control of throat muscles

Tips for Caregivers

- Look for signs of pain and weakness characterized by slowed movement or expressions of pain. Also, look for difficulty swallowing or choking incidents.
- Encourage movement and self-care as tolerated
- Offer regular exercise
- Prevent falls by adding stair railings, non-slip risers on stairs, and non-skid strips or bath mats in bathtubs
- Teach appropriate use of walkers and canes to reduce the risk of injury and falls
- Seating should be comfortable but firm and not too deep
- Discuss ways to reduce osteoporosis with physician

Changes in the Heart

- Slight increase in size and thickening
- Decreased stretching ability of heart muscle
- When heart rate is increased, it takes longer to return to normal level
- Arteries harden and become less elastic causing the heart to pump faster
- Natural pacemaker of the heart loses some cells

Tips for Caregivers

- Look for signs of fatigue, decreased stamina, dizziness, and confusion. Offer activities at a slower pace.
- To prevent dizziness change positions slowly
- Encourage regular exercise
 - » Provide “heart healthy” meals low in saturated fat and salt
 - » Encourage cutting back cigarette smoking
 - » Know the signs and the symptoms of a heart attack

Changes in Lungs

- Shape of rib cage changes
- Decreased elasticity of lungs
- Decreased strength of diaphragm that helps with breathing, this reduces the amount of oxygen inhaled
- Breathing becomes less efficient, and ability to tolerate exercise decreases

Tips for Caregivers

- Look for signs of infection such as an increase in coughing, shortness of breath, increase in amount and color of sputum, increased confusion and signs of sleep apnea.
- Encourage to stop smoking and avoid secondhand smoke
- Encourage deep breathing exercises
- Slow the pace of activities and offer more frequent rest periods
- Stress may cause increase in breathing - help identify stressors and relieve stress
- Avoid airborne irritants
- Follow immunization guidelines for influenza and pneumonia

Changes in the Digestive System

- Less gastric acid is produced causing indigestion and ulcers, symptoms often seen with too much gastric acid
- Stomach holds less food
- Saliva production decreases increasing risk for gum (periodontal) disease
- Constipation is more prevalent due to slowing of movement of contents in large intestine. It is also caused by medication side effects, lack of activity, insufficient fluid intake and lack of fiber in diet

Tips for Caregivers

- Look for constipation and signs of difficulty swallowing. Evaluate fit of dentures that may change as the person ages. Soreness in mouth from ill-fitting dentures may lead to inability to properly chew food, causing the person to avoid nutritious foods that require chewing.
- Provide high fiber and nutrient dense foods
- Schedule regular toilet breaks
- Encourage good oral hygiene
- Discuss incontinence issues and swallowing problems with physician for medical evaluations

Changes in the Urinary System

- Frequent urination due to decrease in bladder capacity and muscle tone. However, incontinence is not a normal part of aging
- Decreased number of filtering cells in the kidney
- Kidneys filter blood more slowly and become less efficient in removing wastes from the blood
- In men, the prostate gland enlarges restricting urinary flow

Tips for Caregivers

- Look for increase in frequency of urination, which may be a symptom of illness such as diabetes or a urinary tract infection. Discuss new incontinence reports with physician.
- Locate nearby toilet facilities that can be quickly accessed
- Implement regular toileting schedule
- Encourage eight glasses of fluid each day unless restricted by physician

Changes in the Immune System

- Decrease in production of cells that respond to new germs and remember them for the future
- Decrease in communication among the various cells and components of the immune system

Tips for Caregivers

- Look for infections that do not heal and report to health care provider
- Avoid crowded areas especially during flu season
- Encourage good hand washing
- Maintain vaccination schedule

Changes in the Nervous System

- Brain and spinal cord lose nerve cells
- Nerve cells send messages more slowly
- Reduction of reflexes and sensation
- Thought, memory, thinking, processing new information slows
- Decreased ability to adjust to internal and external stimuli

Tips for Caregivers

- Look for changes in memory and usual level of functioning. Explore the meaning of nonverbal communication.
- Stimulate the mind and memory by offering activities such as puzzles, songs, social activities, and community outings.
- Remove clutter and decrease environmental stimulation such as loud noises.
- Use visual cues as reminders to perform task
- To communicate:
 - Use simple statements, speak slowly
 - Divide information into manageable portions
 - Repeat or reword statements as needed

Effect on Medications

- Aging causes changes in the liver, kidney and gastrointestinal systems, this has a direct effect on the body's ability to absorb, distribute, and eliminate medications from the body
- May cause toxicity from an increase in levels of the medication in the body
- Side effects from medication increases with the number of drugs an individual takes

Tips for Caregivers

- Look for changes in behavior after medication has been started or dosage increased. Monitor changes that may be attributed to toxicity of medications as the person ages.
- Ensure every physician is aware of all the medications an individual is taking
- Know the reason for each medication and the possible side effects
- Check for drug to drug interactions and food to drug interactions

Promoting good health is important at any age. People with I/DD who are aging, however, may need assistance to understand what this means, why it is important, and how to live healthy. Discussions on nutritious foods, incorporating regular exercise, and encouragement to continue visiting their healthcare providers are ways caregivers can advocate for the quality of life older people deserve.

