Supported Living Services
Your SLS Training Tool Box

Connections for Information and Resources on Community Living (CIRCL)

April, 2001
Supported Living Services
Training Tool Box

General Information
for SLS Staff

Developed for

Connections for Information and Resources on Community Living (CIRCL)
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April, 2001

through a contract with the
Department of Developmental Services

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Acknowledgments

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Department of Developmental Services through a contract with CIRCL.

**Patterns of Supported Living, A Resource Catalogue (1993)**
Department of Developmental Services through contract with Allen, Shea & Associates.

**Learn the Basics, Learn the Process, Apply What You Learn: Service Coordination Orientation and Training Curriculum (1999).**

**Direct Support Professional Training Year 1 (1999).**
Developed for the Department of Education and the Regional Occupational Centers and Programs in partnership with the Department of Developmental Services by Allen, Shea & Associates.

The application tools included in the Tools and Application section were collected from Supported Living Agencies around the state and are referenced.

We want to thank the agencies, organizations and individuals for their contributions to this manual and recognize them for their commitment to helping others learn about supported living services and the service system.
Introduction

Special Welcome and Introduction for New Staff
Congratulations! You have been hired to work in a supported living agency and assist people with developmental disabilities to enjoy all of the benefits of living in their own home and community. You have taken on a very important job. Your work will present you with both rewards and challenges. No one who does this work becomes an expert. We just get wiser. Supported living agencies and their staff are continually learning how to do a better job.

While this document will help you get started in understanding supported living services, your best teachers are the people you support and your most important learning tool will be your ability to listen carefully to what they have to say. Enjoy the journey!

You can now skip ahead to Part One: History. The next brief introduction section is included to help agencies develop their staff training process.

Introduction for Supported Living Agencies
This document can help supported living agencies develop a toolbox of information, materials and resources for learning about supported living. Included in this document are:

1. Ideas for setting up a staff training program including requirements from the SLS regulations
2. History of residential and living arrangement services
3. Introductory information on supported living services
4. The five principles or values of supported living services
5. Information Briefs on basic information about the service system for people with developmental disabilities
6. Tools to help staff do their work and implement the principles.
7. Resources to add to the agency’s staff training/resource library
## Putting Together A Staff Training Process

Every agency will want to organize a Staff Training Manual or new staff orientation process. In fact, the regulations for Supported Living require that agencies train new staff in several topics within the first two weeks of hiring. Following are a few lists of training topics (regulation training requirements are identified) to help your agency organize the staff training process.

### Cross Referenced List of SLS Staff Training Requirements

The regulations for supported living services require that the agency Service Design for funding approval from the Regional Center include a description of the staff training program. This cross referenced list of staff training requirements can help agencies put together their required training process.

<table>
<thead>
<tr>
<th>SLS regulations require that staff be trained in the following areas in the first two weeks of employment:</th>
<th>Where to find the training information: (where the word “required” follows a reference to the Agency Service Design, this is because the regulations for SLS require that the Service Design address this topic.)</th>
</tr>
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<tr>
<td>1. Overview of the mission, policies, practices and SLS philosophy as included in the agency’s service design.</td>
<td>Agency Service Design (required by regulations to become vendored) General SLS philosophy and practices in this Toolbox; Part Two: Principles of SLS</td>
</tr>
<tr>
<td>2. Understanding of the IPP objectives of each person with whom the staff member works directly.</td>
<td>Individual’s Individual Program Plan and the Individual’s Individual Service Plan</td>
</tr>
<tr>
<td>3. Focus on the practical use of SLS to promote a consumer’s self-reliance</td>
<td>Agency Service Design (requirement) Toolbox; Part Two: Principles of SLS</td>
</tr>
<tr>
<td>SLS regulations require that staff be trained in the following areas in the first two weeks of employment:</td>
<td>Where to find the training information: (where the word “required” follows a reference to the Agency Service Design, this is because the regulations for SLS require that the Service Design address this topic.)</td>
</tr>
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<tr>
<td>4. Consumer’s protections and rights, including:</td>
<td>Toolbox; Part Three: Information Brief on the Rights of Individuals Receiving SLS, and the Information Brief on Basic Rights</td>
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<td>• Agency internal grievance procedure;</td>
<td>Agency Service Design (requirement)</td>
</tr>
<tr>
<td>• Fair hearing provisions, pursuant to Title 17, Section 54326 (a)(2);</td>
<td>Toolbox; Part Three: Information Briefs on Rights, Laws and Regulations: Appealing Regional Center Decisions</td>
</tr>
<tr>
<td>• Special incident reporting, pursuant to Title 17, Section 54326 (a)(2);</td>
<td>Regional Center Special Incident Reporting procedures and forms (from your agency’s regional center).</td>
</tr>
<tr>
<td>• Rights of consumers specified in Sections 58620 and 58621; and</td>
<td>Agency Service Design</td>
</tr>
<tr>
<td>• Protection of consumers from abuse, neglect and financial exploitation, including requirements for documenting and reporting such occurrences.</td>
<td>Agency Service Design</td>
</tr>
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Where to find the training information:

- Toolbox; Part Three: Information Brief on the Rights of Individuals Receiving SLS, and the Information Brief on Basic Rights
- Agency Service Design (requirement)
- Toolbox; Part Three: Information Briefs on Rights, Laws and Regulations: Appealing Regional Center Decisions
- Regional Center Special Incident Reporting procedures and forms (from your agency’s regional center).
- Agency Service Design
- Toolbox; Part Three: Rights, Laws and Regulations: Information Brief on Special Incident Reports
- Toolbox; Part Two: Principles of Supported Living
- Agency Service Design
- Toolbox; Part Three: Rights, Laws and Regulations: Information Brief on Protection from Abuse
### SLS regulations require that staff be trained in the following areas in the first two weeks of employment:

5. Review of appropriate conduct of staff in establishing and maintaining personal relationships with consumers; and

6. Participation of consumers in a teaching, consulting, or other instructional resource capacity.

### Where to find the training information:

- **Agency Service Design**
- **Toolbox; Part Two: Principles or SLS, Section 3, Relationships: Relationships and Obligations**

### Continuing training requirements:

1. Recent developments in the theory and practice of SLS.

2. Policies, procedures, and practices of the agency targeted at meeting IPP objectives for SLS; and

3. Identification of service delivery issues and challenges, and the accumulated experience of the SLS vendor’s staff and others in dealing with them.

- **Toolbox; Part One and Two: History and Principles**
- **Conferences, trainings, gatherings and focus groups offered within the agency and offered throughout the state for supported living service providers (i.e., CIRCL trainings and networking, Supported Life Conference).**
- **Agency Service Design**
- **Conferences, trainings, gatherings and focus groups offered within the agency and offered throughout the state for supported living service providers (i.e., CIRCL focus groups, Supported Life Conference). Participation on the CIRCL Supported Living List Serve.**
Information To Include In A Staff Training Manual Or Staff Training Process

While the best training for new staff comes from spending time with the individual or individuals they are hired to support and learning from them and the people who know and love them, it is still very beneficial to pull together all of the written information about the agency and the agency’s mission and methods. The following checklist is designed to make this process a little easier for agencies that want to develop a new staff manual.

Information Specific to the Agency:
- Agency staff training plan/process
- Agency brochure
- Agency Service Design
- Personnel Policies
- Rights of people receiving SLS
- Consumer Grievance Procedure
- Staff Grievance Procedure
- Job Descriptions
- Employment Agreements
- Employee job evaluation
- Organizational chart
- History of agency
- How the agency is funded
- Example of a staff schedule or a description of a day in the life of a staff person
- Examples of Individualized service plans
- Agency quality assurance or agency evaluation process
- Process for handling risky decisions
- Process for assessment and Individual Service Plan development
- Special Incidence Reporting Procedures
- Community Integration Strategies
- Emergency response system
- Protection of financial abuse policy
- Confidentiality policy
- Emergency or 24 Hour Response service procedures

Paper Work:
- Time cards
- Mileage reimbursement
- Expense reimbursement
- Daily and other documentation of services provided

For staff who hire and supervise:
- Recruitment, screening and hiring process
- Interview questions
- Staff evaluation process (if it is not in personnel policies)
- Disciplinary procedures
- New staff training requirements

Information about the individuals the staff person will be supporting:
- General information and facts about the individual
- Everything that was learned during the assessment process and the individual person centered planning processes including but not limited to:
  - What staff need to know and do to help the person be healthy
  - What staff need to know and do to help the person be safe
- Information about how the person communicates
- Who and what is important to the person and what staff need to do to help the person live the way that is important to them
- The individual’s service plan objectives
- Routines and rituals that are important and what staff can do to support these preferences
Ideas About Printing and Setting Up The Training Toolbox to Meet Your Needs

The toolbox is distributed on letter-sized, single-sided paper. This allows agencies the opportunity to copy, set-up and distribute the document in a way that works for them. Here are several ways to organize the toolbox for you and your staff:

- Double-sided copy, three-hole punched
- One binder, four tabs for major sections
- Four binders, tabs for subsections
- Distribute sections to staff as needed for inservice training
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

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
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

<table>
<thead>
<tr>
<th>MOST RESTRICTIVE</th>
<th>LEAST RESTRICTIVE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Segregated</td>
<td>In Neighborhoods</td>
</tr>
<tr>
<td>Large</td>
<td>Smaller</td>
</tr>
<tr>
<td>Institutional</td>
<td>Personalized</td>
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</table>

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 affect 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

<table>
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<th><strong>Supportive Living Services</strong></th>
<th><strong>Services Based on the Continuum Model</strong></th>
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</thead>
<tbody>
<tr>
<td>Everyone can live in a home of their own choice, given the right kinds of support.</td>
<td>Readiness to live in a home of your own has to be achieved through a series of steps.</td>
</tr>
<tr>
<td>People learn things easier with support and in the places where things happen, like in their own home.</td>
<td>As people learn things and get more independent, they move to new places to learn things.</td>
</tr>
<tr>
<td>People know their own needs best and should direct their own lives as much as possible.</td>
<td>People gain privilege and responsibility as they learn to handle it.</td>
</tr>
<tr>
<td>Agencies provide a system of support as long as it’s needed to assist someone to live successfully in the community.</td>
<td>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.</td>
</tr>
<tr>
<td>Helper, advisor, facilitator, advocate.</td>
<td>Landlord.</td>
</tr>
<tr>
<td>System of support is designed around someone’s needs wherever they live.</td>
<td>Responsible for well-being and progress.</td>
</tr>
<tr>
<td>A desired outcome is someone living successfully in the community with support when they need it.</td>
<td>Services based on assessment and tied to a certain living environment.</td>
</tr>
<tr>
<td><strong>Adapted with permission from OPTIONS.</strong></td>
<td>A desired outcome is an improved score on an assessment or graduation to a new place to live with more independence.</td>
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### Supported Living Services

**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.
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.

Supported Living IS…

- A decent & secure home
- Choice
- Personalized assistance
- Support from others who care about & respect you

© John O’Brien (1993)
Part One: History

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

References

Department of Developmental Services through a contract with CIRCL.

Patterns of Supported Living, A Resource Catalogue (1993)
Department of Developmental Services through contract with Allen, Shea & Associates.


Developed for the Department of Education and the Regional Occupational Centers and Programs in partnership with the Department of Developmental Services by Allen, Shea & Associates.
Supported Living Services Training Tool Box

Part One:
Principles and History

Connections for Information and Resources on Community Living (CIRCL)

April, 2001
Part Two: Principles of Supported Living Services

Connections for Information and Resources on Community Living (CIRCL)

April, 2001
Supported Living Services
Training Tool Box

General Information
for SLS Staff

Developed for

Connections for Information and Resources
on Community Living (CIRCL)
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April, 2001

through a contract with the
Department of Developmental Services

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Part Two: Principles of Supported Living Services

The Principles that Guide the Mission, Policies, and Practices of Supported Living Service Agencies

Introduction

Supported living services are based on a set of principles, values or expected outcomes that set the service apart from any other kind of service. These principles give direction to the mission of the agency and guide the development of the agency’s policies and practices. These principles are firmly grounded in the Lanterman Act Welfare and Institutions Code and in the regulations for SLS. The five principles are outlined on the following page.

You will find that your job will be challenging at times. These principles can serve as your guides to lead you in the right direction. When you are confused about what to do in difficult situations it may be useful to refer back to these principles. You will know you are on the right path when you are assisting individuals to achieve these outcomes.

In this section, you will find information on each of the five principles or outcomes of supported living services and resources for getting more information.
Supported living services are based on a set of principles or expected outcomes that set the service apart from any other vendored service. These principles give direction to the mission, policies and practices of the agency.

### 1. A Home of One’s Own
- Individuals live in homes that they own, lease or rent like other members of their community.
- Individuals choose where they live and with whom and they control what happens in their home.
- Individuals’ housing is separate from their services so they are secure in their homes and do not have to move if their needs, their services or their service agency changes.
- Individuals are safe in their home and neighborhood.

### 2. Choice and Self-Directed
- Individuals make their own everyday choices.
- Individuals plan for their futures.
- Individuals direct the services they receive and have a choice of agencies and staff.
- Individuals are supported (e.g., technology, communication devices, behavioral support) to communicate their preferences, choices and needs.
- Individuals are satisfied with the services they receive.

### 3. Relationships
- Individuals have family, friends and neighbors who support them in regular ways or as paid help.
- Individuals and their circle of support work together as a team with the supported living agency and others to share responsibility for his or her well being.

### 4. Community Membership
- Individuals fully participate in the mainstream of community life according to personal choice and preference.
- Individuals have opportunities to join clubs, groups, organizations, and religious groups.
- Individuals use local community resources and generic services.

### 5. Flexible, Tailored Services and Supports
- Individual Service Plans are developed through a person-centered planning process.
- Service plans reflect the support that each individual wants and needs and plans change as wants and needs change.
- Individuals have opportunities to increase their abilities, confidence and quality of life and support to maintain an adequate level of health and safety.
Principles of Supported Living

1. A Home of One’s Own

Introduction
An essential principle of supported living is that the person who receives services controls every aspect of the place in which he or she lives. Individuals choose where they live, who they live with, and control what happens in their home. In fact, they may not receive services in a home in which the SLS agency has any financial or fiduciary involvement unless the individual and the regional center director give consent. In other words, the SLS agency usually does not own the home, act in the role of the landlord or have their name on the lease agreement. In addition, the individual may not receive services in a home where his/her parent or conservator lives.

Individuals live in homes that they own, lease or rent like other members of their community.

Individuals choose where they live and with whom and they control what happens in their home.

Individuals’ housing is separate from their services so they are secure in their homes and do not have to move if their needs, their services or their service agency changes.

Individuals are safe in their home and neighborhood.

Supported living services assist each individual to explore the kind of home they want (i.e., house, apartment, mobile home, upstairs, downstairs, garden) and the neighborhood they want to live in. One of the challenges is finding affordable housing in a safe neighborhood. Many SLS agencies lobby on local, state and federal levels for an increase in affordable housing opportunities.

Instead of renting a home, many individuals across California are choosing to buy a home of their own. There are mortgages that are

This following 5 sections were 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 Two.
designed specifically for individuals with disabilities who have a low or moderate income. Fannie Mae, the nation’s largest source for home mortgages has such a program called a HomeChoice mortgage. HomeChoice addresses the unique housing and home-buying needs of individuals with disabilities by offering new underwriting flexibility including: lower down payments, more flexible use of second mortgage financing for assistance with down payments and closing costs, rehabilitation and access modifications and special qualifying and underwriting for borrowers who earn below 50 percent of the area median income. Advocates in many areas of the state have developed non-profit housing development corporations to assist people to become homeowners. For information about home ownership activities in your area you can ask the regional center liaison to supported living. You can get more information about home ownership from the National Home of Your Own Alliance (NHOYO) toll free InfoLine 800-220-8770.

Wow, Do We Have a Place for You!

Mary and Jane share a place in an apartment complex, which has a swimming pool and 'community room.' Over the years, these two women have gotten to know many of their neighbors. The apartment is cozy, comfortable, near public transit and near other places the women enjoy being.

Community leaders, through a non-profit housing development corporation, decided that Mary and Jane would appreciate owning their own home, and with public assistance rehabilitated a property a few miles away. When it came time for Mary and Jane to move in, the women said "thanks, but no thanks." It had not occurred to the housing developers that the women might prefer their rented apartment to their 'own home.'
Individuals Control the Character and Appearance of their Home

An important feature of SLS is that individuals control the character and appearance of their home. This means that their homes reflect their personal interests and preferences (i.e., their favorite colors, their interests and hobbies and the things that are important to them). They choose their furnishings and decorate the way they want. They also decide who has a key to their house and who can come over the threshold into their home.

Individuals Choose Who, if Anyone, They Live With

Individuals who receive supported living services have the right to choose with whom they live. Supported living agencies learn from the individual whether or not he/she wants or needs a housemate. If a housemate is desired, the agency learns from the individual’s lifestyle preferences about the desired personal characteristics of a housemate and what kind of support, if any, will be needed from that person. They will also help the individual hire a housemate and then provide support to help them have a good relationship and live compatibly with each other.

Individuals are Secure in Their Homes

Most of us feel safe and secure in our homes. Our homes offer us sanctity from the outside world. We can go home to a safe and comforting place after being out in the world of work, pressure, traffic and all the others stresses of community life. We also know that we decide whether or not to move to another home or place. Supported living services offer the same kind of security and sanctity to people with disabilities. Again, individuals live in their own homes so they are not at risk of having to move when their services change or their service agency changes.
Putting the Principles into Practice

This manual is intended to be a “toolbox” to help you implement the principles of supported living services. Part Four includes some practical tools that you can use to help you do this.

Here are some ideas and things to think about to help you put the principles into practice:

A Home of One’s Own

You will want to help the individual you support to consider all of the questions that most people would consider when they shop for a home to rent or buy:

- What is their budget for a home and utilities?
- Are they eligible for subsidized housing? See the generic resource section for more information on subsidized housing.
- Are they interested in buying their own home?
- Where do they want to live (i.e., near family, friends, church, bus lines, work)?
- Are there better opportunities for finding a job or volunteer activity in some neighborhoods than in others.
- Do they enjoy the hustle and bustle of a busy neighborhood with lots of children, or do they prefer a quiet, older community?
- How safe is the neighborhood?
- What features are they looking for in a home (i.e., downstairs, gas or electric stove)? You may want to write down these features and help the individual develop a checklist they could use to compare apartments or homes.
- Do they want a roommate? If yes, what characteristics will their roommate have (i.e., gender, interests, routines, will they provide any support?)?
- What else might they want to consider when they are looking for a home?

See Part Four: Tools and Applications for a sample titled the Housing Resource Checklist.
The individual should participate to the fullest extent possible in the search for a home. You will want to help them decide:

- Who will make the inquiry phone calls and talk to prospective landlords? Will they do this, will you or will someone else? If the individual is going to make the calls, how will you help them prepare to make these calls?

- How will they participate to the fullest extent in finding a home?

- How will they introduce themselves and you to a potential landlord?

- How much will they tell the landlord about the kinds of services they receive and about their disability?

- What else?

**Individuals Control the Character and Appearance of their Home**

Think about how your own home reflects who you are and what is important to you. Help the individual you support to have this kind of autonomy within their home.

- Find out about their hobbies and interests. Help them decorate around these themes.

- Support their decisions about who they invite into their home. You may need to help them make the plans and you may have to help with transportation.

- Support them to maintain their own routines and rituals (i.e., What is their morning routine, what do they want to do in the evenings?).

- Support them to maintain their home. You may want to help them develop a housekeeping checklist, and a maintenance checklist (with things like changing the air filters). You may also help them communicate their maintenance needs to their landlord if they rent.

For more about routines and rituals you may want to find out more about Essential Lifestyle Planning.
• One of your jobs may be to assist the individual to obtain the things they need when they first move out. The Department of Developmental Services has a great handbook called “How to Plans: Home Furnishings for Supported Living”. This handbook includes several lists of startup items someone might need as well as suggestions for how to get furniture and supplies donated. You can order it by calling (916) 654-1956.

Individuals Choose Who, if Anyone, They Live With

• Does the individual want or need a housemate? Why?

• How would they afford to live by themselves if this is their choice?

• Do they have subsidized housing? If they need live in support can they get a two bedroom certificate?

• How do they get along with others when they live with someone else? What does it take for this to work well for them? For example: Do they need a lot of privacy? Do they like their home quiet or do they like a lot of activity? Do they need to have control over a lot of things in their home like where things are placed, the TV station, the lights being on or off, etc.

• What are the characteristics of people they like to spend time with and what kind of people don’t they like.

Individuals are Secure in Their Homes

• Think about your own home and how it feels to you to have your own place. A place that you can retreat to after a hard day. A place you are not at risk of losing very easily. Many individuals with disabilities have not experienced this kind of security and safety unless they grew up living with their parents. Individuals who have lived in any kind of group homes have been made to feel that they live in someone else’s home and they can be asked to leave if they do not follow the expectations for the home (that are set by someone else usually the group home manager or owner). Learn about the person’s history, where they have lived and what these places or homes were like.

• Constantly reinforce to the individual that it is THEIR HOME. Help them experience the security they should feel in their own home.
Part Two: Principles of Supported Living Services

Things to Think About For Your Agency

- Does your agency keep a list of apartments that take subsidized housing?

- Does the agency have any kinds of tools or lists for evaluating apartments? For examples look in Part Four, Section 1 of this handbook.

- How does the agency help someone decide if they need a housemate?

- When does the agency support someone, when it is their preference and need to have a live-in paid housemate?

- How is live-in support arranged? For example, is there a standard contract for a paid roommate and how are the roommate's wages and benefits determined? How is each job description individualized?

- If your agency owns, or holds the lease to the places people live, how does the agency make sure that people experience the value of it being their home?

- What is the agency's relationship with landlords, the local house authority, and non-profit housing development corporations?
Summary
A “home” is something every one of us strives for in our own way. A home is not just a physical place we can go at the end of a hurried, stressful day but it is most important a place of sanctuary. A safe and secure place. A place where we can be ourselves and “let our hair down”. A place we will not be “kicked” out of (unless of course we don’t follow the laws involved in being a tenant or homeowner). A place that we control and a place we are responsible for. Many individuals with disabilities strive for a home of their own also. Too many times they have been asked to move from a place that they thought of as their home when, either they didn’t fit in (i.e., group home), or their needs changed. The beauty of supported living is that it gives people the opportunity to live in a home of their own and have services designed individually for them. The individual is not at risk of having to move and they can create their own sense of home. Staff of a supported living agency experience the emotional rewards of being an important part of helping the individuals they support to find and keep their homes. Everyone grows in the process!
Building your Toolbox: A Home of One’s Own
For More Information/Resources

A Home Of Your Own Guide
By Fannie Mae and the National Home of Your Own Alliance (1998); This comprehensive guide will walk you through the process of buying a home from the decision to purchase a home to the move and settling into your new home. A “must have” for anyone interested in purchasing a home. It covers topics like: applying for a loan, negotiating a purchase price, completing the title search, maintaining your home, tools needed for household repairs, and household budgeting. A copy can be requested by faxing a request, on agency letterhead, to Fannie Mae Publications, Attention Robin, 301-604-0158.

Fannie Mae’s HomeChoice
An affordable mortgage as well as information about other affordable mortgage products: 1-800-7-FANNIE (1-800-732-6643).

National Home of Your Own Alliance
A technical assistance center at the University of New Hampshire. You can call 1-800-220-8770 or use the website <http://alliance.unh.edu>. The Alliance supports a toll-free Information and Referral line and provides technical assistance on accessible, universal design and home modification. The Alliance also produces publications on home ownership and supported living available by order or downloaded from the website. The site also includes a Housing InfoPak that lists resources about financing, government agencies and other groups, as well as publications about home ownership, renter’s rights, and topics of interest to people in supported living. If you have access to the internet, you may want to get on the Alliance listserv by sending your name and e-mail address to the listmaster at <drv@cisunix.unh.edu>.

How To Plans: Home Furnishings for Supported Living
Adult and Supported Living Services, State of California, Department of Developmental Services (1996), (916) 654-1956.

Renters Rights
By Janet Portman and Marcia Stewart, Nolo Press, 1-800-846-9455.

Tenants Rights
By Attorneys Myron Moskovitz and Ralph Warner, Nolo Press, 1-800-846-9455.
2. Choice and Self-Direction

Introduction
Supported living services offer an exciting opportunity for individuals to live the way they want to live in their own homes. They choose what to do each day from morning until evening. Also, like other adults, they plan for their futures based on their personal goals and dreams.

2. Choice and Self-Direction
- Individuals make their own everyday choices.
- Individuals plan for their futures.
- Individuals direct the services they receive and have a choice of agencies and staff.
- Individuals are supported (e.g., technology, communication devices, behavioral support) to communicate their preferences, choices and needs.
- Individuals are satisfied with the services they receive.

Individuals Make Their Own Everyday Choices
The job of a supported living agency is to encourage and support people to make their own choices in everyday matters and in big decisions that affect their life. Some individuals you support may be very capable of expressing their preferences and needs but others may not. Some people will have had a lot of experience making decisions and others may have a history of having other people make all of their decisions for them. If you support someone who does not clearly express their preferences or who is afraid to make decisions, you may be puzzled at times about what they really want. If you spend enough time with the individual and you watch them and listen to them, and if you talk to the people who know them and care about them, you will
begin to discover what their preferences are. You will want to know what is important to them in the areas of:

- Who they like to spend time with
- What they like to do
- Where they like to spend time
- What they like and what they dislike
- Things that are important to them
- Routines and rituals that are important

You will also want to know what areas of life the individual has had control over and what areas were controlled by other people. This includes little everyday choices like picking out their clothes for the day or what to have for dinner and big decisions like how to spend their money, where to go on vacation, where to live, who to live with, and where to work. Part Four, Section 6 (Getting to Know You) includes a Choice Experience Assessment Tool that will help you learn about the individual’s experience making choices.

Many individuals have a hard time expressing their preferences because they have a history of not being listened to and their requests or preferences were not honored. Imagine what you would do, if over and over again you let people know about something that was important to you and they repeatedly told you that you had to go along with what the rest of the group did, or you had to do what others thought you should do. Usually people respond by either getting louder in their efforts to be heard (this sometimes gets labeled as acting out), or they get quieter. So your job is not only to find out what is important to the individual, but then your job is to honor and respect the individual’s preferences and decisions.

**Individuals Direct Their Services**

Individuals who receive supported living services are at the center of planning the services and supports they receive. While their family and friends, their regional center case manager, and the SLS agency participate in the planning process, the individual who receives services has the loudest voice. When an individual is not able to communicate in
typical ways (i.e., they don’t use words to talk), the agency learns about his or her needs and desires by spending time with them observing their preferences and the things that work and don’t work for them. The agency also listens to the people who know and care about the individual to find out how to support him or her.

First, the individual selects an agency (assuming they have decided to use an agency— they could choose to become vendored to manage their own services or their family could become vendored). Then the agency develops an Individualized Service Plan with the individual that reflects the services he or she wants and needs. The service plan describes what services (e.g., cooking, budgeting, hiring of personal assistants), will be provided, who will provide services (e.g., live in roommate, come in personal assistant, community support facilitator), when services will be provided (e.g., time of day, frequency), and how (e.g., instruction, facilitation, supervision) services will be provided. Just as the individual and their needs will be constantly changing the service plan will be continually changing to reflect the current needs and desires.
Always remember that people’s preferences, likes and dislikes will change over time as they have more experiences and learn and grow. Do not get discouraged if you help someone achieve a goal like moving in with a friend only to have them decide a few months later that they would rather live by themselves. We all make decisions, try things and then change our minds. Part of your job will be to help the individual with problem solving, decision making and learning about consequences. The same things we all struggle with throughout our lives.

**Individuals Choose Who Provides Services to Them**

Individuals who receive supported living services have the right to choose who will be hired to work with and for them. They also have the right to change staff. In supported living, the individual participates as much as they are able and willing in hiring, training and supervising staff. The process for hiring looks something like this:

1) A person centered planning and assessment process is used to get to know the individual being referred for services.

2) The individual’s preferences and needs drive the development of job descriptions and employment agreements.

3) The individual is assisted to develop an interviewing and hiring process that works for them. When the individual is not able to participate in interviewing in regular ways (i.e., a sit down question and answer interview) the family or others who know and love the person may help with interviewing.

1) SLS agencies will usually have serious applicants spend some time with the individual who would receive their services. This is the best way for the service recipient to make an informed decision about whether or not they want the person to work with/for them. Also, the applicant has an opportunity to experience spending time with the individual so they can be sure they want the job.
People who are hired to provide supported living services understand that their employment with the person they are supporting is contingent on the person’s continued desire to receive services from them. Individuals and their families are regularly asked by the SLS agency and their regional center case manager how satisfied they are with their services and with the staff who work with them.

When Making Choices and Communicating is a Challenge: The Challenge is on the Agency

Everyone communicates through their behavior, especially people: (1) who do not have a typical way to communicate; (2) or people who have a long history of not being listened to. Supported living agencies learn from each individual and their family and friends, how the person communicates. They must be good at observation, interviewing, listening, and assisting people to access any assistive technology (like computers) that will assist their communication. They have a process for person centered planning (even with people who don’t use words to communicate) that uncovers all of the things that are important to the person and what the agency needs to know and do to help the individual live the life they want. Included in this Toolbox (Part Four, Section 6 inside of Getting to Know You), is a communication tool that can help you identify how an individual communicates and what you should do to honor what they are saying.

A Process for Supporting Individuals Who Make Risky Decisions

One of the serious challenges that supported living agencies face is supporting individuals who make decisions that jeopardize their health and safety (e.g., choosing to employ someone through IHSS who is negligent in providing the assistance the person needs). Supported living agencies struggle with the tension that can come from having two roles in people’s lives. One role is to support and encourage the individual to make their own life choices. The other role is to support the person to live a healthy and safe lifestyle.
Supported living agencies work hard to have a partnership with the individual and a relationship based on mutual respect and trust. Then, they can feel comfortable having some influence over the individual if the individual is making risky decisions. They do not take control away from the person but they may offer increased direction and try a variety of strategies to support the person to stay healthy and safe. They recognize their obligation to try whatever they can to help people make fully informed decisions. It is not appropriate to shrug off responsibility with the justification that “people learn from their mistakes” because not everyone does. Nor is it appropriate to say that there is “dignity in risk taking”. There is no dignity in experiencing pain or tragedy.

Supported living agencies work collaboratively with the individual and their family and friends. This team of people is sometimes referred to as a “circle of support”. Together the circle of support uses a problem-solving process to make decisions about whether or not to offer increased support, supervision, or control. “Circles of Support” are discussed in the Relationship section of this manual.

Supported living agencies rarely terminate services to people even when supporting them becomes a challenge. They make a commitment to stick with the person through life’s ups and downs and recognize that almost everyone makes bad decisions or has a hard time at one time or another. Only when an individual is engaging in acts that are seriously jeopardizing their safety and health or the safety of others and the individual is unwilling to accept support and intervention services, would the agency consider ending services.

**With rights come responsibilities**

Individuals who receive supported living services have the same rights as other adults living in the community (unless their rights and responsibilities are limited by conservatorship or guardianship.) For more about a person’s rights see the Information Brief on Basic Rights. Along with these rights come responsibilities and accepting the consequences of one’s decisions and actions. For example, individuals are responsible for their financial and legal decisions. It is the agency’s
job to help the individual recognize all of their options and the possible results of any decisions they may make.

**Individuals Plan for Their Futures**

Supported living agencies assist each individual to clarify their goals, and their dreams for their future. Agencies typically use a person-centered futures planning strategy (e.g., PATH, MAPS) to facilitate this process. They may assist the individual to bring together their family, friends and others who know and care about them to be a part of the futures planning process. SLS agencies understand the power of bringing together the individual’s circle of support to increase everyone’s commitment to helping the individual move toward their chosen future.

The individual’s supported living service plan describes the services and supports that the SLS agency will provide to assist the person to achieve their life goals, as well as describing how the agency will help coordinate support that the individual receives from other people and agencies. Part Four, Section 6 includes a variety of tools including Getting to Know You. You can use these practical tools to learn more about what is important to the individuals you support.

Some people have a hard time thinking about and planning for their future. Sometimes this is because they are struggling just to get their basic needs met on a daily basis. The beauty of supported living is that services are individually designed around what each person needs and wants so people are able to live the life they want. Once their basic needs are met and they have a good life on a day to day basis they may be able to think about their goals for the future.

*You need a life before you have a dream.*

M. Smull
Things to Learn About Your Agency

- How does your agency support an individual to make their own choices if they do not express themselves in regular ways? For example if someone does not use words to speak or if someone has a limited vocabulary?

- How does your agency support individuals to get assistive technology (i.e., communication devices)?

- How does your agency get to know an individual who is referred for services.

- How does your agency honor both the small everyday choices and the big life changing choices individuals make?

- What is your agency’s process for supporting individuals who make decisions that jeopardize their health and safety or the health and safety of others?

Summary
Having choices and control over our lives in everyday little decisions (like what to do, and where to go) and in large decisions (like where to live, who to spend time with and where to work) gives each of us the quality of life that we want. Individuals with disabilities have the same desire and need to have control over their lives. Supported living services offer them this opportunity.
Building your Toolbox: Choice and Self-Directed
For More Information/Resources

Accessing Assistive Technology

What Can We Count On to Make and Keep People Safe?
Perspectives on Creating Effective Safeguards for People with Developmental Disabilities

David’s Discovery
A video about “Choice”. It is listed on the DDS web site at http://www.dds.gov/OW/videos01.htm. An order form is linked to this site.

Getting to Know You:
Planning for Services in Supported Living
Compiled for Connections for Information and Resources on Community Living (CIRCL) by Claudia Bolton and Bill Allen with help from SLS providers in the Easy Bay area of Northern California (1999); included in the Toolbox, Part Four, Section 6.

Technology links for people with disabilities on the web:

Apple’s Worldwide Disability Solutions Group <http://access.berksys.com/>
Visit Apple’s home page to review some frequently used access devices and software compatible with Macintosh computers.

Berkeley Access <http://access.berksys.com/>
The goal of Berkeley Access is to develop inexpensive software-only products that provide mainstream computer access for people with disabilities.

IBM Special Needs Solutions
Visit the home page of IBM’s Special Needs Systems.

Microsoft - Accessibility and Disabilities Group
This group works to make Microsoft products and services more accessible as well as promote accessibility throughout the computer industry.

Prentke Romich Company <http://dialup.oar.net/~Pprco/>
PRC provides quality language and assistive technology products and services to people with disabilities, their families and professions.
3. Relationships

Introduction
Supported living services are all about relationships - relationships between the agency and the individuals they support and between all of the people who care about the individual (e.g., SLS agency, family members, neighbors, landlords, and regional center staff). Important relationships also extend beyond the people close to the individual to community members like the bank teller or grocery store clerk. An important part of getting to know the individual is learning about the people who are important to them. A few tools to help you in this process are included in this Toolbox, Part Four, Section 6.

3. Relationships

- Individuals have family, friends and neighbors who support them in regular ways or as paid help.
- Individuals and their circle of support work together as a team with the supported living agency and others to share responsibility for his or her well being.
Supported Living – Entering into a Relationship of Support and Commitment

Others can’t support a person with a severe disability to establish and enjoy a household without reviewing and renewing the nature of their relationship to people with disabilities. Support only results from a long term relationship that communicates...

.... a strong sense that the person with a disability deserves a decent home and the assistance necessary to live there with dignity, and

... a willingness to respect and align with the person's emerging sense of self and developing ability to define and pursue individually meaningful objectives.

John O’Brien, 1991

Note: Here is a discussion by John O’Brien (excerpted with permission in Patterns of Supported Living) which discusses the relationship and the obligations between the agency and the individual from his article Relationships and Obligations (1993).

Relationships and Obligations (John O’Brien, 1993)

In many forms of service to people with developmental disabilities, the service provider’s primary obligation is to provide contracted services to eligible clients. If the provider lives up to applicable regulations, any failures belong to the client. Supported living turns this common situation inside out. Supported living workers recognize that people with developmental disabilities need committed, capable allies if they are going to overcome the barriers imposed by widespread prejudice and discrimination. Becoming someone’s ally doesn’t necessarily mean becoming their close friend or endorsing everything they do or want. It means being willing to be involved in a constructive way in helping a person discover and move toward a desirable personal future.

One way to clarify this essential relationship is to say what obligations the providers of supportive living need to accept to the person they assist.
**Obligations to the Person**

We acknowledge that in order to assist you effectively we must earn your trust and the distinction of being your ally by...

... treating you with respect and listening carefully to you so that we can keep getting to know you better

... learning with you about your interests and preferences and identifying the kind of home that will offer you a safe, decent base for your participation in community life

... learning with you about the kind, amount, and style of assistance you need to live successfully in your home and your community

... working with you, and your family and friends, to establish the home life you desire and the assistance you need

... recognizing the social, financial, and personal barriers to the kind of home life you want and assisting you to work to overcome them

... understanding the vulnerabilities to your well being that result from your disability and your personal history and carefully negotiating safeguards with you that balance risk and safety in a responsible way

... being flexible and creative with all the resources available to us to respond as your interests, preferences, and needs change

... keeping responsibilities clear so that, in every area in which we work together, you and we know what you will contribute, what your family and friends will contribute, and what assistance and support we will contribute
... minimizing our intrusion in your life by periodically checking to make sure we are not doing unnecessary things or doing necessary things in intrusive ways

... sticking with you in difficult times

... learning from our mistakes

... following through on our commitments to you and not making promises to you that we can’t keep

We recognize that social, legal, and service developments open many new possibilities for people with developmental disabilities and we accept responsibility to...

... provide you with information

... invite and encourage you to try new experiences

... invite and encourage you to widen your circle of friends and contacts

... hold high expectations for the quality of your life as a full citizen and community member

... stretch our own awareness of possibilities by actively seeking contacts with people involved in building up our communities and with people who are developing more effective and practical ways to assist people with disabilities
We know that you could find yourself in conflict with others: neighbors, landlords, other service providers, or the law. In these conflicts we recognize our responsibility:

... to be on your side, in the sense that we will assist you to achieve the best resolution of the conflict possible in the circumstances

... to assist you to understand the conflict and to consider alternatives for its resolution

... to assist other parties to the conflict to understand your position

... to consider adjusting the kind or extent of assistance we offer you if that adjustment will help to achieve a satisfactory resolution of the conflict

We realize that you may disagree with us or be dissatisfied with our assistance to you and we accept responsibility:

... to negotiate openly with you in search of mutually satisfying outcomes

... to try new ways to assist you and then check to see if the new approach has good results

... to work hard to understand your communications about the adequacy and acceptability of assistance, especially when you can express yourself better through your behavior than in words

... to assist you to explore other sources of assistance if you want to do that
We recognize that you might find close friends among our workers and, while we neither expect or require this kind of relationship, we gladly accept the potential difficulties that this might involve.

**Obligations to the Person’s Friends and Family**

We acknowledge your importance to the person we assist. We want to invite and encourage your active support for a positive future for the person we assist; we do not in any way seek to replace you in the person’s life.

We recognize that you may disagree with us or be dissatisfied with the assistance we provide. We accept responsibility to...

... respond to your concerns about the person’s safety and well being

... negotiate openly with you in search of mutually satisfying outcomes

We realize that you and the person we assist may have different, perhaps even conflicting, ideas about what is possible and desirable for the person; in the event of these differences we agree...

... to uphold the importance of mutually respectful relationships among family members

... to assist you to negotiate a satisfactory resolution to the conflict if our help is acceptable to you and to the person we assist

... if the conflict is serious and you cannot resolve it, we will maintain respectful contact with all parties but honor the choice of the person we assist. (O’Brien, 1993)
**Conclusion.** Mutually respectful relationships are often hard to develop and even harder to maintain over time. These obligations point out the serious commitment a supported living agency makes to stand by an individual through life’s ups and downs and through disagreements and tension. Honoring these obligations takes a considerable amount of commitment to the relationship and endless energy, communication, teamwork, negotiation and collaboration.

**Circles of Support**

Sometimes it is helpful for a group of people to come together to help the individual who receives services figure out how to have the life they want. This group of people is sometimes called a circle of support.

Most of us have informal circles of support that include our families, friends, community members and people we pay (e.g., car mechanic, hair dresser, dentist) to support us. Our circles of support most likely never come together as a group unless it is to celebrate or grieve with us. Individuals with disabilities may benefit from having their circle of support come together formally to: learn more about the individual and the people in that person’s life; listen to the individual’s hopes and dreams for the future; and to see what support and resources each person in the circle can contribute to helping the individual have a good life. A circle of support may be formal or informal. Formal circles agree to meet regularly, whereas informal circles may not have meetings at all. Part Three, Tools and Applications includes a few tools that many agencies have found useful in learning about relationships people have and the groups and organizations they are members of.

At times when an individual is making decisions that place his or her health or safety in jeopardy the supported living agency may want to pull together the individual’s circle of support. They may talk individually or over the phone or they may all come together and have a formal meeting. During these times the circle is invaluable for supporting the individual’s right to make decisions while at the same time providing increased direction or intervention to assist the individual to be safe.
An effective circle of support works together within a culture of mutual trust and respect to share responsibility for supporting the individual. Because relationships are so tenuous and the relationships in supported living have a high degree of obligation and commitment you can expect that they will be continuously tested for their durability.

Individual's lives are enriched when their circles of support include people who are not paid to have a relationship with them. Unpaid people offer ideas, resources and caring relationships outside of the boundaries of the service system. Some individual's in the service system do not have family or friends or if they do, their family may not see them or be involved in their lives. Human beings need to be loved and needed. It is our nature. Individuals with disabilities are no different. An important role of the supported living agency is to help individuals develop caring and durable relationships. The next chapter on Community Building offers some ideas about helping people find places (like clubs, groups, and organizations) where they can develop new relationships and have a valued role as a community member.

**Things To Learn About Your Agency**

SLS agencies, by their mission and nature, develop a culture which encourages caring relationships as well as independence. SLS agencies may have a deeper involvement in the lives of the people they support than other kinds of vendored services. The relationships between the agency, the individuals they support and the individuals’ families may be more complex than with other services. To learn about your agency’s practices for supporting relationships you may want to ask others who work within the agency to share stories. You might want to ask them to share stories that illustrate:

- How does your agency facilitate and support the relationships and the services that might be provided by the individual’s family, friends and other community members?
Part Two: Principles of Supported Living Services

• How does your agency facilitate “Circles of Support”? What are some examples you can learn from?

• How does your agency view the support that individuals receive from their family and friends?

• What are some examples of collaborative relationships that you can learn from?

• What relationships have been challenging for the agency to support?

• Does the agency have any policies or practices about the relationships between staff and the individuals they support? For example do staff give out their home phone numbers? Are staff allowed to visit with individuals when they are not working?

• What are some stories or examples of how your agency honors its responsibilities and obligations to the individual and their family and friends?

Summary
There are really two parts to the SLS principles about relationships. The first principle is to support individuals to have relationships outside of the service system. The second principle is about the agency’s relationship to the individual. Both of these principles can be hard to put into practice because relationships can be just plain difficult to develop and difficult to maintain.

It is important to start with figuring out what the individual’s relationships are like now and what they were like in the past. A good person centered planning process can help. Part Four, Sections 3 and 6 include some tools that can help learn more about the person’s important relationships. Part Four, Section 4 includes some tools you can use to help the person develop new relationships.
Supported living agencies struggle with the tension that naturally comes as a result of their relationships with the individuals they support. It is hard work. Sometimes it feels like it has no beginning and no end. Not every agency and not every staff person have the qualities that it can take to hang in there with someone, or someone’s family, when things get tough or confusing. Staff of supported living agencies frequently struggle with defining their role in a person’s life. John O’Brien’s article in this section can help guide an agency and its staff. Also, the tools to support decision making in Part Four, Section 2 may be useful when the agency is struggling with the agency’s obligation to the person when they are making risky decisions.
Building your Toolbox: Relationships
For More Information/Resources

It's about Learning, A Student Centered Approach to Adult Learning
by Marsha Forest with Bruce Kappel (1988), Frontier College Press, Toronto, Ontario

From Behind the Piano, The Building of Judith Snow's Unique Circle of Friends

What's Really Worth Doing and How to Do It, A Book for People Who Love Someone Labeled Disabled
by Judith Snow (1994) Inclusion Press, Toronto, Ontario


What We are Learning About Circles of Support. A collection of tools, ideas, and reflections on building and facilitating circles of support
By Beth Mount, Pat Beeman, George Ducharme (1988). Communitas, P.O. Box 374, Manchester, DT 06040
4. Community Membership

It has to do with that essential sense of having a “sense of place” in the world.

