My Life,
My Community

Support Coordination

DEVELOPMENTAL DISABILITIES HANDBOOK

Virginia Department of
Behavioral Health &
Developmental Services

VCU
School of Education
Partnership for People
with Disabilities

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Introduction

This Handbook's Target Audience

Support Coordination/Case Management is the core service that Virginians with developmental disabilities and behavioral health disorders use to help navigate and make the best use of Virginia's publicly funded system of services. This service is of critical importance to all dimensions of the services system. Strengthening the Support Coordinator's/Case Manager's role is essential to assuring effective and accountable services within the Development Disability Waivers. The purpose of this handbook is to guide Support Coordinators in all aspects of their work.

Terms Used in Handbook

Although the terms Support Coordinator (SC), Case Manager (CM), and even Services Coordinator may be used interchangeably, Support Coordinator is the term most frequently used in regulations and in most of the material and guidance related to developmental disability Support Coordination/Case Management services developed by the Department of Behavioral Health and Developmental Services (DBHDS). Therefore, Support Coordinator (SC) and Support Coordination will be used throughout this handbook. Glossary of terms and their acronyms used in this handbook.

Use of this Handbook

This handbook is divided into chapters and sub-chapters as seen in the Table of Contents. If you wish to go to a particular chapter or sub-chapter, you can click on that topic in the Table of Contents and it will take you to the appropriate page. Each chapter has one or more At-a-Glance pages that summarize or enhance information covered in the chapter.

Virginia's Public Behavioral Health and Developmental Disability System

The Department of Behavioral Health and Developmental Services (DBHDS) supports people by promoting recovery, self-determination, and wellness in all aspects of life. DBHDS's vision statement is, "A life of possibilities for all Virginians".

DBHDS oversees supports and services for Virginians with developmental disabilities (DD), mental health (MH) disorders and substance use disorders (SUD), and manages day to day operations for the Developmental Disability Waivers.

The state agency that administers the Developmental Disabilities (DD) Waivers in Virginia is the Department of Medical Assistance Services (DMAS). Locally, DD Waiver services are coordinated by SCs employed by or contracted through 40 agencies that are referred to as either Community Services Boards (CSBs) or Behavioral Health Authorities (BHAs). The actual services are delivered by CSBs/BHAs and private providers across the state.

The following are entities that guide, inform, and support the role of the Support Coordinator:

- State Structure chart: The Big Picture
- Department of Behavioral Health & Developmental Services organizational chart
- Departments and people to know from the Department of Behavioral Health and Developmental Services (DBHDS)
    - Community Resource Consultants (CRC) The CRCs help guide SCs with problem solving and offer training and consultation.
    - Regional Support Specialists (RSS) The Regional Support Unit (RSU) oversees management and implementation of the DD Waivers Waitlist by CSBs, as well as all aspects of waiver slot assignments through the Waiver Slot Assignment Committee (WSAC) process.
    - Service Authorization Consultants (SAC) The SACs authorize requested waiver services.
    - REACH (Regional Education Assessment Crisis Services Habilitation) provides crisis stabilization, intervention, and prevention services.
    - Regional Support Teams (RSTs) provide recommendations in resolving barriers to the most integrated community settings consistent with a person's needs and informed choice. See chapter 7 for more information.
    - Office of Integrated Health (OIH): OIH ensures quality supports and community integrated health services by building and improving new, innovative ways to effect change, and decrease inter and intradepartmental barriers across agencies. Employee Directory can be found here.
    - Regional Housing Specialists Housing Specialists are responsible for developing local, regional and statewide relationships and identifying potential resources necessary to increase the availability of and access to affordable and accessible housing for individuals with a developmental disability who are Medicaid Waiver recipients or those who are eligible for a Medicaid Waiver and possibly on the waiver waiting lists ("target population").
    - Office of Licensing (OL): OL licenses providers that provide treatment, training, support and habilitation to those with mental illness, developmental disabilities, or substance use disorders, to people using services under the Medicaid DD Waivers, or those with brain injuries who use services in residential facilities.
    - Office of Human Rights (OHR): OHR assures and protects the human rights of people who use services in facilities or programs operated, licensed, or funded by DBHDS.

A Brief History of Department of Justice Settlement Agreement in Virginia

In August 2008, the Department of Justice (DOJ) initiated an investigation of Central Virginia Training Center (CVTC) pursuant to the Civil Rights of Institutionalized Persons Act (CRIPA). In April 2010, the DOJ notified the Commonwealth that it was expanding its investigation to focus on Virginia's compliance with the Americans with Disabilities Act (ADA) and the U.S. Supreme Court Olmstead ruling. The Olmstead decision requires that people be served in the most integrated settings appropriate to meet their needs consistent with their choice.

In February 2011, the DOJ submitted a findings letter to Virginia, concluding that the Commonwealth failed to provide services to those with intellectual and developmental disabilities in the most integrated setting appropriate to their needs.

In March 2011, upon advice and counsel from the Office of the Attorney General, Virginia entered into negotiations with the DOJ in an effort to reach a settlement without subjecting the Commonwealth to an extremely costly and lengthy court battle with the federal government.

On January 26, 2012, Virginia and the DOJ reached a settlement agreement. The agreement resolves the DOJ’s investigation of Virginia’s training centers and community programs and the Commonwealth’s compliance with the ADA and Olmstead with respect to individuals with intellectual and developmental disabilities.

DOJ's Settlement Agreement.

CHAPTER 1:
Person Centered Practices

Definition

Person centered practices is a term that embodies values and skills used to support and interact with people. Although you may have heard the term most often used in conjunction with the developmental disability field, Person centered practices are used by all people in many different settings and areas of support need. This chapter will describe the values that underlie all person centered practices. Specific tools and skills are abundant and varied. The Person Centered Practices At-a-Glance resource page found at the end of this chapter provides links to training and websites to learn specific person centered skills and obtain person centered tools.

Person centered practices encourage interaction with people with disabilities in much the same way one does with people who do not have disabilities. People with disabilities have the same wants and needs as anyone else. Their needs are not ‘special.’ Like most of us, people with disabilities want to feel a sense of belonging, they want to make contributions, feel useful and productive, love and be loved, govern their own lives, including where and with whom they work, live, and play. People with disabilities are valuable members of the community. People who provide supports, including Support Coordinators, focus on promoting rich and fulfilling lives in the community.

Principles & Virginia’s Vision

Virginia’s vision includes all people, not just those who use the service system. The vision centers on a Virginia where individuals of all ages and abilities have the supports needed to enjoy the rights of life, liberty and the pursuit of happiness and the opportunity to have a good life.

> This vision includes that all people have the opportunities and supports needed to live a good life in their own homes and communities and that a good life is best led by the voice of the individual and by following these person-centered principles:
>
> **Principles of Practice**
>
> **Principle 1: Listening** - People are listened to and their choices are respected.
> **Principle 2: Community** - Relationships with families and friends and involvement in the community are supported.
> **Principle 3: Self-Direction** - People have informed choice and control over decisions that affect them.
> **Principle 4: Talents and Gifts** - People have opportunities to use and share their gifts and talents.

Principle 5: Responsibility - There is shared responsibility for supports and choices.

This broader vision includes having a system of supports and services through which people with disabilities have opportunities for freedom, equality, and the opportunity to participate fully in their community. How a person participates in their community is defined by the person based on what is important to them.

In this system, people with disabilities…

- set their schedules, make decisions about how and where they live, and have opportunities for recreation that reflects their personal desires and interests;
- access their community with the same opportunity as people without disabilities;
- are employed, which increases integration and enables the pursuit of interests through increased income;
- have access to benefits counseling and financial planning services;
- routinely spend time with friends, family, and others not paid to support them;
- have access to home ownership or tenancy rights in affordable integrated settings where they live with whom they choose;
- have knowledgeable, person centered supports to explore and identify services and resources that lead to integration;
- have dependable transportation for community access when needed and desired; and
- choose their healthcare providers and have access to supports and activities that promote health, wellness, and safety.

Promises of Person-Centered Practices

According to the International Learning Community for Person Centered Practices, there are inherent promises made to a person when supporting them using person centered practices.

A Promise to listen

- To listen to what is being said and to what is meant by what is being said
- To keep listening

A Promise to act on what we hear

- To find something that we can do today or tomorrow
- To keep acting on what we hear

A Promise to be honest

- To let people know when what they are telling us will take time
- When we do not know how to help them get what they are asking for

- When what the person is telling us is in conflict with staying healthy or safe and we can't find a good balance between what is **important to** and **important for** the person.

Important to and Important for

At the core of all person-centered practices is the ability to discover what is **important to** a person while balancing this with what is **important for** them. This is true about all people, not just those with a disability. All of us have things in our lives that are **important to** us and **important for** us. We all struggle to strike a balance between doing things that are good for our health/safety and having things in our lives that we cherish or just comfort us. Having what is **important to** us helps all of us handle stressors and issues that weigh on us.

Important To

Those things in life which help us to be satisfied, content, comforted, fulfilled, and happy. They include:

- People to be with/relationships
- Status and control
- Things to do
- Places to go
- Rituals or routines
- Rhythm or pace of life
- Things to have

Important For

Those things that keep a person healthy and safe. They include:

- Prevention of illness
- Treatment of illness/medical conditions
- Promotion of wellness (e.g. diet, exercise)
- Issues of safety: in the environment, physical and emotional well-being, including freedom from fear

Important For also includes what others see as necessary for a person to:

- Be valued and
- Be a contributing member of their community

Chapter 10 discusses health and safety in more detail.

Supporting vs. Fixing

The Support Coordinator (SC) plays a significant role in planning with and supporting a person in achieving their definition of a good life. All people need support, regardless of ability. We may not always recognize the support we ourselves need/receive because we tend to see ourselves as competent adults…but, we are all interdependent beings. It is important to remember that the type of support needed by someone is unique to that person. If someone needs support in one area of their life, say managing finances that does not mean they need assistance in all aspects of their life (The International Learning Community for Person Centered Practices).

Sometimes people confuse support with ‘fixing’. The role of the SC is not to ‘fix’ a person; this has a coercive quality. Fixing is about ‘power over’ not ‘power with’. “When someone tries to fix another, it creates distance between themselves and the person they are fixing. Fixing is a form of judgment. All judgment creates distance, a disconnection, an experience of difference.” (Rachel Naomi Remen)

“In fixing, we see others as broken, and respond to this perception with our expertise. Fixers trust their own expertise but may not see the wholeness in another person or trust the integrity of the life in them”. Rachel Naomi Remen

Below are two documents worth reading about supporting vs. fixing

- Please Stop Trying to 'Fix' My Disability
- A CREDO FOR SUPPORT

Values & Practices

Respect

The term “respect” has many types of meanings. It includes a positive feeling towards another person or the person’s skills, opinions or other characteristics and the honoring of a person’s beliefs, ideas or culture. Respect requires seeing a person as a whole not as a disability. As a SC, respect may be demonstrated by:

- listening;
- developing an understanding of a person’s background and their hopes and dreams;
- presuming competence when meeting with and interacting with a person with a disability maintaining high expectations;
- practicing cultural agility and humility;
- using everyday language;
- supporting a person’s dreams;
- recognizing a person’s talents and gifts;
- facilitating the ways a person can contribute to their community

Cultural Agility & Humility

We are all multi-faceted human beings. For the people a SC supports disability is just one part of who they are and the effects of one’s disability in one’s life are varied and unique to that person. Cultural agility and humility are about giving careful consideration to one’s own assumptions and beliefs that are embedded in one’s goals for a person. There are three tenants to cultural agility and humility:

The first is a lifelong commitment to self-evaluation and self-critique. Cultural agility and humility are not something that can be mastered, arriving at a point where learning is complete. Therefore, it is important to stay humble and flexible and maintain the willingness to look at oneself critically and to maintain the desire to learn more. Recognition that there is no finish line to learning is essential to cultural agility. (Tervalon & Murray-Garcia, 1998)

The second is a commitment to bring about change to power imbalances. This requires recognizing that each person brings something different to the "proverbial table of life" and that helps us see the value of each person. When a SC interviews a person, that person is the expert on their own life, abilities, and strengths. The SC holds a body of knowledge that the person does not; however, the person also has understanding outside the scope of the SC. Both people must collaborate and learn from each other for the best outcomes. "One holds power in scientific knowledge, the other holds power in personal history and preferences" (Tervalon & Murray-Garcia,1998).

"The third commitment to practicing cultural agility requires developing partnerships with people and groups who advocate for others. We cannot individually commit to self-evaluation and fixing power imbalances without advocating within the larger organizations and systems in which we participate. Cultural agility, by definition, is larger than our individual selves - we must advocate for it systemically" (Tervalon & Murray-Garcia, 1998).

Reference: Tervalon, M., & Murray-Garcia, J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. Journal of Health Care for the Poor and Underserved, 9, 117-125.

View this video on Cultural Agility & Humility featuring Melanie Tervalon & Jann Murray-Garcia.

How do you expand your Cultural Agility

The most important thing a SC can do to become more culturally agile is to understand their own culture and assess their natural biases (the lens through which they view their world). Below are some ideas about how to expand awareness.

Take some time to learn about the cultures and languages of communities in the CSB/BHA service area. Attend cultural events, ask questions of people from other cultures, watch movies, listen to music, and read books from different cultures. Try ethnically diverse foods.

Take online tests that deepen your self-awareness. For example:

- Implicit Association Test
- Self-Assessment Checklist for Services to Children with Disabilities

Communication Considerations

SC and the CSB/BHA as a whole should communicate effectively and convey information in a manner that is easily understood by diverse audiences including:

- Persons of limited English proficiency,
- Those who have low or no literacy skills, and
- Those whose disabilities limit their ability to communicate in typical ways.

Remember that SCs have a responsibility to support someone no matter what language they speak. If needed, ask a supervisor how to access interpreters.

Use of Everyday Language

Choice of words in speaking and attitudes conveyed through tone of voice are very important. Language can act as a separator when a SC uses "special" language or professional jargon when talking to or about people with disabilities such as "client," or "consumer." Special language says people with disabilities are different and sets up an "us" versus "them" dynamic. Instead, use everyday language, words, and phrases you would use when talking about co-workers, friends, and family members. For example, instead of saying John was placed in a job, say, he found a job or instead of saying Jane transitioned from high school, say, she graduated. As a SC, how you talk will influence the attitudes and interactions others have with people with disabilities.

"Person First" language emphasizes the person and not the disability. The first choice is always to call someone by their name. If you have to refer to someone and mention disability, always put the person first. The phrase, "a disabled person," can be disrespectful and emphasizes the disability rather than the person. A SC should say, "a person with a disability." Instead of saying "someone with Down's," say, "a person who has Down syndrome." Referring to the person first lets others know that he or she is, first and foremost, a person who deserves respect.

There are some people with disabilities, for example those who are on the autism spectrum, who prefer to be referred to as 'autistic' rather than 'a person with autism'. They assert that autism is part of them and they cannot be separated from their autism as it might be with a person being cured of a disease. Therefore, they prefer to be called "autistics" in order to identify that this diagnosis and way of being is a permanent part of their personality. In instances such as these, it is important to respect and use the language an individual person prefers. To read more visit Autism Mythbusters.

According to the International Learning Community for Person Centered Practices, "How you say what you say matters as much as the actual words you say." Some other things to keep in mind regarding language are:

- **Tone** - The inflection or emotion in your voice. It should be age appropriate (no baby talk for adults), mild and respectful.
- **Volume** - Loudness of your voice. It should be appropriate for the situation. If you are in a noisy location, you may have to speak louder (not yell) to be heard. It can also be effective to lower the volume of your voice in order to draw someone's attention.

- **Context** - Where are you? Is it a comfortable, familiar location? Who else is around? Privacy is important. What is the intensity of emotion being expressed? Are you or others upset, frustrated, sad, happy, etc.?
- **Body Language** - Gestures and movements that accompany the words. Some experts say that 75% to 90% of perceived language is body language. Body language such as crossing your arms can show disinterest. Shaking your finger at a person can show anger. Rolling your eyes can show disbelief. You want your body language to match with what you are saying and how you are saying it.

Personal Choice and Decision Making

Personal choice means making decisions about all the details of our lives. Each day, as soon as we wake up we are engaged in making choices. We ask ourselves: “Should I hit the snooze button or get up?”, “Should I call in sick or go to work?” and “What should I wear?” We also make major decisions about who to live with and what sort of work we want to do. We are in control and it feels good to be empowered and able to make our own decisions. Everyone is entitled to make decisions about their lives. However, it is rare that anyone makes major decisions in their lives in isolation from others. Most of us talk with those we are close to when making major decisions. SCs play a significant role in promoting choice when planning with a person and when evaluating whether a plan is working for them. Efforts should be made to also include others in decision-making, if the person chooses to do so. Individual choice drives the formulation of outcomes on the Individual Support Plans, the way provider agencies operate, the staffing patterns (what staff do and when they do it), and the daily actions of the Direct Support Professionals. Choice should occur naturally and should be expected without unnecessary restrictions. Many people entered supportive services with little to no choice. It is the SCs responsibility to promote personal choice by noticing likes, dislikes, and opinions as forms of choice.

Informed Choice refers to one’s ability to make a decision based on a clear understanding of the facts, results of the choice, and possible future consequences. Some people do not show the capacity for informed consent and need supports from family members, an authorized representative, or a legal guardian. This is typically reserved for decisions or choices that might have an effect on a person’s health and safety. This does not mean that the day-to-day choices or expression of hopes and dreams should be restricted. The role of legal guardians and authorized representatives are discussed in greater length in Chapter 3.

Dignity of Risk

The concept of dignity of risk is the right of a person to engage in experiences meaningful to them and which are necessary for personal growth and development. Normal living often includes risks. Choice inherently involves risk, sometimes in a menial way, in other instances, in life threatening ways. Dignity of risk allows people to lead normal lives. Overprotecting people with disabilities keeps them from many life situations that they have the right to experience, and it may prevent meaningful connections and fulfillment of their hopes and dreams. Rather than protecting people with disabilities from disappointments and sorrows, which are natural parts of life, it is important to support them to make informed decisions. This enables them to experience the possibility of success and the natural risk of possible failure. Occasionally, a SC may believe they know the outcome for those who “dream too big.” Dignity of risk demands we try to help people investigate and reach for their dreams.

Individual Rights

All people, no matter their ability, retain basic human rights. Like all U.S. citizens, people with disabilities are entitled to enjoy the rights and freedoms to privacy, to have personal possessions, to marry, to exercise free speech, to live in neighborhoods, to complain, to vote, etc. It is also the right of a person to be free from abuse, neglect, exploitation and not to have restrictions on his or her rights and freedoms. A SC is a "mandated reporter," and is required to report rights violations of anyone they support, including suspicion of abuse, neglect and/or exploitation. Mandated reporting is discussed in Chapter 2. Some people the SC supports may have had their legal rights limited through the appointment of a guardian, conservator, or another legal process. This does not mean they cannot make day-today choices and decisions or should have their dreams or plans go unheard. It is the SC's responsibility to seek guidance and help with decision making when appropriate and/or needed to preserve the health and safety of the person supported. As an employee of a community agency providing supports to people with developmental disabilities, it is the SC's responsibility to be knowledgeable of the Regulations to Assure the Rights of Individuals Receiving Services from Providers Licensed, Funded or Operated by DBHDS (the Human Rights Regulations). The following link to these Regulations Virginia Law Administrative Code.

Confidentiality

Confidentiality is a right each of us has to privacy and respect of information given to and shared among professionals about us. People generally expect that their medical records, financial records, psychological records, criminal records, driving records, and other personal records are going to be kept in a confidential manner. SCs must remember to have this same respect for the private information about those they support. This includes health information that is covered by the Health Insurance Portability and Accountability Act (HIPAA) and substance use information that is more stringently covered under 42.CFR, Part 2. Your agency should provide additional information about confidentiality and requirements related to sharing information.

LifeCourse Beliefs and Tools

LifeCourse is a collection of person-centered tools that may be useful when supporting someone to reach their dreams and goals. The core belief of Life Course is:
All people have the right to live, love, work, play and pursue their life aspirations in their community.

Principles of LifeCourse

- ALL people are considered in our vision, values, policies and practices for supporting people with intellectual and developmental disabilities.
- People exist and have reciprocal roles within a family system, defined by that individual. Roles adjust as the individual members change and age.
- Individuals and families can focus on a specific life stage, with an awareness of how prior, current and future life stages and experiences impact and influence life trajectory. It is important to have a vision for a good, quality life, and have opportunities, experiences and support to move the life trajectory in a positive direction.

- Individuals and families plan for present and future life outcomes that take into account all facets of life and have life experiences that build self-determination, social capital, economic sufficiency and community inclusion.
- People lead whole lives made up of specific, connected, and integrated life domains that are important to a good quality of life.
- Supports address all facets of life and adjust as roles and needs of all family members change.
- Individuals and families access an array of integrated supports to achieve the envisioned good life, including those that are publicly or privately funded and based on eligibility; community supports that are available to anyone; relationship-based Supports; technology; and that take into account the assets and strengths of the individual and family.
- Individuals and families are truly involved in policy making so that they influence planning, policy, implementation, evaluation and revision of the practices that affect them. Every program, organization, system and policymaker must always think about a person in the context of family.

Using Life Stages and Trajectory with people with DD and families can focus on a specific life stage, with an awareness of how prior, current and future life stages and experiences impact and influence life trajectory. It is important to have a vision for a good, quality life, and have opportunities, experiences and support to move the life trajectory in a positive direction.

The Integrated Delivery of Supports tool helps people with DD and families utilize an array of integrated supports to achieve the envisioned good life, including those that are publicly or privately funded and based on eligibility, community supports that are available to anyone, relationship-based supports, technology, and that take into account the assets and strengths of the individual and family.

Once people have figured out the types of supports needed and/or existing, LifeCourse provides a calendar template as a way to apply the supports to a daily/weekly schedule. The worksheet includes instructions and an example on the back. The calendar is also incorporated into the Waiver Management System (WaMS), which will be covered in a later chapter.

Information about LifeCourse and all of their tools may be found on the Life Course Tools website.

Community

Definition

Community is a group of people who come together for a common reason. People may belong to several communities, of which are based on a common interest, such as bowling or bird watching; or geography, such as a neighborhood; or identity, such as religion or sexual orientation. Being part of a community brings people together, and people learn that although what brings them together is similar, there are many other factors that make us each unique. Positive and regular interactions within a community help people to get to know one another. Since people are, at times afraid of differences or the unfamiliar, it takes intentional effort to involve people with disabilities in their communities. If people with disabilities only experience segregated living environments, segregated work environments, and segregated social environments, they are separated from the larger community. This does not mean that a person should never be involved in a community of only people with disabilities especially if the organizing factor is one's identity as a person with a disability, such as People First or other advocacy groups. People First is an advocacy organization designed for and run by people with intellectual and developmental disabilities. The SC should explore ways a person may be involved in various communities that may be defined by where the person lives, their interests, their culture, religion or other parts of their identity.

Belonging in Community

Just because you live in a community or attend activities in a community does not mean you feel like you belong in that community. According to the International Learning Community for Person Centered Practices, there is a progression of involvement in a community with community connection being the goal.

- **Community presence** may include doing things in the community on a regular basis and being recognized by others who attend, but not really interacting with others. If a person is not there, they are not missed.
- **Community participation** may include doing things in the community on a regular basis, knowing several people by name and having conversations with them about personal lives. The person does things at the event that others depend on and they would be missed if they were not there on a particular day.
- **Community connection** may include a person being included in social gatherings outside of the primary connection, others recognizing and appreciating their contributions, and forming friendships that extend beyond the reason they are gathered. When a person is not there they are missed and people ask about them

With the focus on community life, there is movement away from specialized programs that exclude people from an ordinary or extraordinary life. Using paid supports does not mean a person with a disability has to participate in specialized programs with groups of people with similar disabilities, with little to no access to ordinary activities.

Alternatives to isolated programming refers to supporting a person in natural settings, with families and friends, by providing flexible supports that work well for them. People with disabilities should live in comfortable homes in safe neighborhoods. They should have the choice to work a regular job or to engage in other typical activities that they and the community value.

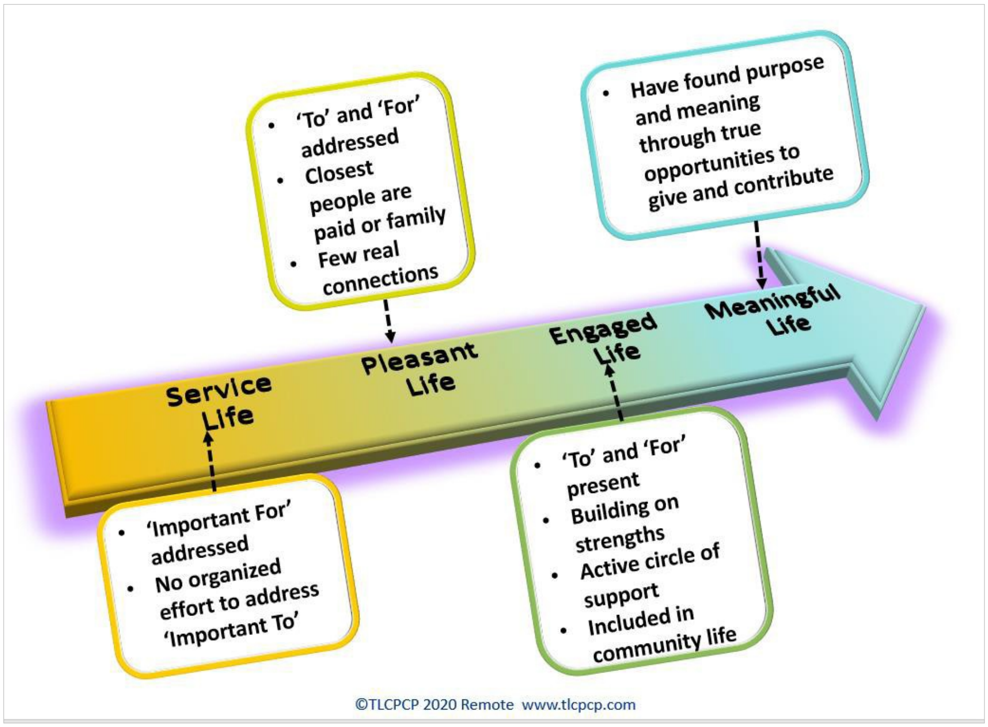
Contribution

People feel better when they contribute to family, community, the world. Often our contributions come through the paid work we do, but there are many other ways in which a person may share their gifts and talents. **Virginia is an Employment First state which means it is incumbent on SCs to offer and explore the option of integrated, community employment as the first choice of day activity for those they support**. Employment and the Support Coordinator's role is described more in-depth in Chapter 12. However, whether we have paid employment or not, there are other ways to make contributions in life. For example, we contribute to family or roommates when we take a fair share of responsibility for the household chores and when we provide an empathetic ear. We may contribute to our communities by volunteering our time or resources for a cause we believe in. We may contribute to the world by changing living habits that affect our global environment. Along with employment, the topic of contribution needs to be explicitly discussed with people the SC supports, not with just one conversation, but in many conversations.

Natural Supports

The term natural supports refer to the resources that are already present and available to all persons in community environments. This includes family, friends, co-workers and neighbors, members of clubs or civic groups, and local merchants. Imagine for a minute what it would be like to wake up every morning knowing that the only people you will interact with all day will be those paid to be with you. This is not how most people live. Most people pay for some services and get assistance from others just because they care. It is part of the SCs role to uncover and set up flexible ways of supporting a person in community settings so they can develop natural relationships. The goal is to move away from dependence on paid supports and move towards supports from friends, family, and others who are genuinely interested in the person. This not only benefits an individual, it benefits a system that cannot meet the all the needs of every person. Whether we like it or not, there is a limited number of resources available to meet the needs of Virginians with disabilities.

The following diagram from The International Learning Community for Person Centered Practices, illustrates the movement from reliance on services to having a place in the community.



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Person Centered Practices Resources

Person Centered Thinking Training in Virginia

Support Development Associates

Helen Sanderson Associates

The International Learning Community for Person Centered Practices

Cornell University Person Centered Planning Education Site

CHAPTER 2:
Support Coordination Overview

Support Coordination

There are two kinds of support coordination, one for people with ID and one for all others who have DD but not an ID diagnosis. They have different rates, different qualifications, but have the same general expectations (with the exception of ongoing support coordination versus special service need while on the waitlist).

Definition

The Administrative Code of Virginia defines Support Coordination in each of the two types as follows:

12VAC30-50-440. Support Coordination/Case Management (Support Coordination) for individuals with an intellectual disability (ID). The Target Group is Medicaid-eligible individuals with an intellectual disability as defined in state law (§ 37.2-100 of the Code of Virginia).

Targeted Support Coordination services are defined as services furnished to assist individuals, eligible under the State Plan, in gaining access to needed medical, social, educational and other services.

Support Coordination for people with ID

1. An individual receiving ID Support Coordination shall mean an individual for whom there is an individual support plan (ISP) in effect that requires direct or individual-related contacts or communication or activity with the individual, the individual's family or caregiver, service providers, and significant others. Billing can be submitted for an individual only for months in which direct or individual-related contacts, activity or communications occur consistent with the ISP.
2. There shall be no maximum service limits for support coordination/case management services except as related to individuals residing in institutions or medical facilities. For these individuals, reimbursement for support coordination/case management shall be limited to 30 days immediately preceding discharge. Support Coordination/case management for individuals who reside in an institution may be billed for no more than two pre-discharge periods within twelve months.

12VAC30-50-490 Support Coordination/Case Management (Support Coordination) for individuals with developmental disabilities (DD). The Target Group is Medicaid-eligible individuals with developmental disability (other than intellectual disability) or related conditions as defined in state law (§ 37.2-100 of the

Code of Virginia) who are on the waiting list or are receiving services under one of the Developmental Disabilities (DD) Waivers. This target group shall be eligible for support coordination.

Support Coordination for people with DD

1. An individual receiving DD Support Coordination shall mean an individual for whom there is a Person-Centered Individual Support Plan (PC ISP) in effect which requires monthly direct or in-person contact, communication or activity with the individual and family/caregiver, as appropriate, service providers, and other authorized representatives including at least one face-to-face contact between the individual and the Support Coordinator/Case Manager every 90-days. Billing shall be submitted for an individual only for months in which direct or in-person contact, activity or communications occur and the Support Coordinator's/Case Manager's (SC) records document the billed activity. Service providers shall be required to refund payments made by Medicaid if they fail to maintain adequate documentation to support billed activities.

2. Individuals who have developmental disabilities as defined in state law but who are on the DD waitlist for waiver services may receive Support Coordination/Case Management services **only if** there is a special service need identified, in which case an ISP shall be developed to address the special service need. In this case, the Support Coordinator/Case Managers shall make face-to-face contact with the individual at least every 90 calendar days to monitor the special service need, and documentation is required to support such contact. A special service need is one that requires linkage to and temporary monitoring of those supports and services identified in the ISP to address an individual's mental health, behavioral, and medical needs or provide assistance related to an acute need that coincides with the allowable activities noted in subsection D of this section. If an activity related to the special service need is provided in a given month, then the support coordinator/case manager would be eligible for reimbursement. Once the special service need is addressed related to the specific activity identified, billing for the service shall not continue until a special service need presents again.

For more detailed information on diagnostic eligibility for Support Coordination, see Chapter 5.

Being a SC is a huge responsibility. Support Coordination is the core service that many Virginias with developmental disabilities and /or behavioral health depend upon to help navigate and make the best use of our publicly funded system of services. In some ways SCs are the most important staff members in our entire system! They make sure individuals have access to services and ensure that those services are effective. When a need has been identified, SCs take the lead in problem solving and advocating in order to hold the system accountable.

Support Coordination is the management of covered services for individuals to ensure that needs are met, covered services are not duplicated by the care-providing organization(s), and resources are used cost effectively. SCs either work directly for a CSB/BHA or contract with one. SCs usually work in a support coordination division or group within a CSB. Although Support Coordination is not a DD Waiver service, it is required for all DD Waiver recipients and paid for by Medicaid.

Types of Support Coordination

The type of Support Coordination provided may depend on the person's disability and age. Below are several examples of the type of Support Coordination services a person may use.

Developmental Disability (DD)

A person qualifying for DD Support Coordination has been diagnosed with a developmental disability but not an intellectual disability. For more specific information and full definition of developmental disability, see Chapter 3 of this handbook.

Intellectual Disability (ID)

A person qualifying for ID Support Coordination has been diagnosed with an intellectual disability. For more specific information and full definition of intellectual disability, see Chapter 3 of this handbook.

Part C

A child receiving Part C Support Coordination has been found eligible under the Infant & Toddler Connection of Virginia for early intervention supports and services to infants and toddlers from birth through age two, who are not developing as expected or have a medical condition that can delay typical development. For more specific information about Part C Support Coordination visit the Infant & Toddler Connection of Virginia website.

Omnibus Budget Reconciliation Act (OBRA)

A person eligible for OBRA Support Coordination are those who meet the eligibility criteria for ID/DD Support Coordination and currently reside in a nursing home. They must be identified to need and benefit from specialized services. For more specific information about specialized services available to a person receiving OBRA Support Coordination visit VA DARS - Nursing Home Outreach Services.

Mental Health (MH) Disorders

A person using mental health Support Coordination services has been diagnosed with a mental health disorder that significantly impacts their functioning in everyday living. Often times, a person using DD/ID SC services may also qualify for MH SC. In this instance it is important to determine from which program (DD/ID or MH) the person will receive primary Support Coordination. Some of the services available for people with mental health needs include:

COMMUNITY MENTAL HEALTH REHABILITATIVE SERVICES

(Medicaid Provider Manual: Community Mental Health Rehabilitative Services Manual 8/22/2018)

Community Mental Health Rehabilitative Services (CMHRS) are behavioral health interventions in nature and are intended to provide clinical treatment to those individuals with significant mental illness or children with, or at risk of developing, serious emotional disturbances. These services may be available to individuals with developmental disabilities who have co-occurring mental health disorders through local community services boards and/or private providers.

Intensive In-Home Services (IIH) for Children and Adolescents

Intensive in-home services (IIH) for children and adolescents under age 21 are intensive therapeutic interventions provided in the individual's residence (or other community settings as medically necessary and documented in the SSPI and ISP), to improve family functioning, and significant functional impairments in major life activities that have occurred due to the individuals' mental, behavioral or emotional illness in order to prevent an out of home placement, stabilize the individual, and gradually transition the individual to less restrictive levels of care and supports.

Therapeutic Day Treatment (TDT) for Children and Adolescents

Therapeutic Day Treatment (TDT) provides medically necessary, individualized, and structured therapeutic interventions to children/adolescents with mental, emotional, or behavioral illnesses as evidenced by diagnoses that support and are consistent with the TDT service and whose symptoms are causing significant functional impairments in major life activities such that they need the structured treatment interventions offered by TDT.

