

Chapter Two

Exploring Supported Living



What You Will Find:

Services and Supports

Roles and Responsibilities

Places to Live

Liaison Network



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Key Information for Decision-Making

- Supports and Services
- Roles and Responsibilities
- Planning Process
- Places to Live
- Liaison Network

Introduction

Prior to deciding to provide or obtain supported living services, interested persons need information about the:

- types of supports and services available and needed;
- role of the supported living coach and other support providers who may be needed;
- options for living arrangements;
- individualized planning process; and
- experiences of others who have received supported living services.

Supported living is one residential option in Florida's system of supports and services for persons with developmental disabilities. The majority of these supports and services are administered by the Agency for Health Care Administration (AHCA) and implemented by the Florida Department of Children and Families (DCF) Developmental Disabilities Program. This vast array of Medicaid Waiver services are identified in the Developmental Services Waiver Services Medicaid Coverage and Limitations handbook. This DS Waiver handbook includes descriptions, requirements, and qualifications for all Medicaid Waiver services. Copies of the DS Waiver handbook may be obtained through the AHCA website (www.fdhc.state.fl.us/medicaid/dev_serv/).

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Successful community living depends on a coordinated network of support to ensure the individual receives assistance, training, and intervention at the right time and in the right way. This network, based on a partnership between formal (paid) and informal (non-paid) supports, may include many people, such as friends, relatives, providers of services and other community members.

This chapter discusses the array of paid supports and services that may be provided through the State's Developmental Disabilities Program. The type, intensity, and frequency of services and supports will need to be addressed when the person is exploring a supported living arrangement.

The Medicaid Waiver was expanded in Florida in 1993 as a means of adding federal funds to the much overburdened State general revenue funding. The Medicaid Waiver currently funds the majority of services for individuals with developmental disabilities statewide, and includes supported living coaching as one type of service option. While there are a wide array of services available through the Medicaid Waiver, funding approval for all services is contingent on the Department of Children and Families (DCF).

The Role of the Support Coordinator

The waiver support coordinator (WSC) serves as the individual's primary contact with the State Developmental Disabilities Program and other needed services and community resources, regardless of the funding source. By definition, support coordination is the "service of advocating, identifying, developing, coordinating and accessing supports and services on behalf of a recipient, or assisting the recipient or family to access supports and services on their own."

The provider of support coordination services, consistent with the limitations described in the DS Waiver handbook, is "legally and financially independent of persons or organizations providing (other) direct services." The Medicaid Waiver encourages each recipient to choose a waiver support coordinator who will coordinate services and supports and assist the person with individualized planning designed to enrich his life.

The planning document, the support plan (SP), and the accompanying plan for outlining the cost of each service, the cost plan, become the authorizing documents for all services and supports needed and desired by the individual. The cost plan identifies the service or support, and how much time and money has been approved for that service. The SP describes the services authorized on the cost plan through the identified goals, outcomes and actions. The

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supported living coach, as with all providers, should implement services consistent with the SP goals and with the amount and duration authorized.

As changes occur regarding the need for supports and services both the SP and the cost plan may be updated. The individual and her guardian, if applicable, can work with the provider and the support coordinator to make adjustments to both the SP and the cost plan. It is the waiver support coordinator's responsibility to request service approval on the cost plan; however, if some elements of the cost plan are denied, it may be necessary to provide additional information to justify the need for that particular service.

The role of the waiver support coordinator may vary based on individual needs and desires, but overall, it is his responsibility to assist the person and her family in the planning and selection of providers, the coordination of all supports and services including the facilitation of communication among all involved parties, act as an advocate, and monitor health and safety across all settings where services are provided. Unlike supported living coaches, support coordinators do not provide training, instruction, or any direct services other than support coordination.

The Role of the Supported Living Coach

A supported living coach is a trained professional who provides assistance, training, and instruction in a variety of activities to support persons who live in their own homes. Supported living coaching always focuses on the health and safety of the individual both in and around his home. Supporting persons in maintaining good health, accessing community health care services, and promoting personal safety are essential components of the relationship that exists between the coach and the person receiving supported living services.

