



A Guide to Single Household Supported Living Services

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A Guide to Single Household Supported Living Services

Developed for

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Noah Erenberg

For the last 32 years, we have fought constantly for the best possible services for our son, Noah Erenberg, through 21 years of public school Special Ed programs— a frustrating and seemingly endless struggle. Then began “adventures in supported living.”

Since 1990 – under a variety of agencies – none satisfactory, but we were apprehensive to go it alone, even though the last agency, their staff and our family had frequent disagreements, and Noah was getting less quality service each year, Noah was miserable for a long time, as were we.

Finally, in 2000, we took the giant step of becoming vendorized, after many consultations with our mentor, Dave Denniston, after submitting three drafts over months of back and forth negotiations with the regional center.

Since we became vendors, the last two years have been amazing. Noah is 100% happier. His family is 100% happier. Noah is in control of who supports him and what supports he receives.

For Noah’s family, it is a great feeling of empowerment to know how every dollar, received for Noah’s support, is spent; and to know that finally he is getting true value for every dollar.

We were very fortunate to have had the resources to purchase a house for Noah. We decided to purchase this house in a college community where there has been, and will be, a constant supply of energetic, educated and caring support people for Noah. Noah enjoys the environment of the college community where he is known and accepted. He lives with four terrific house mates - all former UCSB students who bright stability, fun and compassion into Noah’s life. Our vendorization has made all of this possible and it is a blessing!

P.S. Over the last 10 years, with our help and encouragement, Noah has become a professional artist. He has taken art classes in the studio art department at UCSB and has used UCSB art students as studio assistants. All of which has greatly enriched his life, both socially and economically.

This year Noah has sold two large paintings to the M.I.N.D. Institute, which will open in 2003 through U.C. Davis Medical Center in Sacramento.



Introduction to Supported Living

What are “Supported Living Services” (SLS)?

Supported living is a lifestyle option for individuals with developmental and other disabilities. This term refers to a situation where an individual lives in a home of his or her choice, with or without house mates (roommates), and with support from friends, family and agencies, in order to have a life that is typical of others in his or her community, and achieve maximum independence. Individuals who were previously destined to live in licensed group homes, or other congregate settings, often succeed in creating a more natural, meaningful lifestyle within the community through a supported living arrangement specifically designed for him or her. Every situation will be different from the next, since individual hopes, dreams, desires, talents and needs vary greatly.

Supported living services (SLS) were developed to provide the support necessary to enable people to participate more fully in community life. SLS is based upon the belief that every person has a fundamental right to live in a home of his or her choice and that no person should be forced to live away from his or her community, or in a setting which is segregated, due to the nature or severity of disability. Supported living arrangements are not licensed; people simply receive the services and supports they need to build the lives they desire while living in their own homes and communities. By “their own homes”, we mean an apartment, condo, townhouse, duplex, or typical single family home which an individual has selected from a range of options; and, the lease, rental agreement or, in the case of a purchase the title/deed, is in the name of the person and signed by the person. This is the reason that SLS is available only to individuals over the age of 18, which is the legal age required for contracting in the State of California. Supported living services in California are governed by regulations (see the following paragraph); in regards to a person’s own home, the regulations specify that a home shared with a person’s parent or conservator does not qualify as the person’s “own home”.

The SLS regulations are located within Title 17 of the Welfare and Institutions Code. As regulations go, they are short and relatively easy to read. If you or someone you care about are interested in supported living services, you should read them. If you are seriously considering being an individual or single household vendor for SLS, you must read them; you will be expected to live by them, and you will find them

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helpful as you go through the process. The following page includes the definition of SLS as it relates to direct support, as described in the SLS Regulations.

What's so special about SLS?

SLS is unique. The core philosophies and values of supported living have a strong foundation in individual choice and self-determination. More than any other service, true supported living services are tailored to support each person's own distinctive blend of preferences, wishes, dreams, strengths and needs. Individuals utilizing services have clear and strong voices in selecting their service providers and support staff, the types of supports and services they wish to have, what they do each day, and with whom they do those things.

Having control over our own environments, and deciding who is welcomed into our lives and our homes, is critical for each of us. How many of us would have "behavior issues" or "severe reputations" if we had no voice, choice or control over the direction of our lives or where and with whom we live? In the past, many people have assumed that individuals with developmental disabilities simply did not know enough to have preferences and dreams, or that they were not aware enough to care. In other services labeled "residential", often administrative convenience and practicality must dictate physical environment and staffing rather than the individual preferences or needs of one person, as the needs and services of the whole group must be considered. Many people who were never successful in group settings due to "behavior" have been living successfully in their own homes, using appropriate supported living services, for over a decade.

Unlike some other services, there is no "readiness theory" associated with SLS. Everyone is "ready" to use supported living services, regardless of skill levels in any area. There are no specific requirements for levels of independence that "qualify" a person for SLS. While the SLS regulations do state that the person must express a desire to have supported living services, we also know that many individuals experience difficulty expressing their thoughts, wishes and desires verbally or in writing. In these situations, the person's wishes are often expressed through his or her circle of support (family, friends, advocates, agency personnel, etc.), as they are the people who usually know the person best.

Chapter 3: Community Services

Subchapter 19: Supported Living Service

Section 58614 - Service and Support Components

- (a) Supported Living Service, as referenced in Title 17, Section 54349(a) through (e), shall consist of any individually designed service or assessment of the need for service, which assists an individual consumer to:
- (1) Live in his or her own home, with support available as often and for as long as it is needed;
 - (2) Make fundamental life decisions, while also supporting and facilitating the consumer in dealing with the consequences of those decisions; building critical and durable relationships with other individuals; choosing where and with whom to live; and controlling the character and appearance of the environment within their home.
- (b) Supported Living Service(s) are tailored to meet the consumer's evolving needs and preferences for support without having to move from the home of their choice, and include but are not limited to the following:
- (1) Assisting with common daily living activities such as meal preparation, including planning, shopping, cooking, and storage activities;
 - (2) Performing routine household activities aimed at maintaining a clean and safe home;
 - (3) Locating and scheduling appropriate medical services;
 - (4) Acquiring, using, and caring for canine and other animal companions specifically trained to provide assistance;
 - (5) Selecting and moving into a home;
 - (6) Locating and choosing suitable house mates;
 - (7) Acquiring household furnishings;
 - (8) Settling disputes with landlords;
 - (9) Becoming aware of and effectively using the transportation, police, fire, and emergency help available in the community to the general public;
 - (10) Managing personal financial affairs;
 - (11) Recruiting, screening, hiring, training, supervising, and dismissing personal attendants;
 - (12) Dealing with and responding appropriately to governmental agencies and personnel;
 - (13) Asserting civil and statutory rights through self-advocacy;
 - (14) Building and maintaining interpersonal relationships, including a Circle of Support;
 - (15) Participating in community life; and
 - (16) 24-hour emergency assistance, including direct service in response to calls for assistance. This service also includes assisting and facilitating the consumer's efforts to acquire, use, and maintain devices needed to summon immediate assistance when threats to health, safety, and well-being occur.

Note: The remainder of this section describes SLS Administration and other related components. The SLS Regulations can be accessed via several websites, including the Department of Developmental Services (DDS) website at www.dds.ca.gov and the California Protection and Advocacy (PAI) website at www.pai-ca.org.

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One factor that separates SLS from some other services is flexibility. This is what allows supported living services to be so responsive to each individual. Because services are truly tailored to the individual, it is easier to shift, add, reduce or otherwise customize supports as needs, preferences or desires change. The concerns with impacting the services of others in a group by changing something for one person are eliminated or greatly reduced.

Another key thing to remember is that this is, indeed, assisting a person in creating a unique lifestyle. That person must be provided the freedom to make choices for him/herself, and have those choices honored. At the same time, we know that many people have not had a lot of practice in decision-making. So we want to make sure that people have as much support as they wish and need, as they learn, grow and live in their homes. Sometimes that will require more structure; sometimes it will require being more laid back. It is important that we pay close attention to what people are telling us about their lives.

