

Advocacy Tools Aimed At Improving Communication & Healthcare Quality For Individuals With IDD

Developed and Presented by Office of Community Quality Improvement in collaboration with the Office of Integrated Health Supports Network at the Virginia Department of Behavioral Health and Developmental Services







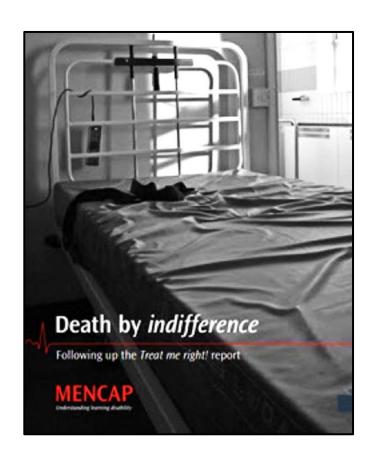
Learning Objectives

- Identify the symptoms of UTI and Urosepsis.
- Describe how to use the Decision Tree to determine if the symptoms the individual is experiencing are a medical emergency or not.
- Describe why the My Care Passport was developed and its purpose.
- State how the My Care Passport can be used as a communication and advocacy tool in acute care settings.
- Describe how the My Care Passport can improve healthcare quality.
- Summarize the information contained in the Consent, Medicaid Waiver, and Discharge Requirements Tip Sheets and their purpose.
- Describe how the use of the Local Medical Care Card can assist with helping individuals receive the healthcare they need in a timely manner.



Why was a communication and advocacy tool needed?

- Individuals with IDD did not always receive the right healthcare.
- Many deaths were determined to be from preventable causes.
- A disproportionate number of individuals with IDD were dying in acute care hospitals when compared to the general public.



A lack of communication was identified as a barrier to quality care.





The breakdown in communication occurred because...

Community Caregivers:

- Did not always know what information hospital staff needed to know.
- Incorrectly assumed that all acute care staff had experience and training focused on caring for individuals with IDD.

Acute Care Hospital Staff:

- Did not always know the right questions to ask.
- Lacked experience and training focused on caring for individuals with IDD.
- Did not know how to "connect" with individuals on a person-to-person basis.

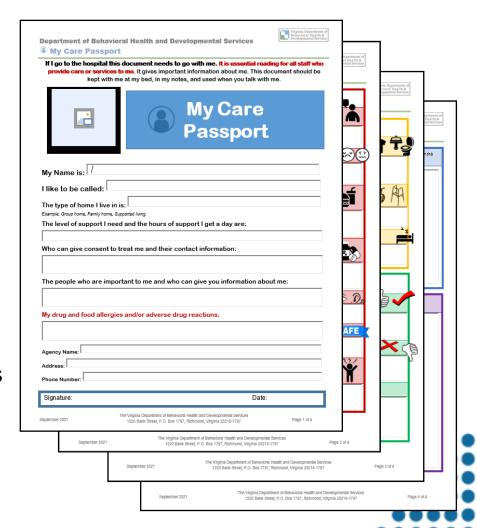
Poor Communication + Poor Information Sharing

Poor Quality of Care



My Care Passport was Created

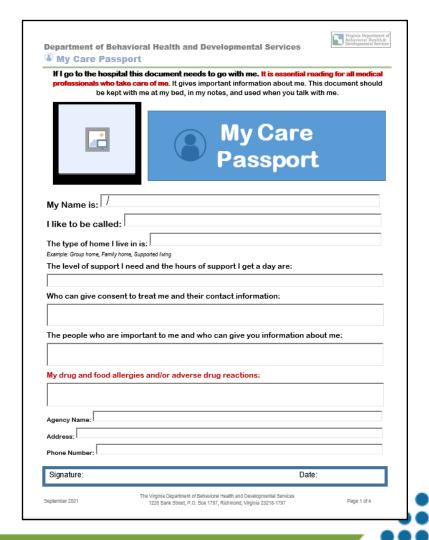
- The My Care Passport is an Americanized version of the Hospital Passport.
- Its use is voluntary.
- Improves communication and information sharing between acute care staff and community caregivers.
- Promotes person-centeredness by familiarizing hospital staff with the unique needs, abilities, interests, likes and dislikes of individuals with IDD.





The 1st Page

- The first page holds basic information regarding the individual.
 - Their photo.
 - Their name.
 - Nick name.
 - Consent information.
 - Important people.
 - Allergies and adverse reactions.
 - Provider agency information.
 - Signature of person completing the "My Care Passport".

