COMMONWEALTH of VIRGINIA

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Office of Integrated Health

My Care Passport and Advocacy Tip Sheets

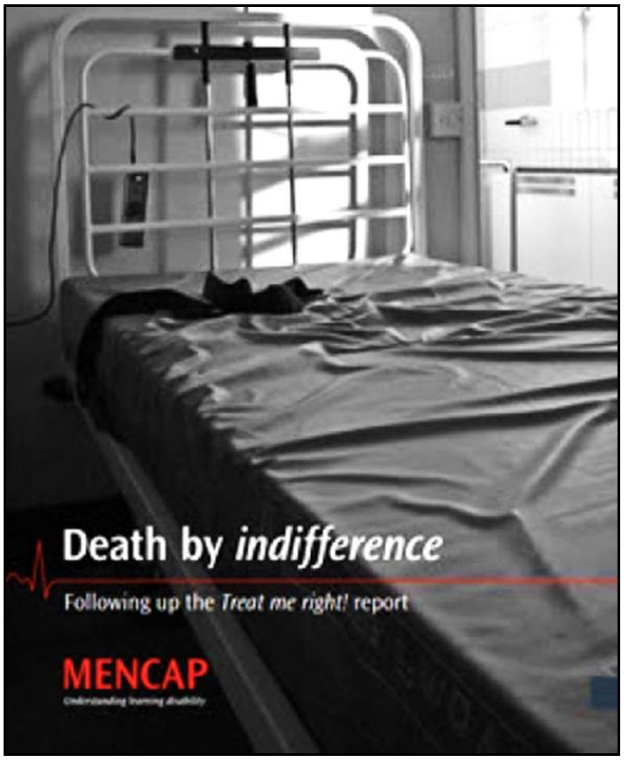
Health & Safety Alert

The Passport's Background

In 2004, the first of the United Kingdom's (UK) inquiries into the deaths of individuals with learning disabilities in acute care settings was published (10). The study revealed many instances in which individuals received inappropriate care and treatment at hospitals and other acute care settings.

Many deaths, were determined to be from preventable or avoidable causes. Statistic revealed individuals with learning disabilities, were dying in acute care hospitals, at a much higher rate, than the general public (9).

Numerous studies report the greatest risk of a preventable or avoidable death occurs during a hospital stay for individuals with learning disabilities or intellectual and developmental disabilities (IDD) (7) (8) (13) (10) (11) (12). However, since individuals with IDD are more frequent users of emergency departments and hospital care than the general public, statistics may be skewed (9).



Death by *indifference*

Following up the *Treat me right!* report

MENCAP

Understanding learning disability

Poor communication between community caregivers and hospital staff, was a repeated theme identified in the first MENCAP study published in 2004. As a result, researchers considered various methods aimed at improving communication between community caregivers and hospital staff.

Since 2004, additional studies have identified poor communication and poor information sharing as being contributing factors to the inability of acute care staff to meet the needs of individuals (8) (16).

Identified Solutions

In response to MENCAP's 2004 study, the UK's National Health System initiated the use of a passport-type communication tool. The tool was promoted as an advocacy and communication tool, which could be used by community caregivers to share details about an individual's likes, dislikes, communication abilities, and support needs, with hospital staff at acute care facilities.

In 2014, the Surrey and Borders Partnership of the NHS Foundation Trust, also known as the "Surrey Center", launched a second version of the hospital passport (7). Additional studies using modified versions of the UK's original hospital passport, seem to have a positive impact on the hospital experiences of individuals with IDD (13). Hospital staff in acute care settings believe the "Passport Tool" helps them to:

- Adapt their approach to care.
- Build relationships with individuals and their community caregivers.
- Improve communication with community caregivers.
- Have a better understanding of the individual's care needs and interests (13).

Communication and advocacy tools which improve the exchange of information between community caregivers and hospital staff have the potential to improve the quality of care individuals with IDD receive in acute care settings (2) (3) (13) (14). Better communication, may lead to improved quality of care, which (in theory) may translate into improved healthcare outcomes, and a decreased risk of a preventable death.

The My Care Passport Tool

The My Care Passport is an Americanized version of the Hospital Passport tool which was previously developed by the Surrey Center in the UK (7). The use of the My Care Passport is voluntary.

Much like the original Passport, the My Care Passport is designed to familiarize hospital staff in acute care settings with the unique needs of the IDD population via improved communication between acute care staff and community caregivers (5) (6) (1) (4).

- The easy-to-read format of the My Care Passport and design are intentional, and are aimed at enabling acute care staff to become familiar "at a glance" with vital information, specific to each individual with IDD.

- The My Care Passport can be used in all healthcare settings, in addition to in-patient hospital admissions, such as visits to the emergency room, urgent care facilities, medical specialist visits, and visits to the individual's primary care provider (PCP).
- All hospital staff, everyone from housekeeping staff to physicians providing treatment, should be encouraged to review the My Care Passport *before* providing any type of services or care to individuals with IDD, in normal circumstances those which are not life-threatening.

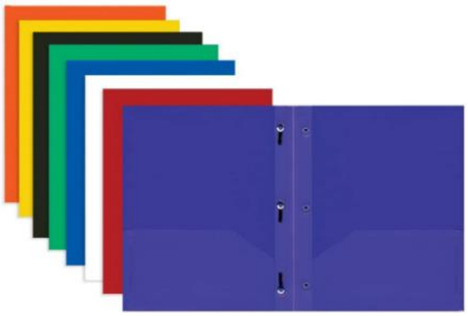
Tip Sheets

In addition to the DBHDS My Care Passport, OIH-HSN has also developed accompanying "Tip Sheets" to assist hospital staff to improve their knowledge relating to the IDD service system in Virginia. They are:

- The Consent Tip Sheet.
- The Waiver Tip Sheet.
- The Discharge Tip Sheet.

Instructions for Use

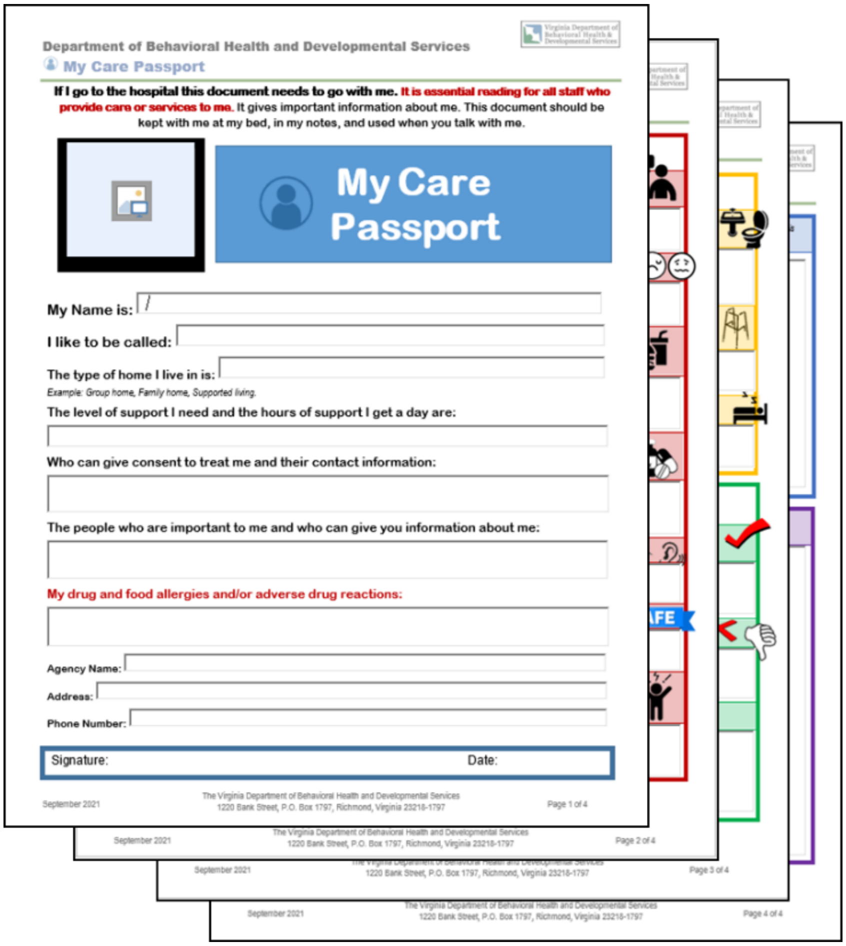
- The My Care Passport is a fillable Microsoft Word document which can be printed either in color or black & white and saved to a computer so it can be easily updated as needed.
- Alternatively, the My Care Passport tool can be printed out and filled in by hand using a ball point pen.
- Community caregivers should complete a My Care Passport for each individual, so it can be used for any care the individual receives in an acute care setting.
- Each section has a limited number of text characters which can be entered. Space has been added on the fourth page for additional information, if needed.
- After printing, the My Care Passport can be put into sheet protectors, then into a thin solid plastic folder to ensure the safeguarding of the individual's personal health information (PHI) and the tips sheets can be added in the pockets to distribute as needed.