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Aging: Physical Changes and Care KEPRO HCQU presentation



Finding Reputable Sources for Health Care Information Online

Elizabeth Hobbs, Behavioral Clinical Educator

Perhaps you have experienced a time when you or someone you support was given a new diagnosis, medication, or treatment and you wanted to learn more about it. You turn to the computer, type in keywords to search the internet only to find a long list of sources and links. How do you narrow the choices and decide which ones have reliable information, and which ones do not?

Finding sources

You can cut down on search time by going directly to health related websites that are created and run by the government. These web addresses typically end in .gov and are often created for the sole purpose of educating non-medical professionals. Searching these sites first may tell you everything that you want or need to know. For example, The Centers for Disease Control and Prevention's (CDC) website www.cdc.gov and The National Institute of Health's website www.nih.gov, are two government resources that may be helpful in beginning a search for medical information. These sites also provide information regarding other reputable sources of information that might be associated with the topic you are investigating.

You may also want to consider websites run by educational organizations such as hospitals, universities and medical schools, as well as foundations related to specific syndromes or diagnoses. Typically, these websites provide current best practice standards for care and information focused on a specific condition. The URLs for these sites usually end in .edu or .org. For example, the American Heart Association, www.heart.org, would be a good resource with reliable information on heart disease.

Consider Your Search Phrase

If you are unable to find what you are looking for by searching the above types of websites, then you will probably need to widen your search on the internet. How you phrase the health care information that you are searching for will bring about different search results. Changing your phrasing when you are searching the

internet can be helpful. For example, typing in “treating the common cold” in the online search bar versus “alleviating cold symptoms” produces different search results.

Search Engines

Typically, people have a favorite, but internet search engines themselves can produce different search results for the same phrase. If you are not finding what you want, it can be worth trying a different search engine than the one you typically use.

Identifying Reputable Sources on the Internet

Once you have found sources on the internet you will need to consider how trustworthy the information they contain is. Below are several questions to consider that will help you to evaluate the reliability of information that you are reading.

Who is operating the site? (Organization or Company)

Names alone are not always helpful. Some sites sound official, but are not. Information to these questions can be found either on the website’s “home” page or on the “about” page. You can sometimes find access to these website pages on the bottom, side bar, or top of the website’s main page. It should explain who is running the website and what the purpose of the site is. Remember anyone can create a website. You want trustworthy and accurate information. Why was the site created?

Consider if the site was created for an educational purpose or to promote use of a certain product such as medication or a specific treatment. If a site was created to encourage the use of a product or treatment, it can impact the dependability of the information. Are there ads on the website? If so, are they clearly labeled? If the ads are not distinguishable from the health information, the information may be less reliable.

What do they want from you?

Consider if the site wants information from you. If a site is asking for your information, seek out the site’s privacy policy to find out what they do with your information. As always, be careful about what information you decide to provide about yourself on the internet.

Who is paying for the site?

A site that supports a particular sponsor will be more likely to present information about that sponsor in a positive manner, stating that sponsor is desirable and effective. If this is the case it is unlikely that this resource will provide information about other similar resources or organizations. This can compromise the integrity of information contained on the site.

Is the information reviewed by experts in the field?

Are there people or agencies named in the information? Is their expertise cited; such as what education degrees they hold, who they work for, where have they studied, or researched? Is there a documented editorial or review policy on the website and who provides these services? Having items such as these can point to a higher quality of information. Is there some vague mention of “experts”, but nothing explaining who? This effects the integrity of the information. Ensure that the information is accurate and created from reliable subject matter experts.

Where is the information coming from?

Does the website cite where the authors obtained the information? Information written by others should clearly identify the author and date of creation. Does the information cite studies or articles published in peer reviewed journals? You may need to do a quick check on the references cited to ensure that they are genuine sources. If there are no citations, the information may not be reliable.

Is the site up to date / how old is this information?

Look for dates on the articles or webpages you are viewing. It may contain a “revised” or “updated” date. These are often at the bottom of the content or page. Content that does not have a date or outdated webpages may not reflect the most current and accurate information.

Does the website make claims that cannot be proven?

Are the sources cited in the content from reputable and well documented studies or research? If the information cites vague studies or testimonials without details the information may not be trustworthy.

