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Recognizing Changing Health, Declining Health and Medical Emergencies Among Individuals with DD

Introduction

When an individual with intellectual and developmental disabilities (DD) has a change in condition or a decline in their health, it is their caregiver's responsibility to recognize the change and take appropriate steps to get the individual the help they need from a healthcare professional (19) (1). A caregiver may be a friend, family member, a licensed DBHDS agency staff member, a program manager, a support coordinator, etc.

All individuals with a diagnosis of intellectual and developmental disabilities are in some degree, dependent on their caregivers (paid or unpaid) for assistance with their physical and mental wellbeing. It is therefore critical for caregivers to regularly observe an individual with DD for changes in their physical and mental health (10) (7).

Help may also be obtained from a healthcare professional if the caregiver has access to a healthcare professional onsite, within the community such as the individual's PCP or medical specialist. Or by calling 911, if the individual is experiencing a medical emergency, or a life-threatening event. The type of healthcare professional and healthcare venue (EMS/911, hospital emergency room, urgent care, PCP office, etc.), the caregiver chooses for evaluation of the individual, should directly relate to:

- The type of change or decline in health the individual is experiencing.
- How rapidly the change took place.
- If the health change is a medical emergency or life-threatening event, or not (19).

A delay in treatment, due to the inability of a caregiver to recognize changing or declining health, is a leading cause in the increasing rates of preventable deaths and negative health outcomes among individuals with DD. Many poor outcomes are directly related to caregiver hesitation in seeking treatment for an individual (11).



Undiagnosed, but treatable conditions, have been connected to higher rates of mortality within the DD population, (when compared to the general population) (20) (16). Researchers believe, many of these conditions could be reduced or possibly avoided through routine preventive healthcare interventions, like yearly well-checks or physicals, dental check-ups, cancer screenings, vision and hearing assessments, immunizations, etc. (19) (5) (16).

Education and training of caregivers is key to empowering them to provide care, as needed, when they:

- 1) Observe a change in an individual’s condition.
- 2) Suspect an individual is experiencing a decline in health; and/or
- 3) Witness a medical emergency or life-threatening event (4).

Barriers to Treatment

Studies reveal some laypersons, (people who are not licensed healthcare professionals), lack the confidence to recognize warning signs of a life-threatening event or medical emergency and initiate first aid before the arrival of emergency medical services (EMS) (13) (18).

If a caregiver delays performing a life-saving measure, such as CPR or delays calling 911, for even a few minutes, those delays increase the risk of a fatality. For example, permanent brain damage may occur among victims of a sudden cardiac arrest (SCA) in as little as three minutes, and the chance of survival drops to nearly 0%, if victims are left untreated for five minutes or more (8) (9) (3).

Barriers to performing CPR experienced by laypersons:

Layperson Barrier	Study
Panic	(Maa et al., 2019)
Disagreeable physical characteristics of the victim.	(Maa et al., 2019)
Fear of getting an infectious disease from the victim.	(Maa et al., 2019)
Fear they will cause more harm than good.	(Maa et al., 2019; Vaillancourt et al., 2008)
Inability to recognize an unconscious victim.	(Pergola and Araujo, 2008)
Do not know, or understand, any state of “unconsciousness” is always a medical emergency.	(Pergola and Araujo, 2008)
Do not know, and/or forget to check, the victim’s vital signs (breathing and pulse).	(Pergola and Araujo, 2008)
No access to home healthcare monitoring devices, (blood pressure cuff, pulse oximeter, thermometer, etc.).	(Pergola and Araujo, 2008)
Poor 911 calling skills.	(Soontorn et al., 2020)
Fear of being sued or arrested, due to errors in performing CPR and first aid correctly.	(Soontorn et al., 2020)

Determining Health Risks for Each Individual

In the Commonwealth of Virginia when an individual with intellectual and developmental disabilities receives DD Waiver services, they have an annual Individualized Service Plan (ISP) developed by a Support Coordinator. The Risk Awareness Tool (RAT) is to be used in conjunction with annual planning to encourage thoughtful conversations and follow-up with qualified medical professionals, about a person's level of risk in 11 health and safety areas. These range from community safety risks to aspiration pneumonia.

