

Supported Living Services
Your SLS
Training Tool Box

Part One:
History

**Connections for Information and Resources
on Community Living (CIRCL)**

April, 2001





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Let's Start with a Little History

Introduction

Sometimes when you are learning about a new concept, like supported living, it helps to know where the idea evolved from and how it is different from other ideas about how people live and how they are supported.

Services for supporting people with disabilities are changing all the time as we become wiser and as we become better at listening to how individuals want to live. This section of the Toolbox gives you a little history about where people with developmental disabilities have been supported to live.

A Brief History of Residential or Living Arrangement Services and Supports ¹

In California, prior to the mid -60's, if an individual with developmental disabilities did not live at home with their parents the only state funded residential option that was available to them was a state hospital. State hospitals, now called developmental centers, housed thousands of individuals in large facilities. In institutions of this size it was impossible to achieve any of the characteristics of a home.

Throughout the country and in California parents began to organize and form coalitions to insist on community alternatives to institutional treatment. In the early 1960's, the civil rights movement and President John F. Kennedy, who had a sister with mental retardation, helped to speed the change process. In addition, exposes (like the photographs and stories of life in institutions featured in Burton Blatt's Christmas in Purgatory) figured prominently in the deinstitutionalization movement.

At the same time, progressive leaders like Marc Gold and Lou Brown were demonstrating that individuals with mental retardation could learn to do complex tasks if the instruction was broken down and taught in



¹ Adapted from Patterns of Supported Living; see References for complete citation at the end of Part One.



steps. Systematic instruction became the rage and soon, men and women - long warehoused in state institutions- learned (and learned quickly) new skills which gave them greater self-esteem and independence from caregivers.

Since resources have always been limited and need has been great, developing a cost-effective system of community services became a necessity. This made the *developmental model* very attractive to professionals and caregivers. That is, people with what seemed to be similar needs based on skill ability, behaviors or diagnosis, would live together in what seemed reasonable and cost effective (6-15 person) homes. Then, with systematic instruction, they would be able to move on to lesser-restrictive places to live as they developed more skills and achieved greater independence.

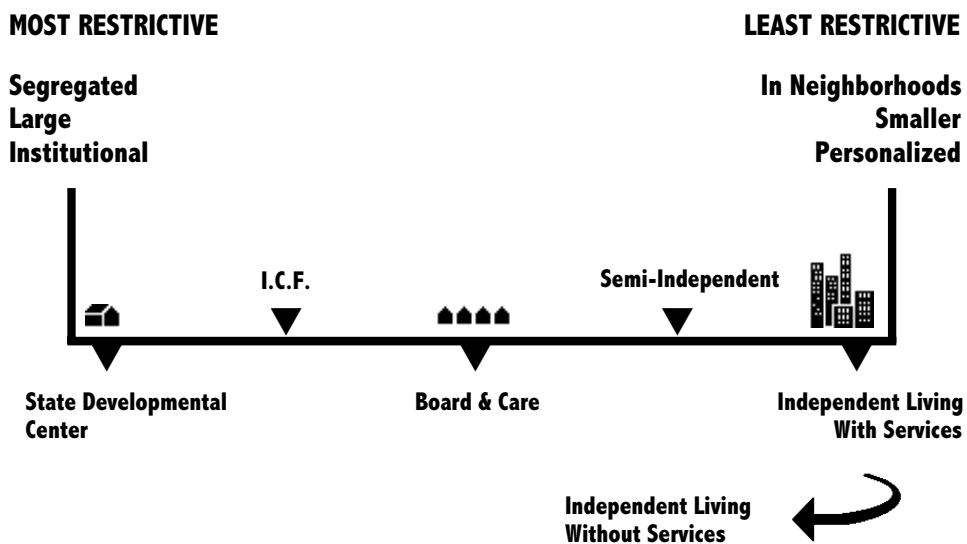
If the individual demonstrated that they could learn to do more for themselves and they did not present any challenges because of their behavior, it was expected that the individual would move from a large, state institution to a smaller place in the community. If the person learned enough to live independently, then moving into one's own apartment would be the final step toward independence. This way of organizing the service delivery system was referred to as the *continuum model*. People moved along the continuum of services in either direction toward smaller places with more independence or toward larger places with more supervision and restrictions. One of the downsides to this model was that people were often threatened with having to move back to a more restrictive setting if their skills, behavior or health declined. Also, people were often moved or placed without their consent and they often left behind people and a community that loved them and cared about them.

