

Chapter One

Defining Supported Living



What You Will Find:

Introduction to Supported Living

Purpose of Supported Living

Overview of Supported Living

Characteristics of Supported Living

Eligibility for Supported Living



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Supported Living Vision

Supported living is described as: *“People with {developmental} disabilities living where and with whom they want, for as long as they want, with whatever support is necessary to make that choice possible.”* (Bellamy & Horner)

Introduction

This guide is designed to help persons receiving supported living services achieve the vision described above. It provides the framework, tools, and processes used to support individuals in establishing themselves in the community. In order to accomplish this, it is important to understand the history of supported living, and identify best practices that will assure the freedom, choices, and autonomy supported living offers.

Achieving this vision can be challenging. Concepts and belief systems are not governed by rules and regulations, but state-funded initiatives and services are.

How do we assure people live the life they choose while also meeting regulations, allowing for dignity of risk, and first and foremost, assuring that the health and safety of those we support is never intentionally compromised?

This guide provides a functional framework for balancing the requirement of supported living services while striving to remain true to the philosophy supported living encompasses. It explores best practice and defines the rules and regulations which govern the supported living initiative.

Service and Philosophy

- Supported living as a *service* establishes supports needed for persons to live where, with whom and how they choose.
- Supported living as a *philosophy* guides and drives the approach to those supports.

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Purpose of Supported Living

In a traditional program approach, services are provided to a group of people in the same way and at the same time, frequently in a segregated setting. All individuals receive similar services and are expected to follow the same rules. People usually are expected to "graduate" through a continuum of services as they learn more skills and become more independent.

In a person-centered (supported living) approach, each support or service is tailored to each individual's unique preferences and requirements. Because the focus is on one person at a time, people are not required to live in groups, and since supports are not tied to any particular location, they do not need to move through a training continuum in order to receive new or additional services. This individualization makes it possible for people to live in their own home in a completely integrated setting with necessary supports and skill training provided within the context of daily life. Supports and services are adjusted in response to changes in life circumstances without requiring people to move to a new location or setting.

People are not expected to demonstrate complete independence in order to participate in supported living. Instead, it is acknowledged that all adults should be able to live in their own homes in the community with whatever level of assistance is needed. An emphasis is placed on the development of non-paid supports, and people are encouraged to engage in natural, reciprocal relationships that focus on each person's abilities and unique gifts to the community.

In traditional residential living arrangements, an agency accepts funds for "slots" or "beds." They then seek people to fill these slots, fitting the person into an existing group home. This provider owns or rents the property, makes the rules, and determines who lives with whom, where they live, even who gets to stay in the home. Supported living is about individual choice, control of housing and assistance, respect, personalized care, and valued relationships. Operationally, the use of supported living funds, approaches to planning, and daily activities of staff differ dramatically from traditional approaches.

Supported living is about the person's preferences, opportunities, and control rather than the provider's. In "Revisiting Choice-Part 1," Michael Smull writes: "Preferences reflect what people want, while opportunities reflect what is available... Control is the authority to make use of an opportunity to satisfy a preference." Supported living is driven by the person's preferences regarding how and where she wishes to live her life. It focuses on supporting her exploration of the wide array of opportunities and means to reach her ideal home life, and to create new opportunities that might not yet exist, in order to

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expand that dream. Supported living assures the person's authority over her own life.

Overview of Supported Living

In order to have a clear understanding of supported living, we must first understand the evolution of living options for persons with developmental disabilities.

History of Supported Living in Florida

- **Restrictive Environments, 1970s – 1980s**
- **Chapter 393, Florida Statutes, 1982**
- **Nonrestrictive Environments, mid-1980's**
- **Supported Living Project, 1988**
- **Supported Living Defined in Law, 1991**
- **Medicaid Community Supported Living Arrangements (CSLA), 1992**
- **"A Place of My Own," 1992**
- **Home and Community-Based Services Waiver (HCBS), 1995 (including Supported Living)**
- **Supported Living Training Curriculum, 1995**
- **"A Guide to Supported Living in Florida," 1995 and 1997**