The RAT is only required to be completed annually. However, it is recommended the tool be completed whenever there is a significant change in an individual's health status. Additionally, while the RAT is primarily a support coordination tool, input from an individual's caregiver(s) and family is critically important to ensure all potential risks are identified and referral to a qualified healthcare professional (regarding the risk identified) is completed.

If an individual receives residential services part of the intake into a licensed DBHDS provider agency's care, requires an initial health assessment by a primary care provider (PCP), which should include: visual observations of the individual, vital signs, weight, a review of previous and current diagnoses, a birth to present health history, (including any surgeries, past illnesses, history of abuse, etc.), current allergies, regularly required health practices or ordered protocols, current medications, and the individual's social history. After all information about the individual is gathered, it can then be used to determine the individual's health baseline (17) (19).



Social History
<ul style="list-style-type: none">Marital status and childrenFamily planningHousing or living situationSocial and financial support from family, friends, or othersEmployment status and occupational historySexual History



An Individual's Health Baseline or Usual State of Health

An individual's health baseline is their usual state of health, sometimes referred to as their "health status". It is important to obtain a health baseline because it can be used in the future to determine if there has been any change in an individual's condition, or a decline in health. Since no person's health stays the same for their whole life, an annual physical or well-check is

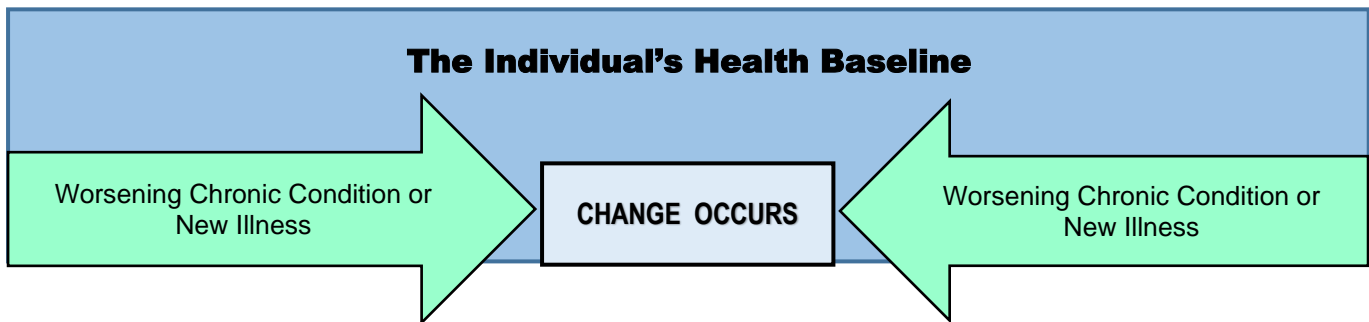
extremely important because it provides the latest update to the individual's health baseline.