- Hospitals and acute care settings in Virginia *may not be familiar with these documents, or have a plan in place to handle this information.* Therefore, some initial education on the part of the community caregivers will be required to familiarize acute care staff on the purpose of the My Care Passport tool, and the three one-page advocacy tip sheets.
- The use of the My Care Passport is on a voluntary basis, and is not meant to be a burden for community caregivers or individuals.
- The My Care Passport is **not** intended to be kept in the individual's medical record, but instead to be readily available for all staff in acute care settings to become familiar with the individual with IDD prior to delivery of care or services. Examples:
  - Nursing staff can become familiar with how an individual takes their medications, communicates, or expresses pain, etc.
  - Staff delivering meal trays might learn the individual needs assistance with cutting their food and setting up their tray, instead of just leaving the meal tray on the bedside table.
  - The CNA can become familiar with the individual's ability to bathe, toilet and walk by reviewing the My Care Passport before assisting the individual.
- In the Emergency Room or during a hospital admission, community caregivers should share the individual's My Care Passport with healthcare professional in the acute care settings during the evaluation or intake period.
- Once the individual is admitted the My Care Passport, enclosed in its solid plastic covering, should be kept with the individual in their room and taken with them when they are transported out of the room.
- If the individual is being admitted for a scheduled surgery or procedure their My Care Passport should be brought to the hospital staff's attention during the admissions process and shared with the acute care staff.

Any questions or concerns regarding the My Care Passport and or the Advocacy Tip Sheets should be directed to the Office of Integrated Health – Health Support Network (OIH-HSN) at the Virginia Department of Behavioral Health and Developmental Services (DBHDS) email: communitynursing@dbhds.virginia.gov

Completing the My Care Passport Tool



Department of Behavioral Health and Developmental Services
My Care Passport

If I go to the hospital this document needs to go with me. It is essential reading for all staff who provide care or services to me. It gives important information about me. This document should be kept with me at my bed, in my notes, and used when you talk with me.

My Care Passport

My Name is:

I like to be called:

The type of home I live in is:
Example: Group home, Family home, Supported living.

The level of support I need and the hours of support I get a day are:

Who can give consent to treat me and their contact information:

The people who are important to me and who can give you information about me:

My drug and food allergies and/or adverse drug reactions:

Agency Name:

Address:

Phone Number:

Signature: Date:

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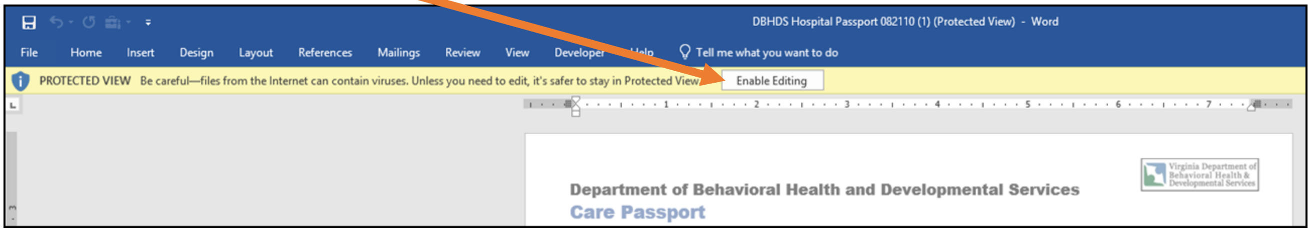
- My Care Passport is designed as a fillable Microsoft Word document.
- The “My Care Passport” document must be downloaded to a computer and the Enable Editing button must be clicked.

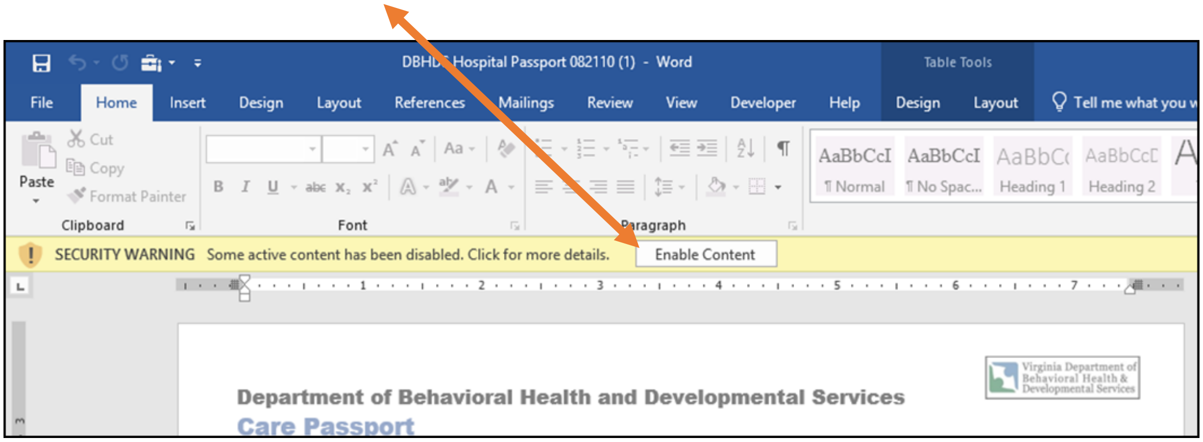


DBHDS Hospital Passport 082110 (1) (Protected View) - Word

PROTECTED VIEW Be careful—files from the Internet can contain viruses. Unless you need to edit, it's safer to stay in Protected View.

Department of Behavioral Health and Developmental Services
Care Passport

- Then the Enable Content button must be clicked to view and fill in the document.

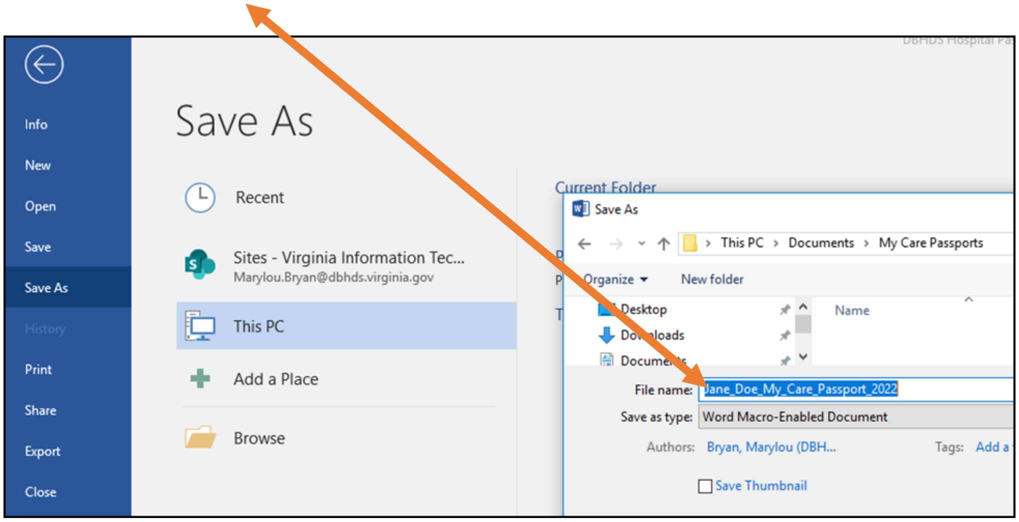


SECURITY WARNING Some active content has been disabled. Click for more details.

Department of Behavioral Health and Developmental Services
Care Passport

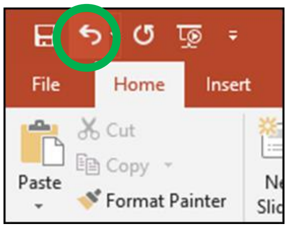
- Once the document is opened and viewable in its complete form the first thing to do is "Save As" under the "File" tab in the far-left upper corner with a new name.

  – Example: If the "My Care Passport" is for Jane Doe, then the file could be saved as Jane_Doe_My_Care_Passport_2022.

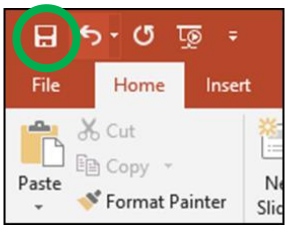


File name: Jane_Doe_My_Care_Passport_2022
Save as type: Word Macro-Enabled Document
Authors: Bryan, Marylou (DBH...
Tags: Add a

- When you are working within the My Care Passport file if you need to undo anything within the document use the UNDO button at the upper left corner of the file.



- Remember to save your document after each entry which can be done using the file icon at the upper left corner of the file.