Restrictive Environments – During the 1970s and 1980s, residential services were organized along a "continuum of placements" toward community life. Individuals with developmental disabilities were expected to meet specific criteria for each setting before moving onto the next (i.e. from the most to the least restrictive arrangements). The continuum began with the most restrictive living arrangement, i.e. a state operated institution, then a large congregate setting, i.e. Intermediate Care Facilities for persons with Developmental Disabilities (ICFs-DD), to a group home setting, where the individual had to conform to living with a large group of strangers in a house organized by rules and regulations to which all must comply, until finally earning the right to live independently. Many individuals, due to the nature of their disabilities and

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the prerequisites established, failed to meet the requirements for progression to the next less restrictive setting along the continuum. As a result, few ever accessed the opportunities and experiences of independent living. The continuum emphasized matching people to places, rather than matching supports to people wherever and whenever necessary.

Chapter 393, Florida Statutes, 1982 – The state legislature found that the treatment of persons with developmental disabilities often unnecessarily placed individuals into unreasonably costly, large facilities that were ineffective in supporting persons to achieve self-determined lives. It further noted that redirection of state funded services was necessary to embrace the concept of "nonrestrictive environments," and avoid the costly problem of institutionalized services. Therefore, the legislature declared that greatest priority be given to the development and implementation of community-based services.

Chapter 393: Definition

Chapter 393 of the Florida Statutes defines supported living as “a category of individually determined services designed and coordinated in such a manner as to provide assistance to adult clients who require ongoing supports to live as independently as possible in their own homes, to be integrated into the community, and to participate in community life to the fullest extent possible.”

Nonrestrictive Environments – In the mid-1980s, the notion of moving through the continuum (i.e., from the most to the least restrictive environment) was replaced with the concept of "non-restrictive" environments. The focus of "non-restrictive" arrangements was on assisting persons in establishing homes of their own and providing whatever supports were needed to enable the person to live there (Taylor, Racino, Knoll, & Lutfiyya, 1987). In many parts of the country, this "non-restrictive" concept was identified as supported living. Florida's supported living initiative resulted from a growing awareness that people who have developmental disabilities are as entitled to control their lives as other citizens. For many individuals, involvement in supported employment, working and holding responsible roles in the community, sparked a desire to live more fully in that community with personal freedom. A grass roots effort, including people who receive services, their families, friends, advocates, and service providers, began to assist individuals in moving from family homes and congregate residences to their own homes.

Supported Living Project, 1988 – The State Developmental Disabilities Program received a grant from the Florida Developmental Disabilities Council

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to explore supported living arrangements and experiences in Florida and other states and to develop a model for more cohesive delivery of services in Florida. Creating New Opportunities: The Supported Independent Living Model was developed and focused on supported living for individuals able to live in the community with occasional or "drop in" support. It was anticipated that a second model, called "Supported Assisted Living," would be developed later for persons requiring more intensive support, such as "live-in" or 24-hour assistance. In March 1992, however, the supported living technical assistance team discussed the need to develop a more individualized and flexible system for all persons who have developmental disabilities, rather than differentiating between those who are fairly independent and those who require more intensive support. This redirection challenged the system to find ways to expand supported living as an inclusive service option for all adults receiving developmental disabilities services, regardless of the type or severity of their disability.

Supported Living Defined in Law, 1991 – Chapter 393.006, Florida Statutes, provided a definition of supported living which laid the foundation for the development of supported living services. The definition states that settings are individually designed for people “to live as independently as possible in their own homes, to be integrated into the community, and to participate in community life to the fullest extent possible.”

Medicaid Community Supported Living Arrangements (CSLA), 1992 – As a result of the Supported Living Project in 1988, a model of supported living services was created and expanded as an inclusive opportunity for all people with varying abilities. Florida, along with seven other states, received a waiver to use Medicaid funds as a method for funding community services. The CSLA waiver was not reauthorized by Congress, and Florida requested and received a Supported Living Waiver.

“A Place of My Own,” 1992 – Training materials were developed through the Supported Living Project to guide the implementation of supported living services and to assure the delivery of those supports and services was consistent with the person-directed philosophy of supported living.