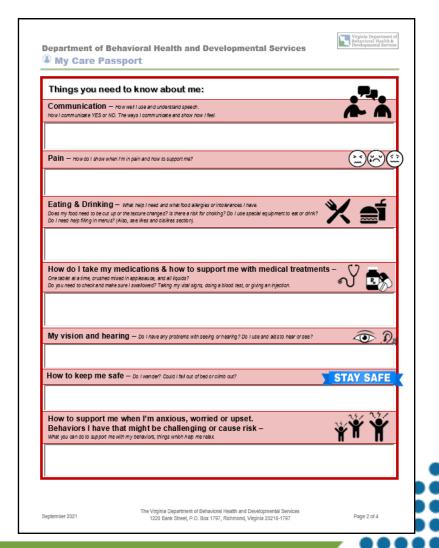






The 2nd Page

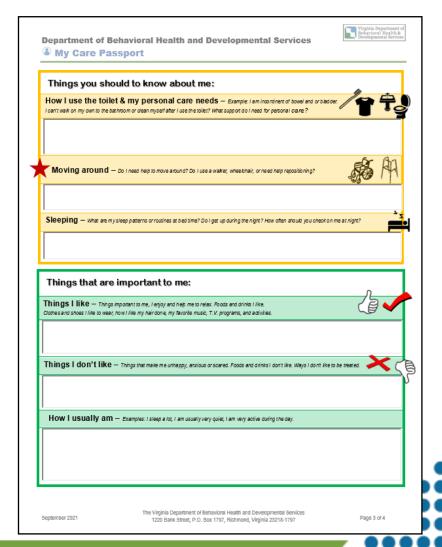
- The second page holds the "Things you need to know about me".
- This section is in RED indicating highest importance.
 - Communication.
 - Pain.
 - Eating & drinking.
 - How medications are taken.
 - Support during medical treatments.
 - Vision & hearing.
 - Safety.
 - Behaviors.





The 3rd Page

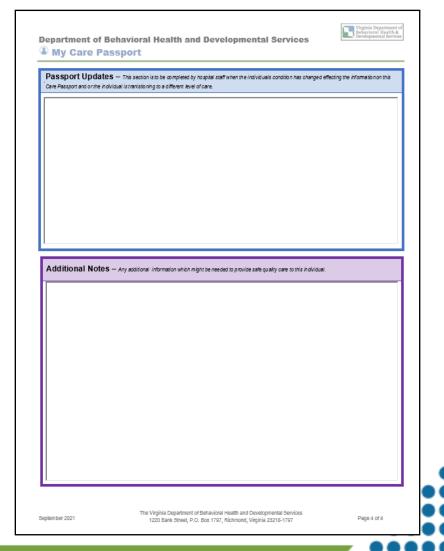
- The third page holds
 "Things you should know about me" are in YELLOW.
 - Toileting.
 - Personal care needs.
 - Mobility needs.
 - Sleeping.
- Then in GREEN are the "Things that are important to me".
 - Likes.
 - Dislikes.
 - Typical behavior.





The 4th Page

- The fourth page is for additional information.
 - Passport Updates in BLUE.
 - Additional notes in PURPLE.







The Consent Tip Sheet

The Consent Tip Sheet

- Shares information about medical care and treatment consent for individuals.
- Indicates who can make medical decisions and who can receive personal health information (PHI) relating to the individual based on their role.

Consent Tip Sheet



making for person Note: Patients	ee Chart below is to help with surrogate decision - ons who lack capacity. are assumed to have capacity unless determined up-to-date capacity assessment.	Person who can make medical decisions	Person authorized to receive PHI
Medical Power of Attorney (MPOA)	Selected by the patient in an advanced directive as the person authorized to make decisions for them if they are ever incapacitated.	Yes	Yes
Legal Guardian	A court appointed guardian has authority to make medical decisions.	Yes	Yes
Legal Surrogate Decision Maker (Next of Kin)	When there is no MPOA, no guardian, and the patient lacks capacity to make medical decisions. This is a family member or close acquaintance who is next in line following Virginia law on surrogate decision-making and who is willing to serve in the role of surrogate decision-maker.	Yes	Yes
Authorized Representative (AR)	A person authorized to receive and disclose medical information. To consent for treatment and services within a designated provider/setting — such as a group home, day program, or work program.	No Not for hospital care decisions. Yes For decisions in the location identified by the AR authorization.	Yes
Designated Direct Support Professionals (DSP)	A person designated by a patient to provide any needed assistance while the patient is in the hospital and in the community, including assistance for communication, and basic care needs.	No	Yes
Community Agency Care Providers	A community agency care provider who supports the individual to live independently in their own home under a Medicaid Waiver.	No	Yes