Health Changes Which Impact an Individual's Health Baseline

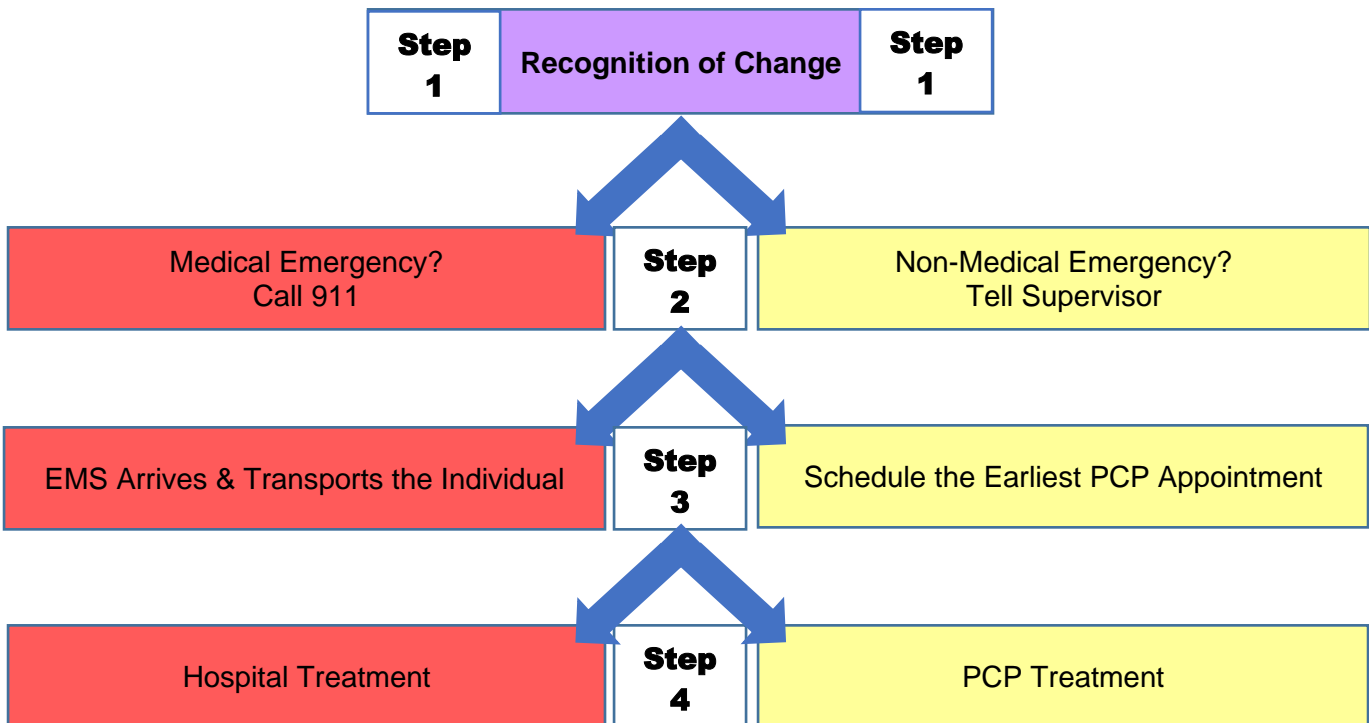
Worsening chronic health conditions or new illnesses which impact the individual's health baseline can lead to changes within the body. Changes within the body may be recognized by visual observations of an individual's general appearance, their behaviors, and/or their vital signs measurements.

Decision trees can assist caregivers in determining what should be done next and can help guide caregivers move through the process. The decision tree below starts with the observation of a change in the individual's baseline and walks you through the steps in obtaining help.

An Individual's Health Baseline



Recognition to Treat Decision Tree



Step 1 - Recognition of a Change

The first step in the **Recognition to Treatment Decision Tree**, is recognizing a change in an individual's usual health or health baseline. The decision to get treatment for an individual is easier when the caregiver is familiar with the individual and their health baseline, or usual state of being.

It is important for each caregiver to orient themselves to each individual in their care. Caregivers who are better acquainted with the individuals they provide care for, will be more likely to recognize a change in an individual's overall wellbeing.

Treatment and survival are dependent on the skills of a caregiver to recognize the earliest, most subtle signs of a change in an individual's health baseline. The ability of a caregiver to recognize changes in condition or declining health, may mean the difference between life and death for individuals with DD.

The risk of a preventable death among individuals with DD may be greatly reduced when:

- All health changes affecting an individual's health baseline are recognized quickly.
- 911 is activated immediately for individual's experiencing a medical emergency.
- A PCP appointment is scheduled for non-emergencies.

If health baseline changes are not an emergency, they should be brought to the attention of staff supervisors (in licensed DBHDS agencies), as soon as possible and documented.

- Hospital treatment, or PCP treatment may include other directions or referrals to medical specialists.

If a person is found unconscious it is ALWAYS a medical emergency or life-threatening event. Call 911 immediately!

Step 2 - Medical Emergency or Non-Emergency Determination

The second step requires the caregiver to determine if the health status change is most likely a medical emergency or not. To be clear, it is not the responsibility of any "layperson caregiver" (a caregiver who is not a healthcare professional) to diagnose or determine why an individual is in distress, or how their health has changed.