Home and Community-Based Services Waiver (HCBS), 1995 – Up to this point, Medicaid had provided funding to large residential facilities on behalf of persons who lived there. The Medicaid Waiver allowed states to waive a number of administrative regulations that governed these facilities, in order to support persons to live where and with whom they desired. The Supported Living Waiver was folded into this Home and Community-Based Waiver. Supported living, in addition to numerous other types of services, was

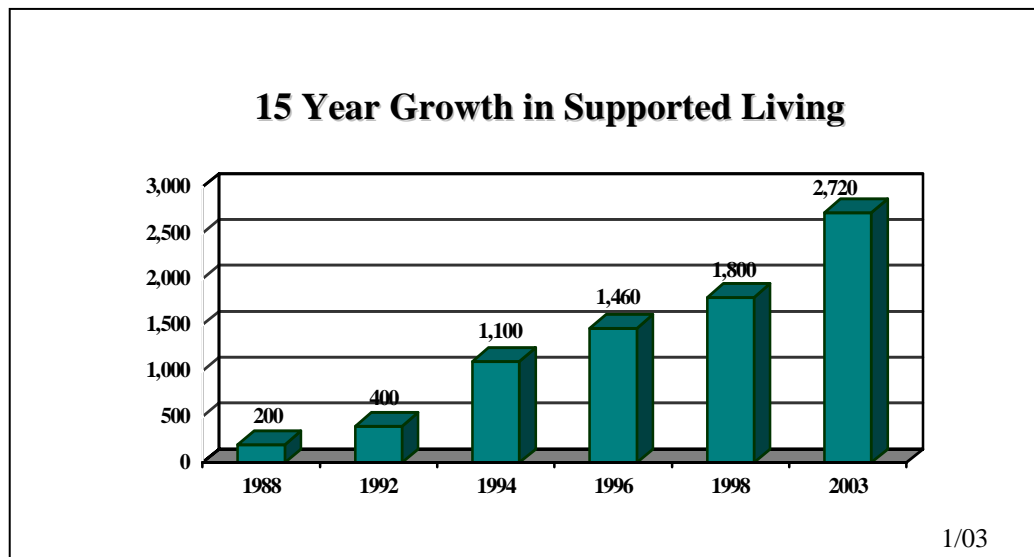
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initiated as one of many Medicaid service options. For the first time, independent supported living providers applied for certification as Medicaid Waiver providers, which increased supported living options for people.

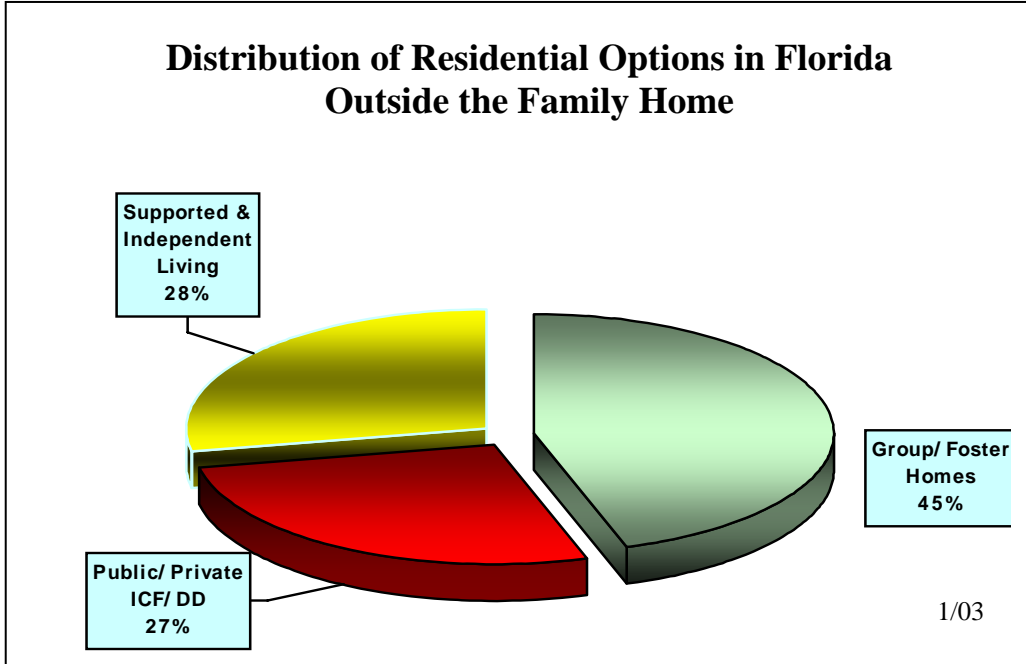
“A Guide to Supported Living in Florida and Trainer’s Guide,” 1995 – These guides were developed with a grant from the Florida Developmental Disabilities Council. Statewide training activities were conducted to provide pre-service training to district staff and providers.