In the event that supported living services and supports do not meet the person's needs, or the person decides that he or she is dissatisfied with the service provider, the person has a right to change service providers. Of course, there are usually conversations about how to make things work better first. This is often an exercise in clarifying expectations and responsibilities, as well as making some compromises on both sides. However, if there is still not a "match" after everyone making best efforts, or if the person decides at any time that the current provider is not his or her choice or not meeting his or her needs, a new SLS provider is chosen. Although this process may take some time, the important thing is that the person being supported has the right to decide whether the service provider is right for him or her, and to make changes as desired. This is usually accomplished with the assistance and support of the person's regional center service coordinator, the person's circle of support and others.

The situation described above is one of the reasons that the SLS regulations separate the provision of housing from the provision of services, again a unique and important feature of SLS. The intent is to remove any possible undue influence by providers, intentional or unintentional, over whether a person feels that he or she

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is “satisfied” with his or her supported living services and SLS provider. This applies to all SLS vendors, including family members who are vendors. When services or the relationship between the person and the provider do not work out, the individual does not have to uproot his or her life to move to a “more appropriate placement” in order to receive SLS. The person’s home remains the person’s home; a simple concept, yes, but not often evident in other traditional services labeled “residential” or “residential placement”. In fact, supported living is never referred to as a “placement”. It refers to a person’s home, and the provision of a set of services and supports tailored for the individual.

People often ask about safety issues when they begin investigating the possibility of supported living services. Ensuring safety is always of primary importance. With SLS, because services and supports are individualized, safety concerns and training can often be addressed on a more in-depth, personalized level. For individuals with intensive needs, SLS can offer the opportunity of one:one support, which may not be available through other services.

What is NOT “Supported Living?”

This list could be very long, but let’s start by saying that, if a service or arrangement does not meet the conceptual framework described above, it is not SLS and should not be called “supported living”. That said, there are certainly many other types of living situations that people desire or find acceptable. For example, continuing to live with one’s parents is a desirable situation for many people. However, continuing to live in a parent’s home with that parent and receive support services is not SLS; it is a different service, and should be called something else to reduce confusion.

These are just a few examples of when you can tell that a situation is not supported living services. SLS is not happening if:

- a person is told where to live or not provided the opportunity to look at different options and make a choice;
- staff are being “assigned” or hired without the person first meeting the proposed employee and deciding to try out the relationship;

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- a provider exerts undue influence over a person;
- a person's housing situation is dependent upon his or her continuing to use a particular provider;
- an individual's choices are unreasonably limited;
- a person's decisions and choices are not respected, acted upon, supported or otherwise honored;
- other people are making important life-changing decisions for a person, as well as daily decisions such as what to do, where to go, what to eat, what to wear, and when to do these things;
- services and supports are unable to be flexible as needs, preferences and desires of a person change;
- a person's situation is consistently unsafe;
- a person is or feels controlled rather than supported.

A Note To Parents, From Parents

The responsibilities of parenting a child with developmental disabilities span a lifetime and can be all-consuming. As parents, we have spent the years of our children's lives learning about our children and becoming experts in their abilities and "limitations"; learning the medical, education, social services, political, legal and developmental disabilities systems and terminology; learning to be advocates; learning how to get what our children and our families need; learning to cope; learning to "fit in" to the community; learning about resources; and learning to compromise, cajole, negotiate, adapt and juggle. We learn to tell the difference between who will help and who will not. Most importantly, we learn the particular importance and power of our love for our children, whether they are toddlers, adolescents or adults. After years of conditioning, we are used to having to be the catalysts for all of the significant events in their lives. At the same time, we are very much aware that our children will be here after we are gone, and the awesome responsibility of ensuring their future is, of course, ours as well.

The one thing we are not taught is how to let go.

One of our hardest lessons to learn as parents of individuals with developmental disabilities is how to balance our children's vulnerability to the world and our desire

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to protect them at all costs with our intent to support them to reach their highest potential, to have dreams, expectations, goals, and independence. We all want our children to have full, productive and happy lives, rich with choices, opportunities and people who love them. Supported living offers people an excellent chance to build that life, complete with the necessary comprehensive services and supports that are essential and unique to each individual. It also offers an opportunity for parents, friends and family members to find the ways that best support the person as an adult, making his or her own way in the world. And, we all like to have a hand on one corner of the safety net; supported living offers a variety of non-intrusive ways to do just that.

Just between us, the danger of being a supported living vendor and being the parent is the ever-present opportunity and overwhelming temptation to take over. There is a fine line between controlling things and having things under control. Utilizing your wisdom and years of experience and expertise are important, and can be one of the defining factors underlying the quality of the supported living services. However, you will need to find appropriate avenues for channeling your input, suggestions, advice and non-negotiables. Even though you are the vendor, you must constantly keep in mind that the home your son or daughter is living in is his or hers, not yours. You may hate the kitchen curtains that he chose, or feel that the underwear should be in the top drawer, not the middle drawer. These decisions are not yours. Having respect for your son or daughter as an adult is critical, regardless of abilities or limitations. Sometimes it helps to think in terms of how you would treat your other adult children or others at this chronological age. For example, most of us would not just walk into our adult children's homes without knocking, or maybe even calling first, even if you do have a key for emergencies. Think about applying the same standard. This sends a message to everyone, including your son or daughter, staff and house mates, that you are showing respect and that you truly are modeling the values and philosophies underlying supported living.

That said, when things impact health & safety or true quality of life, your role as the vendor is definitely to work with your son or daughter and the circle of support (including staff) to bring your concerns forward and work as a team to make positive and necessary changes. This is also your role as a parent, of course. There will be times when you will simply need to say something like, "I'm going to put my Parent

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Hat on for a minute...” The tricky part is figuring out which role to play when, and it will take some time for you to get comfortable with the differences and switching back and forth. You will find it is well worth the effort, and will play a big part in building and enhancing your relationships with everyone involved.

Not every parent wants to be or should be a vendor for SLS. There are certainly pros and cons on both sides. And, there are individuals who do not want their parent(s) to be their vendor, which is of utmost importance in the equation. However, once you decide to make the commitment, realize that it is a journey and that all of you will learn something new each day. If you keep returning to the basic values and philosophies of SLS, your decisions will become easier each time. You will find that being an integral part of your son’s or daughter’s SLS arrangement is one of the most rewarding experiences you can have.

“She’s moved in! Everything is set! The hard part is done.”

Wrong. That was the easy part. One point of caution that experienced SLS vendors will offer, regardless of whether you are a family member, friend or professional associate of a person in a supported living arrangement: change is inevitable. As soon as you feel that “everything is settled”, something will change. People who decide to use supported living services often experience much growth and change as their relationships, skills, interests and tastes evolve. Individual lifestyles and choices will also change over time. Other people’s situations change, and lives may take new directions. Circumstances, relationships, financial and health situations can be altered overnight. Many of these changes are positive, and provide an opportunity to find a new path. Some are not so positive, and will challenge everyone’s creativity and fortitude. Support needs will change, as well; we are all interdependent, and a variation in one person’s life has a ripple effect on others. And, there is always the issue of others getting comfortable with a person having more control over his or her own life. Even though people have been living in supported living arrangements for over a decade, this is still a new concept for many people, including some family members, new friends, and many neighbors in the community.

Isn't This All I Need to Know? Why Should I Read the Rest of This Manual?

There are a million details associated with our everyday lives. Just think of your own life. Then add the components of complex physical, health, emotional and functional needs, as well as the components of organizing and running a business - within the guidelines of SLS -- including complying with labor laws and regulations. This manual will attempt to walk you through some of this maze.

This document was compiled with the emphasis on meeting a person's individual needs, while supporting the efforts of the consumer, family members and/or circle of support when they all choose to work together to create successful individualized lifestyles and lives. It is with great enthusiasm that many people have gone forward to pave the way for this innovative and practical approach. We hope that the adventure of providing this service will not only meet people's needs in meaningful ways, but that it will be fun as well!