Supported living services are defined in the DS Waiver handbook as:

Supported Living Definition:

“The provision of supports necessary for an adult ... to establish, live in and maintain a household of their choosing in the community. This includes supported living coaching and other supports.” These services may include “assistance with locating appropriate housing, the acquisition, retention or improvement of skills related to activities of daily living such as personal hygiene and grooming, household chores, meal preparation, shopping, personal finances, and the social and adaptive skills necessary to enable (persons) to reside on their own.”

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Coach's Overall Responsibilities:

- **Assists** with locating housing and needed household supports.
- **Teaches** the acquisition, retention or improvement of activities of daily living such as:
 - personal hygiene;
 - grooming;
 - household chores;
 - meal preparation;
 - shopping;
 - personal finances; and
 - social and adaptive skills.
- **Coordinates** opportunities for connecting with community resources.
- **Provides** ongoing supports to maintain desired lifestyle.

The supported living coach assumes the main role in providing the ongoing life management support that an individual needs in order to live in and maintain his own household. This can include teaching new skills and/or providing assistance in the areas of support. In addition, the coach plays a pivotal role in assisting an individual to develop interdependent relationships with others in the community.

Supported living coaching is designed to provide instruction and assistance to individuals living in their own homes or apartments. This includes assistance with locating a place to live, negotiating a lease, paying bills and managing money. This also entails acquiring, maintaining or improving personal hygiene and daily living skills, money management, housekeeping, shopping, community awareness, and other skills necessary to successfully maintain a home and community relationships.

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“If you think about life in your community, you are bonded through a similarity of locale, shops, churches, school district, and other community space, yet through the diversity of your neighbors and community, you are inspired to grow and develop. In allowing each person to be welcomed and accepted, all people grow.” Al Condeluci, Interdependence, The Route to Community

Working Together

Considerations for coaches and support coordinators who are working together to support persons in their own homes:

- ↳ **Be Partners:** Work with the individual and each other to support her in reaching her dreams. Remember this is the common goal.
- ↳ **Be Flexible and Creative:** Preferences and needs will vary from person to person as will the roles of providers. Together, search for non-traditional resolutions to problems and creative ways to establish and maintain support arrangements. Maintain as much flexibility as possible within the parameters of state and federal laws, rules, regulations, and guidelines.
- ↳ **Work it Out:** Address and discuss any areas of uncertainty. Identify possible areas of duplication and how they will be handled. Example: The support coordinator and the coach must work hand-in-hand to ensure people maintain eligibility for benefits (such as Social Security, Medicaid, etc.). There should be a clear understanding between all parties so that efforts are not duplicated or necessary activities overlooked.
- ↳ **Write it Down:** The individual support plan (SP) is the guiding document for all supports and services authorized on the cost plan. The expectations of the coach and support coordinator (as well as other support providers) should be clearly specified in the plan. The SP changes and is revised over the course of the year as the needs and desires of the individual change. It is a fluid document reflecting the person’s desired outcomes, scope of service, and current situation.
- ↳ **Communicate:** Be sure the individual knows who to contact for assistance in certain situations and with certain tasks (i.e. Medicaid problems, emergency assistance, etc.).

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Other Medicaid Waiver Services Typically Associated With Supported Living

While supported living coaching provides the training and support for the individual, there are other Medicaid Waiver services available to assist people to be successful in their own home. Each of the service providers must work cooperatively to assure the person receives the benefits of a cohesive support system. Several of the services discussed below cannot be used during the same time. The listing below is not all inclusive. Information describing these services and supports may be found in the current DS Waiver handbook.

Other Medicaid Waiver Services

- **Adult Day Training**
- **Behavior Analysis Services**
- **Chore**
- **Companion**
- **Homemaker**
- **In-Home Supports**
- **Non-Residential Supports and Services**
- **Personal Care Assistance**
- **Personal Emergency Response System**
- **Residential Habilitation Services**
- **Supported Employment**

Adult Day Training (ADT) services are intended to support the preparation of individuals in daily, valued routines of the community. This may include work-like settings that do not meet the definition for supported employment. ADT stresses training in the activities of daily living, self-advocacy, adaptive and social skills and are age and culturally appropriate. Persons may attend an ADT on a full-time or part-time basis.

