# Advocacy in Acute Care Settings

## What is Advocacy?

Advocacy for another person means speaking, writing, or acting on their behalf in order to achieve an outcome that is in their best interest. Advocacy is an important role, especially for those who cannot advocate for themselves (1).

## Healthcare Disparity and Inequity

There is a great need for advocacy in acute care settings in order to lower the risk of preventable deaths. Individuals with IDD often receive a substandard level of care due to negative attitudes towards those with disabilities, communication difficulties, inaccessible medical facilities, and a lack of training and experience among healthcare professionals (2).

## Advocacy in Acute Care Settings

Sending someone who knows the individual well to the hospital with them is considered best practice. Staff should be prepared to assist with answering questions or presenting helpful documentation such as vital sign logs, bowel movement logs, input/output logs, Medication Administration Record's, and health history, and be able to describe any symptoms the individual may be having.

A hospital passport can be beneficial for hospital staff to get a clear picture of the individual's usual health status.

Persons accompanying individuals to the hospital or emergency room should be educated on the Fatal Seven, conditions/disorders which increases fatalities for individuals with IDD. Inform the hospital staff if the individual has a history of any of the following conditions. The Fatal Seven are:

1. Dehydration.
2. Constipation/Bowel Obstructions/Fecal Impactions.
3. Aspiration Pneumonia.
4. Sepsis.
5. Seizures.
6. Falls.
7. Pressure Injuries.

## App of the month

The Patient Safety Movement Foundation's first mobile application, PatientAider, can be a valuable source of medical information for you or your loved one's hospital stay. If you or someone you love is in the hospital or heading to the hospital soon, download PatientAider. Tailor your experience, read articles and watch videos on specific health topics. This App is designed to work on multiple platforms. (*App of the Month is not endorsed by DBHDS Office of Integrated Health. User accepts full responsibility for utilization of app*).

## Tips for Advocating in the Hospital and Emergency Room Settings

- As an advocate, support the individual, who may be frightened and uncooperative.
- A thorough assessment with a full set of vital signs should be taken at the ER. This includes:
  - Blood pressure.
  - Heart Rate (pulse).
  - Pulse Oximetry (Oxygen Saturation Level).
  - Temperature.
  - Respiratory rate/Breathing rate.
- The goal is to obtain a diagnosis quickly. ER staff may need assistance with getting the individual to cooperate for tests necessary to confirm a diagnosis.
- Physicians determine what tests should be completed based on signs/symptoms, history, assessment and presentation.
- Advocate for the following tests to help rule out or confirm a Fatal Seven condition:
  - Urinalysis (rule out a urinary tract infection).
  - Chest X-ray (rule out pneumonia).
  - Abdominal x-ray (rule out fecal impaction/bowel obstruction).
  - Complete Blood Count (rule out infection).
  - EKG (assess heart rhythm).
  - EEG (assess for seizures).

*This is not an all-inclusive list. Physician may order additional diagnostic tests based on signs/symptoms, history, assessment, and the individual's condition.*

## COVID-19 and Acute Care Settings

COVID-19 testing will be performed during all acute care visits. Individuals may not refuse a nasal swab for COVID-19 testing. Individual with viral symptoms such as cough, fever, shortness of breath will be isolated immediately.

If an individual is positive for COVID-19, they may be treated at the triage location and sent home with orders. Everyone entering the ER is required to wear a mask. If an individual has recovered from COVID-19 inform the ER physician.

References
1) 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 intellectual disability. *Journal of Intellectual Disability Research,* 56(11), 1087– 1097. Doi: 10.1111/j.1365-2788.2012.01637. x.
2) 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. DOI: 10.1111/jar.12282
3) Hartnett, K., Kite-Powell, A., DeVies, J., Coletta, M., Boehmer, T., Adjemian, J., & Gundlapalli, A. (2020, May) Impact of the COVID-19 pandemic on emergency department visits-United States. *MMWR Morb Mortal Wkly*, 69. 699-704. DOI: 10.15585/mmwr.mm6923e1.