Day Treatment/Partial Hospitalization

Day treatment/partial hospitalization services shall be interventions that are more intensive than outpatient services and are required to stabilize an individual's psychiatric condition. The services are delivered when the individual is at risk of psychiatric hospitalization or is transitioning from a psychiatric hospitalization to the community.

Psychosocial Rehabilitation

This service provides a consistent structured environment for conducting targeted exercises and coaching to restore an individual's ability to manage mental illness. This service provides education to teach the individual about mental illness, substance use, and appropriate medication to avoid complication and relapse and opportunities to learn and use independent living skills and to enhance social and interpersonal skills within a consistent program structure and environment.

Crisis Intervention

Crisis intervention shall provide immediate mental health care in the home or community and be available 24 hours a day, seven days per week, to assist individuals who are experiencing acute psychiatric dysfunction requiring immediate clinical attention. Crisis intervention activities shall include assessment, short-term counseling designed to stabilize the individual and care coordination. Crisis intervention services may include office visits, Temporary Detention Order preadmission screenings, or telephone contacts.

Intensive Community Treatment

Intensive Community Treatment (ICT) provides long term needed treatment, rehabilitation, and support services to identified individuals with severe and persistent mental illness especially those who have severe symptoms that are not effectively remedied by available treatments or who because of reasons related to their mental illness resist or avoid involvement with mental health services in the community. ICT services are offered outside of clinic, hospital, or program office settings for individuals who are best served in the community. ICT services include psychiatric assessment, counseling, medication management, and care coordination activities through a designated multidisciplinary team of mental health professionals.

Crisis Stabilization

Crisis Stabilization services provide intensive short term mental health care to non-hospitalized individuals (of all ages) experiencing an acute crisis of a psychiatric nature. The goal is to address and stabilize the acute mental health needs at the earliest possible time with ongoing services, avert hospitalization or re-hospitalization; provide a high assurance of safety and security in the least restrictive environment, and mobilize the resources of the community support system, family members, and others for ongoing maintenance, rehabilitation, and recovery.

Mental Health Skill Building Services

Mental health skill-building services (MHSS) shall be defined as goal directed training and supports to enable restoration of an individual to the highest level of baseline functioning and achieve and maintain community stability and independence in the most appropriate, least restrictive environment. MHSS services shall provide face to face activities, instruction, interventions, and goal directed trainings that are designed to restore functioning and that are defined in the ISP in order to be reimbursed by Medicaid. MHSS shall include goal directed training in the following areas: (i) functional skills and appropriate behavior related to the individual’s health and safety; instrumental activities of daily living, and use of community resources; (ii) assistance with medication management; and (iii) monitoring health, nutrition, and physical condition with goals towards self-monitoring and self-regulation of all of these activities.

Substance Use Disorders (SUD)

A person using SUD Support Coordination services has been identified as having a substance use disorder and is in need of medical, psychiatric, psychological, social, educational, vocational, recovery, and other supports essential to meeting the person’s basic needs. Sometimes, a person using DD/ID SC services may also qualify for SUD Support Coordination. In this instance, it is important to determine from which program (DD/ID or SUD) the person will receive primary Support Coordination.

Targeted Case Management (State Plan Option)

Targeted Case Management services are services furnished to assist individuals, eligible under the Medicaid State Plan. This can include:

- A person who is a recipient of the DD Waiver.
- A person with an intellectual disability on the waiting list for the DD Waiver who is eligible for Medicaid (in this instance the person may or may not be a recipient of one of the other Medicaid Waivers).
- A person with a developmental disability on the waiting list for the DD Waiver who is eligible for Medicaid AND has a short-term special need (in this instance the person may or may not be a recipient of one of the other Medicaid Waivers).
- A person with an intellectual disability **not** on the waiting list for the DD Waiver, who is eligible for Medicaid and targeted case management, but **not** DD Waiver (in this instance the person may or may not be a recipient of one of the other Medicaid Waivers).

More detailed information about the service requirements for targeted Support Coordination/Case Management are provided in Chapter 5 of this handbook.

Enhanced Case Management (ECM)

This more intensive level of Support Coordination is provided to people who meet certain criteria that identifies certain situations that history and evidence-based practice indicates increased risk for the individual. ECM requires more active support from a SC including more frequent face to face visits and monitoring of services to ensure that the individual remains stable and or does not further deteriorate.

It is important for SCs to understand the ECM criteria.

For more detailed ECM guidelines, criteria and an optional ECM worksheet, please click on the links provided.

ECM standards at a glance
ECM flow chart at a glance
ECM Guidelines Update April 2014
ECM Optional Worksheet 2021
ECM Q & A 2021

Monitoring/Follow Along

A person who is **not** eligible for Medicaid may still have a need for Support Coordination. Often times, individuals not eligible for Medicaid may be on the DD Waiver waiting list and have unmet needs that require SC. Many CSBs or Support Coordination providers have protocols for how to provide support to a person who is not eligible for Medicaid. This may or may not include an option for the person to pay for SC services out of pocket or at a reduced fee. Some CSBs or SC providers may have different documentation and direct contact protocols for individuals not eligible for Medicaid.

Post Move Monitoring

Post move monitoring is required for anyone who previously resided in a Training Center and is now living in the community. This type of monitoring is a requirement of the Department of Justice Settlement Agreement and involves a collaborative effort between training center staff, the Community Service Board (CSB), community providers and the Community Integration Manager (CIM) to ensure the health, safety and overall well-being of people discharged from Virginia Training Centers. Post move monitoring also takes place for children with Developmental Disabilities discharged from nursing facilities but is not required by the Department of Justice Settlement Agreement or any regulation. For children discharging from an ICF/IID, they receive a 10 and 90 day PMM. This is usually a phone contact with either the provider or SC or both. If the individual is at home, it may be with the parent. For children discharging from nursing facilities, they receive a 7 day and 90 day PMM. The PMM reaches out to the CSB seven days after they are notified of the child's discharge, and again at 90 days to ensure a successful placement. The CSBs are encouraged to reach out to the PMM after these check-ins if there are other needs they come across to maintain the child in the community environment.

The training center post move monitoring (PMM) staff will conduct a minimum of four face to face visits with the person within the first 60 days following his/her move to the community to ensure essential supports are in place. These visits will occur in the home, and at the day support or the employment site. The PMM staff will review/request copies of: support logs/data collection sheets, progress notes, injury/illness/incident reports, medication administration records, new physician orders, etc. Notes are requested from the CSB for the first full year following discharge. PMM staff will make recommendations and assist in developing strategies and securing additional supports as needed to address any concerns identified during the post move monitoring process.

Post Move Monitoring report

Choice of Support Coordinator

Anyone seeking Support Coordination services is required to be offered a choice of Support Coordinator. Choice of providers is **always an option and can be exercised at any time** by a person using SC services and documented on the Virginia Informed Choice form at a minimum on an annual basis. Each provider of Support Coordination shall implement a written policy describing how people are assigned SCs and how they can request a change of their assigned SC or SC provider.

Support Coordination Process Overview

Preparation and Engagement

The first step in the Support Coordination process is preparation and engagement. It is important for a SC to prepare by identifying documentation requirements and engaging the person, their family, support partners, and service providers. A SC should always be aware of upcoming deadlines as they pertain to due dates for service plans and assessments. Organization and preparation is key to ensure positive outcomes for the person. See Chapter 4 for more detail regarding Preparation and Engagement.

Assessment

Assessment is the ongoing process of gathering and summarizing information that guides the work between the SC and the person using services. It also refers to document(s) that synthesize information that has been gathered. The assessment is a time for discovery and determining initial and ongoing eligibility for services.

The goal of assessment is to gather information to continually add to understanding those supported including their strengths, abilities, past successes, hopes, dreams, preferences, needs, and risks. In order to develop a plan that is effective, and in keeping with the person's values and goals, it is important to gather information about a person and their environment.

Effective assessments start where a person is, prioritizing their immediate concerns. Be sure to pay attention to any immediate health and safety issues, risk or risks of harm. The assessment should be precise and accurate and should identify support needs, stressors, goals, value, strengths, resources, health status, activities of daily living (ADL) and support networks.

See Chapter 5 for more detail regarding Assessment.

Plan Development

Planning is the bridge between the assessment and the services to be provided. The assessment process develops an understanding of the person's needs and the resources available. The planning process then translates the assessment information into action planning and desired outcomes and the means to reach them.

Person-centered planning is a set of approaches designed to assist someone to plan their life and supports. It is a planning process that focuses on the needs and preferences of the person- not the system or service availability and empowers and supports people in defining the direction for their own lives. Person centered planning promotes self-determination, community inclusion and independence.
The person with whom a plan is being developed is always at the center of the planning process. The planning team always includes the person using services, his or her substitute decision-maker (if applicable), the SC and providers, and may also include family members, friends, and others who the person chooses.

The Support Coordinator plays a vital role in ensuring that the information that is gathered puts the person's gifts, talents, goals, preferences, needs, and choices in the center of the planning process.

See Chapter 7 for more detail regarding Plan Development.

Plan Implementation

Support Coordination services help people work to improve their health and well-being, live a self-directed life, and strive to achieve their full potential. SCs assist people in accessing needed supports. This process is known as plan implementation which can be divided into the following three categories.

Coordination ensures that activities between the person and service providers are implemented according to the PC ISP.

Linking people to needed resources and services by discussing options and referring as needed.

Advocating for a person by ensuring that their needs and preferences are being implemented and use problem solving when barriers arise. The SC has the knowledge and professionalism to represent the best interests of the person served.

See Chapter 7 for more detail regarding Plan Implementation.

Monitoring and Evaluation

The SC monitors the individual and service providers, assures that the ISP is being implemented appropriately, and evaluates whether changes to the plan are needed. Monitoring is conducted through periodic site and home visits to assess the quality of care and satisfaction of services. Making collateral contacts with the person's significant others, i.e. parent, authorized representative, guardian, etc. and assisting the person to identify problems and modifying the plan are also part of monitoring and evaluation. SCs can follow up with providers and other supports, provide or obtain instruction, education, and counseling to help ensure plan implementation. Regularly meeting with the person in their natural environment, for example their home, day program or workplace is an excellent way to monitor and evaluate. Monitoring and evaluating known risks and identifying new risks, needs and changes in status can help to ensure the person's safety and well-being.

See Chapter 8 for more detail regarding Monitoring and Evaluation.

Transitions, Transfers, Ending Services

There will be times when people will need Support Coordination services of indefinite duration while others will not. A person may need support in transitioning to new services because they have recently received a Waiver slot. Perhaps a person has moved to another catchment area and has requested to be transferred to the CSB of that new locality. Regardless of the reason why someone might need support during transition, transfer or ending services, the SC needs to ensure continuity of care in addition to participation and agreement from the person about how his services will be transitioned, transferred or ended.

See Chapter 9 for more detail regarding Transitions of Support.

Recognizing Limitations

Success as a SC requires skills in organization, problem-solving and good communication. SCs have to anticipate the unexpected and solve difficult problems on a daily basis. Flexibility and teamwork are top priorities as well as understanding individual perspectives in order to overcome barriers to service. When barriers to service have been identified it is important for the SC to seek support as needed. Supports can include, but not limited to the following:

- Support Coordination Supervisors
- Fellow Support Coordinators
- Community Resource Consultants (CRC)
- Regional Support Teams (RST)

Support Coordinators must be knowledgeable of generic resources that are available in the community for those who use the DD Waiver as well as those who are on the waiting list or do not qualify for the DD Waiver.

Additional resources may be found in Chapter 11.

Mandated Reporting

The Code of Virginia states that mandated reporters who may have reason to suspect a child or disabled adult is being abused or neglected should immediately report to the local Department of Social Services. Support Coordinators are considered mandated reporters and are required to report all suspicions of abuse, neglect and exploitation to Adult Protective Services, if the person is an adult. If the person is under 18 years or up to 21 years old while in the care of a legal guardian, Child Protective Services should be notified. For DBHDS licensed providers, the offices of Licensing and Human Rights, as well as the Commonwealth Coordinated Care managed care organizations (MCO), if applicable, must also be notified.

> See Chapter 10 for information about the signs of abuse and neglect.

Department of Social Services/Child Protective Services (CPS)

The Department of Social Services operates a CPS Hotline 24/7 to support local departments of Social Services by receiving reports of child abuse and neglect and referring them to the appropriate local department of social services. The CPS Hotline is staffed by trained Protective Services Hotline Specialists.

Department of Aging and Rehabilitative Services (DARS) & Adult Protective Services (APS)

> To report suspected abuse, neglect, or exploitation of adults 60 years of age or older and incapacitated adults age 18 or older, call the local department of Social Services or the 24-hour, toll-free APS hotline. If protective services are needed and accepted by the individual, local APS workers may arrange for a wide variety of health, housing, social and legal services to stop the mistreatment or prevent further mistreatment. To access a list of mandated reporters visit Code of Virginia § 63.2-1606

Reporting Abuse and Neglect: SC Responsibilities:

- Immediately notify the local Department of Social Services (DSS) if abuse, neglect and/or exploitation is suspected.
- Be aware of your agency's policy on reporting and (supervisor) notification, and follow CSB internal protocols regarding reporting abuse and neglect.
- Virginia Department of Social Services 24-hour, toll-free Adult Protective Services (APS) hotline at:

(888) 832-3858.

- Virginia Department of Social Services 24-hour, toll-free Child Protective Services (CPS) Hotline at (800) 552-7096.

Notify the DBHDS Offices of Human Rights/Licensing along with local DSS if there is suspicion of abuse, neglect or exploitation from a licensed DD Waiver provider. DBHDS Office of Human Rights Contacts.

Office of Licensing/Serious Incident Reporting

The Office of Licensing oversees the serious incident reporting side of the Computerized Human Rights Information System (CHRIS). A serious incident means any event or circumstance that causes or could cause harm to the health, safety, or well-being of a person using services. The term serious incident includes death and serious injury. SC should refer to agency policy and CHRIS roles for further guidance.

More information on serious incident reporting can be found in the licensing regulations on the VA Department of Behavioral Health and Developmental Services website.

Computerized Human Rights Information System (CHRIS): SC responsibilities

When a provider has identified and entered a serious injury, incident or death into CHRIS:

- Follow up with the provider in order to monitor the corrective action plan
- Communicate with the individual and/or the family/guardian in order to determine their ongoing satisfaction with the provider
- Document ongoing monitoring and follow up as it relates to the incident

Office of Human Rights Allegations/Abuse, Neglect and Exploitation

Office of Human Rights

The Department's Office of Human Rights, established in 1978, has as its basis, the Regulations to Assure the Rights of Individuals Receiving Services from Providers Licensed, Funded, or Operated by DBHDS. The Regulations outline the Department's responsibility for assuring the protection of the rights of individuals in facilities and programs operated funded and licensed by DBHDS.

Title 37.2-400, Code of Virginia (1950), as amended, and the Office of Human Rights assure that each individual has the right to:

- Retain his legal rights as provided by state and federal law;
- Receive prompt evaluation and treatment or training about which he is informed insofar as he is capable of understanding;
- Be treated with dignity as a human being and be free from abuse or neglect;
- Not be the subject of experimental or investigational research without his prior written and informed consent or that of his legally authorized representative;
- Be afforded an opportunity to have access to consultation with a private physician at his own expense and, in the case of hazardous treatment or irreversible surgical procedures, have, upon request, an

impartial review prior to implementation, except in case of emergency procedures required for the preservation of his health;

- Be treated under the least restrictive conditions consistent with his condition and not be subjected to unnecessary physical restraint and isolation;
- Be allowed to send and receive sealed letter mail;
- Have access to his medical and clinical treatment, training, or habilitation records and be assured of their confidentiality but, notwithstanding other provisions of law, this right shall be limited to access consistent with his condition and sound therapeutic treatment;
- Have the right to an impartial review of violations of the rights assured under this section and the right of access to legal counsel;
- Be afforded appropriate opportunities, consistent with the individual's capabilities and capacity, to participate in the development and implementation of his individualized services plan; and
- Be afforded the opportunity to have a person of his choice notified of his general condition, location, and transfer to another facility.

OHR Advocates represent individuals receiving services from providers of mental health, developmental disabilities, or substance abuse services in Virginia whose rights are alleged to have been violated and perform other duties for the purpose of preventing rights violations. Each state facility has at least one advocate assigned, with regional advocates located throughout the State who provide a similar function for community programs. Their duties include investigating complaints, examining conditions that impact individuals' human rights and monitoring compliance with the human rights regulations. At times, an individual served or anyone acting on their behalf may request to be linked with their regional Human Rights Advocate.

Local Human Rights Committees (LHRCs) are comprised of community volunteers who are broadly representative of various professional and consumer interests. LHRCs play a vital role in the Department's human rights program, serving as an external component of the human rights system. LHRCs review individuals' complaints not resolved at the program level; review and make recommendations concerning variances to the regulations; review program policies, procedures and practices and make recommendations for change; conduct investigations; and review restrictive programming.

Office of Human Rights: SC responsibilities

If a person requests to be linked with their OHR advocate the SC can:

- Provide the contact information for the advocate.
- Reach out to the advocate on behalf of the individual.
- Document the person's request and the action taken.
- Statewide listing of OHR staff.

Importance of Documentation

Documentation enhances the quality-of-service delivery. Referencing well documented records can assist SCs in remembering important aspects of a person's life. It provides information to colleagues and supervisors who must ensure continuity of care in the SC's absence.

Documentation ensures compliance with regulatory and funding requirements and standards. Records are audited by a variety of internal and external reviewers to ensure that guidelines are being followed and the quality-of-service delivery is optimal. Over a period of time, the SC may be able to see patterns or trends of effective and ineffective interventions and better assess other services that may be helpful.

An essential job responsibility of a SC is documentation which can include paperwork such as applications, service authorizations, documentation of choice, etc. Good documentation supports billing, data collection, and regulatory standards.

The DBHDS Office of Licensing licenses public and private providers of community services throughout Virginia. DBHDS licenses services that provide treatment, training, support and habilitation to people with mental illness, developmental disabilities or substance use disorders, to people using services under the Medicaid DD Waiver, and to those with brain injuries using services in residential facilities. The licensing requirements for documentation specific to support coordination can be found in Article 2 and Article 5 of the DBHDS licensure requirements.

Data Collection

The Department of Behavioral Health and Developmental Services (DBHDS) developed the Community Consumer Submission (CCS) 3 Extract Specifications in collaboration with the Data Management Committee of the Virginia Association of Community Services Boards. In partnership with Community Services Boards (CSBs) and the Behavioral Health Authorities (BHA), DBHDS uses CCS3 to comply with federal and state reporting requirements, including those in the federal substance abuse Treatment Episode Data Set (TEDS) and federal mental health and substance abuse block grants. The CCS3 is used to submit data to state funding sources, including the General Assembly and Department of Planning and Budget and to produce data about the performance of the public mental health, developmental disabilities, and substance use disorder services system.

State and federal policymakers and decision makers and many others use CCS3 data. It provides data for comparisons of and trends in the numbers and characteristics of people using direct and contracted mental health, developmental disabilities, and substance use disorder services from CSBs. The importance of correct coding is just as important as billing. SCs need to ensure that the correct codes have been utilized for a person using services and that CCS3 required data is kept up to date.
Information specific to CCS3 data collection.

Waiver Management System (WaMS)

The Waiver Management System (WaMS) is a web hosted data management system used to manage the Developmental Disabilities waivers. WaMS interfaces with the Virginia Medicaid Management Information System (VAMMIS), and establishes the assessment levels of care based on a person’s needs and automates the service authorization process. WaMS is customized to allow a single process for service authorizations for all three Waivers (Community Living, Family and Individual Supports, and Building Independence) supporting people with intellectual or developmental disabilities (ID/DD). WaMS interfaces with various Electronic Health Record (EHR) systems to transfer data into WaMS.

Support Coordinators use WaMS for a variety of documentation requirements including the PC ISP, VIDES survey, authorizations for Waiver services, and Waiver waiting list management Virginia Waiver Management System (WaMS) Portal.

Appeal Rights

The Code of Federal Regulations at 42 CFR §431, Subpart E, and the Virginia Administrative Code at 12VAC30-110-10 through 12VAC30-110-370, require that written notification be provided to individuals when DMAS or any of its contractors takes an action that affects the person's receipt of services. This includes, actions to deny a request for medical services, or an action to reduce or terminate coverage after eligibility has been determined.

An SC may need to assist a person to request an eligibility appeal in writing within 30 days of receipt of the notice about the action. The person may write a letter or complete an Appeal Request Form that would include:

- Name
- Medicaid ID number
- Phone number with area code, and
- a copy of the notice about the action
- Appeals are then mailed to:

Appeals Division
Department of Medical Assistance Services
600 E. Broad Street
Richmond, Virginia 23219

Telephone: (804) 371-8488
Fax: (804) 452-5454

For reduction or termination of coverage, if the request is made before the effective date of the action and the action is subject to appeal, the coverage may continue pending the outcome of the appeal. The person may, however, have to repay any services received during the continued coverage period if the agency's action is upheld.

After the person files an appeal, they will be notified of the date, time, and location of the scheduled hearing. Most hearings can be done by telephone. The Hearing Officer's decision is the final administrative decision rendered by the Department of Medical Assistance Services. However, if the person disagrees with the Hearing Officer's decision, they may appeal it at their local circuit court.

DMAS Appeal Rights page

DMAS Appeals Form

CHAPTER 3:
Who Does the Support Coordinator Serve?

Introduction

A Support Coordinator (SC) supports **people**. Each person served will have a unique story. This is one of the exciting things about the job of a Support Coordinator. SCs experience the privilege of meeting and interacting with people from all walks of life who honor the SC with their presence and stories. Each person supported will have some form of developmental disability. A diagnosis can inform the SC in general about a person but keep in mind that each person's disability affects them in unique ways. A disability does not define who a person is. It describes what condition(s) they have and is just one aspect of who they are. It is the SC's job to get to know the whole person along with gaining an understanding of how their disability affects them. Person centered values and practices described in Chapter 1 assist in getting to know a person.

Diagnostic & Statistical Manual (DSM-5)

Diagnostic labels are used for medical billing but most settings are moving away from using them in practice, instead focusing on the person, without labels. It is important to keep this in mind in reading the information about the prominent diagnoses of people who use Support Coordination services.

A major diagnostic and classification system used in the U.S. is the Diagnostic and Statistical Manual on Mental Disorders (DSM-5). The Diagnostic and Statistical Manual of Mental Disorders (DSM) is a classification of disorders with associated criteria designed to facilitate more reliable diagnoses of these disorders. (DSM-5 p. xii) The current DSM-5 is a revision that was published in 2013.

It is highly recommended that SCs have ready access to a DSM-5 for reference.

A Support Coordinator is not responsible for determining a diagnosis; however, it is important to know about them since they may:

- Determine eligibility for certain resources and services,
- Inform decisions about the kind of services and supports a person might need, and
- Help gain understanding of other diagnoses someone has in addition to a developmental disability, referred to as a 'dual diagnosis' or 'co-occurring disorder'.

Section II of the DSM-5 includes twenty-two Mental Disorder categories. A major category under this section is entitled Neurodevelopmental Disorders. Many of the people who use Support Coordination services will have a diagnosis from this section. **However, when determining eligibility for a DD Waiver, a person must meet the criteria of a developmental disability as outlined below, regardless of a diagnostic label.** More about determining eligibility may be found in Chapter 5 diagnostic eligibility review.

Neurodevelopmental Disorders at a glance

Developmental Disability

Virginia uses the definition set forth by the Developmental Disabilities Act and adopted by the Virginia General Assembly.

> Definition
>
> A developmental disability means a severe, chronic disability of an individual that:
>
> 1. is attributable to a mental or physical impairment, or a combination of mental and physical impairments, other than a sole diagnosis of mental illness;
> 2. is manifested before the individual reaches 22 years of age;
> 3. is likely to continue indefinitely;
> 4. results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency; and
> 5. reflects a need for a combination and sequence of special interdisciplinary or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.
>
> A child from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting three or more of the criteria described in clauses (i) through (v) if the individual, without services and supports, has a high probability of meeting those criteria later in life.

There are many conditions that qualify as a developmental disability including autism, brain injury (before age 22), cerebral palsy, other mental or neurological conditions (seizures) and intellectual disabilities which include Down syndrome, fetal alcohol spectrum disorder (FASD) and Fragile X syndrome. Other developmental disabilities may be strictly physical, such as blindness or deafness that began from birth or childhood.

Descriptions of the most prevalent developmental disabilities follow.

Intellectual Disability

The term intellectual disability, as defined by the American Association of Intellectual and Developmental Disabilities (AAIDD) and utilized by the state of Virginia, means a person has significant limitations in

intellectual functioning (reasoning, learning, problem solving) and in **adaptive behavior**, which covers a range of everyday social and practical skills. The disability originates before the age of 18.

> **Intellectual Functioning** refers to general mental capacity, such as learning, reasoning, problem solving, and so on. Generally, an IQ test score of around 70 or as high as 75 indicates a limitation in intellectual functioning.
>
> **Adaptive Behavior** is the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives.
>
> - **Conceptual skills** include language and literacy; money, time, and number concepts; and self-direction.
> - **Social skills** include interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.
> - **Practical skills** include activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

Additional Considerations

The AAIDD emphasizes that when determining whether a person has an intellectual disability, many things need to be taken into account including, but not limited to, the person's linguistic diversity, cultural differences, and their community environment.

The clinical characteristics of Intellectual Disabilities can be explored in this article.

Down Syndrome

Down syndrome is the leading cause of intellectual disability. Down syndrome is a common genetic variation that usually causes delays in physical, intellectual, and language development.

Some common physical traits that may or may not be present are:

- low muscle tone;
- small stature;
- an upward slant to the eyes; and
- a single deep crease across the center of the palm.

People with Down syndrome possess a wide range of mental ability and have their own unique personalities, capabilities and talents, just as we all do.

More information about Down syndrome may be found on the National Down Syndrome Congress website and the National Down Syndrome Society website.

Cerebral Palsy

According to the National Institutes of Health (NIH) cerebral palsy refers to a group of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination. Cerebral palsy (CP) is caused by damage to or abnormalities inside the developing brain that disrupt the brain's ability to control movement and maintain posture and balance. The term cerebral refers to the brain; palsy refers to the loss or impairment of motor function.

Cerebral palsy affects the motor area of the brain's outer layer (called the cerebral cortex), the part of the brain that directs muscle movement.

In some cases, the cerebral motor cortex hasn't developed normally during fetal growth. In others, the damage is a result of injury to the brain either before, during, or after birth. In either case, the damage is not repairable and the disabilities that result are permanent.

In addition to effects on the body, about 30 to 50 percent of children with cerebral palsy have some level of cognitive impairment.

For more information about CP, visit MyChild at Cerebral Palsy or the National Institute of Neurological Disorders and stroke website.

Autism Spectrum Disorder

According to the American Psychiatric Association, "autism spectrum disorder (ASD) is a complex developmental disorder that can cause problems with thinking, feeling, language and the ability to relate to others. It is a neurological disorder, which means it affects the functioning of the brain. The effects of autism and the severity of symptoms are different in each person."

People with autism spectrum disorder often have difficulty of varying degrees in social-interaction and communication and have a tendency to engage in repetitive behaviors.

Specific diagnostic criteria may be found in the DSM-5.

With a recent change in diagnostic criteria for autism spectrum disorder, there are a group of people who may have been diagnosed as having ASD but who would now be diagnosed with social (pragmatic) communication disorder (SCD). SCD encompasses problems with social interaction, social understanding and pragmatics. Pragmatics refers to using language in proper context.

The diagnostic criteria for SCD may be found in the DSM-5.

More information about autism spectrum disorder may be found at:

- American Psychiatry Association and Autism Speaks
- Autism at-a Glance series

Aquired Brain Injury

According to the Brain Injury Association of America (BIAA) and acquired brain injury is an “injury to the brain that is not hereditary, congenital, degenerative, or induced by birth trauma. Essentially, this type of brain injury is one that has occurred after birth. The injury results in a change to the brain’s neuronal activity, which affects the physical integrity, metabolic activity, or functional ability of nerve cells in the brain. An acquired brain injury is the umbrella term for all brain injuries.”

There are two types of acquired brain injury: traumatic and non-traumatic.

A traumatic brain injury (TBI) is caused by an external force and be defined as closed (or non-penetrating) or open (penetrating). Examples of a TBI include: falls, assaults, and motor vehicle accidents.

One of the most common forms of mild traumatic brain injury is concussion often caused by an injury during sports. Concussive symptoms may develop over days or even months later and initially may not show up on a diagnostic imaging test, such as a CAT scan.

Non-Traumatic Brain Injury causes damage to the brain by internal factors, such as a lack of oxygen, exposure to toxins, pressure from a tumor, etc. These can include injuries from stroke or heart attack, near-drowning, aneurysm, infectious disease that affects the brain (i.e., meningitis), and drug overdoses.

The symptoms of brain injury can be mistaken for mental illness or even substance misuse and often include behavioral challenges. Other effects of brain injury, such as short term memory problems and delayed processing, may be interpreted as lack of motivation or disinterest in services.

There are simple screening tools that can identify the potential for brain injury that do not depend on diagnosis but rather ask about experiences.

More information about brain injury may be found at Brain Injury Association of America:
https://www.biausa.org/brain-injury

To learn more about brain injury programs and resources in your area contact the Brain Injury Services Coordination Unit at DARS (804-662-7615 or https://www.vadars.org/cbs/biscis.htm) or the Brain Injury Association of Virginia (800-444-6433 or https://www.biav.net/)

Co-occurring Disorders

The term ‘dual diagnosis’ or ‘co-occurring disorder’ most often refers to someone who has both a substance-related/addictive disorder diagnosis along with a mental illness. However, it is also a term used when a person has a developmental disability along with a mental illness, behavioral difficulties or a substance related disorder. The types of psychiatric disorders persons with developmental disabilities experience are the same as those seen in the general population. However, the estimated prevalence of mental illness in the population of people with developmental disabilities is higher than in the general population.

Co-occurring disorders may also occur when an individuals has a mental health, substance related disorder, or developmental disability and another disability, such as a brain injury. In these situations, it is important to understand how the various conditions interact and the services that are needed for support.

Resource: NADD Resources

A Support Coordinator will serve people with co-occurring disorders. Using the DSM-5 as a reference can help the SC gain an understanding of these disorders. It is essential that the SC understands how their organization supports those who present with co-occurring disorders, and the services and supports that are available in the local community. It is also important for the Support Coordinator to be able to work in partnership with Case Managers or Coordinators from other providers when there is more than one diagnosis or disability. More than ever, collaboration across disability providers is crucial.

Communication

A Support Coordinator will meet people who may communicate in different ways. It may sometimes be assumed a person is not communicating because they do not use words to talk. The truth is that everyone communicates in some way. All people have the need to communicate to express choice, feelings, needs, likes and dislikes.

Communication is an exchange of ideas between people through a system of words, signs, or behaviors like gestures, body language and actions. Some people use words to communicate, however, we do not use words alone to get our ideas across. We also employ behaviors to communicate, such as facial expressions (smiles, frowns, eye blinking), pointing or other physical gestures, vocal sounds, eye contact, and body movements. A number of studies have been conducted to understand what percent of human communication is non-verbal. While the studies disagree on an exact percentage, all agree that most communication is nonverbal. In fact, nonverbal behavior is the most crucial aspect of communication.

Although some people may not use words to communicate, it does not mean that they cannot understand what others are saying. Intellectual or physical challenges may be the reason some people lack the ability to talk, but it does not mean that they do not understand what is happening around them. Some people have trouble using words to communicate because of physical (e.g., a hearing or motor impairment) or genetic factors related to their developmental disability. Sometimes medications affect verbal communication, and when medications are changed, the ability to communicate may reappear. Sometimes a brain injury can affect someone’s ability to communicate. A person’s ability to speak language can appear at any age; therefore we should not assume language stops developing at a certain age.

Types of Communication

Communication works two ways: expressing information (expressive skills) or receiving information (receptive skills). Expressive communication means talking or communicating in any form and receptive communication means understanding what someone is trying to tell you. Expressive communication refers to how people “share or express” information. Receptive communication refers to how people “receive” information, or “what information they take in.”

Some people cannot speak (expressive skills), but may understand what is being said to them (receptive skills). Some individuals can speak clearly and are easily understood (expressive skills), yet may not understand what is said to them (receptive skills).

Role of Behavior in Communication

A person's behaviors, even behaviors that we don't like, are attempts to communicate. If you cannot make yourself understood, or feel that no one is paying attention to your requests, you might become so frustrated that you use challenging behaviors to communicate. Knowing what you want and being unable to express it to others is an endless battle for people with limited or poor expressive skills. Think about how you might behave if others could not understand you.

Support Coordinator Role

A Support Coordinator needs to pay close attention to all forms of communication. People who communicate without using language usually develop a way to express their likes and dislikes, ask for things and show pleasure, displeasure, pain, or unhappiness through movements and behaviors. Sometimes, it can be hard to figure out what someone is trying to communicate. People who spend the most time around a person, such as family, friends and direct support professionals, are excellent resources when it comes to understanding how that person communicates. A communication chart (is useful in capturing and documenting unique ways someone communicates. This can be developed and shared among family, friends and the professionals in a person's life. This person-centered thinking tool can save someone from having to continually "teach" a new professional in their lives how they communicate.

To learn more about Communication Charts visit http://helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/communication-chart/

Assistive Devices in Communication

Some people use assistive devices to communicate. The terms assistive device or assistive technology can refer to any device that helps a person with hearing loss or a voice, speech, or language disorder to communicate. Assistive Devices for People with Hearing, Voice, Speech, or Language Disorders.

COMMUNICATION TIPS

1. Be an active listener and be patient when talking with a person with a disability. Wait a little longer for a response.
2. Do not insist on eye contact. Although someone may not be looking at you, they may be listening and understanding every word that you are saying. Do not assume that because someone is not looking at you, they do not know what's happening.
3. When you are in a group that includes the person you support, it is important that you not hold a conversation that ignores them, or speak about them as if they are not there.
4. Pay close attention to gestures, facial expressions, vocal sounds and movements used by the people you support. Be observant, watch for patterns and share what you have learned with your co-workers.
5. Talk to the person's parents, family members, friends, providers. Chances are someone

understands their communication efforts quite well.

6. Use a positive, age-appropriate, and respectful tone of voice.
7. Ask questions. This helps you gather information and shows you are interested in what the person is saying.
8. Do not say you understand the person if you do not. Apologize and remind them that you are trying to understand them and do not give up. If need be, ask a co-worker or someone who knows the person well for assistance.
9. Check for understanding of concepts you have shared. If you are not being understood, find other ways to explain the content of your message.

