



COMMONWEALTH of VIRGINIA

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Office of Integrated Health Health & Safety Alert/Information

The Leading Causes of Fatality for Individuals with Intellectual and Developmental Disabilities

Introduction

Healthcare researchers in the field of intellectual and developmental disability (IDD) and governmental agencies providing oversight of IDD-related programs and services, strive to promote the health, safety, quality of life, and longevity (length of life) of individuals with IDD (7).

Gathering information and performing comprehensive reviews of the previous deaths of individuals with IDD, is one method used to lower risk of future adverse outcomes. The goal of their work is aimed at developing recommendations aimed at improving healthcare services, improving clinical and caregiver education, training, licensing oversight, governmental regulations, and licensed provider policies, etc.

Death-related data is examined to look for similarities and trends among previous fatalities, and a determination of whether or not a death may have been prevented or avoided is made (5). If there is a possibility the death may have been avoided, and has been caused by a particular condition, the information relating to the condition or “cause of death”, is recorded and used to develop a “fatal conditions list”. These lists are a collection of the specific health conditions, which have led to the most deaths among individuals with IDD within the particular group being studied (9).

Public health, governmental agencies and advocates for individuals with IDD use these conditions “lists” as a quality improvement tool (2). The lists are aimed at “bringing attention to” a particular health condition. There is no set number of health conditions on any particular list. One list may focus on the top five causes of fatality, which would then be dubbed a “Fatal 5” list. Other lists may include the top ten causes of fatality, which would be dubbed a “Fatal 10” list, and so forth.

The goal of the “fatality lists” is to:



- Focus the individual's or caregiver's attention on the preventable deaths which are occurring as a result of a particular condition.
- Promote the individual's or caregiver's awareness to the risks related to a particular condition.
- Teach the individual or caregiver how to lower the risks relating to a particular condition.
- Promote a change in the individual's or caregiver's behaviors in order to promote and maintain the health and safety of individuals with IDD.

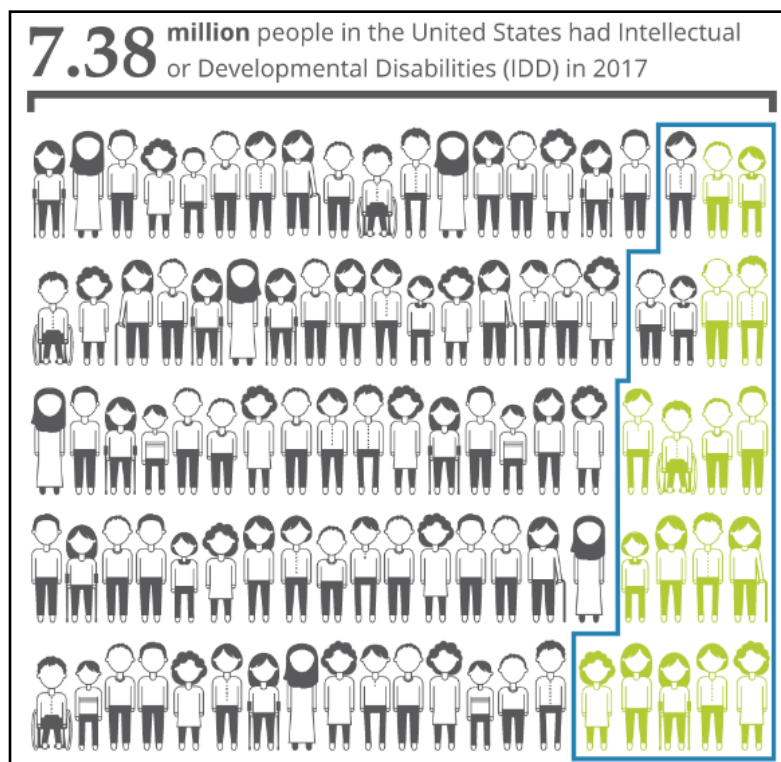
Ongoing monitoring to determine the topmost causes of avoidable deaths (among the IDD population), also encourages healthcare research aimed at identifying the underlying modifiable factors. Modification of the identified factors, may then help improve healthcare outcomes (14).

Individuals with Intellectual and Developmental Disabilities (IDD)

The global census estimates approximately 1 to 3% of the population have some type of intellectual or developmental disability (13).

In 2017, an estimated 7.38 million people in the United States had a diagnosis of intellectual and, or developmental disability (15) (1). Specifically, 5.38 million were children and 2.0 million adults (2).

As of June 2021, in the Commonwealth of Virginia, 15,221 individuals with IDD were receiving services on the DD Waiver and 13,376 individuals were on the DD Waiver waiting list (16) (17).



Healthcare Disparities for Individuals with IDD

The IDD population is a unique group of individuals with specific healthcare needs, which differ from other high-risk populations. Most individuals diagnosed with IDD require some level of support, which can range from minimal supervision to 24 hours a day - 7 days a week, hands-on care, to achieve their best life (3) (11).

Individuals with intellectual disabilities experience higher mortality rates, lower healthcare quality and poorer quality of health (overall) when compared to their cognitively normal peers (8) (4) (1) (18).

Although individual's with IDD have been living longer over the past several decades, current research indicates adults with IDD are dying 20 to 25 years earlier than their peers in the general population (13).

Overall, adults and children with IDD receive less medical and oral preventive care, which results in a high rate of avoidable deaths. These individuals also experience more co-occurring chronic medical conditions, and psychiatric conditions, than do the general population (12) (1).

