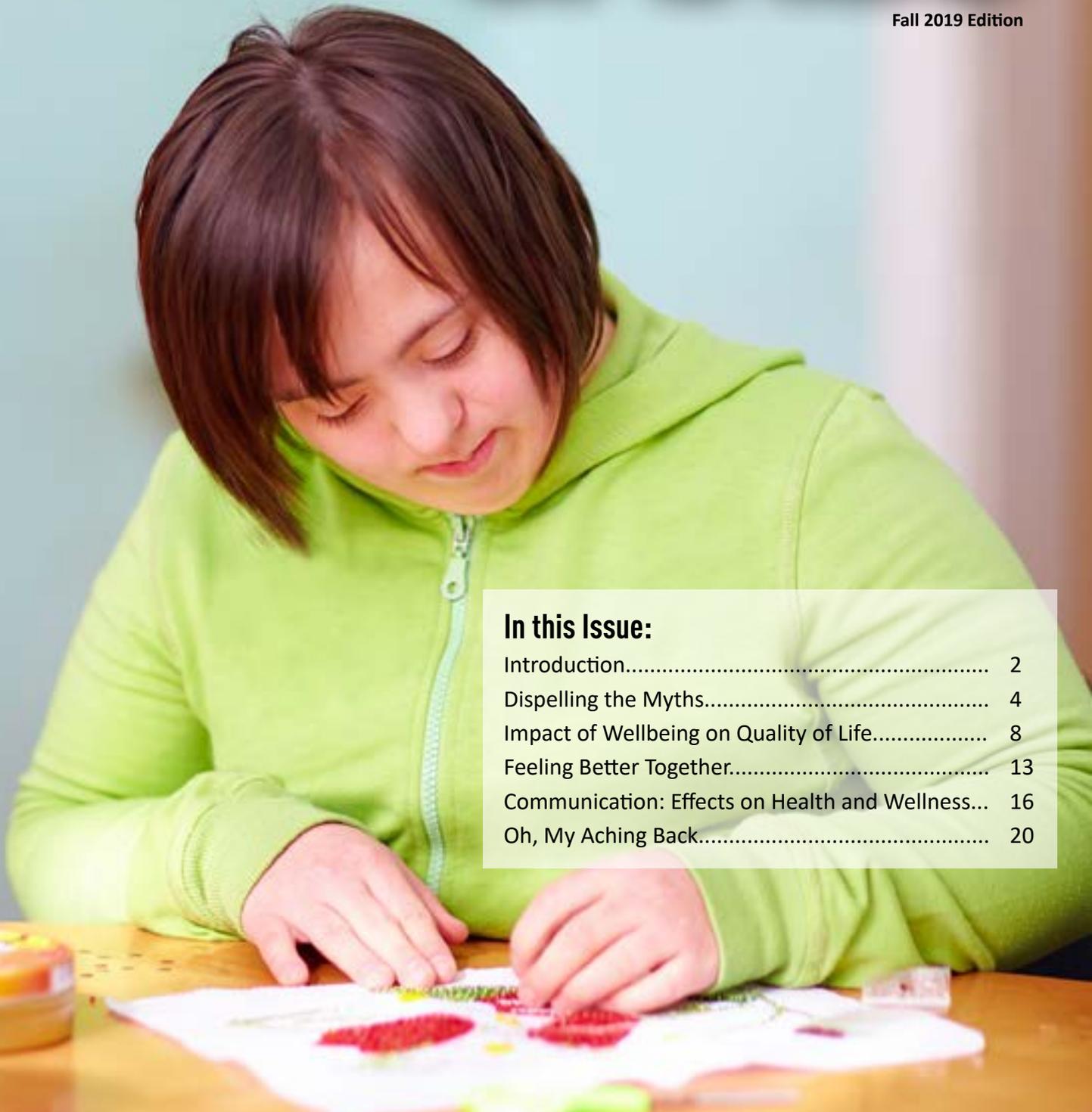


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In this Issue:

| | |
|--|----|
| Introduction..... | 2 |
| Dispelling the Myths..... | 4 |
| Impact of Wellbeing on Quality of Life..... | 8 |
| Feeling Better Together..... | 13 |
| Communication: Effects on Health and Wellness... | 16 |
| Oh, My Aching Back..... | 20 |



Health and Wellness

INTRODUCTION

By: Lydia Lingis, BSN, RN

Health, or the absence of illness and injury, is determined to some extent by factors one cannot control. For example, genetics can increase one's risk for developing high blood pressure, diabetes, high cholesterol, and heart disease. On the other hand, wellness is a choice. By choosing to eat healthier foods and exercise regularly, we can work toward being as healthy and happy as possible.

Many factors contribute to overall wellness, such as relationships, nutrition and diet, and body mechanics. For individuals with intellectual and developmental disability (I/DD), wellness often is influenced by chronic pain, barriers to communicating health concerns with healthcare providers, and myths that surround health and wellness for individuals with I/DD, as well. However, according to the American Association on Intellectual and Developmental Disabilities, "People with intellectual disability and developmental disabilities have begun to participate in their own health promotion and disease prevention activities and are learning to advocate for their own health" (Health and Wellness for People with IDD, 2015).