What Does It Mean?

- Everybody is “ready”, no matter where they are in life
- Having choices, making decisions, developing life skills
- Living interdependently
- Choosing where to live and with whom
- No licensing
- Full community membership
- Enhanced quality of life
- Individualized personal lifestyle
- Taking responsibility
- Building and expanding a circle of support
- Compatibility and friendship with house mates and support persons
- Supported living service provider (vendor) is separate from housing
- Person being supported has control of who is providing support, how and where, including hiring, firing and evaluation
- Long term commitment and security
- Living life vs. being “in a program”

**Section I:
Now That You've Decided
on Supported Living**



I've been living in my own home since 1992. When I first moved, I never thought I would last a month, let alone 10 years. The biggest challenge is finding good people to support me. I've been lucky because I've had the same core staff for the past 5 years. But, that also has its down side. Sometimes I'm so tired of the same people, I think about moving back to a nursing home where I'd have some variety! It's like a marriage - it's the little quirks that can wear on you! The best part of living in my own home is that I can have all my animals.

Now That You've Decided on Supported Living

Now that you have made the decision that Supported Living Services (SLS) is the right choice, there are some important steps to take.

Before we outline the steps, just a reminder about “consumer involvement and participation.” It is essential that the consumer be at the heart of all planning and decision-making throughout the process of discussing, developing, implementing and evaluating his or her supported living services. Some people will readily jump in and want to lead all discussions; others may stand back, unsure of their roles in making choices and decisions about their lives. Still others may want to be part of the big picture, but not of any details.

Each consumer should be supported in making his or her decisions about the level of involvement and participation he or she wants in setting up and implementing the supported living arrangement.

One of the jobs of the circle of support is to assist the consumer by facilitating his or her understanding of supported living and what it means in the daily life of an individual. How will things change? How will they be the same? What types of support, and from whom, does the consumer need to feel comfortable taking a leadership role in the supported living process, and in making both long-term and day-to-day decisions? What types of facilitation are necessary for the consumer to most effectively communicate his or her wishes, ideas, thoughts, questions and concerns about all of these things? How will the circle of support make sure that the consumer is supported in the best ways to feel comfortable and safe in communicating throughout this process?

And finally, for those of you who are conservators or are thinking of becoming conservators...

In terms of the mechanics of supported living vendorization, conservatorship is a silent issue. You are not required to be a conservator, nor are you prohibited from being a conservator. It has no bearing on your eligibility for being a supported living vendor. The pro's and con's of conservatorship are well-debated, and

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there is plenty of other important information to include in this manual without opening that discussion here. As in the Supported Living Services (SLS) Regulations, conservatorship is a silent issue in this manual except to say that it is irrelevant.

There are key considerations to think about and discuss even before the decision is made to choose SLS. For more information on this topic, see Section II of this manual.

What To Do Next...

<p>Step 1 Add a Goal for SLS to the Individual Program Plan (IPP)</p> <p>Call your service coordinator (case manager) at the regional center. Explain that you have decided that supported living is the right choice for you [consumer]. Ask for an addendum to be added immediately to the IPP stating that you are requesting a new goal for supported living services. You may want to word it similar to this: "I want to live in my own home and receive supported living services by [pick a specific target date, such as May 1, 2003]."</p>	<p>Who</p> <ul style="list-style-type: none"> • Individual Consumer • Depending upon the individual and his or her wishes: <ul style="list-style-type: none"> Family member Friend and/or Other advocate
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The target date can be any date that seems reasonable or desirable for the consumer. Remember, you can alter this date later if anything significant changes, or if the consumer and his or her circle decide to delay or move up the date. Having a target date helps everyone focus the energy and attention on making supported living happen for the consumer in a timely fashion. It also helps the regional center in its own planning processes.

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Some service coordinators may want to meet with the consumer and his or her circle of support before adding the new IPP goal. Also, each regional center has its own policies and procedures, and yours may require a face-to-face meeting in order to change the IPP. Scheduling a meeting with the necessary people as soon as possible will help to ensure that things move along in a way that assists the consumer in receiving supported living services in his or her own time frame.

One word of caution...

Do not skip the step of adding a supported living goal to the IPP!

It is critical to have the consumer's wishes and plans documented in the IPP so there are no misunderstandings about what the goal is, when the consumer expects to achieve it, or what resources need to be made available by the regional center and others. Verbal discussions or promises are not the same as goals written in an IPP, which is a legal document.

Later on in the process, when the consumer has definitely chosen a specific vendor as his or her partner in the supported living process, the IPP goal for supported living should be amended to include the name of the vendor selected by the consumer. If the consumer has chosen an individual vendor (such as a parent vendor) at the time the original IPP goal for supported living is written, the vendor's name should be included in the goal to clarify and document the consumer's choice of vendors.

Usually, regional center service coordinators are enthusiastic and excited that a consumer they support has decided to pursue supported living. Sometimes, however, service coordinators are not familiar with supported living services. They may be confused about things such as who is eligible for SLS or how to go about starting the planning process.

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The eligibility criteria set out in the SLS Regulations (Section 58613) is:

- “(a) A consumer shall be eligible for SLS upon a determination made through the IPP process that the consumer:
 - (1) Is at least 18 years of age;
 - (2) Has expressed directly or through the consumer’s personal advocate, as appropriate, a preference for:
 - (A) SLS among the options proposed during the IPP process; and,
 - (B) Living in a home that is not the place of residence of a parent or conservator of the consumer.
- (b) Consumers shall not be denied eligibility for SLS solely because of the nature and severity of their disabilities.”

If the service coordinator does not know how to initiate the process for supported living in your regional center, or feels that the consumer is “not eligible” for any reason, it is important to ask for a meeting with the consumer, members of his or her circle, the service coordinator, his/her supervisor, and the resource developer or other regional center staff person in charge of supported living services. Others may be appropriate, depending upon the situation and the structure within each regional center. The consumer may also want to invite the Clients’ Rights Advocate for your regional center. If this meeting does not result in a positive outcome for the consumer, there are other options, including asking for a meeting with the regional center executive director, contacting Protection & Advocacy or other advocates for assistance, and filing for a Fair Hearing.

Having a good relationship and good communication with your service coordinator and other staff at the regional center is extremely important. Developing a trusting and cooperative relationship, and working in good faith with your regional center, is essential when quality supported living services and consumer satisfaction are the ultimate goals. Consumers, family members, service providers and regional center staff have much to share with each other and much to learn from each other. Walking together through the process of setting up and providing high quality supported living services that enhance a person’s life can be a wonderful learning opportunity for everyone involved.

Now That You've Decided

<p>Step 2 Investigate Options for SLS Service Provision</p> <p>Find out what the options are for SLS in your geographical area. This is important even if you already think you want to be vendor (provider). Generally, the choices are:</p> <ul style="list-style-type: none">• Supported Living Agency• Self (Individual) Vendor• Parent Vendor• Other Individual Vendor (friend, family member, support person as vendor, etc.)	<p>Who</p> <ul style="list-style-type: none">• Individual Consumer• Potential Individual Vendor (someone tentatively identified)• Depending upon the individual and his or her wishes:<ul style="list-style-type: none">Family memberFriend and/orOther advocate
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What is a “vendor?”

Before we go further, let's make sure that everyone understands the term “vendor”. To simplify it, a vendor is an agency or individual that provides services to persons with developmental disabilities through an agreement with the local regional center.

This happens through a process called “vendorization”. The regional center has certain requirements that providers must meet in order to become vendors. This paperwork includes a plan (“service design”) showing what services the vendor will provide, how and where those services will be provided, to whom, and other pertinent information. The regional center wants to make sure that the agency or person is capable of actually providing these services. There is also some standard paperwork that all vendors must sign, as you will see in Section III of this manual. Depending upon the type of service provided by the vendor, rates are either set or negotiated. In SLS, rates are negotiated, and may be hourly, monthly or on a flat rate basis agreed to by the vendor and regional center. More information on individualized rates and negotiation is provided in the section outlining budget and other fiscal information, and in the SLS Regulations.