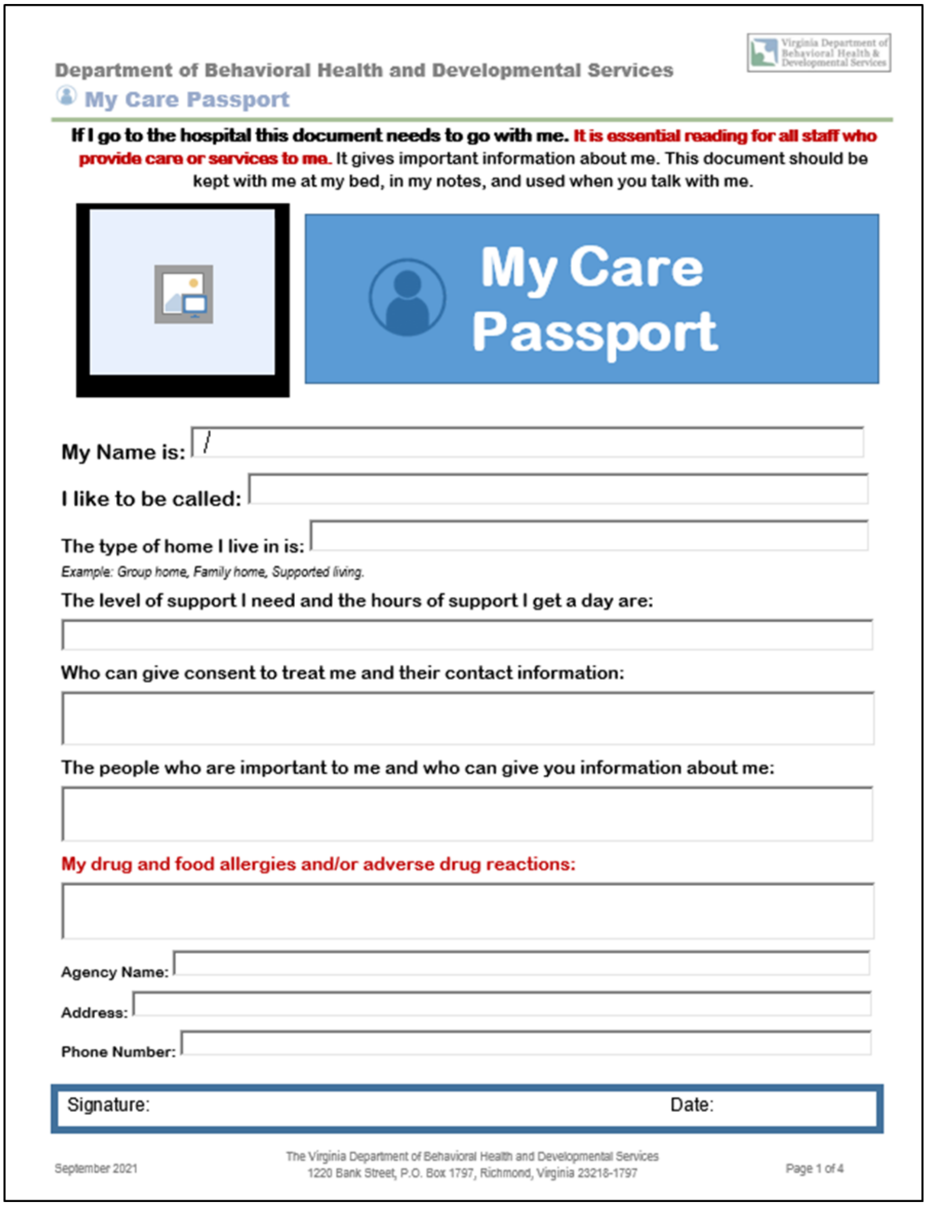


The 1st Page Sections of the My Care Passport Tool

The first page has sections for basic information about the individual.

- A photo of the individual when they are happy and well.
- Their legal name.
- Any Nicknames.
- Consent information.
- Other important people to them.
- Known allergies and adverse drug reactions.
- Provider agency name, address and phone number (if applicable).
- The signature of person completing the "My Care Passport".

Quick Tip: The tab key will help you to move quickly to the next sections in this Microsoft Word document.



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My Care Passport

If I go to the hospital this document needs to go with me. It is essential reading for all staff who provide care or services to me. It gives important information about me. This document should be kept with me at my bed, in my notes, and used when you talk with me.

My Care Passport

My Name is:

I like to be called:

The type of home I live in is:

Example: Group home, Family home, Supported living.

The level of support I need and the hours of support I get a day are:

Who can give consent to treat me and their contact information:

The people who are important to me and who can give you information about me:

My drug and food allergies and/or adverse drug reactions:

Agency Name:

Address:

Phone Number:

Signature: Date:

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First Page Tips

- Once the file is saved for an individual, then all their information can be typed in and or printed, then written in by the caregiver.

- A photo can be added of the individual when at their best, and without illness.
  - Double click on the frame on the photo icon and select a picture from the computer's hard drive.

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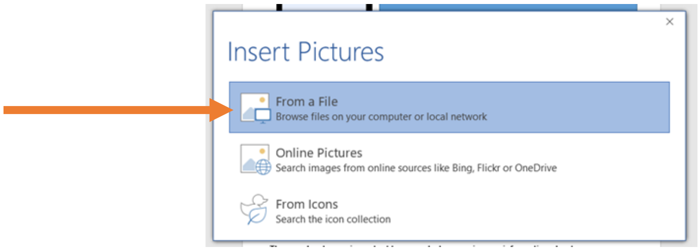
My Care Passport

If I go to the hospital this document needs to go with me. It is essential reading for all medical professionals who take care of me. It gives important information about me. This document should be kept with me at my bed, in my notes, and used when you talk with me.

  - Then a pop-up box will appear with insert options to select a picture from the hard drive.



- Add the individual's legal full name, which should match their medical record.
- What does the individual like to be called?

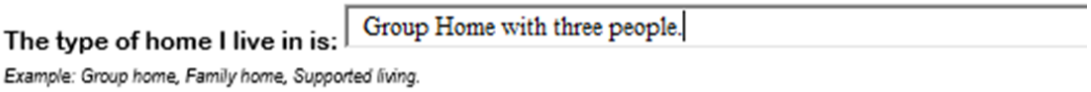
Example

My Name is: *Jane Doe*

I like to be called: Jeannie

- What type of home does the individual live in? Group home, Family home and or Supported living, etc. Additional information in this section, is optional.

Example

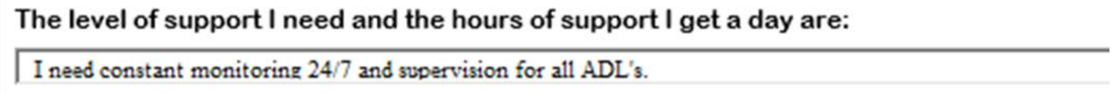


The type of home I live in is: Group Home with three people.

Example: Group home, Family home, Supported living.

- What level of support does this individual need within a 24-hour period?
  - Examples would be: “The individual requires monitoring or supervision 24 hours a day, seven days a week.” Or… “The individual can be left unsupervised for short periods of time with only visual monitoring.” Or… “Hands on care is required for all activities, turning and repositioning, every two hours, and or one to one interaction with staff is required for safety, etc...”

Example

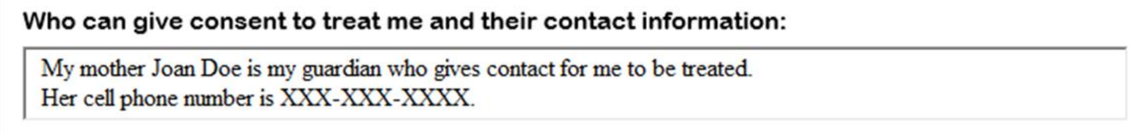


The level of support I need and the hours of support I get a day are:

I need constant monitoring 24/7 and supervision for all ADL’s.

- The next section is for the name of the person who has authority to give a medical consent for treatment of the individual, and should also include that person’s contact information.
  - If the individual is their own guardian, and can therefore make their own decisions regarding treatment, that statement should be made in this section along with the name of any other person(s) who assists the individual in medical care decision-making, such as an authorized representative (AR). Please be sure to include any contact information.

Example

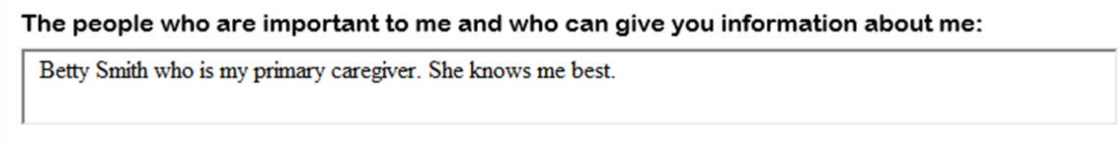


Who can give consent to treat me and their contact information:

My mother Joan Doe is my guardian who gives contact for me to be treated.
Her cell phone number is XXX-XXX-XXXX.

- List everyone else who is important to the individual in the next section. Community care staff who are the most familiar with the individual should be listed in this section.

Example



The people who are important to me and who can give you information about me:

Betty Smith who is my primary caregiver. She knows me best.

- List all known drug and food allergies and/or any other reactions the individual has a history of experiencing. This information is also part of the individual’s medical record.

Example

My drug and food allergies and/or adverse drug reactions:

Sulfa, and Pencillin drugs give my a rash and hives.

- If the individual is receiving care from an agency there is a section for the agency’s name, address, and phone number, if applicable to the individual’s living situation.

Example

Agency Name: Meadow Brook
Address: 1000 Meadow Brook Lane
Phone Number: Hometown, USA.