Behavior Analysis services are utilized to assist individuals with challenging behaviors, which may impact their ability to live on their own. The Behavior Analyst develops a behavior intervention plan that is implemented by all service providers. The plan focuses on supporting individuals in learning or maintaining alternative behaviors while reducing existing behaviors of concern. The behavior analyst works with the individual's circle of support to

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ensure that the individual's use of alternative behaviors is supported in all the environments in which she spends time (i.e. home, work, community, etc.).

Chore services are provided to maintain the individual's home and property as a clean, sanitary and safe living space. These services may include household duties such as washing floors, windows, and walls, tacking down loose rugs and tiles, replacing a broken window, or moving heavy items of furniture that make the home safe.

Companion services consist of non-medical care, supervision, and socialization activities provided on a one-on-one basis. This service must be provided in direct relation to the achievement of the individual's support plan (SP) goals. A companion may assist the individual with such tasks as meal preparation, laundry and shopping. This service does not entail hands-on medical care, but may provide light housekeeping tasks, incidental to the care and supervision of the individual. They may be scheduled on a regular long-term basis.

Companion services are not simply diversional in nature, but are related to specific outcomes desired by the individual. For example an acceptable activity could include going to the library, getting a library card, learning to use the library and checking out books or videos for personal use, etc. Companion services cannot be provided concurrently with Adult Day Training (ADT), Personal Care Assistance (PCA), and Non-Residential Support Services (NRSS).

Homemaker services are those general household activities such as meal preparation, laundry, vacuuming and routine household cleaning provided by a trained homemaker, when the person who usually handles these task is unable to perform them. The intent of this service is to ensure the individual's home remains clean, safe, and sanitary. These services cannot be used for supervision or personal care.

In-Home Supports may be a service used in conjunction with supported living coaching for individuals who wish to live in their own home but need additional assistance or support. In-home supports are services that provide assistance from a support worker(s) four to twenty-four hours per day. The support worker may live in the person's home and share living expenses (e.g. rent, utilities, phone, etc.) or work on an hourly (shift) basis.

This person(s) provides companionship and personal care and may assist with or perform the activities of daily living and other duties necessary to maintain the person in supported living. These services are not a replacement of supported living coaching. Some individuals in supported living may need

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only the services of an in-home support worker, or only the services of a supported living coach. Others may need both services. When both services are used, the providers must coordinate their services to avoid duplication. A person receiving in-home supports is not eligible to receive some of the other services such as personal care, companion, or residential habilitation services.

Non-Residential Support Services are individualized training activities provided in a non-residential setting. These activities are age-appropriate and geared to enhancing the acceptable individual's behavior, increasing those qualities, which are integrative and normative in nature. Support services, which may be provided in a work-like setting, are a process used to attain the necessary skills to control the environment, increase acceptable behavior and provide integrative opportunities. These services are intended to support the participation of persons in daily valued routines in the community.

The primary functions of non-residential support services are the development of skills needed:

- for communication and socialization to support the individual toward maximum independence;
- to increase independent living in the community; and
- to maintain a living environment, use community resources and conduct activities of daily living.

This service cannot be provided concurrently with Personal Care or Companion Services.

Personal Care Assistance (PCA) assists persons, on a one-to-one basis, with eating and meal preparation, bathing, dressing, personal hygiene, and activities of daily living. PCA also includes activities such as assistance with meal preparation, bed making and vacuuming when these activities are essential to the health and welfare of the individual and when no one else is available to complete them.

PCA cannot be provided at the same time as Non-Residential Supports and Services, Companion, Adult Day Training, or In-home Support Services.

Personal Emergency Response is an electronic communication system that supports an individual in obtaining assistance in the event of an emergency. The person may also wear a portable "help" button while out or at home. The system is connected to the person's phone and programmed to signal a response center. The "help" button dispatches qualified personnel to the individual's location.