Consider the story of James Stephen Love:

Stephen is a young man receiving services from a community-based organization that launched an evidence-based health promotion program to address emerging health concerns among people with I/DD. Initially, Stephen had no interest in participating in the new health promotion program; but, after observing the classes, he approached the instructors and asked to participate. He was informed it was too late to join the class that had already started, so he recruited other peers to begin a new one. With the support of the program and others, Stephen was able to make healthy changes to his own behaviors (Health and Wellness for People with IDD, 2015).

By starting a new health promotion program, Stephen changed his health and wellness for the better and encouraged his peers to improve their overall health and wellness, too. Upon completing the program, Stephen wrote a poem, "The Way I Used to Be," to express his experiences in learning about his body, developing skills to take care of himself, and becoming motivated to reach new goals (e.g., exercising, eating healthy foods, and losing weight).



The Way I Used to Be

By James Stephen Love

I used to be as big as a tree

Just like my whole family

They would fill themselves with cakes and pies

And never want to exercise

When I wanted to lose weight

They called me names and filled me with hate

You're not going to lose weight you idiot

You're going to be fat like us you twit

But that drove me to work hard

I pushed myself from the start

I worked hard, fast, and quick

I was losing weight by the look of it

Now they look at me with pain

At the falsehood of what they say

You can do what you envision

You just need will and good motivation

This issue of HCQU CARES offers information and tools to assist caregivers to support people with I/DD in the journey toward wellness.

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Dispelling the MYTHS

By: Patty Kinney BSN, RN

What is wellness? Many people think of wellness as a clean bill of health from their primary care doctor after an annual physical, but it is so much more than that. Wellness takes into account every facet of a person’s life. According to the Substance Abuse and Mental Health Services Administration (SAMHSA), there are eight dimensions of wellness, all of which overlap and affect one’s overall quality of life. The dimensions of wellness are:

- Emotional: Optimism, trust, determination
- Environmental: Pleasant, safe environment that encourages good mental and physical health
- Financial: Understanding and having good financial habits
- Intellectual: Expanding creative abilities; utilizing knowledge and skills
- Occupational: Satisfaction from one’s work, whether paid or volunteer
- Physical: Physical exercise, quality sleep, healthy diet
- Social: Having a support system, friendships, social connections
- Spiritual: Creating and maintaining a healthy support network; being genuine and authentic with others. (SAMHSA, 2016)

Achieving and maintaining wellness in every dimension can be difficult for anyone, and people with I/DD often need the support of others to do so. Unfortunately, there are many misconceptions about people with I/DD and wellness – myths that need dispelled. So, to set the record straight, let’s start myth-busting!

Myth 1 – Emotional: People with developmental disabilities are not our equals.

The belief that people with I/DD are “less than” people can lead to exclusion of people with I/DD from participation in the community. Exclusion from activities such as gym memberships and aerobic classes can cause not only emotional pain but physical harm, as well, since it might discourage individuals from being

physically active. According to Michael Crawley of Think Inclusive, an educational consulting company, this myth is the most damaging of all. “It is a cruel and heartbreaking misrepresentation that is disrespectful and does a disservice to both individuals and society alike” (Crawley, 2017).

- ☑ Reality: Michael Crawley’s article stated the truth simply and clearly – “Our shared humanity makes us all equal – with no exceptions” (Crawley, 2017).

Myth 2 – Environmental: people with I/DD should live in institutions.

For years, society thought people with I/DD were not capable of living safely without constant, professional supervision. As a result, it was believed that it was best for everyone if they resided in institutional settings.

- ☑ Reality: Although there are some people with I/DD who need 24-hour support and supervision, many are able to live safely and independently in the community or with their families (Crawley, 2017). According to The Association of University Centers on Disabilities (AUCD) and the American Association on Intellectual and Developmental Disabilities (AIDD), institutional settings have “negative outcomes for the health, wellbeing, quality of life, independence and overall happiness of people with I/DD” and “more than 3 out of 4 people with I/DD of all ages live in the home of a family member” (AUCD and AIDD, 2015).

Myth 3 – Financial: Individuals with I/DD cannot manage money.

Some people interpret the statement that I/DD is “characterized by a limited mental capacity and difficulty with adaptive behaviors such as managing money...” (NIH, n.d.), to mean that people with I/DD are unable to manage money.

- ☑ Reality: The ability of people with I/DD to manage money ranges from needing little or no help to needing someone to manage it for them, depending on their level of disability. The main thing is to let them be as independent as possible; let them manage their finances to the best of their ability so that they have a sense of self satisfaction.

Myth 4 – Intellectual: People with I/DD cannot learn.

The notion that people with I/DD cannot learn might be rooted in the fact that people with I/DD do not comprehend information as quickly and in the same manner as people who do not have I/DD.

- ☑ Reality: According to the authors of “Myths and Facts about Intellectual Disability”, people with I/DD are able to learn and make academic gains in integrated classroom settings. Supports for learning should be person-centered, based on the person’s capabilities and needs, and might include a slower pace, repetition, and the use of simple language and pictures (Carey and Jones, 2016).

Myth 5 – Occupational: A person with I/DD couldn’t meet performance standards to have a job which would give them personal satisfaction.

Historically, society has had low expectations with regard to individuals with I/DD being capable of performing the tasks necessary to maintain regular employment and their ability to gain a sense of personal satisfaction through employment.

- ☑ Reality: According to The Institute for Corporate Productivity report, *Employing People with Intellectual and Developmental Disabilities*, 75% or more of employers who had employed people with I/DD rated them as good or very good on most performance factors. In this report, a self-advocate stated the skills he learned on his bank job gave him confidence to be a leader and to inspire others (Institute for Corporate Productivity, 2014).