Role of family, Legal Guardians, Authorized Representatives, Powers of Attorney

When working with someone it should be presumed that they can tell everything about themselves, handle of their own affairs and make informed decisions about their goals and support needs to the same degree as someone who does not have a disability. In many instances, however, a person may want/need the input from others who know them well. This can come from family or friends on an informal basis and/or from a legal guardian, conservator or authorized representative on a formal basis. No matter who is included in the process of getting to know someone, it is important to always remember that the person who uses services is at the center of all information gathering and planning. Each of these roles is discussed below.

> "Person-centered planning celebrates, relies on, and finds its sober hope in people's interdependence. At its core, it is a vehicle for people to make worthwhile, and sometimes life changing, promises to one another."
>
> - John O'Brien

Family & Friends

A Support Coordinator will encounter a wide variety of family. It is important to gain an understanding of what "family" means to the person being supported and who they consider a part of their family. An SC should ask for loved ones' names and what they are called by the person. With permission from the focus person, SCs should treat family members and friends as partners in getting to know and planning with them. Including and getting to know family members will go a long way to build trust with someone and their family.

Tips for including families:

- Start with the assumption that families want to make a positive contribution and have the best interests of their family member at heart.
- Resist the temptation to characterize families as 'over-protective', 'not interested,' or 'barriers to. . .'
- Engage families by asking for their side of the story. It may end up providing important information about history and ways to support their loved one.
- Recognize that often family members know the person best. They care about the person in a way that is different from everyone else and they will probably be involved in supporting their loved one for the rest of their lives.
- Appreciate the huge commitment, energy, and knowledge a family brings to the table.

- Make it a priority, as long as a person agrees, to sustain, value, and strengthen family/friends connections.

Source: Person Centered Planning: Key Features and Approaches, Helen Sanderson

At times the goals of a person being supported are at odds with the goals a family member has for them. This can present a challenge for everyone involved. A person-centered thinking tool that may be helpful in these instances is Working/Not Working. This negotiation tool takes into account several perspectives and helps find common ground among the parties involved, while identifying what isn't going well in someone's life.

To find Person-Centered Thinking training visit http://www.personcenteredpractices.org/launch_pct.html

Legal Guardianship (LG) and Conservatorship

> *"Guardian"* means a person appointed by the court who is responsible for the personal affairs of an incapacitated person, including responsibility for making decisions regarding the person's support, care, health, safety, habilitation, education, therapeutic treatment, and, if not inconsistent with an order of involuntary admission, residence. (22VAC30-70-10)
>
> *"Conservator"* means a person appointed by the court who is responsible for managing the estate and financial affairs of an incapacitated person. (22VAC30-70-10)
>
> *"Incapacitated person"* means an adult who has been found by a court to be incapable of receiving and evaluating information effectively or responding to people, events, or environments to such an extent that the individual lacks the capacity to (i) meet the essential requirements for his health, care, safety, or therapeutic needs without the assistance or protection of a guardian or (ii) manage property or financial affairs or provide for his support or for the support of his legal dependents without the assistance or protection of a conservator. (22VAC30-70-10)

In Virginia, one's parent is considered to be a child's legal guardian (LG) until the child reaches the age of 18. Once a child reaches 18, a parent may petition the Circuit Court of Virginia to become a LG for their child with a developmental disability if they feel their loved one is incapable of making life decisions. A person's LG may also be someone unrelated to them. No matter whom the court appointed LG is, it is important as the SC to remember that:

- A legal guardian has to be appointed by the court
- The LG ultimately makes all decisions that are made regarding the care of the "incapacitated person." (This is a legal term and is only used here because it is such. It is not recommended that anyone should be referred by this term in everyday language.) This does not mean that the voice of the person themselves should not be heard. In fact, it is incumbent on the LG as part of their responsibilities to encourage participation in all decision making *and to listen to the individual and support them in their choices.*
- It is also the legal guardian's responsibility to file annual reports with the local Department of Social Services.

A conservator, also appointed by the Circuit Court of Virginia, handles the financial affairs for someone. The LG and conservator may or may not be the same person.

The responsibilities of the conservator are to take care of and preserve the assets and income of the "incapacitated person" and to file annual reports with the Commissioner of Accounts regarding money and property received and disbursed.

Source: VALegalAid

Authorized Representative (AR)

> *"Authorized representative"* means a person permitted by law or the human rights regulations to authorize the disclosure of information or to consent to treatment and services or participation in human research. The decision-making authority of an authorized representative recognized or designated under this chapter is limited to decisions pertaining to the designating provider. Legal guardians, attorneys-in-fact, or health care agents appointed pursuant to § 54.1-2983 of the Code of Virginia may have decision-making authority beyond such provider.

It is important to note that an AR acts on behalf of someone who lacks the capacity to make decisions about informed consent and participation in research. Lack of capacity is not something that can be decided by a Support Coordinator, a family member or even the person using Support Coordination services.

Determining Capacity

If the person who uses services is suspected of lacking the capacity to consent to treatment, services, or research or to authorize the disclosure of information, the Support Coordinator, must, according to the Human Rights Regulations (12VAC35-115-145. Determination of Capacity to Give Consent or Authorization), obtain an evaluation conducted by or under the supervision of a licensed professional who is not directly involved with the individual to determine whether they have capacity to consent or to authorize the disclosureof information.

See the specific requirements at VA Law Administrative Code.

Therefore, before an AR or LG is selected, it must be determined by the above means that the person served is not capable of making informed decisions about care or consent to participate in research. This is true even if the person supported requests an AR or LG to be designated.

Power of Attorney (POA)

> *"Power of Attorney"* is defined as a writing or other record that grants authority to an agent to act in the place of the principal, whether or not the term power of attorney is used.
>
> *"Principal"* means an individual who grants authority to an agent in a power of attorney. (§ 64.2-1600)

There are three types of Power of Attorney: General Power of Attorney, Limited Power of Attorney and Durable Power of Attorney. More about each of these is discussed in the two documents referenced below.

RESOURCE DOCUMENTS

The codes governing consent and substitute decision making are numerous and complex. Below is a document that gives additional information about the roles of legal guardians and authorized representatives in substitute decision making. Another document provided describes a study about Supported Decision Making.

Participation in Decision making
Virginia Supported Decision making

Futures Planning

Families of those served all wonder about their family member's life after they are gone and what it will be like when they are no longer able to be there for their loved one. Whether they seek out guidance about this topic or not, as a Support Coordinator, it is important to broach the topic and at least offer information to the family. The Arc's Center for Future Planning is a great place to start.

Resources: The Arc: Center for Future Planning or Wrightslaw: Special Needs Planning for the Future.

Five Wishes

Five Wishes brings a holistic approach to a living will by including a person's care and comfort choices. It provides a means to legally document one's choices for medical treatment, comfort, and care wishes.

CHAPTER 4:
Support Coordination Process: Preparation & Engagement

Preparation

Most people enter this field because they want to help others and Support Coordinators (SC) do just that. Like most career paths, preparation for this job began with a desire and was followed by education, a job search and obtaining a position. In order to become employed as a SC, there are knowledge, skills and abilities that are required by the Code of Virginia.

Qualifications of Support Coordinator Employees or Contractors

Once hired, there are many things the Support Coordinator can do to prepare to carry out their day to day tasks of providing supports and services to people in need. Above all else, it is imperative that the Support Coordinator keeps this at the forefront of all they do:

Remember that YOU make a Difference!

The suggestions presented below are not things that can be accomplished all at once or before the SC begins their job, but are ways to continue the preparation process throughout their tenure as a Support Coordinator.

Enhancing Knowledge, Skills, Abilities

Get to know resources:

- Stay abreast of the supports and services that are in the region including within one's own Community Services Board (CSB). This includes varied resources such as primary healthcare, behavioral healthcare, social services, employment services, disability services available in your community, various providers of DD Waiver services, and providers of related services (independent living, brain injury, aging, and caregiving services).
- Understand that people are resources. Get to know your co-workers. Find out the gifts each colleague has to offer. Develop relationships with professionals from other service provider agencies.

Become a life-long learner:

- Be open to new concepts and stay up on best practices in, among other things, treatment modalities and intervention techniques, person centered practices, independent living skills training, supportive counseling, family education, and crisis intervention.
- Attend ongoing training, webinars, and conferences.

- Read articles and books.
- Consider joining the Case Management Society of America.
- Use supervision to build skills and knowledge.
- Learn one's organization's particular Support Coordination processes and protocols.
- Memorizing all of the regulations, laws that affect the SC's job would be a daunting task. Know which laws regulate practice and know where to find them.
- Research conditions and disorders that people have that are unfamiliar.
- And above all, do not be afraid to **ASK QUESTIONS**!

Self-examination

- Build awareness of your own attitudes and biases which may affect the helping relationship. All humans hold biases. This can include biases about a number of characteristics as outlined in Chapter 1. These biases can include how one views a person with a disability.
- Identifying topics that are personally uncomfortable (i.e., sexuality and disability, death) and address them with a supervisor.
- Be willing to have an open mind to the shared experiences with those supported.

Understand those Supported

- Treat persons with disabilities as people rather than as their disability.
- Understand that working with someone with a developmental disability can involve many conversations about a particular topic or issue in order for true understanding to take place.
- Know that people with disabilities, including those with an intellectual disability, can speak for themselves. Be open to other communication styles (sign language, use of devices, etc.).
- Be mindful that the expressed negative experiences related to disability are real.
- Consider the effects that labels may have on those served.
- Being aware of how people with disabilities describe themselves.
- Respect the fact that people with disabilities know their own bodies and experiences.
- Recognize the abilities and strengths of persons with disabilities and incorporate them into the helping relationship.
- Recognize that most persons with disabilities do not live their life "focusing" on their disability and limitations.

Reference: Disability and the Counseling Relationship: What Counselors Need to Know. Stuntner (2012)

> "When you see, meet or think about a person with a disability, presume competence."
>
> Disability is Natural - Kathie Snow

Engagement

Engagement is a key component in providing effective Support Coordination services. It significantly increases the likelihood that someone will:

- Access needed services
- Remain connected to services
- Actively participate in services
- Achieve their outcomes

Engagement starts in the first meeting and continues until services are no longer needed. SCs start to build a relationship in the first meeting when they introduce themselves, explain their role in the relationship, build common ground and begin the assessment and planning process.

At times SCs have to reach out to those they support, along with their family members, to encourage them to participate in services. This is particularly important if someone has missed meetings or stopped participating in services. This might include making phone calls and/or visits to the home or places in the community to further develop the relationship and improve the person's engagement in services. People with developmental disabilities may need additional support to understand the consequences of missed meetings/appointments.

Engagement is enhanced by using the following strategies:

- Be respectful.
- Always address someone by the name they prefer.
- Be friendly and use eye contact when talking.
- Respect cultural norms.
- Be responsive to the person's requests.
- Be on time and follow-through with tasks you've agreed to.
- If someone does not want to talk and asks you to leave, remain polite, say goodbye, and let them know when you will return.
- Create an inviting environment.
- Make people feel comfortable and offer private spaces for talking.
- Be sure that meeting areas are comfortable for all people
- Use reflective listening.
- Use person-centered outcomes.
- Make sure all services are helping those supported reach their intended outcomes.
- Reinforce achievements along the way.
- When outcomes are not met have a conversation about why/barriers/whatever and determine the next steps to address.
- Be honest and knowledgeable; if you do not know the answer, then seek guidance first.
- Support informed choices.
  - Support the person to make choices about their lives.
  - Encourage looking at all options involved when making decisions.

  - Discuss ways to cope with lack of choices in certain situations.

Healthy Relationship Core Components

The core conditions of a helping relationship include empathy, respect and authenticity.

Empathy in the helping relationship has long been recognized as the most powerful determinant in someone progressing toward meeting their outcomes. Empathy is the ability to perceive and communicate accurately and with sensitivity, the feelings and experiences of another person. It means not just listening, but actively responding, with compassion, an attempt at understanding the experience of another person's world. Empathy goes beyond the facts, circumstances, and events of someone's life and conveys an understanding of how those circumstances uniquely affect them.

Respect in the helping relationship means having unconditional positive regard for the person seeking services. It means not evaluating or judging their thoughts, feelings, or behaviors as good or bad. Each person is accepted and valued for who they are.

Authenticity, **or genuineness**, in the helping relationship refers to a SC being themselves. It means that the inner experience and outward expression match. Being genuine shows people that the SC is trustworthy. This aids in building a positive relationship. It also serves as a model to encourage those seeking services to be their true selves.

Additional information about the core components of a helping relationship.

Positive Helping Relationship

Other ways the SC can create and maintain a positive helping relationship are by:

- Providing support and encouragement.
- Collaborating with the person seeking services and their supporters.
- Offering reassurance to those seeking services and their supporters.
- Identifying and refraining from expressing personal biases.
- Monitoring and managing personal reactions to the behavior of others.

CHAPTER 5:
Support Coordination: Assessment

How to screen, assess and conduct an intake

The Community Service Board (CSB)/Behavior Health Authority (BHA) is the single point of entry for a person seeking services. The CSB/BHA will schedule an intake appointment with the individual. The individual should be asked to bring required documentation for their intake appointment. Please ask your supervisor for more information, regarding your agencies intake process.

Case Management and Wait List Eligibility Flow chart at a glance

Eligibility for Support Coordination

Intellectual Disability Support Coordination (ID SC)

To be eligible for ID Support Coordination a person must have a diagnosis that confirms an intellectual disability (ID) (See Chapter 3). To be eligible for Developmental Disability Coordination a person must have a diagnosis that confirms a developmental disability (See Chapter 3).

Eligibility for Part C Service Coordination

The Infant & Toddler Connection of Virginia provides early intervention supports and services to infants and toddlers from birth through age two who are not developing as expected or who have a medical condition that can delay normal development. Early intervention supports and services focus on increasing a child's participation in family and community activities that are important to the family. In addition, supports and services focus on helping parents and other caregivers know how to find ways to help their child learn during everyday activities. These supports and services are available for all eligible children and their families regardless of the family's ability to pay.

Assessment and Eligibility for Developmental Disability (DD) Waivers

To be eligible for the Developmental Disability (DD) waiver a person must meet 3 criteria: diagnostic eligibility, functional eligibility and financial eligibility.

Diagnostic Eligibility

Diagnostic eligibility means that a person must have a disability that affects their ability to live and work independently. The Diagnostic Eligibility Review form can be used to ensure that collected documentation substantiates a diagnosis that confirms eligibility for SC services. A psychological or other evaluation of the individual that affirms that the individual meets the diagnostic criteria for developmental disability. For more information on the descriptions, symptoms and other criteria for diagnosing DD please see Chapter 3.

At-a Glance Diagnostic Eligibility Review Form

Functional Eligibility-Virginia Individual Developmental Disability Eligibility Survey (VIDES)

In order to meet functional eligibility requirements a person must need the same support as someone who is living in an Intermediate Care Facility for people with an intellectual/developmental disability (ICF-ID/D). This is determined by the Virginia Individual DD Eligibility Survey (VIDES). There are different versions of this assessment depending on the age of the person seeking services.

- Infant VIDES - under the age of 3
- Children VIDES - between the ages of 3 through 17
- Adult VIDES - 18 and older

Functional eligibility is established when someone meets the following established dependency level for the age appropriate VIDES.

- Infant VIDES - must meet 2 out of the 5 categories
- Children VIDES - must meet 2 out of 8 categories
- Adult VIDES - must meet 3 out of 8 categories

The VIDES should be completed in the online Waiver Management System (WaMS) and/or in an electronic health record. Only an SC who has been trained may administer the VIDES. Ask your supervisor for training.

Virginia Waiver Management System (WaMS)

Financial Eligibility

Financial eligibility means that the person seeking services meets the financial criteria to receive Medicaid. This is determined by the local Department of Social Services following the Medicaid eligibility rules used for people who need long term care.

An SC might determine that a person only meets one or two of the three eligibility criteria for adults to receive a DD Waiver. For example, a person with an ID diagnosis may not meet the minimum functioning criteria on the VIDES, rendering them ineligible to be placed on the DD Waiver wait list. In this instance, the SC would provide that person with appeal rights and work with them to determine alternative options and resources that are available in the community. Community resources are listed in Chapter 11.

*Note: A person can be on the waitlist and not meet financial eligibility criteria.

**Note: A person with a DD diagnosis not eligible for the waitlist is not eligible for TCM.
Information Gathered at Intake (Check with your Supervisor for agency specific requirements)

- Documentation to support diagnosis of developmental disability (to include ID if applicable)
- Consent to Exchange Information
- VIDES
- Human Rights Notification
- Documentation of Choice between Institution and Community based services
- Appeal Rights if placing on the waitlist
- Guardianship/Court Documents (if applicable)
- Voter Registration

Person Centered Individual Service Plan (PC ISP)

The PC ISP is comprised of 5 parts. The Part I Personal Profile, Part II Essential Information, Part III Shared Planning, Part IV Agreements, and Parts V Plan for Supports.
More detailed information can be found in Chapter 7.

Risk Assessment

The Risk Awareness Tool (RAT) was designed to increase awareness of the potential for a harmful event (i.e., bowel obstruction, fall with injury, etc.) to occur and to facilitate the process of taking action to reduce and prevent the risk. The RAT is completed annually.

The RAT is available online at https://dbhds.virginia.gov/case-management/dd-handbook

More detailed information about how an SC can assist in identifying health and safety risks can be found in Chapter 10.

Overview of Psychotropic Medication use at a glance

Human Rights Notification

During the initial assessment and annually thereafter, the SC must ensure that the person is aware of and has reviewed their human rights as described in the Regulations to Assure the Rights of Individuals Receiving Services from Providers Licensed, funded, or operated by the Department of Behavioral Health and Developmental Services (Human Rights Regulations). Support Coordination organizations are required to notify each individual and his authorized representative about these rights and how to file a complaint. The notice shall be in writing and in any other form most easily understood by the person using services. The notice shall provide the name and phone number of the human rights advocate and give a short description of the human rights advocate's role. The provider shall give this notice to and discuss it with the individual at the time services begin and every year thereafter. This notice shall be signed and filed in the person's services record.

More information regarding the Human Rights Regulations is located at https://dbhds.virginia.gov/quality-management/human-rights

Consents to Exchange Information

The SC is responsible for ensuring there is documentation of Consent to Exchange Information. During the initial assessment, as needed, and annually thereafter, the SC should ensure there are current consent forms for any collateral contacts or organizations to which the SC must communicate and/or release information pertaining to the person who uses SC services.

Choice of Waiver/Intermediate Care Facility

During the initial assessment and while screening for the DD Waiver wait list, the SC is responsible for ensuring documentation that indicates the person's desire for ID/DD community based care. This documentation ensures that the person has chosen community-based care over institutional services. The required documentation is known as the Documentation of Recipient Choice between Institutional Care or Home and Community-Based Services DMAS 459. It is completed during the initial screening for the DD Waiver program, and annually until the individual receives a DD Waiver. It should be maintained in the person's electronic health record.

Three Types of Developmental Disability Waivers

Virginia has three waivers for people with Developmental Disabilities. They are the Building Independence Waiver, the Family and Individual Supports Waiver and the Community Living Waiver. More detailed information about the three DD Waivers can be found in Chapter 6, Descriptions of Three DD waivers.

Wait List

In Virginia, the need for DD Waiver services is greater than the number of slots Virginia has to distribute. Therefore, everyone who meets eligibility criteria and requests DD Waiver services is added to a waitlist. Because DD waiver slots are distributed based on urgency of need and the number of waiver slots are made available based on Virginia's budget, there is no way to tell how long a person will remain on the waitlist. There is, however, a method for determining the urgency of need among those waiting for services.

Priority Needs Checklist

The Priority Needs Checklist must be completed and submitted in order to add a person to the wait list. The checklist identifies the reason a person falls into priority category (one, two or three) and is completed after the VIDES has been conducted. The Priority Needs Checklist is located and completed in WaMS under the Screening and Assessments section. Priority status is based on how much and how quickly someone is in need of help.

Key Points to Remember:

- The priority screening should be reviewed anytime there is a change in circumstance to assure it accurately reflects the support needs of the person seeking services.
- Only those who meet Priority One status can be assigned an available DD Waiver slot.
- Those assigned with a Priority two and Priority three status cannot be awarded a CL Waiver or IS waiver, unless every person in the state, who is assigned a Priority One status, already has a slot.
- For assignment of the BI waiver, a person assigned to Priority Two or Three may receive a BI slot if no one in a higher priority category is requesting and qualifies for assignment of the BI waiver.
- DD Waiver Wait List and Slot Assignment Process 3/11/21
- Virginia Waiver Management System (WaMS).

Right to Appeal

Once a person has been placed on the DD Waiver waitlist, the Support Coordinator must send a letter notifying them of appeal rights. Additionally, if a person on the waitlist has a change in priority status, they must also be issued appeal rights if moving to a lower priority.

Sample Right to Appeal Letter at a glance

Critical Needs Summary

The SC must also complete a Critical Needs Summary (CNS) in WaMS for those designated as having a Priority One status. The purpose of the CNS is to determine a person’s level of urgency. This is a required step in placing a person on the waitlist. In WaMS, the CNS option will appear under the Screening and Assessments section after the Priority Needs Checklist has been completed and submitted.

Key point to remember:

When placing someone on the Wait List, the Support Coordinator should ensure the family knows what services they would utilize if offered a waiver slot. The SC should regularly monitor the needs of people and discuss the services that are available under the DD Waiver. Remember that a person must be willing to use services within 30 days of being awarded a slot. The following guide is a helpful tool that can be given to the person requesting services and their family, when placed on the waiting list.

Additionally, once a year the Virginia Department of Behavioral Health and Developmental Services will send a letter to everyone on the DD Waiver wait list. Included in the letter will be instructions to review and sign the Documentation of Individual Choice Between Institutional Care or Home and Community-Based Services form and the Needed Services form.

- DD Waiver Services and Support Options at a glance
- DD Waiver Wait List and Slot Assignment Process 3/11/21
- Needed Services form at a glance
- Virginia Waiver Management System (WaMS)
- Documentation of Individual Choice Between Institutional Care or Home and Community-Based Services form at a glance
- Cover letter choice packet at a glance
- Cover letter Choice (Second reminder) at a glance

DD Waiver Slot Allocation General Information

DD Waiver slots become vacant when someone who was previously using DD Waiver services moves out of state, passes away, moves into a nursing facility or institution, no longer meets eligibility criteria, or chooses to no longer utilize the supports provided under the DD Waiver. Currently the number of slots is limited by the availability of funding for DD Waiver services. Funds are managed at the state level and the appropriation of additional funds to increase the number of slots is dependent upon General Assembly Action and DMAS approval. Each CSB is allotted a designated number of slots. If an assigned slot becomes vacant, the CSB must use it in a timely manner to provide DD Waiver services to another eligible individual. Slots are reassigned to people on the DD Waiver Waiting list by the Waiver Slot Assignment Committee (WSAC).

When the General Assembly allocates more than 40 slots for a given waiver, allocations will be made by providing one slot per board then a standard calculation (considering priority numbers per board) will be used to disseminate the remaining slots.

When the General Assembly allocates less than 40 slots for a given waiver, allocations will be made by combining all WSACs within a region. Each WSAC will be represented by the assigned facilitator and two additional representatives per committee.

Waiver Slot Assignment Committee (WSAC)

Waiver Slot Assignment Committees (WSAC) were developed to establish a means for determining the assignment of DD Waiver slots. The DD Waiver separates the eligibility determining entity (CSB SCs) from the entity who determines slot assignment. There is a WSAC in each locality/region of Virginia. The committee is comprised of people with diverse personal and professional backgrounds, as well as varied knowledge and expertise and no identified conflict of interest. For more information on qualifications for committee members and the responsibilities of the WSAC members please see the links below.

- WSAC Committee Introduction Letter

- WSAC Volunteer Application
- WSAC membership parameters

SCs play an important role in the assignment of a vacant DD Waiver slot. They must ensure that information in WaMS accurately reflects an individual's current needs. When a slot is available for assignment, the CSB contacts the Regional Support Specialist (RSS) and a WSAC meeting is convened. Please see the link below for more information on the SC's role in the operations of WSAC.

- WSAC Sessions Operations
- Slot Assignment Review Form
- WSAC review schedule
- WSACs name ID Key for email

At times, an SC may provide support to someone who needs immediate access to DD waiver services. There is a specific criterion that the person must meet in order for a SC to request access to an Emergency DD Waiver Slot. After exploring all possible alternative options a CSB can request access to an Emergency Waiver slot by submitting an Emergency Slot Request form.

Emergency Slot Request Form

At times, a SC may be providing support to someone who has experienced a change in their assessed needs requiring services available in a different waiver. The reserve slots enable a safety net with which someone can return to the original waiver, if needed. The SC must ensure that the person meets the criteria in order to request a Reserve DD Waiver slot. There is a chronological waitlist that DBHDS keeps for reserve slots funded by the General Assembly action.

Reserve Slot Request Form

Slot Assignment

Once a person is offered a DD Waiver slot, the SC is responsible for ensuring that the transition to Waiver services includes a thorough review of the assessment information and service options under the DD waiver. Those responsibilities are listed below.

Review/update Assessment and VIDES

Upon receipt of a DD Waiver slot, the SC will arrange a PC ISP development meeting to review and update all assessment information including the VIDES, Annual Risk Assessment, Essential Information (Part I) and the Personal Profile (Part II) to ensure accuracy.

Supports Intensity Scale (SIS®)

Supports Intensity Scale® (SIS®) is an assessment tool that identifies the practical supports required by individuals to live successfully in their communities. DBHDS shall use the SIS Children's Version™ (SIS-C™) for individuals five years through 15 years of age. DBHDS shall use the SIS Adult Version® (SIS-A®) for individuals 16 years of age and older.
Once awarded a DD Waiver slot, the SIS process begins. DBHDS routinely communicates to SIS vendors the order for SIS assessment completion. To move forward with scheduling, the SIS® vendors rely on SCs for needed information. The SC is responsible for identifying qualified respondents and dates the SC is available to participate in the SIS assessment.

For individuals who desire additional information about the SIS, The American Association on Intellectual and Developmental Disabilities (AAIDD), the copyright holder and sole owner of the Supports Intensity Scale AAIDD, has developed information for respondents who have questions. The aim is to explain what to expect during the interview, the SIS Family Friendly Report, and provide a SIS Respondent Handbook.

SIS-A Respondent Resources:	https://www.aaidd.org/sis/sis-a/sis-a-resources
SIS-C Respondent Resources:	https://www.aaidd.org/sis/sis-c/sis-c-resources

A completed SIS Family Friendly Report is made available to the board's SIS Point Person via SISOnline. The SC is responsible for sharing a copy of the SIS report with all providers and family members. Team members should use the SIS in conjunction with Virginia Supplemental Questions, the person-centered planning process, and other assessment information to develop an individual's ISP.

A mathematical algorithm uses the SIS scores to assign one of seven levels of need and one of four reimbursement tiers to each SIS assessment. The reimbursement tier sets the reimbursement rate for tiered DD waiver services (group home, sponsored residential, supported living, independent living supports, group day, community engagement, and group supported employment). This process provides greater reimbursement for smaller settings and for supporting those with more intensive needs. For more information on the SIS and the SC's role in the assessment, visit the links below.

- DBHDS SIS Scheduling Procedures
- SIS & the PCP Process in VA
- DBHDS VA SIS Standard Operating Procedures and Review Process
- DBHDS Standard Operating Procedures – Review Form
- DBHDS SIS Interview Respondent Info
- DBHDS VA SIS Reassessment Request Instructions
- DBHDS VA SIS Reassessment Request

Physical Exam

Upon receipt of a DD Waiver slot, the SC must obtain documentation of a recent physical examination, and documented in WaMS. The physical is required upon the initiation of a DD Waiver slot and updated when significant medical changes occur. The physical exam must have been completed no more than 12 months prior to the initiation of DD Waiver services.

DMAS 460 Virginia Informed Choice Form

When working with a person to determine their choice of providers, it is crucial for the SC to ensure the person is aware of all of their options. The person should be given information on all available DD Waiver services and SCs. A great tool that SCs can use is the DD Waiver Service and Support Options guide. Many CSBs keep an up to date list of local DD Waiver providers. Additionally, the SC could direct the person and their family to the DMAS provider search tool.

More information about how a SC can support a person through their personal choices and decision making can be found in Chapter 1.

Once providers have been chosen, the SC is required to complete the Virginia Informed Choice Form (DMAS 460). A signed copy must be retained in the person's electronic medical record. The DMAS 460 should be reviewed and completed with the person and/or substitute decision-maker at enrollment into the DD Waiver, updated annually (and include choice and name of SC), when there is a request for a change in waiver providers, when new services are requested, when the person wants to move to a new location and/or is dissatisfied with the current provider.

Virginia Informed Choice Form DMAS 460 at a glance

DMAS 225 Medicaid Long Term Care (LTC) Communication Form

The Department of Medical Assistance Services (DMAS) 225 is a form that serves as a method of communication between the SC and the Local Department of Social Services (LDSS). Prompt submission of this form is necessary to ensure that LDSS has correct and current information in order to determine patient pay responsibilities and ensure ongoing eligibility for Medicaid. For more detailed information about the SC's role as it pertains to patient pay see the link below. More information about patient pay can be found in Chapter 6 patient pay.

DMAS 225 Form at a glance

Waiver Slot Management

In addition to updating the assessments and obtaining documentation of informed choice, the SC is also responsible for enrolling the person into the newly assigned slot. When a slot has been assigned, the enrollment status of the person, in WaMS, is listed as Projected Enrollment Status. In order to initiate services, the person's status must be moved to Active status. This process is completed in WaMS. See the WaMS CSB User Guide Section 9 for more detailed instructions of how to move a person from Projected to Active status.

WaMS User Guide

Update Person Centered Individual Support Plan (PC ISP)

During the process of initiating DD Waiver services, the Person-Centered Individual Support Plan (PC ISP) should be reviewed and updated to reflect the person's choice of Waiver services and providers. This will include developing a new PC ISP or updating all five parts of the PC ISP. More detailed information about the PC ISP process and plan development can be located in Chapter 7.

Update WaMS Data

In order for DD Waiver services to be initiated the SC should ensure that any information in WaMS is accurate and up to date, including but not limited to:

- Individual's Profile (demographics, contact information, diagnosis etc.)
- Current/updated VIDES

Review, Add, Change Service Providers

Once a person with a new DD Waiver slot has chosen service providers, the SC is responsible for adding the chosen providers into WaMS prior to the authorization of services. Service providers cannot access an individual in WaMS until the CSB has added the provider(s). Attachments related to the PC ISP are then loaded into WaMS in preparation for the authorization process. More detailed instructions on how to add, remove and change service providers can be found in the WaMS CSB User Guide Section 11.

WaMS User Guide

Service Authorization (SA)

Service Authorization (SA) of DD Waiver services is completed in WaMS. The overall process for requesting SA is as follows:

- SC creates the SA in WaMS
- Provider adds services to SA
- SC Reviews/adds/changes as needed
- DBHDS staff approve, reject, deny or pend SA
- VAMMIS processes the SA

Note: SCs complete SAs for environmental mods, PERS and assistive technology as the provider, if the CSB/BHA is licensed to be a provider of these services and chooses to act as the provider. Please check with your supervisor for information on your particular CSB/BHA policy and procedures.

More detailed instructions of how to create SAs can be located in section 12 of the WaMS user guide.

WaMS User Guide

Retain a Slot

At times, the services for a person are delayed in starting or may be interrupted for some reason such as a hospitalization or difficulty in locating a service provider. In this instance, if services are interrupted or delayed for 30 days, the CSB must request that the DD Waiver slot be held for that person. The SC will then complete the Retain Slot Form located in WaMS. More detailed instructions on how to complete a Retain Slot Form can be found in section 10 of the WaMS CSB user guide.

WaMS User Guide

CHAPTER 6:
Developmental Disability Waiver & Services

Introduction

Virginia's Medicaid Waivers, which are referred to as Home and Community Based Services (HCBS), can cover supports a person needs to live independently in their home and in the community by combining federal and state money to provide long-term community-based supports for people who are elderly or have disabilities. In Virginia, the Commonwealth pays 50% and the federal government pays 50% of the cost of each waiver slot.

Waivers enable Virginia to offer a variety of standard medical and non-medical services without the requirement that someone live in an institution in order to use those same services. This handbook focuses onthe Developmental Disabilities Waivers. Medicaid Waivers expand Medicaid eligibility to those who may nototherwise qualify for services based on Medicaid financial requirements. Medicaid Waivers provide an opportunity for people to transition from institutions and large settings to community-based settings. As a result, Waivers allow people to be active in and live in their own community, connect with people without disabilities, and have greater independence and flexibility in their lives.

The state agency that administers the Developmental Disabilities (DD) Waivers in Virginia is the Department of Medical Assistance Services (DMAS). The Department of Behavioral Health and Developmental Services (DBHDS) manages day-to-day DD Waiver operations. Locally, DD Waiver services are coordinated by Community Services Boards/Behavioral Health Authorities (CSBs/BHAs). Support Coordination services are provided by Support Coordinators (SC) employed by CSBs/BHAs and private providers under contract with the CSBs/BHAs across the state.

The proportion of cost the state must pay for Medicaid Waivers services varies from state to state based on the per capita income and other factors related to revenue capacity.

Brief History of Developmental Disability Waivers

HCBS Waivers were established by the U.S. Congress in 1981 to slow the growth of Medicaid spending for nursing facility care and to address criticism of Medicaid's institutional bias. Congress was responding to the growth in institutional costs and to people with disabilities who preferred to live in their own homes with services such as personal care and community living supports. States were given the option to develop waiver programs as alternative services for people who are eligible for placement in an institution.

Virginia first applied for a waiver for those with an intellectual disability in 1990, with the federal Medicaid agency, known as the Center for Medicare and Medicaid Services (CMS). In early 1991, Virginia's waiver application was accepted by CMS and Virginia was able to begin offering services through what was then called the Mental Retardation Waiver. This waiver, which was renamed the Intellectual Disability (ID) Waiver, was amended several times over the next 20 years increasing the scope of community support services.

In 2000, the Individual and Family Developmental Disabilities Support Waiver was established to serve people with developmental disabilities not meeting the diagnostic criteria for the Intellectual Disability (ID) Waiver. In 2005, Virginia began the Day Support Waiver, which focused on day support and employment activities, allowing for additional people to be supported while waiting to use more comprehensive services offered through the ID Waiver.

Description of Developmental Disability Waivers

The DD Waivers provide supports and service options for successful living, learning, physical and behavioral health, employment, recreation, and community inclusion.

The DD Waivers are designed to serve individuals of any age with a developmental disability and children (birth through age 9) with a substantial developmental delay or specific congenital or acquired condition. There are three DD waivers, the Building Independence Waiver, the Family and Individual Supports Waiver and The Community Living Waiver.