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Once a vendor has been approved by the regional center, the regional center refers consumers to the vendor; or, in the case of an individual SLS vendor, the regional center understands that the vendor and consumer have already made the decision to work together. The SLS vendor and the regional center sign a contract according to the Supported Living Services Regulations.

The regional center also issues an authorization for services called a "Purchase of Service" (POS) for each consumer served by the vendor. The POS details the amount authorized for the vendor to bill the regional center for the consumer's supported living services.

Why should we investigate other options if I know I will be the vendor?

There are several reasons that you and the consumer should check out other options, even if you are both sure that you are ready to be the SLS vendor. Your regional center should be able to give you a list of available SLS agencies to talk with, as well as some names of other individual household vendors and, possibly, consumers who are their own vendors. Talking with others is a wonderful opportunity for the consumer and you to ask questions of people who have been providing, and using, supported living services.

1. SLS Agencies

- By talking with the SLS agencies in your area, you and the consumer will learn a tremendous amount about supported living, the role of the vendor, what "quality" supported living services means in a broader context, how they evaluate services, and how agencies provide individualized supports and services. You will learn something different from each agency you visit, all of which is very valuable to you and to the person you will be supporting.
- You may find an agency you both really connect with and feel could provide the quality, individualized supports the consumer needs. Your role could possibly be for quality assurance or as a circle member instead of taking on the entire responsibility of being the vendor.
- You might be able to reach an agreement with an agency to contract with them for assistance with staff training, screening and background checks, or

even payroll. Several parent vendors have successfully partnered with an existing SLS agency to provide administrative support and/or staff emergency back-up.

- Agencies often have valuable information that they might share with you regarding good potential landlords, social and recreational opportunities to meet other consumers in SLS arrangements in the consumer's community, and a variety of information about generic and community resources.
- Agencies may be able to provide you with information about SLS vendor groups, gatherings, or specific SLS vendor resources in your area.

2. SLS Parent Vendors

- Parent vendors can be a valuable source of information and creative ideas, even if you decide not to become a vendor. If you are a parent, and do finalize a parent vendor arrangement for SLS, these contacts are especially invaluable. The benefit of their experiences in planning SLS, negotiating with your regional center, and finding resources available to individual vendors (vs. non-profit or for-profit agencies/businesses) can make the difference between a smooth transition and a difficult road. Who is their local insurance agent? What do they do about payroll services? What does the local regional center require in the way of documentation? Their experiences can help you make key decisions about what to do and what not to do.
- Other individual vendors, such as parents, will be part of your own personal support network. Parents who are SLS vendors for their own children are in a unique situation, and have experience in balancing the complex roles of parent, friend, protector, cheerleader, advocate and service provider. They, more than any other vendor, must work hard at "letting go" of many ingrained habits (like being expected to make all of the decisions), and not over-shadow the independence of the consumer. Their perspective and the issues they confront are different than other vendors, yet the requirements and responsibilities as a vendor are the same. Keep their phone numbers and e-mail addresses handy!

Now That You've Decided

3. Self/Consumer Vendors

- Consumers who are their own vendors also have a perspective not shared by others. Their expertise in finding creative ways to meet their own needs while meeting the requirements of the regional center and the SLS Regulations can be very enlightening.
- Self-vendors can provide insight and ideas regarding ways to assist consumers in learning to become responsible and responsive employers to the people providing their daily support. Learning how to get your needs met while building and maintaining a cooperative, respectful and meaningful relationship with support staff is a balancing act of its own kind. Their experiences can be so valuable for other consumers, even if the others are not their own vendors.
- Some consumers may wish to be their own vendors, but do not feel “qualified” or are afraid to try. Self-vendors can be good role models and inspiration for all of us.

4. Other Individual (“Single Household”) Vendors

- Some vendors are the SLS provider for one consumer, or one household, but are not parents. Siblings, other family members, friends, staff from previous living or work situations, and others who have a strong desire to assist a particular consumer may be providing SLS for someone they care about. While their role as a provider is the same according to regulations, and similar to that of a parent vendor in nature, the difference in the relationship creates a distinct dynamic. This vendor can provide helpful feedback and observations about many of the issues described above, as well as tips on managing the many interconnecting relationships from a more objective viewpoint.

5. Consumers Accessing Supported Living Services

- Your regional center should be able to give you names of people living in their own homes who are willing to talk with the consumer and/or you about their own supported living services. Making a visit to someone’s home is an excellent way for people to get a better idea of what supported living is all

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about. If possible, talk with consumers who use a supported living agency as well as consumers who use an individual vendor. If you are thinking about parent vendoring, it might be very helpful to visit someone whose parent is their vendor. The dynamics of these situations tend to be very different than other consumer-vendor relationships. This will give you both an idea of what you like and don't like about the various arrangements, and it might bring up important discussion points for the two of you to address even before you get too far into the planning of services and supports.

- It will be especially important to remember, and to remind the consumer, that each person's home, standards and other specific decisions are individual choices. For example, visiting someone who lives in an apartment does not mean that you must also live in an apartment if you receive supported living services. Likewise, there are multiple ways to implement and administer supported living services as the vendor, and these are personal choices that the vendor and consumer can make for that individual supported living arrangement.

<p>Step 3 Obtain and Read the Supported Living Regulations</p> <p>The Supported Living Services Regulations are important to read for a variety of reasons; particularly, they will help to define SLS, clarify the scope of services, and outline the responsibilities of the vendor and regional center, and the rights of the consumer.</p> <p>First, the bad news: 1) Regulations are boring; and, 2) If you choose to be the vendor, you must adhere to the SLS Regulations.</p> <p>The good news: The SLS Regulations are relatively short and, for the most part, fairly straightforward.</p>	<p>Who</p> <ul style="list-style-type: none"> • Potential Single Household/ Individual Vendor • Others in the Circle of Support, including Family Members • Individual consumer, if he or she desires* • Individual's Regional center Service Coordinator <p>* If the individual is unable to read and/or understand the actual regulations, it would be beneficial for someone in the circle of support to talk with him or her about the key ideas, especially related to consumer rights and responsibilities.</p>
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Now That You've Decided

Your regional center should be able to give you a copy of the Supported Living Services Regulations. They can be found in this manual in the Resources section, or you can obtain them through the California Department of Developmental Services (DDS) website at www.dds.ca.gov or the Protection & Advocacy, Inc. website for California at www.pai-ca.org. You are looking for:

Title 17, California Code of Regulations

Chapter 3: Community Services, Subchapter 19: Supported Living Services

Article 1, Sections 58600 - 58680

How long will all of this take?

The time it takes to go through the process of becoming a vendor and putting together supported living for an individual can vary. Although SLS should not be considered a “crisis service”, there have been situations that were vendored, planned and implemented in as little as four to six weeks. This, of course, is not typical, nor should it be.

Assisting someone in creating a truly individualized life is a task worthy of significant thought and planning. Allow enough time for the consumer and you to really think through what services and supports the person needs and wants, as well as the best ways to provide them. At the beginning of the process, talk over:

- the **vision** of the consumer, family and/or circle of support of what life will be like for the person when living in his or her own home;
- **outcomes** the consumer, family and/or circle of support are expecting as a result of supported living services;
- the **individual’s expectations** of you, as the vendor; and,
- **rights and responsibilities** of all parties: consumer, vendor, family members, circle of support, the regional center and other agencies, if any.

These discussions can take place over time, and in a variety of formats. Your own knowledge of the person, input from other significant people in the consumer’s life, informal conversations, daily observations in different settings, recent professional

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assessments, and more “formal” planning processes such as a person-centered planning meeting, PATH, Essential Lifestyle Plan, and similar opportunities all have a place in the gathering of information. No one tool or process will capture all of the critical information necessary for a well-rounded supported living plan. The most beneficial process is a combination of many perspectives and thoughtful discussion.

