



# COMMONWEALTH of VIRGINIA

## DEPARTMENT OF BEHAVIORAL HEALTH AND DEVELOPMENTAL SERVICES

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### Office of Integrated Health Health & Safety Alert/Information

## Healthcare Advocacy Health & Safety Alert

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### Healthcare Advocacy Introduction

Advocacy can be defined as speaking, acting or writing as a representative for another person in order to assist, support, and defend the wellbeing of that individual in a way which is forceful and insistent (3).

Being a good healthcare advocate for an individual who has intellectual and/or developmental disabilities (DD) is a very important role, as the individual relies on their caregiver to assist them to schedule, access, and receive the most appropriate care for their physical needs (3).

Although some individuals with DD are in good health, research shows many individuals with DD are more likely to develop chronic conditions such as diabetes, asthma, heart disease and mental illness at higher rates than those individuals who do not have DD (2).

Intellectual disability, particularly severe and profound DD, are associated with high mortality (death) rates due to cardiovascular diseases, intestinal obstruction, diabetes, sepsis, pneumonia, choking, falls, and other health or safety causes (9) (2). Seeking and finding comprehensive healthcare assessments and treatments for individuals with DD who have chronic health conditions can be a challenging process for caregivers. Quality holistic healthcare is vital to each individual's continued health and well-being and should include (at minimum):

- Oral care,
- Preventive care,
- Primary care,
- Specialty care (if needed); and
- Routine screening (16).



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## Healthcare Disparity and Inequity

Several studies have published results of research relating to the health disparity and health inequity experienced by individuals with intellectual and developmental disabilities when compared to the general population (4) (7) (8) (10) (14) (21). The causes of these disparities continue to be studied, but are generally credited to:

- Limited healthcare delivery flexibility.
- Negative provider attitudes about disability.
- Stigmatization and disapproval of disabilities.
- Diagnostic overshadowing (attributing most of an individual's symptoms to their mental, behavioral or DD conditions). This practice results in symptoms being dismissed outright or not taken seriously; delays in care or treatment; and/or health problems being totally overlooked or missed. All of which may lead to a more serious or prolonged illness, more frequent hospitalizations, and poorer outcomes overall.
- Inaccessible medical facilities & equipment.
- Communication breakdowns between healthcare professionals, caregivers/providers and individuals with DD.

There is also considerable evidence, confirming the shortfalls, which exist throughout various healthcare professions' initial educational preparation and continuing education.

### *In medicine...*

- Many physicians are not comfortable with caring for people with physical disabilities and are not prepared to adequately deal with disability-specific issues (29) (27) (26).
- There is an interesting perceptual phenomenon, which has been recognized among physicians. Some physicians tend to discount a person's disability, while other physicians may attribute all symptoms to the individual's disability and may dismiss new complaints or symptoms and may not explore them fully (15). There is a lack of focus on disability or developmental disability within physician's initial education and/or continuing education, which results in educational deficits (17).
- In a study of 501 physicians, 73% stated their need for continuing education related to caring for people with physical disabilities, and a majority of them indicated they would attend a continuing medical education course, if offered.

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*In nursing...*

- Reasonable adjustments in nursing care are not typically made for individuals with disabilities because nurses are not adequately prepared via experience or knowledge to know what those adjustments might need to be (17) (1).
- Only 8% of practicing nurses have received any specific disability-related nursing training (17).
- Nurses in general and/or primary healthcare settings are not adequately prepared to support the healthcare needs of individuals with DD (1).
- There is a high likelihood nurses will not understand specific health issues relating to DD or special needs populations (1).

*In dentistry...*

- More than 50% of U.S. dental schools have devoted less than 5 hours of classroom instruction time focusing on the treatment of patients with special needs (13).
- Seventy-five percent of dental schools allocated less than 5% of their clinical training time on the treatment of individuals with special needs (24).
- In a study of 374 dentists, the majority (over 60%) reported their pre-doctoral dental education did not adequately prepare them for managing patients with special needs, intellectual disability and/or autism (25).

*In emergency services...*

- Emergency responders (law enforcement, fire, emergency medical services [EMS], etc.) may lack sufficient education about disability-related emergency needs (28).
- The special needs of persons with disabilities were largely ignored and neglected during the official planning process in a majority of catastrophic situations which were examined (23).
- Emergency plans often assume that all Americans can walk, run, talk, hear, drive, and quickly follow directions, thereby ignoring the likely adaptations needed for some with disabilities (28).

In addition, research shows individuals with developmental disabilities receive poorer care overall, resulting in poorer outcomes, and higher rates of hospital readmission, which may result in preventable and premature death.

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The UK's *Confidential Inquiry into Premature Deaths of People with Learning Disabilities Report (CIPOLD)* studied avoidable deaths of individuals with developmental disabilities (11). The study determined discrimination, indifference, a lack of training, experience, and a poor understanding of the caregiving needs of individuals with disabilities, were the primary reasons for the majority of premature, preventable and avoidable deaths of individuals.