“A Guide to Supported Living in Florida,” 1997- This guide was updated to present supported living providers with information regarding the implementation of supported living services. The accomplishment of pre-service supported living training was required to qualify for Medicaid Waiver provider certification. As supported living evolved from a concept to a service option in Florida, the number of its citizens accessing the service grew dramatically.

In 1988, there were only 200 persons receiving supported living services. By 2003, more than 2,719 persons were receiving supported living services statewide, due, in part, to the Medicaid Waiver funding available. In addition to supported living options, the shift toward more community-based living options significantly increased. This meant approximately 75% of persons with developmental disabilities were living in their own homes or with family members rather than in group or institutional settings. This information is depicted in the graphs that follow:



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Characteristics of Supported Living

Through supported living, individuals with developmental disabilities are able to live fully in the community. This includes living where any citizen in the community may live, developing relationships with people who do not have disabilities and are not paid staff, making daily decisions regarding how time will be spent, and having control over future plans. Supported living services are carried out amid the rhythms and routines of daily life. Supported living providers assist individuals with developmental disabilities by providing support in practical and familiar routines such as shopping, cooking, personal care, housekeeping, banking, socializing, and recreation. These may seem simple tasks, but in achieving these mundane aspects of living, we enjoy the commonality that is adult freedom. With freedom, comes unparalleled opportunity and promise... the gift of self-discovery, self-assurance, and infinite potential.

Characteristics of Supported Living

- People live in homes they control.
- Home selection and financing are separate from services.
- People define their own lifestyles

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Characteristics of Supported Living, continued

- Providers use new ways to listen.
- Providers accommodate and support rather than “fix.”
- Providers are sensitive and respectful of services in the person's home.
- People exercise control and choice regarding services and supports.
- Providers use flexibility in service delivery.

The following are some of the recognized characteristics of supported living:

- People live in homes of their own which they control. This means the person's name is on the lease of a home in the neighborhood and community he has selected. He lives with whomever he wants, and receives supports from whomever he chooses. If he doesn't like the services he is receiving, he can change providers, not his home.
- Selection and financing of people's housing is separate from the selection and financing of the services and supports they receive.
- People define the lifestyles they want. If a person's life experiences have been limited, she is given information and support to explore opportunities, discover preferences, and express them.
- People who formally and informally support persons with developmental disabilities learn and practice new ways of listening. They listen to what people want and to their dreams. In doing so, they redefine themselves as allies, helping people achieve their desires, and live as many or as much of their dreams as possible. As allies, people supporting others follow the person's lead, rather than decide “what is best on his behalf.”
- Service providers redefine their role to one of accommodating and supporting the personal preferences and desired lifestyles of persons with developmental disabilities, rather than trying to “fix” them.
- Service providers learn how to be less intrusive in delivering services and supports, and are sensitive to and respectful of people's homes and the rights and courtesies associated with them.

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- People exercise choice and control regarding the type and degree of services and supports they receive, and from whom they receive them.
- Service providers improve their ability and flexibility in delivering services rather than limiting personal choice, or offering a "one-size-fits-all" approach.

Supported living is a way of looking at how and where we commit our resources and provide support, by considering people one at a time and figuring out creative and non-traditional ways to provide what each person wants or needs.

Characteristics of Services and Supports

Characteristics of Services and Supports

- Individually - Designed Supports
- Personal Choice and Control
- Family, Friends, and Community Emphasized

Flexible, Individually-Designed Supports Based on Personal Preferences

Supported living services are individually designed, with flexible supports based not only on strengths and needs, but also on personal desires. The pursuit of personal dreams is recognized as an individual's right rather than a reward. Support is provided only where needed and can be arranged in ways that maximize the individual's abilities and compensate for skills an individual doesn't possess.

Supports are provided in accordance with the life outcomes the individual wishes to achieve and may include the teaching of new skills, assistance with activities the individual is unable to perform without support, and help in developing linkages with other people or resources in the community.