Take the necessary time to actually put the supports and resources in place right from the start whenever possible. It is much easier in the long run to do things right the first time instead of having to go back and correct poor decisions made under pressure to rush the start of supported living services.

What is a good rule of thumb? While keeping in mind that the process is very individual, a reasonable average is probably somewhere between a minimum of three to six months. Many people take longer, but feel that the wait is worth the outcome.

There are obviously many variables, including desire and current situation of the consumer, start-up costs and available resources, housing considerations, geographical location, availability of staff, intensity of and accessibility to other necessary supports, adaptive equipment, training issues, general motivation of others involved in the process, and quality of collaboration and cooperation among the regional center, consumer, family and circle of support.

And, having said so much about the importance of planning, the beauty of supported living is that it is a fluid service, meaning that it can and should shift and change as the person's needs and desires change. Living on one's own can be a tremendous growth experience for any of us, and changes in supports and services should mirror that growth. Supported living services should always be responsive to the consumer. Vendors for an individual or single household have the optimal situation for being responsive, as they have only one - or possibly two - individuals to support rather than the larger number to whom agencies must be responsive.

The bottom line is this:

The individual consumer deserves the best possible opportunity to be successful in this new stage of life. The vendor also deserves the chance to provide the high quality supports that will lead to maximum consumer satisfaction with the supported living services, and the overall quality of his or her life. It takes time to build a strong foundation and set the stage properly so the consumer can create the life of his or her dreams.

Section II: Making the Decision to be a Single Household SLS Vendor

Eddie Compton

My son, Eddie, is a 29 year-old autistic man with dreadful behavior problems. He lived in the family home for the first 18 years of his life. We love him so much, but he was so disruptive. He was expelled from his school program and kicked out of every available day program. Because of this, the family decided to relocate to a rural coastal area in Oregon where Eddie could be free to be himself.



It didn't work out. No day programs or services. Eddie became isolated and bored. His behaviors became worse. It got so bad that we were forced to place Eddie into a group home. At that time, we were told that we were doing the right thing and now the family could finally rest and start living a normal life. We were told that once Eddie was gone, we would feel so good, but that didn't happen. Eddie kept getting into trouble in the group home and was finally placed into a developmental center. At the developmental center, his bad behaviors continued.

Instead of relief, the family became more stressed. We couldn't sleep. My wife would call three or four times a week to make sure Eddie had a blanket and wasn't sick or hurt. On several occasions during our visits, we found injuries on Eddie that indicated that he had been assaulted. In one case in particular, we found him in his room with his front teeth knocked out. Because he is non-verbal, we were never able to find out what actually happened. There was an investigation, but no one was ever charged with the assault. Even though we lived over 200 miles from the center, we never missed a weekend visit.

Eddie was upset too. He would cry when we had to leave. Oregon had no community services that could meet Eddie's needs, and the family wanted Eddie out of the institution so bad. We knew that for Eddie had to relocate back to California. With the help of the Delta Project and Alta Regional Center, we were able to return to the Sacramento area and bring Eddie home.

Also with their help we were able to set up a Supported Living arrangement where Eddie is close to his friends and family, but doesn't dominate their lives. It is not easy, but Eddie is really happy. He has had a few set backs, but his life is heading in the right direction. He is able to make his own choices and not disrupt others. He is loving and funny; he can really make you laugh. Who care if he keeps his beanbag chair in the closet or doesn't allow the microwave oven to be plugged in? It is his house, and Eddie likes it that way.

Section II:

Making the Decision to be a Single Household SLS Vendor

Things to Think About ...

Some important considerations when deciding whether or not to become an individual vendor are:

- Needs of the individual;
- The individual's family structure and support structure;
- The individual's and potential vendor's desired involvement in providing services; and,
- The individual's wishes regarding choice of SLS vendor, including whether he or she wants a family member or friend to be the service provider.

In some situations, day-to-day business demands on the vendor, including having to oversee services and supports, may jeopardize an existing nurturing personal relationship between the individual and the vendor. If this is the case, finding an agency that values and supports family involvement and participation may better meet the needs of everyone involved, allowing the family member or friend to remain solely in the personal role. In other cases, various factors such as time constraints and other lifestyle issues determine that the individual would be better served by having an established agency provide services.

When it does seem as if being a "single household vendor" -- meaning the SLS vendor for only one person, or for two or three people who have chosen to share one home -- will best meet the needs of the individual, specific things to think about are:

- **Goals of the Individual**
Both long-term as well as short-term goals need to be considered. How will these goals best be met? Will you, as a vendor/service provider, be able to facilitate the process, including all necessary follow-through, to make sure the desires and decisions of the individual are met? Sometimes it can be difficult to step back from a parent role and facilitate decisions made by the individual, even though he or she is an adult. This can be especially tricky

Making the Decision to be a Provider

when the individual and parent vendor disagree.

- **Share and Communicate Expectations**

In order to facilitate positive results, it is crucial that the expectations of everyone involved be specifically addressed and weighed with the expectations of the vendor. The value of taking an honest approach regarding each person's vision and expectations will be worth the effort. The result will be the ability to set realistic goals and will lead the way to agreement and follow-through with regard to roles and responsibilities.

The expectations of each circle of support member are as varied as the members themselves. This is the value of having friends, family members and acquaintances in our lives! How many times have we experienced a new opportunity because someone shared a new concept we decided to explore? Each circle member will share his or her individual expectations and ideas, always keeping the individual's best interests in mind, while maintaining the commitment to share in the responsibilities generated by the plan. The vendor who is able to provide SLS with expectations that have been clearly defined and agreed to by the individual and circle of support prior to starting services will find it easier to communicate and resolve difficult issues that may arise later. Although the vendor may feel capable of making all decisions for the individual, SLS is built on the philosophy that each person, as an adult, makes his or her own decisions, with the support of his or her circle. While this sounds like a straightforward process, there can be subtleties and tensions at work that make it complex, especially when the individual is unable to speak for himself or herself. Ideally, the circle is comprised only of people who not only care about the person, but know him or her very well and respect the feelings and wishes of the individual. In some cases, after all input from the circle is considered, final decisions are made that the circle determines are in the best interest of the individual. This situation would never intend to strip the individual of self-determination or decision-making; the sole intent is to facilitate the best decision when a person is unable to communicate his or her own independent decision. Again, the vendor sometimes has to step back, recognize and honor the decision making process and then facilitate the change, even though they may not fully agree with it.

Making the Decision to be a Provider

- **Rights, Responsibilities and Roles**

It is important that individuals understand their rights and responsibilities as individuals receiving SLS. When rights are balanced with responsibilities, it is then possible to be realistic about expectations. After becoming familiar with the SLS Regulations, it is a good idea to identify personal expectations, share them with circle of support members and determine if the expectations will drive goals that are attainable.

Each member of the circle, including the individual, needs to take responsibility for “Action Items”. It must be clear that, in order to ensure success, the individual must make a commitment and work at keeping his or her agreements. SLS is not something that just “happens” for an individual. It is a service that has to be thought out and worked through, with a solid commitment and responsibility shared by everyone, including the individual. When the individual seems to have limitations that would affect participation in his or her plan, he or she will receive assistance from the circle of support to find ways to be able to be involved to the fullest extent of his or her ability.

- **Family Participation**

When families are involved in a individual’s life, it is very important that they take many of the same steps that the individual takes in understanding what SLS is and how it will affect everyone. Whether or not a parent or family member makes the decision to be the vendor, often the individual chooses to have them participate as very critical members of the circle of support. They assist with planning and making ongoing decisions, while at the same time, finding ways they can continue to grow the relationship they have established over the years. The transition is much like any other life-changing process we all experience when a family member moves, goes to college, or makes a choice to do something that affects the individual roles we have had previously.