Myth 6 – People with I/DD can't achieve health and wellness.

This myth is perpetuated by continuing health disparities for people with I/DD. People with I/DD are at higher risk for certain health conditions; there is inadequate education related to I/DD for healthcare professionals; not all medical equipment and facilities are physically accessible for people with disabilities; and people with I/DD have limited access to healthcare providers and medications due to insurance programs.

- ☑ Reality: With the right supports, people with I/DD are able to achieve health and wellness. There are many strategies and tools in use to promote the health of people with I/DD. One example is Special Olympics' Healthy Athletes program, through which individuals who are competing in Special Olympics receive screenings from volunteer health professionals in the areas of vision, dentistry, podiatry, sports physical exam, emotional well-being, audiology, and better health and well-being. This program has "trained more than 260,000 health care professionals and students in how to treat and interact with people who have I/DD, and these practitioners then take the skills they learned back to their community settings to provide quality care to people who have I/DD." (Special Olympics, 2019)

Rehearsal guides are a resource the KEPRO HCQU offers to assist caregivers to familiarize individuals with I/DD about common health screening tests, such as mammogram and colonoscopy, to increase the likelihood of the individual's participation in the test. Rehearsal guides contain realistic pictures and clear, brief instructions for guiding a person with I/DD through an up-coming health care appointment. Rehearsal guides are available for downloading at <https://hcqu.kepro.com/resources/rehearsal-guides/>.

Myth 7 – Social: People with I/DD do not require relationships.

Adults with I/DD often have been perceived and portrayed as childlike and, therefore, lacking the desire and need for companionship and intimate relationships.

- ☑ Reality: "People with I/DD desire companionship, community inclusion, and intimate relationships with others. They are more like us than not." (KEPRO, 2017).

On April 30, 2019, The Washington Post published an article about Kris and Paul Scharoun-DeForge, both born with Down syndrome, but neither willing to let it define them (Gormly, 2019). Because they had I/DD, Kris and Paul were required to complete tests and classes to prove they understood consent and the commitment of marriage before the state permitted them to marry. They were happily married for 25 years. The article is available at https://www.washingtonpost.com/lifestyle/2019/04/30/this-couple-may-have-had-one-longest-marriages-any-pair-with-down-syndrome-possibly-one-happiest/?tid=ss_mail&utm_term=.49b02cb6a410.

Myth 8 – Spiritual: People with I/DD don't understand or can't comprehend death, and talking about it is too upsetting.

There are people who think I/DD prevents individuals from understanding the concept of death; they believe people with I/DD do not grieve and that it is better to avoid talking with them about death so as not to upset them.

- ☑ Reality: People with I/DD experience grief in the same way as everyone else, except the effects might last longer and they might experience more anxiety, depression, irritability, or other signs of stress (Vanderbilt Kennedy Center, n.d.). While some individuals with I/DD might not display typical outward signs of grief, their grief can manifest as changes in sleeping and eating patterns, withdrawal, and decreased interest in doing preferred activities. A guide to support someone with I/DD to cope with the death of a friend or loved one is available at <https://vkc.mc.vanderbilt.edu/assets/files/tipsheets/copinglosstips.pdf>.

Myths like these have the power to marginalize people with I/DD, causing them to be viewed as separate, different, less productive members of society. Caregivers who know the individuals they support know that each individual's wellness is comprised of the same eight dimensions as the wellness of any other person. By supporting individuals to work toward improving their health and wellness, caregivers are helping to dispel the myths and empower people with I/DD to achieve their hopes and dreams and live everyday lives.



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The Impact of Wellbeing on QUALITY OF LIFE

By: Margie Grieser, RN, CDDN

Wellbeing is a term that refers to an overall sense of happiness, health, comfort, contentment, success, and stability. While different people might have different ideas about what makes them happy, common contributors to feeling good and having a positive outlook on life include:

- Fairness of opportunities
- Ability to adapt to change
- Overall good health, including sufficient sleep, exercise, and nutrition
- Sense of purpose
- Enjoyable activities
- Spirituality
- Connections to family, friends, community
- Positive relationships
- Fulfilling career
- Financial security (Hall, 2014)

The Centers for Disease Control (CDC) associate a higher level of wellbeing with a lower risk of disease, illness, and injury. Wellness has been shown to improve immune system functioning, recovery times, certain mental health disorders, and longevity (CDC, 2018). Likewise, the presence of disease negatively influences wellbeing and quality of life. To focus on and emphasize the significant impact of health and disease on wellness and

quality of life, the concept of health-related quality of life (HRQoL) evolved. HRQoL takes into consideration the effects of health and disease on a person’s physical, mental, emotional, and social functioning (Healthy People 2020).

In its *Everyday Lives: Values in Action* publication, the Pennsylvania Office of Developmental Programs (ODP) declared that, “People with disabilities have the right to a life that is no different than that of all other citizens.” It stated that, “An everyday life is about opportunities, relationships, rights, responsibilities, being a member of the community, having a valued role, making a contribution to society, and having rights fully respected” (Everyday Lives, 2016). When people with disabilities experience the components of an everyday life, they have a greater opportunity to experience wellbeing. It is the responsibility of caregivers and support teams to assist individuals with I/DD to actively seek to achieve wellbeing.