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## Health Care Advocacy Resources

**You can find the Vanderbilt/Kennedy Primary Care Toolkit:** https://iddtoolkit.vkcsites.org/

**Resources 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** http://www.surreyhealthaction.org/downloads/hospital%20passport%20surrey.pdf

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## ABA Snippets ...

### *Functional Communication Training and Replacement Behaviors*

Identifying and teaching replacement behaviors remains a paramount component of behavior support planning. A replacement behavior can be considered as a behavior that is more socially acceptable than a challenging behavior and meets the same behavioral function as the challenging behavior (5). Functional communication training (FCT) is the procedure that teaches an alternative (or replacement) behavior (1). One of the first studies to outline the use of 'replacement behaviors' came in 1985 with Carr and Durand's successful treatment of challenging behavior for several children with developmental disabilities via the differential reinforcement of functionally communicative behaviors to obtain assistance or attention (2). As a basic rule of thumb, an adequate FBA would identify the functions of challenging behavior and also outline potential functionally equivalent replacement behaviors; subsequently, the tactics selected for behavior change would promote acquisition (or the increased responding) of behaviors that are functionally equivalent to undesirable behaviors (3). At the time of this ABA Snippet, the literature base for FCT is expansive and demonstrates its efficacy, though it can be improved upon in future research by including more diverse treatment settings and also accounting for key social validity indicators (4). Notably, replacement behaviors are a required component of the DBHDS and DMAS Practice Guidelines for Behavior Support Plans, with an expectation established therein that this critical content area is both included in the behavior support plan and also captured and evaluated via ongoing measurement such that the impact of FCT procedures can be evaluated by the practitioner. Watch an ABA video at https://www.youtube.com/watch?v=hbDY27nutXc

References:
(1) Braithewaite, K. L., & Richdale, A.L. (2000). Functional communication training to replace challenging behaviors across two behavioral outcomes. Behavioral Interventions (15), 21-36.
(2) Carr, E.G. & Durand, V.M. (1985). Reducing behavior problems through functional communication training. Journal of Applied Behavior Analysis, 18(2), 111-126.
(3) Cooper, J.O., Heron, T.E., & Heward, W.L. (2020). Applied behavior analysis: third edition. Pearson Education, Inc.
(4) Ghaemmaghami, M., & Hanley, G.P. (2021). Functional communication training: from efficacy to effectiveness. Journal of Applied Behavior Analysis, 54(1), 122-143.
(5) McKenna, J.W., Flower, A., Falcomata, T., & Adamson, R.M. (2017). Function-based replacement behavior interventions for students with challenging behavior. Behavioral Interventions, 32(4), 379-398.
(6) Virginia Department of Behavioral Health and Developmental Services, Virginia Department of Medical Assistance Services. (2021, May). Practice Guidelines for Behavior Support Plans. https://www.townhall.virginia.gov/L/GetFile.cfm?File=C:\TownHall\docroot\GuidanceDocs\602\GDoc_DMAS_7024_v1.pdf

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**DARS** — VIRGINIA DEPARTMENT FOR AGING AND REHABILITATIVE SERVICES

Our Office for Aging Services facilitates the Virginia Caregiver Coalition, which supports efforts across the lifespan by providing networking, education and resources for caregivers.

Our office also coordinates the Lifespan Respite Voucher Program, which has helped over 1,000 Virginia families and provides up to $595 in reimbursement for respite care costs to eligible caregivers to support their well-being.

The governor recognizes Family Caregivers Month in this proclamation.

### It's all about the Caregiver

**1 in 5 Virginians** provide regular care or assistance to a friend or family member with a health problem or disability.

**950 million hours** of unpaid care provided by Virginia caregivers.

**$11 billion annually** value of unpaid care.

*Happy Holidays from the Office of Integrated Health – Health Supports Network.*