January 2022

The Virginia Department of Behavioral Health and Developmental Services 1220 Bank Street, P.O. Box 1797, Richmond, Virginia 23218-1797







The Discharge Requirements Tip Sheet

The Discharge Requirements Tip Sheet

- Communicates best practice discharge instructions for individuals in Virginia's Waiver System.
- Is focused on individuals who reside in a DBHDS licensed setting.
- Aimed at individuals primarily supported by laypersons.

Discharge Requirements Tip Sheet Note: All Individuals beginning discharged into the community require a written order for each medication, treatment, assessment, measurement, protocol, or equipment. Information needed for unlicensed laypersons to administer medications under a Medicaid Waiver system.			
Prescription Requirements	A complete written prescription for each medication, and or oxygen therapy, signed by the physician. Must also include: Purpose of medication and expected therapeutic response. Medication or food interactions, if any. Stop date for medication, if applicable. Specialty administration and/or storage instructions if any. Parameters for 'holding' the dose. (Example: do not give if pulse is lower than). All over-the-counter (OTC) medications have the same requirements as prescriptions. drugs.		
PRN Medication Requirements	Specific instructions must be written to include all of the above and: Exact dosage to be given. Clear parameters for administering. (Example: give if crying for more than 5 min.) Expected therapeutic response. (Example: individual should have a BM within 1 hour.) Follow-up instructions, if therapeutic response is not achieved.		
Psychotropic Medication Requirements	All psychotropic medications require a stated diagnosis and a rationale. May require prescriber to complete an additional form to indicate reason medication is being prescribed.		
Care Requirements & Therapies	Follow-up requirements to the Primary Care Physician or required Specialist. Written orders for all medications, treatments, and therapies for each specialist. Written orders for Home Health nursing. Written protocols for all care concerns, such as: measuring vital signs, positioning, aspiration prevention, respiratory therapy, dietary modifications, wound care, etc.		
Durable Medical Equipment Requirements	All prescriptions should include a diagnosis and reason for equipment. Physician may write a list of possible adaptive equipment needs, to be assessed by the Physical Therapist.		





The Medicaid Waiver Tip Sheet

The Medicaid Waiver Tip Sheet

- Communicates a simplified explanation of Virginia's Medicaid Waiver Support System for individuals with IDD.
- Shares several resources for more in-depth information about Virginia's Medicaid Waiver Support System, if desired.

Behavioral Health & **Medicaid Waiver Services Tip Sheet**

What is a Is in addition to Medicaid, a Medicaid Waiver is a long-term support system for someone Waiver? who has long-term care needs and or could live in an institution, like an individual with an intellectual and/or developmental disability. Once a Waiver is assigned, there are several services available. Frequently used services - Assistants who work 1 to 1 with the person, Respite care so parents can have a break, - Group home supports by direct support professionals (DSPs) where a person with a developmental disability lives in a home shared by other people with disabilities, Long term employment, Meaningful day services. Assistive technology Environmental modifications. - Nursing, and more. These services are offered at no or very low cost. Waiver Community Living Waiver (CL) – is for youth and adults who have extremely high medical. **Options** behavioral, or support needs. It provides 24/7 active services, delivered by direct support professionals (DSPs). · Family and Individual Supports Waiver (FIS) - is for children and adults who need supports from between a few hours to most hours of the day, including overnight monitoring Building Independence Waiver (BI) – is for those 18 years and older who can live and

Resources

work with a fair amount of independence, but need drop in supports.

· Commonwealth Community Care Waiver (CCC+) - is for people who have a developmental disability or are over the age of 65 and have significant medical needs;

- . Individuals with intellectual and developmental disabilities (I/DD) who utilize the Medicaid Waiver services are assessed every three years with a test called the Supports Intensity Scale (SIS) to measure the intensity of their needs https://dbhds.virginia.gov/developmental-services/waiver-services
- Individuals with I/DD who have more needs receive a higher reimbursement rate for some of their services.

primarily attendant and respite care, and some nursing.