- **The Building Independence Waiver** (BI) is for adults (18+) who are able to live independently in the community. Individuals own, lease, or control their own living arrangements and supports are complemented by non-waiver-funded rent subsidies. BI Services at a glance
- **The Family and Individual Supports Waiver** (FIS) is for individuals living with their families, friends, or in their own homes, or in supported living (for those over 18) including supports for those with some medical or behavioral needs. This is available to both children and adults. FIS Services at a glance
- **The Community Living Waiver** (CL) includes residential supports and a full array of medical, behavioral, and non-medical supports. This is available to adults and children and may include 24/7 supports for individuals with complex medical and/or behavioral support needs through licensed services. CL Services at a glance

Services in Waivers

The services available under the DD Waivers are listed below in alphabetical order. This listing provides the most current information available. Waiver services at a glance. The Department of Medical Assistance Services (DMAS is currently developing a manual for the Developmental Disabilities Waiver(s). The Compatible/Incompatible Combinations of services in the DD Waivers can be accessed here.

Assistive Technology

Service Description: Assistive technology is specialized medical equipment, supplies, devices, controls, and appliances, not available under the State Plan for Medical Assistance, which enable individuals to increase their abilities to perform activities of daily living (ADLs), or to perceive, control, or communicate with the environment in which they live, or which are necessary for life support, including the ancillary supplies and equipment necessary to the proper functioning of such technology.

In order to qualify for these services, the individual shall have a demonstrated need for equipment or modification for remedial or direct medical benefit primarily in the individual's home, vehicle, community activity setting, or day program to specifically improve the individual's personal functioning. AT shall be covered in the least expensive, most cost-effective manner. Equipment or supplies already covered by the State Plan may not be purchased under the waiver. The Support Coordinator is required to ascertain whether an item is covered through the State Plan before requesting it through the waiver.

Service Units and Service Limitations: Maximum $5000 per calendar year.

Benefits Planning Services

Service Description: Benefits planning is an individualized analysis and consultation service. This service assists recipients of a DD waiver and social security (SSI, SSDI, SSI/SSDI) to understand their personal benefits and explore their options regarding working, how to begin employment, and the impact employment will have on their state and federal benefits. This service includes education and analysis about current benefits' status and implementation and management of state and federal work incentives as appropriate. Benefits planning involves the development of written resource materials, which aid individuals and their families/legal representatives in understanding current and future rewards that come from working, thereby reducing uncertainties associated with losing necessary supports and benefits if they choose to work or stay on the job. This service facilitates individuals in making informed choices concerning the initiation of work. Furthermore, it provides information and education to individuals currently employed in making successful transition to financial independence.

Allowable activities include but are not limited to:

Pre-employment Benefits Review which may include:

a. Benefits Planning Query (BPQY from Social Security Administration (SSA)
b. Pre-employment Benefits Summary and Analysis (BS&A)
c. Employment Change Benefits Summary and Analysis

Work Incentives Development or Revisions (PASS, IRWE, BWE, IDA):

a. Plan to Achieve Self-Support (PASS)
b. Impairment Related Work Expenses (IRWE)
c. Blind Work Expenses (BWE)
d. Individual Development Accounts (IDA)
e. Student Earned Income Exclusion (SEIE)
f. Medicaid While Working
g. Medicaid Works (Virginia's Medicaid Buy-In Program)
h. Work Incentive Revisions

Resolution of SSA benefits issues:

a. Overpayments. Description
b. Subsidies
c. Work Activity Reports

Other Services:

a. ABLEnow
b. Financial Health Assessment

Service Units and Service Limitations: The annual year limit for Benefits Planning services is $3,000. No unspent funds from one plan year may be accumulated and carried over to subsequent plan years. Providers may not bill for waiver Benefits Planning services while the eligible individual has an open employment services case with the Department for Aging and Rehabilitative Services (DARS) and is eligible for the same service through DARS.

Center-Based Crisis Supports

Service Description: Center-based crisis supports provide long term crisis prevention and stabilization in a residential setting (Crisis Therapeutic Home) through utilization of assessments, close monitoring, and a therapeutic milieu. Services are provided through planned and emergency admissions. Planned admissions will be provided to individuals who are receiving ongoing crisis services and need temporary, therapeutic interventions outside of their home setting in order to maintain stability. Crisis stabilization admissions will be provided to individuals who are experiencing an identified behavioral health need and/or a behavioral challenge that is preventing them from experiencing stability within their home setting.

Allowable activities include but are not limited to:

1. psychiatric, neuropsychiatry, and psychological assessment, and other assessments and stabilization techniques;
2. medication management and monitoring;
3. behavior assessment and positive behavior support;
4. Intensive care coordination with other agencies and providers to assist the planning and delivery of services and supports to maintain community placement of the individual;
5. training of family members and other caregivers and service providers in positive behavioral supports to maintain the individual in the community; and
6. assisting with skill building as related to the behavior creating the crisis in areas such as self-care/ADLs, independent living skills, self-esteem building activities, appropriate self-expression, coping skills, and medication compliance.

Service Units and Service Limitations: 1 day unit up to 6 months in 30 day increments.

Community-Based Crisis Supports

Service Description: Community-based crisis supports are ongoing supports to individuals who may have a history of multiple psychiatric hospitalizations; frequent medication changes; enhanced staffing required due to mental health or behavioral concerns; and/or frequent setting changes. Supports are provided in the individual’s home and community setting. Crisis staff work directly with and assist the individual and their current support provider or family. Techniques and strategies are provided via coaching, teaching, modeling, role-playing, problem solving, or direct assistance. These services provide temporary intensive services and supports that avert emergency psychiatric hospitalization or institutional placement or prevent other out-of-home placement.

Allowable activities include but are not limited to:

1. psychiatric, neuropsychiatry, and psychological assessment, and other assessments and stabilization techniques;
2. medication management and monitoring;
3. behavior assessment and positive behavior support;
4. Intensive care coordination with other agencies and providers to assist the planning and delivery of services and supports to maintain community placement of the individual;
5. training of family members and other caregivers and service providers in positive behavioral supports to maintain the individual in the community; and
6. assisting with skill building as related to the behavior creating the crisis in areas such as self-care/ADLs, independent living skills, self-esteem building activities, appropriate self-expression, coping skills, and medication compliance.

Service Units and Service Limitations: 1 day unit up to 6 months in monthly increments.

Community Coaching

Service Description: Community coaching is a service designed to assist people in acquiring a specific skill or set of skills to address a particular barrier(s) preventing a person from participating in activities of Community Engagement.

Allowable activities include but not limited to: (determined with age sensitivity in mind and reflective of the person’s interests):
Skill building through participation in community activities and opportunities such as outlined in Community Engagement and encompassing:

- activities and events in the community, volunteering, etc.;
- community, educational or cultural activities and events;
- skill-building and support in building positive relationships;
- routine needs while in the community;
- supports with self-management, eating, and personal needs of the individual while in the community; and
- assuring safety.

Community coaching requires 1:1 support and must take place solely in community settings.

Service Units and Service Limitations 1 hour unit, up to 66 hours/week alone or in combination with other day options

Community Engagement

Service Description: Community engagement supports and fosters the ability of a person to acquire, retain, or improve skills necessary to build positive social behavior, interpersonal competence, greater independence, employability, and personal choice necessary to access typical activities and functions of community life such as those chosen by the general population. These may include community education or training, retirement, and volunteer activities.

Community engagement provides a wide variety of opportunities to facilitate and build relationships and natural supports in the community, while utilizing the community as a learning environment. These activities are conducted at naturally occurring times and in a variety of natural settings in which the individual actively interacts with persons without disabilities (other than those paid to support the individual). The activities enhance involvement with the community and facilitate the development of natural supports.

Allowable Activities:

Skill building, education, support and monitoring that assists with the acquisition and retention of skills in the following areas:

- activities and public events in the community
- community educational activities and events
- interests and activities that encourage meaningful use of leisure time (e.g., through participating in sports/exercise, a club or other social group, a class to learn a new hobby)
- unpaid work experiences (i.e., volunteer opportunities)
- Maintaining contact with family and friends.

Skill building and education in self-direction designed to enable achievement in one or more of the following outcomes particularly through community collaborations and social connections developed by the program (e.g., partnerships with community entities such as senior centers, arts councils, etc.).

Community engagement must be provided in the least restrictive and most integrated settings according to the individual’s person-centered plan and individual choice.

Service Units and Service Limitations 1 hour unit, up to 66 hours alone or in combination with other day options; no more than a ratio of 1:3 and must take place solely in the community.

Community Guide

Service Description: Community guide services include direct assistance to promote individuals’ self-determination through brokering community resources that lead to connection to and independent participation in integrated, independent housing or community activities so as to avoid isolation.

To read about details of the service description and requirements for Community Guide Services, go to the Medicaid memo dated September 4, 2018 found at https://www.virginiamedicaid.dmas.virginia.gov/ under Medicaid Memos and Bulletins to Providers.

Companion Services

Service Description: Companion services provide nonmedical care, socialization, or support to adults, ages 18 and older. This service is provided in an individual's home or at various locations in the community.

Allowable activities include, but are not limited to:

1. assistance or support with tasks such as meal preparation, laundry, and shopping;
2. assistance with light housekeeping tasks;
3. assistance with self-administration of medication;
4. assistance or support with community access and recreational activities; and
5. support to assure the safety of the individual.

Unlike personal assistance and residential support, companion services do not permit routine support with activities of daily living (such as toileting, bathing, dressing, grooming). The allowable activities center on “instrumental activities of daily living” (meal prep, shopping, community integration, etc.).

Companion services may be self-directed or agency-directed.

Service Units and Service Limitations: 1 hour unit consumer directed or agency directed up to 8 hours a day 18 and older.

Consumer Directed Services Facilitation

Service Description: Consumer directed services facilitation uses the support of a Services Facilitator who is a Medicaid-enrolled provider. A Services Facilitator can be enrolled as an independent Medicaid provider or as an employee of a Medicaid-enrolled Services Facilitation agency provider. The Services Facilitator supports eligible individuals, and sometimes their families, in properly using consumer-directed services (CD Services). CD services, empowers the person with a disability to have greater control over the services they use. They can assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services they use. CD services may be used in differing degrees and may span different types of services. They range from independently making all decisions and managing services directly, to using a representative to manage needed services. The underlying principle of CD services is that people with disabilities have the primary authority to make choices that work best for them, regardless of the nature or extent of their disability or the source of payment for services.

Service Units and Service Limitations: Per visit, initial and 6-month re-assessments. The online training is found on the Partnership for People with Disabilities website.

Crisis Support Services

Service Description: Crisis support services provide intensive supports by appropriately trained staff in the area of crisis prevention, crisis intervention, and crisis stabilization to a person who may experience an episodic behavioral or psychiatric crisis in the community which has the potential to jeopardize their current community living situation. This service shall be designed to stabilize a person and strengthen their current living situation so they can be supported in the community during and beyond the crisis period.

This service includes: crisis prevention, crisis intervention, crisis stabilization:

- **Crisis prevention services** provide ongoing assessment of medical, cognitive, and behavioral status as well as predictors of self-injurious, disruptive, or destructive behaviors, with the initiation of positive behavior supports to prevent occurrence of crisis situations. Crisis prevention also encompasses providing support to the family and the individual through facilitating team meetings, revising the behavior plan, etc. as they implement changes to the plan for support and address any residual concerns from the crisis situation. Staff will arrange to train and mentor staff or family members who will support the individual long term once the crisis has stabilized in order to minimize or prevent recurrence of the crisis. Crisis support staff will deliver such support in a way that maintains the individual's typical routine to the maximum extent possible.

- **Crisis intervention services** are used in the midst of the crisis to prevent the further escalation of the situation and to maintain the immediate personal safety of those involved. Crisis Intervention is a relatively short term service that provides a highly structured intervention that may include temporary changes to the person’s residence, removal of certain items from the setting, changes to the person’s daily routine and emergency referrals to other care providers. Those providing crisis intervention services must also be well-versed and fluent in verbal de-escalation techniques, including active listening, reflective listening, validation, and suggestions for immediate changes to the situation.

- **Crisis stabilization services** begin once the acuity of the situation has resolved and there is no longer an immediate threat to the health and safety of those involved. Crisis stabilization services are geared toward gaining a full understanding of all of the factors that precipitated the crisis and may have maintained it until trained staff from outside the immediate situation arrived. Crisis stabilization plans are developed by staff trained in basic behavioral treatment and crisis management. These plans may include modifications to the environment, interventions to enhance communication skills, or changes to the individual’s daily routine or structure. Staff developing these plans must be able to train support staff, family, and other significant persons in the individual’s life.

Service Units and Service Limitations: 1 day unit; limits vary by component.

Electronic Home-Based Services

Service Description: Electronic home-based services are goods and services based on Smart Home© technology. This includes purchases of electronic devices, software, services, and supplies not otherwise provided through the waiver or through the State Plan, that would allow access to technology that can be used in a person's residence to support greater independence and self-determination.

The items and services must:

- decrease the need for other Medicaid services (e.g., reliance on staff supports); and/or
- promote inclusion in the community; and/or
- increase the individual's safety in the home environment.

Allowable activities include:

- the assessment for determining appropriate equipment/devices, acquisition, training in the use of these goods and services;
- acquisition, training and use of goods and services; and
- ongoing maintenance and monitoring services to address an identified need in the individual's person-centered service plan (including improving and maintaining the individual's opportunities for full participation in the community.

Service Units and Service Limitations up to $5000 annually. Not available to individuals using residential supports that are reimbursed on a daily basis (e.g., group home, sponsored or supported living residential services).

Employment and Community Transportation

Service Description: Employment and community transportation is offered in order to enable individuals to gain access to waiver and other community services or events, activities and resources, inclusive of transportation to employment or volunteer sites, homes of family or friends, civic organizations or social clubs, public meetings or other civic activities, and spiritual activities or events as specified by the service plan and when no other means of access is available. This service is offered in addition to medical transportation required under 42 CFR §431.53 and transportation services under the State plan.

Environmental Modifications

Service Description: Environmental modifications are physical adaptations to the individual's primary home or primary vehicle that are necessary to ensure the health and welfare of the individual, or that enable the individual to function with greater independence. Such adaptations may include, but shall not necessarily be limited to, the installation of ramps and grab-bars, widening of doorways, modification of bathroom facilities, or installation of specialized electric and plumbing systems that are necessary to accommodate the medical equipment and supplies that are necessary for the individual. Modifications may be made to a primary automotive vehicle in which the individual is transported if it is owned by the individual, a family member with whom the individual lives or has consistent and ongoing contact, or a nonrelative who provides primary long-term support to the individual and is not a paid provider of services.

Service Units and Service Limitations: Up to $5000 calendar year.

Group Day Services

Service Description: Group day services include skill building or supports for the acquisition, retention, or improvement of self-help, socialization, community integration, employability and adaptive skills. They provide opportunities for peer interactions, community integration, and enhancement of social networks. Supports may be provided to ensure an individual's health and safety.

Skill building is a required component of this service unless the individual has a documented degenerative condition, in which case day support may focus on maintaining skills and functioning and preventing or slowing regression rather than acquiring new skills or improving existing skills.

Group Day Services should be coordinated with any physical, occupational, or speech/language therapies listed in the person-centered plan.

Allowable activities include but are not limited to skill development and support in order to:

- develop self, social, and environmental awareness skills;
- develop positive behavior, using community resources;
- volunteer and connect with others in the community;
- engage in career planning to include establishing a career goal; and
- develop skills required for paid employment in a community setting.

Service Units and Service Limitations: 1 hour unit up to 66 hours/week alone or in combination with other day options; Maximum 1:7 ratio.

Group Home Residential

Service Description: Group home residential consists of skill-building, routine supports, general sup- ports, and safety supports, provided primarily in a licensed or approved residence that enable an individual to acquire, retain, or improve the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings.

Group home residential services may be in the form of continuous (up to 24 hours per day) services performed by paid staff who shall be physically present in the home. These supports may be provided individually or simultaneously to more than one individual living in that home, depending on the required support. These supports are typically provided to an individual living (i) in a group home or (ii) in the home of an adult foster care provider.

This service includes the expectation of the presence of a skills development (formerly called training) component, along with the provision of supports, as needed.

Group home residential services shall be authorized for Medicaid reimbursement in the person-centered plan only when the individual requires these services and when such needs exceed the services included in the individual's room and board arrangements with the service provider.

Supports may be provided individually or simultaneously to more than one person living in the home, depending on the required support.
Service Units and Service Limitations: 1 day

Independent Living Support

Service Description: Independent living support is provided to adults (18 and older) and offers skill building and support to secure a self-sustaining, independent living situation in the community and/or may provide the support necessary to maintain those skills.

Individuals typically live alone or with roommates in their own homes or apartments.
These services are not provided in licensed homes. The supports are provided in a person's residence or in community settings. There must be a backup plan for times when Independent Living Supports cannot be provided as regularly scheduled.

Allowable activities include but are not limited to:

- skill-building and support to promote community inclusion;
- increasing social abilities and maintaining relationships;
- increasing or maintaining health, safety and fitness;
- improving decision-making and self-determination;
- promoting meaningful community involvement; and
- developing and supporting with daily needs.

Service Units and Service Limitations: 1 month unit up to 21 hours a week.

Individual and Family/Caregiver Training

Service Description: Family/caregiver training provides training and counseling services to families or caregivers of those who use waiver services. For purposes of this service, "family" is defined as the unpaid people who live with or provide care to an individual served on the waiver, and may include a parent, spouse, children, relatives, foster family, or in-laws. "Family" does not include people who are employed to care for the individual. All family/caregiver training must be included in the individual's written plan of care.

Allowable activities include:

- participation in educational opportunities designed to improve the family's or caregiver's ability to give care and support and
- participation in educational opportunities designed to enable the individual to gain a better understanding of his/her disability or increase his/her self-determination/self-advocacy abilities

The need for the training and the content of the training in order to assist family or caregivers with maintaining the individual at home must be documented in the plan of care. The training must be necessary in order to improve the family or caregiver's ability to give care and support.

Service Units and Service Limitations: 80 hours per plan of care year, billed hourly.

In-Home Support Services

Service Description: In-home support services are residential services that take place in someone's home, family home, or community settings and typically supplement the primary care provided by the individual, family or other unpaid caregiver. In-Home Support services are designed to ensure the health, safety and welfare of the individual.

Allowable services include:

- skill-building;
- routine supports; and
- safety supports, any of which enable an individual to acquire, retain, or improve the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings.

It is permissible to bill this service for up to three people at a time (e.g., siblings); however, the per person reimbursement rate decreases with each additional individual. A backup plan for times when In-Home Supports cannot be provided as regularly scheduled must be in place.

Service Units and Service Limitations: 1 hour; up to 3 people during a single time period.

Peer Mentor Supports

Service Description This service is delivered to waiver recipients by other individuals with developmental disabilities who are or have been service recipients, have shared experiences with the individual, and provide support and guidance to him/her. The service is designed to foster connections and relationships which build individual resilience. Peer Mentor Supports encourage individuals with developmental disabilities to share their successful strategies and experiences in navigating a broad range of community resources beyond those offered through the waiver with waiver participants so that the waiver participant is better able to advocate for and make a plan to achieve integrated opportunities and experiences in living, working, socializing, and staying healthy and safe in his/her own life, as well as to overcome personal barriers which are inhibiting him/her from being more independent. Peer mentoring is intended to assist with empowering the individual receiving the service. This service is delivered based on the support needs of the individual as outlined in his/her person-centered plan. This service is designed to be short-term and periodic in nature.

Allowable activities include:

- The administering agency facilitates peer to peer "matches" and follows up to assure the matched relationship meets the individual's expectations;
- The peer mentor has face to face contact with the individual to discuss his/her specific interests/desired outcomes related to realizing greater independence and the barriers to achieving them;
- The peer mentor explains community services and programs and suggests strategies to the individual to achieve his/her desired outcomes, particularly related to living more independently, engaging in paid employment and expanding social opportunities in order to reduce the need for supports from family members or paid staff;
- The peer mentor provides information from his/her experiences to help the individual in problem solving, decision making, developing supportive community relationships and exploring specific community resources that promote increased independence and community integration;
- The peer mentor assists the individual in developing a personal plan for accessing the identified integrated community activities, supports, services, and/or resources.

Service Units and Service Limitations:

1. Peer Mentor Supports is expected to be a short, periodically intermittent, intense service associated with a specific outcome. Peer Mentor Supports may be authorized for up to 6 consecutive months, and the cumulative total across that timeframe may be no more than 60 hours in a plan year.
2. The Peer Mentor shall not supplant, replace, or duplicate activities that are required to be provided by the support coordinator. Prior to accessing funding for this waiver service, all other available and appropriate funding sources shall be explored and exhausted.
3. Peer Mentors cannot mentor their own family members.
4. Peer Mentors shall be at least 21 years of age and may provide these supports only to individuals 16 years of age and older.
5. Individuals who receive supports through DD or other waivers may be peer mentors.

Personal Assistance

Service Description: Personal assistance services provide direct support with activities of daily living, instrumental activities of daily living, access to the community, monitoring of self-administered medications or other medical needs, monitoring of health status and physical condition, and work-related personal assistance. These services may be provided in home and community settings to maintain the health status and functional skills necessary to live in the community or participate in community activities.
Personal Assistance services may be consumer/self-directed (CD) or agency directed. If self-directed, a Services Facilitator is needed.

Each individual and family/caregiver, family, or caregiver shall have a back-up plan for needed supports in case the personal assistant does not report for work as expected or terminates employment without prior notice.

Allowable activities include:

1. support with activities of daily living (ADLs), such as: bathing or showering, using the toilet, routine personal hygiene skills, dressing, transferring, etc.;
2. support with monitoring health status and physical condition;
3. support with medication and other medical needs;
4. supporting the individual with preparation and eating of meals;
5. support with housekeeping activities, such as bed making, dusting, and vacuuming, laundry, grocery shopping, etc.;
6. support to assure the safety of the individual;
7. support needed by the individual to participate in social, recreational and community activities;
8. assistance with bowel/bladder programs, range of motion exercises, routine wound care that does not include sterile technique, and external catheter care when properly trained and supervised by an RN; and
9. accompanying the individual to appointments or meetings.

Personal Assistance is not available to those who:

- use group home residential services;
- use sponsored residential services;
- Use supported living residential services;
- live in Assisted Living Facilities; or
- have comparable services through another program.

Service Units and Service Limitations: Ratio 1:1; 1 hour unit; not compatible with congregate services.

Personal Emergency Response System

Service Description: Personal Emergency Response System (PERS) is an electronic device and monitoring service that enable certain individuals to secure help in an emergency. PERS services shall be limited to those individuals who live alone or are alone for significant parts of the day and who have no regular caregiver for extended periods of time and who would otherwise require extensive routine supervision.

PERS services may be authorized when there is no one else in the home with the individual who is competent or continuously available to call for help in an emergency. Medication monitoring units must be physician ordered and are not considered a stand-alone service. Individuals must be receiving PERS services and medication monitoring service simultaneously.

Service Units and Service Limitations: One month unit.

Private Duty Nursing

Service Description: Private Duty Nursing is individual and continuous care (in contrast to part-time or intermittent care) for individuals with a serious medical condition and/or complex health care need, certified by a physician as medically necessary to enable the individual to remain at home, rather than in a hospital, nursing facility or ICF-IID. Care is provided by a registered nurse (RN) or a licensed practical nurse (LPN) under the direct supervision of a registered nurse.

These services are provided at a person's place of residence or other community settings.

Allowable activities include, but are not limited to:

- monitoring of an individual's medical status and
- administering medications and other medical treatment

Service Units and Service Limitations: 15 minutes

Respite

Service Description: Respite services are specifically designed to provide temporary, substitute care for that which is normally provided by the family or other unpaid, primary caregiver. Services are provided on a short-term basis because of the emergency absence or need for routine or periodic relief of the primary caregiver.

Such services may be provided in home and community settings to maintain health status and functional skills necessary to live in the community or participate in community activities. When specified, such supportive services may include assistance with instrumental activities of daily living (IADLs).

Respite services may be consumer/self-directed or agency directed. If self-directed a Services Facilitator must be used.

Service Units and Service Limitations: 1 hour unit up to 480 hours per fiscal year, for unpaid primary caregivers only.

Shared Living

Service Description: Shared Living means an arrangement in which a roommate resides in the same household as the person who uses waiver services and provides an agreed-upon, limited amount of supports in exchange for Medicaid funding the portion of the total cost of rent, food, and utilities that can be reasonably attributed to the live-in roommate. For those 18+.

Shared Living supports include:

- fellowship such as conversation, games, crafts, accompanying the person on walks, errands, appointments and social and recreational activities;
- enhanced feelings of security which means necessary social and emotional support inside or outside of the residence; and
- personal care and routine daily living tasks that do not exceed 20% of companionship time such as meal preparation, light housework, assistance with and the physical taking of medications.

Service Units and Service Limitations: 1 month

Skilled Nursing

Service Description: Skilled nursing is defined as part-time or intermittent care that may be provided concurrently with other services due to the medical nature of the supports provided. These services shall be provided for individuals enrolled in the waiver having serious medical conditions and complex health care needs who do not meet home health criteria but who require specific skilled nursing services which cannot be provided by non-nursing personnel. Skilled nursing services may be provided in the individual's home or other community setting on a regularly scheduled or intermittent basis. It may include consultation, nurse delegation as appropriate, oversight of direct support staff as appropriate, and training for other providers.

Allowable activities include, but are not limited to:

- monitoring of an individual's medical status or
- administering medications and other medical treatment.

Training, consultation, nurse delegation or oversight of family members, staff, and other persons responsible for carrying out an individual's support plan for the purpose of monitoring the individual's medical status and ad- ministering medications and other medically- related procedures consistent with the Nurse Practice Act [18VAC90-20-10 et seq., by statutory authority of Chapter 30 of Title 54.1, Code of Virginia]

Service Units and Service Limitations: 15 minutes

Sponsored Residential

Service Description: Sponsored residential services take place in a licensed or DBHDS authorized sponsored residential home. These services shall consist of skill-building, routine supports, general supports, and safety supports, provided in a licensed or approved residence that enable a person to acquire, retain, or improve the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings.

Sponsored residential services shall be authorized for Medicaid reimbursement in the person-centered plan only when the individual requires these services and when such needs exceed the services included in the individual's room and board arrangements with the service provider.

Sponsored residential services to the individual in the form of continuous (up to 24 hours per day) services performed by the sponsor family. Sponsored residential support includes the expectation of the presence of a skills development (formerly called training) component, along with the provision of supports, as needed. These supports may be provided individually or simultaneously to up to two individuals living in that home, depending on the required support.

Service Units and Service Limitations: 1 day; support to no more than 2 individuals

Supported Employment

Service Description: Supported employment services are ongoing supports to those who need intensive ongoing support to obtain and maintain a job in competitive, customized employment, or self-employment (including home-based self-employment) for which an individual is compensated at or above the minimum wage, but not less than the customary wage and level of benefits paid by the employer for the same or similar work performed by individuals without disabilities.

- **Individual supported employment** is support usually provided one-on-one by a job coach in an integrated employment or self-employment situation. The outcome of this service is sustained paid employment at or above minimum wage in an integrated setting in the general workforce, in a job that meets personal and career goals.
- **Group supported employment** is defined as continuous support provided by staff in a regular business, industry and community settings to groups of two to eight people with disabilities and involves interactions with the public and with co-workers without disabilities. Examples include mobile crews and other business-based workgroups employing small groups of workers with disabilities in the community. Group supported employment must be provided in a manner that promotes integration into the workplace and interaction between people with and without disabilities in those workplaces.

Allowable activities include but are not limited to:

- job-related discovery or assessment;
- person-centered employment planning;
- negotiation with prospective employers;
- on-the-job training, evaluation and support;
- developing work-related skills; and
- coverage for transportation when necessary.
- Both the individual and group model must be in an integrated setting.

Service Units and Service Limitations: Individual model is 1:1; group model in groups with 8 or less; 1 hour up to 40 hours per week.

Supported Living

Service Description: Supported living takes place in an apartment setting operated by a DBHDS licensed provider. These services shall consist of skill-building, routine supports, general supports, and safety supports, that enable an individual to acquire, retain, or improve the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings.

Supported living residential services to the individual in the form of ‘round the clock availability of staff services performed by paid staff who have the ability to respond in a timely manner. These supports may be provided individually or simultaneously to more than one individual living in that home, depending on the required support.

Allowable activities include, but are not limited to:

- using community resources;
- personal care activities;
- developing friends and having positive relationships;
- building skills;
- daily activities in the home and community; and
- supporting to be healthy and safe.

Service Units and Service Limitations: 1 day; may be provided individually or simultaneously to more than one individual living in that home, depending on the required support.

Therapeutic Consultation

Service Description: Therapeutic consultation is designed to assist the individual's staff and/or the individual's family/caregiver, as appropriate, with assessments, plan design, and teaching for the purpose of assisting the individual enrolled in the waiver.

The specialty areas are:

- psychology
- occupational therapy
- speech and language pathology
- physical therapy
- behavioral consultation
- rehabilitation engineering
- therapeutic recreation

The need for any of these services shall be based on the PC ISP and shall be provided to those individuals for whom specialized consultation is clinically necessary and who have additional challenges restricting their abilities to function in the community. Therapeutic consultation services may be provided in individuals' homes and in appropriate community settings (such as licensed or approved homes or day support programs) as long as they are intended to advance individuals' desired outcomes as identified in their ISPs.

Service Units and Service Limitations: 1 hour

Required Training: DBHDS requires training that covers 2021 regulatory changes to therapeutic consultation behavioral services. TCBS Training is available on the COVLC. A CSB Staff Account registration guide is available to assist you with setting up an account if needed.

Transition Services

Service Description: Transition services are nonrecurring set-up expenses for those who are transitioning from an institution or licensed/certified provider-operated living arrangement to a living arrangement in a private residence where the person is directly responsible for their own living expenses.

Transition services are furnished only to the extent that they are reasonable and necessary as determined and clearly identified in the service plan, and the person is unable to meet such expenses or when the services cannot be obtained from another source. Transition services do not include monthly rental or mortgage expenses; food; regular utility charges; and/or household items that are intended for purely diversional/recreational purposes. This service does not include services or items that are covered under other waiver services such as environmental modifications or assistive technology.

Allowable costs include, but are not limited to:

- security deposits that are required to obtain a lease on an apartment or home;
- essential household furnishings required to occupy and use a community domicile, including furniture, window coverings, food preparation items, and bed and bath linens;
- set-up fees or deposits for utility or services access, including telephone, electricity, heating and water;
- services necessary for the individual's health, safety, and welfare such as pest eradication and one-time cleaning prior to occupancy;
- moving expenses;
- fees to obtain a copy of a birth certificate or an identification card or driver's license; and
- activities to assess need, arrange for, and procure needed resources.

Service Units and Service Limitations: Up to $5000 lifetime expended within 9 months of authorization.

Workplace Assistance

Service Description: Workplace Assistance services are supports provided to someone who has completed job development and completed or nearly completed job placement training but requires more than typical job coach services to maintain stabilization in his/her employment.
Workplace Assistance services are supplementary to the services rendered by the job coach; the job coach still provides professional oversight and job coaching intervention.

The provider provides on-site rehabilitative supports related to behavior, health, time management or other skills that otherwise would endanger the individual’s continued employment. The provider is able to support the person related to personal care needs as well; however, this cannot be the sole use of Workplace Assistance services.

- The activity must not be work skill training related which would normally be provided by a job coach.
- Services are delivered in their natural setting (where and when they are needed).
- Services must facilitate the maintenance of and inclusion in an employment situation.

Service Units and Service Limitations: Ratio is 1:1; 1 hour up to 40 hours per week.

Patient Pay

Patient Pay is defined as the amount of a member’s income that must be paid toward the cost of their Medicaid Long-term Care (LTC) Services. All members must have a patient pay calculated, but not all members have a contribution to pay to the LTC provider. Whether an amount is due to be paid depends upon the type and amount of a member’s income and allowable deductions.

The local Departments of Social Services (LDSS) are responsible for determining the amount of the patient pay contribution, if any, the member must make.

Commonwealth Coordinated Care Plus (CCC+) Waiver

A new Medicaid Managed Care Program includes the CCC Plus Waiver (CCC+). This Waiver combined what was formerly the Elderly and/or Disabled with Consumer Direction Waiver (EDCD) and the Assisted Technology (AT) Waiver. The CCC+ Waiver is administered by the Department of Medical Assistance Services (DMAS).

CCC+ is an integrated delivery model that includes medical services, behavioral health services and long term services and supports (LTSS).

People eligible are those who:

- meet the Nursing Facility (NF) level of care criteria that is determined using the Uniform Assessment Instrument (UAI) or are dependent upon technological support and require substantial, ongoing skilled nursing care;
- if under age 65, must also have a disability, (Note: mental illness solely does not qualify as a disability for this waiver);
- can have their health, safety, welfare safely maintained in the home when the nurse or personal care aide is not present;
- are determined to be at imminent risk of NF placement; and
- are determined that community- based care services under the waiver are the critical services that enable them remain at home rather than being placed in a NF.

Access

Representatives from the Virginia Department of Health and local Department of Social Services screen people to determine if they meet the qualifications to use this waiver. The screening team includes a Health Department nurse and a Social Services representative. They use a tool called the Uniform Assessment Instrument (UAI) to determine if someone meets the required functional dependencies, medical/nursing needs and are at risk of nursing home placement. Screenings may also take place when someone is hospitalized.

Working with Managed Care Organizations (MCOs) Care Coordinators

Virginia has six (6) Managed Care Organizations available for the CCC+ Waiver. CCC Plus: Health Plans are located on the DMAS website under the link entitled CCC Plus MCO Member Services Contact Information.

Each health care plan offered under the CCC+ Waiver, will provide a Care Coordinator to work with the participant and their doctors to create an individualized health care plan that includes among other things, individual outcomes and needed supports and services.

Each person using CCC+ will also take part in a Health Risk Assessment that entails a survey in which the participant is asked health questions. The questions are meant to better serve a person and the information gathered guides the Care Coordinator/MCO when providing health related education.

If someone uses the CCC+ Waiver, it is important that the Support Coordinator and Care Coordinator collaborate and coordinate supports and services. In addition, if a Support Coordinator believes someone would qualify for the CCC+ Waiver, they can assist them and their family with the application process.

Two approvals need to happen:

- a financial application for Adult Medicaid and Appendix D must be completed requesting Long Term Care and given to the local Department of Social Services and
- the UAI needs to be completed by the Department of Health (DOH). A social worker from DSS or nurse from the local DOH contact the applicant to schedule an appointment.

More information about the CCC+ Waiver.

Addiction and Recovery Treatment Services

Along with providing supports and services to people with Developmental and Intellectual Disabilities, Community Services Boards (CSBs) are the primary point of entry for services to treat substance use disorders. Support Coordinators need to familiarize themselves with how these services at their particular CSB operate and how referrals are made. It is vitally important to collaborate with the Substance Abuse Professional (SAP) when someone supported is seen by both the Support Coordinator and a (SAP).

For more information about the services provided in Virginia, visit VA DBHDS website.