David B. Schwartz, 1992

**Introduction**

Supported living service agencies quickly discover that some of the most important and also the most difficult work they do is supporting individuals to become valued members of their local community. Community membership is more than just being present in the community. Membership is about being welcomed and being known by other members of the community. It is about the teller at the bank recognizing the individual and offering help. It is about the checker at the grocery store helping someone reach items difficult to reach from a wheelchair. It is about the church members who invite the individual to lunch after Church on Sunday. It is about being invited to join the neighborhood equestrian club.

Community membership is especially rewarding for the individual and the community when the individual is a contributing member. For example, the individual may be a volunteer at a local food bank or regularly help their elderly neighbor mow their lawn. Sometimes community members and organizations naturally welcome an individual without the assistance of the SLS agency, while other times the agency must be thoughtful and purposeful at facilitating the individual’s participation.
We often make the mistake of assuming that when individuals move into their own homes in regular neighborhoods that they will naturally meet their neighbors and be welcomed into community life. The experience of people doing this work is that far too often this process does not happen on its own. Our ignorance, or neglect, can result in isolating people and although it is true that some people may enjoy or prefer solitude to being with other people, we may justify this isolation by saying that the person is not very “sociable” or that they’re choosing to spend time alone. Some people become depressed or suffer from other kinds of problems when they are lonely and isolated.

**SOME THOUGHTS ON OPENING UP THE DOORS OF COMMUNITY LIFE**

WHAT CAUSES ISOLATION OF PEOPLE WITH DISABILITIES? PART OF IT IS INTOLERANCE OF DIFFERENCES. EVERYBODY’S DIFFERENT IN SOME WAYS. HOWEVER, THE DIFFERENCES WE’RE TALKING ABOUT GO BEYOND THE BOUNDS OF WHAT WE ARE USED TO. IN THE PAST, PEOPLE WHO WERE DIFFERENT WERE SHIPPED AWAY TO INSTITUTIONS. THE REST OF US BECAME LESS USED TO SEEING SUCH PEOPLE AROUND - AND THUS, EVEN MORE CONSCIOUS OF DIFFERENCES AND LESS SURE ABOUT HOW TO REACT TO THEM.

SHIPPING PEOPLE OFF TO INSTITUTIONS IS THE MOST OBVIOUS FORM OF ISOLATION, BUT EVEN OUTSIDE THE INSTITUTIONS - EVEN FOR PEOPLE WHO PHYSICALLY LIVE AT HOME OR IN A “COMMUNITY SETTING” - THE ISOLATION OF LIVING ENTIRELY IN A WORLD OF PAID SERVICE CAN STILL BE OVERWHELMING. THOUSANDS OF PEOPLE HAVE BEEN MOVED OUT OF BIG INSTITUTIONS AND INTO SMALL GROUP HOMES IN CITY NEIGHBORHOODS OR SUBURBAN STREETS. BUT INSIDE THEY ARE STILL SURROUNDED, NOT BY NEIGHBORS AND COWORKERS AND FRIENDS AND LOVERS, BUT BY OTHER LABELED PEOPLE AND THOSE WHO ARE PAID TO SERVE THEM. THE IRON FENCES OF THE INSTITUTION MAY BE COMING DOWN, BUT THE WALLS OF THE SERVICE WORLD ARE STILL FIRMLY IN PLACE AND PEOPLE FROM EITHER SIDE CAN’T SEE OVER THE WALLS INTO THE LIVES OF PEOPLE ON THE OTHER SIDE.

THERE ARE PEOPLE FIGHTING TO BREAK DOWN THE WALL AND FULFILL THEIR DREAMS. THAT IS WHAT COMMUNITY IS ALL ABOUT.

ADAPTED FROM *THE GIFT OF HOSPITALITY*
As you work in supported living services, you will constantly be struggling with a balance between offering enough and the right kinds of supports with offering too much support. This is a healthy struggle. Many leaders who have been providing supported living services for a long time say that when a colleague experiences this tension it is the sign of someone who is really trying to do this work “with their brain turned on.” They suggest that we look for leaders, mentors, and tools to try, but avoid cookie cutter theories and practices. This is especially important when it comes to helping people with their relationships.

Learning from Community Builders

The best way to learn about community building is to learn from the community and from the people who are community-builders. The next part of this chapter will present reflections, experiences, and stories of people who, in the true spirit of community, are willing to share their work.

Pioneers like Kathy Bartholomew-Lorimer, Sharon Gretz, Catherine Duchesne, Angela Amado and Judith Snow are learning about how to help people be welcomed by the community, and how to support the community in being a more welcoming place. They were more than willing to share ideas and their experiences. There seem to some similar patterns in the work they are doing. Here is what we were able to glean from their experiences:
Patterns of Community Building

1. Focus on a specific geographic neighborhood. Learn about the neighborhood. Spend time hanging out with the people who are part of the community.

2. Find out about organizations and associations which exist in the neighborhood. Figure out which associations are working on building a better community. Find the people who are the welcomers. Every group has some. Get to know them. You can't do community work by yourself. You have to open yourself up to the community members and ask for help, ideas, and contacts.

3. Ask, Ask, Ask! Ask the association to welcome back someone who has been excluded. We have been afraid to ask. Community builders' experiences tell us that community members are waiting to be asked.

4. Pay attention to natural cues to figure out how much and for how long to lend support. Every situation is unique and there are no rules. Pay attention to when you should back out and let the regular community process take over. Be available if problems and conflicts occur but trust the community to work things out. Don't be quick to jump in and intervene in the natural process. Provide support to both the person with disabilities as well as the community members.

5. Stand alongside the person with disabilities and alongside community members as well. Join in. Be a member. Be a regular person. Don't feel like you have to go in as a professional with the answers. In fact, if you do, you will make the community people feel incompetent and they may back off.

6. Establish circles of support around a specific person. Involve community members. Let them know how they can help.
7. Remember that nothing about relationships is fixed and permanent. Informal relationships will change over time. They may grow, fluctuate, or die.

8. Community building work is rarely ever over.

Communitas Inc. (What We are Learning About Bridge-Building, 1988), offers this list of the common practices followed by successful community or bridge-builders:

- They work through trust networks—a network of people who know each other and can open doors on behalf of the person with a disability. If a bridge-builder does not have a network, then she/he is taking the time to build one.

- It works best when the person "guiding" is also connected — when she is part of the town or organization to which a bridge is being built. Familiar, trusted people are the best people to introduce people with disabilities into new settings and associations.

- Bridge-builders take time to get to know the people they are going to connect. They spend unstructured, personal time with each focus person. Building bridges works best when matching the personal interests and choices of the focus person to like-minded people and places in the community. Bridge-builders must spend lots of time with the focus person to gain a good understanding of the interests and preferences of the focus person in order to make a good match.

- All bridge-builders are starting small. They work with no more than 10 people at one time. They receive administrative support to start small.
• Bridge-building takes time and patience before things occur. Bridgers work in their own time and in their own way.

• Bridge-builders spend most of their time in the community. If they work for human service agencies, they have been freed from the demands of human service systems and are exempt from paperwork and other distractions.

• Effective bridge-builders are not "professionals." They are small business owners, beauticians, local politicians, church members, neighbors. They use common language to describe their feelings and experience.

• Bridge-builders who have been human service workers have difficulty giving up control, letting things happen. They have to learn to trust community people to know what to do and to follow-through.

• Bridge-builders do not "fix" or "change" the focus people. They accept and introduce the focus person as she is. They find people and places in the community who also accept the person as she is now.

• Bridge-builders do not teach the community how to integrate. They tell stories about inclusion. They model effective interactions and acceptance by example. They learn a lot about acceptance from people in the community who are naturally inclusive people.

• Bridge-builders must be responsive, present, and they must listen a lot. They are opportunity seekers, and they seize and support every possible opportunity they see to make connections for people. Circles of support provide a unique opportunity for bridge building. Circle members make a personal commitment to the person with a disability. They do their part to make a dream or a goal come true. They extend the circle of support by making new connections.
• Many bridge-builders feel very isolated. They are constantly making creative decisions and judgments along the way, and this level of innovation is stressful. They reach across many cultural lines and settings. They sometimes work closely with a partner.

• Most bridge-builders have unclear roles. They are learning as they go. They are trying lots of things.

Stories of Community Building
Citizen Participation: Connecting People to Associational Life from Crossing the River
Reprinted here with permission by Sharon Gretz

Not too far from Pittsburgh, there is a tiny little town with a funny name which no one ever seems to have heard of. The heart of the town, on the main street, is a delicatessen. At the deli, a steady trickle of townspeople come in the morning and again at lunch for fresh brewed coffee, enticing food and friendly conversation. Several years back I found myself there. This little town with the funny name held a special interest for me. Soon the deli would hold a special significance as well. Stunned and knocked to its knees in the early ‘80s by the collapse of the steel and manufacturing industries, the town was now fighting to come back. Recovery and rebirth were in progress. However, many people were forced to leave to find work and provide for their families. Those who remained in the community were put in the position of needing to pull together if there were going to be any community at all.

In the midst of this process, eight new people had moved into town. These individuals had no ties to the community whatsoever. They had no roots, no history there. In fact, community, any community, was hardly contained in their histories at all. The eight people had severe disabilities. Between them, their histories held over 145 years of life within the walls of institutions.

In 1985 the agency for which I worked led a complex effort to "spring" these eight people from institutions to life in a community. The community picked was the little town with the funny name.
December 23rd, 1985 was liberation day. The whole thing took a tremendous amount of energy, persistence and probably audacity. Oh, it was a great feeling to see them leave. Exhilarating in fact—for the people who moved and for the people who played a part in making it happen. One of the public entities that had made it possible was the state Developmental Disabilities Planning Council. They had initiated a project to get people with disabilities out of nursing homes. They had provided money for people to set up their households.

After several years it was clear that those who had believed that these eight people were not capable of living in the community had been wrong. They were still there. They were making it. They had staff support. They were involved in day training programs to learn skills. There were staff available to attend to their personal care needs. There were staff to take them shopping, banking and out to dinner. Yet something began to gnaw at those of us at my agency who were intimately involved in this whole thing. The feeling was inarticulate at first, but the gnawing arose with the question “Is just being there enough?” Was life in the community about simply being present, or did it have to do with having a presence? Tom Kohler, who is involved in citizen advocacy in Georgia, cut through everything. For me he posed the question, “If you imagined two worlds, the client world and the citizen's world, where would you say most people spend the bulk of their time?” I remember feeling like my heart stopped. There was no need to think about the answer. Our people were clients all of the time. In this little town where they lived, the people I knew, the liberated eight, were virtually invisible. Although they were there, they were not seen and certainly not known. Few, if any, relationships had developed outside of "the program." Belonging had not come by simply being there.

With this reality in our minds, we again looked for a way to help these eight people "live in the community." We wanted to find ways of helping people belong—to be full-fledged citizens.

About this time the state Developmental Disabilities Planning Council made funding available for a new kind of project called "Citizen Participation." We wrote a proposal, and were awarded a grant. It was just a small grant in terms of money. With this tiny little
grant we began. I was hired to figure out what this new approach would be. As it turned out, I didn't know what I was getting myself into. I was used to things like developing policies, designing programs, making assessments, writing reports, supervising staff, counting units of service, coming up with "forms" for this or that, and generally "putting out fires." With this, I couldn't just call someone else in my field and ask for the "how-to's." At the time, I knew no one in my professional world who was doing this kind of work. And so this tiny little town and this small grant held a certain intimidation for me. My own struggle began with the question, "How can I get in touch with the real life of the community?"

We started with the idea of finding a community member who would be a "bridge builder" between the eight people we supported in apartments and the town itself. The "bridge builder" would need to be someone who was well known and respected in the community, who belonged to many associations and groups, and who was innocent of involvement in our human service world.

When the time came to look for our first "bridge builder," I started to become uncomfortable and actually afraid about how to do it. I guess in my mind I knew that putting an ad in the Sunday classified would not do it. But what would? I started by asking people from work if they knew anybody who might know someone else who was very involved in the community. After a few tries, someone told me that his aunt had lived there all of her life and maybe she could help. He called his aunt and she said that the person we should talk to was Sophie.

**Sophie**

I found out that Sophie was a hairdresser who had run a shop in town for many years. She was also the mayor. Would she be well known? If you think about a small-town beauty shop, chances were high she would know just about everybody and everything in town. Would she be well-respected? Well, after all, someone had elected her mayor and trusted her enough to be the top-ranking leader of the community. And finally, she had no ties to the human service world. Perhaps she could help. I needed to call her and ask.
I was given Sophie's telephone number. I want to be perfectly honest here and tell you that I looked at Sophie's telephone number on my bulletin board for many days. As I struggle now to understand my hesitancy to call her, several things come to mind. How could I ask a perfect stranger to get involved? What if she just said no? Would her "attitude" be right? Finally I called.

I went to meet Sophie one day to get to know her. We met at her office as mayor because it was Monday. On Mondays, Wednesdays and Thursdays, Sophie works as mayor. On Tuesdays, Fridays and Saturdays, she cuts hair at the beauty shop. As we began to talk, Sophie's phone rang constantly. No, she hadn't heard about any jobs lately; yes, the town council would meet Monday night; etc. During some of her phone calls I started wondering what I would say. I didn't want to interview her. How would I know if she was the one?

I can't remember now exactly what I said but somehow I told her why I was there. Sophie immediately started to tell a story about a woman she knew who had cerebral palsy and went to live in an institution. Some years later the woman wanted to move out of the institution and back to an apartment high-rise in her town. She kept calling Sophie and asking her to help her come home. Eventually, Sophie was able to help arrange it. Sophie said everyone in the building was nervous and upset when it came time for the woman to move in. Sophie thought that was silly and made it her business to talk to everyone in the building about her friend's abilities, nice personality and desire to come back home. When her friend finally moved in, the people in the building had a welcoming party.

Sophie went on to tell me about some other people with handicaps who had moved into a new special "independent living" building in town. She was worried they might become isolated. So she had invited them to come to a tea party on community day and had made special arrangements so they could get into the building. No one came. She didn't understand why they didn't come. She thought maybe I knew why. Sophie wanted to know if she did something wrong.

Sophie went on to say that if we were going to be working at getting people involved in the community we needed to talk to Frank. She
said Frank knew everybody in a thirty‐mile radius and belonged to every association, group, and club. In fact, Frank had probably started most of them. I made arrangements to come back again to meet Frank. On the way out, Sophie asked me again if she had done something wrong when the new people in the special building didn't come to the tea. As I looked into her questioning face I felt compelled to supply an answer. As I searched my mind looking for words or theories to provide some type of professional explanation, I realized that there were none—none that could or should negate her kind and open gesture. I just quietly said no.

I went back to Sophie's office on a later day to meet Frank. Frank is technically retired from work in a local factory. His handshake and smile are warm and welcoming. We all decided to walk to the deli down the street to have coffee and talk. As we walked I noticed how different my pace was from theirs. Frank and Sophie slowly sauntered; Frank with his hands loosely in his pockets, Sophie casually swinging her purse. Me—I was fighting to slow my typical fast and long strides, carrying my purse and my overloaded briefcase.

As we walked I felt in good company. Everyone we passed said hello to Sophie and Frank—a lady carrying shopping bags; people driving by; men gathered on a bench on the corner outside the post office. In the deli, everyone who worked there knew them too. A small group of people were gathered just inside the door. Some were young and some were old. All had a kind word and a comment the day I was introduced to all of them. Sophie sold some raffle tickets as we waited for coffee.

Sophie and I talked with Frank about what we wanted to do about getting people whom I supported in their apartments more involved in community life. Frank said he thought it was a good idea, but didn't want to commit himself right that minute. He said he had so many activities that he didn't want to say he could help until he had thought about it. Frank pulled out a folded piece of paper from his breast pocket and showed it to me. On the paper were notes of meetings and times—Lions Club, Festival Committee, Food Pantry and so on. I thought it was interesting that he didn't have an appointment book.
Frank started to tell me a story about when he ran a band group of kids that marched in area parades. Frank is very involved in parades. A girl who couldn’t use her right arm wanted to be on the flag team. Some parents of other kids began to complain because she was the only one who carried a flag in her left hand and it messed up the flag formation. The parents said the group wouldn’t be judged well in parades. Frank told them he didn’t care; the girl was marching and she would carry her flag in her left hand. He said the girl is about thirty now and when they run into each other in town he feels good because she always talks about the band group, and how happy she was carrying the flag. Something inside me felt good, too. Then Frank said he didn’t care who a person was, what problems they had, or what people couldn’t do. What was important was, if someone wanted to be included then there was something important that he could find for them to do. Frank told Sophie he could help if we wanted him to.

Meeting Frank and Sophie and spending time with them sensitized me in an unexpected way, as a person as well as a human service worker. They taught me in small ways, never intending to change me as I may have initially meant to change them. Although I didn’t realize it at first, I came to them expecting that I would be the teacher, the educator, the expert who would instill in them and their community how to go about "community integration." While I was busy explaining about people’s physical limitations, they were already brainstorming about what people could do. I sensed in Sophie and Frank this enormous capacity for caring. It didn’t have anything to do with "disability." It had to do with how they felt about all people. They sensed utility and worth in everyone. They wanted their community to be a good place to live. Over the years they had been willing to invest in making it that way.

I initially worried because Sophie and Frank didn’t know about word usage and terms I used. "Social Role Valorization," goal plans and units of service meant nothing to them. Someone at my agency asked me if they were really qualified to do what we wanted them to do. I labored over that thought for a great while. Eventually I
came to just know that their "professional" qualifications were not an issue. The only way I can describe having come to this conclusion is that my heart told me. Inviting people into community life was already their life's passion. They had shown me their capacity to welcome and embrace people. I didn't worry any longer about what words they knew. And finally, when I went to the deli to talk and have coffee with Sophie and Frank, I no longer carried my briefcase. Once we agreed upon what we wanted to do together, we arranged for Frank to receive a small "retainer" to help defray some of his expenses. The first person he started to connect with the community was Albert.

Albert
Albert is a rather heavyset man in his early sixties who spent the bulk of his years living in a nursing home. Albert is a tremendously likable guy who talks and laughs loudly. He frequently dons a straw brimmed hat and wears suspenders and large boots that are seen by some as his trademark. Albert's labels include cerebral palsy and mental retardation. He uses a wheelchair to get around. It almost always takes him a long time to complete a thought out loud as he stutters quite severely. Albert is also quite notorious for being as stubborn as a mule.

Frank arranged for Albert to help out once a week at a local free food pantry for the many unemployed people in town. Frank organized, started and runs the food pantry. Each week Albert joins the other volunteers who give out food. Albert is responsible for handing out tickets to families as they come in. Each ticket is numbered. But since Albert didn't know his numbers, they had to figure out a way to keep them in order. Since Albert started at the food pantry they tried several systems so that he could do his part. Frank and another person also began helping Albert learn numbers in quiet moments at the pantry. Frank told me that Albert has come to recognize more and more of the numbers. The funny thing is that it never happened in ten years of instruction at special day programs.

The people at the food pantry really like Albert. Frank says they kid and joke with him all the time and help him out when he needs it. Albert, originally rather subdued, has warmed up to them as well. Even the families who come in look forward to seeing him there.
When Albert lived in the nursing home, he got in the habit of
securing his most prized possessions by wrapping them in many
layers of handkerchiefs, socks and bags and keeping them close to
his body. Each week at the food pantry, someone asks Albert if he'd
like to put on his name badge, at which time he gets out one of his
bags and proceeds to unwrap the many layers to reveal his prized
badge. In social service circles this is known as "institutional
behavior" that needs to be corrected. At the pantry this is just
known as Albert's ritual. One of the workers there told me that the
ritual means that Albert feels proud to be a part of their group. It
never occurred to them that there was anything wrong with it.

It's important to understand that everything has not been perfect
either. I remember the time after Albert had been at the pantry
several months when Frank called me to say that there was a
problem. Albert wasn't making it to the bathroom in time and was
wetting himself. My reaction was one of horror and fear; fear that
they were going to suggest he not come anymore. Sure that I was
going to beat Frank to the punch, I suggested perhaps someone else
could or should take Albert's place. Frank was shocked. "Absolutely
not!" he replied. Albert belonged with them. They just wanted to
solve the problem. As it turned out, arrangements were made for
Albert's attendant to meet him at the food pantry and help him get
to the bathroom. When things are quieter, Frank helps him, too.

Sometimes Albert dozes off and someone slips by without their
ticket, which messes up the system. Frank comes by and pokes
Albert when this happens. Now he has a sign at Albert's table that
says, "Please stop here and get a ticket." Sometimes Albert would
mix up the tickets and give out the wrong ones. They fixed that by
making a stick post and putting the tickets on it. Albert just has to
pick the one on top. Occasionally there are people who don't want
to deal with Albert. When this happens, Frank's response is "If you
want food, you have to see the man."

Two years have passed and Albert is still there. Everyone associated
with the food pantry has accepted Albert just as he is. I'm sure many
professionally experienced persons would look at Albert's deficits
and deem him unready. At the food pantry Albert's disabilities aren't
denied, yet his unique contribution is accepted and welcomed.
Nobody tries to change him. He has a place.


**Pete**

Pete is a gregarious guy in his fifties. Pete gets immense satisfaction in telling off-color jokes to unsuspecting parties. His laugh afterwards is probably the most infectious I've ever heard. Pete also is devoted to his faith. He loves to read the Bible, talk about Scriptures and about God's presence in his life. Pete fell off a truck when he was a young man. His fall resulted in serious head injury. Pete lived at home with his mom until she could no longer take care of him. He spent many years in a nursing home before moving to his own apartment two years ago. Sometimes Pete gets very agitated, aggressive and hard to reckon with.

I asked Frank if he might get to know Pete and his interests, and Frank decided to take him along to his weekly community Bible study group. The first week people listened silently as Pete told his story and shared his faith. I am told that Pete's presence is appreciated and his remarks respected within the group. Never at a loss for words, Pete at times monopolizes the conversation and interrupts people who are talking. From what I understand, people in the group handle this by lightly squeezing Pete's arm when he starts to take over. Pete has come to understand that in this group when that happens he needs to give someone else a turn.

Frank told me after one Bible study meeting, Pete blew up at a man when he suggested to Pete that it was cold and he might want to put his coat on before he left. That old apprehension still dwelled in me somewhere. I asked Frank what he told the man. Frank told him "Pete doesn't mean anything bad by it. He just does that once in a while." They still wanted Pete to come. I was also surprised to find out sometime after the fact that the people in the Bible study built a ramp for Pete so that he could enter the church with more ease.

Sometime after Pete had become a regular member of the Bible study his day program came to a halt. The agency that had been funding his program had decided he was not capable of working, so they gave up trying to prepare him. Now Pete had absolutely nothing to do with his days. He came down to our agency building and tried to help out but usually ended up just sitting around. By this time I had met Gene, who was a good friend of Frank's. Gene was a helper at the food pantry and had taken a liking to Albert.
Gene told Frank and me that he wanted to get involved in helping our citizen participation efforts. Gene was a lifelong resident who had been an executive in the sales field. When I met Gene he was between jobs and had pretty much given up on wanting to be a part of the sales field any more. He was looking for something different in his life—a way to be of real help to the people in his community. This was what led him to the food pantry, and Frank in particular. As he expressed it to me, he saw in Frank what lived and breathed in his own heart. Frank was a symbol of pure love and an example of how human beings could interact in their world. He started spending time with Frank and learning from him.

Gene already knew Pete. I asked Gene if he thought there might be something for Pete to do in the community that would have some real meaning. Gene contacted his friend named Lynn Ann. Lynn Ann had several years earlier begun, as she put it, "to try and get neighbors helping neighbors. There were many problems facing our community." Her network grew through voluntary efforts of people. She works full time without pay. She and others try to help the situations of single-parent poor families and homeless families. One effort is to help people find affordable housing.

Gene asked Lynn Ann if there might be something in her office that Pete could do. Lynn asked her other volunteers and together they came up with a job for Pete. Now several times a week, Pete's job is to go through apartment rental ads in local newspapers. When he finds an ad below a certain dollar amount, Pete cuts it out. After going through all the ads, Pete organizes the ads by location and price and puts them into a 3-ring binder. When someone calls in need of housing, everyone uses Pete's book. As Lynn Ann says, "Pete is making a real difference in people's lives." She is planning to invite a family who finds a home through the book to come in and meet Pete. Lynn Ann feels that it is important for Pete to see his value to others.

When showing people Pete's book Lynn Ann, with pride, shows how he is getting better and better with organizing it. They saw at first that he was having trouble knowing where to paste the ads in. Their solution was to draw a grid on notebook paper and make lots of copies. Having the lines on the paper has helped Pete to do his job better.
Life in Lynn Ann's office has changed significantly since Pete arrived. There is a new spirit in the office. Lynn Ann says the best thing about having Pete there is simply him being himself. Pete's gift of gab is revered here, especially the jokes. Lynn Ann and Pete have a deal—Pete has to keep telling her jokes because she often gets too serious. In return Lynn Ann's promise is to be a good boss. When Pete yells over "Hey Lynn, I have a joke," the entire office comes to a hush. The punchline is delivered, everyone either laughs or moans—and then they get back to work.

**Bonnie**

Bonnie is a young black woman who is somewhat shy and timid. When she smiles it seems to cover her whole face. Bonnie spent about 24 of her 28 years in a state school and hospital. Bonnie needs a lot of assistance for most physical tasks except driving her electric wheelchair. I asked Sophie if she would spend time getting to know Bonnie and to think of how she could get involved in their community. Sophie invited Bonnie to be a member of a committee that was organizing a community festival. Bonnie was delighted. The one thing she couldn't believe is that none of the other residents living at our residential apartment program were doing it too. I remember her saying, "You mean it's just me, mine alone, no other clients?" Bonnie's jobs for the day were to greet people at the tea, hand out art awards at the children's art contest, and review the parade on the reviewing stand.

Let me insert here that all along I have tried to stay physically away from these community groups and events so as not to impose or intrude on the community's natural way of doing things. I decided in this case I would go to the celebration and imagined all these scenarios of Bonnie's Triumphant Day. The morning of the celebrations I grabbed my daughter and off we went to blend into the crowd.

Well, my expectations differed a lot from what happened for Bonnie that day. She was physically present in all these activities but didn't really seem involved. She was introduced over the microphone at the art awards. People in the auditorium clapped but then she was just sort of ignored as things went on around her. I remember looking down at the ground and feeling embarrassed for her. Sophie
wasn't there. I scanned everywhere for her but she was busy preparing for something else. Soon it was over.

The next day, I asked Bonnie how she felt. She told me she felt funny, like everyone was staring at her, and that she felt left out. She told me she didn't want to do anything like that again. I know Sophie felt bad that others hadn't really included Bonnie that day. She told Bonnie that she was glad she came and hoped next year Bonnie would help on the committee again. Bonnie smiled her immense smile and said she really wanted to try it again.

Some of the people in charge that day told Sophie they were surprised at how the children responded to Bonnie. They weren't afraid of her and gave her a big hand. They thought the kids would be afraid. Perhaps they didn't realize that it was they themselves who were afraid. There are several things that I make of this. Again I say it is not for me to judge—it is not my expectations that are important here. It is clear that individuals with severe disabilities will need to be supported in different ways as they come to be involved in communities. Why did we expect this woman who had lived in an institution for twenty-four years to feel self-assured on a stage alone in front of strangers? Now instead of being horrified I can compare it to my own feelings at walking into my first PTA meeting and not knowing a soul.

Bonnie also had this real desire to sing. Although her voice was quiet, it was a beautiful voice. Where might Bonnie find a place to sing? By now Gene was totally involved in our efforts. He thought that perhaps a church choir might be a place. Bonnie was definitely interested. Gene knew a woman named Gloria who is the matriarch of a large Baptist church. At eighty years old, Gloria has had a rather rough life. One of twenty-five children born to her parents in Alabama, Gloria had struck out on her own at thirteen. After moving to our area, marrying and having six children, she became very ill. She entered a hospital and stayed for five years. In the meantime her family got split up into foster homes and her husband took sick and died. All Gloria could think about in these years was getting well and reuniting her family. She says everyone pretty much decided she would die soon. Her response was to pray. She says it's hard to express how it felt to walk out of the hospital, find her
children and bring them home. She decided at that time that she was blessed and from then on decided to make it her business to "do right by people."

Gene asked Gloria, "Might your church be a place for Bonnie?" Gloria's response was that at her church the doors were open. Gloria asked the church elders, the pastor and the deacons who all in turn asked the congregation to welcome Bonnie. And this they did.

Bonnie originally went to church with her attendant. But after a while the ushers and some others told the attendant that she needn't stay anymore. Bonnie could rely on them to help with anything she needed.

After a little while, Bonnie ran into some financial problems and also stopped going to church because her attendants had become unreliable. Gene told Gloria what was going on and again Gloria went to the deacons and congregation and asked, "What can we do?"

One day the deacons went to Bonnie's apartment and presented her with three hundred dollars. They had asked the church members if they would consider giving a dollar or two to help Bonnie pay her rent. They also said they had volunteers lined up to come and get Bonnie ready for church if it were necessary.

I heard that the day of Bonnie's baptism into the church was quite an event to see. It was different from any other baptism ever performed there. Faced with the problem of taking her wheelchair into the baptismal pool, the deacons conferred and decided on another way. There was some concern about the response of the church elders since they would be breaking down deeply rooted tradition. However, on the day of her baptism, Bonnie, draped in cloaks and doused with water, was met with a resounding eruption of applause.
Community Membership - Getting Started
These stories are not unique to Pennsylvania. Stories of people being included in their communities are being shared all over California by individuals and supported living agencies. Supported living services offer a new opportunity for many individuals to have the support they need to become a valued member. Part Four, Tools and Applications (Section 4) includes A Guide to Developing Community Connections. This guide includes several tools that can help you get started in your journey to becoming a community builder.

Community Membership Means Fully Utilizing Community Generic Resources
Supported living services have an obligation to facilitate the individuals they support so they can fully utilize the community resources that are available in the community to other citizens. A generic resource is a service that is available to anyone. These services are a part of the public service system found in any community. Some of the generic resources like Section 8 Rental Housing Assistance and In-Home Supportive Services make living in the community more affordable for people on a limited income. Everyone who receives supported living should have someone within the supported living agency, usually their Community Support Facilitator, help them access and fully utilize the resources that are available to them. Part Three of this Toolbox includes a section on Generic Resources. If you are hired to help people use community resources you may find this section of the Toolbox extremely helpful.

Things To Learn About Your Agency
Supported living agencies work creatively and purposefully to help people become valued members of their communities. You can learn about your agency’s work by asking the staff who work there to share stories about the individuals they support and how these individuals are involved in their communities.
Part Two: Principles of Supported Living Services

- Does your agency have a data base or listing of community places, groups, clubs, organizations and community activities that people may want to participate in?

- Do all of the staff help support people to become active in the community or does your agency have special staff who have this role? For example, in some agencies they have identified one or a few staff who are considered community builders or bridge builders.

- What kind of transportation is available to individuals who want to be active in the community? Are there any limitations? For example, certain days or times of day when transportation is not available? Do staff transport individuals when public transportation is not available?

- How are individuals supported to attend clubs, churches, or activities during a time of day that staff may not usually work?

- What community connections do the staff, volunteers and Board members have that could be useful for helping individuals make connections.

Summary
Supporting individuals to be active, valued members of the community means more than just helping someone go to the bank or grocery store. It means helping them find their place or places in the community where they have the opportunity to become a valued member and make a contribution. It means we don't just drop them off and pick them up or just help them make the arrangements to go somewhere. It means that we find out what it would take for them to be a valued member and then we do what it takes to facilitate the process. The stories of community building shared by Sharon Gretz in this section illustrate how this process can work. The tools in Part Four, Section 4 can help you get started. It is as much a science (meaning we can find some order and explanation for it) as it is an art.
Building Your Toolbox: Community Membership
For More Information and Resources

The Art of Welcoming
This booklet focuses on ways that community groups can extend themselves to potential new members so that newcomers feel welcomed, comfortable, and valued as important to the group.

A Guide to Developing Community Connections
compiled by Patsy Davies and Claudia Bolton, 1996, CIRCL, Connections for Information and Resources on Community Living. (530) 644-6653. Included in Part Three of this Toolbox.

Crossing the River: Creating a Conceptual Revolution in Community and Disability

Who Cares, Rediscovering Community
A wonderfully engaging book that emphasizes finding humane responses to developmentally and physically disabled individuals that are community driven rather than solely reliant on problem-solution oriented social service organizations.

What About IHSS
by Adult and Supported Living Services Section (1995), Department of Developmental Services, 1600 Sacramento, CA, 95814.

Supplemental Security Income: Questions and Answers for Persons Residing in Supported Living Arrangements
by Adult and Supported Living Services Section (1996), Department of Developmental Services, 1600 Sacramento, CA, 95814.

IHSS Fair Hearing and Self Assessment Packet
by Protection and Advocacy Incorporated, 100 Howe Avenue, Suite 185 North, Sacramento, CA 95825-8282
5. Flexible, Tailored Services and Supports

Introduction
Supported living is a unique service because it offers a full array of services and supports that are designed individually for each person so they can live the life they want and be healthy and safe in their own home. Each person’s service plan and pattern of support is developed through a person centered planning process. The services are based on what the individual needs and wants and the services and supports continue as long as the individual wants and needs them. This sounds pretty simple but it is made complex because every individual is unique and the services are individualized for them. It is like developing a new service or program every time a new person is referred for services.

5. Flexible, Tailored Services and Supports

- Individual Service Plans are developed through a person-centered planning process.
- Service plans reflect the support that each individual wants and needs and plans change as wants and needs change.
- Individuals have opportunities to increase their abilities, confidence and quality of life and support to maintain an adequate level of health and safety.

Getting to Know the Person and Planning for Services
Supported living agencies use a person centered assessment process to get to know the person who is referred for services. They may use a process similar to Essential Lifestyle Planning or Getting to Know You (Part Four, Section 6). They want to discover:

1. What is important to the person in their everyday life.
2. What people, places, activities and things are important.
3. What routines and rituals are important.

4. What the person can do for themselves and what they will need support to do.

5. How the person would like support provided (i.e., time of day, qualities of staff, frequency, order to doing things).

6. The kinds of support the person will need to stay safe and healthy.

7. How the person communicates their needs and desires.

8. What the agency and others will need to know and do to help the individual live in a way that makes sense for them.

This assessment process is done initially to help develop a support plan but the learning and discovery process continues throughout the relationship between the agency and the individual.
**Individual Service Plan**

After the SLS agency has spent a good amount of time (maybe a few or more months) getting to know the person (doing an assessment), the individual, their family and friends, their regional center service coordinator and the agency come together and develop the Individual Service Plan. Support plans quite typically offer a wide range of services and supports based on individual wants and needs.

The Individual Service Plan is expected to change over time as the individual’s needs and desires change. The service plan and services and supports always remain responsive to the individual. As stated earlier, the individual continues to live in his or her own home (if so desired) as their needs change. Here is a list of the kinds of services that can be provided:

| Supportive Living Services Include, But are Not Limited to . .  
(California Department of Developmental Services, 1992) |
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<tr>
<td>financial management</td>
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<td>purchasing activities</td>
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<td>correspondence with official agencies</td>
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<td>cooking</td>
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<td>menu planning</td>
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<td>home and community safety</td>
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<td>household care and maintenance</td>
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<tr>
<td>eating, bathing, dressing, grooming, hire &amp; supervision</td>
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<td>orientation to the community</td>
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<td>mobility training</td>
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<td>access to leisure activities</td>
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<td>cultivating and maintaining friendship</td>
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<td>interpersonal communication skills</td>
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<td>self-advocacy</td>
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<td>parenting skills</td>
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<td>training in the selection and use of assistive technology</td>
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<td>repair &amp; maintenance of assistive technology</td>
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<td>vehicle modification</td>
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<td>interpreters or translators</td>
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<td>facilitating circles of support</td>
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<td>check cashing</td>
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<td>budgeting and bill paying</td>
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<td>meal preparation</td>
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<td>shopping</td>
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<td>personal health and hygiene</td>
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<td>general household activities</td>
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<td>activities essential to health</td>
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<td>assistance with the medical care of children</td>
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<td>obtaining police, fire, or emergency help</td>
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<td>community resource awareness and assistance</td>
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<td>identification of and access to points of interest</td>
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<td>care and repair of durable medical equipment</td>
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<td>use of leisure time</td>
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<td>participation in community recreation</td>
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<td>adaptive social skills</td>
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<tr>
<td>support for marital and sexual relationships</td>
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<td>24-hour emergency assistance services</td>
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<tr>
<td>crafting of unique technology and equipment</td>
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<td>communication devices</td>
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<td>home modifications</td>
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<tr>
<td>canine and other animal companions</td>
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<td>securing suitable housing</td>
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Flexible, Tailored Services: New Patterns of Staffing, New Job Positions, and New Wage and Labor Laws

Supported living agencies organize themselves in a number of ways to provide responsive services. SLS staff must be willing to step into many different roles and do many different kinds of jobs. For example, a staff person may be teaching the individual budgeting at the bank (the role of a teacher) and then provide the physical assistance the individual needs to use the restroom (the role of a personal assistant or an attendant). SLS agencies typically believe that everyone who works for the agency should be able and willing to provide a variety of kinds of services and support.

SLS agencies may employ people to work either full or part time. They may employ people in traditional or in non-traditional ways such as a paid neighbor (e.g., to be on-call overnight) or a paid community member (e.g., to assist with building community connections). They may also employ someone to live with the individual as a companion or they may employ (or help the individual employ through IHSS), staff who support the individual overnight.

Organizing the personnel resources of a SLS agency is not an easy job. SLS agencies must become familiar with the federal and state wage and labor laws that apply to the variety of jobs (e.g., companion, personal attendant, paid roommate) they develop. Agencies continually strive to organize the agency to be responsive to each individual’s pattern of support, stay within the wage and labor laws, and provide the most cost-effective services possible.

Personal Support Services

Personal Support Services are one type of supported living service that can be provided to do the things for an individual that they can not do for themselves because of the nature of their disability. These services should always be provided in the way the individual receiving the service wants. Even individuals who communicate with no or very little language or who use their behavior to communicate have preferences over when and how personal support is provided. This makes it critical...
that the SLS agency know the person’s preferences, routines and rituals in order to provide respectful services. Many kinds of assessments and planning processes will help the agency gather this information. Getting to Know You, in Part Four (Section 6), is one tool that may be helpful.

Personal Support Services are not only funded by the Regional Center through SLS, but they are also funded through the county In Home Support Service, IHSS, program. Supported living personal assistance services do not take the place of IHSS, but fill in with the services and hours that IHSS does not include. Some individuals need more hours of personal assistance services than IHSS will fund. Also, some individuals need on-call support to help them when a regularly scheduled IHSS employee does not show up. Supported living agencies can also assist individuals to hire and supervise their IHSS personal attendants. The IHSS program is discussed in Part Three, Generic Resources.

**Responsive Services**

Supported living agencies provide scheduled, agreed upon services, during the time of day and the day of the week that makes sense for the individual. The individual is not fit into the staff’s schedule; rather the staff person schedules him or herself according to the individual’s schedule and pattern of life or routines. Again, the importance of knowing the individuals preferences, routines and rituals is critical for building a support pattern.

In addition to providing scheduled services, supported living agencies also assist each individual (as needed) to develop a 24 hour emergency response system. For some, this may involve calling on family or friends in a non life-threatening emergency. Other times, this may mean calling a crisis line. While others may call someone who is paid by the SLS agency to be on-call.

The reasons that individuals need on-call support vary. Some need back-up support if a personal support assistant does not show up. Others need emotional support, crisis prevention support or someone with whom to talk. Supported living agencies may use pagers, cell
phones, a 24-hour answering service or a combination of technology all arranged so that someone is always on-call.

**Developing A Pattern of Support**

Developing a pattern of service with someone who uses supported living services is as easy and as difficult as:

- getting to know someone;
- figuring out their support needs and desires;
- assisting them in locating and securing a home;
- assisting in developing formal and informal support;
- and, supporting them in getting connected to their community.

Here is an example of how someone put everything together to develop a pattern of support for Sharon. We're presenting Sharon's story because it offers many challenges.

**Getting to Know Sharon**

When Sharon decided she wanted to leave the institution, she told everyone. She also told us all that she did not want to live in a group home and that she wanted to live in a place that was accessible so her friend Karen could live with her. Sharon had many challenging behaviors (like hitting and scratching herself and pulling her hair out of her head) and was on high doses of medication.

At one time, we would have looked at Sharon's record to find out more about her, but it only told us about the things she couldn't do. To find out about things that Sharon could do, we starting spending time with her (like having a meal together and going someplace we knew Sharon liked). Sharon also let us talk to people who she knows and trusts. They were able to tell us about more things that she could do.

We found out lots of things and not just the usual things that you
A Preferred Lifestyle

Get to Know Someone

Figure Out a Pattern of Support

Recruit and Hire

Use Generic Services

Learning through Person-Centered Planning (ELP, PATH, TRACS, Personal Profile)

ISP, Schedules, IHSS, Family and Friend Support

Home Adaptations, Equipment, Section 8, IHSS

Job Announcement, Job Descriptions, Contracts, Job Duty Lists, Roommate Agreements

Personal Assistance, Facilitation/Instruction, Emergency Assistance, Community Support, Family and Friends
find out from doing some sort of assessment. For example, we found out that Sharon was bothered a lot by the violence that she always saw on the evening news. (In time, she joined a local peace organization to help "end violence in the world.")

**Figuring Out Support Needs and Desires**
We started by finding out what kinds of support that Sharon was used to getting and whether it suited Sharon or not. Our goal was to figure out what would be the ideal support. For example, since Sharon couldn't see, we knew we would have to figure out a lot of adaptations for her. We also knew we would have to support her in learning a lot of things to keep up her home, like vacuuming. Sharon was taking medication for her challenging behavior and she had asked if we could support her in taking less of it.

**Assisting in Locating and Securing a Home**
Since her good friend Karen had decided to live with her boyfriend, Sharon needed to find another roommate. After spending time with Sharon, we knew that she wanted a friendly neighborhood with a bus stop, close to the people she knew and close to downtown so she could walk. So, Sharon and a support person found four neighborhoods that met that description and walked them all to find just the right one. We eventually helped her complete a lease for a two-bedroom house (with a roommate she selected through an ad in the paper) in a neighborhood she had identified as being just right.

**Developing Formal and Informal Support**
After we had learned about Sharon's support needs, we worked with her to write up a job guide that would help her hire just the right support person. It took a while, but she finally found the right person and hired her. Since Sharon could read Braille, we helped by making Braille tags for things so she could find her way around the house a lot quicker. We also helped Sharon set up a back-up plan if her support helper couldn't be around. Her roommate works
a lot, but between her and a neighbor and our agency support staff, we figured out a good plan.

**Getting Connected to the Community**
Sharon told us that she liked horses and had always wanted to ride. It just so happened that one of her support helpers knew someone with a horse ranch a short distance out of town. After a few visits, the horse owner invited her to ride any time she wanted as long as she could bring someone to help her saddle up and to ride with her. We helped Sharon put a notice on the bulletin board of the health club that she had joined and soon enough she got several responses from people who saw a chance to ride and enjoy the country.

After some time in her new house, Sharon's circle of friends began to grow. It included: friends from the health club; people she knew at the local Federation for the Blind; the woman who owned the horse ranch; people in the peace movement; her old friend Karen; support helpers; and her roommate. Once in a while, she invites everyone to her house to celebrate life and help her figure out new ways to build community connections and to support her in reaching some of her dreams.
Things To Find Out About Your Agency

Individualized Service Planning
Supported living agencies use holistic person-centered planning processes to get to know people referred for services. They also use futures planning processes to assist people to clarify their hopes and dreams for their futures.

• How does your agency get to know people (assess their needs and desires)?

• How does your agency help people plan for their futures?

Individualized patterns of support
Supported living agencies are creative and flexible when they are designing job descriptions, wages and benefits for their staff.

• How does your agency schedule staff so that individuals receive the services during the time of day and in the location that makes sense for the individual?

• How does your agency assist individuals to use IHSS? How will you help them recruit, screen, hire, train and supervise?