- My Life, My Community. https://www.mylifemycommunityvirginia.org/ Waiver Options.

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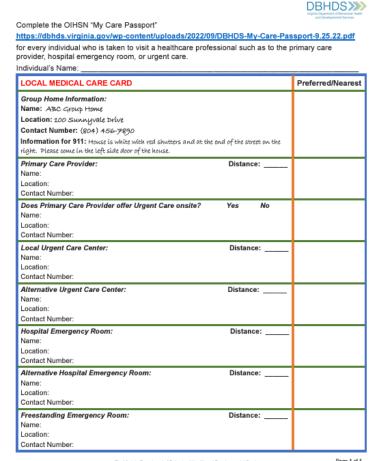






Local Medical Care Card

- The Local Medical Care (LMC) card shares the individual's name, home address, and phone number, as well as the address & contact information for:
 - Primary Care Provider (PCP).
 - Local Urgent Care Center and alternative.
 - Hospital Emergency Room and alternative.
- The distance of all the above from the individual's home.







UTI Case Study #1

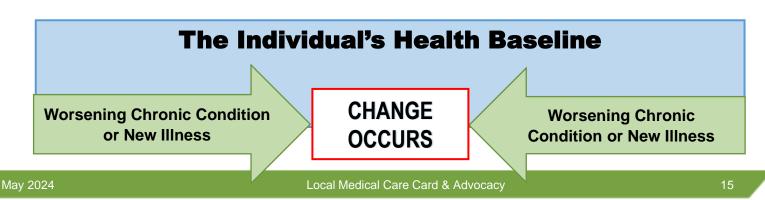


DBHDS>>>

Bobbie is a non-verbal 35-year-old male with severe & profound DD. He is completely dependent on caregivers for all activities of daily living (ADL's) and <u>wears adult briefs</u> due to bowel & bladder incontinence. He uses a condom catheter for increased independence at the day program. He is dependent on caregivers to change his adult briefs and empty his catheter bag at both sites. **BASELINE**

For the last 3-4 days, Bobbie's urine has been <u>dark yellow, cloudy and foul smelling. He</u> has had <u>increased behaviors</u> and started <u>kicking and fighting with his caregivers when being repositioned</u>. He has become <u>increasingly angry and aggressive with caregivers during any interaction</u>. He <u>began refusing to eat, or drink yesterday and also started crying out and fighting when being bathed or dressed</u>. **CHANGES**

Early this morning Bobby started <u>sweating</u>, <u>shivering</u>, <u>crying loudly</u>, <u>and breathing very fast</u>, as if he couldn't catch his breath. <u>His heart rate was 110 (high)</u>. <u>His blood pressure was 80/48 (low)</u>. <u>He is lethargic (lifeless)</u>, and <u>his skin is pale and clammy</u>. **CHANGES**







What Should Be Done Next?

- 1. What should Bobbie's caregivers do next?
 - a. Call his primary care provider (PCP) and make the next possible appointment.
 - b. Take him to the urgent care when you have time this evening.
 - c. Call 911 immediately.
 - d. Do nothing and put him to bed with extra blankets because he shivering.

First: Compare UTI Symptoms verses
Sepsis/Urosepsis Symptoms



DBHDS>>>

UTI is not a medical emergency, but when symptoms of UTI are recognized, individuals with IDD <u>should be assessed, diagnosed</u> <u>and treated as soon as possible.</u>

Symptoms of UTI

- ☑ Dysuria (painful or difficult urination. Maybe
- ✓ Fever. Maybe
- □ Frequent and urgent urination.
- Nocturia (excessive urination at night).
- ☑ Hematuria (blood in urine). Maybe
- ✓ Lower abdominal pressure, pain or cramping. Maybe
- ☐ Urinary incontinence. Baseline.
- ✓ Loss of appetite. Yes
- Mental confusion.
- ✓ Irritability or agitation. Yes
- ☑ Chills, nausea or vomiting. Yes
- ☑ Dark yellow, cloudy or foul-smelling urine.Yes

Sepsis & Urosepsis (a UTI that has progressed to sepsis) is <u>ALWAYS A</u>
<u>MEDICAL EMERGENCY.</u> When symptoms are recognized, call 911.