- At the bottom of the first page there is a signature and date block, for the person completing the form to sign and date the document. This is the only location on the form which holds a date. Every time the form is updated and reprinted a new date should be recorded, so the most recent version of an individual's passport file is easily recognizable. All later versions should be destroyed (shredded), and or handled per agency policy for personal health information (PHI).

Example

Signature: Caregiver Meadows Date: 1-2-22

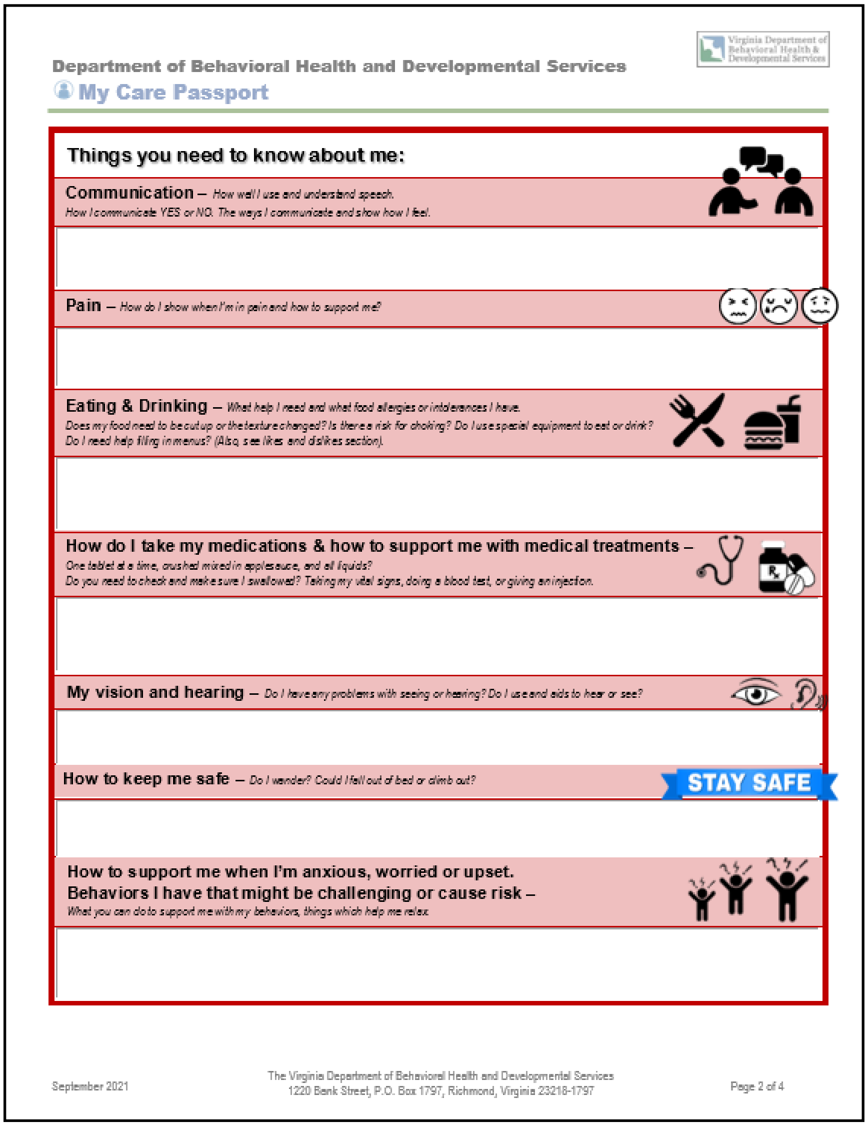
The 2nd Page of the My Care Passport Tool

The second page holds the "Things you need to know about me" section.

This section is in **RED** to indicate the highest importance.

It includes sections on:

- Communication.
- Pain.
- Eating & drinking.
- How medications are taken.
- Support needed during medical treatments.
- Vision & hearing.
- General safety.
- Behaviors.



Department of Behavioral Health and Developmental Services

My Care Passport

Things you need to know about me:

Communication – *How well I use and understand speech. How I communicate YES or NO. The ways I communicate and show how I feel.*

Pain – *How do I show when I'm in pain and how to support me?*

Eating & Drinking – *What help I need and what food allergies or intolerances I have. Does my food need to be cut up or the texture changed? Is there a risk for choking? Do I use special equipment to eat or drink? Do I need help filling in menus? (Also, see likes and dislikes section).*

How do I take my medications & how to support me with medical treatments – *One tablet at a time, crushed mixed in applesauce, and all liquids? Do you need to check and make sure I swallowed? Taking my vital signs, doing a blood test, or giving an injection.*

My vision and hearing – *Do I have any problems with seeing or hearing? Do I use and aids to hear or see?*

How to keep me safe – *Do I wander? Could I fall out of bed or climb out?*

How to support me when I'm anxious, worried or upset.
Behaviors I have that might be challenging or cause risk –
What you can do to support me with my behaviors, things which help me relax.

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> *Quick Tip: Remember each section has a limited amount of text characters which can be entered, so attempt to keep entries concise.*

Second Page Tips

- The first section on page two is communication.
  - How does the individual communicate?
  - How well can the individual communicate and understand speech?
  - How does the individual communicate, if the individual does not use words? (i.e. eye gaze, gestures, etc.)
  - This section is all about how the individual communicates and conveys feelings.

Example

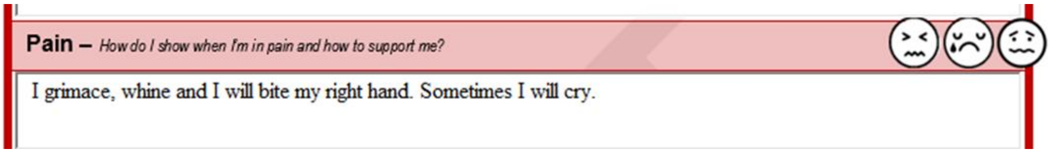
Things you need to know about me:

Communication – *How well I use and understand speech.*
How I communicate YES or NO. The ways I communicate and show how I feel.

I understand some things. It is difficult to determine how much. I talk with my eyes and my expressions. I am non-verbal.

- The second section is about pain.
  - How is the individual supported when experiencing pain?
  - How does the individual indicate or behave when feeling pain?
  - Is it difficult to determine if or when the individual is experiencing pain?
  - Does the individual grimace, or push staff away from them when experiencing pain?
  - Does the individual have self-injurious behaviors (i.e. head banging, hand biting, hitting themselves, etc.) when in pain?
  - Does the individual cry, yell, or make another type of verbal sound when experiencing pain?
  - Do community care staff usually administer PRN (as needed) analgesics, such as Tylenol or Advil when the individual is experiencing pain?

Example



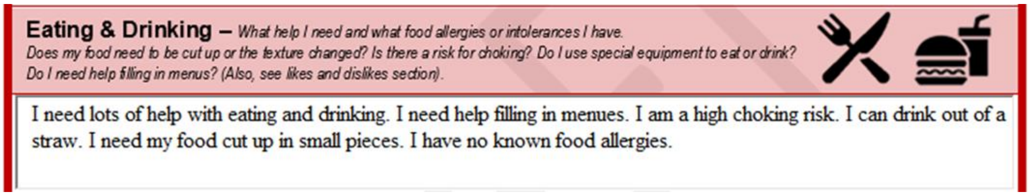
Pain – *How do I show when I'm in pain and how to support me?*

I grimace, whine and I will bite my right hand. Sometimes I will cry.

- The third section is about what assistance the individual needs for eating & drinking.
  - What type of help does the individual need at mealtime? Does the individual need to be fed by someone else?
  - Does the individual require a modified diet, such as a chopped, minced or pureed diet?
  - Does the individual have a diagnosis of dysphagia, or a history of aspiration?
  - Has the individual ever experienced a choking event? Is the individual at an increased risk of choking due to missing teeth?

  - Does someone need to cut-up the individual’s food for them?
  - Does the individual use specialized utensils?
  - Does the individual need assistance to order food from a menu while in the hospital?

Example

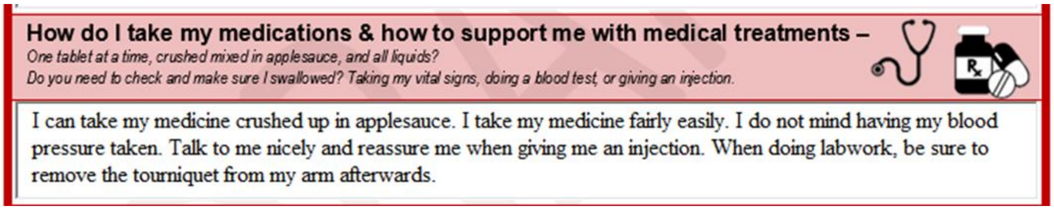


Eating & Drinking – *What help I need and what food allergies or intolerances I have.*
Does my food need to be cut up or the texture changed? Is there a risk for choking? Do I use special equipment to eat or drink?
Do I need help filling in menus? (Also, see likes and dislikes section).

I need lots of help with eating and drinking. I need help filling in menues. I am a high choking risk. I can drink out of a straw. I need my food cut up in small pieces. I have no known food allergies.