Maximized Personal Choice and Control

When people live in group settings, procedures and rules are established to operate the home considering the requirements of all household members. In order to accommodate everyone, some individuals may be subject to undesirable or unnecessary control over personal choices in their lives.

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When people experience individualized supports and services, they are able to exercise greater control and personal choice in all areas of life. An individual in supported living lives in his own home, and it is the individual who establishes the procedures and routines by which the household is operated and through which daily life evolves. Some people may need encouragement to express their preferences and make decisions when they first move to supported living. Others, experiencing personal control for the first time, may make choices that seem inappropriate. Opportunities and support will promote good decisions.

Regarding Personal Choice:

Control: It's the little things that count.

- *Jack, from St. Petersburg, states he can “get coffee whenever I like” and “make sweet tea and keep it in the refrigerator.” In his prior home, the kitchen was locked and only staff were allowed in.*
- *Donna reports, “I can make my own menu and change things when I feel like it. I can plan my own meals every week rather than eating from a menu every week.”*
- *Janice, of Habilitation Management Services, says she never saw anyone as thrilled as “Amy,” when she learned she could store her personal items in the bathroom, and not in the plastic box they made her keep in her bedroom when she was in the group home.*

Family, Friends and Community Supports

Connections to people, places, and activities create the most effective life for anyone who lives in a community. Friends and acquaintances often will notice problems and lend assistance before they intensify. Almost everyone depends on family and friends for support during difficult times and in the course of everyday life. Yet, service systems often prevent these important connections by surrounding individuals with others who are paid to direct their activities in programs and places that are isolated from community life. In supported living, people are encouraged and assisted to form or renew connections with other citizens and family members.

Providers of supports and services play a vital role in helping individual make connections to the community through thoughtful and sensitive actions. For example, taking an individual who has a developmental disability around to

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meet all the neighbors may actually focus on the disability and create an expectation of dependency. Neighbors who have nothing in common are unlikely to form the close relationships that evolve naturally through activities of mutual interest. Yet, supporting someone to meet nearby neighbors as part of the incidental activities of moving in or during regular daily routines opens the way to neighborly hellos and conversation. Connection to a community member, an organization, a church, a business, or a public place often leads to everyday contact with a range of other people so that the individual becomes part of something that is focused around common interests and capacities rather than disability.

While a primary role of the supported living coach is often helping a person move into her own home, an equally important focus must be on how to effectively support the person in becoming a part of the community once the move has occurred. This is usually a slow process that evolves over time. To help promote involvement, the coach may need to begin by simply orienting the person to the neighborhood and what it has to offer. Assisting a person in exploring new activities and interests in the community is not only exciting, but can also serve as the cornerstone for the development of new and lasting relationships.

Eligibility for Supported Living

In supported living, housing monies are separated from support funds. The person with a disability decides where to live and selects a housemate if needed or desired. He purchases a home or signs a lease. Supports are developed individually, taking into account the needs and preferences of the person and his family.

An individual to whom the following applies should be considered "eligible" for supported living services:

<p style="text-align: center;">Who is Eligible for Supported Living?</p> <p>An individual who...</p> <ul style="list-style-type: none"><input checked="" type="checkbox"/> is receiving services from the Developmental Disabilities Program.<input checked="" type="checkbox"/> is at least 18 years of age.<input checked="" type="checkbox"/> desires to live in his own home in the community.
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Eligibility, continued

- is unable to live in her own home in the community without ongoing supports.

In the community, the basic criterion for living in one's own home is whether or not a person has the resources to live there. An additional criterion for supported living is whether adequate supports and services can be arranged for the person. When the answer is "yes," make sure that other circumstances do not become an excuse to deny an individual the opportunity to live in her own home.

The intensity of supports can be designed to meet the requirements of each individual. Many successful supported living arrangements in Florida and throughout the nation have been developed for people who have severe physical disabilities.

Sometimes, seemingly insurmountable behavioral challenges are reduced or disappear when the individual is in a supported living setting. Experience indicates that many individuals leave their histories of "behavior problems" behind when they move from congregate situations to supported living arrangements.