Openly expressing concerns and examining expectations can be a healthy way to prevent problems later on. It may be difficult and alarming for a

Making the Decision to be a Provider

family member who has been involved in every aspect of a individual's life to imagine how others will assist in handling challenges with which, until now, perhaps only they have been familiar. Sharing the wealth of information and experience they have gathered over the years results in a smooth transition, and has, in many cases, allowed everyone to experience things no one thought possible. New relationships form, enthusiasm and excitement breed renewed strength, and a whole new world can open up for everyone.

- **Shifting roles**

Often, when roles change, family members are able to have more of an "adult" relationship with the individual and realize that growth is possible, not only for the person receiving services, but for them as well. Sometimes the expectations of the family include being sole decision makers in the individual's life. As everyone experiences new ideas and creative approaches that often result from the circle of support's team approach, expectations can change and a renewed sense of possibilities allows a new vision to take place.

Facing Reality

Ideal: Serving as an individual vendor for yourself, or someone close to you, can produce exciting and positive results. It can be a way to ensure that every detail of the desired service is fine-tuned and properly administered. If you and the individual agree that you will work together as a team to attain the desired result of an individualized service that truly meets the needs of the person being supported, then individual vendorization is definitely something you should both explore.

Reality: Sometimes being involved with every detail of the desired service, and attempting to properly administer the services, can be cumbersome and confusing. If you and/or the individual would find it difficult to work together as a team, and/or might have difficulty agreeing on how the individualized services would look, individual vendorization might not be the option you will choose.

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Ideal: Being involved with every aspect of providing this service can result in a comprehensive and individualized lifestyle that is naturally safe, comfortable and healthy. If you and/or the individual can be available to oversee the details of making sure everything runs smoothly, individual vendorization is definitely something you should both explore further.

Reality: The commitment to be available when necessary can sometimes be disruptive and inconvenient depending on schedules and lifestyle. If, after thinking about your availability, you realize that this is not a commitment that would be possible for you, individual vendorization might not be the option you will choose.

Ideal: For a family member or friend who desires to be involved with this level of detail, serving as the vendor allows both the vendor and individual to feel confident that individual needs are not only being met, but are as personalized as possible. If you feel that being involved with the level of detail described would increase your confidence in SLS, and is something you are interested in doing, individual vendorization is definitely something you should both explore further.

Reality: For an individual vendor to be confident that needs are being met and are as personalized as possible, a huge investment of effort, energy and time are required. The Single Household Vendor is a small business, with all of the challenges, worries and concerns that go along with any important endeavor. Although the result can be positive and rewarding for everyone involved, the day-to-day business also includes human resource procedures, taking the lead as you assist the individual in hiring and firing support staff, facilitating orientation and training, payroll, budgeting and billing, tax and insurance issues, reporting and documentation, an awareness of resources and agency procedures, keeping up on laws and regulations, overseeing the maintenance issues of another house/condo/apartment, paying bills, negotiating budgets and glitches in services, dealing with tenant/landlord issues, learning and facilitating IHSS, mediating between the individual and staff, mediating staff to staff issues, and counseling, as well as always ensuring that the individual's best interests are at the forefront.

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Essentially, you must be willing to attempt to know everything, be able to do everything, find everything, train everything, fix everything, answer everything, evaluate everything, be available for everything, and remember everything - while you are keeping your patience and advocating! If you are not a person who is able to or enjoys multi-tasking, consider carefully before you commit. If you are a person who needs a great deal of sleep, think carefully before you make this decision. If you are not a “detail person”, this may not be the job for you.

Can you hire people to help with some of these things? Of course. Does it absolve you of the ultimate responsibility and free you from having to think about it? No. As with any business, there are resources available such as payroll services, human resources and legal assistance; however, it is critical that the person making a decision to provide SLS is aware of the complexity of the commitment, the nature of the responsibility, and the time involved in keeping the commitment. On the other hand, if you just know that you otherwise would be spending frustrating hours trying to force a “fit” if the services were provided by an SLS agency or another vendor, the knowledge of your personal situation, your personality, and the individual’s wishes and needs must be weighed against the work of being a vendor.

There are individual vendors who have full-time careers, children, and social lives, as well as additional commitments, and have found the job of providing SLS for one person manageable, productive, successful and rewarding. The key to doing this is to first be sure that all of the aspects of providing services are looked at honestly before making a decision to go forward, and then to continue to ensure that everyone involved is thriving. If the complex issues of managing a small business would not be something you would be interested in doing, individual vendorization might not be the option you will choose.

So, the reality is that being a Single Household Vendor is a huge job and lots of work, but if the conditions are right, it is well worth doing!

Making the Decision to be a Provider

People to Talk to

One of the first things many people exploring the option of being a vendor ask is to whom they should talk about providing services to a consumer. The answer is always the same. Always start by talking to the consumer! No one ever knows the needs of an individual better than that person. Through interviews, casual discussions and informal time spent together, we learn important information.

Sometimes, when the individual does not communicate in typical ways, we need to creatively approach a new way to access the information the person has about himself or herself. Friends, family, and others acquainted with and chosen by the consumer, can meet with the person as a circle of support to assist with difficult, but life-determining, decisions. The focus of these meetings must always be on the consumer, and discussions and decisions made must always honor the consumer's choice. This can be extremely challenging, as it is always easier to make decisions for other people based on what we think they need, rather than honoring what they say they want.

Honoring Consumer Choice

In many situations we have seen very positive results that no one previously thought possible when we have honored the requests of the individual, even when we strongly disagreed with his or her decision. In one case, a young man we know with a label of extremely "challenging", and even self-injurious, "behaviors" decided he wanted to do woodworking and use a power saw. His family and circle of support assisted him to find a way to do this safely, even though it had seemed impossible. Today, that same man has his own business, successfully making and selling furniture that he creates. What would that person be doing today if his circle of support had made a decision based on their opinions or limitation in their thinking, rather than his request?

The philosophy of SLS is the thread that runs through all successful examples of individuals living on their own with supports. Over and over again, we see and hear of instances where someone who was thought to be unable to participate in even the most simple activities or tasks is living with support in a place of his or her own. People have lives that revolve around their choices and decisions, and are

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participating not only in the maintenance of their homes, but are involved in their communities as well.

With adaptations and support, we all make progress. With experience and support, we learn to make better choices and decisions. When we look at abilities rather than disabilities, we begin to see the real person that has likes, dislikes, desires, needs, and dreams that are of his or her own choosing. It is always interesting to look at our own lives and evaluate the kinds of adaptations and supports we've built in to meet our own needs and goals. Supported living services allow every individual the opportunity to explore their dreams and, with support, to live them.

The Final Decision is...

If, after careful consideration, your final decision is to become a Single Household Vendor, the best advice for you is to be open, honest and ready to learn as much from the person you will be supporting as they will learn from you. As you work through difficulties, it is important to remember that SLS is still a relatively new concept in the scope of services, although we always say that parents and families have been providing supported living for years. We need to keep in mind that everyone involved with this service is still "pioneering" the effort to assist people to live as independently as possible, and although we have a long way to go, we've come a long way. The goal is always to assist people to live their lives as close to what their dreams are as possible.

Section III: Creating the Foundation for a Supported Living Arrangement

James Escamilla



My name is James Escamilla. I live in Placerville, CA in my own apartment. I love having my own apartment because I can set the level of activity I can handle at the moment. I love my cat Snoopy. She is a wonderful companion.

I moved into this apartment in January 1997. By being in this Supported Living Program I can pick my own staff to help me with my life challenges. I also enjoy my specialized volunteer program through In Alliance where I can learn and do clerical tasks at the Marshal Hospital - Community Health Library. I am able to participate in the Special Olympics, too. I love Softball in the summer. We usually go to a weekend tournament in Sunnyvale - if we qualify - to play competitively with all other teams in Northern California. We did really well last year. Thanks to my staff support for helping me make all this happen.