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Residential Habilitation Services provide specific training activities that assist the individual to acquire, maintain or improve skills related to activities of daily living. The service focuses on personal hygiene skills such as bathing and oral hygiene; homemaking skills such as food preparation, vacuuming and laundry; and on social and adaptive skills that enable the individual, to live in the community. This training is provided in accordance with a formal implementation plan, developed with direction from the individual and reflects his goal(s) from his current support plan. When an individual lives in his family home or a licensed residential facility, and supported living is identified as a goal on the support plan, supported living coaching may be provided in conjunction with residential habilitation for up to 90 days prior to the individual moving to a home of his own. In a supported living arrangement, residential habilitation and supported living coaching may not be provided together.

Supported Employment services provide training and assistance in a variety of activities to support individuals in sustaining paid employment, which may be especially important for persons living in their own homes. The provider assists with the acquisition, retention, or improvement of skills related to accessing and maintaining employment. Supported employment includes activities needed to sustain paid work at or above the minimum wage. Supported employment services are not a requirement for persons utilizing supported living services.

Additional Supports and Services Are available for individuals who may also need therapies (e.g., physical therapy, speech therapy, etc.); transportation; consumable medical supplies nursing; dietician; durable medical equipment and supplies; environmental accessibility adaptations; medication reviews; private duty nursing; special medical home care; specialized mental health services; etc. Although all services and supports are available through the Medicaid Waiver, access depends on the availability of providers, funds, and the variability of budgets across the various districts and regions within the state.

Many of these services are essential in supporting people to achieve their dreams and assure their well-being. Individuals should be aware of the array of service options before indicating their desire for services. The support coordinator, along with the circle of support, can assist the person in identifying needed services.

Each supported living arrangement is unique, and the needs of individuals may change over time. Some people may initially only need the assistance of a supported living coach; however, as time passes they may require changes to existing supports or additional services to enable them to remain in their own

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home. The support plan will specify and the cost plan will authorize the services that each person receives.

Other Services Do Not Replace the Coach

The Medicaid Waiver offers a vast array of services designed to support individuals in supported living. However, these services should in no way be seen as a replacement for the supported living coach.

The coach maintains the responsibility of promoting safety to assist the person in living on his own. **While the aforementioned services are all extremely valuable, each is independent of the other, and without the coach there is no central point of household coordination.** The coach provides twenty-four (24) hour "on call" services to assist in assuring emergencies are addressed as they arise. The education and experience required for supported living coaching certification is far more extensive than most of the other support services previously mentioned.

It is extremely important that the supported living coach and the support coordinator work together with the individual and her circle of support to identify the supports needed to live in her own home. Once these needs are determined, the individual and her family should interview providers to assure she is comfortable with the people who will be working for her in her own home.

The Support Planning Process

The Support Plan authorizes all services and supports.

When an individual selects a supported living coach and/or other service providers, those providers may become a part of the person's circle of support. The circle of support may include anyone the person chooses such as family, friends, providers, neighbors, etc. The role of the circle of support is to work in conjunction with the individual in planning for his life. This life planning process is referred to as the Support Planning (SP) process. The circle of support meets at least once each year to support the person during this process. As needs and desires change, the circle may meet at any time the person chooses to adjust the plan or to discuss strategies and approaches.

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Each provider has the responsibility to provide information to the support coordinator annually. According to the DS Waiver handbook, this information is often submitted to the waiver support coordinator as an annual report within thirty days prior to the end of the support plan year. During the annual support plan meeting the circle of support assists the person in formulating personal goals and determining the types of supports and services which may be needed to achieve them. **Personal Outcome Measures (POMs)**, as discussed in Chapter Eight, offer a method for supporting persons in determining personal goals and desired outcomes.

The supported living coach works directly with the individual and the support coordinator as the individual's advocate to plan, implement, and maintain the supported living situation. A partnership must therefore be built and maintained between the supported living coach, the individual, and the support coordinator, in order to assure the successful implementation of the support plan. Constant communication, creativity, and flexibility in addressing concerns and clarifying any uncertainty are key to maintaining an effective partnership. This partnership may extend to other members of the circle of support, and will vary significantly in intensity depending upon the person's needs and desires.