Negative attitudes are another contributing factor to the poor care individuals with intellectual disabilities receive. Many of the caregivers and families interviewed as part of the study reported the negative and uncaring statements healthcare professionals made to the individual's family members and caregivers:

- *"If she had been a normal young woman, we would not hesitate to treat her."* **Error! Reference source not found.**
- *"Wouldn't it be better for everyone if we just let him go?"* (18).
- *"In my opinion there is nothing wrong with him and I am not usually wrong. It's just the way he is."* (18).
- The doctor told one family member they were *"worrying over nothing and that Jasseke [their daughter] was perfectly fit"* (18). [Their daughter died weeks later from complete kidney failure.]
- *"They said they didn't think she was in pain, that her screams were just the noises people like that make."* (18).
- *"The doctor took one look at my son and said he was not for resuscitation."* (18).

The study showed that both families and caregivers mistrust the intentions of healthcare professionals to such a degree, they feel compelled to conduct bedside vigils while their loved ones are in the hospital. Their efforts seemed to be aimed at protecting the individual from being neglected or inadvertently mistreated in some way. Researchers view these cumulative failures within the healthcare system as a "cascade of disparities" (12) which result in:

- A higher prevalence of adverse conditions.
- Inadequate attention to care needs.
- Inadequate focus on health promotion.
- Inadequate access to quality health care services.
- Preventable deaths.

The CIPOLD report (11) also highlighted the following:

- Many healthcare professionals do not properly consult and involve the families and caregivers of people with a learning disability.
- Many healthcare professionals do not understand the laws relating to consent.

The Surgeon General acknowledged in his 2005 "Call to Action" that all healthcare-related professionals provide lesser care to people with disabilities due to lack of preparation, education and exposure (22).

**“True and genuine inclusion is only achieved by addressing systems of inequity—therefore it requires intentional collaboration and comprehensive action”.**

Dr. Janice Underwood, the Commonwealth’s first-ever Director of Diversity, Equity, and Inclusion.

## The Best Healthcare Advocates

- Have a good relationship with the individual.
- Have spent a considerable amount of time with the individual.
- Have knowledge of the individual’s present and prior health history.
- Have brought a list of the medications and treatments the individual receives (what, when, dosage, route, frequency, etc.) to share with the health practitioner.
- Are respectful, polite and courteous to healthcare practitioners (3).



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## Well Check-Ups and Preventive Care Appointments

Individuals with IDD have high rates of ER visits, inpatient admissions and readmissions. Studies have shown their care tends to be reactive rather than proactive. Preventive care checks are sometimes neglected, possibly because acute care needs take priority (20) (6).

Due to this, guidelines for the primary care of adults with I/DD are recommended as an appropriate and effective method to ensure annual comprehensive assessments. Annual assessments should include preventive care, physical examination and age- and sex-specific screenings, just as they are for adults in the general population.

A visit to the primary care practitioner's office will be much easier and more helpful to the individual if caregivers are fully prepared to support the individual and are ready and able to provide needed information effectively.

**Tip: Preparing well before the appointment and knowing what questions to ask during the appointment will help you to be a better advocate.**

Several guidelines and recommendations have been developed as shown below (6) (20).

- Preventive Health Recommendations for Adults with Intellectual Disabilities: Guidelines for Community Practitioners [https://shriver.umassmed.edu/wp-content/uploads/2020/07/MA-DDS-health-screening-brochure\\_2019\\_final.pdf](https://shriver.umassmed.edu/wp-content/uploads/2020/07/MA-DDS-health-screening-brochure_2019_final.pdf)
- Massachusetts Department of Developmental Services Adult Screening Recommendations (2019 updates to 2017 revision). [https://shriver.umassmed.edu/wp-content/uploads/2020/07/MA-DDS-Wallchart\\_2019\\_Final.pdf](https://shriver.umassmed.edu/wp-content/uploads/2020/07/MA-DDS-Wallchart_2019_Final.pdf)
- Massachusetts Department of Developmental Services Annual Health Screening Checklist. [https://shriver.umassmed.edu/wp-content/uploads/2020/07/MA-DDS-health-screening-checklist\\_2019\\_final.pdf](https://shriver.umassmed.edu/wp-content/uploads/2020/07/MA-DDS-health-screening-checklist_2019_final.pdf)
- The Center for Developmental Disabilities Evaluation and Research (CDDER) has also developed a computer-based training course on [Preventive Health Screenings](#). This training is focused on educating direct care staff about the importance of preventive health care for individuals with intellectual disabilities, the need for regular preventive health screenings, and how to best advocate for these screenings.

- The Preventive Health Screenings course can be completed online, at your convenience and takes approximately 40 minutes to complete. Certificates of completion are also available. [Click here to register and view the training.](#) CDDER is part of the American Association on Intellectual and Developmental Disabilities (AAIDD) working group on preventive health screening guidelines to develop a set of consistent guidelines across the United States.