What People With I/DD Say About Their Lives

Independent Monitoring for Quality (IM4Q) is a program guided by the principles of Everyday Lives and used by ODP to collect information to monitor the satisfaction of individuals with I/DD with services received, ensure their health and safety, improve their quality of life, and develop services that promote choice, control, and everyday lives. The program asks people with I/DD and their family members questions related to various topics – satisfaction; dignity, respect and rights; choice and control; relationships; and inclusion. There are additional questions that are answered by family members (with the individual’s consent) and the Supports Coordinator.

IM4Q data reported for the fiscal year 2017-2018 indicated 5,354 people with I/DD participated in face-to-face interviews for IM4Q. The summary section of the 2017-2018 IM4Q report spoke to factors related to wellbeing:

- Participants reported high levels of satisfaction, with most responding they are happy and the people in their lives are nice to them.
- Most participants reported high levels of privacy, with an increased number indicating they can see friends, date, and get married if they want to.
- Less than half of the participants indicated they go out into the community weekly; when they do, it is with family or other caregivers.
- More than one-third of the participants responded they are lonely at times.
- Most participants reported high levels of access to general health and dental care; however, 39% reported they experienced difficulty if they chose to see a medical specialist.
- One in ten participants indicated they were employed, while one in three who were not employed said they would like to have a job.
- More than one-third of the participants did not feel all of their caregivers understood their communication.

Importance of Community

Belonging is the feeling of being connected to and accepted by others. Research shows that people who feel connected to their communities are less likely to experience poor health and challenging behaviors (Belonging Guide, n.d.). Relationships can increase self-esteem, improve self-confidence and self-worth, reduce stress, help one cope with difficult experiences, and reduce the risk of depression, high blood pressure, obesity, and

other serious health conditions (Mayo Clinic, 2019). In fact, “[h]aving supportive relationships is one of the strongest predictors of well-being” (CDC, 2018).

The IM4Q report mentioned above demonstrates that improvements to community participation – especially with regard to employment, access to full health care, and participation in community groups – can improve the quality of life experienced by individuals with I/DD. People who have opportunities to participate in their community tend to feel a greater sense of belonging.

Tips for Community Participation

The following are actions caregivers might take to promote relationships and community interaction for individuals they support.

- Adopt a mindset of a health promoter
 - Model healthy habits.
 - Encourage others to be active, eat well, and act respectfully towards each other.
- Interact with people in a way that makes them feel respected and accepted
 - Listen to what they say through their conversations and actions.
 - Assist them to meet their goals and dreams.
- Attend community events and be present in the community
 - Look for community organizations offering community activities or clubs that might be of interest to the individual; encourage participation in meetings and activities.
 - Ask questions like, “Where do you want to go?” or “What do you want to do?” to provide opportunities for choice and control; direct activities to support the individual’s personal goals.
 - Go for a walk or visit the local park with individuals to encourage interaction with others in the community.
- Volunteer
 - Ask what the person is interested in doing; assist the person to arrange the activity.
 - Offer information about the needs of individuals with I/DD to prospective organizations with volunteering opportunities, to increase the likelihood of positive interaction during activities.

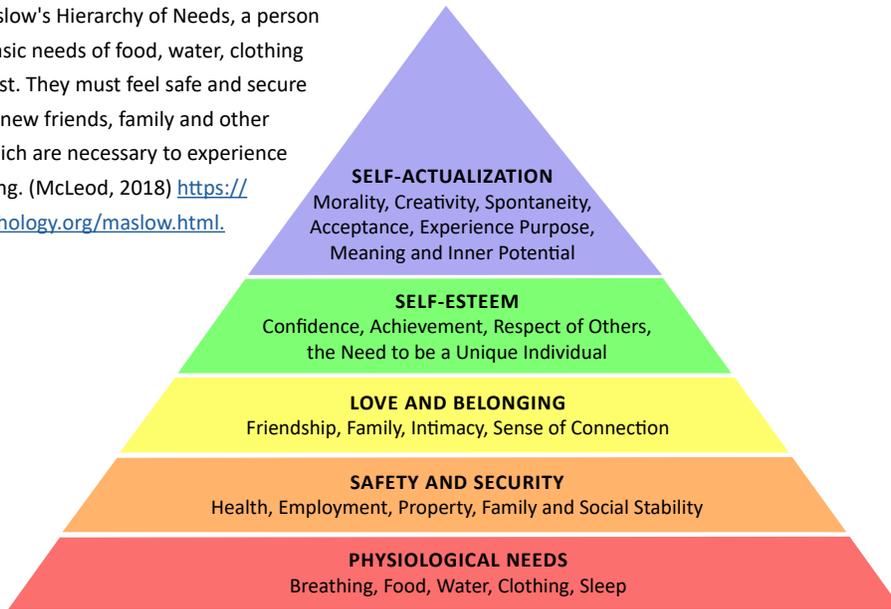
Tools for Monitoring Wellness and Quality of Life

Quality of life can change many times throughout the course of a lifetime. Regular monitoring can help caregivers to detect and address factors that might compromise an individual’s health and wellbeing. Tools available to assist caregivers and individuals to monitor life satisfaction and quality include:

- **Maslow’s Hierarchy of Needs**, illustrated below, explains how a person’s most basic needs (breathing, food, water, sleep) are the foundation upon which more complex needs depend. If a person’s basic, fundamental needs are not satisfied, the person is unable to build upon them to experience fulfillment of needs that create a sense of safety and security. Likewise, the needs that provide a sense of safety and security must be satisfied before a person can experience love and belonging. A person must meet the needs of each preceding level of the pyramid in order to focus on the next level; if circumstances occur that threaten the fulfillment of needs at a lower level, the person will focus on the unmet needs at that level until they are fulfilled again, after which work toward fulfillment of needs at a higher level may resume (McLeod, 2018).
- Caregivers can use the Hierarchy of Needs pyramid to identify which needs are being met and which are not. This enables them to work with the individual to consider ways to meet unmet needs and develop a

plan to ensure the individual experiences the best possible health and quality of life – the highest level on the pyramid (McLeod, 2018).