Many factors contribute to the poor healthcare individuals with IDD receive. They may receive less extensive physical examinations and assessments due to:

- Accessibility.
 - Exam room size may be difficult for wheelchair users to navigate and exam tables may be inaccessible to those with mobility issues.
- Sensory issues.
 - Sensitivity to touch may prompt individuals to pull away or attempt to physically block an examiner from touching them with their hands or body. This can result in a less extensive or thorough exam.
- A lack of social or relationship experience (with individuals who have IDD) among healthcare professionals.
 - Many healthcare professionals have not had any previous social interactions with individuals who have IDD. Some may have experience through a familial (family) connection, or a personal one (a friend or a neighbor).
- A lack of IDD-related academic or clinical training (with individuals who have IDD) among healthcare professionals (physicians, nurses, etc.).
 - Most medical and nursing programs do not include focused hours with the IDD population within their clinical rotations.

- A lack of comprehensive preventive care interventions (12) (1) (18).
 - Individuals may have difficulty tolerating certain tests or test preps. Some may be unable to tolerate the prep required for a colonoscopy. Others may not be able to hold still or tolerate the pressure of a mammogram, or may experience panic during a CT scan or an MRI.
- Communication difficulties.
 - Individuals may lack the language skills needed for effective communication, or may be unable to accurately describe how they are feeling. Others may be completely non-verbal.
- Cognitive issues.
 - Individuals may lack the cognitive ability to understand abstract concepts, and may deny certain symptoms, such as pain or nausea, etc. because they are unable to understand what they mean.
- Behavioral issues.
 - Healthcare providers may make snap clinical judgements based on how they perceive an individual's behavioral issues, without investigating the underlying physical causes.
 - Individuals may have self-injurious behaviors which could be viewed as a tantrum, but may actually be related to severe pain or other symptoms they are experiencing, but cannot communicate.
- Multiple co-occurring conditions.
 - Physicians and other prescribers frequently over and under-prescribe medications due to a lack of experience with the IDD population (12) (1) (18).

The DBHDS Morality Review Committee (MRC)

The Virginia Department of Behavioral Health and Developmental Services has a committee of professionals known as the Mortality Review Committee (also known as the MRC Committee), who review the death of every individual with an intellectual or developmental disability receiving a licensed DBHDS service, per [Virginia Code](#). Each year, for the past seven years, the MRC Committee has produced an annual report based on a fiscal year timeframe beginning on July 1st of any given calendar year, and ends on June 30th of the following calendar year. The findings of the MRC Committee are published in statistical form based on the data reviewed. The reports do not reveal any personal health information (PHI), or identify any specific individual(s).

Their most recent report, dated December 2021, lists the health conditions which led to deaths in the previous fiscal year (16). The complete DBHDS SFY 2021 Annual Morality Review Committee Report can be accessed at the following link:

https://dbhds.virginia.gov/assets/doc/QMD/SFY21_DBHDSAnnualMortalityReport.pdf

Promoting Best Practice Education to Lower Risk of Preventable Deaths

The risk of preventable injuries, avoidable hospitalizations, and premature deaths of individuals with IDD can be lowered by providing best-practice education to individuals with IDD, and their caregivers, regarding:

- The signs and symptoms of preventable/avoidable health conditions (11).
- The benefits of annual physicals and wellness exam appointments with the individual's primary care provider (PCP) to ensure routine screenings and preventative care are provided on a regular basis (11).
- The benefits of follow-up appointments with the individual's primary care provider (PCP) after a hospital admission/discharge, outpatient procedures, or testing, to determine if additional testing or medication changes may be needed, based on the outcome of a procedure, or the results of a test (11).
- The benefits of regularly scheduled appointments to monitor the therapeutic response (effectiveness) of medications prescribed to treat a chronic disorder (11).
- The helpfulness of care protocols developed by healthcare professionals, such as an RN or LPN (under supervision of an RN), a physical therapist (PT) an occupational therapist (OT), a speech language pathologist (SLP), or a primary care provider (PCP).
- The importance of recognizing early signs of illness and/or deteriorating health, in order to reduce repetitive ER visits, and the advancement of a life-threatening illness or condition (11).
- The benefits of using a "passport" type communication tool, which can improve communication between caregivers and acute care staff regarding all aspects of the individual's care (12) (11). An example is the Office of Integrated Health - Health Supports Network "My Care Passport.
- The benefits of the use of a risk assessment tool (RAT) when interviewing an individual with IDD to identify the need for further evaluation by a qualified healthcare professional. (Additional information on the RAT can be found in the Resources section below.)

- If you have any questions about any of the educational materials mentioned in this section, please contact the Registered Nurse Care Consultant in your area via email at: communitynursing@dbhds.virginia.gov

Resources

The Office of Integrated Health (OIH) – Health Supports Network (HSN) currently offers a training which focuses on seven potentially fatal conditions which occur frequently among individuals with IDD. Contact the OIH-HSN for more information. The OIH-HSN DBHDS “Fatal Seven” Training includes instruction on the following:

1. Dehydration.
2. Constipation.
3. Pressure Injuries.
4. Falls.
5. Aspiration.
6. Seizures.
7. Sepsis.



The Office of Integrated Health – Health Supports Network (OIH – HSN) website:

<https://dbhds.virginia.gov/office-of-integrated-health#>

OIH - HSN Community Nursing Email Contact: communitynursing@dbhds.virginia.gov

OIH - HSN Mobile Rehab Engineering (MRE) Team Email Contact:

mreteam@dbhds.virginia.gov

OIH - HSN Dental Team Email Contact: dentalteam@dbhds.virginia.gov

The [Risk Awareness Tool \(RAT\)](#) is another tool to identify risk related to conditions which may need follow-up with medical professionals. The results of the RAT identifies the need for further evaluation by a qualified healthcare professional. Click here for more information relating to the [RAT](#).

The Virginia Department of Behavioral Health and Developmental Services (DBHDS)

Website: <http://www.dbhds.virginia.gov/>

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