Andy's Story

After losing both parents as a very young child, Andy floated from family members to institutions to group homes, until moving to Florida when he was 11. He stayed with his sister for a few years until he was abandoned, and placed into an assisted living facility (ALF). Andy moved from ALF to ALF for years.

In 9 years Andy lived in 18 separate places, where he was physically, sexually, and psychologically abused. Food was taken from him on a regular basis for punishment, and he was assaulted by staff and consumers.

Andy lived in supported living before, and it failed him. He moved from a respite facility, after having been hospitalized from his earlier living situation. He moved into an apartment, with two others without any choice as to with whom he was going to live or where. Due to the need to move quickly, he was "placed" in the apartment before preparations were adequately made. He slept on the couch for weeks, waiting for one of the roommates to move to another apartment. The live-in staff was taking Andy's medications and had

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problems of his own. There was little to no supervision or monitoring by the agency providing live-in staff and supported living coaching.

Andy's behavior continued to deteriorate and he was moved to another apartment without his involvement, or consideration of what was appropriate and effective for Andy. He did even worse there. The live-in staff was untrained and reacted emotionally and personally to Andy's behavior. Staff took Andy to a psychiatric hospital to have him hospitalized because they were "tired of dealing with him." The situation deteriorated quickly and Andy was "placed" in a group home for over one year. It took some time, but Andy finally moved into his own house last year.

Today, Andy lives in his own house with 24-hour staff, some who work with him during the day, and a live-in who stays with him at night. Due to his behavioral challenges, this is needed for Andy to remain safe and to become more independent and successful. He is doing well, with the help of a comprehensive and thorough level of supports. It is an ongoing effort to keep his supports communicating effectively and to ensure that his circle of support acts as a whole in providing him the assistance he needs in the way he needs it.

His level of supports is a model for the efficacy of supported living, and a lesson for all who wish to take this step.

Andy, and those who were with him through turbulent times, learned a great deal. He does poorly in environments where coercion is used as a way of "controlling." He reacts badly to unstructured environments and with a circle of support who do not communicate or are inconsistent and unreliable. He does poorly when he has to compete for the attention of staff. He is not successful in group living environments. He does better when supports are tailored to his needs and not based on a generic model.

Andy has done very well in his current supported living situation. This has been hard earned, by Andy and those who are invested in his success. He takes great pride in living in his own house. He loves having his own space. In group homes and ALF's Andy had no place to call his own. His room, which he usually shared, was not a haven or safe place. Staff would barge in at their leisure. Now, Andy knows his room is a place he can go and be unfettered. This is remarkable to him and one of the best things about where he lives.

He has become adept at saving money. He has learned to take care of his house and is proud of the job he does. He is becoming more skilled at doing

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his own laundry and in other areas of daily living. His behavior has improved dramatically. He has not needed psychiatric hospitalization in over a year, where in the past this occurred regularly.

Andy's success is due to the type of supports he is getting, the dedication of those working for him, the training and competency of those involved, but most importantly, due to the honest caring and concern for Andy shared by those who know him, and see the person he wants to be.

Andy continues to teach us. The other day I was talking with him and, in his charming and congenial way, he said, "I'm doing great, aren't I? How come I'm so smart?" I smiled and told him he has come a long way. A long way from the pain and chaos of his past. But a long way still to go. Andy has the strength of spirit and resiliency to help us support him in getting there.

Ken Winn, Legal Guardian

People do not need to be completely independent or attain a certain skill level in order to live in their own home. Necessary instruction and assistance can be provided within the context of daily life.

People don't fail supported living... supported living fails them.

Individuals do not fail in supported living---arrangements sometimes fail to meet their personal needs and preferences. If one thing does not work, try another. There are unlimited ways to provide supports. The person, her friends, and supports should be persistent and dedicated to finding alternative strategies for success, when faced with a strategy that has failed. Like new strategies, sometimes a different person with a different perspective can find the way to success.

Chapter Summary

Knowing the definitions, history, and philosophy of supported living is not enough. It's just as critical to keep in mind what makes supported living different from traditional group living arrangements.

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Supported living is not about...

- ... being treated like a child.
- ... earning privileges.
- ... being "ready."
- ... financial requirements.
- ... imposing limits.
- ... frequent moves.
- ... fitting into an established program.
- ... merely finding a home, but making a life in it.

Supported living is not about being treated like a child.