Full array of services

• If your agency currently provides instructional services like independent living services: How does your agency support people who are not able to learn to do a skill and instead need someone to do it for them?

• How does your agency support individuals with special needs like individuals who need assistance with parenting or individuals who need personal assistance services?
Responsive Services

- How does your agency organize the staff to be responsive during unusual working times? (e.g., evenings, overnight, weekends, holidays)?

- How does your agency organize agency staff and resources so that the agency can be responsive if someone needs unplanned, unscheduled help in a hurry? For example what kind of on-call system is set up? How will on-call staff or others be reached when they are not in the office or it is after office hours?

Summary

Supported living agencies are unique in their ability to provide individually tailored services and supports to meet the needs of individuals with developmental disabilities who want to live in a home of their own. Services are developed for each person after an extensive process of getting to know them and designing a pattern of support. This kind of service flexibility and responsiveness requires that the agency hire staff who are creative, good problem solvers, team players and great communicators. Most important is the agency’s and the staff’s ability to listen respectfully to the individuals they support and then honor the individual’s unique needs and desires to live a life of their own.

The tools in Part Four, Section 6 can help the agency get to know the individual and develop a person-centered plan for support. In addition, it is highly recommended that staff receive formal training in person centered planning. Most nationally recognized trainers of person-centered planning require that planners complete a plan on themselves before they plan with other people. To get started, you may want to look at the person-centered planning tools in this toolbox and begin to complete the process on yourself. It can be a revealing and healthy process.
The Many Roles of a Supported Living Service Provider

As a supported living service provider, you will play a number of roles in your work. Here's a brief outline of those roles:

**Advocate**

As an advocate, you will help represent the best interests of the individual you support. You will also need to provide the assistance and information needed for individuals and families to represent themselves and to take action when needed.

**Problem Solver**

As a problem solver, you will need to use a common sense approach to identify and resolve barriers to individual service needs and lifestyle preferences.

**Teacher**

As a teacher, you will be providing instructional support to individuals who want to learn new skills that reflect their preferences and needs.

**Community Organizer/Resource Developer**

As a community organizer and resource developer, you will be constantly on the lookout for new opportunities for the individuals you support in the community and helping develop them when they are not available.

**Facilitator**

As a facilitator for the individuals you support, you will provide assistance to them so they can understand and communicate with others in their home and in the community. Your facilitation may help the individual participate on a Board of Directors or be an active member in a club, group or organization. Your responsibility is to help the individual move into a position where they are a full or at least an active participant. You will have to practice the skills of listening, communicating, interpreting, keeping your opinion to yourself and assisting the individual to make their own decisions.

Adapted from Learn the Basics, Learn the Process, Apply What You Learn: Service Coordination Orientation and Training Curriculum (1999). Developed for the Southern California Training and Information Group. See the Reference Section for a full citation.
Part Two: Principles of Supported Living Services

Friend/Companion

As a friend and companion you may be the one who is with the individual when they celebrate the good times and when they grieve their personal hardships. You may be the one to hang in there with them when other people may abandon them. You are an anchor sticking with them and helping them see their way through rough storms. You may develop a friendship that extends beyond the paid services you provide to them. You may become part of their family and they may become part of yours. As someone who is “on their side” you may be their voice when they do not express their preferences or needs.

Personal Assistant

As a personal assistant you may assist the individual to do the things that they cannot do without assistance because of their disability. This can range from helping them with personal care like getting dressed to doing their housework or balancing their checkbook. This will require that you listen carefully to what the individual needs to have you do and that you find out how they like to have things done (i.e., if you are helping them eat; do they like to eat one food type at a time or do they like their food mixed together? If you are helping them bathe; do they like to wash their hair before or after they wash their body?).
**Team Leader**

If you are in the role of coordinating services for individuals who receive services you are not only a team member but also a team leader. You may be responsible for assisting the individual you support to pull together their family, friends and other agencies for several purposes (e.g., problem solving, resource development, celebrating). You may facilitate formal “circle meetings” or you may collaborate with the individual and their family and friends informally outside of meetings. You may play a lead role in making sure that everyone is working together as a team to support the individual’s needs and preferences. You may also be a team leader within the agency mentoring new staff or providing supervision and support.

**Record Keeper**

As a record keeper, you will document many things about the services that are provided and about how the individual is doing. You may have to keep a record of your time and the kinds of services you provide. You may also have to document information about the individual’s health and appointments they have outside of the agency (i.e., Doctor appointments). If you are in a coordinating role you may have to write progress reports and service planning reports. Record keeping, while the least favorite of most people’s jobs, is an important activity. You will need to write clear, concise and accurate records in a timely manner.
Building Your Toolbox: Flexible, Tailored Services and Supports

For More Information and Resources

**A Workbook for Your Personal Passport**
by Allen, Shea & Associates (1996) with special thanks to: Patsy Davies, Claudia Bolton, Mark Rice and Steve Sweet

This workbook is for people with developmental disabilities and their friends and families who want to learn more about person-centered planning. It also provides an easy way to work on a first plan.

**All My Life's A Circle**
**Using the Tools: Circles, MAPS & PATHS**
This booklet (1994) was written by Mary Falvey, Marsha Forest, Jack Pearpoint, and Richard Rosenberg.

It's all you wanted to know about how these three powerful processes work. Available from Inclusion Press International, 24 Thome Crescent, Toronto, ON, Canada M6H 2S5, tel: (416) 658-5363, fax: (416) 658-5067, e-mail: includer@idirect.com, CompuServe: 74640,1124.

**Developing First Plans! A Guide to Developing Essential Lifestyle Plans**
by Michael Smull & Bill Allen; Self-Published (1999)

Essential lifestyle planning is one form of person centered planning. It is a way to learn how what is important to each person in everyday life. This manual is intended for use by those who have completed training in how to develop plans. It is **not** a substitute for training and should not be used without training. For more information about training, visit [www.allenshea.com](http://www.allenshea.com) and click on M. Smull and Friends.
It's Never Too Early, It's Never too Late!
by Beth Mount and Kay Zwernik (1988) from the Governor's Planning Council on Developmental Disabilities

The goals of personal futures planning are to help someone develop a picture of what the future will look like for him or her, to build a circle of people who will help support that picture or plan and to take some first steps. For more information on how to use personal futures planning, you can get a copy of this booklet from the Governor's Planning Council on Developmental Disabilities, 300 Centennial Building, 658 Cedar Street, St. Paul, Minnesota 55155, tel: (612) 296-4018, fax (612) 297-7200.


In this resource guide, you will find some general information about: the basic concepts of individual-centered planning; an example of the process from information gathering to plan development; ideas about facilitating a planning team; additional resources you can purchase which will provide more information about planning in this way; some brief articles about planning in different service environments; and several checklists to help you look at your planning process.

My Life Planner; Letting Go; Dream Deck
by Emilee Curtis and Milly Dezelsky (1993)

My Life Planner and Letting Go (1993) provide a variety of activities to assist people with developmental disabilities and family members in planning for the future and figuring out more about their preferred lifestyles, interests and preferences. Dream Deck (1993) is a visual approach to finding out more about preferred activities and interests. For information on purchasing these and other great documents, contact New Hats, Inc., P.O. Box 57567, Salt Lake City, Utah 84157-7567
References


Department of Developmental Services through a contract with CIRCL.

Patterns of Supported Living, A Resource Catalogue (1993)

Department of Developmental Services through contract with Allen, Shea & Associates.


Developed for the Department of Education and the Regional Occupational Centers and Programs in partnership with the Department of Developmental Services by Allen, Shea & Associates.
Supported Living Services
Your SLS Training Tool Box

Part Three: Information Briefs

Connections for Information and Resources on Community Living (CIRCL)

April, 2001
Supported Living Services
Training Tool Box

General Information
for SLS Staff

Developed for

Connections for Information and Resources
on Community Living (CIRCL)
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April, 2001

through a contract with the
Department of Developmental Services

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Introduction

The material in Part Three was excerpted and adapted primarily from:

*Year 1, Direct Support Professional Training Resource Guide (1999).*
Developed by the Department of Education and the Regional Occupational Centers and Programs in partnership with the Department of Developmental Services.

Overview of Developmental Disabilities
Information Brief

Developmental Disabilities*

What is a Developmental Disability?

According to a California law called the Lanterman Developmental Disabilities Services Act, a developmental disability:

• begins before someone reaches 18 years of age;

• is something that goes on throughout a person’s life;

• is a substantial disability for the individual; and

• often means there is a need for some kind of assistance in daily living.

Included are mental retardation, cerebral palsy, epilepsy and autism. Also included are people who need the same kinds of support as those who have mental retardation. It does not include people who have only physical, learning or mental health challenges.

What Causes a Developmental Disability?

A number of things can cause a developmental disability:

• **Before birth causes**
  For example, the mother has a serious illness, has poor eating habits, poor health care, smokes, drinks alcohol or uses drugs. Developmental disabilities can also be caused by things that are inherited or by chemical or chromosome differences (like Down Syndrome).

• **During birth causes**
  For example, a lack of oxygen to the brain, low weight, or a difficult birth.

• **After birth causes**
  For example, serious accidents, abuse, lead poisoning, or poor nutrition.

Often the cause is not known. A developmental disability can happen in any family.

What Are the Major Kinds of Developmental Disabilities?

The following are the major kinds of developmental disabilities:

**Mental Retardation**
The legal definition has to do with how an individual scores on an intelligence test and how intelligence affects a person's ability to do certain things. However, it is easier to explain that people with mental retardation are likely to:

- learn more slowly;
- have a hard time remembering things that are learned;
- have a hard time using what is learned in a new situation;
- think about things in more real-life or concrete ways; and
- keep learning and developing throughout life like all of us.

There are different levels of mental retardation from mild to moderate to severe. This means that people need different types of assistance in daily living.

Mental retardation is very different from mental illness. Some people who have mental retardation also have mental illness, but most people who have mental illness do not have mental retardation.
Cerebral Palsy
Cerebral palsy is a condition caused by damage to the brain which often happens before, during or shortly after birth. "Cerebral" refers to the brain, and "palsy" to a condition which affects physical movement. As with mental retardation, this condition can range from mild to severe. People with cerebral palsy may have:

- awkward or involuntary movements
- poor balance
- unusual walk
- poor motor coordination
- speech difficulties

Cerebral palsy is not a disease and you can't catch it. While it doesn't usually get worse, people can lead more independent lives through physical therapy and the use of special devices (for example, computers, and wheelchairs). Individuals with cerebral palsy may also have mental retardation and/or epilepsy.

Autism
Autism affects people in many different ways. The causes are not very well understood. Some people who have autism also have mental retardation. People with autism may:

- have a hard time making friends;
- get happy or upset about things that don't make sense;
- have a difficult time communicating with other people;
- hurt themselves; and
- want to stick to a certain way of doing things and get upset if things get changed around

Epilepsy
Epilepsy is a physical condition that occurs when there is a sudden, brief change in how the brain works. When brain cells are not working well, a person may become unconscious, or his/her movement, or actions may be very changed for a short time. These changes are called epileptic seizures. Epilepsy is sometimes called a seizure disorder. Individuals with epilepsy may also have mental retardation, cerebral palsy or autism.

Other
Includes people who need the same kinds of support as those who have mental retardation. It does not include people who have only physical, learning or mental health challenges. Examples are conditions like Neurofibromatosis, Tuberous Sclerosis and Prader-Willi Syndrome.

What is a Developmental Delay?
A developmental delay is a very large difference between a young child’s (up to 36 months of age) abilities and what is usually expected of children of the same age. Infants and toddlers who have a developmental delay can receive early intervention services. These services support the child in learning the things that will help him/her start to catch up.
A Guide to Talking and Writing about People with Disabilities - People First*

In talking and writing about people with disabilities, remember it’s people first, the disability comes second. The subtle difference between calling Joe “a person with mental retardation” rather than a mentally retarded person is one which acknowledges Joe as a person first.

AVOID:

- victim
- invalid
- crippled
- afflicted with
- suffers from
- DDs
- TMRs
- EMRs
- confined to a wheelchair
- mongoloid
- the retarded
- the handicapped
- mentally deficient
- patient

USE:

- individual with a developmental disability
- individual with a seizure disorder
- individual with cognitive disabilities
- a person who is non-ambulatory
- individual with Down Syndrome
- individual
- person
- participant
- worker
- student

* Adapted from Put in a Good Word for Me, North Los Angeles County Regional Center.
Learning the Language

→ Speak of the person first, then the disability,

→ Emphasize abilities, not limitations. “For example, he uses a wheelchair” or “she walks with crutches.”

→ Understand that although a disability may have been caused by a disease, the disability itself is not a disease and is not contagious

→ Don’t label people as part of a disability group—say ‘people with disabilities’ not ‘the disabled.’

→ Don’t patronize or give excessive praise or attention.

→ Don’t say, “Isn’t it wonderful how he has overcome his disability?” People live with a disability—they have to overcome attitudinal, social, architectural education, transportation and employment barriers—not the disability,

→ Be aware that choice and independence are important. Ask a person with a disability if s/he wants assistance before you help. Your help may not be wanted or needed.

→ Treat adults with disabilities as adults. Call the person by his or her first name only when extending that familiarity to all others present. Make eye contact and speak directly to the person, not a companion or interpreter. Do not give the person a nickname s/he does not usually use, say “Bill” not “Billy.”

→ Be aware of the distinction between disability and handicap. A disability is a functional limitation that interferes with a person’s ability to walk, hear, talk, learn, etc. A handicap is a physical or attitudinal constraint that is imposed upon a person. Use handicap to describe a situation or barrier imposed by society, the environment or oneself.

→ Be considerate of the extra time it might take for a person to get things said or done.

• from Community Interface Services, San Diego, CA (Through a PDF Grant from San Diego Regional Center).
YOU… and I
By Elaine Popovich

I am a “resident”. You reside.

I am admitted. You move in.

I have “behavior problems”. You are rude.

I am ‘non-compliant”. You don’t like being told what to do.

When I ask you out to dinner, it’s an “outing”. When you ask someone out, it’s a date.

I don’t know how many people have read the progress notes people write about me. I don’t even know what’s in there. You didn’t speak to your best friend for a month after she read your journal.

I make mistakes during my check-writing program. Someday I might get a bank account. You forgot to record some withdrawals from your account, and the bank called to remind you.

I wanted to talk with the nice-looking person behind us at the grocery store. I was told that it was “inappropriate” to talk to strangers. You and your spouse met each other for the first time in the produce department when you helped him find bean sprouts.

I celebrated my birthday yesterday with five other “residents” and two staff members. I hope my family sends a card. Your family threw you a surprise party. It sounded wonderful.

My case manager sends a report every month to my guardian informing her of everything I did wrong and some of the things I did right. You’re still mad at your sister for telling your mom about the speeding ticket you got.

I’m on a special diet because I’m five pounds over my ideal body weight. Your doctor gave up on your weight loss program.

I’m learning household skills. You don’t do housework because you hate it.

I’m learning leisure skills. You call yourself a couch potato.

After I do my budget program tonight, I get to go to McDonald’s if I have enough money. You use your charge card at the new French restaurant.

My case manager, RN, OT, PT, nutritionist and house staff set goals for me for the next year. You haven’t decided what you want out of life.

Someday I’ll be discharged… if I’m lucky. You will move upward and onward on your career path.
History of the Service System and Supported Living Services
Information Brief

A Brief History of Developmental Disabilities Services

Three Major Changes

There have been three major changes in how citizens in general have thought about people with developmental disabilities. These views have changed the way that services for individuals and families are provided:

1. **Taken Care Of.** Up until the 1960s, citizens thought that individuals with developmental disabilities should be taken care of and that this could be best accomplished in an institution away from the community.

2. **Education and Training.** From the mid-1960s to the mid-1980s, citizens began to see that individuals with developmental disabilities could grow and learn through education and training. During these years, special schools, training programs and group homes were developed in large numbers in communities throughout the United States.

3. **Community Members.** From the mid-1980s to the present, citizens began to see individuals with developmental disabilities as their neighbors, co-workers, friends and fellow community members. Now the focus is on providing the services that individuals and families need and want in the communities of their choice.

These major changes in the attitudes of citizens as well as in the way services are provided were largely due to: (1) the public education efforts of the families of individuals with developmental disabilities; (2) changes in the national and state laws; and (3) individuals with developmental disabilities speaking up for themselves.

**In California**

In California, institutions were the primary way that people with developmental disabilities were served through the mid-1960s. In fact, there was a demand for building more institutions. However, a study by the California Legislature showed that not everyone needed institutional services and that the cost of building more would be very high.

This study encouraged the Legislature to look for alternatives. In 1966, the Legislature funded two pilot regional centers. Their focus was on supporting individuals in their home communities as an alternative to living in a state institution. Those first two regional centers were so successful, the Legislature funded a total of twenty-one as well as a system of community-based services.

In 1972, the Legislature expanded the law to include people with mental retardation, cerebral palsy, epilepsy, autism, and other neurological problems under the term developmental disability. The law that created the service system for individuals with developmental disabilities is called the Lanterman Act.
Paradigm Shifts in Developmental Disabilities Services*

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* Adapted from Harbor Regional Center
Information Brief

The Values of Developmental Disabilities Services in California*

Services for people with developmental disabilities in California are based on an important set of values. These values can be found in the Lanterman Developmental Disabilities Services Act (the Lanterman Act). This is the piece of legislation that helped start our current statewide system of services back in the 1970s. It begins by mentioning that a vision for the future of California is one where individuals with developmental disabilities can participate in everyday life with their friends, neighbors and co-workers.

It also mentions that services for people with developmental disabilities are based on the values of choice, relationships, regular lifestyles, health and well-being, rights and responsibilities, and satisfaction. Below is a brief description of those values.

Here is what California law (the Lanterman Act) says about the value of **choice**:

- services and supports should be based on the individual and his/her needs and preferences;
- individuals (with help from parents, legal guardians or conservators when needed) should take part in decisions about their own lives (like where and with whom they live, their relationships with others, the way in which they spend their time and setting goals for the future);
- people need to have a chance to practice making decisions and choices;
- an individual’s choice (or parents, conservator or guardian where support is needed) of service providers should be honored; and
- services and supports should change based on the changing needs or preferences of an individual.

Here is what California law says about the value of **relationships**:

- people with developmental disabilities have the right to develop relationships, marry, be part of a family and to be a parent if they choose;
- support may be needed to develop intimate relationships (like transportation, family counseling or training in human development and sexuality);
- support may be needed to help people start and keep relationships with friends and other community members.

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*Adapted from *Looking at Life Quality*, Department of Developmental Services (1996).
Here’s what California law says about the value of **regular lifestyles**:

- people should have a chance to be involved in the life of their community in the same ways as their neighbors, friends and fellow community members;
- services should be provided whenever possible in the home and community settings where people live and work;
- cultural preferences should be honored;
- individuals should have the training needed to be as independent and productive as possible;
- when an individual’s needs change, services should be changed as well to make sure that people can stay living where they choose to live;
- people should be comfortable where they live, have privacy when they need it and should have a say in the way their living space is decorated and arranged; and
- there should be services and supports which would allow minors with developmental disabilities to live with their families whenever possible.

Here’s what California law says about the value of **health and well-being**:

- people have a right to be free from harm and to live a healthy lifestyle;
- individuals should have a chance to learn how to keep themselves safe or have services and supports which will provide safety;
- individual’s have a right to quick medical, mental and dental care and treatment when they need it; and
- people should have a chance to learn how to keep themselves healthy or have services and supports which will keep him/her healthy.

Here’s what California law says about the value of **rights and responsibilities**:

- people with developmental disabilities have the same basic legal rights as other citizens;
- individuals with developmental disabilities have a right to treatment and habilitation, dignity, privacy, and humane care, prompt medical care and treatment, religious freedom, social interaction, physical exercise and to be free from harm;
- people have the right to make choices in their own lives, such as where to live, who to live with, who to have relationships with, education and employment, leisure and planning for the future;
- along with all of these rights are responsibilities, such as respecting the privacy of others, and being an informed voter; and
- individuals should have a chance to learn about their rights and responsibilities and how to advocate for themselves.

Here’s what California law says about the value of **satisfaction**:

- individuals should have a chance to plan goals for the future and to work towards them;
- individuals should be satisfied with the services and supports they receive and should have a chance to change them when they are not satisfied; and
- people should have a chance to have a good quality life.
Agencies that Are Part of the Developmental Disabilities Service System
In California, many services for people with (or ‘at risk’ of) a developmental disability are coordinated through a network of twenty-one, non-profit regional centers established by the Lanterman Act. If a person is eligible, regional centers provide planning and related services including service coordination. Service coordinators help individuals and families with information, guidance, and assistance in accessing and using appropriate generic services and natural supports.

If the service is related to the person’s developmental disability and is included on the Individual Program Plan (the IPP is developed by an individual and his/her planning team. It states the goals that an individual is trying to achieve and the services and supports needed to reach those goals), a regional center may purchase the service from an approved service provider. Here are some typical services provided through a regional center:

- **Advocacy** – assisting individuals to get needed services from community and government agencies;

- **Assessment and consultation** – gathering information about individual service needs and supports;

- **Positive Behavior Support** – classes and individual consultation around positive behavior supports;

- **Early intervention programs** – for children not yet in public school; includes neighborhood preschools, and infant development programs with involvement by parents and other specialists;

- **Independent/Supported living** – services and supports for adults to live more independently in their own homes;

- **Medical** – identifying and accessing needed health services, typically (but not always) paid for by private insurance or government health care programs (for example, county hospitals; Medi-Cal fee-for-service; EPSDT; CCS; etc.);

- **Residential** – licensed or certified residential options including long-term health care facilities, foster family homes, community care homes and family home agencies;

- **Respite Care** – added help for the family in order to provide a break from care-giving responsibilities (may involve nursing or positive behavior support as needed);
Part Three: Information Briefs

- Social/Recreational – locating a variety of social/recreational activities through various community organizations;

- Therapy and Counseling – referral to various therapists and public or private mental health agencies; and

- Vocational – assistance in accessing a variety of work-related services and supports that include job placement, job coaching, training for employment, sheltered work and pre-vocational programs, some of which are funded by regional centers, others of which are funded through the Department of Rehabilitation.

In addition to the aforementioned responsibilities, the Lanterman Act requires that the Regional Centers be accountable for the monies received to provide services and supports for individuals. The Regional Center is required to:

- Live within a budget each year.

- Locate and/or develop innovative and cost-effective ways to achieve the desired outcomes for individuals.

- Secure services from qualified service providers and only continue those services where there is reasonable progress and agreement.

- Take into account parental responsibility for minor individuals when making a decision about the purchase of a service or support (this is also known as share of cost).

- Fund only for those services and supports which are required for the individual and that are above what a parent would provide for a child without a disability.

- Pursue all possible sources of funding before accessing Regional Center funds (Regional Centers are considered to be the payer of last resort).

- Ensure that the Regional Center does not pay for services and supports which should be provided by a generic agency such as the Department of Education, Medi-Cal and Social Security.

- Ensure that community service providers provide good quality services for a fair price (services must be cost effective).
Information Brief
Other Agencies Established by the Lanterman Act

In addition to Regional Centers, the Lanterman Act established the agencies necessary to fund and monitor the developmental service system.

**Department of Developmental Services.** The Department of Developmental Services (DDS) is the department in the California Health and Welfare Agency which has the responsibility of providing statewide policy direction and leadership to ensure that persons with developmental disabilities shall have the opportunity to lead more independent, productive and satisfying lives as envisioned by the Lanterman Act.

In order for the State of California to carry out many of its responsibilities to persons with developmental disabilities, the state, through DDS, contracts with Regional Centers to provide the service coordination necessary to obtain the services and supports best suited to each individual.

**Vendor or Service Provider Agencies.** Vendor or service provider agencies are those agencies which have been vendorized by the Regional Center to provide specific developmental services (e.g., supported living, day or residential services, respite). Vendorization is the process that an agency must complete in order to receive state funds for services. It also ensures that the provider has met all Title 17 requirements. The application requirements are different for each type of service (e.g., qualifications of staff). The Regional Center approves or disapproves the vendor application. The rates for some categories of service are established by the Department of Developmental Services while others are determined by the Regional Center.

**State Council on Developmental Disabilities.** The State Council on Developmental Disabilities is a federally mandated and funded organization charged with promoting the development of an individual and family centered, comprehensive system of services and supports for individuals with developmental disabilities. The goals are to enable individuals to achieve independence, productivity and integration and inclusion into the community.
A key responsibility of the Council is to formulate the State Plan that establishes goals and objectives for improving and enhancing the service system in California. To ensure that local needs and priorities are being addressed, the Council funds the thirteen (13) regional Area Boards on Developmental Disabilities.

**Area Boards.** Because of the vast size, complexity and diversity of the State of California, Area Boards were established to ensure that the legal, civil and service rights of persons with developmental disabilities are adequately guaranteed. Area Boards work within their specific geographic region to accomplish the same goals as the State Council.

**Protection & Advocacy, Inc. (PAI)**
Provides a variety of advocacy services for people with disabilities, their families and advocates. These services include: information about legal rights, referral to other advocacy services, technical assistance, advocacy training and, direct representation in administrative hearings and in court.
The following are the major state agencies in the developmental disabilities services system in the State of California:

**Health and Human Services Agency**
The umbrella agency for the Departments of Social Services, Health Services, Developmental Services, Mental Health and Rehabilitation.

**Department of Social Services (DSS)**
The Community Care Licensing Division licenses homes for children and adults with developmental disabilities.

**Department of Health Services (DHS)**
Administers the Medi-Cal program that pays for health care. Also, licenses and monitors homes for people with developmental disabilities and significant health needs.

**Department of Developmental Services (DDS)**
Contracts with 21 Regional Centers to provide services to children and adults with developmental disabilities including service coordination and funding of services which cannot be provided by generic, community agencies. DDS is also responsible for managing the state developmental centers.

**Department of Mental Health**
Oversees county mental health services.

**Department of Rehabilitation (DR)**
Furnishes funding for Work Activity Programs (WAP) which included work support services in sheltered and community-based employment settings.

**Department of Education (DOE)**
Manages special education programs in public school system. Special Education Local Planning Agencies (SELPA)
Determine own structures to provide programs to students.

**Local School Districts**
Provide classes and training to children with disabilities.

**State Council on Developmental Disabilities (SCDD)**
Develops a state plan which looks at the future of developmental disabilities services; reviews and comments on budgets and regulations of state agencies which provide services to people with developmental disabilities; and funds the Area Boards.

**Protection and Advocacy (PAI)**
Protects the civil and service rights of Californians with developmental disabilities through legal advocacy.

**Area Boards**
Protects the rights of Californians with developmental disabilities through public information, education, monitoring policies and practices of publicly funded agencies.

**Organization of Area Boards (OAB)**
Coordinates and supports the activities of local Area Boards.
Information Brief
Regional Center Locations

Alta California Regional Center
2135 Butano Drive
Sacramento, CA 95825
Phone: (916) 978-6400 Fax: (916) 489-1033
Areas served by the regional center: Colusa, Placer, El Dorado, Alpine, Sierra, Nevada, Sacramento, Yuba, Yolo and Sutter Counties.

Central Valley Regional Center
5168 North Blythe
Fresno, CA 93722
Phone: (559) 276-4300 Fax: (559) 276-4450
Areas served by the regional center: Merced, Mariposa, Madera, Fresno, Kings and Tulare Counties.

Eastern Los Angeles Regional Center
1000 S. Fremont Avenue
P.O. Box 7916
Alhambra, CA 91802-7916
Phone: (626) 299-4700 Fax: (626) 281-1163
Areas served by the regional center: East Los Angeles, Northeast Los Angeles, Whittier District, Alhambra District.

Far Northern Regional Center
1900 Churn Creek Road, #319
P.O. Box 492418
Redding, CA 96002
Phone: (530) 222-4791 Fax: (530) 222-6063
Areas served by the regional center: Butte, Glenn, Shasta, Siskiyou, Tehama, Modoc, Plumas, Lassen and Trinity Counties.

Golden Gate Regional Center
120 Howard Street, Third Floor
San Francisco, CA 94105
Phone: (415) 546-9222 Fax: (415) 546-9203
Areas served by the regional center: San Mateo, Marin and San Francisco Counties.

Harbor Regional Center
21231 Hawthorne Blvd.
Torrance, CA 90503
Phone: (310) 540-1711 Fax: (310) 540-9538
Areas served by the regional center: Bellflower, Harbor, Long Beach and Torrance Health Districts.

Inland Regional Center
674 Brier Drive
P.O. Box 6217
San Bernardino, CA 92412-6217
Phone: (909) 890-3000 Fax: (909) 890-3001
Areas served by the regional center: Riverside and San Bernardino Counties.

Kern Regional Center
3200 North Sillect Avenue
Bakersfield, CA 93308
Phone: (661) 327-8531 Fax: (661) 324-5060
Areas served by the regional center: Kern, Inyo and Mono Counties.

Lanterman Regional Center
3440 Wilshire Blvd., Suite 400
Los Angeles, CA 90010
Phone: (213) 383-1300 Fax: (213) 383-6526
Areas served by the regional center: Pasadena, Hollywood, Wilshire, Central Los Angeles, Glendale/Foothill.

North Bay Regional Center
10 Executive Court, Suite A
P.O. Box 3360
Napa, CA 94558
Phone: (707) 256-1100 Fax: (707) 256-1112
Areas served by the regional center: Napa, Sonoma and Solano Counties.
North Los Angeles County Regional Center
15400 Sherman Way, Suite 300
Van Nuys, CA 91406
Phone: (818) 778-1900 Fax: (818) 756-6140
Areas served by the regional center: San Fernando, Antelope, Santa Clarita, Conejo Valleys.

Redwood Coast Regional Center
808 E Street
Eureka, CA 95501
Phone: (707) 445-0893 Fax: (707) 444-3409
Areas served by the regional center: Humboldt, Del Norte, Mendocino and Lake Counties.

Regional Center of the East Bay
7677 Oakport Street, Suite 1200
Oakland, CA 94621
Phone: (510) 383-1200 Fax: (510) 633-5020
Areas served by the regional center: Alameda and Contra Costa Counties.

Regional Center of Orange County
801 Civic Center Drive West
P.O. Box 22010
Santa Ana, CA 92702-2010
Phone: (714) 796-5222 Fax: (714) 547-4365
Area served by the regional center: Orange County.

San Andreas Regional Center
300 Orchard City Drive, Suite 170
Campbell, CA 95008
Phone: (408) 374-9960 Fax: (408) 376-0586
Areas served by the regional center: San Benito, Monterey, Santa Clara and Santa Cruz Counties.

San Diego Regional Center
4355 Ruffin Road
San Diego, CA 92123
Phone: (619) 576-2996 Fax: (619) 576-2873
Areas Served by the regional center: San Diego and Imperial Counties.

San Gabriel/Pomona Regional Center
761 Corporate Center Drive
Pomona, CA 91768
Phone: (909) 620-7722 Fax: (909) 622-5123
Areas served by the regional center: San Gabriel, Pomona, Monrovia, Glendora and El Monte.

South Central Los Angeles Regional Center
2160 West Adams Blvd.
Los Angeles, CA 90018
Phone: (323) 734-1884 Fax: (323) 730-2286
Areas served by the regional center: Compton, San Antonio, South Los Angeles, Southeast Los Angeles and Southwest Los Angeles Health Districts.

Tri-Counties Regional Center
520 East Montecito Street
Santa Barbara, CA 93013
Phone: (805) 962-7881 Fax: (805) 966-5935
Areas served by the regional center: Ventura, Santa Barbara and San Luis Obispo.

Valley Mountain Regional Center
7109 Danny Drive
P.O. Box 692290
Stockton, CA 95269-2290
Phone: (209) 473-0951 Fax: (209) 473-0256
Areas served by the regional center: Amador, Calaveras, San Joaquin, Stanislaus and Tuolumne.

Westside Regional Center
5901 Green Valley Circle, Third Floor
Culver City, CA 90230
Phone: (310) 337-1155 Fax: (310) 649-2033
Areas served by the regional center: Inglewood and Santa Monica West Health Districts.
### Information Brief

#### Area Board Locations

<table>
<thead>
<tr>
<th>Area Board I</th>
<th>Area Board VII</th>
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<tbody>
<tr>
<td>Del Norte, Humboldt, Lake, Mendocino</td>
<td>Monterey, San Benito, Santa Cruz, Santa Clara</td>
</tr>
<tr>
<td>P.O. Box 245</td>
<td>359 Northlake Drive</td>
</tr>
<tr>
<td>Ukiah, CA 95482</td>
<td>San Jose, CA 95117-1261</td>
</tr>
<tr>
<td>(707) 463-4700  Fax: (707) 463-4752</td>
<td>(408) 246-4355  Fax: (408) 246-6658</td>
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<table>
<thead>
<tr>
<th>Area Board II</th>
<th>Area Board VIII</th>
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<tbody>
<tr>
<td>Butte, Shasta, Glenn, Siskiyou, Lassen, Tehama, Plumas, Modoc, Trinity</td>
<td>Mariposa, Madera, Merced, Fresno, Kings, Tulare, Kern</td>
</tr>
<tr>
<td>1367 E. Lassen Ave., #B3</td>
<td>770 East Shaw Ave., Suite 123</td>
</tr>
<tr>
<td>Chico, CA 95926</td>
<td>Fresno, CA 93710</td>
</tr>
<tr>
<td>(530) 895-4027  Fax: (530) 899-1562</td>
<td>(559) 222-2496  Fax: (559) 248-2886</td>
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<tr>
<th>Area Board III</th>
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<tbody>
<tr>
<td>Alpine, Sacramento, Colusa, El Dorado, Sutter, Nevada, Yolo, Placer, Yuba, Sierra</td>
<td>San Luis Obispo, Santa Barbara, Ventura</td>
</tr>
<tr>
<td>1010 Hurley Way, Ste. 195</td>
<td>7127 Hollister Ave., Ste 22</td>
</tr>
<tr>
<td>Sacramento, CA 95825</td>
<td>Goleta, CA 93117</td>
</tr>
<tr>
<td>(916) 263-1150  Fax: (916) 263-1155</td>
<td>(805) 685-8395  Fax: (805) 685-4896</td>
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<tr>
<th>Area Board IV</th>
<th>Area Board X</th>
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<tr>
<td>Napa, Solano, Sonoma</td>
<td>Los Angeles</td>
</tr>
<tr>
<td>236 Georgia St., Suite 201</td>
<td>411 North Central Ave., Suite 620</td>
</tr>
<tr>
<td>Vallejo, CA 94590</td>
<td>Glendale, CA 91203-2020</td>
</tr>
<tr>
<td>(707) 648-4073  Fax: (707) 648-4100</td>
<td>(818) 543-4631  Fax: (818) 543-4635</td>
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<tr>
<th>Area Board V</th>
<th>Area Board XI</th>
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</thead>
<tbody>
<tr>
<td>Alameda, Contra Costa, Marin, San Francisco, San Mateo</td>
<td>Orange</td>
</tr>
<tr>
<td>360 22nd Street, Ste 730</td>
<td>250 S. El Camino Real, Ste 110</td>
</tr>
<tr>
<td>Oakland, CA 94612</td>
<td>Tustin, CA 92680</td>
</tr>
<tr>
<td>(510) 286-0439  Fax: (510) 286-4397</td>
<td>(714) 731-4787  Fax: (714) 573-1839</td>
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<tr>
<th>Area Board VI</th>
<th>Area Board XII</th>
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<tbody>
<tr>
<td>Amador, Calaveras, Tuolumne, San Joaquin, Stanislaus</td>
<td>Inyo, Mono, Riverside, San Bernardino</td>
</tr>
<tr>
<td>250 Cherry Lane, Ste 113</td>
<td>1960 Chicago Ave., Ste E8</td>
</tr>
<tr>
<td>Manteca, CA 95336</td>
<td>Riverside, CA 92507</td>
</tr>
<tr>
<td>(209) 239-6700  Fax: (209) 239-3081</td>
<td>(909) 782-3226  Fax: (909) 781-0896</td>
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<tr>
<th>Area Board VII</th>
<th>Area Board XIII</th>
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<tbody>
<tr>
<td></td>
<td>San Diego, Imperial</td>
</tr>
<tr>
<td></td>
<td>4711 Viewridge Ave., Suite 160</td>
</tr>
<tr>
<td></td>
<td>San Diego, CA 92123</td>
</tr>
<tr>
<td></td>
<td>(619) 637-5563  Fax: (619) 637-5572</td>
</tr>
</tbody>
</table>
Information Brief
Protection and Advocacy, Inc.
Locations and Contact Numbers

- E-mail: legalmail@pai-ca.org
- Toll Free - Legal Offices/TDD - - 1-800-7765746
- Toll Free - Office of Patients’ Rights - - 1-800-254-5166
- Administrative Office, 100 Howe Avenue, Suite 185-N, Sacramento, CA 95825 (916) 488-9955
- Sacramento Legal Office, 100 Howe Avenue, Suite 235-N, Sacramento, CA 95825 (916) 488-9950
- Southern California Legal Office, 3580 Wilshire Blvd., Suite 902, Los Angeles, CA 90010 (213) 427-8747
- Bay Area Legal Office, 449 15th Street, Suite 401, Oakland, CA 94612 (510) 839-0811
- Office of Patients’ Rights, 100 Howe Avenue, Suite 240-N, Sacramento, CA 95825 (916) 575-1610
Individual Rights, Laws and Regulations
Information Brief

Basic Rights

Constitutional Rights

Individuals with developmental disabilities have the same rights as everyone else under the Constitution of the United States and the California Constitution. Those rights include:

- Freedom of Speech
- Right to Due Process
- Freedom of Religion
- Freedom of Association
- Freedom of Assembly
- Equal Protection of the Law
- Right to Privacy

In addition, the United States and California governments have passed statutes, which set out particular rights for individuals who have developmental disabilities.

Citizens of the State of California

In California, the Lanterman Act spells out these rights:

- A right to treatment and habilitation services and supports.
- A right to dignity, privacy and humane care.
- A right to participate in an appropriate program of publicly supported education.
- A right to prompt medical care and treatment.
- A right to religious freedom and practice.
- A right to social interaction and participation in community activities.
- A right to physical exercise and recreational opportunities.
- A right to be free from harm.
- A right to be free from hazardous procedures.
- A right to make choices including, but not limited to, where and with whom to live; relationships with people in their community; the way they spend their time, including education, employment and leisure; the pursuit of their personal future; and program planning and implementation.
- A right to have relationships, marry, be part of a family and to parent if they so choose.

Denial of Rights

Most individual rights may not be denied for any reason. A few rights may be denied for a limited period of time and under a very narrow set of circumstances called the Denial of Rights Procedure. These rights may be denied only when certain conditions are documented and the denial is approved by the regional center.
Information Brief

Rights of Individuals Receiving Supported Living Services

The Lanterman Act and the SLS regulations state that individuals receiving SLS shall have the right to make decisions that shape the nature and quality of their lives. Individuals in SLS have the following rights:

To choose where they live.

To choose who they live with, if anyone.

To control the environment (character and appearance) within their own home.

To receive services and supports that change as their needs change without having to move elsewhere.

To choose and change their SLS vendors and direct service staff.

To receive services based on their needs and preferences.

To receive services and supports that assist them to exercise choice in his or her life while building critical and durable relationships with other individuals.

Throughout this toolbox on supported living services you will learn more about how these rights are implemented in supported living services.
What is the Individual Complaint Process?

The Individual Complaint Process permits each individual or any representative acting on their behalf, to pursue a complaint either against the regional center, developmental center or a service provider.

If I Believe My Rights Have Been Violated To Whom Do I Complain?
Your complaint should be made to the clients' rights advocate assigned to the regional center from which you receive case management. (You can phone 1-800-390-7032.)

How is This Different from Fair Hearing?
A Fair Hearing is a procedure for resolving disagreements between the regional center and individuals or applicants. It may be used to appeal the nature, scope or amount of services. The disagreements may be about services, an eligibility decision or any action concerning services and supports of the regional center with which you disagree. Contact your clients' rights advocate if you need information regarding this process.

Individual Complaint Process
The complaint may be about any right to which the individual is entitled which the individual or their representative believes has been violated, punitively withheld, or improperly or unreasonably denied.

What Will the Client's Rights Advocate Do?
Within ten working days of receiving your complaint, the client's rights advocate should investigate and send you a written proposed resolution.

What if I am not Satisfied with the Decision of the Clients' Rights Advocate?
If you are dissatisfied with the action taken or proposed, the clients' rights advocate shall, within five working days, refer you to the regional center or developmental center director.

What Will the Regional Center Director Do About My Complaint?
The Regional Center Director shall receive and seek to resolve second level complaints within ten working days.

What if I am not Satisfied with the Decision of the Regional Center Director?
If you are not satisfied with the decision made by the regional center director you must notify the regional center director. Within ten working days of receipt of your notification, the regional center director shall refer the complaint to the director of the department. The director of the department shall, within 45 days of receiving the complaint, issue a written administrative decision to the regional center and send a copy to you.

How Will I know What to do if My Rights have been Denied?
All individuals, or where appropriate, their parents, legal guardian, conservator, or authorized representative shall be notified in writing in a language which they comprehend, of the right to file a complaint when they apply for services from a regional center or at each regularly scheduled planning meeting.
Information Brief

Appealing Regional Center Decisions

The Regional Center is frequently in a position to approve and authorize services and supports (unless provided by a generic service agency). However, there will be times when a request from an individual or family is not approved. If an individual or family decides to appeal a decision, the service coordinator is required to send a notice of action which includes information on appeals and fair hearings and advocacy resources. The individual or family is given information on how to present their appeal so that a fair decision can be made.

Here is a summary of the general procedures that both the Regional Center and the applicant [for services] or recipient [of services] or an authorized representative must follow in the appeal of a decision:

1. Any time the Regional Center proposes certain actions without the mutual consent of the applicant [for services] or recipient [of services] or an authorized representative, the Center must send a notice of action. Those actions requiring a notice are:
   - To reduce, terminate or change services that are included in the IPP;
   - To determine that a recipient is no longer eligible for services;
   - To deny initiation of a service or support requested for inclusion in the IPP; or
   - To deny eligibility to an applicant.

2. If the Regional Center proposes to reduce, terminate or change services that are included in the IPP, the Center must send the recipient [of services] the notice 30 days prior to the proposed action. If the Regional Center determines that someone is no longer eligible for services, the Center must send the recipient [of services] the notice within 30 days of the proposed action. Anytime a service is requested and the Regional Center makes a decision to deny that request, the Center must within 5 days send out a written notice with a reason for denying that service.

3. As a result of that notice, a fair hearing may be requested by any applicant or recipient of services or authorized representative who disagrees with the decision made by the Regional Center. The individual must initiate the request for a fair hearing within 30 days of the receipt of the notice. If an individual is currently receiving service from the Regional Center and he/she wishes to continue receiving the service while appealing a decision, he/she must notify the Center of this desire by filing a request for a fair hearing within 10 days from the receipt of the notice.

   If an individual is not currently receiving service, he/she does not have a right to receive the requested service during the appeal process.
A fair hearing may also be requested for any other action or proposed action which the individual believes to be illegal, discriminatory or not in the best interest of the recipient or applicant.

4. A request for a hearing or mediation must be on a form supplied by the Regional Center. If a Regional Center employee receives a verbal request for a fair hearing that employee must provide the recipient, applicant or authorized representative (claimant) with a hearing request form. If the individual requests assistance the service coordinator must assist in filling out the form.

5. Immediately upon receiving a Fair Hearing Request form, the Regional Center Director or his/her designee, shall offer in writing to meet informally with the claimant or his/her authorized representative within 10 days of the date the hearing request form is postmarked or received by the Regional Center, whichever is earlier. Notification that the claimant or his/her authorized representative may decline an informal meeting must be provided at the time the offer is made. At this time, the claimant may proceed to either mediation or directly to fair hearing.

6. If the claimant or his/her authorized representative accepts the opportunity for an informal meeting and is satisfied with the decision of the Regional Center following the meeting, he/she shall submit to the Regional Center a completed Fair Hearing Request Withdrawal form, withdrawing the request for a fair hearing.

7. If the claimant or his/her authorized representative has declined an informal meeting or is dissatisfied with the decision following the informal meeting, the matter shall proceed to either mediation or a fair hearing.