Places to Live

Once the individual has sought assistance in exploring service and support options, the next area of exploration regards the types of living situations available for consideration.

Sandy's Story

Sandy is 68 years old. He grew up on his family's dairy farm in Pennsylvania. He and his mother moved to St. Petersburg in the 1960's. In 1979, his mother was diagnosed with a terminal illness. Sandy had no other family, so he left the home and a lifetime shared with his mother to live in an Intermediate Care Facility for persons with Developmental Disabilities (ICF/DD). There, he learned to live without her, surrounded by 46 other people.

He lived there until 1991, when he moved into a 15-bed group home. The group home afforded less opportunities for going out, and many of the activities Sandy enjoyed at the ICF/DD were unavailable. However, he developed close relationships with his 14 house mates and staff.

As he grew older, Sandy began retreating from group activities, which severely limited his access to the community. He stopped going to church,

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stores, restaurants, the riding stable, etc. He started going to bed before 6:30 on week nights, and spent the majority of every weekend in bed. He began engaging in problematic behavior to gain staff's attention and avoid activities.

His guardian approached Sandy about moving into his own home. No one was sure how he would react to the idea of supported living. Once it was described, Sandy's response was: "When do I move...before Christmas?"

At first it was difficult for Sandy to understand he had choices regarding every aspect of his living situation. Once it became clear, Sandy had a definite picture of what he wanted: a house without stairs, with a fenced backyard, with plenty of space to garden and enjoy the outdoors with his own dog. He also wanted to live close to the program he went to during the day and to his friends' homes. And he wanted to move in before his birthday, so he could hold his birthday party in his new home.

A house was found that matched Sandy's vision. He moved in two days prior to his birthday. There, he celebrated 68 years of living and the fact that for the first time, he had a home of his own. Sandy has had countless new experiences as a result of supported living. He sleeps in a double bed, decides what his meals will be and when he will eat them, buys his own groceries, walks nearly one mile daily... and the list goes on. In short, he enjoys the freedom, individuality, and contentment that can be realized through supported living.

Most people agree that everyone deserves a home; however, they sometimes disagree about what really makes a "home." According to John O'Brien, a nationally recognized consultant in the field of supporting people's disabilities, the elements of place, control, and ownership distinguish housing from a real home. In their own homes, people have a private and secure place for doing things that match up with the lifestyles they have chosen and that reflect their personal routines and tastes. Individuals who have a home control what happens there, including daily routines and who enters to visit or stay. Finally, people in a home have an investment in ownership or a legally assured tenancy.

Unfortunately, individuals who have developmental disabilities have typically been denied these things, often occupying housing that comes in a package with support services (such as a group homes, etc.). Many times, individuals have been expected to change residences as they acquired progressively more "independent" skills.

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Supported living breaks from the residential continuum of the past, by directing attention away from physical settings and toward the services and supports needed and desired in order to become part of community life. Separating housing from support means that individuals do not have to live in a particular place, such as a group home, in order to receive the supports and services they want or need. When services and supports are tied to the person, and not to a facility or program, a person's home can remain the same even when services change, providers change, or life circumstances and needs and desires change.

Having a home is very important to most of us. We all need a place where we can have time and space for ourselves and feel safe, secure, and comfortable (Finding a Home: Practical Information About Buying or Renting A Home, 1995). While exploring supported living, it will be important to determine the types of homes available in the community where the person prefers to live. Homes may be represented by different types of structures including:

- **Apartment** A rental living unit usually within a complex of other units, all of which are typically owned by a corporation. Apartments within a complex are continuous buildings attached to each other. Many apartments are located in buildings of one or more stories, but some may be rented as a separate space attached to a home or garage. The living units may be offered in a variety of sizes and are usually priced from least to most expensive based on the size of the unit. The smallest unit is typically an "efficiency," which is characterized by one area that includes space for livingroom, dining and sleeping. Other units may include one, two, or more bedrooms and bathrooms, in addition to a living room, kitchen, and bathroom/s. Many persons may consider apartment complex living as optimal because of the proximity of the apartments to each other.