- According to Maslow's Hierarchy of Needs, a person must have the basic needs of food, water, clothing and sleep met first. They must feel safe and secure before exploring new friends, family and other relationships, which are necessary to experience love and belonging. (McLeod, 2018) <https://www.simplypsychology.org/maslow.html>.



- The **Satisfaction with Life Scale (SWLS)** tool can be used to assess a person's satisfaction with life based on responses to the questions. The questions should be answered openly and honestly to get the best results. Monitoring the individual's perceived quality of life can complement other monitoring techniques, assisting health professionals to obtain a better understanding of a person's overall wellbeing. The Satisfaction with Life Scale (SWLS) tool is available at: <https://www.thecoachingtoolscompany.com/products/life-satisfaction-scorecard-template/>
- A **Wellness Scale** tool helps a person assess his or her own wellness and identify opportunities for improvement. The tool divides wellness into "dimensions" – physical, social, emotional, spiritual, intellectual, environmental, occupational, and financial. (Not all versions of the tool include all eight dimensions.) Though useful, this tool is more involved than the others and requires more time to complete. Because individual people might prioritize the wellness domains differently, this tool enables a person to select the domain on which he or she would like to focus for improvement. One Wellness Scale tool is available as part of the training materials for the HCQU's Wellness Overview training; another is available at: <https://umatter.princeton.edu/sites/umatter/files/media/princeton-umatter-wellness-self-assessment.pdf>

Wellbeing takes into account the status of all aspects of a person's health – physical, mental, emotional and social – and reflects his or her degree of happiness and satisfaction with life. A sense of wellbeing is fundamental to overall health; it can motivate a person to overcome worry and illness and encourages more holistic approaches to health awareness and disease prevention. The IM4Q program, in effect, measures the wellness of people with I/DD and indicates that individuals with I/DD want to participate more fully in the activities, services, and opportunities available in their communities. By supporting the wellness of people with I/DD, caregivers are supporting individuals to live everyday lives.

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Feeling Better TOGETHER

By: Heather Capo, BSN, RN

It can be hard... hard to make the choice to order healthier food options when at a restaurant; hard to push the cart past the convenience food freezer or snack aisle in the grocery store without stopping; and hard to turn off the television and put on sneakers for an evening walk or a trip to the gym. It can be even more difficult for people to make such choices when they feel they are doing them alone, without encouragement and support of such efforts to improve their health. Healthy eating and physical activity are key components for overall health and wellness, yet many find it difficult to incorporate these components into their daily activities.

For various reasons, obesity is more prevalent in people with I/DD, increasing their risk of developing serious medical conditions (Doherty et al., 2017). Perhaps the complexity of medical and emotional needs of an individual with I/DD overshadow the more basic elements of wellness. Given their large social role in the lives of people with I/DD, caregivers have the potential to influence the health behaviors of the people they support (Leser et al., 2018). Caregivers who assume the role of model, coach, and encouraging partner can lead individuals toward improved health and wellness. In fact, adding caregiver support and participation to healthier food choices and increased physical activity significantly decreases the weight, waist circumference, and sedentary behaviors documented in participants with I/DD (Salomon et al., 2018).

A recent study offered a group of individuals with I/DD and their caregivers the opportunity to learn new skills related to making healthy choices, food preparation, and kitchen safety. Six months later, many individuals and caregivers continued to use the skills they had learned to make healthy food choices, prepare meals, and eat a more balanced diet; and they reported confidence in their skills and satisfaction with the approach of learning together (Barnhart et al., 2019). Working and learning together helps motivate individuals and caregivers to make choices to improve their health and wellness.

Although physical activity contributes to improved cardiovascular health, muscular strength, balance, and weight loss, many people find that establishing and maintaining a routine of regular physical activity can be challenging. People with I/DD often experience additional barriers that can keep them from participating in activities. For some, these barriers might include the level of mobility necessary to participate, cost of gym membership, or access to transportation. For others, the feeling of being perceived as “different” from other participants might be too uncomfortable.

To assist individuals and caregivers to navigate around barriers to physical activity, organizations like the National Center on Health, Physical Activity, and Disability (NCHPAD) have websites that offer a wealth of information related to physical activity and incorporating exercise into the lifestyle of people with disabilities and mobility challenges. The NCHPAD website also offers information on maintaining a healthy diet and cooking resources for people with disabilities and their caregivers. Many “workout at home” videos are available online, as well – even some led by individuals with I/DD. Furthermore, exercise materials often include instructions for modifying exercises to accommodate physical limitations.

■ www.nchpad.org - Founded in 1999, the National Center on Health, Physical Activity and Disability (NCHPAD) is a public health practice and resource center on health promotion for people with disability.