8. If the claimant or his/her authorized representative has elected to pursue mediation, the Regional Center must either accept or decline the mediation within 5 days of receipt of the written request from the claimant or his/her authorized representative. The mediation must be held within 20 days of the date the request form is postmarked or received by the regional center, whichever is earlier. If the issue or issues involved in the mediation are resolved to the satisfaction of both parties, the mediator shall prepare a written resolution. Agreement of the claimant or his/her authorized representative to the final solution shall be accompanied by a withdrawal, in writing, of the fair hearing request. If there is no resolution, the matter shall proceed to fair hearing.

9. If dissatisfied with the decision of the informal meeting or a resolution through mediation cannot be made or mediation is waived, the individual may request a fair hearing with the California Department of Developmental Services. To request a state level fair hearing, the individual completes the bottom-
portion of the hearing request form and returns it within ten (10) days to the Regional Center. The Regional Center will send the hearing request to the State Department of Developmental Services.

10. The individual or another person selected by the individual (an attorney, advocate, or friend) will be expected to present the case at the hearing. This is an administrative hearing at which the technical rules of evidence need not be applied. The hearing must convene within fifty (50) days from the date it was first requested, unless either party requests a continuance for good cause. The hearing officer will hear evidence from both parties and will issue a written decision deciding the case within ten (10) days (and no more than 80 days from the date of initial request). The hearing officer's decision is the final administrative decision and is binding on both parties. Any final administrative decision may be appealed to a court of competent jurisdiction within ninety (90) days. A appeal to a court, however, will not stay enforcement of the administrative order. If the subject of the appeal was a termination of service and the decision is unfavorable for the claimant (individual or family), the service will be terminated ten (10) days after the notice is received by certified mail.

11. If the services in dispute were funded through a Medi-Cal waiver, the Department of Health Services will review the hearing officer's decision and either adopt or modify it.

12. If the reason that the service is to be modified is lack of available funds the Regional Center will request that the Department of Developmental Services provide funding.

13. Individual rights in the fair hearing include the following:

   a. The opportunity to be present in all proceedings and to present written evidence and oral evidence.

   b. The opportunity to confront and cross-examine witnesses.

   c. The right to appear in person with counsel or other representative of his/her own choosing.

   d. The right to access records.

   e. The right to an interpreter.
People First Statement of Rights and Responsibilities

We are PEOPLE FIRST. Our disabilities are a normal part of life. As American citizens, we have the same rights and must meet the same responsibilities as anyone. We’re entitled to the support we need to do that.

Rights

To live like normal people.
To have the relationships we choose.
To have the medical care we need.
To learn all we can.
To control our lives, take risks and make choices.
To come and go as we want.
To be free and not in state hospitals.
To have wishes and dreams.
To be respected as equals.
To have and express our own feelings and opinions - and to be heard and taken seriously.
To be free to ask for what we want.
To stand up for ourselves to people, agencies and the government.
To live free from abuse.
To work.
To have fun.
To get information from professionals.
To have privacy.

Responsibilities

To not harm ourselves or others.
To treat others as equals and with respect.
To take care of our health and to ask for help if we need it.
To use what we learn.
To be responsible for the consequences of our own actions.
To be dependable and let people know where we are.
To accept other places to live, and not act out on other people.
To believe in ourselves, keep control and not get mad at ourselves.
To act like an equal.
To find out what’s right for us and speak up in whatever way we can.
To ask when we want something from someone.
To be strong, face our fears and ask for help when we need it.
To tell if someone is harming us.
To do the job right.
To not hurt anyone in the process.
To think about the information we get.
To ask for a place away from people.

If you have questions or want more information, contact:
CALIFORNIA PEOPLE FIRST, P.O. BOX 3969, Chico, CA 95927
Information Brief

Advocacy

**Advocacy is:**
- Helping people help themselves
- Building self confidence
- Supporting independence
- Telling people their rights
- Telling people their options
- Providing assistance and training
- Helping locate services
- Asking people what they want
- Treating adults like adults

**Advocacy is not:**
- Taking over a person's life
- Making a person dependent
- Doing everything for a person
- Not informing a person of his/her rights
- Making decisions for people
- Controlling people
- Treating adults like children
- Limiting options
- Knowing what is best because you are a professional
- Not respecting choices
Introduction

In addition to the Lanterman Act (see Information Brief The Values of the Developmental Disabilities Services System), there are a number of state and federal laws and regulations that will affect your job as a service provider.

The Americans with Disabilities Act (ADA)

In July 1990, Congress passed the Americans with Disabilities Act, a landmark civil rights bill that extends protection against discrimination to people with disabilities. The ADA defines disability as a mental or physical condition that limits a “major life activity” such as walking, hearing, seeing or working, covering some 900 disabilities. It requires public facilities, transportation and communication services to be accessible to people with disabilities. The bill addresses four main areas:

Employment:

• Employers may not discriminate against persons with disabilities in hiring or promotion if the individual is otherwise qualified for the job.

• Employers can ask about one’s ability to perform a job, but cannot inquire if someone has a disability or subject a person to tests that tend to screen out people with disabilities which are not job related.

• Employers must make “reasonable accommodations” for workers with disabilities, including job restructuring and modification of equipment. Employers do not need to provide accommodations that impose an “undue hardship on business operations.”

Public Facilities

• Private businesses such as restaurants, hotels, theaters and stores must not discriminate against individuals with disabilities.

• Auxiliary aids and services must be provided to individuals with vision or hearing impairments or other individuals with disabilities, unless an undue burden would result.

• Physical barriers in existing facilities must be removed, if removal is readily achievable. If not, alternative methods of providing the services must be offered, if they are readily achievable.
Part Three: Information Briefs

- All new construction and alterations of facilities must be accessible.

Transportation

- New public buses and rail cars ordered after August 26, 1990, must be accessible to persons in wheelchairs.

- At least one rail car per train must be accessible to wheelchairs.

- Transit authorities must provide comparable paratransit or other special transportation services to individuals with disabilities who cannot use fixed route bus services, unless an undue burden would result.

- New bus and train stations must be accessible.

- Key stations in rapid, light, and commuter rail systems must be made accessible by July 26, 1993, with extensions up to 20 years for commuter rail (30 years for rapid and light rail).

- All existing Amtrak stations must be accessible by July 26, 2010.

Communication

- Companies offering telephone service to the general public must offer telephone relay services to individuals who use telecommunication devices for the deaf (TDD) or similar devices.

ADA covers state and local governments

- State and local governments may not discriminate against qualified individuals with disabilities.

- All government facilities, services and communications must be accessible consistent with the requirements of Section 504 of The Rehabilitation Act of 1973.

- Public entities, including schools, must make reasonable modifications to its policies, practices or procedures to avoid discrimination, unless such a modification would fundamentally alter the nature of its service, program or activity and would create undue financial and administrative burdens.

- Alterations to existing facilities will be required if the modification is "readily achievable." If physical modification is not readily achievable, then an alternative accommodation must be found. Some examples of facility modification are: van accessible parking, elevated walkways, lowered drinking fountains, adjusted shelves and storage areas, volume controls on telephones, installation of bathroom stalls and replacement of carpeting.

- Title I of ADA is modeled after those rights and privileges existing under Section 504.
• Individuals with disabilities enrolled in public schools may not be discriminated against in participating in school functions (such as field trips, recreational offerings, or athletic events.)

• Private schools are expected to provide reasonable accommodations and equal treatment for individuals with disabilities.

Rehabilitation Act of 1973, Section 504 (PL 93-112)

This law is known as the first federal civil rights law protecting the rights of people with disabilities. It states that no qualified handicapped individual...shall, solely by reason of the handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Discrimination is prohibited in the following areas:

(1) Education

(2) Vocational education

(3) College programs

(4) Employment

(5) Health, social service programs, welfare

(6) Programs funded with federal dollars

All public education programs are covered by section 504. Students with disabilities must have the same options as others about courses, and colleges and universities must also make reasonable modifications in requirements when necessary to insure full opportunity for students with disabilities.

Section 504 also prohibits discrimination in employment. Equal employment opportunities for qualified people with disabilities must be assured by organizations receiving federal funds.

In 1992, the Rehabilitation Act was amended to authorize rehabilitation services to help people with physical and mental disabilities to become gainfully employed. These services include vocational evaluation, counseling, supported employment, work adjustment and education.

Title 17, California Code of Regulations

Title 17 regulations are developed by the California Department of Developmental Services and are based on the Lanterman Act. These regulations (specifically Chapter 3 – Community Services) govern how services are delivered within the California developmental services system.

Starting with Section 50201, Title 17 covers parental fees, conflict of interest code, rules for conducting research, client rights, fiscal audits and appeals, fair hearings, vendorization procedures, Regional Center administrative practices and procedures, standards and rate-setting procedures for community-based programs and in-home respite services and residential facility care and services.
Information Brief

Protection from Abuse

Introduction
There is a special concern for the abuse of children, dependent adults and the elderly. As they are more vulnerable than others, such individuals face greater risk of abuse. It's important to know your responsibilities should you need to make a report.

**Dependent adult abuse** is defined as physical abuse, neglect, financial abuse, abandonment, isolation, abduction or other treatment with resulting physical harm of pain or mental suffering or the deprivation by a care provider of goods and services which are necessary to avoid physical harm or mental suffering. **Child abuse** is defined as physical injury which is inflicted by other than accidental means on a child by another person, sexual abuse, willful cruelty or unjustifiable punishment of a child, unlawful corporal punishment or injury and neglect.

Protection Against Abuse
You can help protect individuals from abuse through:

**Observation** - pay attention to the individuals you support. Some may not be able to tell you with words when something is wrong.

**Communication** - talk with and listen to the individuals you support.

**Conversation** - talk with others who know and care about the individuals you support.

**Documentation** - write down what you see and hear.

**Review** - your notes and conversations to look for any possible patterns.

**Report** - if abuse is known or suspected.

Reporting Requirements for Adult Abuse
A **dependent adult** is any California resident 18 to 64 years of age, who has physical or mental limitations which restrict his or her ability to carry out normal activities or to protect his or her rights, including, but not limited to, persons who have physical or developmental disabilities or whose physical or mental abilities have diminished because of age. Included is any person 18-64 years of age, regardless of physical or mental condition, who is admitted as an inpatient to a 24-hour health facility. An **elder** is anyone residing in California, who is 65 years of age or older, whether or not impaired mentally or physically.

California law requires that any person who provides care or services for elders or dependent adults (whether or not the person receives compensation) must report certain kinds of abuse.
Mandatory Reporting

Any employee of a supported living agency is considered a mandated reporter with a legal duty to report suspicion or knowledge of child, dependent adult or elder abuse. Failure to report can result in a mandated reporter being held liable for both criminal and civil consequences. Conversely, the mandated reporter has complete immunity from legal actions even if the report turns out to be false.

All allegations of abuse shall be reported by telephone as soon as possible to either Child Protective Services, Adult Protective Services or the Ombudsman's office depending upon the age of the victim and the location of the alleged abuse. If the victim is a child, the report will be made to Child Protective Services with a written follow up report to be submitted within 36 hours. If the victim is an adult and the abuse occurred in a long term care facility, the alleged abuse is reported to the Ombudsman's office. If the alleged abuse occurred at any other location, the report is made to Adult Protective Services. The telephone report concerning an adult shall be followed up with a written report within two working days.

Ombudsman Office
Department of Aging

Each county is required to have an office devoted to the Ombudsman. This office receives reports of abuse to dependent adults if the abuse occurs in any long-term facility (nursing homes, residential facilities, foster homes or any licensed or unlicensed residential facility providing care and supervision).

Adult Protective Services
California Department of Social Services

Each county is required to have an office devoted to Adult Protective Services. This office receives reports of abuse to dependent adults. Each report is assigned to a case worker for investigation, assessment and referral to appropriate agencies. The law requires mandated reporters to make a verbal report immediately, followed by a written report within two working days. When the suspected victim resides in their own home and receives SLS, the abuse should be reported to the county Adult Protective Services Agency. If the abuse occurs in any long-term care facility (nursing homes, residential facilities, foster homes, or any licensed or unlicensed facility providing care and supervision), it must be reported to the local ombudsman program.
Elder and Dependent Adult Abuse
(excerpted from Los Angeles Infoline)

Quick Checklist. When an elderly person or dependent adult is being abused, neglected or exploited, prioritize for safety:

1. Is the person being injured or otherwise endangered at that moment? If YES, call the police or paramedics.
2. Is the suspected abuse occurring in a residential facility or adult day health center? If YES, report to the local Long Term Care Ombudsman.
3. Is the abuse occurring outside of a residential facility (e.g., a person living in his or her own home)? If YES, report to Adult Protective Services.

Definitions. Listed below are possible indicators of abuse (adapted from guidelines developed by Adult Protective Services):

Physical Abuse: Pushing, shoving, shaking, slapping, beating or unreasonable restraint. 
Indicators: unexplained bruises, welts or burns; friction marks; bleeding scalp; detached retina; unset broken bones or other untreated injuries; any repeated injuries. Frequent emergency room visits. Frequent changes of doctors. Conflicting or implausible explanations of injuries.

Neglect: Failure to provide basic needs such as food, shelter, or medical treatment, or abandonment.
Indicators: dehydration or malnourishment; untreated bed sores; medication withheld or improperly self-administered; poor personal hygiene; soiled clothing or bedding left unchanged; keeping appliances the person needs such as bedside commode or walker out of reach; lack of clothing or other necessities; inadequate heat or ventilation; safety hazards in home.

Psychological Abuse: Verbal threats or insults, or other intimidating behavior.
Indicators: caregiver accuses the abused person of being incontinent on purpose; threatens him with placement in a nursing home.

Financial Exploitation: Mismanagement of money; theft of property.
Indicators: missing property; unpaid bills or rent; lack of clothing or other basics; unexplained bank account or auto-teller withdrawals; unexpected changes in wills or titles to property; adult’s money not being spent on clothes or other basics needs.

Other Indicators of Abuse: Abused adult is kept isolated from family or friends and not allowed to speak for himself. Caregiver resists assistance from social service agencies. Caregiver has a history of abusing others. Caregiver appears angry at elder or dependent adult. A abused person may appear fearful, withdrawn, depressed or confused (and these conditions are not caused by mental dysfunction).
Information Brief

About Special Incident Reports*

Special incident reports are made by an SLS agency to the Regional Center when certain things occur. Some incidents just happen (like earthquakes) and some may mean that the service system needs to help an individual develop better or provide different supports. Regional Centers need to know about both of these kinds of things so that they can help the individual and the SLS agency make sure that people get the supports they need to live safely and happily on their own.

Under California state law, SLS agencies are required to let their Regional Center know when certain things occur. These things are:

- A denial of rights
- Any form of abuse
- Things that happen which may lead to criminal charges or legal action
- Serious bodily injury, serious physical harm or death
- Any time someone has to physically help someone to not hurt themselves or someone else by using emergency intervention procedures allowed by law.
- Poisonings
- Epidemic outbreaks
- Catastrophes
- Fires or explosions

The SLS agency must call the Service Coordinator at the Regional Center as soon as one or more of these things have happened, and must write a special incident report and send it to the Service Coordinator or a person designated by their regional center within one day (24 hours). The SLS agency may also have to report the incident to other people or agencies, for example, Adult Protective Services. Supported living agencies are required to train their staff in Special Incident Reporting Procedures. Also, each regional center has the responsibility of informing the supported living agency about reporting procedures and appropriate forms to use.

* Adapted from CHOICESS Supported Living Agency, Arcadia, CA.
Information Brief

Confidentiality

Introduction

Confidentiality can be a professionally and legally complex issue. Treating information confidentially means not releasing it to anyone outside the SLS agency without the express consent of the individual, a guardian (typically a parent of a child under the age of 18) or a conservator (a person appointed by a court to legally represent an adult). Under certain circumstances, information may be released without permission. The main exception to confidentiality rules arise in situations involving child or adult abuse, court orders or subpoena of records or danger to self or others. This section will explore some of the confidentiality requirements.

The Law

The Lanterman Act, specifically section 4514 (Welfare and Institutions Code), specifies that all information and records obtained in the course of providing intake, assessment and services to persons with developmental disabilities shall be confidential. Information shall be disclosed in the following situations:

a. In communications between qualified professionals employed by a Regional Center or state developmental center. Consent of the individual, parent, guardian or conservator is required before information or records can be disclosed by someone NOT employed by Regional Center, State Developmental Center or a program not vendored by either.

b. When a person with a developmental disability who has the capacity to give informed consent designates individuals to whom information may be released, a physician, psychologist, social worker, marriage, family and child counselor, nurse, attorney, or other professional may not be compelled to release information given them in confidence unless a valid release has been signed.

c. For a claim to be made on behalf of a person with a developmental disability for aid, insurance, government benefit, or medical assistance.

d. If the person, guardian or conservator designates in writing persons to whom records or information may be disclosed. Again, certain professionals may require a valid release.

e. For research, if reviewed and approved by the Director of Developmental Services. All researchers must sign an oath of confidentiality.
f. To courts, for the administration of justice.

g. To governmental law enforcement agencies for the protection of federal and state elective constitutional officers and their families.

h. To the Senate or Assembly Rules Committee for the purposes of legislative investigation.

i. To the courts as part of a Regional Center report.

j. To the attorney for the person with a developmental disability upon presentation of a release of information signed by the person. The Regional Center shall release all information for the person who lacks the capacity to give informed consent. Again, professionals may require a valid release.

k. To a probation officer who is evaluating a person after conviction of a crime if the Regional Center determines that the information is relevant to the evaluation. The confidential information remains confidential except for the purposes of sentencing. After sentencing, the confidential information is sealed.

l. Between people on the “multidisciplinary” teams dealing with prevention, identification, management or treatment of an abused child or parents.

m. When a person with a developmental disability dies while hospitalized in a state developmental center, the information related to the diagnosis and treatment of the person’s physical condition is released to the coroner.

n. To authorized licensing personnel or authorized representatives from Department of Health Services or Department of Social Services to perform their duties regarding facilities. Names which are confidential are listed in attachments which are kept separate from the other material. Representatives from these agencies typically identify people by numbers in facilities.

o. To a board that licenses and certifies professionals if there is cause to believe that a violation of law has occurred. Confidential information shall not contain the name of the person with the developmental disability.

p. To governmental law enforcement agencies when a person with a developmental disability is reported lost or missing or if there is cause to believe that a person with a developmental disability has committed or been the victim of a crime.

q. To the Youth Authority or Adult Correction Agency.

r. To an agency mandated to investigate a report of abuse.
In the event that a person, parent, guardian or conservator does not grant or denies a request to release information within a reasonable period of time, an agency may release information if the information is deemed necessary to protect the person’s health, safety or welfare. The person must have been advised annually in writing about the policies for releasing information. That policy statement can become part of the person’s IPP to comply with the notice requirement.
Information Brief

Parents and Others as Legally Authorized Representatives

There are some terms you need to know in order to understand the rights and responsibilities of parents and other legally authorized representatives.

**Competence**

Competence (or incompetence) is about the ability of an individual to make decisions. Until a person reaches the age of majority (age 18 in California), he/she is presumed to be incompetent. That is, not able to manage alone or to come to reasoned decisions about certain important matters. Upon reaching the age of majority, even if the person has a significant intellectual impairment, he/she is presumed to be competent.

**Parents**

Parents are considered natural guardians of their biological or adopted children and have certain rights and responsibilities in making decisions on behalf of their children.

**Guardianship**

Some minors need a court-appointed guardian if parents have died, abandoned a child, or had their parental rights removed by a court of law. The issues surrounding guardianship are few, precisely because the law presumes incompetence. Since 1981, guardianships have only been available for minors.

**Conservatorship**

A conservatorship is a legal arrangement in which a competent adult oversees the personal care or financial matters of another adult considered incapable of managing alone. Some parents incorrectly presume (as was traditional years ago) that as natural guardians of children their legal responsibilities continue for a child with a developmental disability if he/she has “not grown up and left the nest.”

**General conservatorship**

This is the conventional kind of conservatorship for adults unable to meet their own needs or manage their own affairs.

**Limited conservatorship**

The purpose of limited conservatorship is to protect adults with developmental disabilities from harm or exploitation while allowing for the development of maximum self-reliance. If granted by the court, the limited conservator can have decision-making authority (or be denied authority) in as many as seven areas:

1. To fix the person’s place of residence.
2. Access to confidential records and papers.
3. To consent or withhold consent to marriage.
4. The right to contract.
5. The power to give or withhold medical consent.
6. Decisions regarding social and sexual contacts and relations.
7. Decisions concerning education or training.

**Short of a special court order,** the limited conservator **may not**, however, provide substitute consent in the areas of:

2. Electroshock therapy.
3. Placement in a locked facility.
4. Sterilization.

The **limited conservator** should have:

1. Personal knowledge of the conservatee.
2. Knowledge of what constitutes the “best interest” of the conservatee.
3. A commitment to providing that which is in the person’s “best interest.”
4. Financial management skills (as appropriate).
5. A knowledge of programs and services, their availability and effect.
7. Proximity to the conservatee.
8. Availability in terms of time and energy.
Information Brief

A Brief History of the Individual Plan

In the early 1970’s, there were a number of court cases about the answer to the question:

What are the rights of people with developmental disabilities?

In general, the courts answered that people with developmental disabilities have the same rights as everyone else. While this helped, it created a new set of questions. Since everyone is different, the next question became what is the best way to make sure that individuals with developmental disabilities get the services and supports that they need? In the mid 1970’s, many federal and state laws were passed to help clear up this issue.

All of these laws state that to get the right support, a plan of service must be written that looks at each person’s individual needs. This became known as the Individual Plan. As the years have passed, lots of I (fill in the blank) P’s have been created. Here are just a few:

<table>
<thead>
<tr>
<th>Plan</th>
<th>Agency</th>
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<tr>
<td>Individual Program Plan</td>
<td>Regional Center</td>
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<td>Individual Education Plan</td>
<td>School</td>
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<tr>
<td>Individual Family Support Plan</td>
<td>School and Regional Center</td>
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<td>Individual Transition Plan</td>
<td>School Department of Rehabilitation</td>
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<td>Individual Habilitation Plan</td>
<td>Department of Rehabilitation</td>
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<tr>
<td>Individual Work Related Plan</td>
<td>SLS Agency</td>
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While there are some differences in all of individual plans (some are for students, some are concerned with work only, some are about support in the person’s home and community), things that all of them have in common are that they:

- are written down;
- are developed by everyone involved with the person’s life (a team approach);
- outline the things that a person can do well (strengths, preferences, capabilities) and their plans for the future (life goals);
- outline the things that get in the way (barriers) and things that a person needs help with (support needs);
- list the steps that are needed for a person to learn, live or work more independently (goals, objectives, services and supports);
- list who will help with the services (responsibilities);
- list ways to tell if the services help (progress towards goals); and
- state when the plan should be looked at again (review date).
Information Brief

The Person-Centered Individual Program Plan

Introduction

While Regional Center Individual Program Plans may look different, there are some things that California law (Lanterman Act, Title 17) says must be the same. This article is about those things which all Regional Centers must do when working on the IPP.

IPPs are Person-Centered

All regional centers are required to use a person-centered approach when planning for the Individual Program Plan. An IPP describes the needs, preferences and choices of the individual and family. It is developed through a process of figuring out individualized needs. The IPP changes as individual needs and preferences change.

Individual Choice

Individuals have a right to make choices and have them written into the IPP. Those choices include, where and with whom to live, the way people spend their time each day and with whom, choice about things to do for fun and plans for the future. To help individuals and families make good choices, information about different kinds of services must be presented in a way that’s easy to understand.

The Planning Team

A planning team is a group of individuals who work together to support the choices and preferences of one of the team members. The team meets to share what they have learned about the life patterns, interests and preferences of an individual from the person-centered planning process. The person-centered planning process provides the team with a picture of the strengths and abilities of the individual, as well as the challenges that he or she faces.

The planning team is made up of the individual, Regional Center service coordinator and others invited by the individual like family members, friends, neighbors, advocates and SLS staff. If an individual has a legal representative or a guardian or conservator, they must also be on the team. To make sure that individuals are able to actively participate, it may also be necessary to include a translator or interpreter on the team.

Assessment

When the planning team shares what they know about the life patterns, interests and preferences of an individual, they are completing an assessment. When the team decides that more information is needed, a specialist (for example, speech therapist, psychologist) may be asked to complete an assessment as well.
The IPP Meeting

The Regional Center service coordinator helps schedule the meeting of the planning team. The location, time, date, and length of the IPP team meeting should meet the needs and preferences of the individual and family. The idea is to make the meeting as comfortable as possible for everyone involved. For example, some individuals may need a series of shorter meetings and others may ask for phone conferences. Sometimes, individuals and families may ask for an informal meeting place like a restaurant, barbecue or picnic.

When the team meets to develop the person-centered IPP, this is called a planning conference. One of the purposes of the meeting is to bring all the members of the team together for a face-to-face discussion. During the meeting, there are several important roles for team members:

**Team Leader.** This can be anyone on the team who wants to help keep the meeting going. It is quite often the regional center service coordinator.

**Team Recorder.** Someone who will take notes during the meeting.

**Team Members.** Everyone who comes to support the person working on the IPP.

The information discussed at the planning conference and the decisions and choices that are made become the person-centered Individual Program Plan.

The Major Parts of the IPP

The basic parts of the person-centered Individual Program Plan are:

- **Goals**
- **Objectives**
- **Services and Supports**
- **Review Date**

**Goals are the things that people want to do in the next few years.** They are the choices that people make about where to live, what to do during the day, who to spend time with, what to do for fun and hopes and dreams. Here are some examples:

- Learn how to ride the bus.
- Join a church.
- Get a job.
- Live in my own apartment.
- Learn how to ride a bike.
- Save money for a vacation.

**Objectives are the steps needed to move toward a goal.** An objective needs to have a date written into it so the team will know if the goal is getting closer.

If someone’s goal is:
Joan wants to save money for her vacation trip.

Objectives (or first steps) might be:
By the end of January, Joan will open a savings account.
By the end of June, Joan will have saved $50 towards her vacation trip.
If someone's goal is: Travis wants to join a church.

Objectives (or first steps) might be: By the end of June, Travis will have a chance to visit four churches on Sunday.

By the end of July, Travis will choose a church to join.

There are many kinds of services and supports that can be listed in an IPP, depending on the support needs of the individual. Some of those services and supports are:

- **a place to live** (for example, supported living, emergency housing, foster family, group home, help in finding a place, homemaker services);

- **a place to learn or work** (for example, education, day program, workshop, supported employment, competitive employment);

- **getting around** (for example, transportation, travel training, recreation, adaptive equipment); and,

- **staying healthy** (for example, counseling, mental health services, medical or dental services).

The law says that regional centers must first try to use regular community services before it can purchase service and supports from vendorized providers (for example, SLS or day services).
Generic Resources
Q and A on Generic Services

What are generic services? They're services available to anyone in a community. However, generic doesn't necessarily mean free.

Who are they for? Many are a part of the public service system found in any community. Some are for people with low incomes, while others are for people who are smart shoppers looking for bargains.

Is there a core of generic services available everywhere? Yes. While they may be different in quantity and quality, you can find In-Home Supportive Services, Rental Assistance, Utility and Retail Discounts, Health Services, and Public Transportation services everywhere.

How do you find out about them? You can talk to other SLS professionals, regional center service coordinators and local government officials. You can also go to the library, senior citizen and volunteer centers. In addition, many communities have a local resource guide.

Where do you start? It's important to find out as much general information as you can by looking at the customer services pages of the phone book. You might also go to city hall, the local library, community college, chamber of commerce and talk to other service users and providers. You will also need to find out some specific information about what an individual needs and wants and then you start the process of matching.

Basic Rules for Tracking Down Generic Resources

• A request/search should be based on a real need
• If you're helping someone search, it's often better to approach service reps as someone's friend rather than a professional
• The 7 call rule - you might have to make seven calls to find the resource you're looking for
• Be cheerful, humble and optimistic
• Be concise
• Try to get something out of every effort, even if it's just another phone number
• Say thank you and return the favor whenever possible
**Typical Generic Resources***

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<th>CONTINUING EDUCATION</th>
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<td>Adult education:</td>
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<td>High School - Night School</td>
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<td>Parks and Recreation</td>
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<td>Classes offered by the city</td>
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<td>Classes offered by individual businesses (e.g. craft stores, cooking supply stores)</td>
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<tr>
<td>Community colleges - disabled student services (in-class assistance, tutoring, etc.)</td>
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<td>Community colleges - technology centers (adaptive equipment)</td>
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<td>Driver training programs</td>
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<td>Literacy programs</td>
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<td>YMCA, other organizations</td>
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<td>Department of Rehabilitation</td>
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<td>Employment Development Department</td>
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<td>Private Industry Council</td>
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<td>Regional Occupational Program</td>
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<td>Meals on wheels</td>
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<td>Food banks and pantries</td>
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<td>Food stamps (emergency assistance)</td>
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<td>W.I.C. (Women, Infants, and Children)</td>
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<tr>
<td>Community and church assistance leagues</td>
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<tr>
<td>SHARE - 2 hours of volunteer work + $14 = $35 worth of groceries</td>
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<th>HEALTH CARE</th>
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<td>911 for emergency health care</td>
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<tr>
<td>Alcoholic Anonymous, Gamblers Anonymous, Narcotics Anonymous, etc.</td>
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<td>Assisted living providers</td>
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<tr>
<td>California state licensing boards (checking on medical license status, making complaints, etc.)</td>
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<td>County Health Department</td>
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<tr>
<td>Doctor/Dentist referral services</td>
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<tr>
<td>Free medications; for information call 1-800-PMA-INFO, ask for Directory of Prescription Drug Patient Assistant Programs which is free &amp; very detailed.</td>
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<th>HOUSING AND UTILITY RESOURCES</th>
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<td>Adaptive phone equipment, including some emergency calling devices</td>
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<tr>
<td>Bonding - rental discounts available in some cities for low income tenants</td>
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<tr>
<td>Cable (some - for basic only)</td>
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<tr>
<td>Call blocking services (various combinations are possible, at no charge)</td>
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<tr>
<td>Department of Housing and Building Safety (various names in various cities); can help get landlords to make needed repairs</td>
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<td>ECIP (Emergency Crisis Intervention Program) 1-800-433-4327; provides emergency, one time only, payment of utility bills for people facing shut off. Also, can provide deposits for start-up service.</td>
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<td>Free “411” calls</td>
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<tr>
<td>HEAP (One a year assistance with utility bills at 1-800-433-4327)</td>
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<td>Home adaptation providers</td>
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<tr>
<td>Housing insulation and repair programs, many for tenants as well as home owners</td>
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<td>Housing advocates, fair housing councils</td>
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<td>Legal Aid</td>
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<td>Lifeline rates and discounts (gas, electric, phone, water)</td>
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<tr>
<td>Medical Baseline Discounts - increased allowance for lowest rate on utilities, based on necessary medical equipment (e.g., power wheelchairs, respirators)</td>
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<td>Newcomers Clubs</td>
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<td>Police (evictions, etc.)</td>
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<td>Waived or discounted deposit fees for utilities</td>
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<td>Welcome Wagons</td>
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* Developed by Jennifer Pittam, CHOICESS
Typical Generic Resources*

**MENTAL HEALTH SERVICES/CRISIS INTERVENTION**
- Battered women's shelters
- Church sponsored counseling services/programs
- Counseling centers
- County Department of Mental Health
- Crisis intervention teams
- Rape crisis centers
- Suicide hotlines
- Support groups around special issues
- Victim's of violent crime assistance programs

**MISCELLANEOUS**
- California Relay: Voice to TTD and TTD to voice for those with hearing impairments needing to receive/make calls to those without TTD equipment
- California Speech Relay: same idea as California Relay, designed for individuals whose speech is difficult for others to understand. 1-888-377-3324 (for info: 916-445-9692; Tom Burns)
- Centers for Applied Rehabilitation Technology
- City Hall
- Computer Access centers
- Discount camping fees at most state and federal parks
- Federal Information Center:
  - 1-800-726-4995; can direct you to the correct federal resource to answer your question, request for information, etc.
- Free fishing licenses - State Department of Fish and Game
- Immigration / Refugee services
- Independent Living Centers
- Roommate Finders type services
- Senior centers / services
- State Information Office:
  - 1-916-322-9900; can direct you to the correct state resource to answer your question, request for info, etc.
- Volunteer bureaus

**OTHER FINANCIAL RESOURCES**
- BO GG grants pay for registration costs at community colleges for people with low income.
- Consumer Credit Counseling
- Customer service representative at the bank
- Debtors Anonymous
- Dept. Of Public Social Services
  - IHSS, AFDC, Food Stamps (Emergency), WIC
- F.E.M.A. (Federal Emergency Management Agency)

**PARENTING/FAMILY SUPPORT**
- Adoption/foster care services
- Childbirth preparation classes
- Child care referral services
- Head Start
- Legal aid
- Parenting classes
- Pregnancy help centers

**TRANSPORTATION**
- Carpool/Vanpool
- Discount transit vouchers - offered by the city to residents
- Driver training programs
- Para-transit companies
- Para-transit referral service
- Non-emergency medical transportation
- Taxi service

* Developed by Jennifer Pittam, CHOICESS
Information Brief

Generic Services

Introduction

Generic Resources are services typically funded by a government entity, complete with a set of eligibility criteria and regulations of their own. This section will cover the most common generic resources available to adults with developmental disabilities in California.

Department of Rehabilitation

The mission of the Department of Rehabilitation is to assist individuals with disabilities, emphasizing those with the most severe disabilities, toward informed choice and success in education, vocational training, career opportunities, independent living and in the use of assistive technology to improve their employment opportunities and their lives.

Once an employment goal has been determined, the Department of Rehabilitation (DR) counselor will work with the individual to develop a written plan (called the Individualized Written Rehabilitation Program or IWRP) for reaching that goal. DR’s rehabilitation services may include:

- counseling and guidance
- medical services and equipment
- additional assessment
- vocational training and education
- transportation assistance
- reader, interpreter, tutorial and notetaker services
- work tools, equipment and license fees
- personal assistance services
- self-employment services
- post-employment services
The Regional Center typically assists in the referral process to Department of Rehabilitation by providing the information needed to determine eligibility.

The Department of Rehabilitation also provides habilitation services that fund Work Activity Programs (long-term, sheltered work) and Supported Employment (community-based, integrated work) for individuals with developmental disabilities who are served by Regional Centers. The Habilitation Specialist reviews referrals made by the service coordinator and approves the development of an Individual Habilitation Plan (IHP) by a local DR service provider. The Habilitation Section is also responsible for follow along services for individuals in supported employment.

DR administers the California Assistive Technology System (CATS). They provide a toll-free information and referral number to answer any questions relating to assistive technology. Assistive technology is any devise that helps persons with disabilities perform work, education, social activities, daily living activities or anything else they want to do. CATS also coordinates loan guarantee programs to assist people who need modified vehicles, durable equipment, adaptive aids, or assistive devices.

DR is also responsible for planning, developing and funding Independent Living Centers (or ILCs). These centers are designed to assist people with disabilities in living fuller and freer lives outside institutions. The staff of an ILC are trained to assist people with disabilities to achieve economic and social independence. Services include peer counseling, advocacy, attendant referral, housing assistance, information and referral, transportation and training in independent living skills.

**Disabled Student Centers**

Consumers enrolled in college can enlist the assistance of the Disabled Student Center for help required to be successful in school. This might include help in getting around campus, notetakers, readers or other adaptations a student requires.

**Food Stamp Program**

The Food Stamp Program provides monthly benefits in the form of food stamps for low-income households. These benefits are part of the person's food budget for the month. Individuals who qualify for food stamps must: work for low wages, be unemployed or work part-time, receive welfare or other assistance program, be elderly or disabled and live on a small income, or be U.S. citizens or legal permanent aliens.

The food stamp office provides application forms on the same day of the visit. Interested individuals can ask for the application in person, over the phone, by mail or someone else may get one on his/her behalf.
Hill-Burton Free Care Program, County and Community Hospitals

Located by calling the Hotline (1/800/638-9742) to see which hospitals in your area may have a responsibility to provide free or low-cost health care as a “payback” for federal construction or modernization funds. Some hospitals have other funds for similar purposes. County and community hospitals have certain obligations to treat emergencies, whether the person can pay or not.

In-Home Supportive Services (IHSS)

IHSS provides personal care and domestic services to people who are aged, blind or disabled and who live in their own homes. To be eligible an individual must:

- be a lawful resident of California with low income and limited resources
- need IHSS care to remain safely in their own home

Individuals with disabilities can qualify for IHSS services, which might include meal preparation, laundry, shopping, nonmedical and other types of assistance. Eligibility for IHSS services is coordinated through the county Departments of Public Social Services. Authorized hours may range to a maximum of 283 hours per month, depending on the needs of the individual.

IHSS services which are allowable include:

- Domestic services (cleaning, changing linens, etc.)
- Related services (menu planning, shopping, etc.)
- Heavy cleaning services (due to special health problems, etc.)
- Nonmedical personal services (hygiene, grooming, ambulation, etc.)
- Medical transportation service
- Yard work services
- Protective supervision service (to protect against risk of injury / accident)
- Teaching and demonstration service
- Paramedical services under direction of health care professional (exercises, catheter care, injections, etc.)
Medi-Cal (State-federal Medicaid Program)

Serves low-income Californians who would otherwise not have access to medical/health care. About half the money is federal; half State. Medi-Cal covers a variety of services, when they are medically necessary. Recipients of Supplemental Security Income (SSI) are automatically eligible for Medi-Cal. Some others can qualify as medically needy, with a share-of-cost, if they have high medical expenses in any month. Besides primary, specialty (e.g., psychiatry; durable medical equipment) and acute care, the Medicaid program is used to fund a variety of other services and supports, some of which are described below. All told, over half of all funds for “developmental services” (including targeted case management; long-term health care in skilled nursing and intermediate care facilities; and waiver services) in California are financed through the Medicaid program.

California has applied for (and received) several Medicaid Waivers to provide Home and Community-Based Services (HCBS). Some are tied to intensive medical services and support where services can be provided as effectively and less expensively at home than within “an institution.” “Institution” includes many small, community facilities, not just hospitals, developmental centers and the like. Such services are used by some individuals with complex medical care needs, including being technologically-dependent for sustenance, breathing and the like. Other Medi-Cal funded services include (1) adult day health care (a day program option for some); (2) HCBS waiver services, such as personal care, so that more adults with developmental disabilities can live in their own homes (e.g., supported living services); and (3) even some supported employment services.

Medicare

A federally-funded, public health insurance program for the Nation’s elderly and selected others. It covers end-stage renal disease (e.g., kidney failure; transplantation) for people of all ages and in California SSDI recipients automatically have access to Medicare, regardless of age. Part A covers inpatient hospital care, care in a skilled nursing facility or hospice care. Part B covers the services of physicians and selected other professionals, outpatient hospital services, medical supplies and selected other services.

Mental Health Services

Physical medicine and mental health services have historically coexisted. Talk therapy and the use of various psychotropic medicines (to affect thinking and feeling) constitutes the domain of psychiatrists, psychologists, LC SW (Licensed Clinical Social Workers) and Marriage and Family Counselors. Some of these kinds of services, such as behavior management, are often provided through Regional Centers or the schools.

In an ideal world, “dually-diagnosed individuals,” meaning those with both developmental and psychiatric (or emotional) disabilities, would be treated collaboratively by those best positioned to make a positive difference. However, the mental health and developmental services
systems are organized differently. And, mental and physical health practitioners rarely work together. Some mental health practitioners (especially those who do talk therapy) feel that such services are a waste of effort for many people with cognitive impairments. At any rate, in approaching mental health professionals, one should focus on presenting symptoms (e.g., anxiety, depression, behavior) and not identify the person by a developmental disability label until the person’s foot is in the mental health door.

Public Transportation

The array of available and accessible public transportation services varies from area to area. Most individuals with developmental disabilities qualify for price reductions on bus passes to ride the public bus service. In addition, many communities operate a paratransit system (door-to-door van service) for people with disabilities who need to get to medical appointments and other community services. Check with the transportation coordinator or resource developer in your Regional Center for information about paratransit services and transportation discounts (e.g., bus passes, taxi vouchers).

Recreation

Most communities have a parks and recreation program. These programs offer a variety of sports, art instruction, classes, dance instruction, exercise, swimming, etc. Some park locations have adaptive equipment for people with disabilities as well. The programs are available to the public.

Section 8 Rental Assistance Program

The Section 8 Rental Assistance Program is federally-funded through the U.S. Department of Housing and Urban Affairs (HUD). Local housing authorities administer the program. The program provides a subsidy for renters who have low incomes. The program’s purpose is to provide low-income families (including families of one) with safe, decent and affordable housing.

Waiting lists are typically quite long: two or more years in most areas. Sign ups to be on the list may be only an occasional event. Some large cities provide publicly-owned housing (so-called “projects”). Increasingly, subsidies are provided through certificates and vouchers.

If accepted by a private-sector landlord for rent at or below fair market rent (FMR) for units of a given size (say, one-bedroom), a certificate means that the housing authority will pay the difference each month between the FMR and 30% of the family's income. With a voucher, the family can rent units at rates above published FMRs, but the subsidy is the same as if the family
had a certificate. The renter pays extra—that is, the difference between what the landlord charges and FMR. Individuals who need round-the-clock attendant care typically will qualify for a two-bedroom unit on their own account.

Only a few local housing authorities have amended their HUD contracts to take advantage of the “shared housing option,” wherein more than one individual has exclusive right to a bedroom and shared use of common elements of the dwelling. One can sometimes move up on the waiting list if one can obtain preference points, which are given for each of the following: (a) paying over 50% of income for housing; (b) living in substandard housing; (c) being evicted.

Social Security (SSI, SSDI)

The Social Security Administration administers two programs of importance to many individuals with developmental disabilities: Social Security Disability Insurance (SSDI) and Supplemental Security Income/State Supplemental Payment (SSI/SSP). The former is all federal money; the latter is a combination of federal and state funds.

**Social Security Disability Insurance (SSDI)** is a social insurance program wherein a disabled individual receives a cash payment based on their own earnings record or that of a parent who has retired or died. There is no resource (or asset) test for receipt of SSDI. SSDI benefit levels depend on the earnings of the person on whose social security account the benefit is based, and on the number of persons drawing benefits on the same account. One must have a medically determinable disability expected to last 12 months or more that prevents substantial gainful activity (SGA). At present, the SGA criterion is $500 per month ($1,000, if blind). A person eligible for SSDI is also eligible for Medicare, with the premium for Part B services paid for the individual.

**Supplemental Security Income/State Supplemental Payment (SSI/SSP)** SSI/SSP is an income maintenance program for aged, blind, or disabled individuals (and couples) with low income and few resources. SGA is defined the same way as for SSDI. At present, “countable assets” (cash and near-cash) may not exceed $2,000 ($3,000 for a couple). Cash payments are not predicated on prior contributions to the Social Security Fund.

What about income from other sources? — One can receive $20 per month from any source (earned or unearned income) without experiencing a reduction in SSI/SSP. One can also earn up to $65 per month without a reduction in SSI/SSP. Beyond $85 in any month, however, earnings are “taxed” at 50 cents on the dollar. In other words, if a person would otherwise receive $650 per month in SSI/SSP, but has earnings of $185 in a month (and no other income from any other countable source), his or her SSI/SSP benefit would be reduced to $600 per month ($85 ignored; $50 reduction based on added $100 of earnings).
If adults with disabilities continue living with family — Children with disabilities who are living with their families, are often ineligible for SSI because of both family income and assets. But, once the person with a disability reaches age 18, he or she is considered a “family of one” and family assets and income no longer count against eligibility. Continued assistance from the family can, however, affect the amount of the monthly benefit. Hence, many families choose not to continue to provide food and lodging at no cost to the individual. Rather, they choose to keep records, and to “charge” their children fair market rent and their pro rata share of food, utilities and the like.

What assets are “countable”? What assets are ignored? — Countable assets include cash and near-cash (e.g., stocks, bonds). If countable assets exceed certain limits, SSI benefits may be terminated until those assets are spent down — that is, until any excess above the asset limit has been eliminated. Some assets are not countable (they are ignored). Such include a car (of limited value, unless used for work or medical appointments), a home in which the recipient is living, furnishings and clothing to a certain dollar amount, a small insurance policy and selected other assets (e.g., engagement ring and wedding band).