This is the action step. The first person to recognize the change in health must act. Actions may include **CALLING 911 as quickly as possible, when/if they are observing a life-threatening event or medical emergency**. The first person who thinks the individual is having a health change (which is most likely a life-threatening event or medical emergency), should **never delay a call to 911 FOR ANY REASON!!!** If a caregiver "thinks" they should call 911, they probably should.



It is always better to err on the side of caution and to call 911, even if unsure. In licensed DBHDS agencies, remember it is **not** best practice to call your supervisor before calling 911. If it is a medical emergency, please call 911 first.

If the individual has a change in their health baseline which doesn't require a call to 911, but does require a visit to their PCP, caregivers should schedule a PCP appointment for the individual. In licensed DBHDS agencies, it is best practice for direct support staff to notify their supervisor that a PCP appointment should be made for the individual and why. It is the caregiver's responsibility to make the appointment and to communicate to the PCPs office why the individual needs to be seen, and what changes in health have been observed, which are prompting the request for an appointment (19).

Step 3 - EMS Arrives and Transports the Individual or Schedule the Earliest PCP Appointment

When 911 is called, the 911 emergency operator will always send the closest EMS unit to your location based on GPS satellite information. It is best practice for caregivers to stay with and support the individual using first aid skills, CPR training, or the individual's own protocols, as best as they can until EMS arrives.

When Emergency Medical Services (EMS) paramedics arrive, they will provide the most advanced emergency medical care available onsite and will base their recommendation to transport (for additional treatment), on their assessment of the individual.

It is best practice for caregivers to answer any questions they are asked by EMS as best they can. It is also important for caregivers to keep others out of the way (roommates, family members, etc.) during an emergency situation, so EMS can help the individual, without being interrupted.



Valuable time may be lost if the person calling 911 has to go through hundreds of pages of medical records looking for answers to the 911 dispatcher's questions. The My Care Passport can be used to access information quickly, see the Resource section for more information.

When primary care is needed, most individuals with DD cannot schedule their own preventive or sick care visits, they depend on caregivers to schedule medical appointments in a timely manner. Before calling the individual's PCP, gather all information about the individual which may be requested by the receptionist, such as date of birth, and insurance information (19).

Communicate the reason for requesting the appointment. If the individual has high medical needs or is medically fragile (see excerpt of the Federal government's definition below), inform the receptionist at the PCPs office of the individual's current condition. If the individual needs to

be seen by the doctor that day, tell the receptionist about the urgency and ask for the earliest appointment possible.

“Individuals with disabling mental disorders (including children with serious emotional disturbances and adults with serious mental illness), individuals with chronic substance use disorders, individuals with serious and complex medical conditions, individuals with a physical, intellectual or developmental disability that significantly impairs their ability to perform 1 or more activities of daily living, or individuals with a disability determination based on Social Security criteria” ([Centers for Medicare Services, 2022, June 13, p.7](#)).

If the PCPs office doesn't have an appointment available for several days to weeks, consider transporting the individual to the local urgent care center, if one is available in your area, or to the local hospital emergency room, to be seen as soon as possible by a healthcare provider.

Even subtle or slight changes in health, can progress rapidly. Any delay could result in an emergency medical situation, a hospitalization, a new chronic disorder for the individual, a permanent decline in the individual's health, and or a preventable fatality.

Step 4 - Hospital/Acute Care Treatment Begins or Primary Care Treatment Begins

Once the individual has been transported to the hospital, the individual will often be in the emergency department for several hours for assessments and tests. The ER physician in charge of the individual's case will make the decision to treat the individual, admit the individual into the hospital or discharge home with instructions for continuing care (3).

Whenever an individual has been discharged from the hospital or ED a follow-up visit should be scheduled with the individual's PCP at the next earliest appointment unless directed to do differently in the hospital discharge instructions. Discharge instructions and new medication orders should be followed until the individual is seen by the PCP.

Medications ordered during the hospital stay should be obtained as quickly as possible by caregivers. Once the emergency situation has been resolved, the individual's PCP should be updated regarding the medical emergency experienced and the treatment the individual received.