## Sick Visits

- When preparing for a sick visit, make a list of all of the medicines and treatments the individual is receiving (and why), and bring the list with you. Bring a copy of the M.A.R. and copies of any care protocols currently in place (e.g. a skin care protocol, turning protocol, positioning protocol, etc.).
- Make a list of any known allergies and any chronic health issues the individual has. Bring the face sheet, the individual profile, the individual's insurance card, and a copy of the ISP.
- Speak to other direct support caregivers and add any important details you think might help the health practitioner to understand the individual and or the individual's symptoms better.
- Write down the symptoms, aches, pains, etc. the individual has been having including the frequency, the severity (if known) and the time of day the pain is occurring and be prepared to answer the following questions, if the individual is unable to do so on their own.
  - What symptoms does the individual have?
  - Approximately how long has the individual had these symptoms?
  - Has the individual had any changes in the amount of food they are consuming?
  - Has the individual had any changes in sleeping patterns?
  - Has the individual had any changes in their activity level?
  - What other changes have you noticed?
  - Has the individual had any changes in toileting habits?
  - Have there been any significant changes in the patient's life, (a recent move, a death in the family, a break-up, etc.)?
  - Has the individual had any behavior changes?
- Relay information to the healthcare practitioner relating to how the individual typically communicates.

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- Be sure to share how he/she typically behaves when in pain, when agitated, when ill, etc., if you know.
  - If you *think* you might know what is happening, don't be afraid to share your thoughts with the healthcare practitioner, and just remember to be polite and respectful.

Sample descriptive conversation (to have with a healthcare practitioner), which can help explain the individual's symptoms and/or what is happening:

*"We think Billy is having stomach pains after he eats lunch because he becomes very agitated after lunch time. Sometimes after Billy eats his lunch, he hits his stomach, yells out, stomps his feet or throws things. Billy is nonverbal and so he tends to act out what he is feeling. Staff persons have stated this behavior is not typical behavior for Billy. However, previously Billy did have similar behaviors when he was experiencing pain from a UTI. These incidents happen at least 5 times per week and have only occurred after lunch. You know, last year another individual had similar symptoms and it was his gallbladder. Do you think Billy might be having gallbladder pain?"*

- If you are not sure about instructions the healthcare practitioner has communicated to you (the caregiver) during the appointment, ask questions until you have a better understanding.
  - "Would you explain everything again, please? I am sorry, but I still don't understand."
  - "I would like to check that I understand correctly what you said. You said he is to take all of the medicine and call you back if he is still having symptoms when the medicine is gone, is that correct?"

**Tip: Ask the Health Practitioner to write their findings and recommendations on the Office Visit Form. This form is a good record of the appointment and is required by Licensing. You can ask the nurse or your manager to help you understand the information (after the appointment) if you need assistance.**



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- If the healthcare practitioner quickly states several test results, but you do not understand what it means, you can ask:
    - “What do the results of each test mean?”
    - “How do the test results impact caregiving?”
    - “Can we please have a copy of all of the test results, so I (or the legal guardian, parents, etc.) can review them later?”
    - “Can we please have a copy of all of the test results, so I can review them with our agency nurse?”
  - If the healthcare practitioner says more tests will be needed, you should ask:
    - “What are the new tests for?”
    - “How will the new test results impact the individual?”
    - “Will the new tests cause any discomfort or pain for the individual?”
    - “Where will we need to schedule appointments, in order to have the tests completed?”
    - “Will you write down the contact information I will need to schedule the new appointments?”
    - “How will we receive the results from the new tests?”
    - “When will we receive the test results?”
    - “Who do we ask if we don’t get the results when expected?”
    - “Are there other things we could do to make \_\_\_\_\_ feel better and/or recover more quickly?”
    - How will I know if the individual is improving? How often should we take vital signs?
    - Are there any other care protocols you would like for us to follow?
  - If the healthcare practitioner says a new medicine and/or treatment is ordered, you can say:
    - “What condition/illness is the new medicine/treatment for?”
    - “Are there any side effects or risks we should watch for? Who should we call if we notice any of these side effects?”

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- “How long will \_\_\_\_\_ need to take this medicine/treatment?”
  - “How will we know if the medicine/treatment is working and/or not working?”
  - “What will happen if \_\_\_\_\_ won’t take the medicine or misses a dose?”
  - “Is there anything else we can do to help \_\_\_\_\_ get better?”
  - If the health practitioner has explained things, but you are still not sure what happens next, or what you should do next, here are some phrases you can use to help you gain more clarity:
    - “Will you please write down what I should do next?”
    - “Just so I am clear, when did you say \_\_\_\_\_ should come back to see you again?”
    - “Can you explain what changes we should be watching for again?”
    - “One more time please, how will we know if \_\_\_\_\_ is getting better?”
    - “Just so I’m really clear, what did you say we should do if things improve?”
    - “Just to clarify, how will we know if \_\_\_\_\_ is getting worse? Can you please tell me some specific symptoms we should watch for?”
    - “Just to be sure I understand you; can you tell me once more what I/we should do if the individual’s symptoms get worse? Whom should I contact?”