Symptoms of Urosepsis

- ✓ Low blood pressure
- ☑ Rapid heart rate (pulse)
- ✓ High/fast respiratory rate (Tachypnea)
- ☑ Difficulty breathing
- ☑ Shaking chills
- ☑ Extreme pain
- □ Sepsis rash.
- ☑ Clammy or sweaty skin.



Bobbie Has UTI with Sepsis/Urosepsis Symptoms.





SEPSIS

- Life-threatening.
- Must act quickly.
- Administration of IV antibiotics should begin within one hour, once symptoms are identified.
- Each one-hour delay in IV antibiotic treatment drops the survival rate by 8%.



Call 911 For Sepsis/Urosepsis Symptoms



The Decision Tree

Step 1

Recognition of Change

Step 1

Medical Emergency?

Call 911

Step 2

Non-Medical Emergency?
Tell Supervisor

EMS Arrives & Transports the Individual

Step 3 Schedule the Earliest PCP
Appointment

Hospital Treatment

Step 4

PCP Treatment



Additional Advocacy in the ER

- Go to the ER to advocate for the individual whenever possible, even when the individual is transported by ambulance.
- Communicate the individual's baseline functioning (their typical functioning).
- Communicate any recent changes observed, when they started, what the progression has been, and what you know, as best as you can.
- Try to be as specific as possible:
 - "Bobbie has severe and profound IDD."
 - "He is completely dependent on caregivers for his ADL's."
 - "He is incontinent of bladder and bowel."
 - "He wears adult briefs and a condom catheter,"
 - "Bobbie's urine has been yellow, cloudy and foul smelling for 3-4 days."
 - "Bobbie has had increased behaviors over the last week, which may be due to pain."
 - "He was crying loudly, shivering and panting like he couldn't catch his breath this morning before we called 9-1-1."





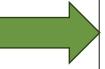


Emergency Room Advocacy Card DBHDS

Condition	Diagnostic Test or Clinical Assessment
Aspiration	Chest x-ray, Vital Signs
Constipation	Abdominal x-ray, CA
Dehydration	CBC, CA, Vital Signs
Falls	X-ray, CT, MRI, CA
Pressure Injury	CA
Seizures	EEG
Sepsis	CBC, CA, Vital Signs, Lactic Acid Levels
Urinary Tract Infection (UTI)	Urinalysis, CBC, CA

The front of the card has a list of conditions and which tests or assessments to request.

The back of the card has definitions, normal vital signs for an adult and who to seek help from while at the hospital.



Emergency Room Advocacy Card DBHDS

Definitions		Normal Vital Signs
CBC	Complete Blood Count – Lab work	Temp: 98.6° F
CA	Clinical Assessment	Pulse: 60 - 100
CT	Computerized Tomography Scan	Resp: 12 - 20
MRI	Magnetic Resonance Imaging	B/P: 120/80
EEG	Electroencephalogram	O2: 98% - 100%

Who to seek help from in the hospital –

The Patient Advocate	The Hospital Social Worker
The Charge Nurse	The Medical Director

May 2024 Local Medical





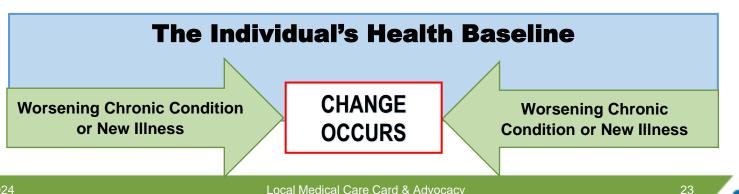
UTI Case Study #2



DBHDS>>>

Patty is a <u>65-year-old female with moderate DD</u>. She is <u>incontinent</u> of bowel, and bladder at night and wears an adult briefs to bed. During the day, without warning, she takes her pants off, then runs to the bathroom to use the toilet. She has a toileting schedule to encourage her to use the bathroom instead of a brief. She can minimally assist with activities of daily living such as dressing, bathing, and eating. She is able to <u>verbally communicate in simple words but</u> doesn't speak in complete sentences. BASELINE

Three days ago, she finished a 7-day course of oral antibiotics for a UTI. Staff noticed she has been picking at her perineal area for the past two days more than normal and has been in and out of the bathroom all day. When she does urinate, her urine is medium yellow in color. Patty's brief has been dry in the morning when it is usually soaked with urinate and she has been refusing to drink water since she started taking the antibiotic. **CHANGES**







What Should Be Done Next?

Patty's caregivers called her primary care provider's (PCP) office to schedule an appointment, but he is out of town for four days and there is no one covering for him.