If the individual experiencing declining health can wait to be seen by their PCP, they may receive testing and assessments to find the cause of their illness (during their PCP appointment) and may also receive referrals to other healthcare specialists for testing and assessments. The visit to the PCP may include changes to the individual's current medications, or the addition of a new medication, orders for treatments, written care protocols or other PCP orders for care.



Medical Emergencies

Certain health changes (symptoms, etc.) are ALWAYS medical emergencies, no matter the person, the age, the disability, the situation, etc.

None of us knows when, where, or what type of medical emergency they may observe on any given day, but one thing is certain, if you have the skills to recognize the symptoms of medical emergency, the person experiencing the medical emergency will have a much better chance of survival (13).

When caregivers are trained and practice their skills in responding to medical emergencies quickly it builds confidence and reduces the likelihood of fatalities.

A caregiver who has developed the skills to respond quickly to an emergency is an asset to the community provider agency and helps to ensure that individuals in their care will receive the help they need. These skills may also benefit the caregiver's family, friends, neighbors and society (in general).

According to [the American College of Emergency Physicians](#) (n.d., p.4), the following are signs of a medical emergency:

- Bleeding that will not stop.
- Breathing problems (difficulty breathing, shortness of breath).
- Change in mental status (such as unusual behavior, confusion, difficulty arousing).
- Chest pain.
- Choking.
- Coughing up or vomiting blood.
- Fainting or loss of consciousness.
- Feeling of committing suicide or murder.
- Head or spine injury.
- Severe or persistent vomiting.
- Sudden injury due to a motor vehicle accident, burns or smoke inhalation, near drowning, deep or large wound, or other injuries.
- Sudden, severe pain anywhere in the body.
- Sudden dizziness, weakness, or change in vision.
- Swallowing a poisonous substance.
- Severe abdominal pain or pressure.

Emergencies for Individuals with DD

Individuals themselves should receive training on how to call 911 and/or activate emergency medical services (EMS) either by phone, or through a Personal Emergency Response Device, a Home Medical Alert System, or through a computer or smart phone application.

Individuals with DD experience the same emergencies as the general public but can also experience more severe symptoms to common conditions which can quickly turn into a medical emergency (11).

These symptoms include:

- Severe dehydration.
- Heat exhaustion.
- Heat stroke.
- Hypoxia/low oxygen saturation level.
- Respiratory distress.
- Bowel obstruction.
- Concussion.
- Choking.
- Anaphylaxis.
- Hypoglycemia (low blood sugar).
- Hyperglycemia (high blood sugar).
- Skin infection.
- Pressure injury.
- Infections leading to sepsis.
- Chest pain.
- Seizure.
- Bleeding emergency.
- Stroke.

Primary Care Physician (PCP) Visit

Subtle to moderate health changes may indicate the need for primary care provider PCP assessment for treatment or referral. The list below highlights a subtle to moderate health change which should be evaluated as soon as possible by an individual's PCP.

- Changes in eating habits or swallowing.
- Unexplained weight loss.
- Changes in day-to-day patterns and behaviors.
- A persistent fever.
- Shortness of breath which goes away quickly.
- Unexplained changes in bowel habits.
- Cognitive, personality or behavioral changes.
- White patches on the mouth or tongue.
- Yellow or greenish tinged pus, mucus, phlegm.
- Strange moles or freckles.
- Behavioral changes.