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- If you would like some educational materials (for the individual, yourself or other caregivers), to provide additional information about the illness, disorder or treatment, you can say:
    - “Do you have any leaflets or handouts about the illness and/or treatment that would help better explain things to\_\_\_\_\_?”
    - “Do you have any leaflets or handouts about the illness and/or treatment that I can share with other caregivers, parents, legal guardians, etc.?”
    - Is there a protocol you would like for caregivers to follow? If so, would you please write an order specifying exactly what steps we should follow to provide care and parameters for when you should be notified?
  - Before you leave the healthcare practitioner’s office, you should:
    - Ask: “Can we please have a copy of the physician’s notes and nurse’s notes from this visit, to refer back to?”
    - Ask for information on whom to reach out to, how to reach out to them (if their office is closed, during holidays, etc.), and when to reach out to them (if the individual’s condition worsens and/or changes, etc.).
    - Know exactly what symptoms or changes you should be looking for (in the individual) which would prompt you to initiate contact with the practitioner.
    - Provide the healthcare practitioner with information on the best way to contact you, the individual, and/or other caregivers, if needed.
    - Provide information on how to contact the individual’s legal guardian or parents, (if appropriate), so the healthcare practitioner can obtain any consents which might be needed.
    - Be feeling confident and capable to provide the best care and support for the individual.
    - Know exactly how to begin to implement all of the steps the healthcare practitioner has outlined for the individual and/or caregivers.
    - Have answers to all of the questions on your list.
    - Have answers for anything you or the individual does not understand.
    - Have knowledge of what happens next, and what you or the individual should do next.

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- Know when the individual should return for another appointment.
  - Have information about where the individual should go for any tests and if there are any special instructions.
  - Have received all prescriptions, orders, instructions, protocols, referrals, etc. that will be needed.

**Tip: Once you have a list of what you should do, you can make a check sheet and mark off when you completed each task, so that nothing is forgotten.**

**Tip: Ask for help from a supervisor or a nurse (if available), if you need support or have any questions about the above.**

- Be sure to document the appointment so all future caregivers understand what the reason for the appointment was, what the health practitioner recommended, and how you have implemented their recommendations.

**Tip: It is also important to document/chart how the person you are supporting responded to the appointment and when (or if), you have implemented any of the healthcare practitioner's orders.**

## Advocacy in the Acute Care Setting

### Emergency Room Visits

- It is best for someone who knows the individual well to accompany them to physician visits or the hospital.
- If an individual is transported by ambulance, a caregiver should follow the ambulance to the hospital.
- If unable to follow the ambulance to the hospital (because you have to arrange for another caregiver to take over), go to the hospital as quickly as possible when you are able.
- Be sure to take a record of all medications the individual is receiving with you.

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- Be sure to take the individual's insurance information with you and their identification card if you have access to it.
  - If you take an individual to the ER for unknown pain or distress, make sure the ER physician checks the individual for an impaction or bowel obstruction. Bowel obstruction is a preventable medical condition (in most situations), but is often overlooked among individuals with DD.
  - Ask for an x-ray to assess whether the individual has a fecal (stool) impaction or a bowel obstruction. Large masses of stool will display on an x-ray. If the bowel ruptures, it is often fatal, so this is very important.
  - In order to obtain treatment for the individual quickly, advocacy is key.
  - If you think an individual is seriously ill, but you feel as though healthcare professionals in the ER are not taking your concerns or the concerns of the individual seriously, focus your attention on advocacy for diagnostic testing.
  - Diagnostic tests can typically confirm either the presence of illness or the absence of illness via scientific data, which is not impacted by opinions.
  - For example, healthcare professionals are more likely to treat the individual for an infection, once they find out the individual's white blood cell count (WBC) is high, which indicates an infection.
  - If an individual is taken to the ER in distress, but the cause of the distress is unknown, there are four basic healthcare checks, which should be considered and investigated before an individual with IDD is discharged from the ER.
  - A caregiver may need to advocate for 1) a full set of vital signs, 2) assessment for all seven fatal conditions, 3) diagnostic tests, and 4) observations of well versus sick.

## Vital Signs

- First, make sure a healthcare professional takes a full set of vital signs. This should include:
  - Blood pressure
  - Temperature
  - Heart Rate/Pulse
  - Respiratory Rate/Breathing Rate
  - Oxygen Saturation Levels

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- To confirm this, ask the healthcare professional if the individual's vital signs have been taken.
  - If you were not present during the individual's initial arrival at the hospital, ask the healthcare professional if the individual's vital signs are normal or not.

### **The Fatal 7 Conditions**

- Second, make sure the healthcare professional is aware of the conditions/disorders most likely to cause a preventable fatality in an individual with intellectual disabilities. These conditions are known as the Fatal 7.
- The conditions/disorders are:
  1. Aspiration Pneumonia.
  2. Constipation/Bowel Obstruction/Fecal Impaction.
  3. Sepsis.
  4. Dehydration.
  5. Pressure injuries.
  6. Falls.
  7. Seizures.