- The fourth section relates to medications and treatments. This section is not meant to be used to list medications. The individual’s list of medications will be in their medical record. This section is to record any other special needs the individual may have, which are related to taking their medications and/or receiving treatments.
  - Does the individual usually take medications crushed, and with applesauce?
  - Is the individual able to swallow one pill at a time or does the individual prefer to swallow all of them at once.
  - Does the individual pocket their medications in their cheek or under their tongue?
  - Does someone need to look in the individual’s mouth to make sure a pill has been swallowed?
  - Can the individual tolerate someone taking a set of vital signs? Is the individual sensitive to touch in any way?
  - What works to help the individual relax during treatments?
  - Does the individual enjoy having a special song sung to help them calm down?
  - Will the individual bite down on oral thermometers, if put into their mouth?
  - Can the individual tolerate a blood draw or does the individual need PRN anti-anxiety medications prior to receiving medical treatments?
  - Does the individual require sedation for medical procedures? If so, what?

Example



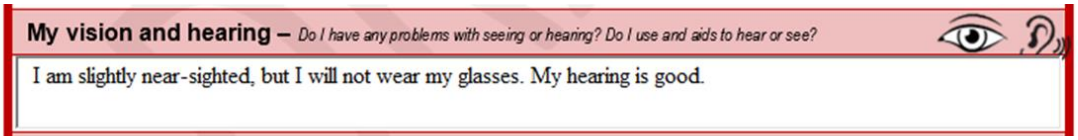
How do I take my medications & how to support me with medical treatments –
One tablet at a time, crushed mixed in applesauce, and all liquids?
Do you need to check and make sure I swallowed? Taking my vital signs, doing a blood test, or giving an injection.

I can take my medicine crushed up in applesauce. I take my medicine fairly easily. I do not mind having my blood pressure taken. Talk to me nicely and reassure me when giving me an injection. When doing labwork, be sure to remove the tourniquet from my arm afterwards.

Quick Tip: Due to the limited number of text characters in each section, attempt to be as to the point as possible, and or use the additional notes section for more space.

- The fifth section is on vision & hearing.
  - Does the individual wear eyeglasses or hearing aids?
  - At night does the individual need assistance with removing their eyeglasses or hearing aids?
  - If so, is there a special container in which to store them?

Example

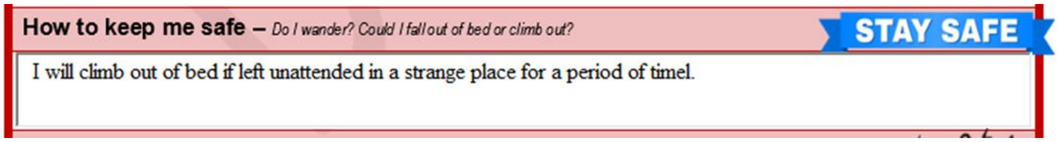


My vision and hearing – *Do I have any problems with seeing or hearing? Do I use and aids to hear or see?*

I am slightly near-sighted, but I will not wear my glasses. My hearing is good.

- The sixth section is on general safety issues the individual might have. For example: “Please do not leave the individual alone in a hospital bed, because he/she will attempt to get out of bed independently, which could lead to a fall.”
  - Does the individual have a diagnosis of pica? Has the individual ever attempted to eat a non-food item?
  - Does the individual wander, and needs to have a staff member walk regularly with them, to reduce anxiety?
  - Does the individual require one-to-one monitoring? If so, why?

Example

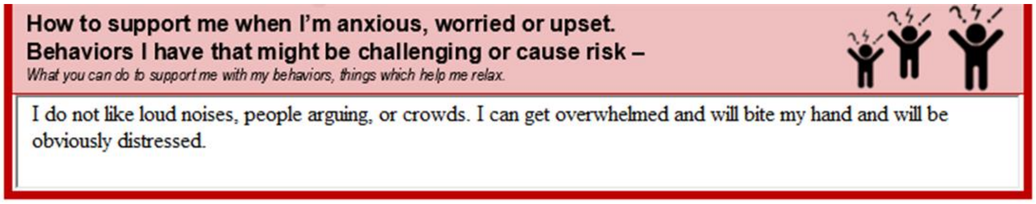


How to keep me safe – *Do I wander? Could I fall out of bed or climb out?*

I will climb out of bed if left unattended in a strange place for a period of timel.

- The last section on page two is about behaviors.
  - What unusual behaviors does the individual have, that hospital staff should be aware of?
  - Does the individual get upset in noisy environments?
  - Does the individual have self-injurious behaviors which may increase when anxious or distressed?

Example



How to support me when I’m anxious, worried or upset.
Behaviors I have that might be challenging or cause risk –
What you can do to support me with my behaviors, things which help me relax.

I do not like loud noises, people arguing, or crowds. I can get overwhelmed and will bite my hand and will be obviously distressed.

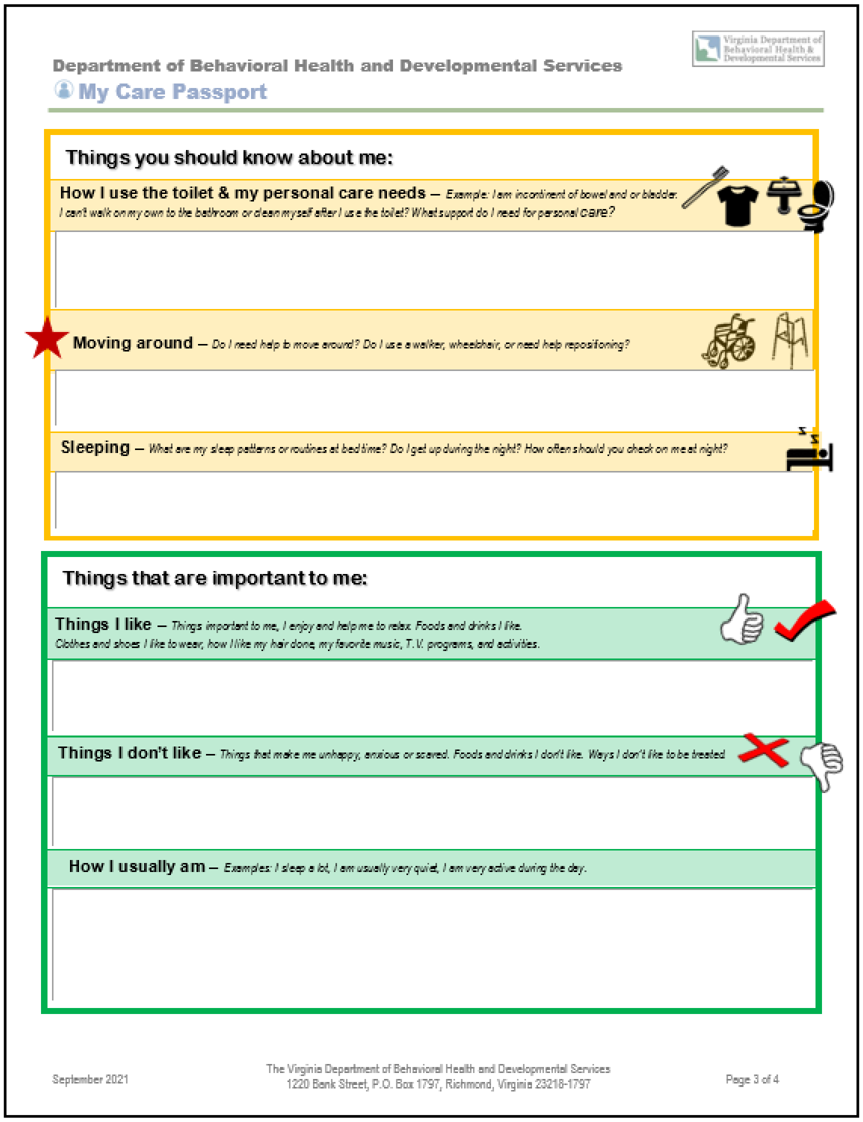
The 3rd Page of the My Care Passport Tool

The third page has sections for entering “Things you should know about me” in **YELLOW.**

- Toileting.
- Personal care needs.
- Mobility needs.
- Sleeping.

Then in **GREEN** are sections for entering “Things that are important to me”.

- Likes.
- Dislikes.
- Typical behavior.