Chapter 7:
Support Coordination Process: Plan Development and Implementation

Introduction

Support Coordination services aim to assist people with disabilities to utilize services while also becoming more independent and active in community life. Support Coordinators (SC) establish a positive and respectful relationship with people and their support networks. Support Coordination starts with a person-centered planning process based on the preferences and needs of the people using services.

Person-centered planning is a set of approaches designed to assist someone to plan their life and supports. **It** is a planning process that focuses on the needs and preferences of the person- not the system or service availability- and empowers and supports people in defining the direction for their own lives. Person centered planning promotes self-determination, community inclusion and independence.

The key areas for consideration in person centered planning are:

- What are the things that are important to and for a person?
- Who are the important people in a person's life?
- What are the person's strengths or gifts?
- What is important to the person now and in the future (their dreams)?
- What kinds of support does the person need to achieve the life they want?
- What do we need to do to support the person?

Foundational Beliefs in Person Centered Planning

Person centered planning (PCP) is a process-oriented approach to empowering people with disabilities. It focuses on the people and their needs by putting them in charge of defining the direction for their lives, not on the systems that may or may not be available to serve them. This ultimately leads to greater inclusion as valued members of both community and society. (Cornell University Person Centered Planning Education Site)

Foundational Beliefs in Person Centered Planning

- The person is at the focus of planning, and is the primary authority on his or her life direction.
- The purpose of person-centered planning is learning through shared action. People who engage in person centered planning may produce documentation of their meetings, but these are only footprints: **the path is made by people walking together.**

- Honest person-centered planning can only come from respect for the dignity and completeness of the person who owns the plan.
- Assisting people to define and pursue a desirable future tests one's clarity, commitment, and courage. Person centered planning engages powerful emotional and ethical issues and calls for sustained search for effective ways to deal with difficult barriers and conflicting demands.

"Those who treat PCP simply as a technique, and those who fail to provide for their own development and support will offer little benefit to the people they plan with."

Resource: John O'Brien and Herbert Lovett in **Finding a Way Toward Everyday Lives**

Supported Decision Making

Each person has a right to participate meaningfully in decisions regarding all aspects of services affecting him or her. This includes the right to consent or not consent to receive or participate in services, as well as the right to give or not give informed consent to the fullest extent possible, to receive or participate in treatment or services. It may be determined that some persons lack capacity to make informed decisions and they receive support from an authorized representative or legal guardian to make decisions. However, it is important to respect, protect, and help develop each person's ability to participate meaningfully in decisions regarding all aspects of services affecting him.

According to the National Guardianship Association's Standards of Practice and Ethical Principles, a guardian:

- Treats the person with dignity.
- Involves the person to the greatest extent possible in all decision making.
- Selects the option that places the least restrictions on the person's freedom and rights.
- Identifies and advocates for the person's goals, needs, and preferences.

It is important for SCs to support people in having a voice to express their preferences in services, providers, and plans, even when they have a substitute decision maker.

More information about supported decision making can be found in the Code of Virginia § 64.2-2000.

Participation in Decision Making and Consent At-A-Glance
Virginia Supported Decision Making Study 2015 At-A-Glance

Linking to Services

When a person receives a DD waiver slot, SCs need to have a conversation with them about the life they want to live, and the supports they might need to access in order to achieve their vision of a good life. In order to link people with appropriate resources, Support Coordinators must be knowledgeable about community resources that are available and should maintain regular contact with these resources in order to facilitate access and stay informed. Many CSBs create and maintain shared information files internally about available resources and service providers, including medical, housing, residential, vocational and employment, community and civic, and spiritual resources. The SC should check with their supervisor to obtain access to resource guides. DBHDS and DMAS also maintain online lists of providers throughout the state of Virginia for persons seeking services outside their region. SCs can also access the My Life My Community Website, the DBHDS Licensed Provider Location Search , or the DMAS provider search to look for service providers in their region.

Touring/Visiting Providers

When a person expresses interest in exploring new services, they may be ready to begin touring and visiting potential service providers, and the SC can play a key role by doing the following:

- Provide the person with information about all available services and qualified providers
- Provide contact information for reaching the organization
- Support the person in making the initial contact
- As necessary, contact the organization and accompany the person to the first meeting
- Make sure the person has the ability to access and utilize the service or resource
- Follow-up as needed to address any barriers to access and ensure a successful connection

Virginia Informed Choice form (DMAS-460)

When a person who uses a DD waiver is considering their options for services, the Support Coordinator must offer the person a choice of all services available to them, as well as a choice of all of the providers qualified and willing to provide the desired services, including SC services. After making sure that the person has been given the opportunity to make an informed choice, the SC must document this by reviewing and completing the Virginia Informed Choice Form DMAS-460. More information and a copy of the DMAS-460 can be found in Chapter 5.

An SC can ensure informed choice by doing the following:

- Identify the needed resource and the person’s preferences.
- Review of existing services and providers and person’s satisfaction
- Discuss all available options and choices (especially more integrated options such as independent living, employment, and community engagement)
- When the person chooses a service, explain to him or her, in a manner that they can understand, the nature of the chosen services, any alternative services that might be advantageous for them, and any accompanying risks or benefits of the proposed and alternative services.

Referrals

A referral is the process by which an SC helps a person apply to use a service or other resource. Once a person has made a choice of service providers, the SC will work with the person and the service provider to share pertinent documentation, such as assessment information, service preference, and any other documentation the provider may request. The SC needs to ensure that a signed consent to exchange information has been completed for each new service provider before providing information about the individual. More information about the Consent to Exchange Information process can be found in Chapter 5.

How to Utilize Assessment Information to Begin Plan Development

In Chapter 5 of this handbook, the elements of the assessment process were described. The assessment process includes the completion of the SIS®, the Risk Awareness Tool, the Crisis Risk Assessment Tool, and Parts I and IIof the PC ISP (Personal Profile and Essential Information). Other assessments that should be reviewed may include medical reports, school reports and psychological evaluations.

Effective assessments start with prioritizing the person's immediate concerns. It is important for an SC to pay attention to any immediate health and safety issues, risk, or risks of harm which can include:

- Medical conditions,
- At risk behavior,
- Restrictive protocols
- Special supervision requirements
- Other presenting needs, as expressed by the person and / or their team and as documented in the referral information; and
- The strengths and preferences of the person and resources that might be available

Conducting an assessment is really about eliciting someone's personal story. Since they are the expert on their life, most information gathered should be from them, and supporters who know the person best, which may include their substitute decision maker, if applicable. When using the assessment to begin plan development, it is important to:

- Listen to concerns without interrupting,
- Respect preferences, needs, and values,
- Use the assessment interview to begin to engage the person served,
- Help them identify strengths, resources, interests, and preferences,
- Include the family and other supporters with the person's permission,
- Determine together the person's current level of support needs, and
- Share the findings from the assessment with the person seeking services.

Once the assessment is complete, it is time to move on to the development of the plan.

Person Centered Planning and the Team Meeting

Once a person has chosen their initial services and supports, and again on at least an annual basis, the SC should arrange for a team meeting. The team consists of the person and the SC, at a minimum, and should also include people who are chosen by the person and who know the person best. The person with whom a plan is being developed is always at the center of the planning process. The degree of their involvement depends on their desire to participate, along with the extent to which they are able to participate. When planning with someone, it is best to bring together a group of people that want to contribute their time and talents because they know and care about the person and want to help them identify and achieve their goals. The Centers for Medicare and Medicaid Services (CMS) Home and Community Based Settings (HCBS) Regulations require that the person centered planning process:

- Is driven by the individual
- Includes people chosen by the individual
- Provides necessary information and support to the individual to ensure that the individual directs the process to the maximum extent possible
- Is timely and occurs at times/locations of convenience to the individual

Given these requirements, it is not acceptable for the SC or any provider to schedule meetings and inform the person, rather, SCs and providers should work with the person to support them to drive the scheduling process. This may require some flexibility on the part of the SCs and providers, but remember that meetings and plans belong to the people using services.

Annual person-centered planning meetings should ideally be held approximately six weeks prior to the due date of the Person Centered Individual Support Plan (PC ISP). This time frame allows for last minute rescheduling, as well as time for SCs and providers to write their parts of the plan, individuals (and substitute decision makers, as appropriate) to approve the written plans, and submission for service authorization approvals. Service authorization requests should be submitted 30 days prior to the requested start date.

SCs, providers, and people using services (and their chosen planning partner, as appropriate) should **draft** Part I Personal Profile and Part II Essential Information prior to the meeting. All team members contribute to its completion during the annual meeting with a draft or notes, or in writing before the meeting. The SC/CM combines the information that is then discussed and finalized at the annual meeting, with the final product shared by the support coordinator with all team members following the meeting. The information included in the sections of the Personal Profile is intended to be gathered through conversations with the person and those that know him or her best.

Person centered planning meetings can often feel like an overwhelming amount of work, and it is tempting to conduct a meeting as if checking everything off of a list. However, the only way to write a true person-centered plan is to have robust discussions and gather information about the person what is important to and for them, and their needs and preferences first.

Facilitating Conversation

In his Keynote presentation for the conference “The Promise of Opportunity”, March 2000, Michael Kendrick says that person centered work begins **within** each of those involved in the plan and includes:

- A commitment to know and seek to understand
- A conscious resolve to be of genuine service

- An openness to being guided by the person who owns the plan
- A willingness to struggle for difficult goals
- Flexibility, creativity, and openness to trying what might be possible
- A willingness to enhance the humanity and dignity of the person
- To look for the good in people and help to bring it out

Having conversations is the primary mechanism used in planning and often it is the SC who facilitates these conversations. It is important to know that gathering information from people who know a person well, professionally or personally, may be done outside of a meeting as long as it is done with informed consent. The documents listed in the box below offer guidance in gathering information for a plan and having conversations with a person with a disability, family members, and professionals.

As the facilitator, the SC must always keep the person as the focus of the discussion. Starting the meeting with asking team members what they like and admire about the person sets a positive tone for a meeting and allows everyone to be heard and recognized. It is also good to talk first about the good things that have happened in the person's life since the last meeting. Person centered planning does not mean we ignore the things that are of concern, but it should not be the initial or primary topic of discussion. While facilitating the meeting, talk directly with the person, rather than talking around and about the person. Ask questions, and gather information. When possible, empower the person to share their personal profile with the team and include information about things that are important to them, what is working and needs to stay the same, and what is not working and needs to change. Team members can offer ideas and suggestions, which can be added to the profile with agreement from the person. SCs should also facilitate a discussion about what the person's vision for a good life is. A person's dreams and goals should be a driving force in the plan.

The person and their team should also discuss things that are important for a person (issues of health and safety and being a valued member of one's community), as well as any risks that have been identified. After ensuring that the person's needs and preferences have been identified and that the team is supporting the person to find a balance between what is important to and for them, the discussion can address specific, measurable outcomes to include in the shared plan.

- A Checklist for Person Centered Information Gathering and ISP Development Mary Lou Bourne 2008.
- A Guide for Developing Preliminary Essential Lifestyle Plans: Conversation with the Person with Whom You are Planning Smull & ASA 2001 link at.
- A Guide for Developing Preliminary Essential Lifestyle Plans: Conversations with Family and Support Services Smull & ASA 2001.

Read about Myths and Misconceptions about Person Centered Planning pages 69 through 73.

Completing the Person-Centered Individual Support Plan (PC ISP) Trainings in the Virginia Learning Center

Prior to completing PC ISP documentation, all Support Coordinators should complete the PC ISP Training Modules in the Virginia Learning Center. Here, SCs will learn how to complete Virginia's PC ISP documentation.

Parts of Virginia’s PC ISP

Virginia’s Person-Centered ISP has 5 distinct parts:

Part I- Personal Profile

Facilitating a conversation with the person, with input from the rest of the team, is essential in order to gather the information necessary in Part I of the plan. The Personal Profile first outlines the person’s preferences for their meeting and how they prefer to be supported during the meeting, so it is essential that this conversation happens prior to planning the meeting.

The Personal Profile then discusses the person’s talents and contributions. When completing this section, the SC should have discussions with the person, those who know and love them, and providers about the things that people like and admire about the person, as well as the truly great things about them. SCs should consider how they talk about their own friends and family, and how they themselves would want to be introduced to others. Saying things like the person has a great sense of humor and loves sculpting clay is more genuine than listing “disability praise” such as “he ambulates independently.”

The next section in the Personal Profile discusses those things that are important to and for a person. Remember that “important to” things make the person happy, content and fulfilled, while “important for” are matters of health and safety and being a valued member of one’s community. These questions should be answered with regard to the seven life areas indicated in the plan: Employment, Integrated Community Involvement, Community Living, Safety and Security, Healthy Living, Social and Spirituality, and Citizenship and Advocacy.

The next section in the Personal Profile asks about the life that the person wants. The team should have a discussion with the person about the things that are working well for him or her, what things in his or her life should remain the same or be enhanced, and what needs to be changed. The person should be empowered to share their dreams and visions of what they want their good life to look at.

The final section of the Personal Profile asks the opposite question – what are the things that the person does not want in his or her life? The person should be supported to openly talk about things that are currently not working or making sense for them, or things that may not currently exist or be happening that they want to avoid having in their life.

All of the information in the Personal Profile should be used as a tool to determine what is important to a person in those areas of their life, and act as a bridge to developing the outcomes in Part III of the PC ISP, Shared Planning.

Part II - Essential Information

Part II of the PC ISP, or Essential Information, contains a wide variety of information necessary to provide supports to an individual. Part I provides information across the following areas:

- Representation
- Disability Determination
- Health Information
- Behavioral and Crisis Supports
- Medications
- Physical and Health Conditions
- Last Exam Dates
- Allergies
- Social, Developmental, Behavioral and Family History
- Communication, Assistive Technology, and Modifications
- Education
- Employment
- Future Plans
- Review of Most Integrated Settings

Part III- Shared Planning

Part III of the PC ISP, or Shared Planning, lists outcomes shared across providers, as necessary, in order to help the person on a path to the life they want. The Part III contains measurable outcomes listing an achievement the individual wants to pursue, the steps to get there, when it will be accomplished, and who is responsible for helping the person reach that achievement. The Shared Plan is completed at the annual meeting and holds the outcomes that lead to the life the person wants.

In the development of outcomes, it is important not to lose sight of the purpose of planning, discovering and setting in place plans to pursue the life the person wants. In shaping outcome statements, three considerations are recommended. Outcomes that are meaningful to the individual can support a person with achieving independence, integration, or an increased quality of life. As outcomes are developed, teams may benefit from asking if the outcome speaks to one of these three areas in determining if the outcome supports the person in a meaningful way. Tips for How to Write Measurable Outcomes can be found here.

It is important to remember that services themselves are not outcomes. "Mary goes to day support" is not an outcome. Think about the reasons someone goes to day support. Is it so they can develop their ability to communicate better, learn to use resources in their community or develop the abilities they need in everyday life? The service is just what supports a person to get what matters to them based on their own particular needs and interests.

While the SC is responsible for entering Parts I-IV into WaMS, outcomes and key steps to get there are developed at the planning meeting with input from the entire team. SCs do not "assign" outcomes, rather, the person, the SC, the provider and other planning partners discuss possible outcomes as they relate to the life that the person wants. Every team member is responsible for contributing to the discussion, and providers should be aware of the allowable activities and limitations of their service when agreeing to outcomes and key steps. **It is critical that outcomes and key steps are developed and agreed to by the team during the planning meeting.**

Part IV- Agreements

Part IV, or the Agreements section, is an evaluation of the annual planning meeting. It contains questions for the individual and team, as well as a signature page that is signed by all present at the meeting. Answer all questions and record any plans to address or resolve objections. This is also a place to record any inability to meet a request and the related team decision. All parties involved in planning will sign the Part IV, and it will serve as the signature page for the plan.

Part V- Plan for Support (PFS)

Part V, or the Plan for Supports (also called a PFS) is the provider-completed part of the ISP. All service providers must have a PFS that details the activities and instructions that are expected to lead toward the agreed upon outcomes. The PFS includes:

- Support Instructions that are constant in a person's life,
- The individual's Desired Outcomes from the Shared Planning (or a PFS revision),
- The Support Activities the provider has agreed to provide to support the person with each outcome,
- What will be seen or obtained to resolve each activity,
- Any additional Support Instructions needed to complete activities,
- A General Schedule of Supports, and
- When applicable, documentation of consent for any safety restrictions.

Avoid Jargon –

When writing plans, use ordinary language rather than professional jargon. The SC can use themselves as a yardstick. If they would not use the same words or descriptions for themselves, then they should not be used to describe someone else. Also remember, the language needs to be understood by the plan owner. Here are just a few examples:

- Instead of 'interpersonal skills,' use 'easy to get along with.'
- Instead of 'ambulates independently,' use 'walks on her own'—or consider whether this needs to be said at all.
- Instead of 'verbal cues or prompts,' use 'remind her by saying…'
- Instead of 'auditory monitoring distance,' use 'within earshot.'
- Instead of 'off-task behaviors,' use 'distractions.'
- Instead of 'on-task behaviors,' use 'pays attention.'

How to Write Measurable Outcomes

An individual's desired outcomes should be based on what is important to the person with regards to their personal preferences; however, outcomes need to also be written in a way that is measurable. For example, having more spending money might be important to a person but does not establish what this means in measurable terms. In additional to being observable, a few additional considerations can increase measurability of outcomes – the frequency of the outcome, the target date, and the steps that lead to the outcome.

The statement “John has more money” can be improved by considering how this could describe an achievement that John would find meaningful such as: “John saves 50 dollars per month so that he can go on vacation next year,” or “John earns at or above minimum wage for 12 months so that he has more shopping money.”

Each outcome in the PC ISP will have a target date noted as “by when,” which indicates that the outcome is expected to be accomplished or will be reassessed by that date. When desired, a frequency should be included in the wording of the outcome statement.

The next step for planners and teams to increase measurability is to describe the basic steps that lead to the outcome. These steps are shared across the planning team to contribute to achieving the outcome. To make an outcome measurable, we would ask, “What are the steps to get there?” These steps lay out the plan to pursue the achievement which is in line with action planning, a foundational person-centered practice. These steps should be logical and when considered together be expected to result in the time-bound achievement that is defined in the outcome.

For support teams who struggle with forming outcomes, there is a suggested formula, which has been noted as helpful and remains an option to support meaningful outcomes. This formula has been slightly modified as follows for the examples provided. The asterisk* is a reminder to include a frequency when desired:

> [Person’s name] [activity/event/important FOR]* so that/in order to [important TO achievement]
> (From DBHDS Person Centered ISP Guidance Document. For more detailed information and examples, see this document at the Virginia Regulatory Townhall website.

How to Evaluate and Document Implementation of a PC ISP

Once a PC ISP is complete, it is time to work towards completion of support activities in the SC’s Part V, complete documentation regarding progress towards completion of the outcomes, and review that documentation quarterly in a Person-Centered Review.

Throughout the plan year, the SC will work to complete tasks related to supporting a person reach their outcomes as specified in the SC’s Plan for Support.

Progress Notes

An SC is required to complete documentation regarding contacts with the person and significant others in regards to the individual, progress towards outcomes, and significant events, health and safety concerns, such as falls, hospitalizations, etc. This documentation, called progress notes, should include specific details, such as full date of contact, who reported the information to you (name, title, and/or relationship to the individual), place of contact, type of contact, summary of contact- including what the SC did in regards to linking, coordinating, and advocating, and should always have a signature/electronic signature and title of the SC completing the note, as well as date. Notes are required to be completed on the day the described supports were provided. Documentation that occurs after the date supports were provided shall be dated for the date the entry is recorded and the date of supports delivery shall be noted in the body of the note.

Person Centered Review (PCR)

Quarterly, the SC will complete a Person-Centered Review (PCR). This will include not only progress on outcomes for which the SC is responsible, but also a summary of the PCRs received from all service providers. Because of this, a provider has a 10-day grace period after the end of a quarter to complete their PCR and submit to the SC, then the SC has a 30-day grace period after the end of a quarter to complete their PCR.

The PCR includes information regarding outcome status, including a summary of significant events from the quarter in regards to each outcome. If a change to the plan is needed, this will be documented in the PCR. Additionally, the PCR will include information regarding safety risks identified over the quarter, changes desired or needed regarding supports and services, satisfaction with supports and services, as well as plans to address any dissatisfaction, whether or not all Medicaid Services were implemented and how to address if not, and finally, any other significant events not included elsewhere in the PCR.

Information in progress notes and PCRs, as well as in continued conversations throughout the year with the individual and team members, will be helpful in preparation for the upcoming plan year.

Regional Support Teams

At times, an SC may encounter difficulties or barriers to community supports for someone. In this instance, the Regional Support Team (RST) may offer assistance to the support team. RSTs can provide recommendations and assistance in resolving barriers in the most integrated community setting consistent with someone’s needs and informed choice. Submission of RST referrals are required to ensure informed choice and availability of services. Through referrals, the RST will monitor, track, and trend choice, integrated option availability, and challenges that require further system development. The SC shall notify the Community Resource Consultant (CRC) and RST in the following circumstances: a.) within five calendar days of an individual being presented with any of the following residential options: i. an intermediate care facility, ii. a nursing facility, iii. a training center, or iv. a group home with a licensed capacity of five beds or more; b.) if the CSB is having difficulty finding services within 30 calendar days after the individual's enrollment in the waiver; or c.) immediately when an individual is displaced from his or her residential placement for a second time. Recommendations from the RST are explored by the individual receiving services and their authorized representative/substitute decision maker with assistance of the Support Coordinator. The recommendations provide opportunities for the individual to choose more integrated options. For more information on RSTs please see the links provided below.

Regional Support Teams: SC Responsibilities

If a referral to RST has been recommended, the SC should:

- Use the RST Referral Flowchart to identify required steps and documentation requirements.
- Complete the RST Referral Form
- Document the referral to RST in the person's record

Additional information and RST forms are available online at https://dbhds.virginia.gov/developmental-services/provider-development under Regional Support Teams (RST)

Service Authorizations to Initiate Services

Once a person has made an informed decision about support options and chosen service providers, the SC can begin the process of authorizing services in WaMS. It the responsibility of the SC to ensure that the information in WaMS is up to date, add all service providers into WaMS, review all requests, modify the amount or type of services as needed, and submit the service authorization for processing. More detailed information about the initiation of Service Authorizations can be found in section 12 of the WaMS User Guide.

WaMS User Guide At-A-Glance
"When to Submit What" At-A-Glance
Service Authorization Guidance At-A-Glance

PC ISP Training Modules and Examples 2020

Self-Directed Training Modules are available in the following areas:

PC ISP 1 - PCT 2020
PC ISP 2 - Before the Meeting 2020
PC ISP 3 - Identifying Risk 2020
PC ISP 4 - The Planning Meeting 2020
PC ISP 5 - After the Meeting 2020

Corresponding Samples are also available:

Sample Part V Skilled Nursing
Sample Parts I - IV
Sample Parts V CE - Modified
Sample Part V Residential - Completed Use

CHAPTER 8:
Support Coordination Process:
Monitoring Billable Activities and Evaluation

Support Coordination Timelines

Support Coordinators (SC) are knowledgeable of Person Centered Thinking and Person Centered Planning as part of the Person Centered Individual Support Plan (PC ISP) planning process. What is working and what is not working for the individual, as well as what is Important To and Important For the person drives outcome development for the PC ISP (what needs to be maintained, what needs to change, what could be enhanced). Through monitoring and evaluations, the SC takes the lead in ensuring that the support team follows through with the commitment(s) they made to support the person to reach their desired outcomes. This is accomplished through a number of billable and non-billable activities. It is important to know the difference, to assure that not only has a review of progress, satisfaction, and risk been completed, but also that an allowable activity has occurred so that the community services board/behavioral health authority (CSB/BHA) can bill for the support provided. To accurately monitor and evaluate each person, there are tasks that will need to occur, depending on the person, every 30, 60, or 90 days. Each SC is responsible for keeping up with their timelines and billable activities.

Monthly Contact

SCs must conduct a minimum of one contact or activity every month, defined as:

- Direct or individual-related contacts, communication or activity with the individual, their family/caregiver (as appropriate), service provider, or other organization on behalf of the individual.

The assigned SC will provide Support Coordination services as frequently and timely as the person needs assistance. There must be at least one documented contact, activity or communication, as designated previously, and relevant to the Individual Support Plan, during any calendar month for which Support Coordination services are billed. **SCs are responsible for proactively identifying risks, implementing plans to mitigate previously known and newly identified risks, and resolving them in a timely manner.**

Billing will be submitted for an individual only for months in which direct or individual-related contact, activity, or communication occurs and the SC's records document the billed activity. Service providers will be required to refund payments made by Medicaid if they fail to maintain adequate documentation to support billed activities.

The allowable support activities can include but are not limited to:

- coordinating initial assessment and annual reassessment of the individual and planning services and supports, to include history-taking, gathering information from other sources, and the development of a PC ISP. This does not include performing medical or psychiatric assessments, but may include referral for such assessment;
- coordinating services and supports planning with other agencies and providers. This includes making appointments;
- linking the individual to services and supports specified in the PC ISP;
- assisting the individual directly for the purpose of locating, developing, or obtaining needed services and resources, including crisis supports;
- enhancing community integration by contacting other entities to arrange community access and involvement;
- making collateral contacts with the individual to promote implementation of the PC ISP and successful community adjustment;
- monitoring implementation of the PC ISP through regular contacts with service providers, as well as periodic site visits and home visits;
- instruction and counseling which guides the individual in problem-solving and decision-making and develops a supportive relationship that promotes implementation of the PC ISP. Counseling in this context is defined as problem-solving activities designed to enhance an individual’s ability to live in the community. Allowed instructional activities would include discussion about the benefits of the activities listed in the service plan;
- monitoring the quality of services;
- assisting the individual to secure services in an Intermediate Care Facility/Intellectual or Developmental Disability (ICF/IDD), if the individual or family member requests institutional placement; and
- monitoring the PC ISP to ensure it is implemented as written and making **TIMELY** referrals, service changes, and amendments to the PC ISP.

The activity of writing the PC ISP, Person-Centered Review, or progress note is not considered a billable case management activity. However, developing the PC ISP through a team meeting is a billable activity.

There will be no maximum service limits for Support Coordination services, except for individuals residing in institutions or medical facilities. For these individuals, reimbursement for Support Coordination will be limited to 90-days pre-discharge (immediately preceding discharge) from the institution into the community. While individuals may require re-entry to institutions or medical facilities for emergencies, discharge planning efforts should be significant to prevent readmission. For this reason, Support Coordination may be billed for only two 90-day pre-discharge periods in a 12-month period.

Ongoing Assessment/Monitoring

In Chapter 2, assessment was identified as the on-going process of gathering and summarizing information that guides the work between the SC and the person using services. The assessment not only helps to determine initial eligibility for services, but ongoing eligibility as well.

Is the PC ISP implemented appropriately?

Monitoring the PC ISP to determine if it is being implemented appropriately involves doing the following activities:

- actively observe the person and service providers to make sure the plan is being properly implemented, including the completion of the On-site Visit Tool (OSVT)
- make periodic site and home visits to assess the quality of care and satisfaction;
- make collateral contacts with people who support the individual (with whom there is a signed consent to exchange information) in various aspects (school, work, medical, friends, paid providers, family, etc.) to obtain a well-rounded picture of the person;
- consistently support the person in identifying concerns, and modify the plan to reflect concerns and how concerns are addressed as necessary; and
- follow-up with the individual and support partners to determine if instructions provided by qualified professionals are being followed.

Regularly meeting with people in their natural environment, for example their home, day program, or workplace will allow proper assessment of the plan implementation. Keep in mind that visiting someone at their worksite may be considered intrusive by the employer; therefore, the SC should identify alternative ways to monitor that service.

Status of Current Risks and Identifying New Risks

Ongoing assessment includes gathering information to make sure health and safety needs are met, as well as assessing the person's ability to independently care for themselves. Some risks, like pressure sores/decubitus ulcers, can be reduced by understanding who is at risk, recognizing early signs of skin breakdown, and implementing interventions early. While the SC may not be the one to see skin breakdown, they can promote risk mitigation by having knowledge of risk factors, who is at risk, and ensure that outcomes are added to the PC ISP to prevent skin breakdown for those at risk. SCs can inquire directly with support personnel; ask to see positioning logs, skin check logs, etc. to further monitor the risk. Prevention is the key! For more information, go to the Department of Behavioral Health and Developmental Services (DBHDS) Office of Integrated Health (OIH) website for the presentation on Promoting Skin Integrity as well as other health and safety information.

The SC should assess the status of current risks and evaluate the person's current living situation to determine if there are new risks. Some examples of areas the SC may want to pay close attention to are:

- the person's dietary and nutritional needs;
- the current living situation;

- activities of daily living (ADLs);
- risk of suicide or self-harm;
- social or environmental risk factors (family situation, lack of social support, or isolation); and
- change in mood or behavior.

The use of the On-site Visit tool (OSVT) will detail the assessment of current risks and new risks. The OSVT is to be completed monthly during months where visit occur, but no less than at one face-to-face visit each quarter. The OSVT helps ensure consistency for support coordinators across the state to confirm the ISP is implemented appropriately and the evaluation of a change in status is completed. Based on observation and report, this form helps guide the SC through a detailed checklist, allowing the findings and any actions that will be taken to be incorporated into the corresponding note. Information from this tool/notes should be included in the quarterly Person-Centered Review.

Access the OSVT online at https://dbhds.virginia.gov/case-management/dd-handbook

Documenting Newly Identified Needs, Preferences, Supports, and Services

When the SC is conducting monthly contacts, face-to-face visits and person-centered reviews, all newly identified needs, preferences, supports and services should be documented in the progress notes. The PC ISP is updated when changes occur or new information is discovered, and updates are communicated with others supporting the person. Having ongoing and regular contacts with the person, service providers and family members, as appropriate, can help the SC assess and identify needed modifications to the PC ISP.

Refer to the 2020 PC ISP Training Modules – Module 3 Identifying Risk for more information.

Face-to-Face Visits

SCs will meet with each individual face-to-face as dictated by the person’s needs. At face-to-face meetings, the SC will:

- Observe and assess for any previously unidentified risks, injuries, needs, or other changes in status.
- Assess the status of previously identified risks, injuries, or needs, or other change in status.
- Assess whether the person's service plan is being implemented appropriately and remains appropriate for the person.
- Assess whether supports and services are being implemented consistent with the person's strengths and preferences and in the most integrated setting appropriate to the person's needs.

"Face-to-face visit" means an in-person meeting between the Support Coordinator and the individual and family/caregiver, as appropriate, for the purpose of assessing the person's status and determining satisfaction with services, including the need for additional services and supports.

Documentation must clearly state that:

- The SC was in the presence of the person, the date, and the location of the visit.

- Unmet needs were identified, and a plan was developed to address the unmet need, if applicable.
- Satisfaction with services was assessed.
- Status of services was evaluated and adjusted as needed.
- A face-to-face visit occurred, and there are observations or assessments of:
    - a newly identified need
    - change in status or preference
    - an inadequately addressed risk or need
    - any issues with implementation of the PC ISP
- Then the SC will:
    - Review and update the PC ISP as needed
    - Develop a mitigation plan
    - Document the issue

If any issues are identified during the face-to-face assessment, the individual's status or preferences have changed, or the PC ISP is not being implemented as written or needs to change, document this in your face-to-face visit note (and OSVT as appropriate).

It may be appropriate to convene a team meeting to review and update the PC ISP. This can be done via conference calls with the individual/family and team members to update the PC ISP. If they receive DD Waiver services, it should also be determined if the individual needs assistance advocating for a change in their outcomes. If the CSB/BHA is the only service provider, determine whether the SC Part V should also be revised to address the identified needs. Determine if new services are needed, or if current services/support activities need to be modified. The SC should ensure that the PC ISP is amended when the reassessment indicates that revisions in the plan are needed to address and meet an individual's changed needs. The ISP should be updated as indicated and should include an implementation schedule for the changes needed to address the individual's needs.

Any identified issues should be addressed. Remember, the SC is responsible for coordination of services. The SC will make sure all team members are made aware of changes or newly identified risks that may affect their implementation of PC ISP outcomes.

Documenting and communicating information is very important. It also confirms and validates that support was provided and received. If an issue is identified, it must be documented along with its resolution and/or the attempts to address barriers.

The SC will conduct a face-to-face visit once every 90 days (with the allowance for a 10-day grace period) unless one of the following criteria are met.* The individual:

- receives services from providers having conditional or provisional licenses;
- has more intensive behavioral or medical needs as defined by the Supports Intensity Scale® ("SIS®") category representing the highest level of risk to individuals*;
- has an interruption of service greater than 30 days;
- encounters the crisis system for a serious crisis, or for multiple less serious crises within a three-month period;

- has transitioned from a Training Center within the previous 12 months; and
- resides in congregate settings of 5 or more individuals*.

*Some exceptions apply

If one of the above criteria are met, the individual meets criteria for Enhanced Case Management.

Enhanced Case Management

1. The Department of Justice (DOJ) Settlement Agreement (SA) identifies certain situations that history and evidence-based practice indicates increased risk for individuals with developmental disabilities. These high-risk situations require more vigilant oversight to ensure that the individual remains stable and/or does not further deteriorate. This oversight is called Enhanced Case Management (ECM). Refer to the Case Management Guidelines (Nov 2012) and the April Update (April 2014).

Review the individual's need for Enhanced Case Management criteria at each face to face AND update as changes occur. ECM criteria will be applied to anyone:

- with a DD Waiver; or
- receiving ID Targeted Case Management who is on the DD Waiver Waitlist and has a CCC+ Waiver; or
- receiving DD Targeted Case Management while on the DD Waiver Waitlist with a specialized service need

ECM criteria as identified by the SA:

- **Receive services from providers having conditional or provisional licenses**

SCs will fulfill the above face-to-face obligation for the entire time a provider is on a **conditional** (i.e. new) license or **provisional** (i.e., compliance violation) license. This level of face-to-face contact will continue for at least three months after a provider has been removed from **provisional** status.

The list of providers with either a conditional or provisional license can be found on the DBHDS website.

- **Have more intensive behavioral or medical needs as defined by the Supports Intensity Scale® ("SIS") category, representing the highest level of risk to individuals**

If any response to the Virginia SIS® Supplemental Risk Assessment (also referred to as the Annual Risk Assessment), regarding an individual is "yes," the SC will meet with the individual in order to initiate ECM.

> *Exception*: A "yes" response to SIS Supplemental Risk Assessment Item #5 (fall risk) does not automatically constitute a more intensive behavioral or medical need requiring more frequent Case Management visits. Only if the individual has experienced an injury as a result of a fall in the past 90 days will a "yes" to item #5 necessitate the more frequent Case Management visits. In this circumstance, the SC will meet with the individual in order to initiate ECM.