### **Diagnostic Tests**

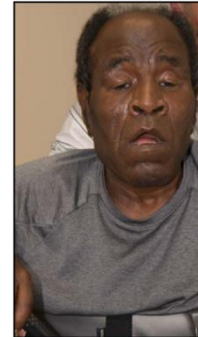
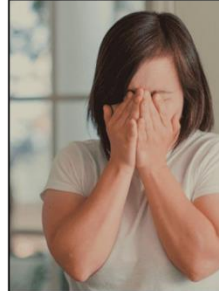
- Third, remember the goal is to diagnose, and quickly treat those conditions/disorders, which lead to preventable deaths.
- Therefore, the presence of the condition/disorder must either be confirmed or ruled out. The healthcare professional will make decisions regarding which tests will be order, etc. However, as an advocate for the individual's well-being, you can ask the healthcare professional to consider the following tests to assess the presence of (or rule out) a Fatal 7 illness or condition:
  - Urinalysis (to rule out a urinary tract infection).
  - Chest x-ray (to rule out pneumonia.)
  - Abdominal x-ray (to rule out a fecal impaction or bowel obstruction).
  - Complete Blood Count (CBC) (to rule out an infection).
  - Pulse Oximetry to assess oxygen (O<sub>2</sub>) saturation rates.
  - EKG (to assess heart rhythm).
  - EEG (to assess the presence of seizures).

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- The above list is not all inclusive. Additional testing may be needed depending on the results of the initial tests shown above, the vital signs, the physical assessment, and the history of the illness/disorder/condition/symptoms shared by the caregiver and/or the individual.

### Well vs. Sick

- Fourth, remember the phrase “*A picture speaks a thousand words*”. As mentioned previously, most healthcare professionals lack experience with individuals who have intellectual and/or developmental disabilities. Due to this, they may wrongly assume a lethargic, listless state of being is the individual’s “normal” or “baseline” way of being. In other words, they may not realize the seriousness of the individual’s condition. To counteract this phenomenon:
  - Take a picture of the individual when they are alert, happy, healthy and well, and perhaps participating in a daily activity. (Remember to seek permission from the parent, legal guardian or authorized representative first.)
  - Place this photograph in a plastic sleeve in the individual’s MAR, or the file or folder, which will accompany the individual to the physician’s office or to the hospital.
  - When you arrive with the individual at the ER, and you are attempting to explain the seriousness of your concerns about the individual, their symptoms, etc., share the picture of the individual with the healthcare professional.
  - When the healthcare professional compares the picture of the individual taken when the individual is alert, healthy and well to the presentation of the individual they are visualizing in the ER (in which the individual is experiencing discomfort, distress, listlessness, etc.); the healthcare professional in the ER will better understand the seriousness of the individual’s illness or health status decline.
  - If another medical specialist is assigned to the individual (a cardiologist, gastroenterologist, neurologist, etc.), be sure to share the picture of the individual with them also.
  - It is in this way; pictures can be an extremely useful tool to help you advocate for an individual.

A picture is worth a thousand words.



Well, happy individuals.

Unwell, unhappy individuals.

## In-Patient Care

- It is best if individuals with IDD have a support person/advocate with them in the ER and throughout their hospital stay whenever possible.
- This person may be a paid caregiver, a parent or another relative. It is important for this advocate to relay important information about the individual, such as:
  - Diet modifications.
  - Sensory issues (hearing, vision, sensitivities to light, sound, etc.).
  - Likes and dislikes.
  - Health history information (prior hospitalizations, surgeries, procedures, etc.).
  - Current medications.
  - Current diagnosis/diagnoses.
  - Mobility issues. (Do they need assistance to walk, change position, etc.?)
  - Durable Medical Equipment the individual typically uses. (Do they use a special chair to eat, shower, watch TV, etc.?)



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- Communication abilities. (Do they have a special device to help them communicate, a communication board, etc.?)
  - Any legal guardian, authorized representative, parent/family contact information.
  - Behavioral issues (Has the individual ever bitten anyone, been violent, had any prior elopements, self-injurious behaviors, or risk-taking behaviors, etc.?)
  - Any prior traumatic experiences (physical abuse, etc.).
  - ADL's (Can the individual dress themselves, brush their teeth, put on their clothing, independently, etc.? If not, what level of assistance do they usually need?)
  - History of any prior pressure injuries or skin infections, etc.
  - Allergies. (Is the individual allergic to latex, bandages, tape, medicines, etc.?)
  - Any prior safety issues? (Falls, choking incidents, accidents, near death experiences, etc.).
- It is sometimes helpful to make use of what is commonly referred to as a hospital or healthcare passport.
  - A healthcare passport is a document that can serve as a framework for compiling and recording information about the individual (their interests, likes, dislikes and preferred method of communication, health history, specific needs, etc.).
  - Healthcare passports can be a useful tool advocates and caregivers can print out and use to provide information about the individual's health and other personal preferences, when/if they are admitted into the hospital.
  - There are several different versions of the "passport" which can be downloaded from the internet. Two of those versions are listed in the Resource section below.