Department of Behavioral Health and Developmental Services
My Care Passport

Things you should know about me:

How I use the toilet & my personal care needs – *Example: I am incontinent of bowel and or bladder. I can't walk on my own to the bathroom or clean myself after I use the toilet? What support do I need for personal care?*

Moving around – *Do I need help to move around? Do I use a walker, wheelchair, or need help repositioning?*

Sleeping – *What are my sleep patterns or routines at bedtime? Do I get up during the night? How often should you check on me at night?*

Things that are important to me:

Things I like – *Things important to me, I enjoy and help me to relax. Foods and drinks I like. Clothes and shoes I like to wear, how I like my hair done, my favorite music, T.V. programs, and activities.*

Things I don't like – *Things that make me unhappy, anxious or scared. Foods and drinks I don't like. Ways I don't like to be treated*

How I usually am – *Examples: I sleep a lot, I am usually very quiet, I am very active during the day.*

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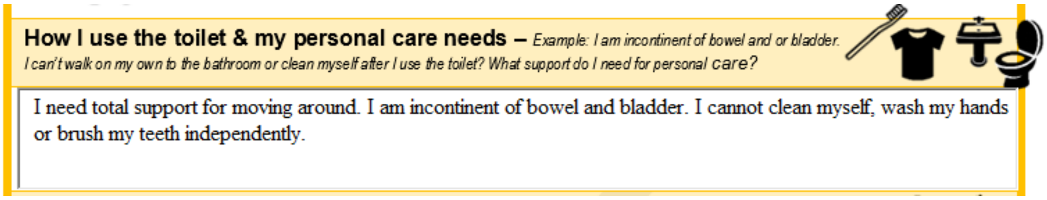
> *Quick Tip: Make a note “See Additional Notes” if the additional notes section is used for more information in a particular topic section, so the acute care staff know to also check the last page if needed. This way important information isn’t missed.*

Third Page Tips

- The first space in the yellow section relates to the individual's activities of daily living, which should include information on toileting, bathing, grooming, oral care and dressing.
  - Is the individual incontinent of bowel or bladder?

  - Does the individual need assistance with perineal care after toileting?
  - Can the individual bathe independently, or is the individual completely dependent on others?
  - Is the individual capable of using the nursing call bell or does a staff member need to check on the individual regularly?

Example

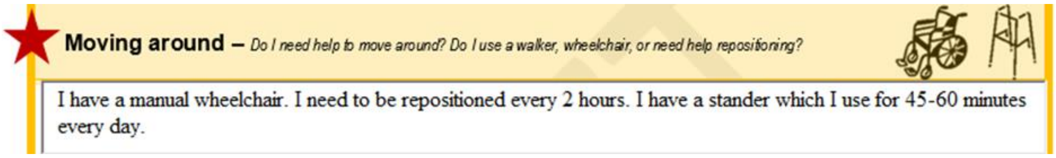


How I use the toilet & my personal care needs – *Example: I am incontinent of bowel and or bladder. I can't walk on my own to the bathroom or clean myself after I use the toilet? What support do I need for personal care?*

I need total support for moving around. I am incontinent of bowel and bladder. I cannot clean myself, wash my hands or brush my teeth independently.

- The second section relates to the individual's mobility needs, and is of higher importance noted by the RED star, due to the increased risk of mobility-related injuries individuals with IDD experience.
  - Is the individual able to walk independently? If so, for what length of time, or distance is the individual able to walk independently?
  - Does the individual use any type of durable medical equipment such as a wheelchair, walker, or cane?
  - If the individual is not able to walk or move independently, how often does the individual need to be repositioned?
  - How many hours per days does the individual typically spend in a wheelchair?

Example

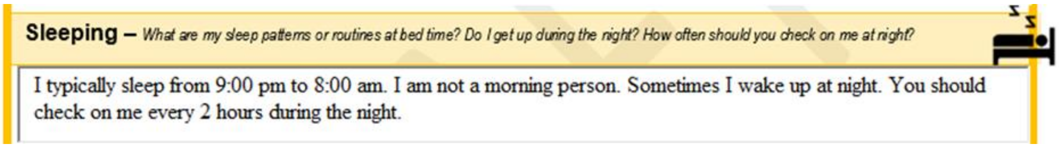


Moving around – *Do I need help to move around? Do I use a walker, wheelchair, or need help repositioning?*

I have a manual wheelchair. I need to be repositioned every 2 hours. I have a stander which I use for 45-60 minutes every day.

- The third section relates to sleep.
  - How does the individual sleep at night? (In a regular bed, a hospital bed, etc.?)
  - Does the individual usually take naps? If so, when, and for what length of time?
  - Should the individual sleep in a bed, which can be lowered to the floor, due to risk of a fall? Has the individual ever fallen out of bed at night?
  - Does the individual attempt to climb out of bed at night?
  - Can the individual move around in bed independently?
  - Does the individual usually sleep through the night, if so, what is their typical bedtime, and waking time?

Example

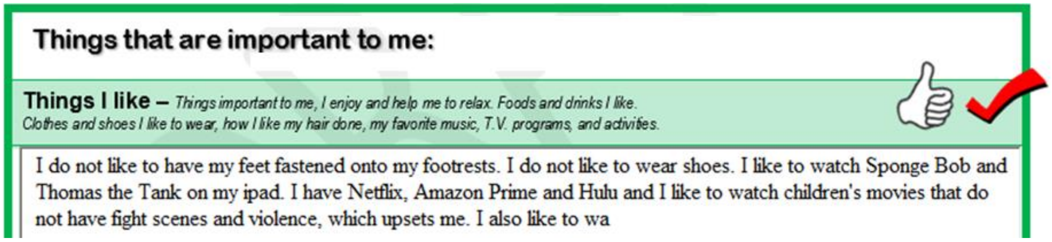


Sleeping – *What are my sleep patterns or routines at bed time? Do I get up during the night? How often should you check on me at night?*

I typically sleep from 9:00 pm to 8:00 am. I am not a morning person. Sometimes I wake up at night. You should check on me every 2 hours during the night.

- The first green section on page three, is about the individual's likes, and favorite things.
  - What is the individual's favorite television shows, type of music, or movies?
  - Does the individual have a special stuffed animal to help feel safe?
  - Does the individual use a weighted blanket?
  - Can the individual color or draw independently or is assistance needed?
  - Does the individual prefer a darkened room or lots of light?
  - What types of things does the individual enjoy while away from home?

Example



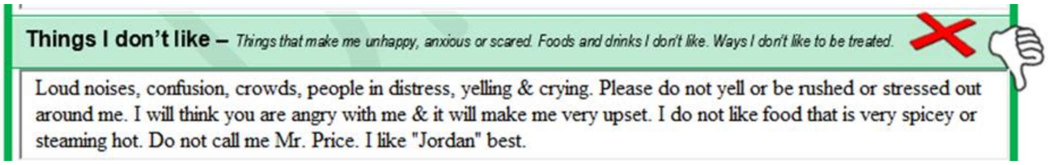
Things that are important to me:

Things I like – *Things important to me, I enjoy and help me to relax. Foods and drinks I like. Clothes and shoes I like to wear, how I like my hair done, my favorite music, T.V. programs, and activities.*

I do not like to have my feet fastened onto my footrests. I do not like to wear shoes. I like to watch Sponge Bob and Thomas the Tank on my ipad. I have Netflix, Amazon Prime and Hulu and I like to watch children's movies that do not have fight scenes and violence, which upsets me. I also like to wa

- The second section, is all about what the individual doesn't like.
  - What things tend to upset the individual?
  - What things tend to increase anxiety in the individual?
  - Is there anything which should always be avoided?

Example

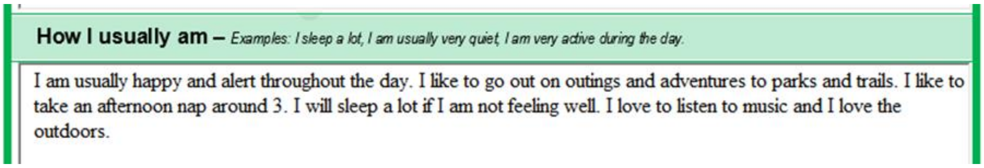


Things I don't like – *Things that make me unhappy, anxious or scared. Foods and drinks I don't like. Ways I don't like to be treated.*

Loud noises, confusion, crowds, people in distress, yelling & crying. Please do not yell or be rushed or stressed out around me. I will think you are angry with me & it will make me very upset. I do not like food that is very spicey or steaming hot. Do not call me Mr. Price. I like "Jordan" best.

- The last of the green section is about the individual's general mood and behavior when feeling well. Attempt to put into words the general attitudes, moods, and behaviors, the individual exhibits on a typical/average day. This will help the hospital staff know if the individual's illness is getting better, or worsening.
  - Does the individual usually sleep most of the day?
  - Is the individual usually full of energy, moving about and curious most of the time?
  - Do the individual typically have a pleasant attitude, and is the individual typically compliant?
  - Is the individual grouchy, or bad-tempered much of the time?