Are there ways of keeping more of one’s earnings or assets? — Yes, there are a set of “work incentives,” under Sections 1619(a) and (b) of the Social Security Act, that can be used. Being able to buy needed health insurance for awhile is one work incentive. Being able to claim certain “impairment-related work expenses” (IRWEs) against earnings can help. An approved “plan to achieve self-sufficiency” (PASS) can shelter some assets and earnings to buy work-related equipment (e.g., a specially equipped van; tools of a trade), to complete an educational program (e.g., bookkeeping certificate program), or to start a business.

Does where a person live matter for SSDI and SSI? — The answer is “Yes,” because residential services are funded in different ways. Services of ICF/DD-H and DD-N (Intermediate-care facilities/developmentally disabled-habilitative or nursing), for example, are charged to Medi-Cal. If the person is SSI-eligible, he or she will receive $42 per month for “personal and incidental needs,” nothing more. If a person lives in a licensed community-care facility, on the other hand, the person currently receives $796 per month in SSI/SSP, must turn over $703 to the residential service provider, and keeps $93 for “personal and incidental needs.” If a person lives “independently,” he or she will typically receive about $650 per month (more if no access to cooking facilities) and no distinction is made as to purpose. All is for the basics of food, clothing, shelter, and incidentals.

(Another resource is SSI Questions and Answers for Persons Residing in Supported Living Arrangements, Department of Developmental Services, Adult and Supported Living Services, 1600 9th Street, Sacramento, CA 95814, 916-654-1956.)
Information Brief

Generic Housing Services

In your area are a number of generic housing services to consider when developing a pattern of support.

County Community Food and Housing Division

This service is typically made up of two programs: 1) Food Protection Program; and 2) Housing Program. The Housing program is responsible for enforcement of State Housing Codes. For example, they're interested in substandard housing conditions due to lack of electricity, potable water, heat, natural light, ventilation, infestations of rodents or insects or a lack of connection to sewage disposal and structural hazards. These two services are usually a division of the local Department of Health Services.

Public Housing

This is a program of U.S. Department of Housing and Urban Development (HUD) administered by County Housing Commissions. A rent supplement makes it possible for very low income families, senior citizens and persons with disabilities to live in city owned, managed or subsidized rental housing while paying no more than 30% of their income for rent. Resident screening for eligibility (income), credit references and past tenancies are also provided. Contact city or county housing authority for income levels and other information.

Temporary Housing Services

You can usually find information on temporary housing through local community organizations such as a United Way Information Line or a Community Shelter service. Referrals for these services are typically made through a local human service agency, regional center, community service association, etc.

Shared Housing Programs

Local shared housing efforts match individuals with homeowners who want to reduce their cost of living, increase their expendable income and provide companionship and security. Information on shared housing is typically provided through local community service organizations (e.g., Catholic Social Services, Volunteer Center, Service Center for the Blind). You can typically find this housing support in a local service directory from the United Way or by looking under Social Services Organizations in the yellow pages.
General Information and Resources on Renting

There are a number of ways to get information about renting. For example, many counties have rental information and mediation services who provide handbooks on renter rights and responsibilities. In many areas, you'll find a listing in the State Government Offices section of the phone book titled Homeowners and Renters Assistance for Senior Citizens and Disabled and Blind.

Utilities Services

Local Gas and Electric Companies offer programs for low income rate assistance. You can contact your local electric company for information on eligibility. Another program for low income customers is available through H.E.A.P. (Heat, Electricity, Available Program). The customer completes a form and the electric company determines amount of refund which should be made based on information. Contact your local utility for specific information.

Adaptive Telephone and Communication Services

Local phone company offers numerous programs such as:

1) Universal Lifeline. Offers low income customers substantial savings on telephone service. Eligibility is based on annual income, one phone number and not claimed as a dependent on another person's tax return. Contact your local phone company for specific information.

2) Telephone equipment and services for people with physical impairments. Offers specialized communication equipment at no charge to make using the telephone easier for people who have physical limitations that interfere with hearing, speaking, seeing, dialing or holding a telephone. Many options are available. To qualify for services you need the following:

- have telephone service
- must be medically certified as disabled, or
- medically certified as "temporarily disabled"

Contact your local phone company's and ask for the Deaf and Disabled Services.
Teamwork and Diversity
Information Brief: Teamwork and Diversity

Diversity*

Definition of Diversity

Diversity is the important mixture of people who bring different backgrounds, styles, values, perspectives and beliefs as assets to the groups and teams with which they work.

Diversity and Work

We all have an opportunity to experience diversity in our lives every day. It may be diversity in age, ethnicity, nationality, religion, gender, ability or disability. Our openness to those experiences will determine whether we thrive in the diversity of the people we encounter or struggle with it.

It’s projected that by the year 2000, the majority of individuals with developmental disabilities in California will be non-white and non-Anglo. Even if you did not know this information, it just makes good sense to be as culturally aware as possible in your work.

What is It to Appreciate Diversity?

Sensitivity is the awareness of the feelings, values and attitudes of others. To be sensitive to and appreciate diversity, it’s important to:

• Let yourself try to experience life situations from the perspective of the individuals and families you support as well as your co-workers.

• Be aware of your own thoughts which might exaggerate and misinterpret the differences of individuals from another culture.

• Remember that, your role as a Supported Living Service Professional and team member is to support and respect the decisions of individuals and families.

* Cultural Sensitivity, prepared by Jose Hurtado, Eastern Los Angeles Regional Center (1996); Cultural Connection: Cross Cultural Competency Training, prepared by the Eastern Los Angeles Regional Center and the University of Southern California (1993).
Information Brief: Teamwork and Diversity

The Platinum Rule*

A good starting point for valuing and appreciating diversity is to view everyone as different from us, and to view them as people about whom we can’t make assumptions. Appearances are deceptive; people who appear to be very similar to us are often different, and those who appear to be very different can turn out to be quite similar.

The most important principle for valuing diversity is The Platinum Rule. This is an expansion of The Golden Rule. The Golden Rule is a time-honored practice that is a foundation of many religious disciplines. In telling us to "treat others as you want to be treated," its intentions are sound. It was designed to prevent us from doing harm to others – things which others obviously would not like.

With the increasing complexity of our society, we now need to extend The Golden Rule because it does not account for people's different and unique needs. We cannot assume that others want to be treated exactly the way we do. By assuming that everyone else wants what we do, we perpetuate the values and beliefs of the dominant culture. The Platinum Rule gives others permission to be different from us, and reminds us to honor that difference.

The Platinum Rule is:

Treat others as they want to be treated.

Using The Platinum Rule makes it okay for us to have differences. In the classic 1973 Harvard Business Review article, "What It's Like to Be a Black Manager," Edward Jones notes that removing the "taboo" of discussing differences is the first step toward valuing them.

The "fine line" of discussing differences is that they should be work related and behaviorally oriented. People should not feel they are being judged or labeled because of their differences.

Information Brief: Teamwork and Diversity

Diversity, Communication, and Teamwork*

Differences in Culture and Communication

There are some important differences in communication style that are influenced by culture. Here are some things to think about in communicating with individuals or families who are culturally different from you.

Eye Contact and Facial Expressions

Individuals with European cultural backgrounds (for example, English, German) usually appreciate eye contact. However, among many Asian cultures, eye contact between individuals who do not know each other is not appreciated and long periods of eye contact may be seen as not respectful.

Many individuals from European cultures show their emotions through expressions on the face (for example, lifting the eyebrow). However, individuals from Native American or Asian cultures may not communicate emotion through facial expressions unless they know someone well.

Closeness and Touching

Individuals from European cultures tend to stay a distance of about 3 feet, or an arm’s length, between themselves and others during conversations. However, individuals from Latin cultures are comfortable with closer conversational distances, while those from Asian cultures often prefer more space between the speaker and listener.

Among many Asian cultures, hugging, back slapping, and handshaking are not typical and should be avoided. Among some individuals from Middle Eastern cultures, use of the left hand to touch another person is not okay because the left hand is used for personal hygiene.

Many individuals from European cultures show affection for children by patting them on the head. However, this is not an acceptable form of touch among many Asians who believe that the head is the where the soul lives. Also, some East Indians believe that the head is fragile and should not be touched.

Gestures

Individuals from European cultures tend to use some gesturing while they talk as do some Latinos and Middle Easterners.

Nodding the head up and down is taken as a sign of understanding and agreement in many cultures, but among Asian, Native American, Middle

* Developing Cross-Cultural Competence, by Eleanor W. Lynch and Marci J. Hanson, Brookes Publishing (1992) and Regional Center Service Coordinator Orientation, Southern California Regional Center Director’s Association (1999).
Eastern, and Pacific Island groups, it often only means, I hear you speaking. It does not mean that the person understands what is being said or agrees.

Also, individuals from European cultures often ask people to come their way by pointing with the index finger palm up and curling it toward the body while people from other cultures use this gesture only when summoning animals. In those cultures, it is never used with children or adults.

**Good Communicators**

Effective communication with individuals from other cultures works best when you:

- are flexible and can tolerate different points of view;
- make sincere attempts at trying to understand things from another point of view;
- are open to learning about another culture; and
- have a sense of humor.

**Diversity and Teamwork**

You will find diversity in the people you work with as well as the people you support. The information above about differences in culture and communication will also help you work as an effective team member. Teamwork is a key to successful service for people with developmental disabilities. In addition to the people you work with and support, your team will likely include family members, consultants, health professionals and regional center staff, as well as staff from other community services. So, it's important to know some basics about teams and how they work best.

**Some Team Basics**

**What is “teamwork”?** Teamwork is about sharing, cooperating and helping one another. An effective team is a group of people working together with a common purpose who value each others contributions and are working toward a common goal. Working through teams usually gets better results than a lot of individual efforts which may be working against each other.

Many experts say trust is basic to successful teamwork. Trust takes time because it depends on people sizing up each other to see whether they say what they mean, do what they say and contribute to the work of the team.

Besides trust, other values that support teamwork are:

- open, honest communication;
- equal access to information; and
- focus on the goal.
Staying Healthy
Information Brief
General Information About Medications

Medications

Medications are powerful substances which many of us have come to depend on as an important part of our lives. Medications are substances taken into the body (or applied to) for the purpose of prevention, treatment, relief of symptoms or cure. Medications include the following:

- Prescription medications which must be ordered by a physician (or other person with authority to write prescriptions).
- Over-the-counter medications which can be purchased without a prescription.
- Vitamins, naturopathic remedies and homeopathic remedies are all medications.

Some Reasons Why Learning About Medications Is Important

Many medications do a lot of good. However, medications or drugs may also cause harm. Knowing about medications, their use and abuse and how to assist individuals in using them is vital to the health and well-being of those you serve.

Sometimes when a person takes a medication, it might make them feel confused, dizzy, anxious or cause change in one or more of the body functions (for example appetite, sleep, elimination). This is called an unwanted effect or side effect from the medicine. It is not uncommon for two or more medications to interact with one another causing an unwanted side effect.

In order for the physician to prescribe the best treatment and medication, he or she needs to be informed of the person’s medical history, any drug allergies, current medications the person is taking and the purpose, medical and dental conditions and observations of recent physical or behavioral changes.

In addition, it is a good idea to get all prescriptions and over-the-counter medications at the same pharmacy or drug store so the pharmacist can maintain an active listing of all medications and check for potential drug-drug or food-drug interactions.

Consider the following:

✓ The Food and Drug Administration estimates that hospitalization resulting from inappropriate prescription drug use costs the nation $20 billion annually.
✓ Seventeen percent of hospitalizations of elderly Americans are the result of adverse side effects.

✓ Of the 2.3 billion prescriptions that are filled annually, approximately one half are not taken properly.

✓ Americans’ failure to take their medications as instructed costs more than $100 billion a year in increased hospital and nursing home admissions, lost worker productivity and premature death.

Abbreviations and Symbols Related to Medications Usage

A variety of abbreviations and symbols used by health care professionals that you may see and need to know are listed below:

q. (Q) = Every
Oz. = Ounce
d. = Day
tsp. = Teaspoon (or 5 ml.)
h. = Hour
Tbsp. = Tablespoon (3 tsp., or 15 ml.)
b.i.d. = Twice a day
gr. = grains
t.i.d. = Three times a day
mg. = milligrams
q.i.d. = Four times a day
GM, gm. = grams (1,000 mg.)
h.s. (HS) = Hour of sleep (bedtime)
Cap = Capsule
p.r.n. = when necessary, or as needed
Tab = Tablet
A.M. = Morn ing
OTC = Over-the-counter
P.M. = Afternoon/evening
Rx = Prescription
Qty = Quantity
Key Points When Assisting With Medications

In order to safely and effectively assist individuals with medications, you must:

- Assure that all medications are correctly self-administered.
- Watch carefully for adverse reactions and other side effects;
- Document changes in the illness or behavior, and in symptoms, adverse reactions, other side effects and apparent interactions in the individual's record.
- Bring this information to the attention of appropriate persons (for example, the individual's physician, other staff) in a timely manner and be sure it is acted upon.
- When accompanying a person on a physician visit, or getting a prescription filled, ask the physician and the pharmacist questions to get necessary information about the medication: what is the name of the medication? when to take it? what food or drinks should be avoided?; and, are there any side effects?
- Read up on any medications being considered or prescribed.

Getting More Information (Books, Web Sites)

Most bookstores will have The PDR (Physician's Desk Reference), which is the most comprehensive source of information on prescription drugs. It is fairly expensive ($75 - $100). There are a number of other excellent sources. Ask the individual's physician or pharmacist to recommend one. Here are a few to consider:


http://www.intelihealth.com This is home for Johns Hopkins Health Information.

http://www.fda.gov This is the web site for the United States Food and Drug Administration.
Information Brief

Safe Practices When Handwashing

Assemble Equipment: Soap (bar or liquid), paper towels, warm running water, waste container.

Standing away from sink, turn on faucet and adjust water temperature. Keep your clothes dry moisture breeds bacteria.

Wet hands and wrists, keeping your hands lower than your elbows so water runs off your fingertips, not up your arm.

Use a generous amount of soap, rubbing hands together and fingers between each other to create a lather. Friction helps clean.

Continue to rub, push soap under your fingernails and cuticles with a brush or by working them in the palm of your hand. Use soap above your wrist about two inches. Wash for one minute.

Being careful not to touch the sink, rinse thoroughly under running water. Rinse from just above the wrists down to fingertips.

Do not run water over unwashed arm down to clean hands.

Using a clean paper towel, dry from tips of fingers up to clean wrists. Again, do not wipe towel on unwashed forearm and then wipe clean hands. Dispose of towel without touching waste container if your hands ever touch the sink or waste container, start over.

Using a clean paper towel, turn off faucet, which is considered contaminated. Properly discard towel. Apply lotion if hands are dry or chapped.
Information Brief

Safe Practices When Using Gloves

Putting on non-sterile gloves

- Wash your hands following proper procedure.
- If you are right handed, remove one glove and slide it on your left hand (reverse, if left handed).
- Pulling out another glove with your gloved hand, slide the other hand into the glove.
- Interlace fingers to smooth out folds and create a comfortable fit.
- Carefully look for tears, holes or discolored spots and replace the glove if necessary.
- If wearing a gown, pull the cuff of the gloves over the sleeve of the gown.

Removing non-sterile gloves

- Touching only the outside of one glove, pull the first glove off by pulling down from the cuff.
- As the glove comes off your hand it should be turned inside out.
- With the fingertips of your gloved hand hold the glove you just removed. With your un gloved hand, reach two fingers inside the remaining glove, being careful not to touch any part of the outside.
- Pull down, turning this glove inside out and over the first glove as you remove it.
- You should be holding one glove from its clean inner side and the other glove should be inside it.
- Drop both gloves into the proper container.
- Wash your hands using proper procedure.
Information Brief

Safe Practices When Lifting and Assisting Others

Lifting and Protecting One’s Back

At some time during their lives, four out of five people experience back problems (muscle spasms, slipped discs, etc.). Minimizing back problems calls for two things: (1) proper use of your body when lifting, pushing or reaching for things; and (2) exercises to strengthen your back. Regarding the former, it is a good idea to:

- Push, not pull (a garbage container; a dolly; a cart);
- Move, not reach (to get the things you need);
- Squat, not bend (when you have to reach down to get something); and
- Turn, not twist (when you want to go in a different direction).

The next page shows proper body mechanics when lifting, moving or reaching for things.

| ✓ Push, not pull (a garbage container; a dolly; a cart); |
| ✓ Move, not reach (to get the things you need); |
| ✓ Squat, not bend (when you have to reach down to get something); and |
| ✓ Turn, not twist (when you want to go in a different direction); |

Helping with Transfers, Positioning

Helping individuals with impaired mobility

Individuals with greatly impaired mobility (for example, due to cerebral palsy, spinal cord injury, spina bifida and the like) need extra, more skillful support to remain comfortable and healthy.

- Hypertonus (spasticity) is too much muscle tone. Muscles become stiff and resist moving.
- Hypotonus is too little muscle tone, such that they have too little strength to move.
- Fluctuating muscle tone (athetosis or ataxia) involves unpredictable fluctuation from too much to too little tone. The movements appear uncontrollable.

Individuals need to be up as much as possible, rather than lying in a horizontal position. Gravity (2.2 pounds per square inch of body surface) plays havoc with body systems, especially respiratory, digestive and urinary. Disability stemming from immobility or lack of motion was identified in 1960, by the U.S. Public Health Service, as one of ten preventable health problems.¹ Pneumonia,

Principles of Good Body Mechanics

**Keep the natural curve of the spine intact**
A commonly recognized problem is lifting loads from the floor. But overhead loads can also be hazardous. It is better to build platforms to store loads off the floor (above knee height) to eliminate bending over, and to keep loads below shoulder height.

**Lift loads at about waist height**
Ideally, loads should be at about waist height when lifted. For example, adjustable height stands can be used to raise pallets of boxes up and down to the right height (and also accommodate employees of varying heights).

**Eliminate twisting motions**
Twisting motions, especially with a heavy load, place considerable stress on the spine. Improved layout is usually the best approach for eliminating this issue.

Reaching down into tubs and bins is a common source of back stress. Possible solutions include hydraulic tilters, springloaded bottoms and drop-down or removable sides.
osteoporosis (due to absence of weight bearing), gastro-esophageal reflux disease (GERD), and other conditions arise. Poor muscle tone often impacts chewing and swallowing. The person may push food out of the mouth; bite down forcefully on a metal utensil causing discomfort if not injury; or not be able to cough well enough to expel food or fluid that slips into the air pipe. Abnormal posture, combined with gravity, can make eating punishing. Pressure within the abdomen can rise; the normal opening in the diaphragm may be stretched; food (mixed with acid) may back up into the esophagus causing damage. Constipation, bowel obstruction and impaction are common, and often exacerbated by years of taking laxatives, seizure and other medication.

Positioning and movement

One should seek advice from an individual’s physician for any individual who needs help with positioning or mobility, so that ways of assisting are safe and effective. Typically, physical or occupational therapists are consults for plans regarding an individual’s position or movement needs. If a person cannot change position on his/her own, someone must assist in repositioning. Because the absence of movement can result in discomfort and skin breakdown, someone needs to watch for places on the skin that are red or warm to touch. These are warning signs of skin breakdown. They should be written down in the individual’s record and brought to the attention of the individual’s physician.

Body mechanic principles

The North Dakota Center for Disabilities’ staff training module on “Positioning, Turning and Transferring” (1995, pp. 60-62) recommends these basic principles:

1. **Do not lift loads heavier than those prescribed by your agency.**
   Prior to lifting or moving an object or person, test the weight of the load to make sure it can be moved safely. Get help or use an assistive device if necessary.

2. **Plan the move.**
   Do not move the object any further than is absolutely necessary. Arrange the surface to which the object is to be moved as close as possible to the surface from which it is to be transferred. Provide firm, stable surfaces and, if possible, transfer between surfaces of equal height.

3. **Use a wide, balanced stance with one foot ahead of the other.**
   The solid base of support reduces the likelihood of slipping and jerking movements. Keep your feet flat on the floor and spread them about the width of your shoulders. Place one foot in the direction toward which you will move. This foot position gives you a wider base of support and allows a weight shift from one foot while maintaining your stability.

4. **Keep the lower back in its normal, arched position while lifting.**
   Bend at the knees or hips. With the back arched, the forces are more evenly distributed on the support structures.
5. **Bring the load as close to the body as possible.**
Throughout the move, keep your arms and the object or person as close to your body as possible. This keeps your back from acting as the fulcrum and reduces the stress.

6. **Keep the head and shoulders up as the lifting motion begins.**
This helps to keep the arch in the lower back.

7. **Tighten the stomach muscles as the lift begins.**
This shifts some of the weight of the load from the spine to the abdominal cavity.

8. **Lift with the legs and stand up in a smooth, even motion.**
Using the large, strong muscles of the legs to straighten the knees and hips as the lift is completed decreases the lower back stress. Use your whole body when pushing, pulling or lifting, not just your back and arms.

9. **Move the feet (pivot) if a direction change is necessary.**
Throughout the move, your back, feet and trunk should all move together in the same direction, going to the same place. Avoid keeping your feet flat on the ground while twisting your body to move an object or person. When a turn is necessary, shift your feet and take small steps rather than twisting at the waist. Keep your feet pointed in the direction in which you are moving.

10. **Communicate if two or more individuals are involved in the movement.**
This helps ensure the movement will be smooth, rather than sudden or jerking. It’s a good idea to count 1, 2, 3... with the person helping.

11. **Don’t lift when you can pull or push an object.**
It’s safer and easier that way.

12. **Teach and preach.**
Help fellow employees use the rules of good body mechanics.

**Some specific transfers and positioning guidelines**

Individuals vary in size, muscle tone and control of their bodies. They also have different needs with regard to help in moving about. Some people need help turning in bed. Some need help to sit up. Some need help in scooting forward or backward in a chair or bed. Some need help moving from bed to a chair, from a chair to the toilet, from a chair to bed, or from a chair (or bed) to the floor. Some need help walking from one place to another without falling. A plan (with whatever training is needed) should be devised for each person. Sometimes, a single helper can assist someone. Sometimes, two or more people may need to work together. Sometimes, mechanical aids (for example, lifting equipment) may be needed.
In general, helping people with positioning and transfers should attend to the following principles:

- Good planning;
- Asking the person how they want to be assisted;
- Encouraging as much participation as possible by the person being assisted;
- Using equipment (boards, sheets, lifts, etc.) when possible;
- Teaming up with another person when a two-person lift is needed; and
- Use of good body mechanics (good technique).

**Wheelchair Safety**

Wheelchairs are an example of adaptive equipment. Handrails, lifts, sliding seats (for example, into and out of the shower) and other devices are available to help with mobility and to reduce the risk of injury to both the person assisted and the person(s) assisting. Here are some guidelines for helping individuals who use wheelchairs:

- **Self mobilization:** Can the individual move themselves? If yes, encourage them to transport themselves as much as possible.

- **Individual sitting position:** Before starting check for the following:
  - Are the individual’s hips all the way back in the wheelchair?
  - Does the seat belt need to be attached?
  - Are footrests in place and are the person’s feet on the footrests?
  - Are the individual’s hands on the armrests or in his or her lap away from the wheels?
  - **Brakes:** Make sure that brakes are locked prior to assisting a person into or out of a wheelchair.
  - **Holding on:** Grasp both push handles on the wheelchair firmly.
  - **Starting and stopping:** Always start and stop slowly, take corners slowly and maintain a steady pace while moving. This is to avoid jostling the person or throwing him/her off balance.
  - **Surface levels:** Be alert for changes in surface levels—for example, doorjambs or the floor of an elevator. Hitting a half inch rise at standard wheelchair speed can bend the front casters and pitch the person forward.
  - **Opening doors:** Never open doors by pushing with the front of the wheelchair. This can damage the wheelchair’s footrests, the person’s feet, or the door. Stop the wheelchair, open the door by hand, and bring the wheelchair through. If the door does not stay open on its own, hold it with one hand or your backside. Do not let the door bang the side of the wheelchair.
  - **Inclines and ramps:** The person’s weight should always be pushing
back toward you on inclines and ramps. Going uphill means pushing the person; to go downhill, turn the chair around and walk backwards. In this manner, the person’s weight will be pushing back toward you.

• **Outdoor surfaces:** Be alert for anything that can trap front casters or cause the wheelchair to tilt, such as holes, cracks, stones, sand or soft shoulders.

• **Curbs:** **Up curbs**—Stop at the curb, raise the front casters by pressing down on the foot lever, roll the front casters onto the sidewalk and roll the large wheels over the curb by lifting slightly on the push handles as you push forward. **Down curbs**—Always come down curbs facing backwards with the large wheels coming first. Maintain some upward pressure on the push handles as you pull the wheelchair toward you.

**Exercises to Strengthen Your Back**

Anyone who lifts or moves people or objects around should do exercises to strengthen the back. However, be sure to check with your physician or other health care professional before starting the exercises shown on the next page.
Strengthening your entire body prevents future back problems and also improves your general health. Many exercises and sports strengthen your arms and legs. Doing special exercises to strengthen your abdominal muscles is also encouraged.

Keeping your body flexible helps you to use proper body mechanics that protect your back.

These exercises are not recommended for use during an acute back problem or spasm.

- If any exercise causes increased or continuing back pain, stop the exercise and try something else. Stop any exercise that causes the pain to radiate away from your spine into your buttocks or legs, either during or after the exercise.

- You do not need to do every exercise. Stick with the ones that help you most.

- Start with five repetitions three to four times a day, and gradually increase to 10 repetitions. Do all exercises slowly.

The basic types of exercises that can help your back include: flexion, extension, and stretching and strengthening.

**Flexion Exercises**
Flexion exercises stretch the low back muscles and strengthen the stomach muscles.

**Curl-Ups**
Curl-ups strengthen your abdominal muscles, which work with your back muscles to support your spine.

- Lie on your back with knees bent (60° angle) and feet flat on the floor, arms crossed on your chest. Do not hook your feet under anything.

- Slowly curl your head and shoulders a few inches up until your shoulder blades barely rise from the floor. Keep your low back pressed to the floor. To avoid neck problems, remember to lift your shoulders and do not force your head up or forward. Hold for 5 to 10 seconds (do not hold your breath), then curl down very slowly.

**Pelvic Tilts**
This exercise gently moves the spine and stretches the low back.

- Lie on your back with knees bent and feet flat on the floor.

- Slowly tighten your stomach muscles and press your low back against the floor. Hold for 10 seconds (do not hold your breath). Slowly relax.

**Extension Exercises**
Extension exercises strengthen your low back muscles.
Press-Ups
Begin and end every set of exercises with a few press-ups (see illustration).

- Lie face down with hands at shoulders, palms flat on floor.
- Prop yourself up on your elbows, keeping lower half of body relaxed. If it’s comfortable, press your chest forward.
- Keep hips pressed to the floor. Feel the stretch in your low back.
- Lower upper body to the floor. Repeat 3 to 10 times, slowly.

Backward Bend
Practice the backward bend at least once a day, and do it frequently when working in a bentforward position.

- Stand upright with your feet slightly apart. Back up to a counter top for greater support and stability.
- Place your hands in the small of your back and gently bend backward. Keep your knees straight (not locked) and bend only at the waist.
- Hold the backward stretch for one to two seconds.

Strengthening and Stretching Exercises

Prone Buttocks Squeeze
This exercise strengthens the buttocks muscles, which support the back and aid in lifting with the legs.

- Lie flat on your stomach with your arms at your sides.
- Slowly tighten your buttocks muscles. Hold for 5 to 10 seconds (do not hold your breath). Slowly relax.
- You may need to place a small pillow under your stomach for comfort.

Hamstring Stretch
This stretches the muscles in the back of your thigh that allow you to bend your legs while keeping a natural curve in your back (see illustration).

- Lie on your back in a doorway with one leg through the doorway on the floor and the leg you want to stretch straight up with the heel resting on the wall next to the doorway.
- Keep the leg straight and slowly move your heel up the wall until you feel a gentle pull in the back of your thigh. Do not overstretch.
- Relax in that position for 30 seconds, then bend the knee to relieve the stretch. Repeat with the other leg.

Hip Flexor Stretch
This stretches the muscles in the front of your hip, which avoids "swayback" caused by tight hip muscles.

- Kneel on one knee with your other leg bent and foot in front of you. Keep a natural curve in your back.
- Slowly shift your weight onto your front foot, maintaining a natural curve in your back. Hold for 10 seconds. You should feel a stretch in the groin of the leg you are kneeling on. Repeat with the other leg.
Supported Living Services Training Tool Box

Part Three:
Information Briefs

Connections for Information and Resources on Community Living (CIRCL)

April, 2001
Supported Living Services
Your SLS
Training Tool Box

Part Four:
Tools and Applications

Connections for Information and Resources on Community Living (CIRCL)

April, 2001
Supported Living Services
Training Tool Box

General Information
for SLS Staff

Developed for
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April, 2001

through a contract with the
Department of Developmental Services

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- **Getting to Know You: Planning for Services in Supported Living** 341
This section of the Training Toolbox includes practical tools to help you do the work of supported living and to help you implement the principles of supported living services. These tools were gathered from supported living service agencies all over the state. These tools are intended only as examples and should be modified and individualized so they are useful to the individual who is receiving services. For example if the individual cannot read you may want to use pictures instead of written words.

CIRCL, Connections for Information and Resources on Community Living, is building a library or database of useful tools that can be shared among people doing this work. We hope that you will send any tools that you develop to CIRCL, 4171 Starkes Grade Road, Placerville, CA  95667 it would also be nice if you would share them with others who are on CIRCL’s supported living list serve (computer e-mail list). For information on how to participate on the list serve you can go to www.allenshea.com/CIRCL/CIRCL.html (remember to bookmark the website) and scroll to the bottom of the page.
Section 1.
A Home of One’s Own
Finding the Ideal Neighborhood  
(from Towards Maximum Independence, San Diego, CA)

This list can be used to help you think about the neighborhood you would like to live in. Choosing a home of your own is about choosing the neighborhood you live in and choosing your own home or apartment in that neighborhood. You will want to drive around and see a lot of neighborhoods before you choose the one you want to live in.

<table>
<thead>
<tr>
<th></th>
<th>Would you like to live in the same area you live in now?</th>
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<tbody>
<tr>
<td></td>
<td>Do you have any family or friends that you would like to live near? Where do they live?</td>
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<tr>
<td></td>
<td>What are your favorite places to go?</td>
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<tr>
<td></td>
<td>When you go out in the community how do you get around? Will you need to be near a bus stop or near a center of town so you can use public transportation?</td>
</tr>
<tr>
<td></td>
<td>Will your family, friends or the supported living agency be driving you to any of the places you like to go? What areas or neighborhoods are they coming from?</td>
</tr>
</tbody>
</table>
6. **What is your weekly schedule for going out?** For example, do you go to a job everyday, or to a day program? Do you go to church or attend any other community groups or organizations? Where do you like to go and where do you need to go in the community?

7. **Places I Go:**

<table>
<thead>
<tr>
<th></th>
<th>How I Will Get There:</th>
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</table>

8. **Are there new places you want to go in the community?**

9. **Do you have any favorite places that you go to now like grocery stores, banks, parks, or recreational centers?**

10. **Would you like to live in a quiet neighborhood (for example with retired people and not much traffic) or a louder busy neighborhood with children?**
### Part Four: Tools and Applications

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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<tbody>
<tr>
<td>11. Would you be happiest and safest living with neighbors close by or</td>
<td></td>
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<td>would it be better if you lived on a large lot away from neighbors.</td>
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<td>12. What areas have you lived in before? What did you like about any of</td>
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<td>these neighborhoods? What didn’t you like?</td>
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<tr>
<td>13. What are some other things you might want to consider when you</td>
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<td>choose a neighborhood?</td>
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<td>14. Is housing affordable in the areas you would like to live? If the</td>
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<td>rent is high, do you want to consider having one or more housemates?</td>
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<tr>
<td>15. Does the neighborhood seem safe? If you take a bus would you feel</td>
<td></td>
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<tr>
<td>comfortable waiting at the bus stop?</td>
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<tr>
<td>16. Have you talked to any of the neighbors? Are they friendly?</td>
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</table>
House or Apartment Checklist
(from Towards Maximum Independence, San Diego, CA)

Here is a way to look at a house or apartment where you might want to live. It will help you decide what is good about the place and what could be better. The best way to use this checklist is as follows:

1. Make sure you get a chance to view the house or apartment and the immediate neighborhood.

2. If you need assistance with the checklist, ask your Community Support Coordinator or someone else you feel comfortable with.

3. Write notes about what you find out about the place in the box provided.

4. Think about all of these things before you decide if you want to live in the house or apartment or not.

5. You may be looking at several different places - use this checklist to decide which house or apartment is best for you.

1. The place is close to stores, banks, places to eat and other resources I will need.

2. The place is clean inside and outside.
3. The place is in an area of my choice.

4. The place is near and easily accessible to bus routes.

5. The neighborhood feels safe and I'm comfortable when I leave the house or apartment.

6. The rooms in the house or apartment are spacious and wheelchair accessible, if needed.

7. The place is in good repair.
8. I can afford the deposit required by the landlord.

9. The rental agreement is a: _____ month to month _____ lease and I am comfortable with this arrangement.

10. I have read over the rental agreement or had someone assist me to understand it.

11. The stove is gas or electric and it works well.

12. There is a refrigerator that works well.
13. There is a dishwasher that works well.

14. The heater/air conditioner works well.

15. A credit check is required: _____ Refundable _____ Non-refundable

16. The neighbors are friendly and supportive.

17. IHSS referral has been made.
18. If others will live there, they have agreed upon "house rules."

19. I am comfortable with the level of privacy I will have there.

20. The place is wheel chair accessible with ramps and enough space to get through gates.
House or Apartment Availability Checklist
(adapted from Towards Maximum Independence)

<table>
<thead>
<tr>
<th>House or Apt?</th>
<th>Address</th>
<th>Contact Person</th>
<th>Phone #</th>
<th>#Bedrms</th>
<th>#Bath</th>
<th>W/C Access</th>
<th>Pool</th>
<th>Deposit</th>
<th>Rent</th>
<th>Avail.</th>
<th>Extras</th>
<th>Subsidy?</th>
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Used during the home hunting process. If several individuals are looking for a place together, this can help them reach a consensus.
# Accessible House or Apartment Checklist*

*This can be used when looking for accessible apartments or houses.

<table>
<thead>
<tr>
<th>Apartment Name: ________________________</th>
<th>Address:_______________________</th>
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<tbody>
<tr>
<td>Phone: ____________________________</td>
<td>Manager: ______________________</td>
</tr>
</tbody>
</table>

1. What type of apartment do you have available?
   - □ Studio
   - □ 1 Bedroom
   - □ 2 Bedroom

2. What is the rent? $________ Studio    $________ 1 Bedroom    $________ 2 Bedroom

3. Is the apartment on the ground floor?
   - □ Yes
   - □ No

   If no, is there an elevator?
   - □ Yes
   - □ No

   Is there a step at the apartment entrance?
   - □ Yes
   - □ No

4. Is there a laundry room?
   - □ Yes
   - □ No

   Are there steps?
   - □ Yes
   - □ No

5. Are the entrances into the apartment at least _____ inches wide? (Put width needed to accommodate your wheelchair)
   - □ Yes
   - □ No

6. Is there a bathtub with/without (circle one) shower?
   - □ Yes
   - □ No

   Is there a shower stall?
   - □ Yes
   - □ No

7. Is there room in the kitchen for a small dining table?
   - □ Yes
   - □ No

8. Do you have off street parking?
   - □ Yes
   - □ No

9. Is the stove next to the kitchen sink or connected by counter space?
   - □ Yes
   - □ No

   Is the stove: ___ electric    ___ gas

   Is the refrigerator self-defrost?
   - □ Yes
   - □ No

10. Do you have a wheelchair accessible apartment?
    - □ Yes
    - □ No

**IF YES, PLEASE CONTINUE.  IF NO, YOU MAY STOP HERE.**
Part Four: Tools and Applications

11. Are there disabled parking spaces near the apartment? □ □

12. Are there grab bars around the toilet? □ □

13. Has the kitchen sink been lowered? □ □
   Has the kitchen counter space been lowered? □ □
   Has the stove top been lowered? □ □

14. Are the hanging rods in the clothes closet lowered? □ □

15. Is there an emergency call system in the bedroom? □ □

16. Is there space enough under the kitchen sink for a sitting person to comfortably put his legs? □ □

17. Do doors have ___ round or ___ straight door handles? □ □

18. Is the carpeting ___ shag, ___ short nap, ___ indoor/outdoor? □ □

19. Is there a ___ tub or a ___ roll-in (no step) shower? □ □

20. Is there an incline on the approach to the apartment? □ □
Things You May Need for Living on Your Own
(Adapted from CHOICESS, Arcadia, CA)

KITCHEN

___ DISHES

___ GLASSES

___ BAKING PANS

___ CONTAINERS

___ COOKING SPOON

___ PEELER

___ BOWLS

___ FRY PANS

___ POTS

___ SPATULA

___ MEASURING SPOONS

___ MEASURING CUPS

___ COLANDER

___ GRATER

___ SILVERWARE

___ FRY PANS

___ PITCHER

___ WHISK
KITCHEN

- Cutting Board
- Coffee Maker
- Toaster
- Can Opener
- Kitchen Towel
- Sponges
- Dish Soap
- Broom
- Mop and Pail
- Kitchen Knives
- Microwave
- Blender
- Hot Pad
- Dish Rack
- Trash Bags
- Paper Towels
- Dust Pan
- Waste Basket
Part Four: Tools and Applications

BATHROOM

___ RUG

___ TOWELS

___ SOAP

___ WASTE BASKET

___ CLEANSER

___ BATH MAT

___ WASH CLOTHS

___ TOILET PAPER

___ TOILET BRUSH

___ HAIR DRYER

BEDROOM

___ SHEETS

___ BLANKET

___ PILLOW

___ CLOCK RADIO

___ WASTE BASKET
MISCELLANEOUS

___ VACUUM
___ FIRST AID KIT
___ WASHER
___ TRASH CAN
___ SCALE
___ RAMPS
___ FLASHLIGHT
___ LIGHT BULBS
___ TOOL KIT
___ PICTURES
___ DRYER
___ BARBECUE
___ YARD TOOLS
___ TELEPHONE
___ ANSWERING MACHINE
___ SHELF PAPER
1. It is suggested that you complete the “condition on arrival” section prior to moving in and give it to your apartment manager for verification. **Please Note:** Some apartment managers may have their own form they use. If so, use their preferred form.

2. Have the apartment manager verify the condition as reported.

3. Sign the form and give it to the manager within two (2) days; any discrepancies should be resolved at that time. You could be held responsible for all discrepancies not listed after two days from your move-in date.

4. Keep a copy of this for your records and use the copy for a checklist when you move out.

<table>
<thead>
<tr>
<th>Item</th>
<th>Quantity</th>
<th>Condition On Arrival</th>
<th>Condition On Departure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carpets</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>T.V. Adapter</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walls/Ceilings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Windows (Drapes, Screens, Tracks)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Closets</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Miscellaneous</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* This form is completed within the first 2 days of the move-in. It is used to check the apartment’s condition when a deposit for the apartment is required. A copy is made for the apt mgr and the original is maintained by participant in notebook kept in the apartment.
<table>
<thead>
<tr>
<th>Item</th>
<th>Quantity</th>
<th>Condition On Arrival</th>
<th>Condition On Departure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carpets</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walls/Ceilings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Closet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Windows (Drapes, Screens, Tracks)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Miscellaneous</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Floor Coverings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walls/Ceilings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shower &amp; Tub</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Toilet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plumbing Fixtures</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicine Cabinet (Including Mirror)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sink</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Windows (Drapes, Screens, Tracks)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Light Fixtures</td>
<td></td>
<td></td>
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<tr>
<td>Miscellaneous</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item</td>
<td>Quantity</td>
<td>Condition On Arrival</td>
<td>Condition On Departure</td>
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<tr>
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</tr>
<tr>
<td>Carpet</td>
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<tr>
<td>Walls/Ceilings</td>
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<td></td>
<td></td>
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<tr>
<td>Closets</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Light Fixtures</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heating System</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cupboards</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Floor Coverings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walls/Ceilings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counter Tops</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stove (oven, hood, pan, filter, etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refrigerator (drip pan, ice trays)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sink/Garbage Disp</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dishwasher</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Windows (drapes, screens, tracks)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doors (knobs, locks)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Light Fixtures</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Miscellaneous</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patio (Porch, Deck)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yard</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carport/Garage</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Other</td>
<td></td>
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</tbody>
</table>
Now that you are moving to your own home you have a chance to decorate any way you want. Here is a list of things you might want to think about as you make your decorating decisions. You can write your answers in the boxes.

You may want to ask someone to help you think about each of these questions and help you understand all of the options you have. You may want to look at decorating magazines or go to furniture stores to think about what you want in your home. You may want to think about places you like to go and things that make you happy.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td><strong>What are your favorite colors? What colors do you not like?</strong></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td><strong>What are your hobbies or special interests?</strong> For example, some people love football and decorate with a sports theme or some people love country music and decorate with a country theme.</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td><strong>Do you collect anything? How do you want to display these things or will they be stored?</strong></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td><strong>Do you have items that are important to you that you want to use or have out?</strong></td>
</tr>
</tbody>
</table>
5. Will you have any pets or house plants?

6. If you already have some pieces of furniture that you plan to use – what colors are they?

Keep in mind every room can be decorated with different colors and with a different theme if you want.

I want to use the following ideas/themes and colors:

- **In my living room:**

- **In my bathroom:**

- **In my bedroom:**

- **In my kitchen:**
Monthly Budget Worksheet
(Adapted from CHOICESS, Arcadia, CA)

Telephone Bill __________
Rent __________
Haircut __________
Gas & Electric Bill __________
Groceries __________
Laundry __________
Dial-A-Ride or Bus __________
Fun __________
Out to Dinner __________
Savings __________
Vacation/Holiday Savings __________
Other __________

TOTAL __________
Section 2.
Tools and Applications for Supporting Choice and Self-Direction
Tools to Support Decision-Making
Considerations for Increasing Staff Support in the Face of Risky Decisions

If someone is making decisions which are putting him/her at risk, the following considerations should be addressed at an at risk meeting to determine whether more staff support/intrusiveness is justified.

A. What is the person's history of decision making?
   - previous experience or practice in exercising autonomy and rights
   - ability to learn from the natural consequences of poor decision making

B. What are the possible long and short term consequences associated with poor decision making?
   (What is the worst that could happen?)
   - death
   - exploitation
   - illness, injury
   - isolation, rejection by others
   - involvement with law
   - substandard living conditions
   - financial difficulties
   - lack of enriching experiences

C. What are the possible long and short term consequences of increased direction and control by staff or system?
   - decreased confidence or self esteem
   - likelihood of increased dependence on staff
   - improvement in person's quality of life
   - possibility of person refusing to work with Options. If this is likely, the following issues should be reviewed:

1. Under current circumstances, how is the person benefiting from Options involvement?
2. What would be the impact of Options terminating services if the client refuses our increased involvement?
3. Does the client require protective measures to be taken, i.e. guardianship, protective placement, other?

D. What are the trade offs of continuing the current situation?

E. Existence of safeguards to protect person's rights?
   - Is the person sufficiently assertive to advocate for his/her rights?
   - Is there the presence of an advocate, friend, or guardian to represent the person's interests? If not, should Options locate such a person?

F. Should more control and direction be provided? If yes, list proposed support.

(Originally adapted from OPTIONS, Madison, WI; reprinted from Patterns of Supported Living, Department of Developmental Services, 1993)
Considerations for Increasing Staff Support in the Face of Risky Decisions

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C. What are the possible long and short term consequences of increased direction and control by staff or system?

D. What are the trade-offs of continuing the current situation?

E. Existence of safeguards to protect person's rights?

F. Should more control and direction be provided? If yes, list proposed support.
Excerpts from
A Guide to Training in Decision-Making for People with Developmental Disabilities

Horrigan Cole Enterprises

Originally Printed, June 1996
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For more information on this guide, contact
SherryBeamer@compuserve.com
Basic Steps in See Think OK Go (STOG)

Step 1: “See”

The first step is “What do I see”? or “What is the choice or problem?”

Step 2: “Think”

List all the possibilities or solutions to the choice or problem.

Step 3: “O.K.?”

Go back to the list of ideas and decide which solution or choice you like best.

Explore all parts of the possible solution or choice by thinking about four symbols and answering some questions that go along with these elements. The four elements are:

- HEAD
- HEART
- HANDS
- FUTURE
HEAD
The head stands for the sensible part of the choice. To decide if a choice is right for you, ask yourself the following questions:

- Can I afford this choice?
- Will this choice help me get other things I need and want?
- Is this the best choice for me?
- How will this affect me in the future?
- How will I feel about this choice tomorrow?