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## Resources

### **My Care Passport, Virginia Department of Behavioral Health and Developmental Services Office of Integrated Health Supports Network**

<https://dbhds.virginia.gov/wp-content/uploads/2022/09/DBHDS-My-Care-Passport-9.25.22.pdf>

### **My Hospital Passport, National Autism Society**

<https://www.mefirst.org.uk/wp-content/uploads/2016/05/My-Hospital-Passport.pdf>

### **My Hospital Passport, Surrey Centre**

<https://www.royalsurrey.nhs.uk/hospital-passport-what-is-the-hospital-passport/>

### **You can find the Vanderbilt/Kennedy Primary Care Toolkit here:**

<https://iddtoolkit.vkcsites.org/>

### **Tip Sheets and Resources from the [Vanderbilt/Kennedy](#) website**

- What are Tip Sheets?
- Tip Sheets are one-page, free downloadable for individuals and families with and without disabilities, service providers, students and trainees, and anyone interested in learning more about disabilities and disability-related topics.
- Tip Sheets are offered on a variety of topics. Some are about the science of specific disabilities, the effects disabilities might have on the individual and family, and treatment and service options. Others outline interventions or strategies for use in places like school classrooms, faith communities, or health care provider offices. They always promote (directly or indirectly) the values of independence, self-determination, community integration, and inclusion as best practice.
- Each Tip Sheet is a single page, easy-to-hand-out flyer that can be downloaded at no cost. The front provides facts and information on the specific topic and the back is a summary of Vanderbilt Kennedy Center and local, state, national, international resources that relate to the topic and that point people to places where they can find more information.
- By developing and disseminating Tip Sheets, we can link people with disabilities, families, clinicians, and educators to important resources.

### **Self-Advocate/Family/Sibling Supports Resources at the Vanderbilt/Kennedy website:**

- [Accompanying an Individual to the Doctor Tip Sheet](#)

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- [Accompanying an Individual to the Doctor Tip Sheet - Spanish translation](#)
  - [Adolescent and Young Adult Siblings of Individuals with Disabilities Tip Sheet](#)
  - [Children Mental Health Tip Sheet](#)
  - [Emergency Preparedness For Individuals With Hearing Loss Tip Sheet](#)
  - [Going to the Doctor Tip Sheet](#)
  - [Intellectual Disabilities Tip Sheet](#)
  - [Preparing for an Emergency Tip Sheet](#)
  - [When a Child is Hospitalized Tip Sheet](#)
  - [Teaching Stranger Safety Skills to Children and Adults With Disabilities](#)
  - [Oral Health for Children With Disabilities Tip Sheet](#)

**Resources about Specific Disabilities at the Vanderbilt/Kennedy website:**

- [ADHD Tip Sheet](#)
- [Angelman Syndrome Tip Sheet](#)
- [Angelman Syndrome Tip Sheet \(Spanish\)](#)
- [Autism Spectrum Disorders Tip Sheet](#)
- [CHARGE Syndrome Tip Sheet](#)
- [Children Mental Health Tip Sheet](#)
- [Down Syndrome Tip Sheet](#)
- [Fragile X Syndrome Tip Sheet](#)
- [Intellectual Disabilities Tip Sheet](#)
- [Prader-Willi Syndrome Tip Sheet](#)
- [Rett Syndrome Tip Sheet](#)
- [Williams Syndrome Tip Sheet](#)
- [Williams Syndrome Video Tip Sheet](#)

**References:**

- (1) [Appelgren, M., Bahtsevani, C., Persson, K., & Borglin, G. \(2018\). Nurses' experiences of caring for patients with intellectual developmental disorders: a systematic review using a meta-ethnographic approach. \*BMC Nursing\*, 17\(1\), 1-19.](#)
- (2) [Bobbette, N., Ouellette-Kuntz, H., Tranmer, J., Lysaght, R., Ufholz, L. A., & Donnelly, C. \(2020\). Adults with intellectual and developmental disabilities and interprofessional, team-based primary health care: A scoping review. \*JBI Evidence Synthesis\*, 18\(7\), 1470-1514.](#)
- (3) [Brolan, C. E., Boyle, F. M., Dean, J. H., Gomez, M. T., Ware, R. S., & Lennox, N. G. \(2012, November\). Health advocacy: a vital step in attaining human rights for adults with](#)