Example



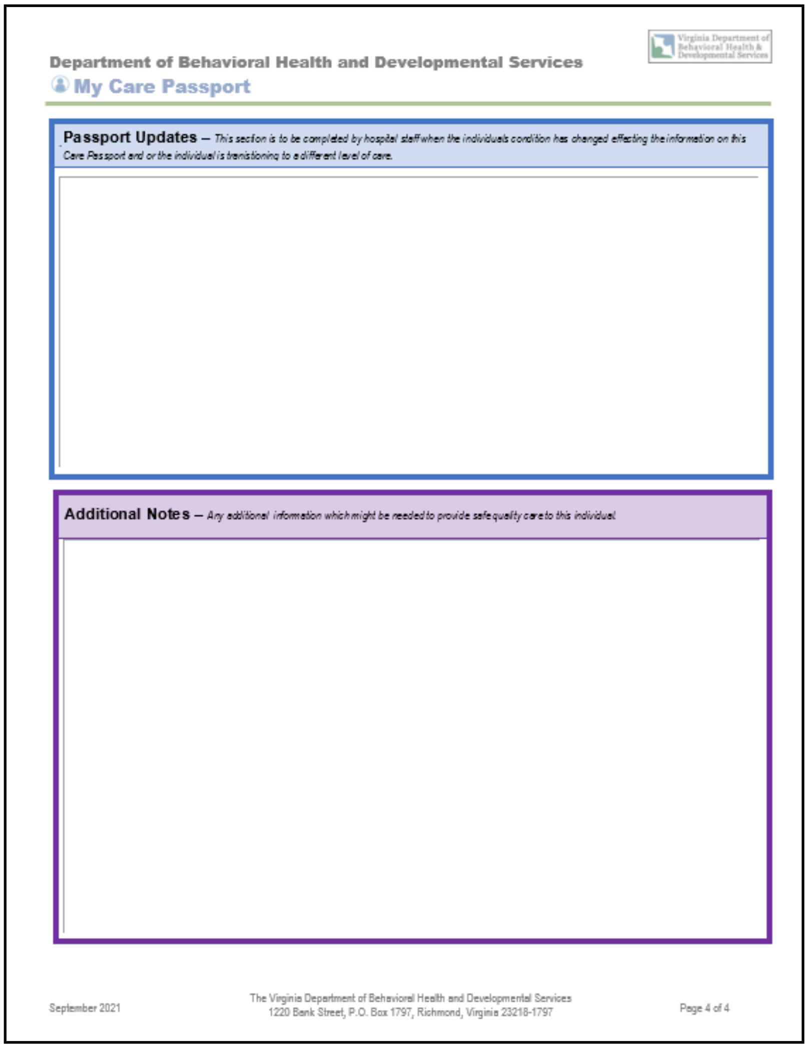
How I usually am – *Examples: I sleep a lot, I am usually very quiet, I am very active during the day.*

I am usually happy and alert throughout the day. I like to go out on outings and adventures to parks and trails. I like to take an afternoon nap around 3. I will sleep a lot if I am not feeling well. I love to listen to music and I love the outdoors.

The 4th Page of the My Care Passport Tool

The fourth page contains a **Blue** section to be completed by acute care staff.

The **Purple** section is for additional notes from the community caregiver if needed.



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My Care Passport

Passport Updates – *This section is to be completed by hospital staff when the individuals condition has changed effecting the information on this Care Passport and or the individual is transitioning to a different level of care.*

Additional Notes – *Any additional information which might be needed to provide safe quality care to this individual.*

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- The blue section at the top of page four is a space where acute care staff can add pertinent, up-to-date information, which may impact the rest of the document. Example: “The individual should remain nothing by mouth (NPO), until after their swallow study scheduled for Thursday.” This might include changes in the individual's physical or mental health, the need for new durable medical equipment, or increased need for assistance while performing activities of daily living. This space might also be used for the next unit an individual is moved to, prior to returning home. **The space should not be used for discharge instructions.**
- The final section in purple, should be used if there was not enough space when completing other sections by community caregivers. When using the additional notes section, it is helpful to make the statement “see additional notes”. So, acute care staff understand to review the additional notes section for more information on a particular subject.

The Three One-Page Advocacy Tip Sheets for DBHDS Licensed Providers

The three one-page advocacy tip sheets are to be used by licensed waiver providers of congregate residential settings.

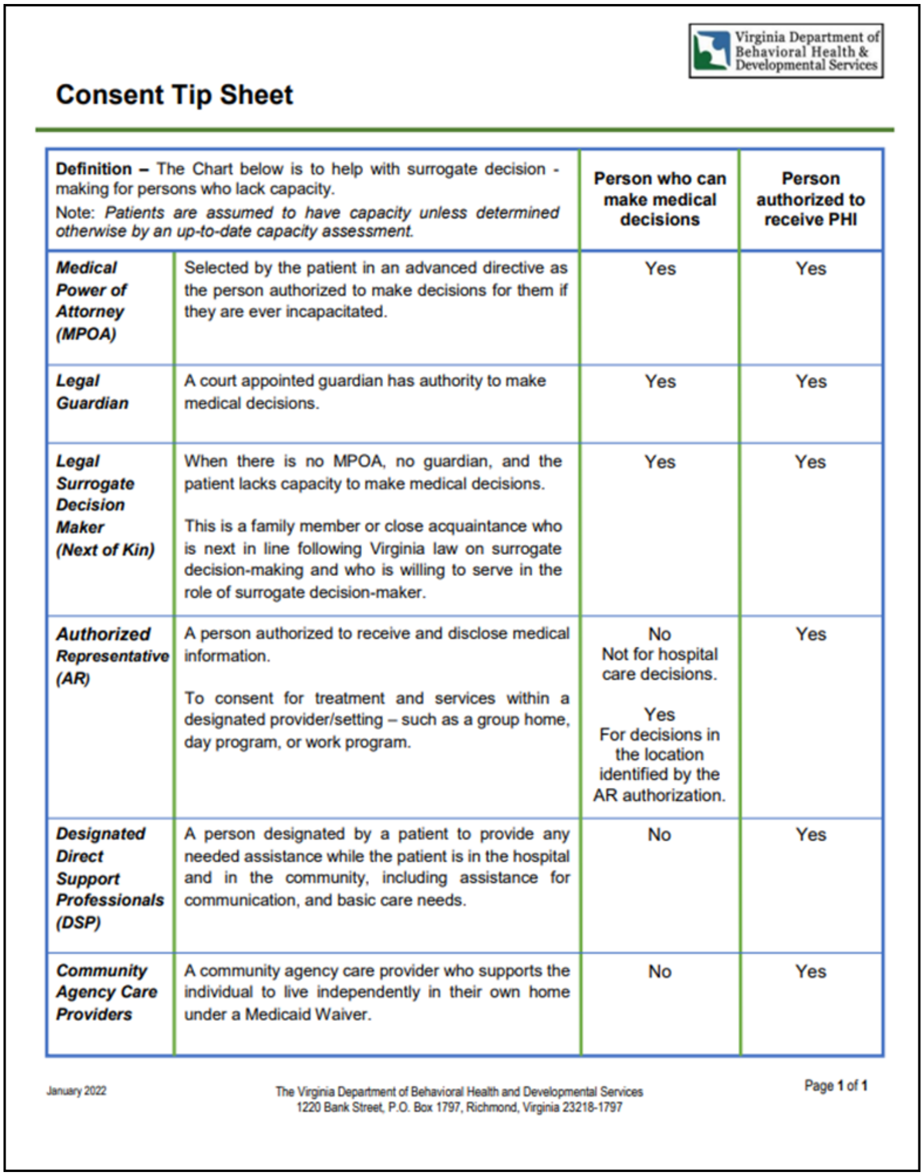
They were designed to "at a glance" help acute care staff to become familiar with information relevant to care requirements for individuals with IDD. These tip sheets should be printed and given to staff in acute care settings when an individual with IDD is being treated or admitted.

The Consent Tip Sheet

The Consent Tip Sheet is an educational document which captures information about medical care and treatment consent for individuals. It indicates who can make medical decisions and who can receive PHI relating to the individual.

It includes information on the following:

- A Medical power of attorney, or MPOA.
- A Legal Guardian.
- A Legal Surrogate decision maker, or Next of Kin.
- An Authorized Representative, or AR.
- A Designated Direct Support Professional, or DSP.
- A Community Agency Care Providers



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Consent Tip Sheet

Definition – The Chart below is to help with surrogate decision - making for persons who lack capacity. Note: *Patients are assumed to have capacity unless determined otherwise by an 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