HEART
The heart stands for how you feel about your choice. The following questions will help you learn how you feel:

- What do I think about this choice today?
- Do I feel happy? Why?
- Do I feel afraid? Why?

Sometimes a person feels one way about a decision, but after some thought changes his or her mind. It’s okay to change your mind about a decision if it’s truly what you want. Make sure the decision is based on what is best for YOU. Your decision should not be based on what someone else has “talked you into.” Your first reaction to a decision is usually the right choice.

HANDS
Hands represent how a choice will affect other people. Ask yourself:

- Whom will my decision affect?
- How will my decision affect others?
- Will anyone try to stop me from making this decision? Why?
- Is there someone I should ask for advice?
- What are my responsibilities (legal)?
- Is it safe?
FUTURE
Future talks about if and how your decision will affect the rest of your life. Hopefully you have a dream for your life. Your choices and decisions should help you to live your dream.

<Assist the group in reviewing each choice or solution by using the pictures on the following page: “Head, Heart, Hands, Future.” Then, ask the group to discuss which choice or decision seems the best. This will be their choice or solution.>

Step 4: “Go!”

The last step is to try out your choice or solution. This is an important step because many people do not actually do what they say they will. When you are finished, ask yourself if the choice or solution worked. If not, you can use the S.T.O.G. again to find another choice or solution. Use S.T.O.G. for making decisions in your self-advocacy group, or for personal decisions in your life.
Part Four: Tools and Applications

S.T.O.G.
A Good Way to Make Decisions

See

What do I see? (What is the choice or problem?)

Think

Think about and list the possibilities or solutions.

1. 🌟
2. 🌟
3. 🌟

Then think about:

Head - Is this the best choice for me?
Heart - How do I feel about this choice?
Hands - Who will be affected by this choice?
Future - How will this affect my life and/or dreams?

O.K.?

Make a decision

Go!

Go for it! How did it work?
S.T.O.G.
A Good Way to Make Decisions

**See**

What do I see? (What is the choice or problem?)

I want to find a boyfriend.

**Think**

Think about and list the possibilities or solutions.

1. **Try to find someone through the telefriend program.**
   - Yes
   - Heart - The regional center telefriend program is safe
   - n/a
   - I want to leave the group home to live with a boyfriend

2. **Go to a party or dance given by a group I know.**
   - No
   - Heart - It’s safer to go to a party given by people you know
   - n/a

3. **Meet somebody at work.**
   - OK
   - Heart - I work
   - n/a

Then think about:

- Head - Is this the best choice for me?
- Heart - How do I feel about this choice?
- Hands - Who will be affected by this choice?
- Future - How will this affect my life and/or dreams?

**O.K.?**

Make a decision

I will try the Regional Center telefriend program.

Go!

Go for it! How did it work?

I called the Regional Center. I am waiting for the information.
Part Four: Tools and Applications

S.T.O.G.
A Good Way to Make Decisions

See

What do I see? (What is the choice or problem?)

Some decisions (like planning meals or choosing foods at the market) take a long time to make. When I'm under pressure I get nervous and I can't make a decision.

Think

Think about and list the possibilities or solutions.

1. Tell, in a polite way, the person who is putting pressure on me to make a decision, to give me some more time.
   Yes - I need I may get verbally more time.
   I want to think faster to make decisions on my own.
   Others may have to wait.
   My mom may get upset.

2. Make a choice and don’t worry if it’s completely right.

3. Plan or get information before I need to make a decision, or find someone to discuss it with, so I know what I need to do.

Then think about:

Head - Is this the best choice for me?
Heart - How do I feel about this choice?
Hands - Who will be affected by this choice?
Future - How will this affect my life and/or dreams?

O.K.?

Make a decision Tell, in a polite way, the person who is putting pressure on me to make a decision, to give me some more time.

Go!

Go for it! How did it work?

I don’t have the courage yet to say “give me more time.”
As more and more people with significant disabilities are moving from group homes to supported living the challenges in supporting them in their choices increase. The staff involved with these individuals are often told to simultaneously support choice, build community relationships (and acceptance) and assure health and safety. Staff blessed with common sense understand how to achieve this balance instinctively. However, many other staff members solve the perceived dilemma by only hearing the first or the last part of the message. They either support choice regardless of consequences or overly restrict people in the name of health or safety. The middle part of the message, building community, gets lost in the struggle between choice and concerns over health and safety. What staff (and managers) often miss is that this is a balance, a balance that needs to be defined with each person supported.

In searching for ways to help people understand how to achieve a balance in supporting people I came across Charles Handy’s “doughnut” principle (see figure 1). As adapted for use in supporting people with developmental disabilities, it suggests that there are three areas of responsibility that we can define with each person we support. At the center of the doughnut are the core responsibilities, those things that we expect staff to do without fail. These “core responsibilities” are typically a mix of issues of health or safety and those things that are most important to the person supported. The ring just outside of the core represents those areas where we expect staff to use judgment and creativity. They may continue to include issues of health and safety but they are in areas where staff are expected to try new ideas and not be punished if the ideas do not work. Outside of the doughnut are those areas that are not our responsibility, that are none of our business.

The boundary between core responsibilities and areas where people are to use judgment should be sharp and clear. If this conceptual framework is to be helpful, sufficient time must be taken with staff to be certain that each person understands what responsibilities are within
the core and which are in the area requiring judgment. On the other side, the boundary between what is and is not our business, is deliberately kept “fuzzy”. For example, what someone wears might be “none of our business” on a day to day basis but should fall into the area of “use judgment and creativity” when something inappropriate is being worn for a job interview.

The content of each area within and outside of the doughnut varies widely from person to person. Two people who illustrate how this works are Jon and Elizabeth. Jon lives in his own apartment in Benicia, California. Jon is a man with a great imagination who is also an eloquent presenter. He has found that traditional disability system employment programs (workshops, enclaves, and work crews) do not work for him and is trying to build a career as a speaker and consultant. Jon also has Prader-Willi syndrome and much of his support revolves around helping him maintain the independent life that he loves while staying within his very limited diet. Some examples of the 3 areas of staff responsibility inside Jon’s life are shown in figure 2.

Elizabeth is a woman who one friend described as a busy lady who wants to be busier. People who met her during her recent presentations to the Presidents Committee on Mental Retardation and at TASH in New Orleans have commented on her charm and wit. Those who have taken the time to talk with her have realized how much we have to learn from what Elizabeth has to say. As this is being written, she is living with her family but this will change as soon as she can recruit a qualified paid roommate. Because
Elizabeth communicates by pointing slowly to words it is easy to not listen to how she wants to be assisted and Elizabeth needs a great deal of personal assistance. She relies on others for most of her personal care and eats using a G-tube. On the other hand she gets around quite well in her power chair and doesn’t need anyone with her when she is off visiting during a conference. It will be critical for Elizabeth’s life that staff understand their three areas of responsibility, some examples of which are shown in figure 3.

In the not too distant past we were quite comfortable in deciding where people with disabilities should live, who they should live with and how they should spend their time. Now we are trying to help people direct their own lives. We plan with people rather than for them and struggle to support the choices of each person. When we are careful and successful we help each person find the balance in their lives. A balance that reflects what people want, the resources available to them, and any issues of health or safety. Not surprisingly one of the lessons that we are learning is that we need to help staff find the same balance in the support they provide. This adaptation of Handy’s “doughnut principle” provides a structure to help staff find that balance with each person they support.

December, 1996

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Choice is the most powerful word and the most abused word in the current lexicon of the disabilities services system. For some people choice means that how they want to live has been discovered and carefully supported. For others choice is an excuse or the basis of a bizarre rationalization. Perhaps because choice is the word de jour, it has been used to argue that congregate facilities are needed in order to ensure residential "choice". An even more egregious example is justifying the use of pain to control behavior to allow "choice among a full range of treatment options". (The same argument could be made to retain "bleeding" as a treatment option for the flu.) Other abuses are more subtle. When you look behind the rhetoric of agencies which say "we offer and teach choice", you find places that ask people what they want to wear but not who they want to live with. What appears to be absent is depth of understanding and a sense of balance. A single word is being used for complex concepts. Too often, there is no recognition of the need for an individual balance between honoring choice and ensuring safety.

Preferences, opportunities, and control
Choice, as it is being used in current disability discussions, appears to have 3 related concepts embedded in it - preferences, opportunities and control. Preferences include not only what someone likes but also their desires and dreams. Preferences includes: who people want to spend time with; what to do during that time; and where to spend their time.

Opportunities are the available array of: people to spend time with; things to do during that time; and places to spend that time. Opportunities should also include being able to spend time by yourself.

Preferences reflect what people want while opportunities reflect what is available.

Control is the authority to make use of an opportunity to satisfy a preference.

Looking at preferences, desires and dreams
Any effort to support choice should start with discovering what is important to the people who are being supported. What do people want in their relationships with others? How do people want to spend their time? What do people want to do (and not do)? What kinds of environments in general and what specific places do people want to spend time in or avoid? Do people have dreams about how they would like to live and do they have nightmares about what they are afraid will happen to them?

While answers to these questions are sought (with varying degrees of emphasis) in all of the formal processes for person centered planning, careful efforts are required. Many people lack the life experiences necessary to know what they
like and dislike. Will something that sounds desirable to a person feel that way when it is experienced? Some people want to try things or live in ways that put their safety or health (or both) at risk. Many people need to have a life of their own before they can have a dream of their own. As people try things (and as they age) their preferences change. In a system that offers real choice, people continuously have opportunities and are continuously supported in expressing their preferences. Supporting choice requires that there be recognition that everyone has preferences and desires regardless of the severity of disability.

Supporting choice also requires that we recognize that what we need to know is taught by the people that we support. Some of what my colleagues and I have learned about preferences from the people that we have listened to follows.

We have taught learned helplessness, now we need to teach trust
Many people have experienced systematic ignoring of their preferences. This is an unintended consequence of current "individual" planning and professional practice within the disability system. We cope with the poverty of opportunities for the people we support by suppressing their preferences for what is absent. "Learned helplessness" has been taught and many of those we support have learned this lesson well. For these people, what needs to be taught is that we can be trusted. Trust is "taught" by having those with control listen to all expressions of preference and, where possible (and sensible), to help people get what they want. "Teaching choice" is a poor label. Those who teach must remember that they are not "offering choices" but soliciting preferences and then demonstrating that staff can be trusted to honor the preference expressed. Staff must learn to acknowledge the preferences that people are expressing with their behavior while not asking what people want until there is a commitment to honor their requests.

Shouting (with behavior) has been the only way to be heard
Most of us have had the experience of raising our voices in the belief that it will increase understanding. We shout so that we will be heard. A number of people with disabilities have learned to "shout" with their behavior because it is the only way that they are heard. If you do not like your current job, complaining about it does not produce change. Acting in unacceptable ways does produce change. Complaining about who you live with is unlikely to get you a new roommate, but aggression often works. "Shouting" gets our attention, but rarely gets people what they really want. We need to listen for the preference that is underneath the shouting. Once real preferences are understood (and acted on), the need for "shouting" with behavior is eliminated (although the person may always be someone who has a loud "voice").

Most of what people want is modest
What people want is usually modest. When critics say that we cannot afford choice they have typically confused what is important to people with what might be nice to have. There is also a difference between learning what is important to people and taking someone on a guided fantasy. Careful planning discovers preferences such as: having a say in who
helps me; having privacy in the bathroom; being asked not ordered; going for a walk when I want; and (for one person who uses a wheelchair) to be able control the direction in which I face.

**A few people's desires are not modest**

While the vast majority of people have modest desires, there are a few people who sincerely want frequent trips to the tropics, a car continuously at their disposal and support staff who take on the role of servants. They may see these as essential to a reasonable quality of life. They are "virtual yuppies", without the income needed to support their desired lifestyle. They are also unusual, as careful planning identifies very few people with these expensive tastes. Where rational decisions are being made about allocation of resources, these people are disappointed with the outcome.

Some people have reasonable requests that are difficult to afford

The fact that someone wants something, even if they see it as very important, does not mean that it has to be delivered. However, we do have an obligation to respond to sincere requests as we can. For example, there are many people who would like to try living by themselves. The cost of support (in staff and housing) presents a real challenge to those attempting to create a system of support. The demand for living alone is somewhat reduced when there is more careful listening. For example, some people really do not want to live alone but simply do not want to live with other people who have disability labels. Other people have always had to share lives (e.g. it is Tuesday so we all go bowling) and have not learned that you can also live with someone where you only share space.

After these situations have been clarified there are still many people who simply want to have the experience of living by themselves. Where people have been able to live by themselves for a year or two, many would like to have a roommate for company (but not to share lives with). Some people, however, find that living alone is the only way they wish to live. The support costs for most of these people decline dramatically as behaviors change, skills are learned and connections to the community are built. However, the cost of support for some people remains high. From the perspective of a system, a small percentage of people can always be supported in relatively expensive lives. The challenge is to not have that percent exceed the resources available.

What people don't want is as important as what they do want

In learning people's preferences, it is important to discover what they dislike. Simple lists are not adequate. We must go beyond a statement that George likes barbecues and dislikes broccoli. We have a significant degree of control over who we spend time with and what we do. We use that control to avoid people and activities that we strongly dislike. People with disabilities have not had that control. In the absence of being able to "vote with your feet" we need to insure that those things that people hate or strongly dislike are absent.

Choice making is not a solitary activity

Figuring out what we want is usually not a solitary activity. To tell people that
yesterday we made the choices and that today they are in charge is to ignore that few of us make significant choices without discussion. Before we make major decisions, such as changing jobs or changing partners, we have typically discussed the "pros and cons" at some length. We seek advice, support and people who just listen. We strive to determine what is right for us. We frequently get conflicting advice and pick the advice that agrees with what we want. We reserve the right to make "bad" choices after we have heard the "good" advice. People with disabilities need the same opportunities.

What people ask for may not be what they want
People will ask for those things that they know about. One woman who was being assisted in leaving an institution said that she wanted to move to a "group home". One man said that he wanted to live alone. The woman who said that she wanted to live in a group home spoke very little English. She knew that she wanted to leave the institution and the only place away from the institution that she knew of was a "group home". The man who said he wanted to live by himself thought that the only choices that existed were to live by himself or with other people with disabilities. The woman is living happily in supported living and the man is living in a house that he wanted where he rents rooms to 5 people who have no formal disability labels.

When people express a desire for a job (or anything else) where their disability or circumstances preclude obtaining what is asked for, we need to listen to what lies beneath the surface. One man said he wanted to be a pilot. After a lot of discussion we discovered that while he did want to be a pilot he also just loved airplanes. We could not help him become a pilot, but we could help him get a job at an airport. Some years ago I worked with another man who said that he wanted to have a job just like his father's. His father is a well known research scientist with the federal government who determined what projects got funded. Many conversations later we found that the characteristics that mattered to him were that he be treated with the same respect that his father received and that he wear a tie to work. We helped him find a job where he wore a tie and ran a large copying machine at a facility that did scientific research. If you were a scientist who wanted your latest journal article copied you went to his copy center. If you just filled out the form your article would get copied in turn, if you treated him with "respect" he would do your copying while you waited.

Sometimes what people want is not possible
A woman I met in the Midwest, Susie, wants to live with her mother. It is so important to her that she sees it as the only acceptable place for her to live. Unfortunately this is not possible. Susie had lived with her mother for several decades and her mother had been the person who provided care and support. After a sudden loss of capacity, Susie left her home and entered a hospital and then a nursing home. The supports necessary to support Susie in her mother's house are available and affordable. However, Susie's mother would not agree to her return regardless of the supports that could be provided. This is not to disparage Susie's mother. She continues to be deeply caring and
intimately involved in Susie's support, but she is "burnt out" as a caregiver. In these circumstances our obligation is to acknowledge and honor the positions of both Susie and her mother. Honoring her mother's position requires that we not use guilt or otherwise coerce her to support Susie's return to her home. It requires that we support her in developing her new relationship with her daughter. Honoring Susie's position requires that we acknowledge what is important to her and help her get on with her life. We have to avoid the temptation to deny the presence of a preference that cannot be realized. We also have to help Susie deal with a very real loss and to help her begin to develop new relationships. She needs support in her changing relationship with her mother and in developing new relationships.

Helping people be safe and happy requires thought and effort

One of the traps of the current system of planning is that we determine how people can be safe before we look at what they require to be happy. We forget that there is no such thing as a risk free life, that risk is relative and has a context. What we need is to begin with an understanding of what is required for the "pursuit of happiness" and then seek to reduce or avoid risk within that context. What is not acceptable is to simply say it was his choice, that is why I stood by while he hurt himself. Helping people be happy and safe requires thought and creativity. The following stories give some examples of the efforts needed.

A story that I enjoy telling (and writing about) is that of a man who wants to go for walks whenever he wants and who also thinks that, when he crosses a street, traffic should stop for him. The initial thinking was that he needed one to one staffing across all waking hours. The cost of the staffing necessary for a couple of walks each day was an expense that was disproportionate to the result. On the other hand, not being able to go for walks on his schedule significantly reduced the quality of his life. Further discussion lead us to realize that this man would be happy to live in a rural setting. He moved to a house on a five acre Christmas tree farm where he goes for walks whenever he wants without having to cross a street.

One man that we did planning with liked to use "found objects" in his art projects. The challenge was that he would "find" objects in stores and leave without paying for them. He understood the concept of money but was remarkably uninterested in it. The people who supported him could have said that it was his "choice" and let him be arrested. Instead they would go to stores with him, with his money in their pocket. (He would give his money away if it was in his pocket.) As they left each store the support staff would ask if he had "found" something in that store and, if yes, the staff would pay for it.

We got a phone call several years ago from a service provider asking for help with someone who was severely injuring himself. This man is now described as a tall, charming, ladies man who does not use words to talk. At the time, his brother said that he looked like a hockey goalie with the helmet and all of the padding that he wore to keep from injuring himself. There were people who said that he needed a "more restrictive" setting and there were people who said that pain
should be used to control his behavior. The service provider could have argued that an institution would be the "safe place" for him to be. Instead we were asked to help the provider "listen" to what this man was asking for. After listening to what he was saying with his behavior and after listening to what those who loved him knew, we found that there was no single answer. However, there were a host of simple things that we could do. There were many ways in which we were not listening to how he wanted to live. Some examples include that he: needs to close all doors (except for his bedroom door at night) and to line up all shoes; must be able to make and eat his own snacks when he wants them (including raw onions with salt); must not be ignored (even if it is planned); and he must always have a non-glossy magazine to hold onto. His life is not perfect and he still gets upset occasionally. On these infrequent occasions he still needs people who keep him from hurting himself. However, because we have been listening carefully to what he is asking for, he is living in his community. He lives (and goes to concerts with his brother) without pads, splints or a helmet.

Choice requires opportunities and sharing control
A preference is something that people want. Unless they have already experienced it, they will not know whether or not they like it or not. Many people with disabilities have never had the life experiences necessary to determine how they really want to live. Honoring choice for these people requires opportunities and taking advantage of the opportunities may require encouragement. As people begin to find that their choices are honored they want control over those choices. Honoring choice requires that control is shared. This is the subject of part 2 of revisiting choice.

Revisiting choice - part 2
Choice, as we are using it, is a simple word that contains 3 concepts - preferences, opportunities and control. Learning people's preferences is a complex and ongoing activity. What people want (and the values that underlie their desires) provide a picture of how people want to live. This was the subject of part 1 of "revisiting choice". However, learning how people want to live is only the beginning. It is the necessary foundation but just the foundation. In order to get the life that you want and to maintain it, you need opportunities and control.

For people with disabilities, the absence of control and opportunities is a devastating combination. Flooding people with opportunities or simply handing over control can be equally devastating. Everyone needs opportunities and everyone needs control but they need them on their own terms. People who have never had opportunities need to sample life in their own way. Some people need to dive in. They do not want and cannot tolerate transitions. Others are most comfortable with first putting a toe in. They want lengthy and careful transitions. Both need the control necessary to change their minds. Some people have been demanding control over significant aspects of their lives and we have seen them as having challenging behaviors. Some have given up hope and we see them as withdrawn or even as compliant. However, regardless of the severity of disability,
people want control over parts of their lives.

Providing opportunities, sharing control

Having control is how we maintain a balance in our own lives. Each of us needs control sufficient to keep (or secure) what we value in our lives and to reject (or leave) situations that we cannot stand. One definition of emotional health is that we recognize what a balance is and that we recognize opportunities that enable us to maintain or enhance that balance. That is, we are able to use opportunities to get more of what we value or less of what we dislike. Control is what allows us to try new things and discard them when they do not fit. Control is what we require when we find our lives out of balance and we look for the opportunities that will bring a positive balance. The situations we find the most frustrating are those where we lack control and/or where the opportunities that we need are absent.

Control is a complex concept. Having control means that we have to make decisions and all of us create a set of positive rituals or routines that allow us to get through much of our day without treating each situation as if it were new. Most of us do not want absolute control. We may joke that if we were in charge of the world we could fix things, but most of us want (and welcome) limits to the areas where we have to make decisions. We conform to large sets of societal rules without much thought and only remark on those few areas where we disagree. Those of us who live with others find that we have to share control. Each of us has our own rules that we insist that our partner honor and our partners expect the same of us. Where expectations regarding behavior are not met, or are mutually exclusive, conflict arises. The outcome of a resolved conflict is a mutual agreement on the behaviors expected. Our vision of the best outcome is that our partners will see the error of their ways and the wisdom of our words. A more rational outcome is that each of us will better understand the other and make the compromise that works for the relationship. In reciprocal relationships control is shared.

If we apply what works for everyone to people with disabilities, then we should be helping people with disabilities to have sufficient control to maintain a balance in their lives and to create their own rituals and routines. We should help them develop relationships (both paid and unpaid) where control is shared. A brief description of what the disability system should be doing is: to discover how people want to live; provide them with the opportunities necessary to get the lives they want; and help them have the control needed to maintain it. Many of the challenges in doing this arise from the disabling environments in which people have lived. We have created these environments with a binary view of control. Either I have control or you have control. The idea that control can and should be shared seems to be an alien concept.

Control, opportunities and preferences as developmental triplets

Parents support the development of their children by asking the child to choose from alternatives and then honoring the choice the child makes. As children grow in capacity and experience, the span of control gets broader. Children may move from what they will wear, to when they
will go to bed, to how they spend most of their waking hours. They move from nearly constant supervision to doing what they want within defined (and often disputed) boundaries. Parents transfer control slowly. All parents worry about whether their children are "ready". When a child breaks a rule about the boundaries of behavior, the child loses control for a time (smaller children may go to their rooms, older children may be "grounded"). Parents share control with their children while they are transferring it. Typical children go through phases where they rely on their parents control for most things, go through a period were they both want and do not want parental control (teenagers can simultaneously tell their parents that they are ruining their lives while wanting limits to push against), and end up, as adults, with control regardless of their parents desires.

For people with disabilities the analogy with the developmental process that children pass through is both helpful and dangerous. It is helpful in that it provides some guidance as to where someone is and how we might help them move forward in a safe and rational way. The analogy breaks down as the inevitability of autonomy for typical children is not present for people with disabilities. It is dangerous in that we are talking of supporting adults who may have already been trapped by developmental concepts such as mental age.

**Control and capacity**
How much control we have and what we have control over should be a function of desire and capacity. However, our stereotypes of people with severe cognitive impairments cause us to over look the capacities that are present. I have met a number of people who do not use words to talk but who are good at training staff in listening to their behaviors with regard to what they want. They demonstrate a much greater capacity for (and interest in) controlling their lives than they are given credit for. At the same time, we need to recognize that positive control is learned and control should coupled with a knowledge of consequences.

We need to ask, what are people asking for and how can we help them get it without putting them at unnecessary risk. It can be as simple as supporting Rhonda, who uses a wheel chair, in being where she wants to be. Any sunny warm day she will want to go outside and enjoy the sun. Unfortunately, she is also very allergic to pollen and needs to be told, on days with a high pollen count, that she would not enjoy the consequences of going outside.

**Timing and opportunities**
Timing is important in how people respond to opportunities. We tell our friends that we are not ready or that we will do it when we are ready. Opportunities have a developmental sequence. People need to be offered what they are ready to try. What people are ready for and when they will be ready requires judgment. Given the uneven, but generally impoverished, life experiences that people have had, they need to be encouraged to try new things. They may need to have an opportunity presented again and again. Judgment is required to determine where encouragement stops and coercion starts. At the same time a lack of experience coupled with uneven deficits in skills and capacities makes people more vulnerable. Opportunities can lead to
injury and judgment is again required. There is little growth that comes without risk. People need to be able to fail and to feel hurt. Supporting people in having opportunities so that we will know what they will want tomorrow is as important as it is to learn what people want now.

What opportunities we provide, hold back, encourage people to find, or protect people from, depends as much on our values as they do on the preferences and capacities of the people we support. We need to listen to ourselves when we say that someone is not ready or that they should be able to do something simply because it is their choice. Our values influence and often control what we support. We need to talk about what our values are so that we understand the basis on which we are making decisions. We need to remember that the opportunities that are made available depend on the values of those with control.

Looking for control
Most of us seek, and to a large degree achieve, the amount and kind of control that we want over major aspects of our lives. Control is part of what gives us the predictability that we value. One of the more devastating feelings that people report is being out of control or experiencing a loss of control. When we have less control than we desire, increased emphasis is placed on the control that remains. For people with disabilities who live in very controlled settings, control is sought where ever it can be found. Some of the behaviors that we want to change around food, aggression, self-injury and sexuality are a reflection of a lack of desired control over other aspects of life. When people gain positive control over their lives, the behaviors that have caused us concern may diminish and with some people vanish.

The difference between sharing control and giving control
Control is not a fixed quantity. It ebbs and flows in our relationships and it can ebb and flow with the people we support. An agency in North Carolina that is supporting people with severe and persistent mental illnesses as well as cognitive impairments sees control as moving toward the person supported whenever possible but also returning to staff when the person supported has an acute episode. Someone with a severe seizure disorder may be able to do some things when the seizures are under control and should not have the same opportunities when the seizures are not under control.

Rethinking choice
Our recent history is filled with stories of people whose lives were totally controlled and who now live in happy interdependence. People who were seen as not competent to select what to wear are now living in their own homes. We are also hearing of the people who have been injured when some one used choice as an excuse to not think. We need to recognize that the people we support are the experts on what they want, while we are their partners in helping them get it. We need to have relationships where we share control and continuously support people in gaining as much control as is possible. Many people, especially those with severe disabilities, are only asking for modest control. They want to be able to: control the pace of life (to not be rushed); to be listened to (to only got to bed when they
are sleepy); and to have a say in who their staff are (to only be supported by people that they trust).

In our relationships, we should help people grow and remember that there is a dignity to risk. At the same time, there is no dignity in serious injury. We need to see the key to growth as starting with understanding what people want today and then helping people find opportunities so that they will know what they want tomorrow. We need to recognize that everyone wants and needs control over some aspects of their lives. Our jobs include supporting people in gaining that control.

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Tools to Help People Hire Their Own Staff
Some Tips on Hiring a Personal Assistant  
(adapted from Becoming Independent, Santa Rosa, CA)

About Your Lifestyle
Before considering hiring someone to work for you in your home or looking for a roommate it is helpful to assess what kind of person you want to be with by first looking at your own personal lifestyle preferences. Once you have an idea of the kind of lifestyle you prefer you will be able to decide what kind of person will fit into your lifestyle. Ask yourself the following questions:

Personal habits, etc.
1. Do I smoke?
2. Do I drink alcohol?
3. Do I take drugs or smoke pot?
4. Do I like to sleep late in the morning or get up early?
5. What time do I usually go to bed at night?
6. Do I go out to visit friends or participate in activities?
7. Will I want to entertain friends and family at my home?
8. Am I ok with my roommate having overnight quests?
9. What do I like to do for entertainment?
10. Do I like to watch TV? What are my favorite shows?
11. Do I like to listen to music? What kind? What volume?
12. Do I like a quiet atmosphere?
13. Describe my personality?
14. Do I consider myself easygoing?
15. How do I react if I have to change my plans at the last minute?
16. Is there a spiritual aspect to my life which is important?
**Food and eating arrangements**
1. What kind of foods do I usually eat?
2. Do I like to cook?
3. Where do I shop for groceries?
4. Do I eat at regular times or when I feel like it?
5. How do I feel about eating with my Personal Assistant?
6. Do I have kitchen appliances and/or dishes, pots and pans?

**Housekeeping**
1. What do I do around my home for cleaning and laundry?
2. Do I like things very neat or am I not particular?
3. Would I like a definite cleaning schedule or a casual arrangement?

**Personal Care**
1. How often do I bathe and/or shower?
2. What are my basic grooming habits? How long does it take?
3. Do I need any help from a Personal Assistant with my personal care?
Job Description

Now that you have clearly defined your needs and examined your lifestyle preferences, you are ready to make a formal job description. This job description will be a major tool with your face-to-face interview in the hiring process. You may want to ask for assistance in this process from your supported living agency.

Benefits of Job Descriptions

• Gives you an opportunity to define your lifestyle, strengths and limitations.

• It can be used as a guideline for more in depth questions in the interview process.

• It will give a prospective employee an idea of what the position requires.

• After an individual has been hired, it can serve as a checklist of duties of the position.

• You, the employer, can use it as an evaluation tool for your Personal Assistants.

• It can be used if there are disagreements regarding the job responsibilities.

• This job description can help to keep the relationship open.
Developing a Personalized Job Description

1. State the title of the job you are describing:

2. Describe the schedule of the job including days and hours of work:

3. Describe the areas that you need assistance with:
   - Personal care needs:
   - Grooming needs:
   - Bathroom needs:
   - Lifting/Transferring needs:
   - Meals:
   - Housekeeping:
   - Mobility/Transportation:
   - Medication:
   - Communication:

4. Describe what kind of training you will provide for this job:

5. Describe the Supported Living Agency’s policies and/or record keeping duties:

6. Describe the wage, pay schedule, benefits and other compensations.
How to Write a Personal Employment Ad

Writing an ad to find someone to hire as your personal assistant or companion is a real skill that will help you get started on hiring the right person to work for you. Here are some suggestions for writing an effective ad.

**Step 1: Cost of the Ad**

Figure out how you will get funding for an ad if you decide to advertise in a newspaper. Some supported living agencies may be willing to pay this nominal fee to assist their consumers in this step of the hiring process. If there will be no costs for your form of advertising, you may want to gather the materials (e.g., marking pens, typewriter, or colored paper for flyers) you may need to begin this project.

**Step 2: Research**

Read the classified ads in the newspaper or other sources for attendants, caregivers, aides, etc. This can give you an idea of how to or how not to write your own ads. See which ads seem attractive to you and develop an ad with some of those ideas in mind.

**Step 3: Writing**

Start with the bare essentials (See Precautions):

1. Title or name of position available
2. Job prerequisites (e.g., needs car, non-smoker, prior experience)
3. Pay and schedule
4. Where to contact for more information, e.g., a phone number

**Precautions**

When writing your personal employment ad there are some precautions to take as this information is going to the general public and not to people you already know and trust. Some general guidelines:

1. Do not give your full name in the ad
2. Do not give your street address
3. For newspaper ads, do not mention if you are a male or a female

**Step 4: Finish**

Now you can have fun and make some additional descriptive statements that may make the ad more attractive to someone interested in the job. For example:

1. Energetic, young woman.....
2. Active man in his thirties looking for.....
3. College student with disability needs help with...
4. Very social woman with physical disability needs....
Phone Interview Questions

- What is your name and how do you spell it?
- What is your address and phone number?
- How did you hear about the job?
- What experience do you have that relates to my job?
- Do you have any experience doing personal care with intimate contact?
- Why are you currently looking for a job?
- What do you use for transportation?
- Do you have car insurance?
- Are you willing to drive for me?
- Do you smoke or use alcohol?
- Do you have any physical limitations that may affect your ability to do my job?
- Can you lift up to ____ pounds?
- What hours and days of the week are you available to work?
- Would you consider a Live-In position?
- Would you consider Relief or On-Call work?
- How much money do you expect to be paid?
- Would you like me to send you a job description and application?
- After I receive your application could you come meet me for an interview?
- Do you have any questions about me or the job that I have available?
Tips for Interviewing

Conducting a good interview is a true skill. A “good” interview is one that results in both parties being heard and understood by each other. Here are some tips.

- Arrange for privacy.
- Limit physical barriers (such as desks or extra furniture) to ease conversation and make applicant comfortable.
- Introduce yourself and anyone else involved with the interview.
- Describe the job.
- Preview the interview process.
- Explain you will be taking notes.
- Tell the applicant when they will hear from you again.
- Ask each applicant the same questions for ease in comparing answers.
- Use prepared situational questions like....
  
  Can you tell me an interaction you had with a disabled person that was positive/negative?

  Describe a time you were overwhelmed and how you resolved it.

  What makes you want to be a paid roommate?

  In terms of time, what kind of commitment to such a position (to me) are you willing to make?

  What other interests or activities are you involved in which would affect the amount of time or support you will be able to provide to me?

  What will you expect from me as a roommate?
Hiring People to Provide Personal Support Services

*(Towards Maximum Independence, San Diego, CA; reprinted from Getting to Know You: Planning for Services in Supported Living, CIRCL, 1999)*
ADVERTISING FOR AN ATTENDANT

Be creative and imaginative as you can in selecting where and how to advertise. Ask others who have done this what has worked for them. This is a very individual thing and will depend on your specific needs and the resources in your community.

Places to Advertise
- Local newspaper, weekly advertiser, etc.
- Financial Aid Office (i.e., community colleges, etc.)
- Bulletin Boards (i.e., apartments, grocery stores, libraries, etc.)
- Word of mouth
- Social Service Agencies/Church Newsletter

Sample Ads
Full-time personal care attendant needed for female with a disability. Assist with personal care, grocery shopping, housekeeping, etc. Minimum wage, hours vary. Ideal for student. Call ________________.

Part-time personal care attendant needed for male. Eight to twelve noon weekdays, $____ per hour. Call ________________.

TELEPHONE SCREENING

1) It is important when talking on the phone to be friendly and pleasant.*

2) Give a brief description of what the job is, the pay and the hours.

3) Ask if this is the type of position the person is looking for or interested in.

4) If the person is not interested, thank them for their inquiry and hang up.

5) If the person is interested, set up a time to meet and conduct a formal, personal interview. Be sure and get the person’s name and phone number in case you need to reschedule. For safety reasons, it is highly suggested you have someone you trust present at the formal interview, perhaps a parent, friend, casemanager, etc.

* Suggestion: Limit information about yourself over the phone - maybe have it written down so that you can share it during the personal interview.
Attendant Application

Part A -
Name: ___________________________
Phone No#: Home_________________/Work__________________________
Address: ___________________________
                        ___________________________
                        ___________________________
Contact in case of an emergency: ________________________________
Emergency Phone No.# __________________

Part B -
1. Are you looking for a Come-in _____ or Live-in _____ position?
2. Dates available for hire: ______________________________
3. Are you looking for a Permanent_____ or Temporary_____ position?
4. What hours and days are you available to work? ________________________________
5. Do you have another job?______________ / Are you a student? ______________
6. What is your schedule?_________________________ How flexible can you be?
   __________________________________________________________________
7. Are you willing to do emergency attendant work? ______________

Part C -
1. What is your means of transportation? ____________________________
2. Do you have a valid California driver's license? ____________________________
3. Are you willing to run errands? ____________________________
4. Are you willing to drive me to the doctors? ____________________________
Part D -

1. How did you hear about this job? ____________________________

2. Who referred you? ____________________________

3. Are there any jobs that you would not want to do? (ex: driving, asst. doctors appts. or any other jobs included on the job description, etc.)

Work Record

Part E -

List most recent employer first:

1. Employer: ____________________________
   Address: ____________________________
   ____________________________
   ____________________________
   What type of work: ____________________________
   Dates of Employment: From:_____/ To:_____
   Reason for leaving: ____________________________

2. Employer: ____________________________
   Address: ____________________________
   ____________________________
   ____________________________
   What type of work: ____________________________
   Dates of Employment: From:_____/ To:_____
   Reason for leaving: ____________________________

May I contact current employer?
Applicant Profile - Continued

Skills:

___ CPR
___ First Aid
___ OT/PT Training

Comments:

Personal:

___ Pet(s)
___ Children
___ Smokes
___ Willing to assist with personal care/IHSS

Comments:

Reason For Desiring Roommate/Neighbor Position:
(If applicable)

On File:

___ Fingerprint
___ DMV Printout
___ Professional References
___ Personal References
Important Things To Know About Me

Name: __________________________________________

(This is information that you will want to share with an attendant or roommate that you're thinking of hiring. Do not share anything you do not wish to share. Consider ways people can be most helpful yet respectful of your rights and privacy.)

A. Routines (Consider daily needs related to getting up in the AM, preparing for work, personal care, mealtimes, etc.)

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

B. Complex/Medical Needs (Think about specific assistance you will require with such things as medication, equipment, lifting, transferring, etc.)

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
C. Interests, Hobbies, Preferences  (What do you like to do? Where do you like to go? Favorite foods. Pet Peeves. Allergies, etc.)

B. Other (Consider any other important things someone might need to know about you.)

This allows a person to share valuable information about themselves in a way which suits them as opposed to sending them off to read "collateral". It gives the prospective or new roommate/neighbor or support worker an idea of what is/will be expected of them.
### What Services You Need and When You Need Them

<table>
<thead>
<tr>
<th>SERVICES</th>
<th>WHEN</th>
<th>OTHER INFORMATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domestic Services:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Related Services:</td>
<td></td>
<td></td>
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<tr>
<td>• Prepare meals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Meal clean-up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Laundry</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Shopping for food</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Other shopping errands</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Medical Personal Services:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Respiration Assistance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Bowel, bladder care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Eating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Routine bed baths</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Dressing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Menstrual Care</td>
<td></td>
<td></td>
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<tr>
<td>• Ambulation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Move in/out of bed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Bathe, oral hygiene/grooming</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Rub skin, repositioning, help on/off seats, in/out vehicle</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Care/assistance with prosthesis</td>
<td></td>
<td></td>
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<tr>
<td>Transportation Services:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Medical Appointment</td>
<td></td>
<td></td>
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<tr>
<td>• To alternate resources</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protective Supervision:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teaching Demonstration:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paramedical Services:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Monthly Hours:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Basic Schedule:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
HIRING

Now it is time to make a decision.

1. Call the person you have chosen to tell her/him the good news. Also, be prepared to give a start date.

2. Call all the other applicants saying you have hired someone else for the job. Then ask if for some chance the position reopens if you could call them back.

   - OR -

   Ask them if they are willing to work relief when necessary.

TRAINING

It is best to have a former attendant assist with training if possible, or someone who knows what you need and how to do it.

1. Explain your disability and challenges.

2. Explain any technical words that you use.

3. Be sure to emphasize anything relating to safety or emergencies.

4. When giving instructions involving a procedure - include each step and why it's important that it be done a certain way.

5. Don't take for granted they know what you meant; ask for feedback.

6. Be patient - your new attendant will probably not get everything right the first time.

HINTS:

It may be helpful to have technical words, procedures, etc., written out or taped on a cassette.
COMMUNICATING WITH YOUR ATTENDANT OR HOW TO BE A "GOOD BOSS"

Note: Throughout this guide you will find a strong emphasis on communication. Learning good communication skills and using those skills are the keys to working effectively with an attendant.

Good Work Environment
It is a fact that attendant work is usually not well paid and offers few, if any, fringe benefits. Therefore, those who take this kind of job often do it because it has other rewards, such as personal satisfaction or a chance to work closely with other people. That makes the work environment a most important factor in keeping your attendant.

Good employers create a work environment that will bring out the best an attendant has to offer. You will want your attendant to have good morale, be happy and satisfied with his/her work and therefore, be a productive employee. Good communication between you and your attendant can help do this.

To create that good work environment:

1. Reward attendants for the work they are doing. Besides paying them, it is important to praise them frequently as well. Everyone wants to feel appreciated, needed and important.

   For example, your attendant has transferred you very smoothly from your bed to your wheelchair. You might say, "That was a really smooth transfer. You do it very well and I feel very safe." You have communicated your appreciation in a very concrete way and your attendant will know that he/she has performed this task well.

2. When you must criticize something your attendant has or has not done, it is important to be open and honest and to criticize the action, not the person. For example, your attendant has returned an hour later than planned. He/she did not call to explain and you are angry. You might say, "You said you would be home an hour ago. I feel frustrated and angry when people are late. In the future, I would appreciate it if you would call me and let me know you'll be late." Don't say, "You stupid idiot--you're always late! I don't know what I'm going to do with you." This will only make your attendant defensive and angry and you won't resolve anything.
3. Don't let small irritations build up until an angry explosion occurs. Anger vented in these explosions often is expressed in a hurtful and destructive way. If you feel irritated about something that is happening, talk about it as soon as possible. This may happen daily, especially if you have just begun to work together.

4. Respect your attendants. They are human beings and should be treated accordingly. Use the Golden Rule and treat your employee as you would like to be treated. Be honest, fair, kind, respectful and patient.

5. Attendants have their own lives too. Especially with people who live-in, it is important to be sure to respect their privacy, leave them alone during their time off and realize that unexpected events sometimes disrupt schedule. Although your attendant has responsibilities to you, you should not attempt to control his/her life. Flexibility and compromise are important qualities for both of you.

6. Ask your attendant how he/she feels about their work and about you as an employer. Set a regular time to share feelings about your relationship. And then, both of you be open to making changes in the routine, in attitude or in anything else that can correct a problem. After all, you are not in a nursing home where routines are set--this is your home where changes can and should be made.

7. When things just don't work out even after repeated attempts, it is time to terminate the agreement. There are good and poor ways to do this as well.

Do state your reasons clearly without attacking him/her personally.

Do give a period of notice, usually two weeks. This allows time for him/her to find a new job and/or place to live and you to find a replacement.

Do not withhold payment of wages even if you are not satisfied with his/her work. Just give notice and terminate the agreement.

To summarize, you as the employer, have the opportunity to provide a positive work environment for your attendant. This in turn helps him/her to be happy, productive and motivated to work for you. Good communication between the two of you is the key to this interdependent relationship. An attendant who is happy in his/her work will stay with you longer and do a better job, which will benefit both of you. If you are interested in learning more about communication skills, check with your local social service organization, colleges, universities or technical schools for classes in assertiveness, conflict management or basic communication skills.
GIVING PRAISE

1. Always be sincere. Don't say something you don't really mean.

2. Give compliments often.

   TWO STEPS FOR GIVING COMPLIMENTS

   Step 1: Describe the situation or event which you liked.

   Step 2: Tell what your feeling was when it happened.

   or
   Say that you appreciated it

   or
   Say "Thank you"

GIVING CRITICISM

1. Give the criticism as soon as possible after the situation that you dislike occurs.

2. Criticize only one incident at a time.

3. Do not bring up things from the past. Stick to the present.

4. Criticize the person's actions; not the person.

5. Keep the criticism brief and to the point.

USE CRITICISM AS A TOOL FOR SHARING INFORMATION WITH YOUR ATTENDANT THAT WILL HELP HE/SHE TO WORK WITH YOU MORE EFFECTIVELY. THREE STEPS FOR GIVING CRITICISM:

   STEP 1: Describe the situation or event that you disliked.

   STEP 2: Tell what your feeling was when it happened.

   STEP 3: State what would make it better next time. Give a suggestion.

WORK TOGETHER TOWARDS A SOLUTION.
Section 3.
Tools and Applications for Relationships
Some Tips on Organizing and Nurturing a Circle of Support

1. Interview the focus person (and family and friends) and get names, addresses and the telephone numbers of people to invite (for example, parents, siblings, other family, friends, neighbors, teachers or therapists, pastor, physician, etc.). Note: If the purpose of developing a circle of support is clear (for example, helping the person decide where to live and with whom), be sure to invite people who can make a difference.

2. Set a convenient time and place for the initial meeting. This should be the focus person’s home or other comfortable, non-agency place. Suggest that the focus person (or family) prepare or bring cookies, cheese & wine or whatever.

3. Send a letter inviting people to come to an initial meeting. The person with a disability may wish to follow-up by telephone.