This program has helped me manage my life and reduce the stress medication I take by 75% over the last 5 years. I hope more people can have this opportunity to live in their own "space" by having wonderful people helping them where they need help.

Creating the Foundation for a Supported Living Arrangement

By now, three major decisions have been made by the individual and/or circle of support (including the regional center service coordinator), and potential SLS vendor: 1) supported living, or SLS, is the chosen option, 2) a single household (individual) vendor, rather than an agency, will best meet the individual's need for a service provider, and 3) you will be the vendor. Next comes the fun and the challenge of creating the actual services and supports.

Talking and thinking about being a "single household" vendor (parent, self or other individual) can create excitement, energy and apprehension all at the same time. Once you have finally made the decision to take the big step and actually do it, the tasks can be daunting. There are what seem to be a million details, and many of them are about things you may not feel prepared to address. Suddenly the issues of support for the person seem like the easy part; time sheets, payroll, regional center billing, budgets, insurance coverages and contracting with the regional center loom. And, how do you balance all of this with your personal relationship with the individual?

Don't let it overwhelm you! The best plan of attack is to start out with one thing at a time. It is true that you will have many balls in the air during the process, but this is good practice. Anyway, especially if you are a parent, you've been multi-tasking for years. This is no different.

Let's begin by taking one step at a time.

1. Collaborate with your Regional Center

Building and nurturing a collaborative relationship with the regional center is essential. In addition to the fact that they need to pave the way for supported living services, the sooner they are involved, the more ownership the service coordinator will feel for the success of the SLS arrangement. If the service coordinator is not already aware of the individual's most recent decisions, contact her or him immediately. It's important to bring the

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regional center into this process as quickly as possible in order to agree on time lines and other key issues. Different regional centers handle planning for new services in varying ways, however, every regional center has internal processes to which service coordinators must adhere when requesting new services for any individual. Remember to keep communicating progress, any anticipated delays, and special needs that arise during planning or implementation to the service coordinator so he or she can help to move things along at the regional center.

□ ***Beginning the Vendorization Process***

Most regional centers have a “vendor packet”, with forms and instructions for how to become a vendor. This is fairly straightforward. Generally, the packet includes a request for the description of services (“service design”); a related budget; standard tax paperwork like the W-9 and I-9; and a Medi-Cal Provider form, which is required. The Medi-Cal form sometimes concerns vendors because it says that you agree to be a Medi-Cal provider. This is a formality, and does not mean that the regional center is intending to refer more individuals to you, that you must serve more individuals than the one person you wish to support, or that they are going to hold you to Medi-Cal rates. Your signature on the form allows California to capture additional Medicaid funds.

2. **Involve the Individual’s Circle of Support**

If the individual does not already have a formalized “circle of support”, sit down with the person and make a list of people that he or she would like to have in the circle. Assist the individual in setting a date, time and place for the meeting, and help the person, if necessary, create an invitation to a circle meeting. It can be as simple as several sentences:

“I am thinking of moving into my own home, and I would like you to be part of a group of friends who can help me plan and make decisions for this exciting new experience. On Saturday, September 21st from 2 to 4, I am having a get-together at (location) to talk about this. Please come.”

This can be written in letter or traditional invitation form, e-mail format and/or by telephone. Assist the individual in distributing or mailing the

invitations, planning and purchasing some light refreshments, and thinking about what things he or she would like help with from the circle of support. It will also be important that someone within the circle take notes or otherwise document the discussions and any decisions made there.

Sounds Good... But What is a Circle of Support?

As referenced earlier in this manual, a circle of support is, as the name implies, a unique support system and team who care about a particular person and want to share in his or her life. Members of the circle of support can be friends, parents, other family members, personal attendants and other support people, co-workers, neighbors, professionals from agencies providing services, and any other person the individual chooses. One of the important things about a circle is that it is comprised of people the individual likes, trusts, and feels will support him or her in making good choices and decisions. Circle members should be invited to participate by the individual, although sometimes self-selecting can work out fine, if the individual agrees (for example, a co-worker or neighbor may ask to be included).

Circle members' roles includes encouraging the individual to voice his or her own opinions, choose and meet his or her own goals, and to make choices and decisions based on his or her own value system. A circle can also be effective in helping a person think through difficult decisions, as well as supporting the person in taking responsibility for his or her own life and standing up for personal rights. Circle members can be great cheerleaders, and can assist individuals and family members in the job of advocating for the individual. They can also utilize their personal networks to access resources, jobs, opportunities, and help expand the person's social circle.

Some individuals start with a circle of support that includes, literally, only themselves and one other person. That's fine, too. A goal might then be developed for the IPP and SLS service design that would address assisting the individual to expand the circle if he or she chooses to do so.

Another Kind of Circle of Support ...

As a SLS service provider for a single household or person, you might want

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to develop your own personal circle of support. Being an individual vendor can be lonely sometimes. In addition to your friends and family members, you may want to access a network of other individual vendors. In California, there is an informal organization called the California Supported Living Network. While many people in the network represent SLS agencies, there are some people in various locations around the state who are parent, self (individual) and other individual SLS service providers. Access www.supportedliving.com to get basic information about this group. Connections and Information on Resources for Community Living (CIRCL) is an excellent source of support that can be accessed at www.allenshea.com/CIRCL/CIRCL.html.

3. Gather Information and Resources

Begin gathering personal information from the individual, such as any thoughts about places he or she might like to live, special goals, health issues or concerns, and any “assessment-type” information about skills or other areas of need.

Professional Assessments

Previous or current professional reports may or may not be helpful, depending upon the age and quality of the report. Often, quality professional assessments are helpful in planning for situations or potential circumstances that may require additional resources. Ideally, useful assessments provide helpful strategies as well as diagnoses or technical explanations. Assessment information is most valuable when it includes these strategies and ideas for implementation.

Sometimes, these types of reports tell us more about how other people, or certain people in a given professional community, perceive this person. Keep in mind that many reports of this nature are written by professionals who generally have not had a long or meaningful personal relationship with the individual or his or her family. The point in mentioning this is simply to help keep the information in perspective, and to see it for the type of information it is. Often this equates to a snapshot in time as opposed to a lengthy feature film.

Medical and Related Areas

Medical, dental and vision issues and data about medications, side-effects, specific reactions or allergies, treatment plans and other therapeutic information is obviously critical information for people working with any individual. Medication tracking, follow-up blood work, and understanding medication interactions is particularly important on a daily basis. It is also, of course, important to ensure that medical, dental, vision, mental health and other therapeutic appointments are made and kept as recommended. Health insurance(s) and/or Medi-Cal and Medicare issues must be handled promptly and as efficiently as possible to avoid any potential glitch or lapse in coverage. Wheelchair fittings, communication device appointments and similar needs also fit into this “must do on time” category. A regularly updated calendar of medical and related appointments for the coming year can be a big help in reminding someone of the appointment that was made six months ago.

Under no circumstances should a individual ever run out of medications! This could create a life-threatening situation, and personal attendants must be made aware through training and ongoing monitoring that lapses in medications could potentially pose an immediate health and safety risk.

Daily Personal Routines and Rituals

To be most helpful in planning, the information on day-to-day skills, tasks and preferred routines or personal rituals (we all have them!) should be as specific as possible. Talk through a typical day, from waking up to going to sleep. Do you shower in the morning or at night? If it’s morning, is it before breakfast or after? Do you wash your hair or your body first? When do you brush your teeth? Although at first glance, someone may consider these types of questions “invasive” or “personal”, they are important things to know if you are responsible for supporting someone through the most intimate details of his or her life. In fact, they are very personal questions. And, supported living is a very intensive and personal set of supports. The point in asking the questions is to help keep the services from being invasive or disruptive to the

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person's preferred routines. Imagine needing this type of intimate service, being unable to communicate verbally what you really want and need, and having someone new come into your home to provide support. Would you prefer to let the personal attendant do things his or her own way, or your way? For most of us, if we were repeatedly subjected to someone else's idea of what our daily routines and rituals should be, we would surely have labels such as "aggressive", "non-compliant" and "challenging behaviors"!