No matter what information you find, always be sure to consult with your doctor first before making decisions regarding health care. If you experience difficulty finding health care information online, KEPRO’s HCQU is always happy to help. You can contact us via our website at <https://hcqu.kepro.com> or call our office toll-free at **1-888-321-5861**.

For more information on identifying the validity of health information resources online, visit <https://medlineplus.gov/webeval/webeval.html>.

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Supporting an Individual With I/DD and Dementia

Carrie Perrell RN

Thanks to advancements in medicine and improved living conditions, people are living longer than ever before, (NIH, 2015). This is true for all Americans, including those with intellectual and developmental disabilities (I/DD). Along with this trend of longevity comes an increased risk for some individuals to develop dementia.

What is Dementia?

Dementia refers to:

- Progressive and irreversible loss of cognitive function
- Changes in judgment, personality, memory, language, problem solving and attention
- Leads to significant medical concerns
- Eventually causes death due to physical deterioration, illnesses, and/or infections

Common types of dementia include: Alzheimer's, Vascular dementia, dementia with Lewy bodies. There is no cure, but there are medications to treat the cognitive symptoms.

How Will Dementia Progress?

The disease of dementia progresses differently in each individual. Thus, there is no exact timetable which one may follow to know exactly what changes will occur or when to expect them. The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) is a group of experts in the field of I/DD, which was formed to examine information specific to people with I/DD and dementia.

As far as progression, the NTG found:

- People with I/DD and dementia generally are affected by dementia in the same manner as those without I/DD
- Individuals with Down Syndrome have a higher risk of developing dementia
- Individuals with Down Syndrome and dementia may experience a more rapid decline in functional ability
- Life expectancy following diagnosis of dementia may be shorter for those with Down Syndrome (NTG, 2016)

Early Warning Signs:

Early signs of dementia may be vague or subtle and caregivers may overlook or dismiss them. Some of the signs include sporadic memory loss, getting lost, problems with walking, confusion, frustration, impatience, and personality changes. A person experiencing early symptoms of dementia may ask the same question repeatedly, forget or mix up words, take longer to complete a task, lose items, experience mood changes, or be unable to follow directions.

Behavioral changes can be due to an undiagnosed medical or mental health issue. Documenting and reporting changes to the person's primary care physician (PCP) or as per agency protocol, would be a best practice to ensure the health and safety of an individual and helps the doctor provide an accurate diagnosis.

Screening Tool:

The NTG developed an Early Detection Screen for Dementia, (NTG-EDSD). This is not a diagnostic tool but rather a tool for documenting changes in a person's functional abilities and health for review and discussion with the individual's PCP. It can be used when signs are noted and/or as a tool to establish a person's baseline. NTG recommends completing the tool to establish a baseline at age 40 for people with Down Syndrome and at age 50 for all other individuals with I/DD. For access to this tool and to a variety of resources and educational materials related to individuals with I/DD and dementia, visit <http://aadmd.org/ntg/screening>.

Supporting a Person with Dementia:

Supporting a person with I/DD and dementia involves meeting the person's current needs as well as anticipating and planning for the person's needs as dementia progresses. Progression of this disease is typically referred to in stages. The Alzheimer's Association at www.alz.org has extensive resources and information about the stages of dementia and ways to support individuals through all the stages.

The stages and a few caregiver considerations for each stage are listed below:

Early stage dementia: In the early stage a person may function independently but with lapses of memory, increased confusion and anxiety, communication difficulties, reduced zest for life, (NTG, 2013). This person may misplace items and have difficulty performing tasks.

- Caregivers' focus of care:
 - Adapt environment to person's abilities:
 - » Remove clutter
 - » Organize house and furniture
 - Consider environmental changes which will accommodate future needs:
 - » Specialized equipment
 - » Wheelchair accessibility
 - Engage in advanced care planning

- Keep familiar possessions nearby
- Caregiver education:
 - » Communication
 - » Modification of expectations
 - » Safety
 - » Changing behaviors as dementia progresses

Middle stage dementia: Further decline is noted in this stage though abilities may fluctuate. For instance, a person may remember what to do with a toothbrush in the morning, but be confused about its use in the evening. Behavioral changes include outbursts, mood changes, sleep changes, wandering, agitation, restlessness, pacing, suspiciousness, forgetfulness, and poor bladder/bowel control. Communication becomes more difficult as the person has trouble understanding and being understood.

- Caregivers' focus of care:
 - Increase supervision to maintain safety
 - Increase assistance with activities of daily living:
 - » personal hygiene
 - » meals
 - » toileting
 - » dressing
 - Offer encouragement and opportunities for the person to perform tasks independently
 - Speak calmly
 - Enhance quality of life and safety by engaging the individual in enjoyed activities
 - Follow a routine
 - Attempt to understand behavior; is the person hungry, fearful, stressed?
 - Observe and document change- report to physician
 - Change consistency of food as per physician recommendation when chewing/swallowing difficulties noted

Late stage dementia:

During the late stage a person with dementia will need help with all self-care. This person will eventually be unable to sit, walk, and may experience seizures. This person will need full time care as this person will have difficulty eating and drinking, is susceptible to infections, and loses the ability to communicate.