- **Condominium** (condo) A living unit within a complex, which can be purchased or rented, similar to an apartment, in which an individual or a corporation owns each separate living unit. A condominium management group provides oversight for all of the units within the complex for a fee. This fee is assessed to the owner of the unit to cover maintenance of landscaping and other amenities such as pools, spas, etc. If renting from the owner, it will be important to determine if the maintenance fee is included in the rent.

- **Townhouse** A living unit usually built as "side by side" housing. Townhouses can be one or more stories in height and share a common landscape or yard with other units. Like condos, a fee may be assessed to pay for the maintenance of the landscaping and other amenities such as pools, etc. If renting from the owner, it will be important to determine if

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the maintenance fee is included in the rent. If purchasing, assure the fees, taxes, and insurance are included in monthly budgets.

- **House** Typically a building without other structures attached, within a neighborhood of other dwellings of a similar nature. Frequently, houses are characterized by a building with one or more bedrooms, a kitchen, living and dining areas, as well as exterior space including a yard or patio space.
- **Manufactured or Mobile Homes** A separate house, which can be moved from place to place. Like a house, manufactured homes have one or more bedrooms, a kitchen, dining, and living area, and some yard or landscaped areas. Most mobile homes are located in manufactured home parks, where each is assigned a lot. Although persons may rent or own their mobile home, there is usually a lot fee assessed monthly. When choosing a mobile home, make sure it complies with current building codes and standards.

Supported Living Liaison Network

When first considering supported living, many questions will arise. For many people, change is easier when supportive relationships are available. In many ways, supported living depends on the establishment of new relationship, and the continuance of those already formed.

Relationships take time to develop, whether formal or informal. The quality of these relationships, in terms of mutual respect, trust, and clear communication, often impacts the quality of each life experience.

As with any change or major move, making the choice to utilize supported living services and move into your own home can be difficult. Many people with developmental disabilities have spent their lives in large group living situations. Others, because of the need for additional supports and safety, have lived their entire adult lives in their families' homes. For many of these individuals, it may seem impossible to consider having their own home. Group living settings, by design, have a support network of their own. Frequently, parent and advocacy groups emerge from group situations to support each other through their similar experiences. New relationships may need to be initiated that will provide immediate support, even during the initial stages of exploring supported living.

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The Supported Living Liaison Network was established in 2003 to link individuals who are living in their own homes to people and their families who are considering supported living as an option. Learning from others about their experiences with supported living services may make a difference in understanding the types of supports and services needed for success.

In addition to connecting individuals considering supported living services with those currently receiving services, the '*Network*' will also assist in linking family members. This provides opportunities to discuss fears and concerns regarding their children or siblings living on their own. Parents who have watched their son successfully transition into supported living may be able to answer questions that can only be answered by someone with similar experiences.

The '*Network*' provides a listing of individuals, organized by various categories, who are currently receiving supported living services. For each person or family member listed there is a brief biography which includes basic information about the person's supported living experiences. Persons who are considering supported living will be able to access contact information so they can talk with an individual and possibly visit him in his home. Visits will depend on each '*Network*' member's desired level of participation.

Supported living coaches and support coordinators will be able to access the listing of individuals by District or Region who have agreed to be part of the '*Network*'. The '*Network*' was developed and funded by the Florida Developmental Disabilities Council. Copies are available in print and on the internet beginning July, 2003, through each District/Region Developmental Disabilities Program and the Florida Developmental Disabilities Council Office (Phone: 800-580-7801 and web: www.fddc.org).

Chapter Summary

During the initial exploratory stage of decision-making, a general understanding of supported living is gained. Supported living provides for a wide-array of supports and services that are individualized to each person's unique situation. Some supports and services are funded as Medicaid Waiver services and some through general revenue (tax) dollars. The support coordinator and supported living coach are key to this service, and have clearly delineated roles and responsibilities. They work as a team, along with the circle of support, through the support planning process, always keeping sight of the person's desired home life, and finding the means to support the person in its attainment.

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Unlike residential continuums of the past, people decide where their homes will be, and the type of housing they desire.

Chapter Three provides specific information regarding supported living coaching services and requirements. It includes details regarding qualification, certification, and training requirements.