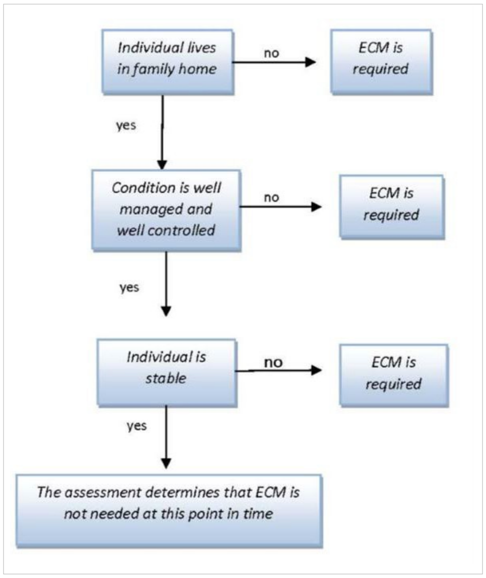
If any item in sections **1a** or **1b** of the SIS® Supplemental Risk Assessment are scored "2" (i.e., extensive support needed), the individual will receive the more frequent face-to-face SC visits while those responses remain scored "2." The exceptions are a score of "2" on:

a) **1a #14** (lifting and/or transferring) unless an adverse event has occurred in the context of lifting or transferring in the past 90 days, in which case this level of contact will continue until the individual is stabilized, or
b) **1a #15** (therapy services).

Exception: For individuals who live in their family home and have more intensive behavioral or medical needs as defined by the SIS®, enhanced visits are not be required if their medical/behavioral condition is well-controlled and well managed and the individual is stable.

Decision Tree:

Starting point: Has at least one "yes" on the SIS® Supplemental Risk Assessment or a score of 2 or higher in 1a or 1b on the SIS Exceptional Medical and Behavioral Supports Needs.



As with Support Coordination, when completing a face-to-face ECM visit, there is a 10-day grace period.

[ECM Flowchart at a glance]

[ECM Guidelines Update April 2014 at a glance]

[ECM Optional Worksheet 2021]

[ECM Q & A 2021]

If it is determined that ECM is not needed at this point in time, SCs would be required on at least a quarterly basis to assess whether the family member/caregiver is following medical orders and/or behavior treatment plan recommendations. If the individual were to encounter any of these triggers, then ECM would be provided and continue until the person was stable, as defined below.

Stable is defined as:

Living in the same home for at least one year, without significant events that threaten serious injury or death such as founded abuse and/or neglect; bowel obstruction; aspiration pneumonia; falls resulting in serious injury; or encounters with the crisis system for a serious crisis or for multiple less serious crises within a three-month period.

- **Have an interruption in service greater than 30 days**

This means an interruption of any of the following waiver services:

- congregate residential (including sponsored residential);
- in-home residential;
- personal assistance (agency-directed or consumer-directed);
- supported employment;
- day support (including Community Coaching and Community Engagement); and
- ongoing therapeutic services.

The SC will meet with the person face-to-face at least every thirty (30) days, with at least one such visit every two months in the individual's residence, until either services have resumed or the individual has lost his/her slot.

An extended vacation, when the person and his or her family are out of town, does not constitute an interruption of service. Extended vacations must be clearly documented in the individual's record.

- **Encounter the crisis system for a serious crisis or for multiple less serious crises within a three-month period**

Crisis includes both behavioral/psychiatric and medical events.

> *"Serious crisis"* means admission to a Crisis Stabilization Unit (CSU), REACH, hospital (other than for routine or elective procedures), hospital followed by admission to a Long-Term Rehab facility, an out of home placement due to CPS or APS involvement, or incarceration.
>
> *"Multiple less serious crises"* means assessment for admission to a CSU, REACH, hospital (other than for routine or elective procedures), hospital followed by admission to a Long-Term Rehab facility, an out of home placement due to CPS or APS involvement, or incarceration three or more times in a twelve (12) month period.

The SC will meet face-to-face with the person at least every thirty (30) days, with at least one such visit every two months in the individual's residence, for six months after discharge or until stabilized, if not stabilized within six months.

"Stabilized" means that the individual has returned to his/her pre-crisis --i.e., typical or as near to typical as possible following the crisis – mode of functioning.

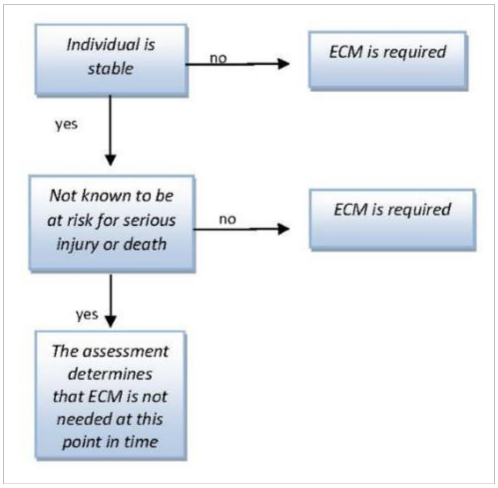
- **Have transitioned from a Training Center (TC) within the previous 12 months.**

The SC will meet face-to-face with the person at least every thirty (30) days, with at least one such visit every two months in the individual's residence, for twelve (12) months post TC discharge.

- **Reside in congregate settings of 5 or more**

If individuals qualify for enhanced visits solely because they live in a congregate setting of 5 or more individuals, and are known not to be at risk for serious injury and/or death, then enhanced visits may not be required. Prior to a person being designated as not needing ECM visits, the person has to be stable (defined above) for at least one year. The SC will meet face-to-face with the person at least every thirty (30) days, with at least one such visit every two months in the individual's residence.

Starting Point for Assessment – Lives in a congregate setting of 5 or more individuals



Ways to Minimize Risks

A SC can help to minimize the risks by:

- identifying strengths (competencies, accomplishments, resources, support network);
- understanding the capability of service providers to meet the person's needs and preferences;
- reviewing assessments completing by qualified professionals;
- making referrals as appropriate to help mitigate newly identified risks or potential risks;
- following-up with the individual and any support partners to assure plan to mitigate risk are being developed and followed;
- link with assistive technology (AT) and environmental modifications (EM) as appropriate;
- being knowledgeable of community opportunities and resources;

- helping people make informed decisions; and
- ongoing collaboration with the person, family members, and service providers.

Person Centered Review (PCR)

The SC will conduct a Person-Centered Review (PCR) once every quarter, based on the start date of the ISP.

These reviews will evaluate the continued relevance of the ISP and the person's progress toward meeting their outcomes. The SC is reviewing not only the provider's Part V (if the individual has a DD Waiver), but is also reviewing their own Part V. The SC will update the PC ISP, if indicated, and implement any updates made.

These reviews will document evidence of progression toward or achievement of a specific targeted activity for each outcome.

For outcomes that were not accomplished by the identified target date, the SC and any appropriate team members will meet to review the reasons for lack of progress and provide the individual an opportunity to make an informed choice of how to proceed.

The Person Centered Review form is available online at https://dbhds.virginia.gov/developmental-services/provider-development under Training Resources.

Ways to address changes in needs, preferences, supports, and services

SCs can address changes in needs and preferences by:

- educating service providers about the person and their plan;
- updating team members about significant events or changes that impact the person;
- collaborating to achieve outcomes;
- emphasizing opportunities for increased community integration, employment, and independent living;
- providing information about the process and options for change;
- assisting in problem solving; and
- not prejudging who can and cannot achieve success.

Problem Solving and Addressing Barriers

There are many situations in which problems can arise and SCs can help bring resolution and overcome barriers. This can be done by:

- clarifying the problem;
- listing possible options;
- teaching and modeling problem solving for people with disabilities and supporters;
- assessing situations;
- defining barriers;

- listing solutions to barriers;
- identifying pros and cons; and
- facilitating meetings to work together with the person/support team to accomplish any of the points listed here.

Sometimes the problems are about conflicts between people. In those cases, SCs can manage the conflict by doing the following:

- anticipate and help resolve emerging tensions between people;
- remain calm and constructive when confronted with people who are angry, critical, or threatening (seeking assistance if needed); and
- mediate conflicts among people with disabilities, family members, and other care providers.

PC ISP Updates

When the SC identifies the need to update or modify a PC ISP, they must:

- review current outcomes and make changes to the PC ISP to reflect any modifications. This includes updating the Case Management Plan for Supports;
- review modified provider service plans in WaMS (for DD Waiver only);
- submit the modified provider service plan (Part V Plan for Supports) for service authorization if there is a request for a change in hours or service providers;
    - For SC responsibilities related to modifications in Service Authorizations (SA) use the WaMS CSB User guide section 12;
- update the PC ISP Part I Personal Profile, Part II Essential Information, and Part III Shared plan (remember the SC can only update the Part III if they are adding or removing a provider from the outcomes. Any other changes to the Part III come from the provider,) as needed;
- obtain consent to exchange information forms for any new service providers; and
- update the Informed Choice DMAS 460.

Chapter 9:
Support Coordination Process: Transitions of Support

Life Transitions

Charting the Lifecourse is a person-centered framework that was “created to help individuals and families of all abilities and all ages develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live.” This framework includes key principles that center on a different way of thinking about how people can be supported to move toward their definition of a “good life.” One of the principles is “Trajectory of Life Experiences Across the Lifespan,“ which recognizes that each one of us has our own unique life trajectory shaped by our beliefs, cultures, and experiences. Learn more about the framework including the Life Stages and tools to assist in discussing and planning for a desired future by visiting the links below (Charting the Lifecourse Nexus © 2020 Curators of the University of Missouri | UMKC IHD, UCEDD)

Charting the Lifecourse Life Stages
Charting the Lifecourse tools

Support Coordinators (SC) frequently work with people who are transitioning between services. In order to assure continuity of services, guidelines for transitions are outlined in the following pages.

Part C to Intellectual Disability/Developmental Disability Support Coordination (ID/DD SC)

When children who receive Part C Early Intervention (EI) supports and services reach the age of two, the Early Intervention team will begin to transition the child and their family to Part B services, and potentially ID/DD Support Coordination. It is important for the EI SC and the ID/DD SC to work collaboratively to ensure continuity of services if Support Coordination services will continue.

Part of this transition also includes Early Childhood Education through the Virginia Department of Education. The ID/DD SC can work with the EI team and the family to ensure the child is linked to their local Special Education division. More information about the transition from Early Intervention to Early Childhood Education can be found below.

Transition from Part C to Part B at a glance

The SC should check with their organization’s policies specific to documentation regarding transitions.

School to Adult Services to Retirement

When a person with a disability is transitioning from school to adult services, it can be an exciting and challenging time for everyone involved. This transition period can be an extended process, as students may engage in career exploration, experience changing needs and a change in DD Waiver priority. During this period, especially as graduation nears, students and their families begin to think about life after high school. Starting at age 14, teams work to identify the student's and family's desired outcomes and to plan their community and school experiences to assure that they acquire the knowledge and skills needed to achieve their goals.

Additionally, the transition to retirement and older adulthood can also be a challenging and exciting time for people with disabilities. SCs providing support to adults with disabilities who are considering retirement can help the person develop a plan that focuses on their health, continued participation in their community, and security.

The transition planning processes should enable the person to move successfully to postsecondary education and training, employment, independent living, retirement, retirement living and community participation based on the person's preferences, interests, and abilities.

Transition planning for adult services can involve many topics including but not limited to:

- Employment opportunities
- Community integration
- Unpaid relationship development
- Post-secondary education
- Social Security benefits
- Retirement benefits
- Senior Navigation resources

Supported decision making, can help guide the person and team to consider a variety of opportunities, identify barriers, and make decisions to achieve the life he/she wants. An SC can work with the person and their family by providing information and resources. See the websites and resources provided below. See Supported decision making Chapter 3.

- Alzheimer's Association
- Area Agency on Aging (support for individuals 60+ and caregivers)
- National Task Group on Intellectual Disabilities and Dementia Practices
- No Wrong Door Virginia
- Supported Decision Making information
- Virginia Department of Education Transition Resources
- Social Security Benefits
- The Virginia Department of Aging and Rehabilitation Services Transition Guide
- Aging and Disability Networks
- Virginia Navigator

Transfers between Support Coordinators Within the Same CSB

The relationship between the SC and the people they support is very important. At times, the person may feel the need to request a new SC. Licensing regulations dictate that all CSBs should implement a written policy describing how people are assigned SCs and how they can request a change of their assigned SC. To proactively promote choice, SCs will review choice of providers when service changes occur, and include choice of current providers and SC at least annually by completing the Virginia Informed Choice form (DMAS 460) as required by Medicaid. When a person requests a change in SCs, the SC should check with their supervisor to learn their agency's policy and honor the request from the person for a change in SC whenever possible. Once the change has occurred it is important for the newly assigned SC to ensure that the record indicates the change in SC. Documentation of this change might include:

- updating the PC ISP Part I Essential Information;
- recording the request from the person in the progress notes;
- completing the Virginia Informed Choice form (DMAS 460); and
- notifying all collateral contacts (family members, providers, professionals).

Transfer Protocols to/from Other CSBs

When a person moves to another locality it may become more challenging for a Support Coordinator to continue to monitor services. In this instance, the SC should work with the person to transfer Support Coordination services to another Community Services Board (CSB). For more detailed information about the protocol for transferring Support Coordination to another CSB, please see The VACSB Transfer Protocol at a glance.

Transfers: SC Responsibilities

The referring CSB, (typically the I/DD Director or designee) will notify, by telephone, the receiving CSB (typically the I/DD Director or designee) of the expected date of transfer. Date of transfer is usually 90 days from receipt of initial communication regarding the request to transfer.

The referring CSB will send a follow-up letter to the receiving CSB to formally inform the receiving CSB of the planned transfer. An SC should check with their supervisor on the internal guidelines for this process.

The letter must contain:

- The individual's name
- Medicaid number
- Date of transfer
- A listing of current services, providers and approved funding for services
- Any changes in providers or service levels that will occur with the move

The referring CSB's SC will work with the receiving CSB and provide copies of current assessments, PC ISP, and other relevant documentation required on the Transfer Summary. The receiving CSB will respond in writing accepting the transfer, confirming the transfer date and identifying the SC who will be assigned, so both SCs can collaborate in the transfer.

The referring SC will:

- participate in any intake meetings required by the receiving CSB;
- update the date of transfer, the new CSB and new SC in WaMS; and
- check with a supervisor for any additional internal procedures related to discharging the person from SC services at their CSB. This will typically include completion of a discharge Summary, final Person-Centered Review and final progress note at a minimum.

Additionally, there are protocols developed by the Developmental Disabilities (DD) Council specific to transferring a person from one CSB to another, please see The VACSB Transfer Protocol At-A-Glance, linked above. For the most recent protocols, the SC should check with the Developmental Disability (DD) Director of the CSB.

Discharge/Transition Planning

All licensed providers are required to have written procedures that define the process for transitioning a person between or among services operated by the provider. At a minimum the policy shall address:

- continuity of services during and following transition;
- participation of the person or his authorized representative in planning;
- process and timeframe for transferring access to the record and ISP; and
- process and timeframe for completing the Transfer Summary.
- For more information, read 12VAC35-105-691 (Transition of Individuals Among Services) and 12VAC35-105-693 (Discharge).

Training Center Discharges

As mentioned in Chapter 2 of this handbook, anyone who previously resided in a training center who now lives in the community is required to have a more intensive level of support from the SC. When a person residing in a training center is seeking discharge into the community, the SC plays an important role of ensuring a smooth transition. The assessment and plan development process for a person being discharged from a training center is similar to the process for someone already residing in the community. Additionally, there is further funding available to help someone move into the community. Please ask your supervisor for assistance with funding resources available in your locality. Virginia has approved limited funding as a part of the plan to support individuals transitioning from a Training Center or other state facility according to the "Community Move Process" to a community home of their choice. Transitional funding, formerly known as "Bridge Funding," can be used in a variety of ways to support the planning and move of these individuals to their own homes or to a provider home licensed by the DBHDS. The application is available on the Department of Behavioral Health and Developmental Services (DBHDS) website.

Transitional Funds Guidelines at a glance
Transitional Funds Application at a glance

State Psychiatric Hospital Discharge

Both CSBs and state psychiatric hospitals recognize the importance of timely discharge planning and implementation of discharge plans to serve persons in the community, as well as to ensure the ongoing availability of state hospital beds for people presenting with acute psychiatric needs in the community.

Please read the collaborative discharge protocols for state psychiatric hospital discharges for more information.

Private Medical/Psychiatric Hospital

The SC may support a person who resides in a private hospital and is seeking discharge into the community. The SC should work collaboratively with the person, their family/guardian, and the hospital staff in order to assess the person's needs upon discharge, identify risks, needs and preferences, address barriers and ultimately develop a plan that meets the person's desired outcomes. Once the person returns to the community, the SC provides ECM services for one year and then determines if the person continues to meet the criteria for ECM services.

Moves to Different Level of Care

There are times when a person will need to move to a different level of care, such as a move from the family's home to a group home, or the transition from high school to adult services. The SC should work with people to assess the need, identify resources/ service options and address barriers. As discussed earlier in this chapter, transitions can be challenging but with the correct resources and tools, the SC can ensure a smooth transition. Chapter 8 identifies strategies the SC can use to help assess the situation and modify the plan as needed.
One major transition occurs when a person no longer needs Support Coordination. There are a number of reasons why a person may be discharged from SC services. Reasons may include, but are not limited to:

- person moves out of the CSB catchment area or out of the state;
- death;
- person chooses to no longer use Support Coordination services;
- person is no longer eligible for Support Coordination services;
- person no longer meets financial eligibility for Support Coordination services; and
- person no longer has active or specialized need for Support Coordination services.

It is essential for the SC to work carefully through the transition and discharge process. SCs must ensure there is agreement for ending of SC services with the person, the agency, and other appropriate parties. The SC should provide reasonable notice of discharge that is based upon the facts and circumstances of each person's life. The SC should document both verbal and written notice to the person leaving services and the other participating service providers. It is important to communicate pertinent information, with permission, when transitioning to other providers and supports to maximize positive outcomes. As part of a Discharge Summary, the SC will include linkage to other resources as needed for a smooth transition. Documentation includes completion of the required Discharge Summary, notice of appeal rights, final Person Centered review, and a progress note.

Discharge from Support Coordination-SC responsibilities:

- complete SC agency's documentation requirements for discharge (discharge summary, case notes, final Person Centered Review, etc.) and submit a Notification of Right to Appeal letter regarding termination, if the person is receiving Medicaid billed State Plan Option (SPO) Targeted Case Management.
- An exception to the need for a Notification of Right to Appeal letter is when the person has moved to another locality in Virginia and the receiving CSB will continue to provide TCM services. Because the SPO case management will continue, there is no need to send the appeal notification because no Medicaid services will be terminated.

  DBHDS Licensing regulation 12VAC35-105-693 regarding Discharge.

Death

When a person who uses SC services passes away, there are a number of steps the SC takes to document the event. Each CSB has internal procedures, so the SC should check with their supervisor to ensure all documentation requirements have been completed.

Licensure regulation 12VAC35-105-160 (D2) states that all serious incidents, including death, should be reported in writing to the DBHDS Office of Licensing within 24 hours. The state database system used to document serious incidents, such as death, is known as CHRIS (Computerized Human Rights Information System), training is accessible via the following link under Advocate Information:
https://dbhds.virginia.gov/quality-management/human-rights

Chapter 10:
Health & Safety

Introduction

People with disabilities need health care and health programs for the same reasons anyone else does - to stay well, active, and a part of the community. Having a disability does not mean a person is not healthy or cannot be healthy. Being healthy means the same thing for all of us - getting and staying well so we can lead full, active lives. People with disabilities experience all the same common health issues as the general population, yet as a group, they have much greater health needs. People with disabilities can also be at higher risk for injuries and abuse. For these reasons, health and safety are core concerns for people with disabilities, however, these concerns do not override a person's fundamental right to the dignity of risk, the right to take risks when engaging in life experiences, and the right to fail in those activities. All too often people are limited from living their best lives under the guise of health and safety concerns when it is really a lack of a creative, committed effort to provide individualized and meaningful supports.

Resource: Disability and Health Information for People with Disabilities

Support Coordinator's Role in Health & Safety

The Support Coordinator (SC) should perform the same process steps regarding a person's health and safety that they do for other supports and services for waiver individuals. Some of the particular duties regarding health and safety are outlined below.

Assessment

- Complete the Risk Awareness Tool at or prior to the initial Waiver meeting and annually thereafter to increase awareness of the potential for a harmful event (e.g., bowel obstruction, sepsis, fall with injury, self-harm, elopement, etc.) to occur and to facilitate the process of taking action to reduce and prevent the risk.
- Complete the Crisis Risk Assessment Tool at intake and every face to face meeting thereafter to capture information that may put an individual at risk for crisis or hospitalization, and to foster proactive referrals to the REACH programs if such a risk is determined.
- Complete the Onsite Visit Tool at one face to face meeting with each person, no less than one time per quarter to observe the person and the environment to assess for risks.
- Request copies of and/or results of health risk assessments (HRA) completed annually by CCC+ care coordinators.

- Participate in SIS® meetings.

Plan Development

- Document risk and medical and behavioral support needs, which can be gathered from a variety of sources to include but not limited to: needs as determined by the SIS® assessment, the Risk Awareness Tool, the Crisis Risk Assessment Tool, the Onsite Visit Tool, and the CCC+ HRA.
- Include linkages to services and providers in the Person-Centered Individual Service Plan (PC ISP) Part III and SC Part V to address risk and ensure health and safety. For example, assist a person to obtain a ramp through an environmental modification, link someone to a psychiatrist to obtain needed for mental health support and medication monitoring, link a person to a physician for an assessment for wound care, etc.
- Review provider Part V plans for supports to ensure they include supports as agreed upon in the shared planning regarding risk and medical and behavioral needs.

Plan Implementation/Coordination

- Communicate with all providers to share vital information. Example: a residential provider reports that someone they support has received a new order from their physician that blood sugar levels have to be tested every 2 hours. The day support program will need to be informed so that they can also make sure the blood sugar levels are tested every 2 hours while that person is at their program.
- Communicate with Care Coordinators of the Managed Care Organizations (MCOs) to update them on an individual's needs and services and obtain results of their HRAs.
- Collaborate with care coordinators regarding medically related issues to develop coordinated plans to mitigate risks.
- Report alleged abuse, neglect or exploitation to Adult Protective Services (APS) and Child Protective Services.

Monitoring

- Review provider Person Centered Reviews and other documentation to obtain input on medical information, appointment information, and to ensure that all needed follow up has been done for all medical conditions and concerns.
- Obtain input from the person using services and their authorized representative or legal guardian, as appropriate, on satisfaction with all services and providers.
- Follow through with service providers regarding implementation of physician's orders, etc.
- Obtain information on all medications a person takes and obtain side effect information from websites and other sources such as the Physician’s Desk Reference (PDR).
- Document medication changes and communicate information to all providers.
- Review CHRIS Case Management Report and provider incident reports for injuries and medical concerns, and document communication with providers to ensure that all needed follow up occurred.
- Request needed medical records from family members, group home providers, and medical providers.
- Ensure that an individual obtains a physical within 12 months prior to enrollment into a DD Waiver.

List of suggested considerations/questions to ask regarding Health & Safety when conducting face to face visits.

Advocacy

- Advocate for annual physicals, dental exams, and other recommended preventative screenings and immunizations based on medical history, age and gender.
- Advocate for needed referrals. Example: Someone has been having increased seizure activity. The Primary Care Physician has not ordered any blood work, medical tests, or shown any concern about this increased seizure activity. The SC can advocate for a referral to a specialist, such as a neurologist for more specialized care.
- Link to needed funding sources to cover someone's needs. Example: drug companies frequently offer reduced rate medications programs for those unable to pay for their prescriptions.

Optimal Health

Maintenance of optimal health is one of the most basic supports provided by the team supporting a person with a disability. This is a shared responsibility among all entities who work with the person. It is a primary responsibility of the SC to lead the team in identifying health and safety risk factors, develop individualized supports, and to monitor the implementation of those supports and the person's wellbeing. The level of active involvement with health care practitioners depends on the risk factors of each person.

Achievement of OPTIMAL HEALTH is based upon these principles:

- **Person Centered:** People participate in decisions about their health and are supported in making person-centered decisions about healthy lifestyles, such as food choices, and activity.
- **Access:** People have adequate contact with health practitioners regarding their physical and mental health, receiving preventative health care and services, including recommended physical and dental exams, and timely assessment, treatment, and follow up for acute and chronic health issues.
- **Support:** People are supported, as needed, in all aspects of their health care including decision making, access, and following their prescribed treatment plans (e.g., medications, diets, mealtime instructions).
- **Documentation:** People's health related information, both current and historical, is documented accurately and available when needed. People have some form of identification, which includes emergency contact information, with them at all times.

PROACTIVE STEPS TO HEALTH

In the area of health and safety, there are proactive steps that can be taken that can contribute to optimal health in people with disabilities just as they do for the general population. These topics should be included in the discussion when developing a support plan. These include:

Good Nutrition

People with disabilities have the same needs for good nutrition and proper weight management as people without disabilities. Since developmental disabilities are often associated with other medical conditions, it may be recommended that a person adhere to a special diet for health reasons or food allergies. This may involve exploring outcomes with those supported about potentially serious consequences of consuming food items, such as nuts if allergic, nutritious and well-balanced meals, meal preparation, and food choice and amounts. Aging adults, whose nutritional needs, appetite, and vulnerability to illness are often changing, may require additional guidance and assistance. Note: No special diet should be implemented without checking first with the person's medical professional.

Attention to Personal Hygiene

Personal hygiene plays a major role in how others view a person. It is important for all of us to wear clean clothing, keep our hair clean and to bathe regularly. Because people with disabilities are often seen by others as "different," it is even more important to have good personal hygiene. Dirty clothing and sloppy appearances get in the way of meeting new people and making friends. When dressed in clean, well-fitting clothing, people are more likely to be seen in a positive manner. Some people with disabilities may need reminders, guidance, or physical intervention to assist with maintaining their personal appearance. Good hygiene, especially dental care, is also important for health reasons. Lack of attention to bathing or to routine care of teeth and gums can lead to serious medical conditions.

Exercise

Along with regular medical care and good nutrition, exercise is another important element for a healthy life. Many people have never experienced a regular exercise program. Though they may face some physical challenges, there are a variety of activities designed for older adults and people with disabilities. Exercise can be fun and exciting. All people benefit from moving more, so exploring physical activities the person enjoys doing and finding ways to include these activities in their daily routine can positively impact their overall health and wellbeing. Most major health organizations recommend at least 30 minutes of exercise most days of the week, using a combination of cardiovascular exercise (walking, swimming, and/or aerobics) and resistance exercise (weights). Encouraging creativity on the part of the person's support team can be a role of the Support Coordinator. No new exercise program should be implemented without checking with the person's medical professional.

Assistive Technology

Assistive technology refers an item, device, piece of equipment, or set of products that is used to maintain or improve ability. Assistive technology allows people to function with more independence, provides more choices, and results in an increased sense of confidence. Assistive technology devices may range from simple and inexpensive everyday items to complex computer systems.

Some devices are not designed just for people with disabilities; they can make life easier for anyone. Examples of assistive technology that enable people to carry out daily activities include: eating and cooking utensils fitted with oversize handles for easier gripping, shower benches and bathtub lifts, wheelchair ramps, programmable telephones, and picture boards. There are also assistive technology communication devices that provide assistance for people who do not communicate using words. The device can include speech, gestures, sign language, symbols, synthesized speech, dedicated communications aids, or microcomputers.

Assistive technology benefits people as they age. It may be a key element in helping people remain in their home and community. It also helps maintain as much independence as possible, as physical and cognitive abilities change due to the aging process. If any of these devices are thought to benefit an individual, the SC is responsible for investigating funding for such devices. It is possible that the needed item may be available through Medicaid or Medicare.

Regular Medical and Dental Care

Regular medical and dental care is crucial in helping people enjoy a healthy life. It is important for team members to work closely with each person's primary care physician and other medical and health professionals to make sure regular routine tests and screenings are completed and to assist in communicating to the health professional issues someone might be experiencing. All team members should be on the lookout for changes in appearance or behavior that may indicate some symptom of illness. Some people may not be able to fully communicate what they are feeling (physically and emotionally). It is important to be diligent in observing, monitoring, and reporting any of these changes. This role is usually done by the direct support professional (DSP) as they, are likely to have the consistency of contact needed to be aware of and note changes. It is the role of the SC to monitor changes in health and safety and to work with the person and the team to adjust supports accordingly.

Resource: Direct Support Professional Orientation Manual

Medication and Side Effects

Some people take multiple daily medications. All medications can have side effects - some of which can be harmful. Side effects may indicate that the medication dosage or type may need to change. In addition, people on more than one medication may experience symptoms related to the interactions of their medications.

While it is impossible to remember all the possible side effects for medications, it is important that the SC know where to find this information. Reputable sites that include information about drugs, dosage, uses and side effects are:

- Drugs & Medication A-Z
- Find Drugs and Conditions
- Rx List

Barriers to Quality Healthcare

Barriers to Quality Healthcare for People with Disabilities

- Difficulties communicating signs and symptoms to a health care provider about treatable yet untreated health conditions.
- Attitudes and assumptions of medical staff including discrimination and lack of empathy or caring for people with disabilities.
- Untreated specific health issues related to the person's disability due to health care providers' inadequate knowledge.
- Decreased access to generic/preventative health screening as well as to specialists services
- Lack of independent mobility causing reliance on others to attend appointments.
- Behavior problems that may manifest themselves out of untreated medical conditions, fear or disorientation.
- Lack of time and resources.

Resource: Barriers in health care for people with disabilities: It's not what you think.

Common Health Issues

People with disabilities experience all the same common health issues as the general population yet as a group, they have much greater health needs. Identification and treatment may be more complex, due in part to associated difficulties with communication, which leads to under - recognition of common illnesses and disorders. These common conditions include:

- Coronary heart diseases, e.g. high blood pressure, high cholesterol, cardiovascular disease
- Respiratory diseases,
- Oral health issues,
- Gastrointestinal diseases, e.g. dysphagia (difficulty in swallowing), aspiration pneumonitis, Gastroesophageal reflux disease (GORD), constipation)
- Endocrine diseases, e.g. diabetes, thyroid conditions
- Epilepsy
- Bone health
- Visual impairment and/or hearing loss
- Cancer
- Mental and behavioral health issues
- Dementia, e.g. Alzheimer's, vascular dementia
- Dermatitis (skin issues)
- Sleep disorders
- Obesity
- Hepatitis B

These conditions while not unique to people with disabilities may occur more often or more seriously than in the general population and so are an important part of any assessment for the purpose of identifying and planning for appropriate supports. An online resource for looking up health information about these and other conditions is the National Institutes of Health. In addition, the DBHDS Office of Integrated Health has prepared many Safety Alerts on a variety of health topics, which are available online.

Resource: Assessment in Primary Care.

Eight Health Risks

The following is a list of areas in which changes may indicate signs of illness or a change in health status. There are **8 health issues** that are often overlooked and need to be more carefully monitored. These conditions can progress rapidly and result in bigger problems, even death. They are most likely to be identified and addressed by the DSPs who have regular contact with the person. However, the SC needs to be aware of the signs and symptoms of these health issues as well, so that they can properly monitor these conditions. The Department of Health and Developmental Services (DBHDS) Office of Integrated Health (OIH) has issued safety alerts on these conditions and provides a monthly newsletter that addresses health and safety issues. The 8 health risks include:

Skin Care (general)

Healthy skin aids in regulating body temperature, protecting internal organs from injury and environmental elements, and protecting against infection.

Things to look for, but not limited to, and/or reports of:

- unusual or abnormal color (pale, pink, red, or bluish);
- rashes, cuts, open sores, raised bumps, blisters, bruises;
- changes in skin temperature (such as moist, hot, or cool to the touch); and
- Parasites.

Decubitus ulcers/ pressure ulcers (bed sores) Decubitus ulcers are injuries to skin and underlying tissue resulting from prolonged pressure on the skin. Bedsores most often develop on skin that covers bony areas of the body, such as the heels, ankles, hips and tailbone. People most at risk of bedsores are those with a medical condition that limits their ability to change positions or those who spend most of their time in a bed or chair.

Bedsores can develop quickly. Most sores heal with treatment, but some never heal completely. Most pressure sores are preventable with the proper supports such as regular changes in positioning, different seating, use of adaptive equipment. When pressures sores are a risk, physician orders for positioning protocols need to be developed and implemented. Documentation should be maintained on positioning logs which can be monitored by SCs. Skin integrity training is routinely offered by OIH.

Things to look for include:

- unusual changes in skin color or texture;
- swelling;
- pus-like draining;
- an area of skin that feels cooler or warmer to the touch than other areas;
- tender areas; and
- if there are signs of infection, such as a fever, drainage from a sore, a sore that smells bad, or increased redness, warmth or swelling around a sore, immediate medical attention should be sought, visit the Mayo Clinic website for more information.

Aspiration Pneumonia

Aspiration pneumonia is an inflammation of the lungs and airways to the lungs from breathing in foreign material. Aspiration pneumonia develops from inhaling food, vomit, liquids, or saliva into the lungs. This may occur when someone has difficulty swallowing (dysphagia) and has watery eyes or coughing while consuming food or fluids.

Things to look for, but not limited to, and/or reports of:

- chest pain,
- cough,
- fatigue,
- nausea,
- fever,
- shortness of breath, wheezing, and
- bluish discoloration of the skin caused by lack of oxygen (e.g., mouth, nail beds, finger tips).

Falls

Fall risk is important to address as 1 in 3 older adults fall daily. Fall complications can include broken bones, head injuries, problem with daily activities, and need for home health care.

Things to look for, but not limited to, and/or reports of:

- health issues and medication;
- being shoved or running into a barrier;
- cluttered rooms, area rugs, wet or slick surfaces, improper lighting;
- wet or slick surfaces without non-skid footwear; and
- lack of appropriate medical adaptive equipment, inappropriate footwear.

Urinary Tract Infections (UTI)

A UTI is an infection of the urinary tract, which is the body's system for removing wastes and extra water. Women are more susceptible than men due to their anatomy and reduced bladder function later in life and symptoms vary by age and gender. People who use wheelchairs and/or have reduced mobility are also more susceptible to developing UTIs. There are **two different types of UTIs** - the **lower UTI** relates to infections that occur in the urethra (a short narrow tube that carries urine from the bladder out of the body) and bladder - and the **upper UTI** is more severe and relates to infections that may involve the kidneys.

Things to look for, but not limited to, and/or reports of:

- pain or burning during urination;
- increased frequency, urgency of urination, incontinence;
- lower abdominal, pelvic or rectal pain or pressure;
- confusion, behavioral changes, increased falls;
- mild fever or "just not feeling well;" and
- changes in urine (such as milky, cloudy, bloody or foul-smelling).

Upper UTI symptoms develop rapidly and may not include the symptoms for a lower UTI and **require emergency care**.