4. Typical ground rules are (1) to ask people to come to the first and at least one follow-up meeting; (2) no one should feel obligated to offer support (advice, information, personal assistance, etc.); and (3) keep it light and have fun.

5. A facilitator should be recruited in advance. He or she should have an easel, flip-chart, marking pens and be good at writing things down and keeping the conversation moving along. Note: If possible, someone other than a parent should do this so that it is a community (rather than an exclusively family) affair.

6. After introductions, you can agree on additional ground rules, which might include:
   - Take turns
   - Listen to one another and probe only to clarify
   - Be respectful of each other’s ideas and information
   - Keep all information [at least private information] in the room
   - If you say you will do something, follow through
   - Support one another.

7. Go through a set of questions that will provide information and direction for the future. Ask the focus person first, then family, then friends. Note what people say. Move to the next question. Summarize the consensus and wrap-up the meeting with the three or four bottom-line questions (for example, what kinds of support do you need to get there).
8. Set date and time for follow-up meeting (say, in 4 weeks). Write up what was learned, the vision of what is wanted, the steps to get there and what people offered to do. Send out these notes, perhaps with a second letter.

Some lessons learned

The following factors are often critical or very important in maintaining a personal team, constructively involved in supporting the person:

Communication. One person agrees to write up the results of get-togethers and to send out notices of upcoming get-togethers.

Listening. Trying to respond to what the person wants and building consensus. Teams which listen carefully to the focus person and each other, who respect each person’s views and who base offers of assistance on what the person wants or on what the group perceives as in the person’s best interests do best.

Facilitation. Someone may need to facilitate meetings by keeping track of time, identifying issues and offers of assistance and seeing that each person has an opportunity to contribute.

Having fun. Teams whose members enjoy each other and have fun together, often stay together longer and are eager to continue to be involved with the focus person within the context of a circle of support. Having fun can help maintain a group, but sometimes people need to share their anger, despair and outrage. Not all circle meetings are light.

There is no single, best way. One needs to be adaptable and responsive to the needs and desires of the focus person. One person may not like or do well with large, formal get-togethers. If so, try strictly social meetings. One person may wish to keep friends at some distance from one another; let this person direct the group. One person may want a full-blown personal futures plan; another may have a more limited need (like additional recreation). The circle and its processes should reflect these differences.
Why Friends Are Important?
(Adapted with permission from Direct Support Professional Training Curriculum, Year 1)

Introduction
We all take friendship for granted. We might miss our friends if they are gone for a while, but most of the time we don't really think about the fact that we have friends. We have started to see the importance of people with developmental disability labels having connections with ordinary people. So many of the people in the lives of the people we support are paid to be there. While those may be satisfying relationships, there still is the element of paid friendships that is very different from most of our lives.

Friends don't care what's in the person's IPP objectives. They like the person “just because.” There is no program for starting a friendship. There are no data to maintain.

Friends can offer people a way to practice what we teach in our programs. Have you ever had to do something difficult – like give a speech or register a complaint – and you practiced first with a friend?

Friendships have an energy that can't be otherwise created. When two people do things together, more can be accomplished than if they had each tried on their own.

Friends accept us as we are. Our friends are used to some of our unusual behaviors or mannerisms, and don't try to change them. The people we support need someone who also accepts unusual behavior as “just a part of the person they like.”

We can't write programs for making friends. We can, though, help to set up ways in which friendships can happen. People can join activities that they enjoy and meet people in the course of the activity. People can “hang out” at places where other people get to know them. Think about some ways that you can help people make connections.

As Relationships Grow
Studies show that the reason friendships grow is because people live close to each other and are able to see each other on a regular basis. Supported living support staff may have to assist people in starting relationships and be available to encourage their continuation. We might have to provide transportation so people can spend time away from our homes, assist in planning activities and assist with training on social skills that are needed to continue relationships.

Some of the skills that friendship requires have never been taught to people with developmental disabilities. People need to know things like how to listen to another person. We know that listening is a very difficult skill requiring practice. All people have a very tough time listening. Yet, listening to someone is the best way to learn more about them.
A friend needs to be able to communicate well enough to get their message across to another person. A person needs to know either what words or what gestures to use to assure that the person to whom they are speaking will understand what they are trying to say.

Friends are thoughtful and do thoughtful things for each other. Are there ways that people you support either need to learn to think about what might please another person or think about ways they can let another person know they care?

These are some of the skills that are important to starting and keeping friendships. Perhaps you can think of others as well.

Natural Supports

Natural supports are something often talked about when working with people with developmental disabilities. For so long there have been very few natural supports in the lives of people with disabilities, particularly adults. In the case of children, the only natural support has been family members.

Natural supports are services and supports, freely available, from family members, friends, co-workers and associations of one kind or another (e.g., churches; clubs; community service organizations). Natural supports are for all people and not specifically for people with disabilities.

Natural supports make you feel part of something, give you friends, are your most important relationships, help you and make you feel good.

There are many ways that natural supports can assist individuals in leisure and recreation activities including: helping make friends, being a “buddy”, helping make accommodations, “smoothing the way” if there are problems, leading to more independence and “just feeling good.”

There are a few questions that come to mind:

**Is the natural support needed by the person?**
Many times a person with a disability doesn’t really need any help once he or she becomes familiar with a situation or the natural support may develop without assistance.

**Is the natural support available to the person?**
Although the most common natural support is the family, sometimes family just isn’t available. Parents may be too ill to be supportive... or, in some cases, there may be no family at all.

**Does the natural support meet the person’s needs?**
Sometimes people prefer someone other than family to provide assistance. For instance, an adult with personal care needs may prefer a paid attendant to help with toileting instead of a friend or family member.
Sex is Natural*

People with developmental disabilities have heard for years that sex is not meant to be pleasurable, and people who want sex are bad and will take advantage. Many people have been told that harmless pleasure, like masturbation, is bad as well.

Studies show that teaching people about sex makes it less likely that they will be sexually abused. Hingsburger outlines what needs to be taught so that people can protect themselves from sexual assault.

1. **Vocabulary** - Body parts need names, and people need to know what purpose the body part serves. People need to be taught accurate terms.

2. **Pleasure** - People need to know that they have parts on their body that give a lot of pleasure. This is a good thing.

3. **Context** - People need to know that giving and getting sexual pleasure belongs in the context of a loving relationship. They need to know that both people agree to provide and get pleasure.

4. **Responsibility** - People need basic information about pregnancy, and safe sex behavior. Pregnancy is a choice people may make, but they must be informed.

5. **Facts** - People need to have information about sexually transmitted diseases and how to protect against their spread. Hingsburger recommends teaching from the point of view of love, and not fear of death, particularly about HIV. Rather than tell people that not using a condom could lead to death, he has found a more effective way to teach safe sex: If you really love and care for someone, you want to keep them healthy. [Note: It’s important to remember that condoms, even when properly used, do have a relatively high failure rate and do not guarantee protection from contracting HIV and other serious sexually transmitted diseases.]

Note: It’s important to remember that most individuals have very strong beliefs about sex. These beliefs may originate from religious, cultural, familial, and/or experiential sources. However, whatever the personal beliefs of the people we’re supporting may be, our job is not to try and change their beliefs but rather to ensure they have accurate information.

(Adapted from Hingsburger, Dave, Just Say Know: Understanding and Reducing the Risk of Sexual Victimization of People with Developmental Disabilities, Diverse City Press, Eastman, Quebec, 1995.)
How Much Do You Really Know About Sex?*

Mark a T if you believe the sentence to be true.
Mark a F if you believe the sentence is false or a myth.

1. People with developmental disabilities do not know and cannot learn the basics of sex.
2. Most people get information about sex from their parents.
3. People with developmental disabilities will always have babies that are developmentally disabled.
4. Masturbation makes people go blind or become crazy.
5. People with developmental disabilities cannot control their sexual drives.
6. People with developmental disabilities are not capable of having good relationships or marriages.
7. People with Down Syndrome cannot make babies.
8. A person will be homosexual as an adult if they acted sexually with a person of the same sex when they were a child.
9. A woman can get pregnant during her menstrual period.
10. A woman must have an orgasm to get pregnant.
11. People who have developmental disabilities do not masturbate as much as other people.

* Adapted from material from Committee on Sexuality training program.
12. People with developmental disabilities do not want sex.

13. Alcohol can make a person better at sex.

14. You can contract or get HIV or AIDS from someone if they cough on you, hug you, or shake hands with you.

15. Using a condom can be effective in stopping the spread of sexually transmitted diseases, but they are not foolproof.

16. The clitoris is the main place on a woman’s body that helps her reach orgasm or get sexual pleasure.

17. Sex education can teach people to be safe from sexual abuse.

18. Women who are sterilized (so that they cannot get pregnant) will not have a menstrual period.
How Much Do You Really Know About Sex?

1. **People with developmental disabilities do not know and cannot learn the basics of sex. (F)**

   Many people with developmental disabilities don’t have enough knowledge of intercourse, pregnancy, menstruation, sexually transmitted diseases and other parts of their sexual lives. There is some misinformation and ignorance among people without disability labels as well.

2. **Most people get information about sex from their parents. (F)**

   People with developmental disabilities report peers and personal experience is how they learned about sex. Many people report that their parents never discussed sex with them. For those that did discuss sexual behavior, it tends to be out of fear that someone will take advantage of their child.

3. **People with developmental disabilities will always have babies that are developmentally disabled. (F)**

   Less than 10% of the known causes of developmental disabilities are genetic and those occur in the total population.

4. **Masturbation makes people go blind or become crazy. (F)**

   Masturbation is a harmless source of sexual pleasure that helps relieve sexual tension and helps people learn about their own bodies. Masters and Johnson, in an early study, report that 90% of men and 60% of women masturbate at some time. It is not physically harmful and doesn’t harm your mind. It is only harmful if the person feels guilty about it.

5. **People with developmental disabilities cannot control their sexual drives. (F)**

   It is not true that all people with developmental disabilities show poor self-control. There are people who need emotional and social support to learn how to best interact in certain situations.

6. **People with developmental disabilities are not capable of having good relationships or marriages. (F)**

   Many people with developmental disabilities are successfully dating and marrying. Some people may need additional supports if they become parents.
7. **People with Down Syndrome cannot make babies.** (F)

Women with Down Syndrome have become pregnant and have had children. Men with Down Syndrome are almost always unable to produce children. Their sperm is known to not move quickly enough in the woman’s body.

8. **A person will be homosexual as an adult if they acted sexually with a person of the same sex when they were a child.** (F)

Same-sex experiences are common during the growing up years. According to an early Kinsey study, 60% of men and 33% of women had some kind of homosexual sex play before they were 15 years old. This does not lead to becoming homosexual.

9. **A woman can get pregnant during her menstrual period.** (T)

A woman could have a short cycle, so she would ovulate on the 7th day of her menstrual cycle. Sperm can live in the fallopian tube for up to 5 days. So the woman could get pregnant between day 3 and day 7 of her cycle.

10. **A woman must have an orgasm to get pregnant.** (F)

This is false AND a woman could get pregnant even if the MAN doesn’t have an orgasm. There are thousands of sperm in what’s called the preseminal fluid that comes out of the penis before orgasm. Any time sperm enter the vagina (even on a finger) there is a possibility of pregnancy. So, “playing around” has the risk of pregnancy.

11. **People who have developmental disabilities do not masturbate as much as other people.** (T)

There is less masturbation among people with developmental disability than other groups of people. They may be noticed more because they are less able to find privacy, but they do not masturbate more.

12. **People with developmental disabilities do not want sex.** (F)

Sexual drive is not related to disability. Sex drive is present, although some conditions and how severe the disability is may affect it.
13. Alcohol can make a person better at sex. (F)

Alcohol may make people think they are better at sex or may make a person less able to say no to sex. In men, alcohol may make it more difficult to become erect or to have an orgasm. However, alcohol can lower the inhibitions of someone who does not want to have sex.

14. You can contract or get HIV or AIDS from someone if they cough on you, hug you, or shake hands with you. (F)

HIV is spread through semen, vaginal fluid, blood or breast milk according to the Center for Disease Control.

15. Using a condom can be effective in stopping the spread of sexually transmitted diseases but they are not foolproof. (T)

The best protection against sexually transmitted diseases is abstinence. Condoms are not foolproof. The only way to be absolutely protected is to not have sex.

16. The clitoris is the main place on a woman’s body that helps her reach orgasm or get sexual pleasure. (T)

The clitoris is much more sensitive than the vagina, which has few nerve endings. The clitoris has the same amount of sensitive tissue as the penis.

17. Sex education can teach people to be safe from sexual abuse. (T)

Sex education can teach people about body parts and how those parts work, about how to meet people that they might want to get to know and to report when someone touches them in a way they don’t like.

18. Women who are sterilized (so that they cannot get pregnant) will not have a menstrual period. (F)

Tubal ligation, a surgery, doesn’t affect a woman’s periods. The only way that periods stop is if the uterus and/or ovaries are removed. This is called a hysterectomy. A hysterectomy cannot be done to sterilize someone.
Section 4.
Tools and Applications for Community Membership
Activity Checklist:
My Own Leisure/Recreation Style
(from Year 1 Direct Support Professional Training Resource Guide, 1999)

I prefer activities where I am:

<table>
<thead>
<tr>
<th>Alone</th>
<th>With a couple of friends</th>
<th>In a big group</th>
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</table>

When I have free time, I: (circle as many as you wish)

- Watch TV
- Go to the health club
- Read a book
- Work on a hobby
- Go out to dinner
- Travel
- Go on a walk
- Listen to music
- Take a class
- Make something
- Hang out with friends
- Camp
- Take a nap
- Play on a team
- Go shopping
- Hike
- Go to a concert
- Play
- Think
- Watch sports
- Play with pets

(Other) (Other) (Other)

(Other) (Other) (Other)
Excerpts from
A Guide to Developing Community Connections

Compiled by
Patsy Davies and Claudia Bolton
October, 1996
Associational life is rich in all of our communities. Learning about where the community networks are is useful information to have on hand. This is a guide to help you learn about the possible associations in your community. Use this list to think about the various organizations people belong to. You can identify groups in your area in a number of ways - talking to others, looking in the phone book, reading area and neighborhood newspapers, surveying churches and existing groups, checking with the Chamber of Commerce, etc. Make your own listing and use it as a resource as you think about connecting specific people.

<table>
<thead>
<tr>
<th>Associations (examples)</th>
<th>Your Area</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Artistic Organizations</strong></td>
<td></td>
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<tr>
<td>chorale, theatrical, writing</td>
<td></td>
</tr>
<tr>
<td><strong>Business Organizations</strong></td>
<td></td>
</tr>
<tr>
<td>Chamber of Commerce, business associations</td>
<td></td>
</tr>
<tr>
<td><strong>Charitable Groups &amp; Drives</strong></td>
<td></td>
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<tr>
<td>Red Cross, Cancer Society, United Way</td>
<td></td>
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<tr>
<td><strong>Church Groups</strong></td>
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<tr>
<td>service, prayer, men’s, women’s, youth, seniors</td>
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<tr>
<td><strong>Civic Events</strong></td>
<td></td>
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<tr>
<td>July 4th, art fair, festivals, Halloween</td>
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<tr>
<td><strong>Collectors Groups</strong></td>
<td></td>
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<tr>
<td>stamp collectors, flower dryers, antiques</td>
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<tr>
<td><strong>Community Support Groups</strong></td>
<td></td>
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<tr>
<td>Friends of the Library, nursing home, hospital</td>
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<tr>
<td><strong>Elderly Groups</strong></td>
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<tr>
<td>Senior Citizens</td>
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<tr>
<td><strong>Ethnic Associations</strong></td>
<td></td>
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<tr>
<td>Sons of Norway, Black Heritage Club, Hibernians</td>
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<tr>
<td><strong>Health &amp; Fitness Groups</strong></td>
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<tr>
<td>bicycling, jogging, exercise</td>
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<tr>
<td><strong>Interest Clubs</strong></td>
<td></td>
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<tr>
<td>poodle owners, antique car owners</td>
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</tbody>
</table>
## Associations (examples)  

<table>
<thead>
<tr>
<th>Associations (examples)</th>
<th>Your Area</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Local Government</strong></td>
<td>town, fire department, emergency units</td>
</tr>
<tr>
<td><strong>Local Media</strong></td>
<td>radio, newspaper, local access cable TV</td>
</tr>
<tr>
<td><strong>Men’s Groups</strong></td>
<td>cultural, political, social, educational, vocational</td>
</tr>
<tr>
<td><strong>Mutual Support (Self Help) Group</strong></td>
<td>Alcoholics Anonymous, LaLeche League</td>
</tr>
<tr>
<td><strong>Neighborhood &amp; Block Groups</strong></td>
<td>crime watch, beautification, Christmas decorations</td>
</tr>
<tr>
<td><strong>Outdoor Groups</strong></td>
<td>garden clubs, conservation clubs</td>
</tr>
<tr>
<td><strong>Political Organizations</strong></td>
<td>Democrats, Republicans, caucuses</td>
</tr>
<tr>
<td><strong>School Groups</strong></td>
<td>printing club, PTA, child care</td>
</tr>
<tr>
<td><strong>Service Clubs</strong></td>
<td>Zonta, Kiwanis, Rotary, AAUW</td>
</tr>
<tr>
<td><strong>Social Cause Groups</strong></td>
<td>peace, rights, advocacy, service</td>
</tr>
<tr>
<td><strong>Sports Leagues</strong></td>
<td>bowling, swimming, baseball, fishing, volleyball</td>
</tr>
<tr>
<td><strong>Study Groups</strong></td>
<td>literary clubs, bible study groups</td>
</tr>
<tr>
<td><strong>Veterans Groups</strong></td>
<td>American Legion, Veterans of Foreign War</td>
</tr>
<tr>
<td><strong>Women’s Groups</strong></td>
<td>cultural, political, social, educational, vocational</td>
</tr>
<tr>
<td><strong>Youth Groups</strong></td>
<td>4H, Future Farmers, Scouts, YMCA</td>
</tr>
</tbody>
</table>
In addition to formal and informal associations, learning about the places in your community is an important exercise. The following map was developed by Allen, Shea & Associates as a way for you to explore the various places in your own community. It is helpful to do this exercise with someone else who lives in your community (two heads can be better than one!). Consider the various places, setting, activities and gathering places that are part of your community.
COMMUNITY, WHAT DO YOU SEE?
These Are The Opportunities In My Community

**Brainstorming Places That Enhance Community Contributions.** Be creative and develop a wide variety of opportunities. Consider all of the possible sites, settings and roles in which people can contribute.

<table>
<thead>
<tr>
<th>Summarize the interests, gifts, qualities and identities you hope to develop.</th>
<th>List the community opportunities, settings, associations, networks and places where people come together with similar interests, talents and values.</th>
</tr>
</thead>
</table>

Adapted from *Capacity Works: Finding Windows for Change Using Personal Futures Planning*, Mount, 1995

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Five Action Steps for Getting Started

Identify several ideas that seem most appealing and then outline five specific strategies for getting started. Remember to include who you will contact, when and any additional information you may need to get started.
Community Groups, Organizations and Places

Thinking about how to connect a person to a place requires: knowing the person well; knowing the place; thinking about the supports everyone involved will require; providing support in the most effective, flexible manner; and thinking, rethinking and evaluating your approaches.

The next exercise was adapted from one developed by Kathryn Kemery McClain as a way to think through the characteristics and rituals of a particular place or organization. It is designed to assist you to explore the various possibilities for involvement in a particular activity or place. It is important to know about the setting, the demands and the opportunities it may place on the person. This activity helps us remember the progression of activity one would go through in order to participate. The next step for you after this exercise is to consider the supports a specific person will need during each stage of interaction.

THE STAGES OF INTERACTION.

**Arrival:** List things related to how other people arrive at the group or place.

**Entry:** List things related to how people actually get into the building or location. Do people have to walk up steps, knock, open the door?

**Getting started:** List anything that happens from the point that you get into the building until the activity actually starts. This could include things like finding a seat, knowing to be quiet when the meeting begins, greeting other people, introducing yourself, etc. Sometimes the atmosphere is very informal while other situations have more formality. Are there unwritten ground rules?

**Participation:** List anything that occurs during the main portion of the situation or meeting. This varies greatly. Look for the unwritten rules, types of interaction and types of conversation as well as the “things” that are required. For example, you would want to go to a coffee house with money.

**Finishing up:** How can you tell the activity is winding down? Are there specific things that occur? Again, remember the unwritten rules.

**Exit:** List whatever is required to leave the building. Pay attention to whether people talk with one another on the way out, whether folks go out for coffee after the activity, etc.

**Departure:** List how people leave.

**Characteristics.** A running description of anything relevant that occurs at that particular stage. This can include things like how people are dressed, seating arrangements or anything else that seems relevant given the setting and the person you will be supporting.

**Expectations and Demands.** Includes anything that the setting demands during a particular stage. It could be a response such as shaking hands or saying good-bye, an ability or skill, etc.

**Describe the people who are part of the social setting.** This can include a variety of things such as age, sex, “type” of person or anything that strikes you as relevant or defining about the group.
Name of Group or Place: __________________________________________

Location: _______________________________________________________

<table>
<thead>
<tr>
<th>Stages of Interaction</th>
<th>Characteristics</th>
<th>Expectations and Demands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arrival</td>
<td></td>
<td></td>
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<tr>
<td>Entry</td>
<td></td>
<td></td>
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<tr>
<td>Getting started</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Finishing up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Departure</td>
<td></td>
<td></td>
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</tbody>
</table>

Describe the people who are part of this place or group:
________________________________________________________________________________________________________________________________________
________________________________________________________________________________________________________________________________________
________________________________________________________________________________________________________________________________________
Section 5.
Tools and Applications for Flexible, Tailored Services and Supports
SUPPORTING PEOPLE
WITH CHALLENGING BEHAVIORS
(by LaShawn Wells and Krista Loomis, Consultants, CIRCL)

Introduction
There may be times when the person you are supporting communicates through behaviors that are dangerous or could be perceived as dangerous to their well-being, others well-being or the environment. The following information describes what types of challenging behavior could occur, why it may occur, how to try and prevent it from occurring and how to respond if it does occur.

It is important to remember that the responsibility of a support staff is to support the person to be safe, make choices and live a quality lifestyle in the community. This responsibility as it pertains to a person who is exhibiting challenging behavior is to: (1) support the person to not have the need to exhibit those behaviors; (2) respond in a manner that is respectful and non-judgmental; and (3) not attempt to control or “fix” the person. Each supported living agency should have specific guidelines on how to respond to challenging situations but the main focus should always be supporting the person in a respectful manner to be safe.

The following information attempts to give broad guidelines on challenging behaviors, why they occur and how to respond. Almost all human behavior is complicated and occurs for a multitude of reasons and there is never a simple explanation or reason why challenging behaviors may occur. Very often, it is almost impossible to know exactly why challenging behaviors occur so it is important to never try to classify or label the person by their behavior. By having a better understanding of challenging behaviors, a support staff will be able to respond in a manner that is safe and supportive.

Each agency should provide training to staff on their guidelines, policies and procedures on how to support people with challenging behaviors. It is also the agency’s responsibility to provide the staff with information on the individuals that they are supporting so that they are able to know how to support the person. This information could include the person’s ISP (Individual Service Plan), an ELP (Essential Lifestyle Plan) and their support plan as well as talking to the individual’s family, friends, staff and others who know and care. The staff’s responsibilities are to learn as much as they can about the person, uphold
supported living philosophies as well as the agencies and honor the rights of the person they are supporting.

The questions that many people face is how can they receive support in SLS if they are someone who manifests their actions through challenging behavior. The very idea that someone can be supported within the philosophy of SLS and yet that person exhibits challenging behaviors is an oxymoron. The concepts of “choice”, “dignity” and “support” collide with ideas like “control” and “restricted movement”. Two key concepts to remember.

**Control versus Support**

A staff person who restricts a person’s right to move about freely or who controls the person in any way whatsoever is not only denying that person their civil right to move about freely, they are also not acting in accordance with the principles of SLS. Control over the person takes place when the person who is receiving support is not allowed to go through the process of choice that is fundamental to everyone. Support is the process of working with the person to find out what he or she likes and supporting them in the choices that they make. This does not mean supporting them to hurt themselves or to break the law. Support means having a responsibility to them as a human being, not as a disabled person. Support may mean supporting people through bad decisions. If a person chooses to be overweight like many Americans, they should be supported to know the risk involved, yet they should not be controlled to go on a diet. It is important for the individual to feel that the people who support him or her are assisting them to be in control. At times, the individual may need the staff to be in control, but not be controlling, there is a difference. This may help to relax the individual, making them feel at ease especially when they are out of control.

**Informed Choice**

Many would argue that because individuals may not understand the consequences of their choices, their choices should be limited. What needs to be stressed is that as support staff for people with disabilities, it is our role to help people understand the consequences of their choices but not to limit their choices. For many people disabled or non-disabled, understanding the consequences of making poor choices requires personal experience with the consequences of those choices. Also, understanding the consequences of one’s choices doesn’t always affect one’s choice. Most people who smoke know and understand the dangers of smoking but still choose to do so.
Information on Challenging Behaviors

For years the field has used the word “behavior” to describe actions that are not considered “normal” or “appropriate” ways of acting. A different way of looking at challenging behaviors is to see them not as behaviors but as coping mechanisms for very valid feelings, conditions or situations. The way a person responds to a situation or copes with a situation may not be the most socially appropriate but it is often what has worked best for the person, given their history, or it is the quickest, most direct way to deal with the emotions and feelings they are experiencing. So rather than looking at the actions described below as challenging behaviors, look at them as coping mechanisms or strategies for dealing with difficult emotions and situations. Trying to come up with a list for the challenging situations that may occur is difficult. The following list is not exhaustive and sometimes some of the actions or situations, which are listed here as challenging are very real and appropriate responses to situations or other people’s behavior.

<table>
<thead>
<tr>
<th>Physical aggression</th>
<th>Self-injurious behavior</th>
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<tbody>
<tr>
<td>Property destruction</td>
<td>Verbal threats</td>
</tr>
<tr>
<td>Screaming</td>
<td>Throwing things</td>
</tr>
<tr>
<td>Nudity in community</td>
<td>Unsafe sexual behavior</td>
</tr>
<tr>
<td>Stealing</td>
<td>False accusations and reports</td>
</tr>
<tr>
<td>Unsafe behavior with strangers</td>
<td>Ingesting hazardous materials</td>
</tr>
<tr>
<td>Refusal to follow good health practices</td>
<td>Sexual intimidation</td>
</tr>
<tr>
<td>Fire starting</td>
<td>Alcoholism and drug abuse</td>
</tr>
<tr>
<td>Refusing to take medications</td>
<td>Refusing to eat, or overeating</td>
</tr>
<tr>
<td>Disappearing without notice</td>
<td>Suicide attempts</td>
</tr>
</tbody>
</table>

Here are 4 general categories for explaining why challenging behaviors may occur. The 4 categories were taken from PART-R (by Paul A. Smith, Ph.D., 1993) training material. Some of the information included has been added by the authors.

1. **Fear** – Person may feel under attack or think that something is going to be taken away. Person may feel threatened, out of control and vulnerable or that there is a need to escape, defend against or eliminate a perceived threat. This response/behavior could be a result of the person having a personal history as being a victim of
abuse. The person who is feeling fearful may become aggressive either physically or verbally, become destructive to their environment or become aggressive to themselves.

**Signals to watch for:**
- Posture could be tense and the person could look like they are prepared to defend, hide or run away
- Person could have a fearful expression, wide-eyed, pupils could be dilated
- Breathing could be rapid, shallow and irregular
- May be unable to speak or gasping

**How to respond:**
- Posture should be relaxed and open; hands in full view
- Gestures should be slow and palms up
- Should be positioned slightly off to the side of the person and far enough away to make it clear that they are not under threat of attack
- Voice tone should be soft but firm, reassuring and confident
- Speech content should be logical, encouraging calmness, use the rule of 5 (Sentences consisting of 5 words or less)
- Eye contact only if the person seeks it otherwise don’t force it on them
- Physical contact only if the person gives permission and should be light with slow movements

2. **Anger/Frustration** – Person feels angry/frustrated and not in control of their environment or situation, as in fear may feel out of control, threatened and vulnerable, behavior is an attempt to gain control of situation by attacking the source of their anger/frustration. The person may have a history of low tolerance for frustration and impulsiveness. The person who is feeling angry/frustrated may become aggressive either physically or verbally, become destructive to their environment, or become aggressive to themselves.
Part Four: Tools and Applications

Signals to watch for:
• Posture is tense and ready to attack
• Skin color may be splotchy with tones of purple and red
• Facial expression may be tense, focused and angry
• Voice quality may be menacing, aggressive and loud
• Breathing could be loud, deep, long and heavy

How to respond:
• Posture should be self-confident and commanding
• Gestures should be firm and commanding, palms out or down
• Position should be directly in front just outside striking range
• Voice quality should be quiet, firm and commanding in tones low enough to make the frustrated person strain to hear
• Speech content should be repetitive and confident and commands should be without threat
• Eye contact should be direct

3. **Manipulation** – Person is trying to control the environment. Person may lose control of themselves in order to manipulate others in an indirect attempt to obtain or avoid something in exchange for not losing control. A person may make a calm but unreasonable request and when the request is not met they may threaten to lose control i.e. yelling, threatening behavior or aggression. It can be especially effective when out in public. Remember: Beneath every manipulative demand there is a legitimate request.

How to recognize: (May be difficult)
• Person keeps increasing their demands with their voice tone becoming more and more strident or demanding. Tone of voice may become more aggressive and the person may begin to make threats.
**How to respond:**

- Posture should be closed and relaxed
- Gestures should be relaxed and causal
- Position should close but far enough away to show noninvolvement
- Voice quality should be detached, mechanical and slightly bored
- Speech should be quiet and repetitive
- Eye contact should be avoided, look at the person’s chin or shoulders

4. **Intimidation** – Similar to manipulation but the person threatens physical injury. A calculated attempt to get something in exchange for freedom from the threat of injury.

**How to recognize:**

- The person’s voice and posture may be menacing. They may use threatening words and gestures or may crowd or stand too close. They may have a history of physical assault.

**How to respond:**

- Posture should be poised and ready to react or move quickly, but not giving the impression of fear
- Gestures should be few
- Position should be of the greatest defense advantage, not allowing exit to be blocked or keeping something (furniture) between you and the person
- Voice quality should be matter-of-fact, monotone and emotionless
- Speech content should be clear and direct, repeated as often as needed, threats avoided, unrealistic consequences are not offered
- Eye contact should be used sparingly to emphasize a statement
There are other factors to consider in trying to understand why someone is exhibiting challenging behaviors. This is a broad list and there are many reasons aside from the ones listed below. Things to consider:

- **History of the person** - Did the person previously live in a large institutional setting or a group setting where their choices were not honored and they had little input about their day to day life? Is there a history of being abused or mistreated (post traumatic stress syndrome may be factor)?

- **Difficulty with communication** - Is the person able to communicate their wants, needs and feelings in a way that is understood? If they do not use speech to communicate, is there a system in place to help them communicate?

- **Health issues** - Does the person suffer from PMS, allergies, chronic pain or other medical problems? Are there problems with their medications or side effects from their medications? Is the person having difficulty sleeping? Are there mental health issues or is the person facing aging issues of dementia? Has there been a recent change in health or medications? Could the person be suffering from depression (can be somewhat prevalent in people with disabilities)

- **Support issues** - Has there been a change in support staff? Has staffing been inconsistent with many changes? Has there been a change in routine outside the person’s control?

- **Relationship issues** - Are there problems with family members, friends, significant others, roommates, co-workers, neighbors or support staff? Is there a loss of an important person from the person’s life?

- **Environmental issues** - Is the temperature too hot, too cold, too dry or too wet for the person? Has there been a sudden change in weather? Is it a hard time of year for the person (e.g., change of seasons, holidays, anniversary of a painful event)?
Preventing the Need for Using Challenging Behaviors

The best way to try and support someone who has challenging behaviors is to learn all that you can about the person and develop a relationship with that person. If you really know and have a relationship with the person you are supporting, you will have a greater ability to help the person in a difficult situation. The better you know what situations, conditions, or problems can upset the person or make them angry, the better you can be prepared to help the person you are supporting deal with it, possibly without them feeling the need to engage in actions that might result in injury or further problems.

You can also possibly help the person avoid situations that upset them (for example, if crowds are bothersome you would try to help the person avoid crowded areas). If the upsetting situation cannot be avoided, you can at least warn the person that the event is coming up and that you will be there to support them (for example, if the person is afraid of the doctor but needs to go, you can help prepare them). There will be times that even with the best of preparation, challenging behaviors will occur. The better you know the person the better you are able to assist them.

Learning about the person can happen in several ways. First, from the person themselves through watching and observing them. Second, from others who know the person. When developing a relationship with the person you are supporting, it is important to do it at a speed that is comfortable and relaxed. In all relationships it takes time to get to know someone. It is also important to not judge or label the person by their actions. You must also respect the person’s right to be different and understand that they might respond in ways that don’t seem to make sense. By learning about and observing the person you will also learn what helps the person feel more relaxed during stressful situations. By honoring the person and their choices you will be showing that you respect the person. As you develop this honest and caring relationship with the person, you will also be building trust, which is the key factor in supporting someone.
Part Four: Tools and Applications

Responding to Challenging Behaviors

Once you get to know someone you will be aware of what situations can possibly cause the person to become upset or engage in challenging behaviors. In more technical terms the situations that can cause challenging behaviors are called antecedent conditions and the warning signs (person wringing their hands, crying, becoming tense) are called antecedent behaviors. It is important to look at antecedents on a personal level as it relates to the individual you are supporting. In other words “knowing” the person you are supporting so well that as a result you have a good idea of every possible antecedent condition that may affect the person you are supporting. You also must remember to not see the “behavior” as something that is negative or take it personally. Some ways to respond to challenging behaviors can be found on the following page.
Tips for Responding

- See the “how to respond” section in the description section for tips on how to respond.

- Once you know the person, you will know when to back off, when to leave and when to get assistance or have someone else take over.

- Remember the rule of five – when someone is upset, use sentences of five words or less with words of five letters or less. Keep it simple.

- Try not to overreact. Sometimes you have to act rather than react.

- Your goal is to keep everyone safe. You may have to ask others leave the area if the person is becoming agitated.

- Remember that when the person is upset or agitated that it is usually not the time to try and lecture on consequences. You have to know the person well enough to know when they can hear what you have to say and when they can’t.

- Knowing the person well will help you be able to read the person and their moods or state of mind so that you can adequately judge if the crisis is over.

- Dealing with challenging behaviors out in public can be very difficult. If someone has a history of this, ask for ideas from others on how to handle the situation.

- Good communication with the person you are supporting is one of the most important aspects of assisting them through challenging times.

- Be knowledgeable of the agency’s policies.

- Remember to do your best to stay calm in crisis situations.

- There is a difference between breaking a dish and breaking a window, don’t overreact.

- You may have to let go of a routine or plans when the person is having a hard day.

- There are very few things that are so important that it is worth risking someone getting hurt over it.
Support Staff and Agency Responsibilities

- There should always be a section in a person’s support plan outlining how to respond if the person has a history of challenging behavior.

- Anytime the person you support engages in behavior that you believe could result in injury to themselves or others, you must report it to your supervisor who then may have to report it to the person’s case manager, the regional center, or the person’s physician. It is important to be very detailed, especially if the incident results in injury or property damage.

- It is not uncommon when beginning to work with people with disabilities to feel fear or anxiety. What is important, is to realize when the fear and anxiety is not lessening and is affecting your ability to provide good services.

- As a support staff, you have to develop a relationship based on trust and respect. The person needs to know that you will be there through good days and bad.

- When out in public you must remember that if something happens that involves a community member, you must be professional. You may have to explain your role (remembering the person you support has the right to confidentiality) and you may have the police become involved.
In Summary

In conclusion, there are four final points that need to be made.

1. **Commitment** – Anyone who chooses to work with people with disabilities needs to be committed to providing good services in a respectful manner. Being committed to the person being supported means more than showing up and doing your job. It requires developing a caring relationship that is based on mutual respect and trust. Without this, it is very difficult to provide support in a manner that is beneficial to the person.

2. **Rights of the people served** – The fundamental rights of people with disabilities should be guaranteed in the same manner as people who do not have disabilities. Those rights should be advocated for people with disabilities in a proactive way to insure that people who can not speak or defend those rights for themselves will have them.

3. **Rights of staff** – At no time are the rights of staff put aside because of the rights of the people who are being served. In order for staff to be able to look at the people they are serving as equals, their rights or safety should never be in jeopardy because of the people they are serving.

4. **Responsibility of the agency** – Lastly, it is important for each agency to know and realize that they are ultimately entrusted and responsible to the individuals being served. To do that the agency must provide staff with the philosophies, guidelines, information and training to be responsible, respectful, caring support staff.
Supporting Individuals with Children:  
Family Support Services  
(by Sharon Fallis, CIRCL consultant, June 2000)

The need to provide support to parents with developmental disabilities and their children is becoming more and more common within our communities. However, most staff who work with disabled adults often feel their expertise is inadequate when it comes to the specialized support which families require. Although there is definitely much more to know when it comes to wrap-around services for an entire family vs. an individual, Family Support Services (FSS) can be considered an extension of supported living services.

The most effective methods for providing family support services include offering services which take place in a family’s own home and community. Parent Support groups help to reinforce skill building, socialization, role-modeling and advocacy. However, group instruction should be in conjunction with individual family support services to be most effective. There are several roles which a Family Support Services Facilitator (staff of the supported living agency) would need to manage when working with a family:

**Mentor Parent**

FSS Facilitators provide role modeling and guidance for building effective parenting skills. The facilitator will often spend chunks of time with a family and offer hands-on learning while in the family’s home. It is important that the facilitator has experience with teaching parents, and is comfortable modeling nurturing and consistent parenting skills. It is equally important to understand that modeling parent behaviors should not be confused with the actual parenting of the children. Helping to build on the relationship between the parent and the child should be the main objective - model a skill or behavior and then refer to the parent for example and follow through.

**Parenting Educator**

Each appointment with a family should be carefully considered for the “teachable opportunities.” Whether the appointment is focusing on money management, cooking, a visit to the pediatrician or the park, teaching parenting skills should be overlaid in each activity and recognized as an essential objective for each family visit. There are curriculum-based models available for teaching parenting skills and there are individual family plans which can be created to reflect the specific needs of a family. Which ever way your organization chooses to teach parenting, there are key elements which should be considered in each family support services plan: parent-child bonding; child development; the importance of play (Lekotek philosophy); child management and positive discipline; health and wellness; nutrition and meal planning; personal/home/community safety; family communication; stress/anger management; child abuse prevention; drug and alcohol abuse prevention; and family social/recreational time - just to name a few.
Redesigning or modifying parenting materials to meet the learning needs of an individual parent is strongly recommended. Collection of available training materials is a great way to start. The following companies offer free materials and information on such topics as nutrition, breast feeding, bathing, etc.: Mead Johnson (800•422•2902), Gerber (800•828•9119), Carnation (800•782•7766), Wyethlabs (800•999•89384), Ross Productions (800•227•5767), Mount Vernon Foods (800•932•5525), Beechnut Foods (800•523•6633), Proctor and Gamble (800•285•6064), Kimberly Clark (800•544•1847). Other companies which offer parenting education materials through their catalogs include: ChildBirth Graphics and Health Edco @ WRS Group, Inc., Waco, Texas 76702-1207; Health Education Services, P.O. Box 7126, Albany, New York, 12224; Channing L. Bete Company (800•628•7733); March of Dimes, 1275 Mamaroneck Avenue, White Plains, New York 10605. Remember that OB/Gyns, pediatricians, Head Start, WIC and the health departments are other avenues for obtaining instructional information.

Resource Developer
Because there have not been a lot of materials and resources developed specifically for families headed by parents with cognitive challenges, it is important to gather, keep and share materials and resources as you find them. A facilitator who is most effective is sure to have their own resources library bursting at the seams of their desk or trunk! It’s extremely helpful to cultivate working relationships with staff from other agencies: regional centers; Area Boards; family resource centers; early intervention programs; Protection and Advocacy; Public Health, etc. The Community Services Directory for your area is extremely valuable, as is, knowing the healthcare providers within your area who work well with special needs parents and their children.

Family Advocate
It is important to embrace the role of “advocate” when working with parents who have a disability. There are many biases and stereotypes that people have when it comes to raising children. The parents we offer support services to are mostly impoverished, often isolated and are often devalued by their own families, neighbors, and communities. Making a commitment to a family to provide support services certainly would be lacking if you were unable to also offer yourself as a competent advocate. Advocacy efforts need to be coordinated with the parents, support staff and professionals working with the family, and natural supports - such as family and friends. Introducing parents to support groups, self-advocacy groups, People First chapters, etc. gives them every opportunity to learn how to be a strong advocate for themselves and their children. Establishing ways for a parent to understand more about self-confidence, self-esteem, and community inclusion will go a long way to benefit the entire family. Advocacy on behalf of a family should be a unified effort between the parent, facilitator and other supportive people.
Family Networker
A facilitator who provides family support services does not have to be an expert on every topic related to parenting. However, they should be good at finding the experts. Developing an assortment of people and organizations to reference for specialized assistance for a family is valuable. By working with others on behalf of a family, a couple of things can happen: First, the focus of supporting a family is no longer on the one FSS facilitator, but instead on a group of professionals - all having various expertise. Second, the family becomes involved with others within the community which can translate into ongoing working relationships. Another important role of the FSS facilitator is that of “The Hub.” Keeping track of all the players involved with the family helps to insure effective, consistent service provision. Collecting information on the family’s medical providers, social services, school information, family and friends, family routines and schedules, and preferences and styles allows a facilitator to be better informed and prepared for how best to support the family. Get into the habit of NEVER throwing anything away! Collecting pertinent information about the family will allow for an easier time when cultivating natural/generic supports; preparing “Family Futures Plans;” and passing updated information on to new or transitioning staff.

FSS Facilitator Training Requirements
In addition to an organization’s routine training requirements for supported living staff, family support facilitators should also be trained and competent in the following areas:

- basic parenting skills
- child-proofing and household safety
- child development/parent-child bonding
- community access for families
- child abuse prevention and reporting requirements
- infant/child/adult CPR and first-aide
- communicable diseases and bloodborne pathogens

FSS facilitator skills and knowledge base can be greatly enhanced by participating with various organizations, conferences and workshops which promote family issues. Networking with generic agencies helps to provide community awareness to the needs of parents with developmental disabilities. Networking with other agencies who also provide family support services helps to create collaborative situations which benefit all families being served.

Finally, working with parents and families can be complicated. Providing this type of support is not for everyone or every agency. Facilitators should extensively consider their own biases, stereotypes and value systems prior to making such a commitment.
Family Support Services
Resources

American Red Cross
Parenting: Your Child From Birth To Three
Parenting: Your Child From One To Six
Parenting: For Special Needs Parents
First Aid Fast
The American National Red Cross (Check Your Local Listings); 1998.

Baladerian, Nora J.
SURVIVOR: For People with Disabilities - Sexual Assault Series. Mental Health Consultants in Culver City (310-391-2420); 1985.

Booth, Tim and Wendy

Dinkmeyer, Don

Feustel, Joyce

Franz, John P.

Heighway, Susan

Jones, Deb
Let’s Prevent Abuse: Prevention Hndbk. for Early Childhood Professionals. PACER Center (612-827-2966); 1990.

Jones, Deb
Risky Situations: Vulnerable Children. PACER Center (612-827-2966); 1993.

Mandeville, Howard
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<thead>
<tr>
<th><strong>Mount, Beth</strong></th>
<th>Person-Centered Planning - Using Personal Futures Planning Graphic Futures, Inc. in New York (212-362-9492); 1992.</th>
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<tr>
<td><strong>Sweet, Mark</strong></td>
<td>Discovering The Parent’s Language Of Learning. Wisconsin Council on Developmental Disabilities (608-266-7826); 1990.</td>
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<tr>
<td><strong>Webster, Susan Kidd</strong></td>
<td>Preserving The Bond: A collection of family stories. Wisconsin Council on Developmental Disabilities (608-266-7826); 1993.</td>
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Section 6.
Person-Centered Planning
Tools to Help Learn What is Important to the Person
Getting There From Here!