In the early 1980's the logic of the developmental and readiness models as well as continuum of services was questioned. It finally occurred to many that no matter how talented a teacher might be, many people with developmental disabilities would never be *ready* to move to their own place or to a real job in the community. *Ready* was defined as



being able to accomplish something in the *usual* way. For example, being ready to manage your own money meant that you had the math skills to balance a checkbook. It also became apparent that many people could learn things in natural settings (like on the job or in their own kitchen) and with support could do things far before they were considered to be *ready* and without knowing certain developmental skills like reading or writing. Critics of the continuum model sometimes refer to it as the *readiness model*.

The Traditional Residential Continuum Model



Independent Living Programs - One End of the Continuum

The idea for independent living programs in California was developed during the 1970's and 1980's at the same time the continuum was the preferred model for the service system. Independent living programs were defined as the end of the continuum for people with developmental disabilities who had the capability and motivation to learn the skills they needed to live on their own with no paid support. These services, as originally developed, were intended to be time-limited.



Personal Choice
(to the tune of "Blowing In the Wind")
Lyrics by Robert Stack, TASH Conference (1988)

How many goals must one man achieve
Before he's allowed to be free
Yes, how many meetings will it take
Before he sees his last IHP
Yes, and how many laces can one man lose
Before we get some loafers for his feet

The answer, my friend, might be personal choice—
The answer might be personal choice.

How many trials does it take til they know
That he can put his socks in the drawer
And how many charts must people fill out
Before he can find the exit door
Yes, and how many consumers will need to tell the team
That the whole damn thing is a bore

The answer, my friend, might be personal choice—
The answer might be personal choice.



At the time they were developed, independent living programs were viewed as radical and ground-breaking. People who had previously been limited to living with a group of other people with disabilities or living with their families, made the transition to living in their own homes. However, from the beginning, independent living programs were challenged by people who needed more than instruction and minimal services to live in the community. Some agencies were successful in negotiating an array of services (and a lift of time limits) with their regional centers.



Supported Living Services: A New Opportunity for Individuals to Live in Their Own Homes

The idea of supported living grew out of a combination of forces including independent living programs willing to push themselves beyond existing regulations and limits, people with developmental disabilities and their families who were asking for more options, and the California Department of Developmental Services and some regional centers who recognized that choosing how to live was a basic right.

Problems with the 1980's Continuum of Living Arrangements Model

- “Clients” are always getting *ready* to progress to the next program/home/level;
- “Clients” must physically move from one place to the next as they progress or decline;
- New needs = New buildings;
- Legitimizes restrictive, large , segregated environments;
- Confuses people’s needs for normal housing with their needs for specialized services and supports;
- Assumes that a more restrictive setting prepares a person for a less restrictive setting;
- “Clients” must earn the right to be part of the community; and,
- Personal choice is denied on the basis of professional judgement that the person is not *ready, appropriate, motivated, responsible, etc.*





Supported Living – A New Way of Thinking and Providing Services: A Paradigm Shift

Introduction

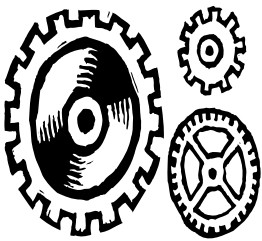
Supported living services offered, for the first time in California, the opportunity for any adult with a developmental disability to live in their own home and receive individualized services and supports regardless of the severity and nature of their disability. This was quite a shift in the way living arrangement services had been provided and in the way the service system viewed people with disabilities. This shift in the values for providing services is called a paradigm shift. It is worth spending some time understanding this paradigm shift so you can better understand the values of supported living services and how these values may be different from other kinds of services provided by the service system.

What is a Paradigm?