Things to look for, but not limited to, and/or reports of:

- fairly high fever (higher than 101F);
- shaking chills;
- nausea;
- vomiting; and
- flank pain (pain in the back or side, usually only on one side at waist level).

Dehydration

Dehydration occurs when we lose more fluids than we are taking in. The lack of water in the body may result from either a decrease in fluid intake or an increase in fluid loss. Water helps transport waste, supports tissue and cell hydration and helps regulate your temperature. Dehydration can be an important factor in illness and even death. Diarrhea and vomiting are the most common reasons why someone loses excess fluid.

Things to look for, but not limited to, and/or reports of:

- urine is concentrated and more yellow;
- dry mouth and nose;
- dry skin;
- decreased tear production;
- headache;
- dizziness;

- sleepy or tired; and
- light headed (especially when standing).

SEVERE dehydration symptoms can include, but are not limited to confusion, lack of sweating, little or no urination, weakness, coma, organ failure (especially kidney), changes in vital signs (increase in pulse and decrease in blood pressure), and "tenting" of skin (sticks together, stays upright when pinched together).

Constipation and Bowel Obstruction

Constipation is the slow movement of feces through the intestine which results in infrequent bowel movements and hard, dry stools. The longer it takes for stool to move through the large intestines, the more fluid is absorbed and the harder stool becomes, making it difficult and sometimes impossible to pass.

Things to look for, but not limited to, and/or reports of:

- changes in bowel habits;
- infrequent bowel movements (less than 3 a week or more than 3 days between);
- difficulty passing stools - straining, painful;
- hard, dry, lumpy, small stools;
- belly pain relieved by bowel movements, swollen abdomen;
- bright red blood in stools; and
- leaks of wet, diarrhea-like stool between regular bowel movements.

Severe constipation can result in serious complications including rectal bleeding, nausea, vomiting, weight loss, bowel obstruction, fecal impaction, hemorrhoids, anal fissures and rectal prolapse**.** Two **serious constipation issues** are fecal impaction and bowel obstruction. **Fecal impaction** is when hard, dry stool is in the large intestines, often the rectum and cannot be passed. Individuals with fecal impactions often have breathing difficulties due to the collection of the stool in the colon. Fecal impaction can be life threatening. A **bowel obstruction** is either a partial or complete blockage of the small or large intestines and requires immediate medical attention! People who use wheelchairs and/or have reduced mobility are also more susceptible to developing a bowel obstruction. Use of a log to track bowel movements may be recommended to ensure people are having regular adequate bowel movements. This log would typically be maintained by DSPs and can be monitored by SCs.

Bowel obstruction: Things to look for, but not limited to, and/or reports of:

- abdominal pain;
- swelling and fullness;
- vomiting; and
- diarrhea; and odor to breath.

Sepsis

Sepsis is a serious medical condition caused by an overwhelming immune response to infection. Sepsis can arise unpredictably and can progress rapidly. Sepsis springs from two factors: an infection (such as pneumonia or a urinary tract infection) and a powerful and harmful response by the body's own immune system.

In severe cases, one or more organs fail. In the worst cases, blood pressure drops, the heart weakens and the patient spirals towards septic shock. Once that happens, multiple organs - lungs, kidneys, liver - may quickly fail and the person can die.

Seizures

Seizures are defined as abnormal movements or behavior due to electrical activity in the brain. Seizures might include shaking and convulsions, and can last a few seconds or over 5 minutes. Seizures have many causes and can lead to brain damage or even death. Diagnosis occurs when a person has had two or more seizures. Providers should track and report seizures. SCs should routinely monitor seizure activity. There are many types of seizures.

Things to look for include, but not limited to, and/or reports of:

- brief blackout followed by a period of confusion;
- changes in behavior;
- drooling or frothing at the mouth;
- eye movements;
- shaking of the entire body;
- grunting or snorting;
- loss of bladder or bowel control;
- sudden falling;
- teeth clenching;
- tasting a bitter or metallic flavor;
- temporary stop in breathing;
- uncontrollable muscle spasms with twitching and jerking limbs; and
- mood changes such as sudden anger, unexplainable fear, paranoia, joy or laughter.

Specific Developmental Disabilities and Co-occurring Medical Concerns

The most common developmental disability is intellectual disability. According to the Centers for Disease Control (CDC), more than one out of every 100 school children in the United States has some form of intellectual disability. Cerebral palsy is the second most common developmental disability, followed by autism spectrum disorders:

Other Developmental and Behavioral Disorders

For some syndromes or disability types, there are commonly co-occurring health issues. While people may not present with all of the co-occurring conditions that are associated with their disability, it is helpful to keep in mind these issues when supporting a person in their medical care. Following are the conditions associated with the most common developmental disabilities.

Down syndrome (the most frequently occurring form of ID)

- heart disease
- early onset dementia
- obesity
- disrupted sleep patterns and sleep disorders
- musculoskeletal conditions
- hearing loss
- vision problems
- Hypothyroidism (underactive thyroid)
- diabetes
- infections
- blood disorders
- hypotonia
- gum disease and dental problems
- epilepsy
- digestive problems
- celiac disease
- mental health and emotional problems

What conditions or disorders are commonly associated with Down syndrome?

Cerebral palsy

- oral motor impairment
- speech impairment
- intellectual disabilities
- learning difficulties
- visual impairment and blindness
- seizure disorder (epilepsy)
- sensory disorders

Conditions Associated with Cerebral Palsy

Autism spectrum disorders

- Anxiety
- ADHD

- Depression
- Epilepsy
- immune disorders
- intellectual disabilities
- OCD
- sensory disorders
- sleep problems
- Tourette syndrome
- Social (pragmatic) communication disorder

Conditions that can occur with autism
Medical Comorbidities in Autism Spectrum Disorders

Abuse, Neglect, and Exploitation

It is estimated that people with disabilities are between two and five times more likely to be victims of abuse as those without disabilities (Martin et al., 2006; Mitra, Mouradian, & Diamond, 2011; Plummer & Findley, 2011). Further, research has indicated that most abuse perpetrators are known by the person with DD and often include parents, intimate partners, extended family members, caregivers, teachers, bus drivers, and other paid service providers (Stevens, 2012). People with disabilities are also at greater risk of experiencing domestic and sexual abuse by non-intimate partners, including other family members and care providers within and outside of institutions (Chenoweth, 1996; Oktay & Tompkins, 2004; Saxton, et al., 2001; Young, et al., 1997).

With these statistics in mind, the chances that an SC will support someone who is experiencing or has in the past experienced abuse, neglect or exploitation will be great. The SC is a mandated reporter. The responsibilities of the SC regarding mandated reporting are found in Chapter 2.

The definitions for abuse, neglect and exploitation as outlined in Administrative Code of Virginia (22VAC30-100-10) are:

- "Abuse" means the willful infliction of physical pain, injury or mental anguish or unreasonable confinement of an adult as defined in § 63.2-1603 of the Code of Virginia.
- “Adult” means any person 60 years of age or older, or any person 18 years of age or older who is incapacitated and who resides in the Commonwealth as defined in § 63.2-1603 of the Code of Virginia.
- “Neglect" means that an adult as defined in § 63.2-1603 is living under such circumstances that he is not able to provide for himself or is not being provided such services as are necessary to maintain his physical and mental health and that the failure to receive such necessary services impairs or threatens to impair his well-being. However, no adult shall be considered neglected solely on the basis that such adult is receiving religious nonmedical treatment or religious nonmedical nursing care in lieu of medical care, provided that such treatment or care is performed in good faith and in accordance with the religious practices of the adult and there is written or oral expression of consent by that adult. Neglect includes the failure of a caregiver or another responsible person to provide for basic needs to maintain the adult's physical and mental health and well-being, and it includes the adult's neglect of self.

Neglect includes:

- the lack of clothing considered necessary to protect a person's health;
- the lack of food necessary to prevent physical injury or to maintain life, including failure to receive appropriate food for adults with conditions requiring special diets;
- shelter that is not structurally safe; has rodents or other infestations which may result in serious health problems; or does not have a safe and accessible water supply, safe heat source or sewage disposal. Adequate shelter for an adult will depend on the impairments of an adult; however, the adult must be protected from the elements that would seriously endanger his health (e.g., rain, cold or heat) and could result in serious illness or debilitating conditions;
- inadequate supervision by a paid or unpaid caregiver who provides the supervision necessary to protect the safety and well-being of an adult in his care;
- the failure of persons who are responsible for caregiving to seek needed medical care or to follow medically prescribed treatment for an adult, or the adult has failed to obtain such care for himself. The needed medical care is believed to be of such a nature as to result in physical or mental injury or illness if it is not provided;
- medical neglect includes the withholding of medication or aids needed by the adult such as dentures, eye glasses, hearing aids, walker, etc. It also includes the unauthorized administration of prescription drugs, over-medicating or under- medicating, and the administration of drugs for other than bona fide medical reasons, as determined by a licensed health care professional; and
- self-neglect by an adult who is not meeting his own basic needs due to mental or physical impairments. Basic needs refer to such things as food, clothing, shelter, health or medical care.

“Exploitation" means the illegal, unauthorized, improper, or fraudulent use of an adult as defined in § 63.2- 1603 of the Code of Virginia or the adult’s funds, property, benefits, resources, or other assets for another's profit, benefit, or advantage, including a caregiver or person servingin a fiduciary capacity, or that deprives the adult of his rightful use of or access to such funds, property, benefits, resources, or other assets.

"Adult exploitation" includes:

- an intentional breach of a fiduciary obligation to an adult to his detriment or an intentional failure to use the financial resources of an adult in a manner that results inneglect of such adult;
- the acquisition, possession, or control of an adult's financial resources or property through the use of undue influence, coercion, or duress; and
- forcing or coercing an adult to pay for goods or services or perform services against his will for another's profit, benefit, or advantage if the adult did not agree, or was tricked, misled, or defrauded into agreeing, to pay for such goods or services or perform such services.

Signs of abuse, neglect and exploitation

Caregiver Stress and Burnout

As a Support Coordinator providing in-home visits, it is important to recognize the emotional, physical, mental and financial demands of being a caregiver. Some caregivers are well connected, while others may be isolated, and you may be one of the few people who visit the home. While you are there to support the individual, be attentive to the caregiver(s). Listen for requests they make for additional supports as well as comments about their lack of sleep or their own health (physical or mental) problems or their additional financial burdens. If possible, assess other responsibilities the caregiver may have. Don't be afraid to ask about their own support system. Offer information for resources that are available in their community. Be proactive. If you believe supports are needed sooner than later, don't hesitate to escalate those concerns to your supervisor.

Caregivers commonly experience high levels of stress, anxiety, depression and other mental health effects. Read more at the Family Caregiver Alliance (https://www.caregiver.org/resource/caregiver-health/).

Signs of caregiver stress and burnout are listed below.

Signs of caregiver stress

- Feeling overwhelmed or constantly worried
- Feeling tired often
- Getting too much sleep or not enough sleep
- Gaining or losing weight
- Becoming easily irritated or angry
- Losing interest in activities once enjoyable
- Feeling sad
- Having frequent headaches, body pain or other physical problems
- Abusing alcohol or drugs, including prescription medications

(https://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/caregiver-stress/art-20044784)

Signs of caregiver burnout

- Withdrawal from friends, family and other loved ones
- Loss of interest in activities previously enjoyed.
- Feeling blue, irritable, hopeless and helpless.
- Changes in appetite, weight or both.
- Changes in sleep patterns.
- Getting sick more often.
- Feelings of wanting to hurt self or the person being cared for.
- Emotional and physical exhaustion.
- Irritability.

(https://my.clevelandclinic.org/health/diseases/9225-caregiver-burnout)

Caregiver stress and/or caregiver burnout can lead to a mental health crisis. Warning signs include having trouble with daily tasks, sudden, extreme changes in mood, increased agitation, abusive behavior, isolation, paranoia and symptoms of psychosis. Warning signs are not always present when a mental health crisis is developing. Be attentive to these warning signs of **suicide**:

- Giving away personal possessions
- Talking as if saying goodbye
- Taking steps
- Making or changing a will
- Collecting and saving pills or buying a weapon
- Saying things like “Nothing matters anymore”
- Withdrawing from friends, family and normal activities
- Increasing drug or alcohol use

Emotional support can help to deal with the stress of caring for someone with a disability. The impact on the caregiver cannot be minimized. Caregivers experience elevated levels of depression and anxiety, higher use of psychoactive medications, worse self-reported physical health, compromised immune function and increased risk of early death https://www.cdc.gov/aging/caregiving/index.htm.

Signs of Abuse and Neglect as a Result of Caregiver Burnout

- Injuries of unknown origin
- More restrictive supports in the home
- Less restrictive supports in the home
- Reports by the individual of use of:
    - Intimidation
    - Humiliating or aggressive language
- Failure to protect from harm
- Failure to meet essential needs to include:
    - Essential medical care
    - Nutrition
    - Hydration
    - Hygiene
    - Basic activities of daily living or shelter

In extreme cases, suicide and filicide (the killing of one’s son or daughter) are carried out. Read An Overview of Filicide (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2922347/) to learn more. If you have concerns with a caregivers’ level of stress or behavior, or fear for any family member in the home, please reach out to your supervisor for guidance. As a mandated reporter, you are required to report concerning suspicions. The Virginia Department of Social Services has two 24-hour, toll-free hotlines (one for concerns about children and one for adults). The hotline staff are trained to provide crisis counseling and intervention if needed, and can provide information and referral assistance to callers to locate prevention and/or treatment programs in their area as appropriate. The hotline numbers are provided below.

Connecting a caregiver to resources is the first step to providing support. Please review and share these resources and information related to caregiver support.

My Life My Community Website

https://www.mylifemycommunityvirginia.org/

Resources for People on the DD Waiver Waiting List

Disability & Health Information for Family Caregivers

https://www.cdc.gov/ncbddd/disabilityandhealth/family.html

Partnership for People with Disabilities – Center for Family Involvement

https://partnership.vcu.edu/programs/community-living/center-for-family-involvement/

Suicide Prevention: 1-800-273-8255 and website: https://suicidepreventionlifeline.org/

Child Abuse/Neglect hotline (Virginia): 1-800-552-7096

Adult Protective Services hotline (Virginia): 1-888-832-3858

DARS APS Division: https://www.vadars.org/aps/

Virginia Department of Social Services: https://www.dss.virginia.gov/about/abuse.cgi

Virginia COPES (Support through talking or texting about struggles and mental health; Spanish speaking counselors are available): 1-877-349-6428

Family Violence and Sexual Assault Virginia Hotline: 1-800-838-8238

LGBTQ Partner Abuse and Sexual Assault Helpline: 1-866-356-6998 (Instant messaging and texting options available – for texting: 1-804-793-9999

National Domestic Violence Hotline: 1-800-7993-7233

National Alliance for Mental Illness (NAMI): 1-888-486-8264

National Alliance for Mental Illness (NAMI) Virginia Chapter: 1-804-285-8264

End of Life

It is inevitable that Support Coordinators will experience the death of someone they are supporting. In some instances, the SC will have had a relationship with this person for years and they will experience grief and sadness. It is important that the SC reach out and rely on their own support systems during these times of loss. The relationship is a professional one, but also a human relationship, one with feelings, caring and regard. It is okay to acknowledge this and grieve. SCs may need to assist persons in obtaining end of life care through hospice or other medical providers

Learn more at https://www.nia.nih.gov/health/end-of-life.

CHAPTER 11:
Community Resources

Introduction

In addition to the private providers who provide services to individuals with developmental disabilities, the Support Coordinator (SC) relies on the supports and services of many organizations to help them carry out their job responsibilities. Below are just some of the resources.

Virginia Department of Behavioral Health & Developmental Services (804) 786-3921

- Division of Developmental Services https://dbhds.virginia.gov/developmental-services
- Waiver Services https://dbhds.virginia.gov/developmental-services/waiver-services
- Crisis Services - (REACH Adult DD Crisis Services, REACH Children DD Crisis Services, Statewide and Regional Resources/Documents) https://dbhds.virginia.gov/developmental-services/Crisis-services
- Community Integration and Transition Supports (Training Center Transition Services, Regional Support Teams, Guardianship, Family Resource Consulting, Single Point of Entry for ICF/IIDs, Incident Management/Quality assurance) https://dbhds.virginia.gov/developmental-services/training-centers
- Community Support Services (Employment, Housing, Individual Family Support Program) Employment https://dbhds.virginia.gov/developmental-services/employment
- Housing https://dbhds.virginia.gov/developmental-services/housing

Individual Family Support Program (IFSP) - IFSP is designed to assist those on the DD Waiver Wait List and their families to access short-term, person/family centered resources, supports and services. These services and items funded through the IFSP are intended to support the continued residence of an individual in their own or family home in the community. Support Coordinators can encourage families and individuals to apply for this funding and offer support, as needed, in the application process. More information can be found at the IFSP website. Individual and Family Support Program

- Department of Justice Agreement
- Home and Community Based Settings Regulations
- My Life My Community
  - Search for Providers
  - Virginia DD Waiver Guidance (select Navigating the DD Waivers Guidebook) (844) 603-9248
- Office of Integrated Health
- Office of Human Rights
- Office of Licensing, Licensed Providers and Provider Inspection/Investigation Reports Search

American Association on Intellectual and Developmental Disabilities (AAIDD)
(202) 387-1968

The Arc of Virginia

Centers for Independent Living

Centers for Medicare & Medicaid Services

Community Health Clinics

Department for Aging and Rehabilitative Services

Department of Education: Special Education

Department of Health

Department of Medical Assistance Services
(804) 786-7933 (General Information), (800) 343-0634 (TTY)

Department of Social Services
(804) 726-7000 (General Information)

disABILITY Law Center of Virginia
(800) 552-3962

Disability Navigator

Early Periodic Supports Diagnosis & Treatment (EPSDT)

National Gateway to Self-Determination

The Olmstead Initiative

Parent Educational Advocacy Training Center

Partnership for People with Disabilities/Virginia Commonwealth University
(804) 828-3876 (Voice), (800) 828-1120 (TTY)

Positive Behavioral Supports

Social Security Administration

Virginia 2-1-1

Virginia Association of Community Service Boards
(804) 330-3141

Virginia Board for People with Disabilities

Virginia Navigator

Virginia Parks & Recreation

CHAPTER 12:
Employment and Post-Secondary Opportunities

Why Work?

We derive meaning and a sense of self from many things in our life including our family, our friends, and our work. Employment contributes much to the way we view ourselves. Employment can impact our sense of self in many positive ways especially when we find the right job with the right support. These simple truths are no different for a person with a disability.

Impacts of Employment

Economics. Unlike the majority of the population, most people with developmental disabilities live at or near the national poverty level. Income from paying jobs can supplement resources and improve the quality of lives.

Relationships. Employment is where people develop relationships, friendships, and acquaintances with other people. Through work, people with developmental disabilities have more opportunities to become connected to the greater community. People with disabilities who are employed report having a higher number of friendships with people without disabilities than those who do not work.

Meaning. Our society values employment for all adults. Through employment, people with developmental disabilities gain skills, experience, and often a better understanding of the world around them. Being employed, in addition to the financial benefits, can make people feel there is a purpose to their lives.

Self Esteem. Employment can contribute to a sense of accomplishment, increasing one's sense of competence and self-worth. People with developmental disabilities who work believe more in their abilities and develop higher expectations for what they can accomplish. This can spread to other areas of their lives.

Identity. Much of who we are and how we are perceived by others is related to our employment in where we work, what we do, and the connections we make. People with development disabilities can benefit in the same way from employment.

Virginia's Recognition of the Importance of Work

On October 4, 2011, by a certificate of recognition signed by governor, Bob McDonnell, Virginia joined a number of states who have declared themselves as Employment First states.

The **Association of People Supporting Employment First (APSE)** defines Employment First as the following:

Employment in the general workforce is the first and preferred outcome in the provision of publicly funded services for all working age citizens with disabilities, regardless of level of disability.

In its official statement on Employment First, APSE maintains the following:

- access to "real jobs with real wages" is essential if citizens with disabilities are to avoid lives of poverty, dependence, and isolation;
- it is presumed that all working age adults and youths with disabilities can work in jobs fully integrated within the general workforce, in typical work settings, working side-by-side with people without disabilities, earning regular wages and benefits and being part of the economic mainstream of our society;
- it is presumed that individuals with disabilities are capable of working until proven otherwise, and employment in the general workforce is the first option pursued.
- as with all other individuals, employees with disabilities require assistance and support to ensure job success and should have access to those supports necessary to succeed in the workplace;
- all citizens, regardless of disability, have the right to pursue the full range of available employment opportunities, and to earn a living wage in a job of their choosing, based on their talents, skills, and interests; and
- implementation of Employment First principles must be based on clear public policies and practices that ensure employment of citizens with disabilities within the general workforce is the priority for public funding and service delivery.

Ethical Standards and Guidelines from APSE that influence SC work

APSE believes:

- everyone has employable strengths and can work in the competitive labor force with the right measure of support and in jobs well-matched and sometimes customized to their interests and abilities;
- people with disabilities are the experts about themselves and should play a leading role in decisions that affect their lives;
- companies who hire people with disabilities will profit in many ways, including financially;
- the focus of publicly funded services should be strengths-based - what people can do, not what they cannot do;
- an important role of the organization is to educate policy makers, including elected officials, on advocating for equal opportunities and fair treatment in the workplace.

The case has already been made for employment for all based on economics, relationships, meaning, self-esteem, and identity. Who can argue the value of each of these aspects and how they improve one's quality of life? Yet, according to the U.S Bureau of Labor Statistics, in 2020, 17.9 percent of people age 16 and older with a disability were employed. This is down from 19.3%- in 2019. That compares with 61.8 percent of people without a disability.

In Virginia, the concept of Employment First, means offering the option of integrated, competitive employment as the first choice of day activity to people entering services; it means no longer asking whether a person can work, but instead asking what employment best matches the person's strengths, skills, interests and conditions for success.

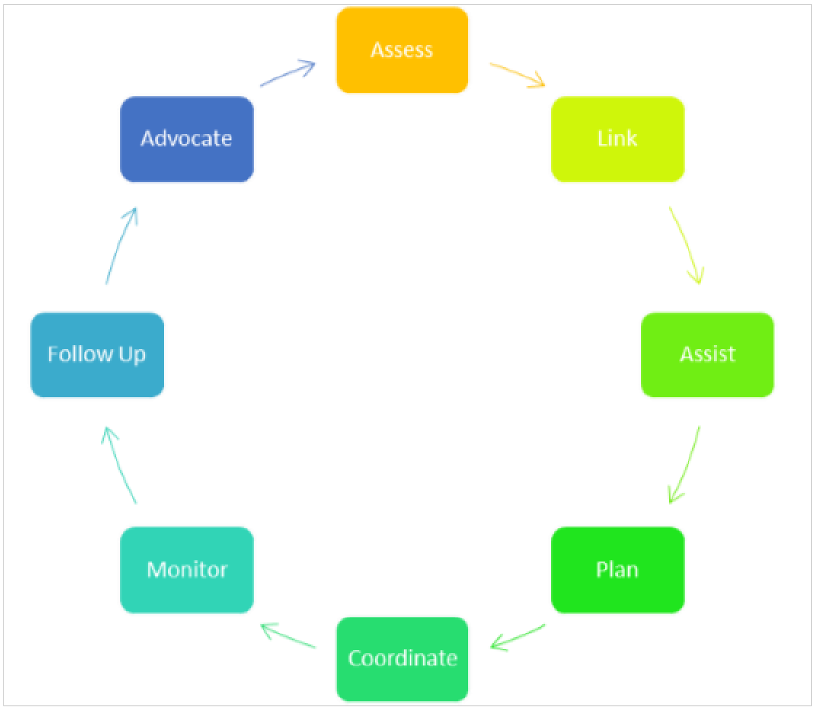
Definition of Employment

Employment means

- working in a typical work setting where the employee with a disability works along-side co-workers without disabilities;
- earning a competitive wage, i.e. minimum wage or better along with related benefits; and
- doing meaningful tasks i.e. work/tasks that contribute to the organization or business, with an opportunity for career advancement.

Role of the Support Coordinator

The role of the Support Coordinator (SC) is multi-faceted. A SC needs to be able to wear a variety of hats in supporting a person achieve their employment goals. Below is a diagram illustrating the diversity of the SC's



role. Each facet of the wheel will be discussed along with how these activities translate into helping a person achieve meaningful employment.

Assess

An SC should begin by using active listening skills to discover how the person they serve views employment, whether they want to work, what their employment dreams and goals are, what interests, experiences and skills they have that will lead the way to paid employment, and how they would be best supported in a working environment.

Often a person with a developmental disability will have no reference for choosing work. In order to appropriately assess this, the person who is being assessed has to understand what work is, what the benefits of work are, and what the possibilities of working can be. The provision and review of all the relevant information can help to ensure the person is making an informed choice. Examples of relevant information include such things as:

1. potential opportunities to learn about work, the types of jobs people do, and exposure to working people within their interest areas;
2. the skill sets required by different jobs;
3. what the person may need to do to acquire those skills;
4. which supports the person may need on the job.

Information gathered from both the person who wants to work and the team who knows them well may come from asking the following types of questions:

1. From the Personal Profile, what is there that demonstrates a skill or talent that might be used in a work environment or would be valuable to a prospective employer? For example, does the person have a good memory, are they friendly, are they organized?
2. Has the person had experiences that could lead to paid work? Have they held volunteer or paid jobs in the past? What did they like/dislike in each of these experiences?
3. Does the person have career interests and/or places where they may want to work?

(Word of caution: the obvious isn't always the best. An interest in animals does not mean that someone wants to work with them. Also do not make the assumption that a first job will be the only job a person will ever hold. Just as employment is an exploratory process for most of us; so to it should be for a person with a disability. Imagine being placed in a job and the expectation of keeping that same job until retirement.)

4. From the Essential Information, under Employment, a conversation regarding employment is expected. Topics to discuss include employment interests, available options, satisfaction or dissatisfaction with current services, barriers related to pursuing employment options, addressing barriers, as applicable, a timeline for reviewing options in the future, at least annually, any related actions that will be taken, what the person is working on at home and school that will lead to employment, and alternate sources of funding (such as school or DARS). Which of these topics are relevant for the person supported?

5. Looking at "Important To and Important For" (part of developing the Person Centered Plan), is there anything that could help the person be successful in their areas of interest or places where they want to work?
6. Does the person have behavioral support needs either in the past or present that are causing the person to be held to a higher standard around employment, in order to be given a chance to work, than others in the community? Should overcoming them be a requirement of becoming employed? Is this fair? Can some of these issues be addressed through the right job match?

A good resource for collecting information about interests, possible job avenues, best support and involving someone in writing their own resume is the I Want to Work Workbook and Partner Guide. Free copies may be obtained, as long as supplies last, from the Partnership for People with Disabilities/VCU. Contact Dawn Machonis.

Link

As a SC, linking a person with the right resources, including resources already present in their lives is another key element of success. While all efforts around work should focus on the person first, it is important to remember we all have support networks that help us to achieve our goals. Family, friends, professionals and advocates are often members of the "typical" team for a person with disabilities, yet the truth is the team can be comprised of anyone the person thinks can support them in achieving their employment goals. Part of getting the answers and helping the person achieve their goals is helping them to identify and leverage their personal networks. Many people find their first job and other jobs through people they know. This is no different for someone with a disability. Therefore, understanding and knowing the people who comprise the person's personal network can be critical to ensuring success. Success is equally dependent on linking personal networks with other professionals supporting the person in achieving their employment dreams. There can never be enough linking or educating about organizations that support people in working towards employment. The SC can:

- explore personal networks for employment resources and connect them with professionals if needed;
- connect the person to appropriate professional resources;
  - Department of Aging and Rehabilitative Services (DARS);
  - Employment Service Organizations (ESOs);
  - Benefits Planning Services;
- connect DARS and Employment Service Organizations to people in the person's network;
- discuss educational and post-secondary educational opportunities to enhance skills for employment (link post-secondary section); and
- connect to community learning opportunities.

Assist

Assisting the person means supporting them to reach their goals. There are legitimate things that may have to occur in order for a person to be successful in the job that they choose. Supporting persons in selecting among options based on the relevant information and then honoring individual choice is essential. Recognizing that the choices people make may be different from the choices other team members might make for them is fundamental to creating a respectful, supportive environment. Identifying any barriers is critical, and equally important is developing a game plan to break down those barriers. All members of the person's team are needed to address barriers. The team should not identify a barrier and simply determine it to be insurmountable. Moving from a mind-set of "can't" to "how" is imperative. Team members will need to be focused and creative in addressing issues around barriers that interfere with the choices a person has made, especially issues involving staffing and transportation. In this instance, the "more heads are better than one" adage could not be truer. The more minds there are trying to find solutions to overcome barriers, the better, as there will be more creativity involved.

It is the SC's role to lead the team in creativity, ingenuity and determination to problem solve.

- Who is in the person's personal network that can help work toward finding and keeping employment?
- Ask the question: What could we do NOW to help the person be employed in the future?

What are skills and talents that could be tapped into?

  - What activities are available in Day Support or Community Engagement that could expand their options and knowledge of work and career possibilities?
  - Ask about obstacles - what are they? What could be done NOW to help overcome these obstacles?
  - Garner support from current providers to think outside the box and put something into place in the person's current plan to address these obstacles.

Common Barriers

Barriers to employment will be unique to each person served but several barriers are common. These barriers include:

Lack of funding. If someone does not have waiver services, paying for job development and support services for many families is impossible. DARS may be used as a resource, but often their resources are limited as well.

Misconceptions about benefits. Families at times fear that employment will mean a loss of government benefits such as SSI and Medicaid.

Attitudes. Lack of belief that a person with developmental disabilities can work may be present in families, employers, and even the person themselves.

Lack of opportunity. This is true especially in rural areas where job opportunities for all people are limited.

Lack of transportation. Resource: Employment Programs for Persons with Developmental Disabilities- Department of Health and Human Services OFFICE OF INSPECTOR GENERAL August 1999.

Possible ways to address barriers:

- explore local funding and new services;

- consider self-pay;
- consider natural supports;
- use work incentives;
- ABLE accounts;
- PASS plan;
- educate job seekers and family members- show videos from (www.realworkstories.org);
- advertise with personal networks;
- look at small business and local companies;
- ride share, community transportation; and
- family peer mentoring.

Building a Resume

Anyone interested in working needs a resume. Throughout the process of assisting someone in securing employment, there are many activities a person can do to add to and build their resume. While working on finding a paid job, meaningful, productive activities can help increase skills, knowledge, experiences and be fun. As with all employment-related pursuits, these should be based on the interests and preferences of the person being supported. Activities may include but are certainly not limited to:

- volunteer work;
- taking classes at technical school, community college, community adult education, and/or local cultural sites, such as museums or art studios;
- taking online courses;
- attending workshops, seminars or conferences;
- internships;
- joining service or charitable organizations;
- participating in charitable events;
- attending camps that stress academics, teach skills, or show team-building;
- joining advocacy organizations; and
- developing hobbies in which one learns job related skills.

All of these activities should be tracked and added to a resume.

Plan

Recognizing that a person you support knows the most about their situation necessitates the involvement of them in every decision. The person should be an active participant in developing their person-centered plan, including discussion of integrated, competitive employment services at least annually and inclusion of employment goals or goals that breakdown barriers to employment in an individualized support plan. Remember “nothing about me without me!” How can this be done?

In thinking about a first job, imagine it to be the only job or employment to which one is tied until retirement. Many of the general population today would be working as camp counselors, fast food employees, grass cutters or babysitters. With people with disabilities, we sometimes forget that a person’s first job is not necessarily meant to be their last job. In fact, the people we support should have the same opportunities to grow, learn and change as the rest of the population.

The SC's role is to help people they support identify what they want their future to look like. This is called career planning and it involves:

- Recognition that planning goes beyond getting the person a job yet at the same time understanding and communicating with the job seeker and their family that most first jobs help people develop valuable work skills that may lead to advancement.
- Identifying what someone's long term career aspirations are and assisting in developing plans for 2, 5, or 10 years into the future.
- Identifying what additional educational and/or training opportunities will help the person get where they want to go.

Planning is also an opportunity to expand a person's understanding of the importance of employment through conversations:

- asking the person why they are working and explaining the importance of the tasks they are being asked to complete.
- helping them to see where they fit in the organization and brainstorming opportunities for advancement that might exist.
- explaining the dignity of work, the value that they add to the organization through the tasks they perform, and how they earn a paycheck.

It is important for the Support Coordinator to talk with the person about how it is possible that advancement in a job may happen over time; but this may not be the case for everyone. Teaching the person how to grow in their current position, to master new skills, and to branch out to learn other areas, actually supports the person in becoming a more valuable and hopefully more satisfied employee.

Coordinate

Coordination of services ensures that multiple people providing support are not working on the same things. Teams can move more quickly if they divide up responsibilities and each member take a role in helping the person achieve their employment goals. Having a coordinated plan will minimize confusion.

- Coordinate Responsibilities
    - Who will be carrying out which duties?
    - Who will make necessary appointments with other professionals?
    - Who will accompany them to intake appointments?
    - Does the person need supports and services – not all of the people SCs support do?
    - Is there funding available for services/supports? How can it be accessed?
    - Are the right supports available? Who will coordinate their involvement and implementation?
- What are transportation options open to the individual if they have a job? How are they accessed? How will they be paid for?

- Is there a provider that a referral could be made to now? If not, what information could be provided that would assist in the choice of provider at a later date?

Monitor

Monitoring services will ensure that the person maintains the paid and unpaid supports and assistance that they need. The Support Coordinator's role in monitoring is different depending on whether or not the person has a job and whether or not paid supports are in place. Monitoring when the person does not have a job means ensuring the team continues to identify and address barriers, while at the same time providing education and training around realistic expectations of themselves and of potential employers. When the person has a job, monitoring ensures that the person still has the job they want, that their hours are working for them, and that they are happy where they work. This monitoring ensures that a person has an opportunity to share when/if they are unhappy in their work or would like to pursue another job.

Questions to Ask

- Is the person working? If no
    - Are the barriers that have been identified being addressed? This requires thinking "outside the box" in many instances.
    - Is the team job developing consistently?
    - Are they (the person and other team members) satisfied with the supports and services implemented towards securing employment?
    - Refer them to experts who can provide counseling on benefits such as SSI, SSDI, Medicaid and Medicare (see the box below under Misinformation about Employment and People with Disabilities for information about these experts).
- Is the person working? If yes
    - Are they happy in their job?
    - Is it the job they want?
    - Do the hours work?
    - Are there any unmet employment needs?
    - Is the team actively involved, on the same page?

Supporting the person through training in self-advocacy and/or encouraging discussion with the job coach, supervisor, employer and/or the employment service provider by role playing to increase effective communication can help a person raise and address changes that are needed in order to ensure greater job satisfaction. It is also helpful for the Support Coordinator and the rest of the support team to share with the person the fact that people aren't always 100% happy in their jobs. It may be that a person cannot always be accommodated for everything that they want. However, there is a balance to be achieved between the perfect job and an awful job; that is a job that meets our most important needs, provides fair compensation, and engages us in meaningful work and gain skills for our next opportunity.