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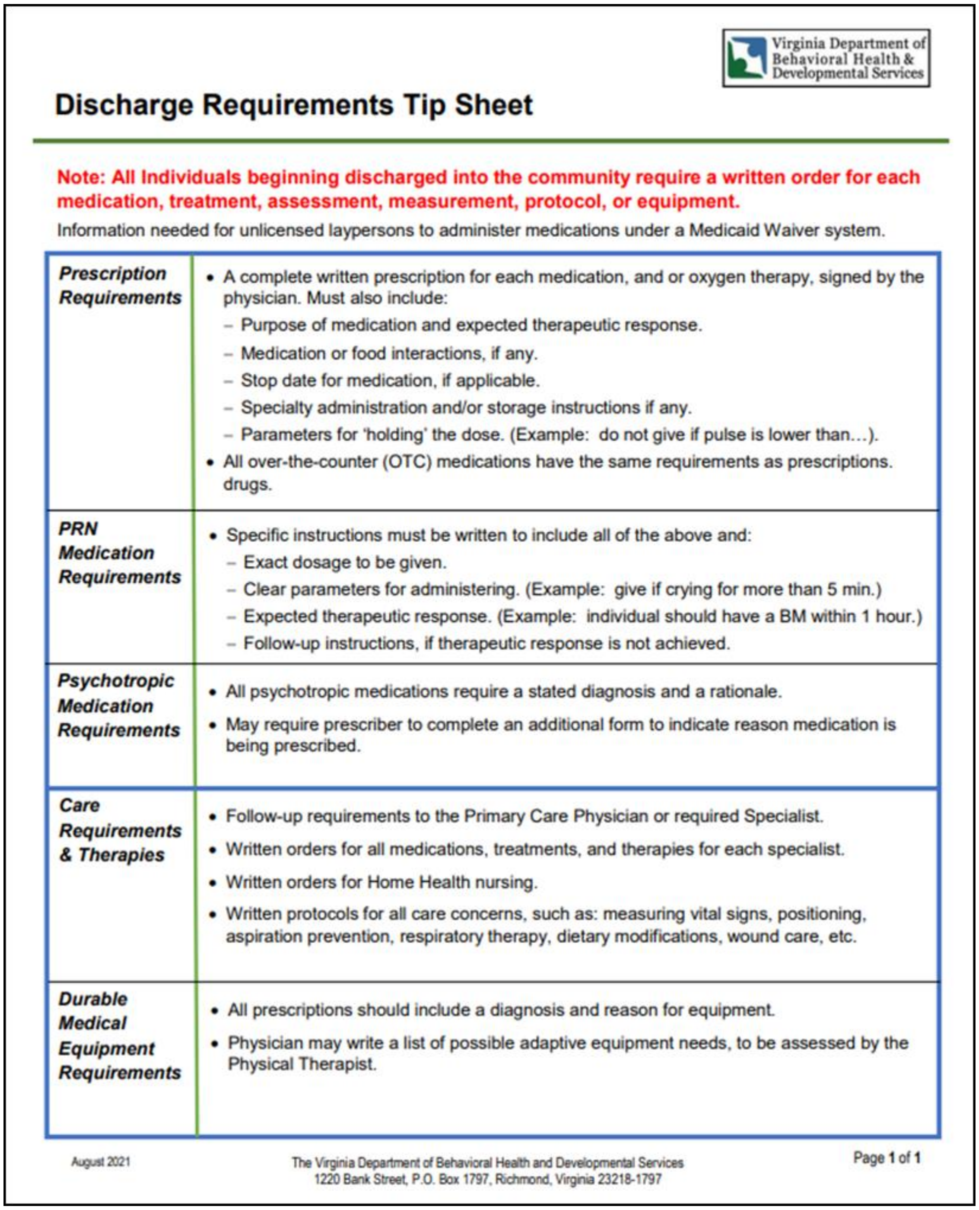
The Discharge Requirements Tip Sheet

The Discharge Requirements Tip Sheet was created to assist with the development of discharge instructions for individuals who reside in a DBHDS licensed setting, and are typically supported by laypersons.

It includes requirements on:

- Prescriptions.
- PRN medications.
- Psychotropic medications.
- Care Requirements.
- Therapies.
- Durable medical equipment.



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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.

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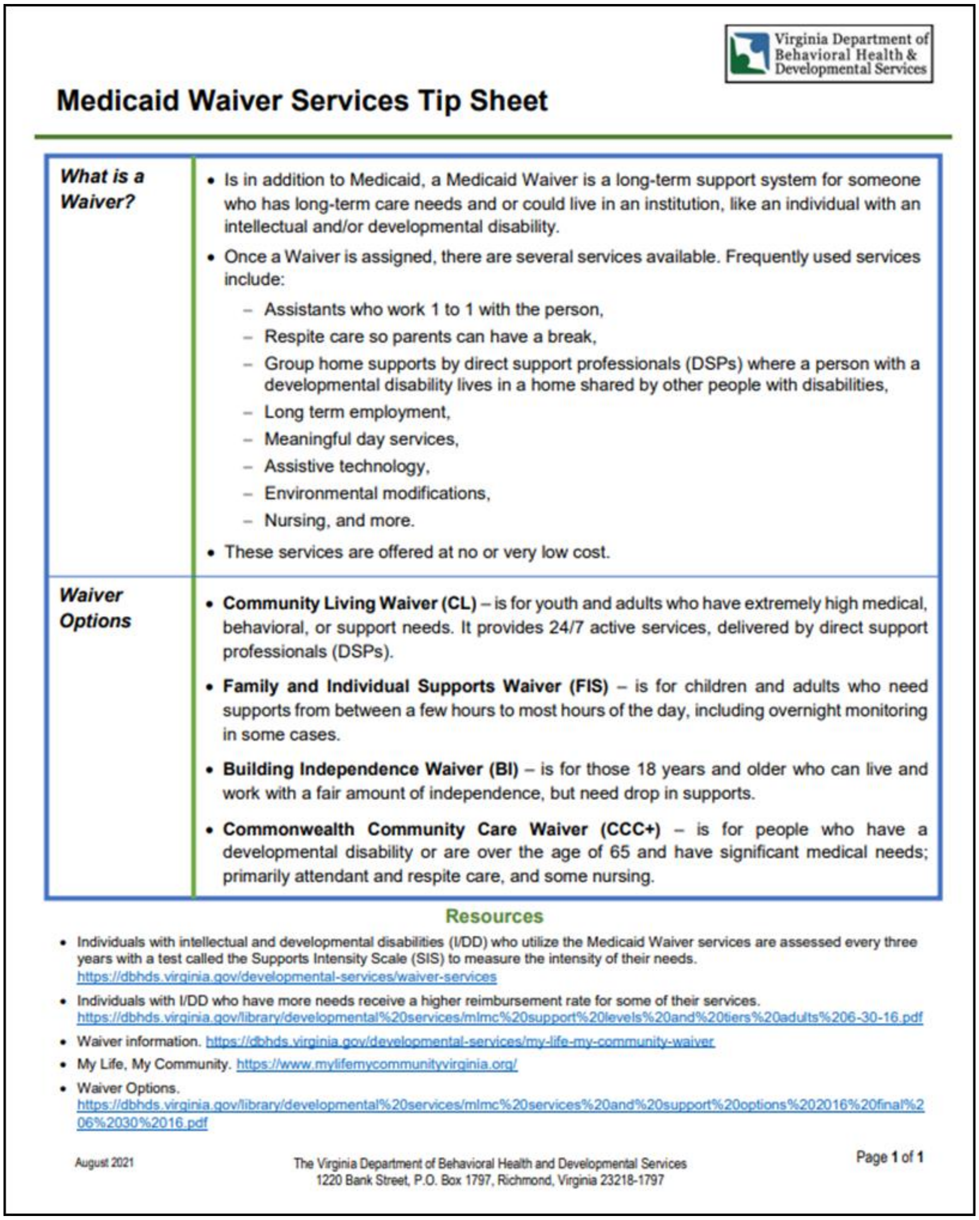
The Medicaid Waiver Tip Sheet

The Medicaid Waiver Tip Sheet is a snapshot explanation of the Commonwealth's Medicaid waiver support system for individuals with IDD. Several resources are listed at the bottom of the page for a more in-depth review of the Medicaid waiver system, if desired.

This tip sheet highlights information about waivers in general, support options, and a recap of all of the different types of waivers currently offered in Virginia for individuals with IDD, to include:

- Community living (CL).
- Family and individual supports (FIS).
- Building independence (BI).
- Commonwealth community care plus (CCC+).



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Medicaid Waiver Services Tip Sheet

What is a Waiver?

- Is in addition to Medicaid, a Medicaid Waiver is a long-term support system for someone 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 include:
  - 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 Options

- **Community Living Waiver (CL)** – is for youth and adults who have extremely high medical, 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 in some cases.
- **Building Independence Waiver (BI)** – is for those 18 years and older who can live and 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; primarily attendant and respite care, and some nursing.

Resources

- 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. https://dbhds.virginia.gov/library/developmental%20services/mlmc%20support%20levels%20and%20tiers%20adults%206-30-16.pdf
- Waiver information. https://dbhds.virginia.gov/developmental-services/my-life-my-community-waiver
- My Life, My Community. https://www.mylifemycommunityvirginia.org/
- Waiver Options. https://dbhds.virginia.gov/library/developmental%20services/mlmc%20services%20and%20support%20options%202016%20final%206%2030%2016.pdf

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The Office of Integrated Health – Health Supports Network wants to give a special note of thanks to the 6 agency IDD Advocacy Coalition, in Staunton-Waynesboro and Augusta Health hospital located at Fishersville, Virginia, for their commitment and collaboration on the creation of the DBHDS My Care Passport, the Consent Tip sheet, the Discharge Tip sheet, and the Waiver Tip sheet.

Your willingness and dedication were greatly appreciated!

Resources

- The Office of Integrated Health - Health Support Network is here to assist you in the successful use of the My Care Passport and the Advocacy Tip Sheets. All questions or concerns should be directed to OIH - HSN at nursing@dbhds.virginia.gov
- The Virginia Department of Behavioral Health and Developmental Services (DBHDS) Website: http://www.dbhds.virginia.gov/
- The Office of Integrated Health – Health Supports Network (OIH – HSN) website: https://dbhds.virginia.gov/office-of-integrated-health#
- OIH Mobile Rehab Engineering (MRE) Team Email Contact: mreteam@dbhds.virginia.gov
- OIH Dental Team: dentalteam@dbhds.virginia.gov
- 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
- Vanderbilt/Kennedy Primary Care Toolkit: https://iddtoolkit.vkcsites.org/
- University of Virginia Chat-Advocacy Training Passport: https://cdl.partnership.vcu.edu/health-advocacy-training-chat/chat-partner-guide/my-health-passport-/

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