Leading and encouraging people toward healthier choices does not mean they will be willing to accept or participate in them. One of the leading barriers reported by caregivers as preventing them from keeping an individual’s diet aligned with the physician’s recommendations for overall health and wellness is the fear of violating the individual’s rights (Leser et al., 2018). While the Office of Developmental Programs (ODP) upholds each individual’s right to make decisions, it also maintains that provider agencies are responsible for maintaining the health and safety of the individuals they support.

Techniques to encourage individuals to follow dietary and physical activity plans include:

- Offer educational resources to help the individual and family members understand why the plan is necessary.
- Request the individual and caregivers receive training on nutrition, meal planning, and/or physical activity.
- Model physical activity and healthy eating in a fun, interactive way.
- Be an active participant in the individual’s wellness efforts.
- Consider using motivational charts to illustrate progress and promote adherence to nutritional and/or physical activity goals.
- Celebrate small successes, such as pounds/inches lost, achievement toward goals, improvement in health, improvement in physical endurance, and improvement in attitude toward healthy lifestyle habits.
- Reinforce the need for all caregivers, family members, and visitors to be “on the same page” and try to avoid bringing food items that are not included in the person’s meal plan into the home.
- Include and account for occasional treats in a dietary plan, to reinforce the concept of moderation. Seek physician approval if the dietary plan was prescribed for reason(s) other than weight management.

It is easier to make lifestyle changes that support health and wellness when others support and participate in the effort. Caregivers who support individuals with I/DD to make positive changes toward overall wellness contribute to their own emotional wellness and might even experience the benefit of improved physical health, too.

Links to dietary and fitness resources:

- [20 Simple Steps to Improving Your Diet: Simple Substitutions](#)
- [Food Labels: Nutrition Fact Labels](#)
- [Better Nutrition in the New Year: Setting Yourself up for Success](#)
- [Strength Training Video for People with Intellectual Disabilities: Upper Body Exercises](#)
- [Strength Training Video for People with Intellectual Disabilities: Lower Body Exercises](#)
- [Home Exercise Videos: Cardiovascular Activity](#)
- [Fall Injury Prevention: Modes of Exercise](#)

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COMMUNICATION: EFFECTS ON HEALTH AND WELLNESS

By: Pamela Lodge, RN

Communication – the sending and receiving of messages – is vital to a person’s wellbeing, mental health, and quality of life. It enables people to connect and to share emotions and feelings, hopes and dreams, successes and challenges with each other. Communication also makes it possible to share information about a person’s health conditions and prescribed care plan.

For people with I/DD, communication might be complex, difficult, and overwhelming, which increases the likelihood that others might misinterpret their messages. Likewise, people with I/DD might have difficulty understanding messages received from others. When communication involves messages about an individual’s condition and the care plan prescribed by a healthcare provider, such misunderstandings of messages can affect the individual’s health and wellbeing.

Consider this scenario

A nurse was asked to examine David, who was reporting that he could not breathe. When she saw him, David was doubled over and holding his stomach, but he was breathing well and did not appear to be in distress due to breathing. When the nurse asked him what was wrong, David replied, “I can’t breathe!” The nurse checked his vital signs, including his oxygen saturation, and all were within normal limits. David’s skin was pink, not blue, so his condition did not appear to be related to breathing. Knowing that people with I/DD might have difficulty finding the words to express what they are experiencing, the nurse turned to David’s caregivers to learn more about the situation.

The caregivers explained that David had eaten 4 grilled cheese sandwiches and 4 bowls of tomato soup an hour earlier. With this information, the nurse was able to conclude that David’s discomfort was caused by indigestion, the result of overeating.

Caregivers tend to play an important role in helping others understand messages individuals with I/DD use to express their wants and needs, as well as helping individuals to understand messages received from others. They might be asked to assume the role of communication partner and to assist an individual to send and receive messages. Individuals often require caregiver support to communicate symptoms, medical history,

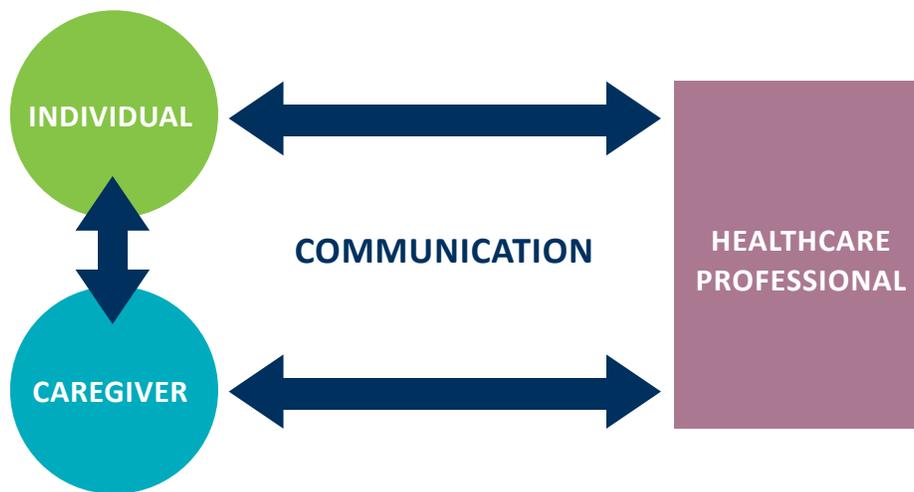
progression of a current illness, pain level, and effectiveness of treatment accurately to other caregivers and healthcare professionals. Together, a caregiver and individual can work with healthcare professionals to design a health and wellness plan suitable to the person’s needs and abilities.