If you are the person's parent, you may feel you already know these things. Even so, gather as much information directly from the individual as possible. This is a good time to begin supporting the individual to take more responsibility for himself or herself in this area. Supported living services are a wonderful safety net for individuals while they are learning to take on more self-responsibility, give directions to staff, and to let people know in a cooperative but firm way, what they need.

Other Resources

Begin your search for resources in your local area, including various community assistance programs to help with housing, furnishings or utility costs for people in the "low" to "very low" income designations. Think beyond "disability" to generic resources. More information on community and/or generic resources is found in Section V of this manual.

4. Develop the Individual's Person-Centered Plan

Whether you use a specific format or process, such as a PATH, MAP or Essential Lifestyle Plan (ELP), or just get together more informally with the circle of support, including the regional center, it is critical to talk about the key issues:

- Who is this person? From our collective knowledge, what can we say about him or her? What have you learned from him or her?
- What qualities, talents, skills and strengths does he or she possess?
- What are the desires and dreams of this person? What are the "non-negotiables" in this person's life? What does the individual need to be happy and stay safe on his or her own terms?

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- What are the concerns that the individual or circle members have? How can they be addressed?
- What services, supports and trainings are needed and desired by the individual?
- What unique goals does the person have? What will his or her life look like next year at this time? Several years down the road?
- How can the circle come together to assist the individual in creating the individualized lifestyle that he or she wants to live?
- What specific tasks and/or commitments can each of us take on to assist the person in having the life that he or she desires?

Once we have this information, together with the information discussed previously in Item 3, we can get serious about developing a unique SLS service design that truly meets the desires and needs of the individual, and the coordinated IPP.

5. Assign Tasks to Circle Members Willing to Help

This is where the rubber meets the road for the circle of support. Who is willing to assist the individual with looking at housing? Who is willing to check the papers and talk to property managers, real estate agents and landlords? Who can help check out Section 8 housing assistance? Does anyone know someone at a local college or other potential source of personal attendants? Is someone willing to make informational phone calls to a list of agencies or people they know to “spread the word” that the person is looking for support staff? Who can work with the individual to develop a list of questions that he or she would like to ask potential employees? Who wants to go shopping with the person so he or she can begin to visualize what “home” will look like (colors, styles, etc.)? Who would like to work with the individual on a list of household items needed, and maybe register at Target or some other stores where people could go to purchase something to help out? Who has unneeded things at home that the individual could look at to

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see if he or she could use them? Can anyone help write parts of the service design? Does anyone know a banker or insurance agent who might be helpful? Does anyone know someone with a truck, who would volunteer to help move things? Who will physically pack and move everything? Who is interested in just going to a movie or out to dinner with the person during this exciting, but somewhat uncertain, time?

Of course, these are part of the vendor's responsibility, but how the responsibility gets met can be very individual. There are a million details to take care of. The circle of support is a perfect vehicle for accomplishing the work of many in a shorter time. Together, make a list, then ask people to choose some tasks they can and will do. Set time lines and deadlines for task check-points and completion! Sometimes people mean well, but don't understand the timing or urgency of a particular task. One thing could hold up a whole list of other things that need to be accomplished.

Don't be shy about asking people to help out in specific ways. Circle members may also have friends, relatives, co-workers or children who would love to be part of this exciting time. If other people offer to help, take them up on it. Keep a detailed task list with the name and contact information for each person helping with these tasks, and ask each person to report back to you when the task is completed or at some pre-determined point.

One word of caution... remember to monitor and document that the tasks really got handled. Few things are worse than having a person excited and ready to move, an enthusiastic group of volunteer friends and movers, a stack of boxes, and no truck.

6. Start on the Nitty-Gritty Details

Even before you develop your service design, there are things you can begin to investigate and do. This is not an exhaustive list, but rather an overview of suggestions to get you started.

- ***Spread the News***

Tell everyone you know what you are doing. People love to be involved

in positive and exciting things, and you never know what will come to you and the individual by letting the world know (confidentiality issues, of course, should be respected). Personal attendants and other support staff, resources and good surprises can come from the most unexpected places.

- *Help the Individual Start Collecting Household Items*

Once the basic decisions are made and planning has begun, it's exciting and motivating to begin looking for and accumulating things for the person's new home.

This can be such a big step for everyone. Many parents who never thought their children would be able to live in homes of their own have said that, although they saved certain dishes and household items for the person's siblings, it never occurred to them to save things for the individual's future home. What a nice right of passage to be past the old limitations, and on to helping the person choose just the right items to "make a house a home".

When we think of all of the items, big and small, that it takes to furnish our homes, we realize it's never too early to start collecting things! If storage is an issue, call on the circle of support for ideas or space.

- *Basic Business*

Start working on getting the basics lined up. Employer forms, insurances, a bookkeeper or accountant, bank, computer software, supplies and other daily necessities will all have to be dealt with. While you are developing the service design and budget, then waiting for regional center approval, these other things can be in process so you and the individual will be ready when the regional center gives the O.K. For a start:

- ❑ Contact your current insurance agent for your personal coverages, and talk about what you are doing. Ask for quotations on a renter's policy (or homeowner's, if the person will be purchasing a home), general liability, employer's liability, and an umbrella policy. Workers'

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Compensation information may need to be supplemented when you have more specific information about support configurations and people's hours; this can also be provided for some personal attendants as an "inservant" rider to the renter's or homeowner's policy, which is often the most cost effective way to provide the coverage. Remember that IHSS covers Workers' Comp for all IHSS hours worked, which is a major benefit. Ask your agent for additional recommendations and quotations. Find out how much money you will need to put all necessary insurances in place up front (even payment plans often require an initial deposit that is somewhat larger than the regular installment payment will be).

- ❑ Check out the federal requirements for employers and related forms at www.irs.gov.
- ❑ Check out the state requirements and forms at www.edd.ca.gov.
- ❑ Apply for employer numbers from the IRS and from the California Employment Development Department.
- ❑ Contact bookkeepers, payroll services, CPA firms and banks with payroll processing for small businesses. Explain what you will be doing and get quotations.
- ❑ Talk with your own and several other banks, or even credit unions to which you may belong, regarding your needs for a checking account. An initial line of credit would be wonderful, to help defray some of the cash flow crunch of the first few payrolls before you begin to receive the regional center reimbursement. A separate, dedicated credit card is also helpful when purchasing supplies and other necessities. Although you can use the dedicated checking account or reimburse yourself, it is sometimes easier to have a card just for this purpose.
- ❑ More specific information is in Section V.

Although you may feel that some of these things are a bit premature, realize that they take time to initiate and process. For example, you cannot employ people without Workers' Compensation in place and your employer identification numbers. For the sake of keeping things separate from your own resources, it is recommended that you not use just your social security number, or the employer number from any other business that you may have.

7. Begin Developing the Service Design

Once again, collaboration with the regional center is critical at the beginning of the SLS process, and remains a crucial focal point throughout the time that the person is receiving supported living services. Regardless of who the vendor may be, if the regional center service coordinator does not understand supported living philosophies and values, there may be an unnecessary tension in the relationship.

Make every effort to involve the service coordinator and keep him or her updated as to progress. Even if the person does not have time to come to every circle meeting or have regular phone contact through the planning process, keep him or her posted through e-mail, voice mail messages and/or minutes of circle meetings. He or she will appreciate your willingness to keep the regional center informed of progress, and to provide the service coordinator with the tools and information to do a good job for the individual. When you continue to promote the opportunity to work as partners in this process, you will create credibility, trust and a positive working relationship. This will be an essential part of working as a team to ensure quality supported living services to the individual, and respect for you as a vendor.



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CIRCL's mission is to create opportunities for building and sharing individual, organizational and community strengths in supported living.
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