A paradigm is a set of rules that:

1. Define the boundaries; and,
2. Tells you how to behave inside the boundaries in order to be successful.

A paradigm shift is a change to a new set of rules. The following offers a discussion about some of the changes in the *rules* which compare supported living services to more traditional services:



A Shift from Getting Ready to Choice and Support

Individuals don't have to get ready for supported living the way they had to get ready or prepare for independent living which is the ultimate goal of the continuum model. The basic idea of supported living is that if a person wants to live in their own home, it's up to the person, family, supported living service and others who care about the person to help him or her identify what they'll need in the way of supports and services. Supported living services can be available to anyone over age 18 regardless of the nature or severity of the person's disability. In contrast, the continuum model was based on the idea that people



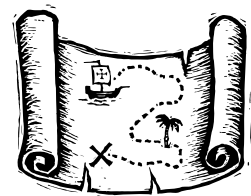
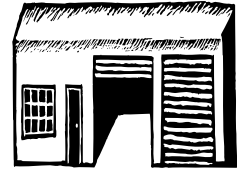
would live with others or in an arrangement like others who had similar support needs. The continuum model was developed when another service system breakthrough – the developmental model – was considered state of the art. Services were designed to help people increase their skills so they could move to another, usually smaller and less restrictive, living arrangement or the next step on the continuum. As stated earlier, one of the downsides to this model was that people were often threatened with having to move back to a more restrictive setting if their skills, behavior, or health declined. Also, people were often moved, or placed, without their consent and they often left behind people and a community that loved them and cared about them.

A Shift from Living in Someone Else’s Home to Living in a Home of One’s Own

A condition of supported living is that individuals live in a home of their own choosing and under their control. It’s important that the person’s name (not the supportive living program’s name) should be on the lease, rental agreement or on the mortgage. This practice separates a person’s housing needs from their needs for support. This power of the lease lessens the chance that people will be uprooted as their support needs change. In our society, having control of the lease or mortgage says *this is my place*. Having the home in the name of the person who lives there is also an important distinction between SLS and licensed board and care homes.

A Shift from Independence to Interdependence

The continuum model offered independence as the reward for increased competence. Independence from paid support and families was seen as the ultimate evidence of success or “making it”. What we learned from this model was that independence can be isolating and depressing. What we missed in our efforts to help people live better lives was the importance of relationships and interdependency in all of our lives. Supported living services value interdependence. The goal is not complete independence from other people. Instead, the goal is to help people experience the interdependency or give and take of





relationships within families, neighborhoods and communities. The goal is relationships that will support people in ways that everyone needs support and offer friendships, a sense of belonging and feeling important and valued.

A Shift from a Program Curriculum to Flexible and Tailored Services and Supports

Supported living services and supports are patterned differently for each person. Each pattern is unique and not repeatable. This method of providing services contrasts with programs which use a curriculum model that everyone moves through regardless of their service needs. Supported living requires a shift in thinking for programs and funding agencies from valuing only time limited, measurable, instructional and behavioral goals to valuing the choices, needs, and satisfaction of people with disabilities.



A Shift from Professionals Having Power Over People to Sharing Power and People with Disabilities Having Power

Supported living services require that the agency, the individuals they support and the individual's family, friends, and regional center case manager work collaboratively as a team to make decisions. Ultimately, the individual who receives services has the loudest voice in all decisions small and big that effect their life and their services. This shift in power to people with developmental disabilities requires that professionals use new skills in facilitation, communication, listening, team work and negotiation.



Comparison of Service Assumptions

Supportive Living Services

Everyone can live in a home of their own choice, given the right kinds of support.

People learn things easier with support and in the places where things happen, like in their own home.

People know their own needs best and should direct their own lives as much as possible.

Agencies provide a system of support as long as it's needed to assist someone to live successfully in the community.

Helper, advisor, facilitator, advocate.

System of support is designed around someone's needs wherever they live.

A desired outcome is someone living successfully in the community with support when they need it.

Services Based on the Continuum Model

Readiness to live in a home of your own has to be achieved through a series of steps.

As people learn things and get more independent, they move to new places to learn things.

People gain privilege and responsibility as they learn to handle it.

Agencies evaluate strengths and needs for and develop a plan to work on those needs until someone is ready to move on to the next level of independence.

Landlord.
Responsible for well-being and progress.

Services based on assessment and tied to a certain living environment.

A desired outcome is an improved score on an assessment or graduation to a new place to live with more independence.

Adapted with permission from OPTIONS.

This figure was adapted from Patterns of Supported Living; see References for complete citation at the end of Part One.

Supported Living Services²

What are Supported Living Services?

Supported living services (SLS) are a relatively new type of vendored service in California. SLS regulations were first adopted in 1995, however, some agencies have been providing supported living services under other vendor categories, like independent living, since the mid-eighties.