Adults with challenges in communication or affect are often viewed differently, as though they are children who lack capacity and therefore need others to make decisions for them. All adults enjoy a degree of choice and control over their lives. Individuals receiving supported living services enjoy a greater degree of control over their lives than do those living in group settings.

Supported living is not about earning privileges or being ready.

In traditional group living situations, once people are accepted they are thought of as needing to progress through some type of continuum. Staff determine what the person must accomplish before moving on to other types of living arrangements. An arbitrary criteria of needed skills may be used in making this determination. People are frequently not "allowed" to live in their own home until deemed "ready."

There is also a perception that those things which enrich daily life must be earned as privileges, rather than occur naturally. For example, people who live in their own homes don't require themselves to complete a task before going out. People in group living arrangements may often be required to clean their bedroom before going out.

Supported living doesn't require making people ready by simulating how it will be to live in a home, rather, it begins to immediately support people to live in their homes. Supports are flexible and are adjusted based on the person's changing needs, preferences, and desires.

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Supported living is not about financial requirements.

People don't need a set amount of money in order to live on their own. Rather, supported living assists an individual in finding a place he can afford, given his financial situation. The coach may also assist in locating a roommate or offer suggestions to defray expenses.

Supported living is not about imposing limits.

Supported living is about clarifying expectations, so dreams may become reality. As an effective service, supported living is built upon the relationship that emerges between the individual receiving services and the person providing them. Getting to know the individual, how she learns best, and how she manages various situations will help the coach in supporting her to move beyond her own perceived limitations toward a desired life. Rhetoric like "you can't do this because..." is replaced with "let's see what it's going to take to support you in getting there."

Supported living is not about frequent moves.

In the past, when problems arose in group living arrangements it usually meant that someone had to move out of the home to alleviate the situation. Frequent moves are unsettling and can create a sense of loss. Supported living is about individualized services. Supporting people to live where and with whom they choose, in homes and neighborhoods in which they feel comfortable, often alleviates the need to move.

According to Klein (1994), this does not mean everyone must live alone, nor does it mean people must choose to live with a friend. It means if people want to live with someone else, they choose with whom they live. For example, some people with disabilities need intensive assistance to accomplish everyday routines. In these situations, people may choose to live with someone who can assist them or may have their assistance provided on a regular schedule or an "as needed" basis. This also means making an informed choice and knowing the full range of options. This may require trying a few options before finding the best one.

Supported living is not about fitting into an established program.

Although many of the places people live are called houses or homes, both people who work and live in these places describe them as programs. They often have professional sounding names, and meet the requirements of congregate living settings. Programs employ staff who come and go (generally in shifts) turning the "home" into a place of business and the driveway into a parking lot. This fact alone separates "programs" from the rest of the neighborhood.

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At times, programs evaluate people's abilities through the use of assessments to determine and legitimize their programming. This information is then compiled and a score determines into which program a person fits. Supported living is not a program or simply a service, but a process through which persons are individually matched to living arrangements and learn to access the locale and all it has to offer. The types and levels of supports each person needs are developed, and may be provided by paid staff, friends, or others who wish to be involved in the person's life. These supports are not determined by criterion-referenced assessment. Places accessed, personal relationships, and the means for being successful at home and in the community are determined by the person's interests and wishes. There is no prerequisite to community-based life. There are needs and desires that must be addressed.

Supported living is not about merely finding a home, but is also about making a life in it.

Although supported living usually takes place in and around the person's home, having a nice home is not the only necessary component of supported living. Many people have a desire to be part of their community, experience life in their neighborhood, make friends, and contribute to their community through employment or other means.

Despite the common belief that people's presence in a community makes them an actual part of that community, in reality, this is hardly the case. People living in group settings generally spend their free time with those same groups. Going to the store or to a movie in a group does not connect a person to that community. Participation in the community occurs on an individual basis and valued roles in the community take time to develop.

Deciding how and where to live involves a process of self-exploration, research, and planning. For people who will move into their desired homes and define their own lives with the help of a supported living provider, the first step toward these decisions may actually be consideration of this service option as it compares to others that have been discussed in this chapter.

Chapter Two provides the kind of information all persons need in order to make an informed decision about whether to provide or obtain supported living coaching services.

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