Caregiver Considerations During Emergency Situations

Education and Training

- Empowering caregivers by helping them acquire the skills needed to determine whether a serious medical emergency is occurring, or a PCP appointment is needed, will ensure individuals with DD receive medical treatment or emergency care without delay (19).
- Training on how to activate emergency medical services (EMS) should be directed to family, caregivers, and coworkers of high-risk individuals (22).
- It is best practice for all caregivers to complete advanced competency training if providing care to individuals with multiple co-morbidities and/or higher Supports Intensity Scale scores.
- CPR training is a skill which has been shown to be an effective method to improve confidence in a layperson's ability to recognize a medical emergency, summon help, and willingness to perform CPR (15).
- Learning activities which increase a layperson's knowledge relating to first aid, CPR and emergency situations, may increase a layperson's confidence to act in an emergency (13).
- Practicing critical thinking and early recognition skills using case-based scenarios which include the most common medical emergencies and illnesses builds self-assurance in staff. Case-based learning has the potential to help improve layperson's decision-making process (2).
- A caregiver who can communicate well with healthcare professionals is better equipped to ask questions and able to follow care instructions without mistakes. Improving health literacy and health-related communication skills, among layperson caregivers, may translate into a decreased risk of death for individuals (12) (14) (6).
- Caregivers should be able to accurately identify normal ranges of vital signs for adults and children (if providing care to children).
- Caregivers should be trained on how to use home monitoring devices to measure vital signs and be able to accurately demonstrate their skills back to the trainer. In order to maintain vital signs measuring skills, caregivers should practice on a regular basis (monthly, quarterly, etc.) to remain competent.
- Caregivers should know where to retrieve information about the individual's vital sign measurements (i.e. their baseline measurements). This is especially important for those individuals who have high medical needs, those who are medically frail, and/or those who have multiple medical conditions.

Practice Drills

- Participation in hands on practice trainings focused on teaching caregivers the skills for recognition of medical emergencies has been shown to improve outcomes (2).
- Ongoing training on emergency medical services activation helps build confidence and decrease risk of panic in an actual emergency.
- Caregivers in provider agencies should be empowered by the provider agency to act quickly in a life-or-death situation. Staff should know they will not be “in trouble” if they call 911 and EMS decides it is not an emergency situation.
- Make sure all family caregivers know their home address and all licensed providers know their work address, so there is no delay in summoning help. Posting a large sign in a well-trafficked area on the inside of the home or agency site with the address clearly displayed can be helpful.
- Have all caregivers participate in pretend medical emergency training drills to increase their confidence to call for help quickly.
- During a drill, practice each step of the activation process, and give caregivers tips along the way if they get stuck.
- Caregivers should be praised for steps done well during practice drills.
- During practice drills, if glitches in the process are found, work on improvement in those specific areas and then re-group to practice those areas repetitively, until all caregivers are confident in their abilities to respond to an emergency.

In summary, medical emergencies are rapidly declining health changes, which tend to occur when there is a sudden insult to the body through injury, infection, chemical imbalances, neglect, or chronic conditions (3).

Survival often depends on:

- Quick recognition of a health status change (often by a layperson/direct caregiver).
- A quick decision (often by layperson/direct caregiver) to determine if the health change is a medical emergency.
- Direct caregivers who know how to activate and request assistance from EMS.
- Prompt transportation by emergency medical services teams.
- Rapid assessment by acute care/healthcare professionals.
- Appropriate treatment interventions to stabilize the individual experiencing the medical emergency (13) (3).



Resources

For any provider licensing questions, please contact the DBHDS Office of Licensing at:
<https://dbhds.virginia.gov/clinical-and-quality-management/office-of-licensing/ol-contact-info/>

Provider Regulations (Chapter 105. Rules and Regulations for Licensing Providers by the Department of Behavioral Health and Developmental Services) can be found at the following link:

<https://law.lis.virginia.gov/admincode/title12/agency35/chapter105/>

Provider Development resources can be found at this link:

<https://dbhds.virginia.gov/developmental-services/provider-development/>

The My Care Passport Health and Safety Alert can be downloaded from the OIH-HSN website at <https://dbhds.virginia.gov/wp-content/uploads/2022/09/DBHDS-My-Care-Passport-9.25.22.pdf>. You can also download additional information about the My Care Passport on the OIH website. Once there, click on the Educational Resources button and the My Care Passport (and all of its resources) will be listed there. All documents can be downloaded.

For a more in-depth, narrated, educational experience, please check out The My Care Passport Training on the Commonwealth of Virginia Learning Center (COVLC). To learn how to sign up for trainings on the COVLC <https://dbhds.virginia.gov/assets/Housing/DBHDS-External-Entities-Domain-GuideCOVLC.pdf>, please read this instruction sheet for DBHDS outside entities (providers, etc.).

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