Follow-up

Once the Support Coordinator has assessed, linked, assisted, coordinated, and monitored, the next step in supporting a person achieve their goals is follow-up. The Support Coordinator with the assistance of the right people, work together to ensure the person and their dream is not forgotten.

- Are the barriers that have been identified being worked on?
    - Have alternatives been identified?
- Are they job developing consistently?
    - If no why not, how can this be resolved?
- Are they satisfied with the supports and services implemented towards getting them a job?
- Who can help them to become satisfied?

Does the person still need the same level of supports and services?

Does the person need assistance with managing their benefits?

Advocate

Support Coordinators serve a critical role in advocating for the person in several instances such as:

- when support network members in their effort to act in what they believe is the person's best interest, may hinder the person;
- dispelling myths and misconceptions, both positive and negative about a person's ability or lack of ability; and
- creatively addressing barriers and concerns that are raised. The Support Coordinator need not have all the answers but instead should know where to connect the person to get them. The Support Coordinator should be the initiator of brainstorming efforts and steer clear of shutting down discussions that may be "outside the box."

Support Coordinators also play an important role in system transformation, as this can only occur when advocates come together, united to educate and change the system. Often Support Coordinators are leaders in this effort as they can do much to educate the community at large through their day-to-day responsibilities. Support Coordinators:

- educate families, individuals and team members about the value of employment;
- identify barriers to employment in communities;
- leverage personal and professional networks and communicate the value of employing individuals with disabilities; and when needed
- work with Employment Service Organizations to overcome those barriers.

Three resource documents

Employment Support Coordinator FAQ at a glance
Employment Family FAQ at a glance

Employment Options Discussion at a glance

Transportation Resources

As stated above, lack of transportation is a common barrier to obtaining and keeping employment. Support Coordinators can link those they support with a variety of options, granted that as with other problem solving, this may take some creativity. Some resources are:

Personal Networks

When looking for work, is it possible for the job seeker to find work within walking distance or at or near a business in which they already know someone? Explore networks in a person's life for transportation resources. Family, friends or a privately paid acquaintances may be transportation resources. "Carpooling" with a co-worker may be an option in which the non-driver contributes gas money in place of their turn to drive. Also private companies such as Uber or Lyft could be used for occasional needs. A program called Go Go Grandparent (open to anyone 18+) acts as an intermediary with transportation companies for those who may not have a smartphone (GoGo Grandparent website)

Public Transportation/Travel Training

Many people get to their places of employment by using public transportation, such as buses and subways.

Travel training teaches people a variety of travel skills that will enable them to ride local transportation independently. Depending on what part of the state the Support Coordinator works, will determine if travel training is available. Here are some of the available resources in Virginia but the SC should continue to search for others on the internet.

The Arc: Northern Virginia
ENDependent Center of Northern Virginia, Inc.
MetroReady Travel Training and System Orientation for People with Disabilities and Outreach
Richmond metro

Paratransit

Paratransit is a specialized, door-to-door transport service for people with disabilities who are not able to ride fixed-route public transportation. Fact Sheet: Paratransit Services.

Employment and Community Transportation

For people who use waiver services, each of the three DD Waivers includes a service entitled Employment and Community Transportation, which includes assistance with getting and going to a job. See chapter 6 for more about this service.

If someone has Fee-For-Service (FFS) Medicaid, Managed Care Organization (MCO), or Commonwealth Coordinated Care Plus (CCC+) they may be eligible for Non-Emergency Medical Transportation (NEMT) services. This service will take you to Medicaid-covered services such as medical and health care appointments, supported employment and day support programs.

Parking placards and plates for people with disabilities

DMV offers parking placards and plates for customers with temporary or permanent disabilities that limit or impair their mobility. They are also available to customers with a condition that creates a safety concern while walking (examples are Alzheimer's disease, blindness or developmental amentia).

These placards and plates entitle the holder to park in special parking spaces reserved for individuals with disabilities. Institutions and organizations that operate special vehicles equipped to carry persons with disabilities may also obtain parking placards and plates entitling them to special parking privileges Parking Placards and Plates for Virginians with Disabilities.

Vehicle Modifications

For those who use waiver services, environmental modifications are included on all three DD Waivers and may include reimbursement for changes to a personal vehicle: Vehicle Modifications.

Misinformation about Employment and People with Disabilities

There are assumptions about people with disabilities and employment, such as:

- **Not everyone can work!** Everyone should be given the opportunity to explore work. Even people with the most significant disabilities can and do work. https://www.thinkwork.org/project/real-work-stories
- **You can’t work and keep benefits!** Support Coordinators recognize that the person (and their family) may have real concerns about work, income, and its impact on benefits. It may have taken them a long time to be approved for benefits. They are concerned that they will lose their benefits. Fear of losing cash benefits, as well as medical coverage under Medicaid (SSI) or Medicare (SSDI), often persuades individuals to severely limit their employment participation and earnings or, more commonly, not to enter the labor force at all. Unfortunately, beneficiaries are often told that employment will lead to the loss of their benefits.

Additional Information about Benefits

- Special rules make it possible for an individual with disabilities receiving Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) to work and still receive monthly payments and Medicaid or Medicare. Social Security calls these rules **“work incentives."**
- If the person currently receives Medicaid, they should be eligible to continue to receive Medicaid even after they stop receiving Supplemental Security Income (SSI) cash benefits due to work. Section

1619(b) of the Social Security Act provides some protection. To be eligible, they need to meet certain requirements, which include earnings below a threshold amount set by Virginia. Even if their earnings exceed the state threshold, they may still be eligible under certain circumstances.

- If they earn enough that their Social Security Disability Insurance (SSDI) checks stop, Medicare can continue for up to 93 months.
- Individuals do not need to reapply if their benefits have ended within the past five years due to their earnings and they meet a few other requirements, including that they still have the original medical condition or one related to it that prevents them from working. This is a work incentive called **“Expedited Reinstatement."**
- Social Security ordinarily reviews an individual’s medical condition from time to time to see whether they are still disabled, using a process called the medical Continuing Disability Review, or medical CDR. If they participate in the Ticket To Work program with either the State Vocational Rehabilitation Agency (DARS) or another Employment Network (EN), and make “timely progress” following their individual work plan, Social Security will not conduct a review of their medical condition. If a medical CDR has already been scheduled for them before they assigned their ticket, Social Security will continue with the medical CDR.
- MEDICAID WORKS is a work incentive opportunity offered by the Virginia Medicaid program for people with disabilities who are employed or who want to go to work. MEDICAID WORKS is a voluntary Medicaid plan option that will enable workers with disabilities to earn higher income and retain more in savings, or resources, than is usually allowed by Medicaid. This program provides the support of continued health care coverage so that people can work, save and gain greater independence. More information on Medicaid Works may be found at Medicaid Works (Medicaid Buy-In).
- **You only get one chance to work!** Sometimes, a job comes along but it is the wrong job, the wrong time or, the wrong supervisor. People with disabilities are no different in this regard; sometimes it takes a couple of times to find the right job, at the right time, with the right people!
- **People with disabilities can only do entry level work in the food, cleaning, and manufacturing industries!** This is not true. People with disabilities in Virginia are working as advocates, data entry specialists, mechanics, hospital workers, etc. People are only limited by society’s perception of them.

Employment Services under Waivers

If someone has one of the three Developmental Disabilities Waivers, there are employment services offered. All three waivers provide:

- Supported Employment, both individual and group; and
- Community Engagement - a service where employment skills can be built.

An additional employment service, Workplace Assistance, is also provided under the Community Living Waiver and the Family and Individual Support Waiver.

Ordinarily DARS would be a first option for referral for employment services for people who use waiver services. However, when DARS has a waitlist, this may be bypassed.

All of these services are described in Chapter 6.

Integrated Employment Models

There are a variety of community integrated employment models used in Virginia and across the country such as:

- **Individual Supported Employment** is one person, one job, with supports based on the needs of the person
- **Entrepreneurship** involves a person starting their own business
- **Business within a Business** is an employment model where someone opens a complimentary business within an existing business. For example, a barista at a local hotel.
- **Group Supported Employment**, involves small groups (no more than 8 individuals) working in a community business, while they have ongoing supports. The supports are there to fully integrate the person into the work environment and help them develop meaningful relationships with their coworkers while supporting them with their tasks.

The goal of each of these employment models and services is to support individuals in integrated work settings, doing meaningful work, for which they are paid at least the minimum or competitive wage and benefits.

Benefits Counseling

The Support Coordinator need not, nor should they, act as a benefits advisor to the people they serve. Knowing all the rules governing work and its impact on an individual's benefits is best left to the experts. Benefits analysis is complicated and work incentives are specific to the type of benefit(s) a person receives. Inaccurate information can lead to an "overpayment" and even a loss of benefits. Income can also have an impact on other federal, state and local programs including food stamps, Section-8 housing vouchers, etc. Below is information on experts to whom you may refer those you support.

Experts on Benefits and the Services Provided

Work Incentive Planning and Assistance (WIPA) projects are funded by the Social Security Administration (SSA) to provide information and benefits planning to enable beneficiaries with disabilities to make informed choices about work. WIPA projects hire and train Community Work.

Incentives Coordinators (CWICs) who work with individuals receiving Social Security Disability Insurance (SSDI) and/or Supplemental Security Income (SSI) to provide in-depth counseling about benefits and the effect of work on those benefits. In Virginia, The vaACCSES - WIPA project provides Community Work Incentives Counselors and Benefits Specialists to provide all SSA disability beneficiaries (including transition-to-work aged youth) with access to benefits planning and assistance services. The ultimate goal of the WIPA project is to assist SSA's beneficiaries with disabilities in meeting their employment goals.

To learn more about the function of these specialists and how to contact them, go to:

- contact the Ticket to Work Help Line at (866) 968-7842 or (866) 833-2967 TTY
- visit Welcome to The Work Site
- visit Ticket to Work
- visit Work Incentives Planning & Assistance (WIPA)

Work Incentive Specialist Advocates (WISA) Work Incentives Specialist Advocates (WISA's), are individuals who have been certified to provide work incentives counseling services to DARS clients who are receiving Social Security Disability (SSDI) and/or Supplemental Security Income (SSI) benefits. To learn more about the function of these specialists and how to contact them go to Grants & Special Programs.

Benefits planning service Benefits planning is an individualized analysis and consultation service for recipients of a DD waiver and social security (SSI, SSDI, SSI/DDSI) to understand their personal benefits and explore their options regarding working, how to begin employment, and the impact employment will have on their state and federal benefits.

CHAPTER 13:
Housing

Introduction

Historically, people with developmental disabilities (DD) have experienced major barriers to living in their own homes, including affordability, accessibility, and lack of supportive services options. Over the past several years, the Commonwealth has focused on addressing these obstacles and making significant investments to:

- redesign its system of Home and Community based services for people with DD and offer a broader array of services to support people in their own homes;
- offer rent assistance;
- provide funds to assist with upfront costs to secure housing; and
- help modify units so people can live in the same types of housing in the community that people without disabilities do.

As people learn about these new opportunities and see others enjoying greater choice and control over where they live, with whom they spend their time, who supports them, and what they do with their day, more people with disabilities are opting to live in integrated, independent housing.

> Virginia envisions Virginians with DD, including those in the Settlement Agreement population, will have greater access to housing resources that offer increased opportunities for integrated, independent living.

The Department of Behavioral Health and Developmental Services (DBHDS) has placed Regional Housing Coordinators in each of the five Developmental Services Regions to assist in making this plan a reality. See https://dbhds.virginia.gov/developmental-services/housing/housing-team for information on how to contact your Regional Housing Coordinator.

What Is Integrated, Independent Housing?

Integrated, Independent Housing has its roots in the following paradigm:

Individuals have the right to:

- choose where they live;
- choose who to live with;

- choose who will provide supports needed to be safe, healthy and independent (supports can be paid or natural supports); and
- community inclusion.

Integrated, Independent Housing has the following core features:

- the individual does not reside with a parent, grandparent or guardian;
- the individual can live in housing types that anyone without a disability lives in, based on income;
- the individual has social, religious, educational and personal opportunities to fully participate in community life;
- housing is affordable (the individual pays no more than 30% to 40% of his/her adjusted gross income);
- housing is accessible (barrier free);
- housing is leased or owned by the person using services; and
- housing is not contingent upon participation in services (and vice versa).

Support Coordinator's Role in Integrated, Independent Housing

Support Coordinators (SCs) are primarily responsible for assessing individual needs, developing plans for support to help reach individual outcomes, linking individuals to services and supports, assisting individuals with locating or obtaining needed services and resources, coordinating services, enhancing community integration, offering education and counseling to guide individuals and monitoring whether services are helping achieve intended outcomes. When it comes to integrated, independent housing, the responsibilities are very similar. SCs convene the person-centered planning team and "coordinate" with members of the team to ensure a person's plan for housing is fully implemented.

Here is a more detailed description of what the SC's role is specific to housing:

Support Coordinator's Role	What This Role Looks Like in Housing
Offer education and counseling to guide individuals	Provide education about integrated, independent housing options (contact the Regional Housing Coordinator for assistance). • Review housing assistance options available in the individual's community. • Share links to housing videos and information sessions about housing options. • Encourage individuals to connect with their peers to learn about living in integrated, independent housing Explore the person's vision for housing. • What does the person's desired housing arrangement look like?

Support Coordinator's Role	What This Role Looks Like in Housing
	• Where does the person want to live? With whom? • What is important to/for the person in housing?
Assess individual needs	Assess individual's preparedness for housing and specific housing needs • Who (if anyone) will the individual live with? • What supports does the individual need to obtain and maintain housing? Who does the person want to provide these supports? Can the person access these supports? • Does the person have a realistic budget to obtain and maintain housing? What income and assets does he/she have? • Does the person have the documents he/she will need to obtain housing (e.g., Social Security card, birth certificate, government photo I.D.)? • What specific housing features does the person need (e.g., specific location, unit size, accessibility features)? • What barriers does the person face to obtaining rent assistance and housing (e.g., poor credit, prior evictions or lease violations, criminal history, etc.)?
Develop the individual service plan	Based on the assessment above, develop the plan to help the individual transition to independent housing and to maintain housing. • Identify and get commitments from any roommates and/or live-in aides. • Outline plans to secure needed supports in housing, including funding sources, providers, and proposed support schedule. • Determine ways to increase income, reduce expenses and access alternative resources to offset living expenses (e.g., SNAP, fuel assistance, etc.). • Define financial responsibilities (e.g., who will pay for specific upfront and ongoing housing expenses and how will payments be made). • Identify documents needed to apply for housing and who will assist with securing them. • Review potential housing options and locate properties that may meet the individual's needs.

Support Coordinator's Role	What This Role Looks Like in Housing
	• Identify housing assistance programs for which the individual is eligible and would like to apply. • Investigate approaches to reduce or remove barriers (e.g., reasonable accommodation requests, building or repairing credit, tenant training).
Link to services and resources Assist individuals with locating or obtaining needed services and resources Coordinate services	Based on the plan above, SC activities may include: • Submitting a DBHDS housing resource assessment and referral for housing assistance. • Assisting the individual with completing housing assistance applications and eligibility interviews. • Supporting the individual with applicant briefings for housing assistance. • Connecting the person to affordable rental properties that may meet his/her needs and/or accept rent assistance. • Coordinating resources and services to assist with the housing search, lease review and the move (e.g., family, support services such as Community Housing Guide). • Helping individuals access funding sources to cover upfront expenses related to securing housing (e.g., application fees, security deposits, utility deposits, etc.). • Assisting individuals with requesting reasonable accommodations and modifications in housing assistance programs and housing.
Monitor whether services are achieving intended outcomes	If an individual who lives in independent housing receives no Waiver services in the home, the SC should do the following: • Provide two in-home visits per year to review whether the housing environment continues to meet the person's needs. • Complete two telephone contacts per year with the individual to monitor rent and utility payments and satisfaction with the housing arrangement. • Make two collateral contacts per year with the landlord and two contacts with the housing program to support compliance with the lease and the housing assistance program's participation requirements.

Support Coordinator's Role	What This Role Looks Like in Housing
	If an individual live in independent housing and receives Waiver services in the home, the SC should do the following. • Provide at least one, in-home visit per year to review whether the housing environment continues to meet the person's needs. • Complete two telephone contacts per year with the individual to monitor rent and utility payment, satisfaction with housing arrangement. • Make two collateral contacts per year with the landlord, and two contacts with the housing program, to support compliance with the lease and housing assistance program participation requirements. • Review quarterly reports from the service providers to determine whether service providers that support the individual in the home report changes in the person's housing needs, satisfaction with the housing arrangement, rent/utility payment status, or compliance with lease or housing assistance program requirements.

Support Coordinators work closely with others on the person-centered planning team to help individuals with developmental disabilities obtain and maintain housing, including Community Housing Guides, residential service providers, landlords and property owners, and the DBHDS Regional Housing Coordinator. For more information about how support coordinators' roles intersect with these partners, see the Community Housing Transition Collaboration Map in Appendix 1 at the end of this chapter.

Support Coordinator Training, Resources and Tools

DBHDS has created Independent Housing Training for SCs. This training consists of three modules and is **required** within the first 30 days of employment to ensure SCs are aware of independent housing resources and options available, as well as the process to access those resources. The Independent Housing Training for SCs can be found on the Commonwealth of Virginia Learning Center (COVLC). To access the Independent Housing Training, after logging in, please type in "Housing" in the search bar. Please note, there is also an Independent Housing Training in COVLC for Community Housing Guides, so make sure you complete the modules for support coordinators.

There are a number of tools and resources available on the DBHDS Housing website for SCs. For example, the following helpful tools are available:

- **Housing Assessment and Referral**: The purpose of the housing assessment is to help assess a person's eligibility for DBHDS housing resources and preparedness to successfully obtain rental assistance and rental housing. DBHDS requires support coordinators to complete a Housing Assessment and Referral for anyone being referred for DBHDS housing resources.

- **Housing Action Plan:** Using the information from the Housing Assessment and Referral, individuals and SCs can develop a housing action plan to guide the transition to independent housing. A comprehensive plan will help address barriers and ensure a budget, supports, accommodations and modifications are in place to facilitate a smooth transition into a home of one's own.
- **Independent Housing Monitoring Assessment:** When visiting individuals who have transitioned to their own homes, SCs can use this tool to monitor and record observations regarding an individual's housing stability in the areas of lease compliance, ability to maintain the unit, and general health and safety. If issues are observed, SCs and individuals can address these issues in the context of the individual service plan.

Please use one of the links below to access these tools and other resources.

https://www.dbhds.virginia.gov/developmental-services/housing/the-path-to-housing

https://www.dbhds.virginia.gov/developmental-services/housing/resources-for-support-coordinators-and-case-managers

Community Housing Guide Collaboration Map

Integrated, Independent Housing Resources and Options

SCs must submit a DBHDS Housing Assessment and Referral form to access the following housing resources for individuals they serve. The Housing Assessment and Referral is currently available at https://www.dbhds.virginia.gov/developmental-services/housing/resources-for-support-coordinators-and-case-managers

If the assessment reveals the individual is likely to face major barriers to housing, has not firmed up the household composition, or does not have a feasible budget or needed supports, the SC must develop a Housing Action Plan with the individual and his/her planning team and submit the Action Plan for DBHDS review. The purpose of the Action Plan is to address issues that could negatively affect the individual's ability to obtain or maintain housing. The individual and the planning team will work on the Action Plan together. Once the person has a viable plan to address these issues, DBHDS will place the referral in the queue to be assigned a housing resource.

Individuals on the waiver waitlist also access their housing resources through the DBHDS referral system and support coordinators submit the same Housing Assessment and Referral form. In the absence of waiver support coordination, CSBs may utilize Medicaid SPO case management for eligible individuals to complete support coordination activities associated with housing.

Housing Choice Voucher Special Admissions Preference and the State Rental Assistance Programs

The Housing Choice Voucher Special Admissions Preference Program and the State Rental Assistance Program are rent assistance resources for eligible people with DD in the Settlement Agreement population. Typically, the individual/household receives a voucher or certificate that can be used at any rental property in the community. A unit's "gross rent" (e.g., rent plus tenant-paid utilities) that is reasonable and affordable based on the program's maximum subsidy limit. The unit must also pass a safety inspection. If the unit is approved, the individual/household will pay 30%-40% of their monthly adjusted income towards rent, minus an allowance for tenant-paid utilities. The balance of rent (up to the maximum allowable by the program) is paid directly to the landlord by the rental assistance program administrator.

Rental Properties with a Leasing Preference for the Settlement Agreement Population

Certain rental properties, known as Low Income Housing Tax Credit (LIHTC) properties, have units that are available on a preferential basis for people with DD in the Settlement Agreement population. A growing number of LIHTC properties, including some with project-based rental assistance, provide this leasing preference. The leasing preference gives individuals in the Settlement Agreement population priority in applying for available units at these rental properties. Individuals must still qualify for the apartments (e.g., meet income and other tenant selection criteria). Rental assistance may or may not be available at the property. For information about rental properties with a leasing preference in your region, contact your Regional Housing Coordinator.

DBHDS Flexible Funding

DBHDS has partnered with one or more Community Services Boards (CSBs) in each region that serve as Flexible Funding program administrators to help people with DD in the Settlement Agreement Population afford the costs associated with (1) making the ***initial*** transition to their own rental housing or (2) maintaining housing if they are at risk of eviction. Some examples of costs that Flexible Funding could help pay for are:

<u>Assistance with the Initial Transition to Housing (one-time allotment of up to $5,000 for the **initial move only**)</u>

- rental application fees
- utility deposits and/or connection fees
- security deposits
- moving expenses
- essential furniture and other household supplies (these items have maximum allowable payment/reimbursement limits)
- non-reimbursable environmental modifications or assistive technology
- temporary rent to allow completion of environmental modifications
- direct support with housing location and pre-tenancy activities
- temporary support staffing to help individuals get acclimated to new housing (e.g., orientation to an apartment building and the surrounding community, instruction in use of appliances and environmental controls)

- shared living provider start-up activities (e.g., identifying roommate preferences, advertising for a roommate, assisting with interviews, performing background checks, arranging for required trainings, conducting visual inspection of the housing unit, facilitating discussions of support expectations, assisting with completion of the Supports Agreement)

Assistance with Maintaining Housing/Eviction Prevention (one-time allotment of up to $5,000 – can be drawn down until allotment is depleted)

- emergency rent and associated late fees
- last resort utility assistance
- household management activities (specialized cleaning, pest extermination)
- unit repairs
- temporary relocation

SCs complete and submit applications for Flexible Funding on behalf of individuals. CSB Flexible Funding program administrators can either reimburse individuals (or their families) for eligible, out-of-pocket expenses, purchase items on behalf of individuals or pay vendors directly. Documentation of expenses is required for all requests and must be submitted by the deadlines indicated on the application.

For more information about Flexible Funding, contact your Regional Housing Coordinator or visit https://dbhds.virginia.gov/developmental-services/housing/flexible-funding.

Role of Regional Housing Coordinators

Helping someone through the housing process can seem like a daunting task. Housing Coordinators are available in each region of the Commonwealth to make the transition process as smooth as possible. Housing Coordinators provide technical assistance to help SCs access housing resources in the community for eligible individuals. Housing Coordinators can:

- provide information about available housing resources;
- assist with submitting a DBHDS Housing Assessment and Referral;
- assist with developing a Housing Action Plan and implementing the Plan;
- assist with locating housing and completing rental and housing assistance applications;
- assist with preparing reasonable accommodation or modification requests;
- assist with developing approaches to address fair housing and/or tenant-landlord concerns; and
- assist with securing resources to cover transition expenses such as security deposits, utility connection fees, and essential furniture and household supplies.

Find your Regional Housing Coordinator at https://dbhds.virginia.gov/developmental-services/housing/housing-team

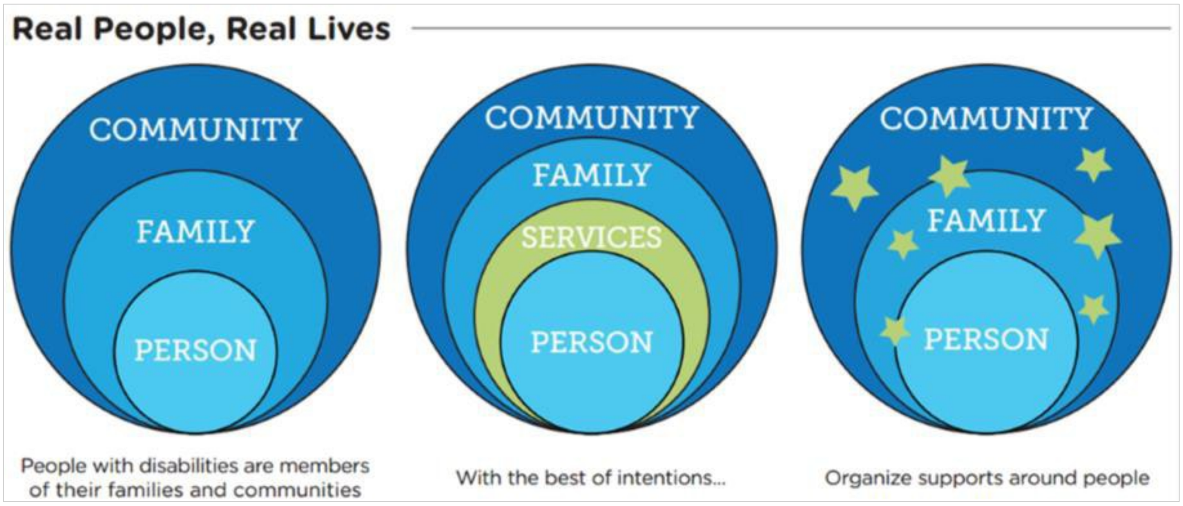
Centers for Medicare & Medicaid Services (CMS) Setting Regulations

The Home and Community-Based Services (HCBS) settings regulations (previously known as the "Final Rule") published in the Federal Register, became effective March 17, 2014. They were designed to enhance the quality of HCBS, provide additional protections, and ensure full access to the benefits of community living. Settings regulations establish requirements for the qualities of settings for those who use Medicaid-reimbursable HCBS services.

Mandated Qualities for Residential/Non-residential Settings

- *Supports full access to the greater community*
  - *Provide opportunities to seek employment, work in competitive integrated settings, engage in community life, control personal resources, and*
  - *Ensure that people use services in the community, to the same degree of access as those not using HCBS;*
- *Selected by the person served from among setting options including non-disability specific settings and options for a private unit in a residential setting;*
  - *Person-centered service plans document the options based on the person's needs, preferences, and for residential settings, resources available for room and board*
- *Ensures a person's rights of privacy, dignity and respect, and freedom from coercion and restraint;*
- *Optimizes one's initiative, autonomy, and independence in making life choices, including, but not limited to, daily activities, physical environment, and with whom to interact; and*
- *Facilitates one's choice regarding services and supports, and who provides them.*

The integration of services in a person's life, family and community are depicted in the third circle in the following diagram.



Resource: Michelle 'Shelli' Reynolds, PhD UMKC Institute for Human Development

A residential setting that is provider-owned or controlled is subject to additional requirements. These settings include group homes, sponsored placements and supported living situations.

Mandated Qualities for Residential Settings

- *Have a lease, or other signed legally enforceable agreement providing similar protections*
- *Have access to privacy in their sleeping units*
- *Have entrances lockable by the individual, with keys provided to appropriate staff as needed*
- *Have a choice in selecting their roommate(s), if they share a room*
- *Have the freedom to decorate and furnish their sleeping and/or dwelling unit*
- *Have the ability to control their daily schedules and activities and have access to food at any time*
- *Be able to have visitors at any time; and,*
- *Be able to physically maneuver within the setting (e.g., setting is physically accessible).*

Though it is not the responsibility of the SC to ensure that providers adhere to the additional requirements, it is important that the SC familiarize themselves with these requirements as they may need to discuss the settings regulations with providers.

To learn more about the HCBS settings rule go to: https://www.medicaid.gov/medicaid/home-community-based-services/guidance/home-community-based-services-final-regulation/index.html

CHAPTER 14:
Reviews

Importance of Reviews

There are several different types of reviews and audits in the DD service system. Some are intended to ensure that people are being provided with supports that ensure their health and safety, some reviews examine compliance with regulations, some are quality reviews, and some reviews look at documentation in order to justify Medicaid billing. It is important for Support Coordinators (SC) to know and understand the different entities that currently review the DD service system.

Internal

All DBHDS-licensed providers are responsible for conducting qualitative and quantitative reviews to evaluate clinical and service quality and effectiveness on a systematic and ongoing basis. SC supervisory and internal quality assurance reviews are conducted regularly to ensure the SC is consistently interpreting and applying licensing regulations and Medicaid requirements. Internal reviews allow the SC to learn methods to improve the quality of services they provide and ensure that the supports are in line with agency standards and state regulations.

External

Reviews and audits are conducted by several agencies that are not part of the Community Services Board (CSB) or SC organization. External reviews are often conducted by an independent review organization or a state or federal organization. The goals of external reviews are to provide a review free from conflict of interest, establish standard requirements and qualifications, and to provide fair and impartial reviews.

Department of Behavioral Health and Developmental Services (DBHDS)

DBHDS provides oversight to a number of different units that provide regular reviews of the DD service delivery system. Some of those units are employed by DBHDS and others are contracted to provide the reviews. Below is a description of the four review units associated with DBHDS.

DBHDS Office of Licensing (OL)

Licensing specialists are employed by DBHDS in the Office of Licensing (OL) to license, monitor and provide oversight and technical assistance to licensed public and private providers that deliver services to people with mental illness, developmental disabilities or substance use disorders. They conduct announced or unannounced onsite inspections, inspect buildings and locations, review staff qualifications, review individual plans, and investigate complaints regarding potential violations of licensing regulations.

DBHDS licenses services that provide treatment, training, support and rehabilitation to people who have mental illness, developmental disabilities or substance use disorders, to people using services under the Medicaid DD Waiver, or to people with brain injuries using services in residential facilities.

You can learn more about this department at the DBHDS Homepage.

DBHDS OL Annual Reviews

On an annual basis DBHDS will conduct announced and unannounced onsite reviews to determine compliance on preventing specific risks to people with disabilities. More information about the DBHDS Annual Medical and Behavioral Health Reviews can be located in the Licensing regulation 12VAC35-105-70.

Licensing regulations can be found here:
https://law.lis.virginia.gov/admincode/title12/agency35/chapter105/

DBHDS Office of Human Rights (OHR)

Human Rights advocates are employed by DBHDS in the Office of Human Rights (OHR). They advocate for the rights of people using services in DBHDS licensed programs and facilities. They monitor provider compliance with human rights regulations, provide consultation and education to people with disabilities, families and providers about the human rights regulations. OHR manages the DBHDS human rights dispute resolution program by investigating complaints regarding potential violation of the human rights regulations, reviewing provider’s policies to ensure compliance with the human rights regulations, and providing technical assistance to the Local Human Rights Committees (LHRC’s).

SCs help protect the basic human rights of people with disabilities. They ensure that people are treated with dignity and respect and are free from abuse, neglect and exploitation. The SC should ensure that the person and their legal guardian (LG)/authorized representative (AR) is involved in all aspects of care including person centered planning and signed consents for treatment. In the event that a person’s rights have been violated, the SC should ensure the person, their family and the LG/AR know who to contact if they have a complaint.

You can find more information about OHR at the following site:
https://dbhds.virginia.gov/quality-management/human-rights
https://law.lis.virginia.gov/admincode/title12/agency35/chapter115/

Quality Service Reviews

DBHDS contracts with a separate agency, the Health Services Advisory Group (HSAG), to conduct Quality Service Reviews (QSRs) of those with a developmental disability (DD) who use services under the Department of Justice (DOJ) settlement agreement. This includes people using services through the Medicaid Home and Community-Based (HCBS) Services DD Waivers who live the community.

The purpose of the QSRs is to evaluate the quality of services and determine if people are achieving outcomes, particularly in the areas of person-centered planning, integrated settings and community inclusion. The QSR consists of Person-Centered Reviews (PCR) and Provider Quality Reviews (PQR). The person using services has a voice as part of each process which is measured during interviews with the person, their authorized representative or legal guardian. During a QSR, the SC can expect to be interviewed by HSAG reviewers. QSRs also include provider and SC record reviews.

National Core Indicators (NCI)

DBHDS contracts with the Partnership for People with Disabilities at Virginia Commonwealth University to collect National Core Indicators (NCI). NCI is a voluntary effort by public developmental disabilities agencies to measure and track their own performance. The core indicators are standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern including employment, rights, service planning, community inclusion, choice, and health and safety. NCI gathers information through face-to-face interviews about satisfaction with supports and services from the people who use them. The survey instruments are used by a majority of states in the U.S. Information is also gathered from families about satisfaction with supports and services via mail-in surveys. Major activities of NCI include conducting interviews with people who use supports and services across the state, and sending mail-in surveys to family members of people who use supports and services. Analyses and reports of findings may be found at Virginia's NCI website and at the National NCI website.

Department of Medical Assistance Services (DMAS) Reviews

Quality Management Reviews (QMR): QMR Reviewers are employed by the Department of Medical Assistance Services (DMAS). QMR reviews are intended to ensure the health, safety and welfare of individuals receiving home and community based waiver services. Federal regulations require that DMAS assure that necessary safeguards have been taken to protect the health and welfare of the recipients of services, assure that all providers are in compliance with applicable State and federal standards, and assure financial accountability for funds. Reviewers complete reviews of provider documentation and personnel records for compliance with Medicaid policies and regulations, and provide technical assistance related to onsite reviews. They may refer providers to the DMAS Program Integrity unit when fraud is suspected or retractions in funding are warranted. A link to the website is provided on this slide. You can find more information about the QMR on the LIS website.

Utilization Reviews are financial audits conducted by DMAS Program Integrity staff or its contractor, Myers and Stauffer, LLC. Audits are conducted to: 1) assure that Medicaid payments are made for covered services that were actually provided and properly billed and documented; 2) calculate and initiate recovery of overpayment; 3) educate providers on appropriate billing procedures; 4) identify potentially fraudulent or abusive billing practices and refer fraudulent and abusive cases to other agencies; and 5) recommend policy changes to prevent waste, fraud and abuse.

Department of Justice (DOJ) Settlement Agreement Independent Reviewer

As a result of the DOJ settlement, an independent reviewer, separate from the state of Virginia conducts reviews and submits reports every 6 months on their findings. These reviews can include document reviews and discussions with Support Coordinators, provider, DBHDS staff and others in Virginia's DD system of supports and services. To learn more about the Settlement Agreement and read past reports, visit: https://dbhds.virginia.gov/doj-settlement-agreement.