1. What should Patty's caregivers do next?

- a. Call her PCP and take the next possible appointment even if it is 5 days away.
- b. Take Patty to the urgent care listed on her Local Medical Care card today.
- c. Call 911 immediately.
- d. Do nothing but keep a close eye on her.

First: Compare UTI Symptoms verses Sepsis/Urosepsis Symptoms

DBHDS>>>

UTI is not a medical emergency, but when symptoms of UTI are recognized, individuals with IDD <u>should be assessed, diagnosed and treated as soon as possible.</u>

Symptoms of UTI

- ☑ Dysuria (painful or difficult urination. Maybe)
- Fever.
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- Nocturia (excessive urination at night).
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- Lower abdominal pressure, pain or cramping. Maybe
- ☐ Urinary incontinence. Baseline.
- ✓ Loss of appetite. Yes
- Mental confusion.
- Irritability or agitation.
- Chills, nausea or vomiting.
- ☑ Dark yellow, cloudy or foul-smelling urine.
 Yes

Symptoms of Urosepsis

- Low blood pressure
- ☐ Rapid heart rate (pulse)
- ☐ High/fast respiratory rate (Tachypnea)
- Difficulty breathing
- □ Shaking chills
- □ Extreme pain
- □ Sepsis rash.
- ☐ Clammy or sweaty skin.

Patty has UTI symptoms, but she does not have any lifethreatening symptoms, so it is not a medical emergency.



The Decision Tree

Step 1

Recognition of Change

Step 1

Medical Emergency?

Call 911

Step 2

Non-Medical Emergency?
Tell Supervisor

EMS Arrives & Transports the Individual

Step 3

Schedule the Earliest PCP
Appointment

Hospital Treatment

Step 4

PCP Treatment

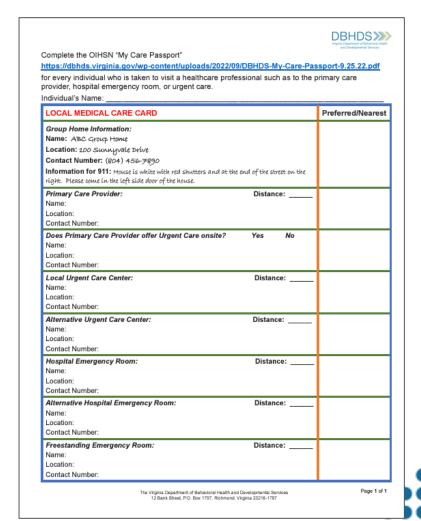




Local Medical Care Card

Take Patty to the Urgent Care
 Center listed on her Local Medical
 Care Card.

Take a copy of the Medication
 Administration Record (MAR), and
 the her My Care Passport with you.

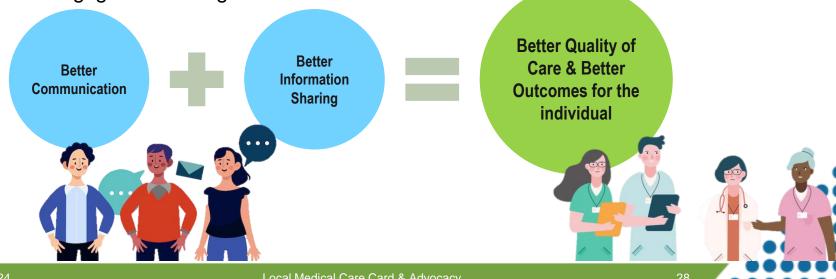




Conclusion

- The **My Care Passport** and **Tip Sheets** are advocacy tools that can improve communication and information sharing between community caregivers and acute care staff.
- The **Local Medical Care Card** will take the guess work out of getting the individual with IDD to the healthcare they need.
- The **ER Advocacy Card will ...**
 - Helps caregivers know which diagnostic tests to advocate for to ensure positive outcomes in a timely manner for the individual with IDD.

- Whom to seek help from if the individual's human rights are being violated or their needs are being ignored or neglected.







Questions

- Please direct any questions or concerns regarding this training to:
 - Tammie Williams, RNCC, Community Nursing and Educational Lead.
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 - Joy Richardson, RNCC, Region 4.joy.Richardson@dbhds.virginia.gov
 - Brian Phelps, BCBA.brian.phelps@dbhds.virginia.gov







Thank You!







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