SUPPORTING COMMUNICATION AT MEDICAL APPOINTMENTS

In the scenario, David’s caregivers enhanced the communication between David and the nurse, which enabled the nurse to identify the cause of David’s discomfort. To enhance communication at medical appointments, caregivers can **think about what information the healthcare professional needs to know** to make an accurate diagnosis and develop an effective care plan.

To facilitate and enhance communication with healthcare professionals, caregivers need to **establish a positive relationship with the individuals** they support, becoming familiar with various aspects of their lives – their history, health conditions, likes and dislikes, wants and needs, behaviors, and methods of communication. Familiarity heightens a caregiver’s awareness to changes in the individual’s physical, emotional, and behavioral condition; it encourages the caregiver to recognize a change in behavior as communication of a symptom, need, or want. A positive relationship improves communication between the caregiver and the individual, which can encourage the individual to share with the caregiver information needed for the appointment. It can create opportunities for the caregiver to educate the individual on what to expect at the appointment and help ease anxiety the individual might be feeling about the appointment.

Relevant information from members of the individual’s interdisciplinary team (e.g., agency nurses, therapists, dieticians, supports coordinator, and others) can provide a more complete understanding of the individual’s current health situation. Active communication among caregivers, supervisors, and healthcare professionals allows the team to support the individual more effectively and facilitates consistency of care.



To provide effective support, caregivers need to be knowledgeable of treatment plans prescribed for individuals by healthcare professionals. Exercises for both physical and mental health, such as practicing strengthening exercises and coping skills, might be prescribed for the person to complete at home, and the individuals might need assistance to do so. Because of reluctance by some healthcare providers to share treatment plans with caregivers, due to the Health Insurance Portability and Accountability Act of 1996 (HIPAA), the U.S Department of Health and Human Services’ Office of Civil Rights published the “Communicating with a Patient’s Family, Friends, or Others Involved in the Patient’s Care” guide (available at https://www.hhs.gov/sites/default/files/provider_ffg.pdf). This document offers healthcare professionals guidance as to what, when, where, and to whom an individual’s protected health information may be shared.

According to the guide, one of the most common questions is:

If the patient is present and has the capacity to make healthcare decisions, when does HIPAA allow a healthcare provider to discuss the patient's health information with the patient's family, friends, or others involved in the patient's care or payment for care?

The guide indicates that, if the patient is present and has the capacity to make healthcare decisions, a healthcare provider may discuss the patient's health information with a family member, friend, or other person, provided the patient agrees or, when given the opportunity, does not object. Furthermore, a healthcare provider may share information with such people if, using professional judgment, he or she decides that the patient does not object. In either case, the healthcare provider may share or discuss only the information that others involved need to know about the patient's care or payment for care. A similar question involves sharing information with people if the person is not present or able to make healthcare decisions. In this case, the healthcare practitioner must be reasonably sure that the person asked the individual to be involved in his care.

The guide includes other questions frequently asked by caregivers and a table that summarizes the relevant requirements. When a caregiver is an individual's communication support, both the individual and the caregiver need a fundamental understanding of the HIPPA Privacy Rule and to whom it applies. If necessary, caregivers can refer healthcare providers to the "Communicating with a Patient's Family, Friends, or Others Involved in the Patient's Care" guide.

People, including those with I/DD, have a right to be informed about their care. Caregivers accompanying individuals to appointments should be prepared to assist the individuals, as needed, to ask questions of the healthcare providers. The questions suggested below might help facilitate the communication of information about an individual's health and treatment plan, so the individual and his or her caregivers understand the treatment plan and the home treatments prescribed.

- 1. What is the purpose of the procedure/test prescribed?** The response should explain the procedure or test and the reason it is being prescribed; caregivers may then search for resources to help them explain it in terms the individual will understand.
- 2. How long does it take to get the results?** It is important that caregivers know when to expect the results of a procedure/test so they know when to follow up with the healthcare professional, if necessary, and prepare to assist with decisions based on the results.
- 3. What is the benefit of a prescribed treatment?** Caregivers need to understand how a treatment will help the individual in order to explain it to the individual with words and pictures easily understood by the person. When the importance and benefits of a prescribed treatment are clear, compliance and positive outcomes are more likely.
- 4. Are there alternative treatments?** Familiarity with an individual and knowledge of previous situations can enable caregivers to anticipate how the individual will react to a prescribed treatment. The healthcare professional can address concerns about the treatment plan and consider if more tolerable treatment options are available.
- 5. What are the possible complications?** To make a fully informed decision regarding a proposed plan of care, the people making the decision need to be aware of all possible complications, especially if the plan involves an invasive procedure or a medication with serious potential side effects. Caregivers may need to assist individuals to understand potential complications and weigh the options.
- 6. What doctors and/or facilities offer the procedure/treatment?** Individuals with I/DD might have difficulty adjusting to new people and situations. If possible, arrange for procedures/treatments to be provided at facilities and by personnel who are familiar to the individuals, or by practitioners familiar

with working with people who have I/DD.