Supported living services (SLS) support people who want to live in their own homes. Supported living services offer an array of services that are available to anyone who desires (or whose family, advocate, or conservator desires for her or him when someone cannot express their own choice) facilitation, instruction, support, and assistance to live in the home of his or her choice.

² Adapted from Developing Supported Living Services: A Guide to Essentials for Service Agencies and Regional Centers; see References for complete citation at the end of Part One.



In addition to the Lanterman Act, Title 17 is of particular interest to supported living service providers. Chapter 3, Subchapter 19 of Title 17 includes the regulations that govern supported living services. The regulations describe:

- Regional Center Responsibilities
- Housing Financial Involvement and Responsibilities
- Vendor Status Requirements
- Consumer Eligibility Determination
- Service and Support Components
- Service records that must be maintained by providers.
- Consumer rights in SLS
- Service Design requirements
- Standards for Vendors
- Regional Center and Vendor staff training requirements
- Rate Negotiations
- SLS contract standards
- Performance Evaluations

Here is a good description of supported living services taken from the Lanterman Act Welfare and Institutions Code 4689.

Consistent with state and federal law, the legislature places a high priority on providing opportunities for adults with developmental disabilities, regardless of the degree of disability, to live in homes that they own or lease with support available as often and for as long as it is needed, when that is the preferred objective in the individual program plan. In order to provide opportunities for adults to live in their own homes, the following procedures shall be adopted:

- (a) *The department and regional centers shall ensure that supported living arrangements adhere to the following principles:*
 - (1) *Consumers shall be supported in living arrangements which are typical of those in which persons without disabilities reside.*
 - (2) *The services or supports that a consumer receives shall change as his or her needs change without the consumer having to move elsewhere.*
 - (3) *The consumer's preference shall guide decisions concerning where and with whom he or she lives.*
 - (4) *Consumers shall have control over the environment within their own home.*
 - (5) *The purpose of furnishing services and supports to a consumer shall be to assist that individual to exercise choice in his or her life while building critical and durable relationships with other individuals.*
 - (6) *The services or supports shall be flexible and tailored to a consumer's needs and preferences.*
 - (7) *Services and supports are most effective when furnished where a person lives and within the context of his or her day to day activities.*
 - (8) *Consumers shall not be excluded from supported living arrangements based solely on the nature and severity of their disabilities.*
- (a) *Regional Centers may contract with agencies or individuals to assist consumers in securing their own homes and to provide consumers with the supports needed to live in their own homes.*
- (b) *The range of supported living services and supports available include, but are not limited to, assessment of consumer needs; assistance in finding, modifying and maintaining a home; facilitating circles of support to encourage the development of unpaid and natural supports in the community; advocacy and self-advocacy facilitation; development of employment goals; social, behavioral, and daily living skills training and support; development and provision of 24-hour*



emergency response systems; securing and maintaining adaptive equipment and supplies; recruiting, training, and hiring individuals to provide personal care and other assistance, including in-home supportive services workers, paid neighbors, and paid roommates; providing respite and emergency relief for personal care attendants; and facilitating community participation.

Who Can Receive Supported Living Services?

Supported living services are available to any adult who desires supports and services to live in a home of their own. Individuals do not have to have any particular skills or meet any entry criteria in order to receive supported living services. In fact, by law, individuals may not be excluded from receiving supported living services solely because of the nature or severity of their disability. The only criteria is that the individual's Individual Program Plan with the regional center state that supported living services is a needed and requested service.

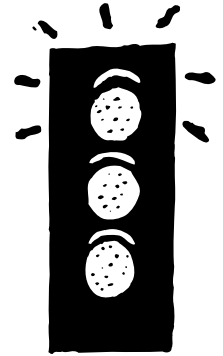
Supported Living services are for adults who:

- Want to live in their own place; and
- Want to make more of their own decisions.

Supported living is also an excellent option for individuals who have a hard time living with other people with disabilities, or who need more privacy or individualized support than they could get living in a group home.

Who Provides Supported Living Services?

There are three ways that supported living services are provided. An individual or their conservator makes a decision about which way they want services provided. The first way - through a supported living service agency - is the most typical way services are provided. Agencies that provide supported living services may have this service as their only purpose or they may provide other kinds of services as well. For example, they may also operate a vocational program or they may have licensed group homes. The other ways an individual may receive services is through becoming their own vendor or selecting a family member who becomes vendored.