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Post Office Box 1797  
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- [intellectual disability. \*Journal of Intellectual Disability Research\*, 56\(11\), 1087–1097. Doi: 10.1111/j.1365-2788.2012.01637.x](#)
- (4) [Burke, M. M., & Heller, T. \(2017\). Disparities in unmet service needs among adults with intellectual and other developmental disabilities. \*Journal of Applied Research in Intellectual Disabilities\*, 30\(5\), 898-910.](#)
  - (5) [Durbin, J., Selick, A., Casson, I., Green, L., Perry, A., Abou Chacra, M., & Lunskey, Y. \(2019\). Improving the quality of primary care for adults with intellectual and developmental disabilities: Value of the periodic health examination. \*Canadian Family Physician\*, 65\(Suppl 1\), S66-S72.](#)
  - (6) [Durbin, J., Selick, A., Casson, I., Green, L., Spassiani, N., Perry, A., & Lunskey, Y. \(2016\). Evaluating the implementation of health checks for adults with intellectual and developmental disabilities in primary care: the importance of organizational context. \*Intellectual and Developmental Disabilities\*, 54\(2\), 136-150.](#)
  - (7) [Durkin, M. S., Maenner, M. J., Baio, J., Christensen, D., Daniels, J., Fitzgerald, R., & Yeargin-Allsopp, M. \(2017\). Autism spectrum disorder among US children \(2002–2010\): socioeconomic, racial, and ethnic disparities. \*American Journal of Public Health\*, 107\(11\), 1818-1826.](#)
  - (8) [Dykens, E. M. \(2016\). Psychiatric disorders in people with intellectual disabilities: Steps toward eliminating research and clinical care disparities. In \*International review of research in developmental disabilities\* \(Vol. 50, pp. 277-302\). Academic Press.](#)
  - (9) [Ervin, D. \(2018, August\). Health advocacy for people with IDD. \*Exceptional Parent Magazine\*. 20-22.](#)
  - (10) [Fisher, K. \(2004\). Health disparities and mental retardation. \*Journal of Nursing Scholarship\*, 36\(1\), 48-53.](#)
  - (11) [Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. \(2013\). \*Confidential Inquiry into premature deaths of people with learning disabilities \(CIPOLD\)\*. Bristol: Norah Fry Research Centre.](#)
  - (12) [Krahn, G. L., Hammond, L., & Turner, A. \(2006\). A cascade of disparities: health and health care access for people with intellectual disabilities. \*Mental retardation and developmental disabilities research reviews\*, 12\(1\), 70-82.](#)
  - (13) [Krause, M., Vainio, L., Zwetchkenbaum, S., & Inglehart, M. R. \(2010\). Dental education about patients with special needs: a survey of US and Canadian dental schools. \*Journal of Dental Education\*, 74\(11\), 1179-1189.](#)
  - (14) [Magaña S, Parish S, Morales MA, Li H, & Fujiura GT. \(2015\). Racial and ethnic disparities among adults with intellectual and developmental disabilities. Research Briefing to the University Association on Developmental Disabilities.](#)
  - (15) [McCull, M. A., Forster, D., Shortt, S. E., Hunter, D., Dorland, J., Godwin, M., & Rosser, W. \(2008\). Physician experiences providing primary care to people with disabilities. \*Healthcare Policy = Politiques de sante\*, 4\(1\), e129–e147.](#)
  - (16) [Medline-Plus. \(2021, February\). Health screenings for men ages 18 to 39. U.S. National Library of Medicine \(NIH\).](#)
  - (17) [Melville C., Finlayson J., Cooper S.-A., Allan L., Robinson N., Burns E., Martin G. & Morrison J. \(2005\) Enhancing primary health care services for adults with intellectual disabilities. \*Journal of Intellectual Disability Research\* 49, 190–198](#)
  - (18) [Mencap, R. \(2012, p.14\). Death by indifference: 74 deaths and counting. A progress report 5 years on.](#)

**DEPARTMENT OF  
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- (19) [Prokup, J. A., Andridge, R., Havercamp, S. M., & Yang, E. A. \(2017\). Health care disparities of Ohioans with developmental disabilities across the lifespan. \*The Annals of Family Medicine\*, 15\(5\), 471-474.](#)
  - (20) [Smith G, Ouellette-Kuntz H, Green M. Comprehensive preventive care assessments for adults with intellectual and developmental disabilities. \(2018\). Part 1: How do we know if it's happening? \*Can Family Physician\*, 64 \(Suppl 2\):S57–S62.](#)
  - (21) [St. John, B. M., Hladik, E., Romaniak, H. C., & Ausderau, K. K. \(2018\). Understanding health disparities for individuals with intellectual disability using photovoice. \*Scandinavian Journal of Occupational Therapy\*, 25\(5\), 371-381.](#)
  - (22) [Symons, A. B., McGuigan, D., & Akl, E. A. \(2009\). A curriculum to teach medical students to care for people with disabilities: development and initial implementation. \*BMC Medical Education\*, 9\(1\), 1-7.](#)
  - (23) [United Nations. \(2015\). Global Status Report on Disability and Development Prototype 2015.](#)
  - (24) [Vainio, L., Krause, M., & Inglehart, M. R. \(2011\). Patients with special needs: dental students' educational experiences, attitudes, and behavior. \*Journal of Dental Education\*, 75\(1\), 13-22.](#)
  - (25) [Weil, T. N., & Inglehart, M. R. \(2010\). Dental education and dentists' attitudes and behavior concerning patients with autism. \*Journal of Dental Education\*, 74\(12\), 1294-1307.](#)
  - (26) [Werner, S., Yalon-Chamovitz, S., Rinde, M. T., & Heymann, A. D. \(2017\). Principles of effective communication with patients who have intellectual disability among primary care physicians. \*Patient Education and Counseling\*, 100\(7\), 1314-1321.](#)
  - (27) [Wilkinson, J., Dreyfus, D., Cerreto, M., & Bokhour, B. \(2012\). "Sometimes I feel overwhelmed": educational needs of family physicians caring for people with intellectual disability. \*Intellectual and Developmental Disabilities\*, 50\(3\), 243-250.](#)
  - (28) [Wolf-Fordham, S. B., Twyman, J. S., & Hamad, C. D. \(2014\). Educating first responders to provide emergency services to individuals with disabilities. \*Disaster Medicine and Public Health Preparedness\*, 8\(6\), 533.](#)
  - (29) [Ziviani, J., Lennox, N., Allison, H., Lyons, M., & Del Mar, C. \(2004\). Meeting in the middle: improving communication in primary health care consultations with people with an intellectual disability. \*Journal of Intellectual and Developmental Disability\*, 29\(3\), 211-225.](#)