7. **How is the name of the medication spelled?** Pronunciation and spelling of medication names can be challenging for individuals and caregivers alike. Knowing the correct spelling of the medication name can prevent misunderstandings and/or miscommunications, especially when there are medications that function very differently but for which the names sound similar.
8. **What are the potential side effects and desired outcomes?** This information can assist caregivers to identify side effects and determine effectiveness of medications and treatments.
9. **Will the medication interact with medication already prescribed?** Providing the individual's complete list of medications, including over-the-counter medications, enables the healthcare provider to identify possible medication interactions and/or foods to avoid when new medication is prescribed.
10. **What can we do to at home to improve the condition?** When caregivers understand the home treatments, including diet and exercise plans, they are able to support the individual by encouraging participation and assisting with performance of home treatments, when needed.

Caregivers who know the individual and gather useful information are prepared to bridge any communication gap that might exist between an individual and a healthcare professional. They are able to inform healthcare providers about people with I/DD, the individual's specific needs, and the unique design and requirements of the individual's support systems. At the same time, these caregivers are able to assist the individual to navigate the healthcare system, communicate with healthcare professionals, and follow a prescribed treatment plan. The result is improved and effective communication that has a positive effect on the health and wellness of people with I/DD.

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"Oh, My Aching BACK"

By: Jodie Dale, RN

Back pain and injury are wide spread throughout the world today. It is estimated that approximately 80% of adults in the United States experience back pain at some point in their lives, often the result of work-related injuries (National Institute of Neurological Disorders and Stroke, 2019). Back pain affects men and women equally. The pain can be acute (short term) or chronic (lasting 12 weeks or longer), and the intensity can vary from a dull ache to debilitating severity.

Healthcare workers are at particular risk for back and other musculoskeletal injuries. According to a segment on National Public Radio (NPR) that aired on February 2015, "nursing assistants and orderlies suffer roughly three times the rate of back and other musculoskeletal injuries as construction workers". In fact, data from the Bureau of Labor Statistics show that nursing assistants are injured more than any other occupation (NPR, 2015).

Caregivers in community group homes perform many of the same tasks as nursing assistants, namely assisting people to transfer, bathe, and dress. Such activities require a significant amount of lifting, stretching, twisting, and bending, all of which put strain on the caregiver's back; and performing them in close quarters or with people who are overweight can cause additional strain. Back pain and/or injury can make it difficult for a caregiver to perform routine daily tasks, both on and off the job, and result in time away from work.

Effective measures caregivers can take to prevent back pain and/or injury and improve their overall wellness include stretching their muscles and using proper body mechanics, especially when lifting or transferring. Body mechanics can be defined as "the safe use of the body using the correct posture, bodily alignment, balance and bodily movements to safely bend, carry, lift and move objects and people" (Registerednursing.org, 2019).

Principles of Good Body Mechanics

- **When standing**, position feet flat on the floor approximately 12 inches apart, with shoulders down, chest out, and back straight.
- **When sitting**, keep head straight (not tilted), knees level or slightly lower than hips. Change position every half hour to support the lower back to reduce pressure.

- **When lifting**, position feet shoulder width apart; bend at the knees instead of the waist, keeping the back straight; tighten abdominal and glute muscles; and hold the person or object being lifted close to the body. Reaching while lifting can cause pain and/or injury.
- **When transferring a person**, consider the level of assistance necessary based on the person’s ability and willingness to assist in the transfer; check the environment for obstacles; minimize the distance involved in the transfer; and explain the plan with the person and others assisting in the transfer, specifying what each person is to do. Those performing the transfer should pivot the whole body, not twist at the waist. Begin the transfer by positioning the person to face you. Bend at the knees and keep your back straight while performing the transfer; avoid sudden, jerking motions and use leg muscles, not the back, to lift. Counting aloud, “1-2-3”, helps to make all involved in the transfer aware of when to begin the lift and/or transfer.
- **When special equipment is used** to transfer an individual, obtain proper training and become comfortable using the equipment prior to performing a transfer.
- Follow agency policies and procedures for lifts and transfers.
- Ask for assistance if a lift or transfer appears unsafe to perform without it.

Other measures caregivers might take to prevent back pain and injury include wearing comfortable low-heeled shoes, maintaining a healthy weight, and engaging in regular exercise. Proper footwear helps to maintain the natural curve in the spine. Reducing excess weight around the abdominal area can reduce strain on the lower back. Regular exercise improves physical fitness, which improves one’s ability to perform job duties without pain or injury.

In addition to reducing the risk of back pain and injury for caregivers, the use of proper body mechanics by caregivers decreases the risk of injury to the person being lifted or transferred – especially if the person does not or cannot follow instructions given during the transfer. People with I/DD might need extra support to participate in a transfer.

Helpful tips when transferring someone with I/DD

- Explain the transfer clearly, using words the person can understand.
- Demonstrate how the person can help.
- Consider using pictures or a social story to help the person understand what to do.
- Allow ample time for the person to comprehend what is said.
- Answer all questions the person might ask about the transfer.
- Ask if the person is ready to begin the transfer.

Teaching people with I/DD how to use the principles of body mechanics to move safely while completing routine tasks in the home and the community can help them avoid back pain and injury, too. Caregivers can demonstrate proper techniques for moving objects and performing tasks to prevent back and other musculoskeletal injuries. Offer the level of assistance the person needs to correctly complete the task, and assist the person to make a plan before moving heavy items.

Back pain and injuries can be life changing, both for healthcare workers and for those in their care. Don’t become a statistic. Practice good body mechanics and educate the people you support to reduce the risk for pain and serious injury for all of you.

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