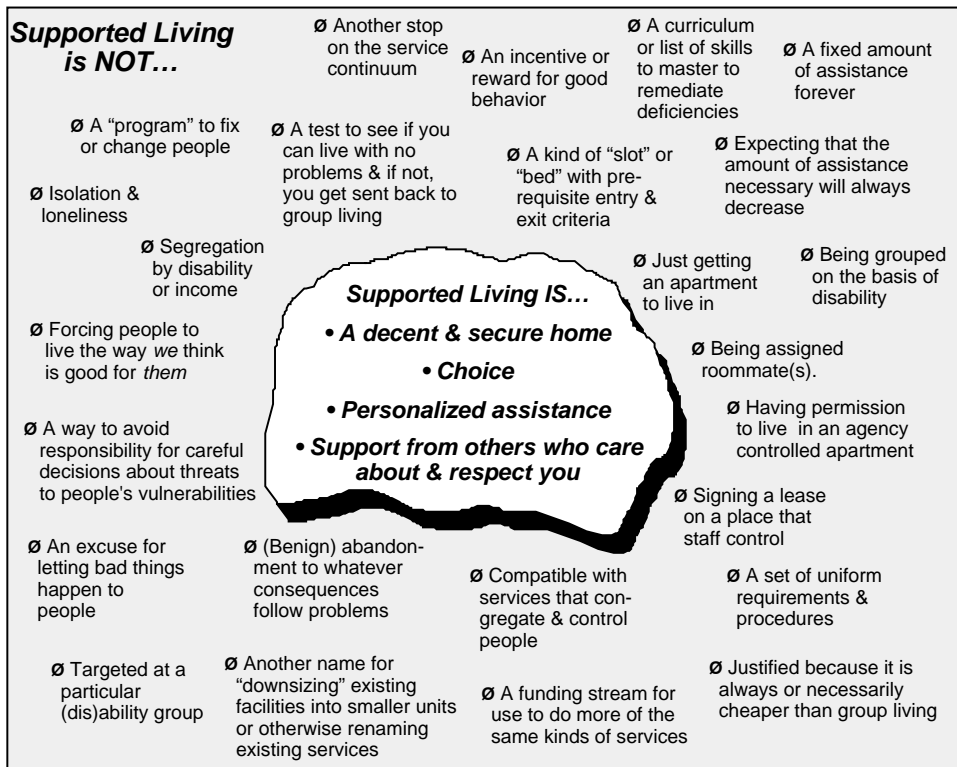


Who Pays for the Individual to Live in Their Own Home?

In supported living, an individual pays for his or her own living expenses (for example, rent, utilities, food, and entertainment) out of SSI, work earnings or other personal resources. The regional center pays the vendor (an agency, individual or family) to provide the supported living services. The individual may also receive other kinds of publicly funded services like MediCal, mental health services, vocational services, and In-Home Supportive Services (IHSS).

Supported Living is Not.....

Sometimes it is helpful when learning about a new idea like supported living to think about *what it is not*. The following graphic was developed in 1993 when several people who provide supported living services from around California came together to try to define supported living services. As you learn more about supported living services and as you struggle with your job responsibilities and your agency's policies and procedures, this is a reference you may want to refer back to from time to time.



• This figure was adapted from Patterns of Supported Living (VPD Section, page 16); see References for complete citation at the end of Part One.



Building your Toolbox: General Information on the Values of Supported Living Services

Supportive Living: A Single Solution? (No) A Value? (Yes)

By Jay Klein, Institute on Disability University of New Hampshire, National Home of Your Own Alliance, Website (<http://alliance.unh.edu>). A discussion of what supported living is and what it is not.

Celebrating the Ordinary – The Emergence of Options in Community Living As a Thoughtful Organization

By John O'Brien, Connie Lyle O'Brien, and Gail Jacob (1998), Inclusion Press, 24 Thome crescent, Toronto, Ontario M6H 2S5 Canada, (416) 658-5363.

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Patterns of Supported Living, A Resource Catalogue (1993)

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Developed for the Southern California Training and Information Group by Allen, Shea & Associates and Rhonda Mayer with revisions by Donna Schwann and Maureen Wilson.

Direct Support Professional Training Year 1 (1999).

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Supported Living Services Training Tool Box

**Part One:
Principles and History**

**Connections for Information and Resources
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April, 2001