# Healthcare Advocacy Quiz/Evaluation

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Email Address: \_\_\_\_\_

## Quiz:

1. Healthcare Advocacy is defined as...
  - a. A medical power of attorney
  - b. Someone who is speaking, acting or writing as a representative for another person in a medical situation
  - c. The individual's next of kin or family member
  - d. Someone who bathes, dresses, toilets and feeds an individual in a healthcare facility
2. A healthcare advocate might need to be ...
  - a. Forceful, insistent and persistent
  - b. Quiet, keep their thoughts to themselves, and don't speak up
  - c. Angry, aggressive, and rude
  - d. Honest, open minded and willing
3. Regular care which should be arranged by a healthcare advocate, caregiver and/or direct support professional (DSP) for an individual with I/DD are...
  - a. Routine health screenings
  - b. Oral care
  - c. Primary care
  - d. Specialty care
  - e. Preventive care
  - f. A, B, C, D, & E.
4. Inequities and disparities experience by individual with intellectual and developmental disabilities are attributed to...
  - a. Diagnostic overshadowing by physicians
  - b. Stigmatization and disapproval of disabilities
  - c. Communication breakdowns between healthcare professionals, caregivers/providers and individuals with DD
  - d. A, B, & C
5. In the state of Virginia which healthcare professionals receive adequate training about individuals with DD?
  - a. Physicians
  - b. Nurses
  - c. Dentists
  - d. None
6. First Responders who receive adequate training in the Commonwealth to deal with individuals with DD are...
  - a. Emergency medical services (EMS)
  - b. Firemen
  - c. Law enforcement offices
  - d. None
7. Current research shows individuals with DD receive...
  - a. The same overall healthcare as the general population
  - b. Better overall healthcare than the general population
  - c. Poorer overall healthcare than the general population
8. Avoidable and preventable death of individuals with DD have been attributed to...
  - a. Discrimination
  - b. Indifference
  - c. Lack of training
  - d. A, B, & C

# Healthcare Advocacy Quiz/Evaluation

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Email Address: \_\_\_\_\_

9. The best person to accompany an individual with DD to the hospital, urgent care, or primary care providers (PCP) office is...
  - a. The newest staff member or caregiver who just met the individual
  - b. The staff member or caregiver who knows the individual best
  - c. A friend of the individual who sees them twice a year
  - d. No one, the individual should always go by themselves
10. It's very important for caregivers and/or DSPs to...
  - a. Ask questions about anything they don't understand
  - b. Take notes while assisting at the PCPs office, hospital or urgent care
  - c. Ask for specific medical testing to be done before discharge
  - d. A, B, & C
11. If an individual with DD is taken to the hospital Emergency Room, a caregiver and/or DSP may advocate for the individual to receive...
  - a. A full set of vital signs
  - b. Certain laboratory tests
  - c. Current diagnostic tests
  - d. A, B, & C
12. Common diagnostic tests which can be asked for at the hospital are...
  - a. Abdominal x-ray
  - b. Chest x-ray
  - c. Electro-Cardiogram (ECG)
  - d. A, B, & C
13. Common laboratory tests which can be asked for at the hospital are...
  - a. Complete Blood Count (CBC)
  - b. Cardiac Enzymes
  - c. Urinalysis
  - d. A, B, & C
14. The top most fatal common conditions for an individual with DD are...
  - a. Sepsis
  - b. Dehydration
  - c. Aspiration Pneumonia
  - d. Falls
  - e. Pressure Injuries
  - f. A, B, C, D, & E
15. A passport tool can be used to communicate with hospital staff about an individual with DD to inform them about...
  - a. The individual's diet
  - b. The individual's ADL abilities
  - c. The individual's likes and dislikes
  - d. A, B, & C

## Evaluation:

1. Was the information presented in this Health & Safety Alert helpful?
  - a. Yes
  - b. No
2. Will you use this Health & Safety Alert information to train other staff?
  - a. Yes
  - b. No
3. What topic(s) would you like to have presented in a Health & Safety Alert for CNE's?

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