- Caregivers focus of care:
 - Total care 24/7:
 - » feeding
 - » dressing
 - » hygiene
 - » positioning
 - » hydration
 - Maintain skin integrity-keep clean, dry and moisturized, follow a re-positioning schedule
 - Observe for signs of pain and respond according to care plan - pain medication may be more effective taken on a regular basis rather than as needed
 - Consult occupational/physical therapists to acquire equipment to safely move, support, transfer the person
 - High touch care - talking, holding hands, staying close to the person
 - Care for the caregiver - watch for signs of stress burnout, identify self-care methods and coping strategies, seek assistance when needed

While this article highlights the stages of dementia and offers some care tips, a caregiver for someone diagnosed with dementia would be well advised to further his/her knowledge on the topic. This knowledge will help the caregiver support the person with dementia to live safely with dignity and preserve their quality of life.

The HCQU has compiled a dementia care handbook, which includes the NTG-Early Detection Screening for Dementia along with additional care tips and environmental suggestions for each stage of dementia.

Your local HCQU nurse can provide you with a copy of this handbook and can also provide an instructor-led training on dementia. To schedule a training, visit https://hcqu.kepro.com/content/pages/training_request.aspx and click on “request a training.” To receive contact information for your local HCQU nurse, call **1-724-864-3750**.

KEPRO Southwestern Pennsylvania Health Care Quality Unit (Kepro HCQU) also offers an online training on Dementia. To sign up, visit https://hcqu.kepro.com/content/pages/online_training_registration.aspx.

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Brian J. Leech, MS, Behavioral Clinical Educator

A Health Care Quality Unit (HCQU), like the KEPRO Southwestern Pennsylvania HCQU, is an agency that helps individuals with intellectual and developmental disabilities (I/DD) to live an everyday life by working with those who care for them.

The staff of HCQUs includes clinical educators (nurses and behavioral consultants) who have extensive training in working with people who have intellectual and developmental disabilities, as well as other physical or mental health issues. HCQUs offer caregiver and self-advocate trainings on medical and mental health topics, with the goal of helping individuals to be as healthy as they can to enjoy an active life in the community.

HCQUs began in 2000 and were based on a program run by Philadelphia Coordinated Healthcare. The overall goal of HCQUs is to help people with I/DD find good physical and mental health care. To do that, the KEPRO Southwestern Pennsylvania HCQU offers trainings and information that caregivers can use to better understand an individual's behavior, wants, and needs.

These services are free of charge and can include:

- **Trainings** – These are offered on medical and mental health topics that focus on best practices for supporting people with I/DD who have a variety of health conditions. (A full list of trainings is available at KEPRO HCQU's website at https://hcqu.kepro.com/content/pages/online_courses.aspx. The website allows caregivers to view samples of the PowerPoints for each topic to see if the training would be helpful. Online trainings are offered as well, which caregivers can take at their convenience for credit and training hours. Online trainings can be found at https://hcqu.kepro.com/content/pages/online_training_registration.aspx.
- **Capacity Building** – The HCQU works to help increase the ability of agencies and caregivers to meet the needs of people with I/DD. There is an emphasis on working with healthcare professionals, and prior projects have included working with occupational therapy students at Duquesne University, training the entire nursing department on best practices for interacting with people who have I/DD to reduce restraints at a large local hospital, training employees of a local health insurance plan on how to work

with people who have I/DD and how to navigate the ID system, and training for social workers and counselors to increase their effectiveness in working with individuals who have I/DD and mental health concerns. Most recently, the HCQU trained staff on a psychiatric unit at a local hospital in best practices for interacting and communicating with those who have I/DD.

- **General & Complex Technical Assistance** – The HCQU’s nursing and behavior staff also work with teams who are experiencing challenges supporting someone with ongoing medical, behavioral or psychiatric issues. The HCQU can provide suggestions on ways to deal with issues that can affect an individual with I/DD. This can be done by providing general information on a condition or topic important to an individual’s care, or through meetings to help the team and the individual explore different approaches and ideas. In both cases, the goal is to provide tools to the team that help improve the individual’s quality of life. However, it is important to remember that the HCQU cannot provide direct treatment, diagnosis, or create behavior plans for individuals. Only suggestions are provided; it is the responsibility of the team to determine if those suggestions are helpful or worth considering. To get in touch with the KEPRO HCQU, please call **1-888-321-5861** or visit <https://hcqu.kepro.com>.

HCQUs can provide a great deal of information, resources and support for individuals and caregivers to help an individual live their best life.

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