Excerpts from Tips on the Person-Centered Planning Process

Originally Developed for
Harbor Regional Center
21231 Hawthorne Blvd.
Torrance, CA 90503
(310) 540-1711
11/92
What's this all about? This is a chance for people with disabilities and their families and friends to sit down and think about where they're going in the future and the support that they might need to get there. This map will help you to start working towards your hopes and dreams right now. It will also help us at Harbor Regional Center get an idea of where we fit into your lives. It was written to be used in several ways: (1) you can fill it out by yourself; (2) someone can ask you the questions and write down your answers; (3) you can work on it with your counselor or case manager; or (3) family and friends can fill it out if you need help in answering. This is not something you have to do, it's voluntary. However, we think that you'll find it useful as well as fun!

1. Who is this about?

2. Who's on your team? Who helps or supports you? Who are your friends? Who do you turn to for help when you need it?

3. What are some great things about you?

Adapted from Personal Futures Planning (Mounts) for R.C.E.B. & H.R.C by Allen, Shea & Associates; revised 4/92.
How to Get There From Here!

Things About You


5. What new things would you like to do? around town? at home? for fun?

6. What makes you happy?

7. What makes you mad or sad or frustrated?
How to Get There From Here!
About Work

8 If you're not working right now, what do you do during the day?

9 If you're interested in working, what jobs have you had?
If you're not interested in working, please turn to the page called Things About How You Live and Would Like to Live. If you're already working, please go to question #12.

10 If you're interested in working, what kinds of jobs interest you?

11 Do you need support in getting a job?
Are you looking for your first job? ___ yes ___ no
Does it take you a long time to learn a job? ___ yes ___ no
Do you get social security benefits? ___ yes ___ no
Do you need support in things like using money or getting to work? ___ yes ___ no
If you answered yes to any of these questions, you could probably use some support in getting and keeping a job.

12 Already Working, How's Your Job?

Is it the kind of job you like? Yes No
Are the hours and days okay? ___ ___
Do you get the support you need? ___ ___
Does the pay cover your bills? ___ ___
Do you get benefits? ___ ___
How do you get along with people at work? ___ great ___ okay ___ not very well

When you think about your job (check the one that shows how you feel most of the time)
___ Are you glad you got it
___ It's okay that you got it
___ You're sorry that you got it
How to Get There From Here!

Things About How You Live and Would Like to Live

13 How do you live now?
   - Alone? □
   - With a roommate? □
   - With your parents? □
   - With other relatives? □
   - In a group home? □
   - Other? ________________ □

14 What do you see as the best things about where you live right now?

15 What do you see as the biggest challenges of where you live right now?

16 What kinds of support do you need where you live right now?

17 Are you living where you want to live and with whom you want to live?

18 All things possible, where would you like to live and with whom?

If you’re living where you want to live for now, please go to question #19.
19 What are your dreams and hopes for the future?

20 What scares you the most about your future?
How to Get There From Here!
Looking Ahead

21. What do you see yourself doing in 3-5 years?

22. What support would you need to get there?

23. Who can help you with that support? How?

24. Who worked on this plan?
How to Get There From Here!
Looking at Adult Life

What's this all about? This is a chance for people with disabilities and their families and friends to sit down and think about where they're going in the future and the support that they might need to get there. This map will help you to start working towards your hopes and dreams right now. It will also help us at Harbor Regional Center get an idea of where we fit into your lives. It was written to be used in several ways: (1) you can can fill it out by yourself; (2) someone can ask you the questions and write down your answers; (3) you can work on it with your counselor or case manager; or (3) family and friends can fill it out if you need help in answering. This is not something you have to do, it's voluntary. However, we think that you'll find it useful as well as fun!

1 Whose plan is this? Jeanette Arnopole, age 22

2 What are some great things about you? Jeanette mentioned things she does, but not characteristics of her personality. Others, including parents, shared the following observations:

- Out-going
- Almost always happy
- Plans ahead/like to schedule things
- Hard worker
- Veryindependent
- Concern for others/animals
- Makes people feel comfortable
- Good with John, a neighbor's child (e.g., organized East Egg Hunt)

- Honest
- Dependable -- If Rebecca says she will do something, she will follow through
- Brave (taken airplane trips on own; learned buses)
- Plans activities
- Talks things through 'til comfortable
- Thoughtful (e.g., gifts, cards for friends)

Adapted from Personal Futures Planning (Mounts) for R.C.E.B. & H.R.C by Allen, Shea & Associates; revised 4/92.
How to Get There From Here!
Things About You

4 What things do you like to do? around town? at home? for fun?

Jeanette said:
Crush cans to make money (and later it was learned that this relaxes neck muscles and relieves tension)
Going for walk with dog in neighborhood

Others said:
Going out to eat
Talking with people
Talking with pets, and taking care of them
(Sister mentioned chasing bird in the bathroom, and getting it back in its cage.)
Making pizza and other items
Games, such as Parcheesee, Hearts, Jenga
Planning parties and giving them
Holidays (decorating, shopping, etc.)
Using coupons and shopping for groceries

5 What new things would you like to do? around town? at home? for fun?

Jeanette said:
A job, such as handing out coupons at a store

Others said:
Learn how to type/use computer
Doing crafts with sister
Helping at Humane Society as volunteer (This is in the works, currently.)

6 What makes you happy?

Jeanette said:
Parties
Listening to music

Others said:
See old friends, etc.
Going out to eat
Jan, Papa, Brian coming to visit
Walking to store on own
Planning trips, parties, etc.

7 What makes you mad or sad or frustrated?

Jeanette said: Sometimes angry with sister
Dad telling her to be quiet, if he's watching TV

Others said: Sometimes looses cool
Brother and sister doing things that she cannot do
Seeing a dog in neighborhood chained and not being petted
The family dog (Toby) died
When treated like a child
If people say she is 'little'
If things are not ready on time; if people are late
If change in unanticipated, or not scheduled, or not announced
If she doesn't understand directions
If she really wants to do something, and it is interrupted
How to Get There From Here!
About Work

8 If you're not working right now, what do you do during the day?
Jeanette said:
Crushing cans (about $8 per week)
Others said:
Takes up offerings at church
Folds bulletins for Lutheran Church (Pastor lives up the street)

9 If you're interested in working, what jobs have you had?
Jeanette said: See #8, above.
Others said: See #8, above. Red Cross (volunteer couple of hours per week: rolling pennies; stamping paper; labels; ink stamps); Humane Society (volunteer couple hours per week: feeding; grooming; etc.); Convalescent Hospital (quit; couldn't understand what was wanted; staff not helping enough); Eden Express in San Pedro (dishes, ironing, folding napkins, etc.); JTPA/ROP job at Vet's Hospital (swept, napkins, towels, aprons, etc.; didn't like yard work); Work experience job (addressing at Special Services); Dollar Saver (delivering papers; stuffing envelopes); and, Pet Store (volunteer work: too confusing; too many different types of birds and of bird seed that needed to be matched, etc.)

10 If you're interested in working, what kinds of jobs interest you?
Jeanette said:
Animal care (feeding, watering, grooming, cleaning cages)
Others said:
In general, Jeanette likes working around people and animals, and her mother feels that Jeanette is best if there are breaks interspersed with more focused work.
Being a greeter at a party
Restaurant work is probably out (doesn't like it)
Messenger (e.g., delivering mail between offices in a complex)

11 Do you need support in getting a job?
Are you looking for your first job? X yes
Does it take you a long time to learn a job? X yes
Do you get social security benefits? X yes
Do you need support in things like using money or getting to work? X no
Others said: Making change is sometimes difficult
Jeanette did well rolling pennies and didn't need close supervision. There was a discussion about whether supervisors/co-workers provide accurate, candid feedback as to their experience with Jeanette as a worker/volunteer. Julie, at ARC-Long Beach, is said to see a need for a lot of supervision. Others, including Jeanette's tutor, don't see it this way. Perhaps different supervisors report different things to family and Julie.

12 Already Working, How's Your Job?

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
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<td>Is it the kind of job you like?</td>
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<td>Are the hours and days okay?</td>
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<td>Do you get benefits?</td>
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</tr>
<tr>
<td>How do you get along with people at work?</td>
<td>great</td>
<td>okay</td>
</tr>
</tbody>
</table>

When you think about your job (check the one that shows how you feel most of the time)

X Are you glad you got it
X It's okay that you got it
X You're sorry that you got it
How to Get There From Here!
Things About How You Live and Would Like to Live

13 How do you live now?
Alone?
With a roommate? ★
With your parents?
With other relatives?
In a group home?
Other?

14 What do you see as the best things about where you live right now?

Jeanette said:
Having a tutor to do things with

15 What do you see as the biggest challenges of where you live right now?

Jeanette said:
Cleaning up the house (shares vacuuming, dusting, and other responsibilities with sister)

16 What kinds of support do you need where you live right now?

Others said:
Jeanette is fine at home, without anyone around for substantial periods of time, and can keep herself appropriately occupied.
If away for a few days, mother suggests having friend over, and would not be comfortable with either daughter being home alone.

17 Are you living where you want to live and with whom you want to live?

Jeanette said:
Would like to live somewhere else, with a roommate
Doesn't know who or how
Would like to live with one or two other people

Others said:
Close to friends/family

18 All things possible, where would you like to live and with whom?

Jeanette said:
A place that is 'affordable'
Jeanette has friend Lee Ann, who stayed over and was 'bossy' and 'nosey'

Others said:
Close to friends/family

If you’re living where you want to live for now, please go to question #19.
19 What are your dreams and hopes for the future?

*Jeanette said:* Not sure

20 What scares you the most about your future?

*Jeanette said:* She can take her own meds (oral, 2x per day)

*Others said:* Sister fears that Jeanette is not more independent, she could come live with her but would likely be disgruntled. Jeanette may fear loss of health/function (e.g., some possible progressive hearing loss; etc.) Jeanette is probably fearful of not having enough money for food, etc., if she moves away from home.
Part Four: Tools and Applications

How to Get There From Here!
Looking Ahead

21 What do you see yourself doing in 3-5 years?

Jeanette said:
Getting a job
Leaving home

Others said:
These are the two things Jeanette talks about often

22 What support would you need to get there?

Jeanette said:
Need help from Julie at ARC-Alameda County in finding and learning a job
Regarding living on own, I need help cooking (e.g., using the oven; etc.) and how would I shop for groceries? Jeanette can shop for groceries, but would need getting groceries home. There was discussion of getting a cart, and living near a grocery store where there are curb cuts.

Others said:
Is there any way to get information and work with others to help find and develop a job for Jeanette?
Others asked Jeanette if she would need help (training/assistance) in changing sheets, getting oriented to use of public transit, getting to the doctor’s office for appointments, going to places not on bus routes, doing own laundry, keeping her place clean? In many of these areas, she may need prompts or assistance.

23 Who can help you with that support? How?

Carol will look into getting Jeanette a cart to haul groceries from the store.

Susan and Karen can help by asking supervisors: “What can Jeanette work on to improve her work performance?” and asking people to be candid.

Family/friends will see about putting marks on oven dial, so that Jeanette can use oven properly.

Susan would like information on conservatorship.

Carolyn is seeking information/support on special needs trust, and has had person from Los Angeles (Estate Planning for the Disabled) out to talk about it.

John Shea was asked, and agreed to share results of meeting with Julie at ARC-Long Beach, because (a) there may be ways to collaborate, and (b) some of the ideas/information shared might be useful to Julie.

Looking at alternative living arrangements was identified as a likely area of interest.

24 Who worked on this plan?

Susan Arnopole, mother; Carol Arnopole, sister (age 19); Virginia May, friend from church; Joy, friend and [adopted] aunt; Jenny Jackson, friend and next-door neighbor; and, Karen, tutor
An Overview of Essential Lifestyle Planning

Our quality of life everyday is determined by the presence or absence of things that are important to us - our choices, our rituals.

M. Smull, 1996
An Overview of Essential Lifestyle Planning
Adapted from an article by Michael Smull and Susan Burke Harrison

Essential lifestyle planning is a guided process for learning how someone wants to live and for developing a plan to help make it happen. It's also:

- a snapshot of how someone wants to live today, serving as a blueprint for how to support someone tomorrow;
- a way of organizing and communicating what is important to an individual in “user friendly”, plain language;
- a flexible process that can be used in combination with other person centered planning techniques; and,
- a way of making sure that the person is heard, regardless of the severity of his or her disability.

Essential lifestyle plans are developed through a process of asking and listening. The best essential lifestyle plans reflect the balances between competing desires, needs, choice and safety.
Developing plans that really reflect how people want to live requires:

- the perspectives of those who know and care about the person;
- their stories about good days and bad; and,
- what they like and admire about the person.

Good plans reflect the perceptions of the focus person and those who know and care about him or her. Learning how people want to live is just the beginning, the foundation. Helping people have their own lives requires changing:

- how we think;
- how we are organized; and
- how we act.
Each of us want lives where we:

- have our own dreams and our own journeys
- have opportunities to meet new people; try new things; change jobs; change who we live with & where we live
- have what/who is important to us in everyday life; people to be with; things to do, places to be
- stay healthy & safe (On our own terms)

(with apologies to Abraham Maslow)

For more information, contact:

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(410) 626-2707 • FAX 626-2708
e-mail <mwsmill@compuserve.com>

Or, check out the M. Smull and Friends website at <www.allenshea.com/friends.html>
Rituals ease us through our day
Every morning when you arrive at work, you head for that first cup of coffee. Only after the cup is in your hand and you have chatted about the prior evening’s events with your co-workers do you feel that you are really at work and ready to start. If there is an urgent phone call before you have that first cup of coffee in your hand, you grumble to yourself because you are not really in the office until you have your coffee. When you arrive home from work you do not feel like you are home until you have changed out of your "work clothes." Both of these are examples of the daily rituals that we employ to help us cope with transitions.

We give our daily rituals and habits scant conscious attention as they ease us through our days. Perhaps it is the absence of conscious attention that has lead us to neglect the role of ritual in the quality of life of people with disabilities. However, rituals are as much a part of quality of life for people with disabilities as they are for everyone else. Families know this. They have looked for substitutes for acquisition of the driver's license, realizing that this is the American secular rite of passage to adult life. They worked to make confirmation, bar mitzvah, and graduation ceremonies accessible to their sons and daughters. It is time for those of us who support people with disabilities to consciously consider the role of ritual and to insure the presence of positive rituals.

Daily rituals
Rituals begin every day with our morning routines. Each of us has a pattern of waking up and getting ready to face the day. These daily rituals are comforting. An example is bathing. Each of us has a pattern in how we wash our bodies. Is your face washed first or last? For those people who need assistance in bathing and cannot speak for themselves, the pattern of bathing may change with every change in staff. Yet when one mother in Ontario, Canada requested that her daughter's face be washed last, this was seen as an example of her being overly involved and controlling.

"John" (who was learning how to do "essential lifestyle planning") was sharing the person centered plan done on himself. He noted that he gets up slowly in the morning and does not want bright lights, loud music, or perky people around him until he has had his first cup of coffee. He described his fiancé as one of those perky morning people who bounce out of bed ready to go at full speed. Their accommodation is that she leaves the bedroom and is perky elsewhere. Because they respect and love each other, their incompatible morning rituals are accomplished without intruding on each other. Supporting the daily coping rituals of people with disabilities begins with paying attention to the personalities of those we support. Many direct care staff can tell you how they already do this, but the absence of sanction from professionals means that
rituals that are supported today may be seen as non-compliant behavior tomorrow.

**Maintaining and building rituals**

In *Rituals for our times*, Imber-Black and Roberts describe the importance and nature of rituals for all of us. They note that: "Daily rituals define the boundary between the family and the outside world." They include all of the important minutia of our lives at home. Common rituals around food include: the times at which we eat, what food is served on special occasions; where does each person sit at the table; and do we watch TV while we eat. These reflect our current preferences and our histories. Every time new people come into a home we need to remember that they bring their preferences and history with them. In houses owned or rented by the service provider, the rituals are often those of the service provider and change as staff turn over. Where people have spent decades in institutions they may not have any rituals that work in small settings. People with disabilities and staff who come from families rich in positive rituals can help to create new rituals in the homes in which they live. However, systematic efforts to discover, build and sustain these rituals is required.

Our efforts need to begin with these daily rituals. We have found that some of the people referred to us because of "non-compliant" or aggressive behavior simply have daily rituals that were not recognized. Our obsessions implementing program plans and continuous training have resulted in our ignoring, suppressing and trying to replace rituals that are positive, individual adaptations to the rhythms of daily life. Once the issues are seen in this context, staff were able to accommodate the positive rituals of the individual within program schedule requirements and offer training as it made sense.

Beyond the daily rituals there are others that also deserve our attention. The topography that Imber-Black and Roberts use divides rituals into those that express "relating, changing, healing, believing and celebrating (p. 56)." To consider the significance of these, we need only look to the importance of Sundays in our own patterns of rituals. For some of us, Sundays are days of spiritual renewal and relating to those who share our faith. For others of us, Sunday is the day when you not only sleep late you pad around in sleeping garb well into the afternoon. During football season, Sundays are the day when family and friends gather to yell at the television set. The Sunday rituals of each home should be the rituals of the people who live there and not be subjected to the vagaries of changing staff.

**Rituals of comfort**

We also need to remember that some rituals are rituals of comfort. We have sets of behaviors that we use to help us feel better when the "slings and arrows of outrageous fortune" strike us. After a bad day at work, we will go home and say to our partner "I do not want to do the chores planned for this evening. I had a really bad day at work. Let's go out for dinner or the movies instead." We say it even when it was our behavior that resulted in the bad day at work. If you are someone with a disability who goes to a day program, it is not unknown to have your day program counselor call your residential counselor and say: "he was really bad at his day program, do not let him have any privileges at home tonight."
We need to ask ourselves why there is a saying among self-advocates that says "Never tell them what you like because they will make you earn it. Never tell them what you dislike because they will do it to you when you are bad."

**Rituals and relationship**

As we look at supporting people in their communities we need to remember that much of the richness of "community" comes from the relationships that we have and the rituals that celebrate and build those relationships. Despite its central function, the role of ritual is rarely discussed. In our rapidly changing, mobile and fragmented society, positive rituals deserve attention for all of us regardless of the presence of disabilities. For people who need substantial support to get through life, developing positive rituals should be a priority. For many people with disabilities, these rituals will need to be developed with the assistance of the staff and then supported by the staff. Once established, however, they should change at a pace dictated by the individual, not by the rate at which new staff arrive. The rituals must be rooted in who each individual is as well as each person's current circumstances. Properly used, rituals will help people through major life changes as well as daily existence. In the support plans of the future more space should be spent on how to support people in their positive rituals and less on how to program every waking moment of their lives.

April, 1993


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Getting to Know You:
Planning for Services in Supported Living

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

by
Claudia Bolton (NorthStar Services) and
Bill Allen (Allen, Shea & Associates)

1999
Getting to Know You:
Planning for Services in Supported Living

Compiled for Connections for Information and Resources on Community Living (CIRCL)
4171 Starkes Grade Road
Placerville, CA 91006
(530) 644-6653

by Claudia Bolton (NorthStar Services) and Bill Allen (Allen, Shea & Associates)

1999

This workbook may be copied with permission from CIRCL. However, since much of the material is adapted from Essential Lifestyle Planning, we would recommend training in that process. For more information about Essential Lifestyle and Person-Centered Planning, contact Claudia Bolton at (530) 644-6653 or Bill Allen at (707) 258-1326.
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## Part One: Information Gathering
- The People in Your Life
- Your Relationships and Groups that You Are a Part Of
- What Are Some Great Things About You
- Your Experiences and History
- Your Lifestyle
- Your Experience Making Choices
- Information About Your Health
- Hopes and Dreams for the Future

## Part Two: Individual Assessment Options
- Important Facts
- Daily Living Skills Assessment
- Personal Assistance Needs Assessment
- Medical Information Checklist
- Listen to Me Communicate
- Your Pattern of Support When You Live on Your Own

## Part Three: Summing It All Up
- The People Who Contributed to This Plan
- What is Most Important?
- Things I Want to Learn to Do
- Things We Need to Know or Do to Help the Person Get What is Important
- Things We Need to Know or Do to Help the Person Stay Healthy and Safe

## References
Introduction

This workbook for getting to know someone was developed from two methods of person centered planning, the Personal Profile and Essential Lifestyle Planning. We want to acknowledge the creative work of John O’Brien, Connie Lyle O’Brien and Beth Mount for the Personal Profile (Framework for Accomplishment Workshop) and Michael Smull for the Essential Lifestyle Planning process.

We also want to recognize USARC/PACE (Solano County) and Bill Allen (Allen, Shea & Associates) for developing training materials that support people who use the Essential Lifestyle Planning process. Their helpful instructions are included in this workbook.

This workbook was compiled with the assistance of several supported living providers in the Regional Center of the East Bay area of California. Becoming Independent from Santa Rosa allowed us to revise their Community Supported Living Curriculum Guide, and Personal Assistance Needs Assessment. We thank them for their thorough work.

The integration of these two methods of person centered planning can assist supported living agencies to begin to know and understand a person referred for services. Getting to know someone is an ongoing process of uncovering who they are and what is important to them. Much as an onion has layers that can be peeled back one at a time, we all have complex layers of information to be unfolded throughout our relationships with one another.

We hope this framework for getting to know someone helps you as you begin this journey. The best way to get started is to complete the workbook on yourself. We also recommend that you receive training in Personal Futures Planning (e.g., PATH and MAPS) and Essential Lifestyle Planning.
Some Things to Think About as You Gather Information

Some Hints for Effective Conversations

Here are some ideas for starting and holding a successful conversation (adapted from Interviewing Adults . . . by Mary F. Hayden, University of Minnesota):

- pick a place where everyone is comfortable;
- make sure everyone knows each other and why they are there;
- start with something to break the ice;
- use body posture and facial expressions to encourage conversation;
- show acceptance of whatever is said;
- try to keep the interview experience positive;
- when someone gets off the topic, try to redirect or suggest talking about it later;
- allow up to 30 seconds with no response before asking someone the question again or moving to someone else;
- respect someone’s right to choose not to answer a question;
- if someone becomes uncomfortable or upset, offer to end the interview and try again later; and,
- end the interview with a positive summary of what was discussed.
Three Approaches to a Conversation
by Michael Smull

There are many ways to go about holding a successful conversation. The following are descriptions of three techniques. You will probably find yourself using all three in the course of a conversation:

**Linear**
A linear approach is the easiest way to have a conversation without asking leading questions. If you are talking with the individual with whom you are planning you simply start with getting up and then walk through the day with the person. You ask what a “typical” morning is like and then ask if some are better than others and what is a good one like and what is a bad one like. You move through the day in pieces asking for what usually happens and then asking for good and bad versions of that part of the day. Try to get the person you are talking with to tell you stories that illustrate what they mean. Be prepared to adapt this approach to the circumstances and capacities of the person. One man could not tell us what a good or bad day was like but he could describe his last week, day by day, in great detail. Another man had not had any good days in some time but could tell us about good days from his past. When talking with someone who is involved during regular hours (e.g. 9 AM to 3 PM) simply start at the beginning of that time and walk through it asking questions about typical, good and bad versions of each part of the day.

**Branching**
A branching approach starts in the same way, walking through time with the person, encouraging stories that illustrate the good day and the bad day. However, in a branching approach you look for opportunities for the person to tell related stories about other parts of a persons life. The result is a conversation that branches from one point in time and then meanders a bit until that line of conversation end. At that point you go back to where you where in time when the branch started. For example, if the branch started with breakfast and wandered off from there, at the end of that branch you would ask “and what happens after breakfast?”

**Meandering**
A meandering conversation is the most natural and also the most difficult. In a meandering conversation, instead of walking through time with someone, you start wherever your initial questions lead you and then shape the conversation so that
you hear stories about what is important to the individual’s life across all of the areas that the person you are interviewing knows about. Having a meandering conversation requires that you keep the conversation moving and cover all the areas in the time that you have. The facilitator must be skilled and have a mental map of what she or he wants to learn, while always listening for the unexpected.

Remember that a Plan is a Promise
When you spend time asking a person what is important to them, who is in their life, and their hopes and dreams for the future, you are asking them to trust you with this information and you are building a relationship with them. Do not ask a person to divulge themselves to you unless you are willing to give power to what they tell you. Put another way, you must be willing to make a commitment to help them get what is important in their daily life and to move toward their desired future. If you and your agency decide that you can not provide services to the person, then make a commitment to sharing the information you learn with the people who will stand up for the person to help them get what they need and want.

Getting to Know You - Information Gathering Process
Get as much information as you can from the focus person. What the person wants for themselves and how they want to live is the most important information. Second is what others want for the person. You will most likely want to interview others about the person. Ask the person who is important them, who knows and cares about them. The first two exercises in the workbook will help you identify these people. You will need to ask permission to interview them and you will want to ask the focus person if they would like to be present when you interview others about them. When you record the information, distinguish the information the person tells you from information others give you.

If the person does not communicate with words, you will want to interview the people who know, like and care about the person. Everyone communicates. People who do not use words to talk usually communicate with their behavior. The Listen To Me Communicate section of this workbook will be especially helpful for clarifying how and what the person is communicating and what we can do to support the person.

Your interviews with the person should occur in a place that is comfortable for the focus person. This may be their home, their day program, at school, in a coffee shop, park or in your office. The person should decide where they are most comfortable.
Getting To Know The Person:
Planning for Services in Supported Living - Assessment Process

Part One: Information Gathering:
People in Your Life
Your Relationships and Groups You Are A Part Of
Great Things About You
Your Experiences and History
Best and Worst Day Exercises
Positive Rituals Survey
Your Experience Making Choices
Information About Your Health
Your Hopes and Dreams for the Future

Part Two: Individual Assessment Options
Listen to Me Communicate
(When the person uses behavior to communicate or when the person doesn't communicate in typical ways)

Daily Living Skills Assessment
(When the person wants to learn to do things by themselves or with little assistance)

Personal Assistance Assessment
(When the person needs physical assistance, close support or significant assistance to complete activities of daily living)

Pattern of Support - Weekly Schedule
(For people who need assistance to complete their daily rituals and other activities of daily living)

Part Three: Summing It All Up:
What is Important to Me
1. Non Negotiables
2. Strong Preferences
3. Highly Desirables

Things I Want to Learn to Do

Things You Need to Know or Do to Help Me Get What is Important to Me

Things You Need to Know or Do to Help Me Stay Healthy and Safe

Notes, Comments, Recommendations and Things that are Unresolved
Getting to Know You:
Planning for Services in Supported Living

Part One:
Information Gathering

This workbook belongs to:

Connections for Information and Resources
on Community Living (CIRCL)

1999
Getting to Know You: Planning for Services in Supported Living

Part One: Information Gathering

Compiled for

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

Claudia Bolton (NorthStar Services) and
Bill Allen (Allen, Shea & Associates)

1999
Getting to Know You will help your team from the supported living agency figure out the services and supports that will work best for you. Learning more about how you want to live now, will save everyone a lot of time later.
The People in Your Life?

Who are the people you are close to? people in your family? people at work or school? neighbors and friends? Who are the people you do things with? talk to? turn to for help?

Who do you spend the most time with? Who are the people who know you best? Who are the people who are most important to you? These are people who might be able to support you in your plans for the future.

Think about who they are and write their names in these circles. Write down when you see them and your relationship to them. Some people write the names of people who are closest to them in the middle, but you can do it any way you want.
Closest to you
Your Relationships and Groups that You Are A Part Of?*

Another way to look at the people we know is to think about the role they play in our lives. To think about their relationship and commitment to us.

**Who are the Anchors in your life? These are people who you have known for a while. They are not new friends.**
Who loves you? Who is concerned about you and gives you advice or support? Who protects you or sticks up for you? Who protects you? Who has helped you get what you wanted in the past?

**Who are your Allies?**
Who spends time with you and does things with you? Who knows what you like and what you need to be happy? Who introduces you to other people? Who helps you? Who do you like to spend time with? Who supports your goals for the future?

**What Assistance do you get?**
Is there any one who gets paid to provide services or support to you? Do you pay anyone to do things for you? Like instructors, job coaches, personal assistants, counselors, doctors, dentists, gardeners or hair dressers.

**What Associations are you a part of?**
What groups, clubs and organizations do you belong to? Do you get together with other people to share common interests?

**What Political agendas are you a part of?**
Are you active in advocating for change? Do you participate in any self-advocacy groups or councils? Are you on any Boards or committees?

What are some great things about you?

What are some great things about you? What do you like about you? What are some things you're good at? proud of? What are some nice things that people say about you? What do people thank you for? This is sometimes hard for people to answer, so you might want to start by asking a friend or relative.

These are important things to think about when you are figuring out the kinds of services and supports you need and want.

(Note to Facilitator: This is not a place to discuss or list “disability” accomplishments, e.g., is able to read, can cook three meals, accomplished IPP goals.)
Great Things About You

Part One, p. 7
Your Experiences and History

What important things have happened in your life?
Where have you lived, worked, gone to school?
Describe the best times of your life.
Are there people who were important to you whom you no longer see?
Are there things you used to do that you’d like to do again?

Notes About Your Life
Notes About Your Life
Your Lifestyle - Best and Worst Day Exercises and Positive Rituals Survey

The next two sections, Your Lifestyle - Best and Worst Day Exercises and Positive Rituals Survey, will help you identify what is important to the person right now and what we need to know and do to support the person. These exercises come from the Essential Lifestyle Planning process. These exercises will help you get information about:

Who and what is important to the focus person -
   - in relationships with others and their interactions;
   - in things to do, things to have;
   - in rhythm or pace of life;

What others need to know and do -
   - to help the person to get what is important to them;
   - to help the person stay healthy and safe within the context of how the person wants to live.

How much you need to learn about each of these areas varies with the person. Some examples -

We all have positive rituals and routines. However, the more physical assistance the person needs to accomplish them the more detail you need to learn. You need to explore how much help is needed or wanted and the importance (to the individual) of things like the order in which they get help, how the help is given and how they communicate this.

For many individuals with challenging behaviors there are (or have been) people involved in their lives whose behaviors and/or attitudes result in fewer instances, less severe instances or even an absence of the challenging behavior. You need to learn what it is about these people that had this positive result. This will begin to tell you what is important to these individuals in how they are treated and who needs to be present (or absent) in their lives.

Where the people you are planning with have health issues, especially complex health issues what others need to know and what they need to do to help the person stay healthy has to be learned and described.
Your Lifestyle

**Best week day**

Imagine the best of week days. Close your eyes, lean back and visualize what it would be like.

Where would you be?

What time and how would you wake up?

Would you be by yourself or would someone be with you?

What would your morning ritual be like?

What would you do between breakfast and lunch? Who would you do it with? (Being by yourself is acceptable, just unusual.)

Would you be at work, in a program or at school?

What would you have for lunch? Where would you eat?

How would you spend your afternoon and who would you spend it with?

It is now early evening. Are there any afternoon/evening rituals that would improve your day?

What would you have for dinner, where, with who?

How would you spend the evening?

When would you go to bed? What night time rituals would improve the evening?

Would you be with someone?

Would you end this best of days with special dreams? What would they be like?

Are there other things that would be present? For example, is there music that you would be listening to? What would the weather be like?

*Part One, p. 12*
Best week day
Worst week day

Imagine the worst of week days. Close your eyes, lean back and visualize what it would be like.

Where would you be?

What time and how would you wake up?

Would you be by yourself or would someone be with you?

What would your morning ritual be like?

What would you do between breakfast and lunch? Who would you do it with? (Being by yourself is acceptable, just unusual.)

Would you be at work, in a program or at school?

What would you have for lunch? Where would you eat?

How would you spend your afternoon and who would you spend it with?

It is now early evening. Are there any afternoon/evening rituals that you really dislike?

What would you have for dinner, where, with who?

How would you spend the evening?

When would you go to bed? What night time rituals would worsen the evening? Would you be with someone?

Would you end this worst of days with special dreams? What would they be like?

Are there other things that would be present? For example, is there music that you would be listening to? What would the weather be like?
Worst week day
Best vacation day

Imagine the best of vacation days. Close your eyes, lean back and visualize what it would be like.

Where would you be?

What time and how would you wake up?

Would you be by yourself or would someone be with you?

What would your morning ritual be like?

What would you do between breakfast and lunch? Who would you do it with? (Being by yourself is acceptable, just unusual.)

What would you have for lunch? Where would you eat?

How would you spend your afternoon and who would you spend it with?

It is now early evening. Are there any afternoon/evening rituals that would improve your day?

What would you have for dinner, where, with who?

How would you spend the evening?

When would you go to bed? What night time rituals would improve the evening? Would you be with someone?

Would you end this best of days with special dreams? What would they be like?

Are there other things that would be present? For example, is there music that you would be listening to? What would the weather be like?
Best vacation day
Worst vacation day

Imagine the worst of vacation days. Close your eyes, lean back and visualize what it would be like.

Where would you be?

What time and how would you wake up?

Would you be by yourself or would someone be with you?

What would your morning ritual be like?

What would you do between breakfast and lunch? Who would you do it with? (Being by yourself is acceptable, just unusual.)

What would you have for lunch? Where would you eat?

How would you spend your afternoon and who would you spend it with?

It is now early evening. Are there any afternoon/evening rituals that you really dislike?

What would you have for dinner, where, with who?

How would you spend the evening?

When would you go to bed? What night time rituals would worsen the evening? Would you be with someone?

Would you end this worst of days with special dreams? What would they be like?

Are there other things that would be present? For example, is there music that you would be listening to? What would the weather be like?
Worst vacation day
Imagine the best of Saturdays. Close your eyes, lean back and visualize what it would be like.

What time and how would you wake up?

Would you be by yourself or would someone be with you?
What would your morning ritual be like?

What would you do between breakfast and lunch? Who would you do it with? (Being by yourself is acceptable, just unusual.)

What would you have for lunch? Where would you eat?

How would you spend your afternoon and who would you spend it with?

It is now early evening. Are there any afternoon/evening rituals that would improve your day?

What would you have for dinner, where, with who?

How would you spend the evening?

When would you go to bed? What night time rituals would improve the evening? Would you be with someone?

Would you end this best of days with special dreams? What would they be like?

Are there other things that would be present? For example, is there music that you would be listening to? What would the weather be like?
The best of Saturdays
The worst of Saturdays

Imagine the worst of Saturdays (if you are on shift work imagine any great day off). Close your eyes, lean back and visualize what it would be like.

What time and how would you wake up?

Would you be by yourself or would someone be with you?

What would your morning ritual be like?

What would you do between breakfast and lunch? Who would you do it with? (Being by yourself is acceptable, just unusual.)

What would you have for lunch? Where would you eat?

How would you spend your afternoon and who would you spend it with?

It is now early evening. Are there any afternoon/evening rituals that you really dislike?

What would you have for dinner, where, with who?

How would you spend the evening?

When would you go to bed? What night time rituals would worsen the evening? Would you be with someone?

Would you end this worst of days with special dreams? What would they be like?

Are there other things that would be present? For example, is there music that you would be listening to? What would the weather be like?

Would you end this best of days with special dreams? What would they be like?

Are there other things that would be present? For example, is there music that you would be listening to? What would the weather be like?
The worst of Saturdays
Positive Rituals Survey

Positive rituals ease us through our days and help us mark special occasions. For each of the following questions, include as much detail as you can. (Do not be trapped by the space provided, use extra sheets of paper.)

1. List some of this individual's daily coping rituals. Pay particular attention to the beginning of the day and the end of the day rituals. Each of us have specific activities that we do every morning that comprise our morning rituals, including whether we brush our teeth before bathing, during our shower, before we leave the bathroom or after breakfast.

List morning (getting up) rituals -

List nighttime (going to bed) rituals -

2. List some of this individual's rituals of transition - What does he or she do everyday when arriving at work, school or training? When arriving home from work, school or training?

List arriving at work rituals -
List arriving at home rituals -

3. List some of this individual's weekly rituals -

List Sunday rituals (if there are a couple of different ways, list them all) -

List any regular weekly rituals (friends that always visited, TV shows always watched) -
4. List some of this individual's rituals of celebration and comfort -

Indicate how he/she likes to celebrate when something good happens.

Indicate how this individual comforts him or herself when something unpleasant happens, how does he/she make him or herself feel better?

5. List some holiday rituals -

What has to happen in order for it to be his or her birthday?
What foods have to be on the table at which holidays?

What does he or she have to do during some holidays (e.g., go look at the Christmas lights)?
Your Experience Making Choices*

Let’s talk about decisions you make for yourself, decisions other people help you make, and decisions made by other people in the following areas of choice.

Note to recorder: In the assessment area of “What I Need to Know and Do to Support the Person” record any areas of life in which the person will need support to make decisions.

**Daily routines** - Which decisions do you make about your daily routine (such as what to wear, what and when to eat, when to go to bed, etc)

**Scheduling decisions** - Which decisions do you make about your schedule for doing things like going out, choosing activities and choosing who you go with?

**Do you decide how to use your money?** Does anyone help you now? If so, how do they help you?

**Big Decisions** - Did you decide on the job you have or the program you go to? Do you decide when to visit friends and who you visit? Did you decide where to live and who you live with?

* Adapted from Person Profile, Frameworks for Accomplishment, John O ’Brien and Connie Lyle O ’Brien, and Beth Mount.
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<thead>
<tr>
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<th>Own choices</th>
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<th>Choice made by others</th>
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<td>Major Choices:</td>
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<td>Where to live</td>
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<td>Who to live with</td>
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<td>Where to work</td>
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</table>

Part One, p. 29
Information About Your Health

☐ Check here if all health care needs are handled independently

Or by: ____________________________________________

**Physicians:**
Name: ____________________________ Type: ________________ Phone #: ________________
Address: __________________________________________________________________________

Name: ____________________________ Type: ________________ Phone #: ________________
Address: __________________________________________________________________________

Name: ____________________________ Type: ________________ Phone #: ________________
Address: __________________________________________________________________________

**Dentists:**
Name: ____________________________ Type: ________________ Phone #: ________________
Address: __________________________________________________________________________

Name: ____________________________ Type: ________________ Phone #: ________________
Address: __________________________________________________________________________

**Ongoing Medication Required:**
Name: ____________________________ Dosage/Frequency: ________________________________
Purpose: _____________________________________________ Used: ___________ to ___________

Name: ____________________________ Dosage/Frequency: ________________________________
Purpose: _____________________________________________ Used: ___________ to ___________

Name: ____________________________ Dosage/Frequency: ________________________________
Purpose: _____________________________________________ Used: ___________ to ___________

**Check Box if Health Assistance Needed To:**
☐ Make/keep doctor or dentist appointments  ☐ Get prescriptions refilled
☐ Purchase medications  ☐ Monitor specific health care need
☐ Take medications as prescribed  ☐ Monitor general health care needs
More About Your Health

When did you last go to a doctor?

Do you visit the doctor a lot?

When you go see a doctor, what kinds of health problems do you have?

Do you have health problems that are with you all the time? What are they?

Do you have seizures?
If yes,
When did you last have a seizure?

How often do you have seizures?

How long do your seizures usually last?

What do you do when you have a seizure?

Other Information About Your Health
Hopes and Dreams for the Future

Collect images and ideas about how the person would like to live. Use the person’s own words as much as possible. Encourage the person and his/her family and friends to dream about a desirable future. Don’t let barriers stop the dreaming. Ask the person:

What do you look forward to in your future?
How do the people who care about you describe a desirable future?
What would you like to have? Do? Be?
Where would you like to live?
Is there anyone you would like to live with?
Your Hopes and Dreams for the Future are . . .
Getting to Know You
Planning for Services in Supported Living
Part Two:
Individual Assessment Options

This workbook belongs to:

Connections for Information and Resources on Community Living (CIRCL)

1999
Getting to Know You:
Planning for Services in Supported Living

Part Two:
Individual Assessment Option

Compiled for

Connections for Information and Resources on Community Living (CIRCL)
4171 Starkes Grade Road
Placerville, CA 91006
(530) 644-6653

by

Claudia Bolton (NorthStar Services) and
Bill Allen (Allen, Shea & Associates)

1999
These **Individual Assessment Options** are available to help gather additional and more specific information as needed.
Important Facts

Name: _______________________________
Birthdate: ___________________ Social Security Number: ______________________
UCI #: _______________________ Medl-Cal #: ______________________________

Address
Phone Home: _______________________ Phone Work: _______________________
Landlord:___________________________ Landlord Phone: ____________________

New Address
Phone Home: _______________________ Phone Work: _______________________
Landlord:___________________________ Landlord Phone: ____________________

New Address
Phone Home: _______________________ Phone Work: _______________________
Landlord:___________________________ Landlord Phone: ____________________

Directions to Home

Income Sources
Income Total: ______________________
New Income Total: ______________________
New Income Total: ______________________
Soc Security Payee? ______________________
Conservator? ______________________

Part Two, p. 2
Case Manager: ________________________________

New Case Manager: ________________________________

New Caso Manager: ________________________________

People Information (attendant, neighbor, friend, family member, etc.)

Name: ________________________________ Relationship: ________________________________
Address: ________________________________ Phone: ________________________________

Name: ________________________________ Relationship: ________________________________
Address: ________________________________ Phone: ________________________________

Name: ________________________________ Relationship: ________________________________
Address: ________________________________ Phone: ________________________________

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Name: ________________________________ Relationship: ________________________________
Address: ________________________________ Phone: ________________________________

Name: ________________________________ Relationship: ________________________________
Address: ________________________________ Phone: ________________________________

Part Two, p. 3
Work, School or Program Information

Work, School or Program Name: ________________________________
Address: ________________________________ Phone: ________________________________
Contact Person: ________________________________
New Work, School or Program Name: ________________________________
Address: ________________________________ Phone: ________________________________
Contact Person: ________________________________

Emergency Assistance System Description

Person to notify in case of an emergency

Name: ________________________________ Home Phone: ________________________________
Address: ________________________________ Work Phone: ________________________________

Important Emergency or Health Information

Community Support Facilitator Name: ________________________________
Phone Number: ________________________________
New Community Support Facilitator Name: ________________________________
Phone Number: ________________________________

IHSS Case Manager: ________________________________ Phone: ________________________________
Address: ________________________________
Hours of IHSS: _______ New Hours of IHSS: _______ New Hours of IHSS: _______
Getting to Know You: Planning for Services in Supported Living

Adaptive Equipment Resource:

Other Notes
# Daily Living Skills Assessment

(Adapted from Harmony Home SLS)

<table>
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<th>Name of Person</th>
<th>Date</th>
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## 1. BUDGETING, BANKING AND PAYING BILLS

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<td>Uses money orders</td>
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<tr>
<td>Fills out deposit slip</td>
<td></td>
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<tr>
<td>Fills out check register</td>
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<tr>
<td>Balances check book</td>
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</tr>
<tr>
<td>Follows budget plan</td>
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</table>

## 2. SHOPPING

<table>
<thead>
<tr>
<th>Activity</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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</thead>
<tbody>
<tr>
<td>Makes a list</td>
<td></td>
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</tr>
<tr>
<td>Locates items in store</td>
<td></td>
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</tr>
<tr>
<td>Reads prices</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Compares prices</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Pays for purchase</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses coupons</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Asks for assistance</td>
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## 3. SSI/SSA

<table>
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<tr>
<th>Activity</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
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<tbody>
<tr>
<td>Knows Social Security number</td>
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<tr>
<td>Knows what SSI/SSA is</td>
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<tr>
<td>Carries ID card</td>
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<tr>
<td>Knows how much each month</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reports wages to Social Security</td>
<td></td>
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### 4. TRANSPORTATION

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<th>Has a bus card</th>
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<th>Update</th>
<th>Comments</th>
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<table>
<thead>
<tr>
<th>Uses Dial-A-Ride</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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<tr>
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<table>
<thead>
<tr>
<th>Uses other transportation</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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<tbody>
<tr>
<td></td>
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### 5. EATING OUT

<table>
<thead>
<tr>
<th>Chooses restaurants</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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<td></td>
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<table>
<thead>
<tr>
<th>Orders meals</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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<td></td>
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<table>
<thead>
<tr>
<th>Pays for meals</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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<table>
<thead>
<tr>
<th>Eats properly</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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<table>
<thead>
<tr>
<th>Requires assistance to eat</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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### 6. TIME

<table>
<thead>
<tr>
<th>Tells time</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
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<table>
<thead>
<tr>
<th>Sets a clock</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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<table>
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<tr>
<th>Sets an alarm</th>
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<th>Update</th>
<th>Comments</th>
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<table>
<thead>
<tr>
<th>Reads/Uses calendar</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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<table>
<thead>
<tr>
<th>Knows current date</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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<table>
<thead>
<tr>
<th>Makes appointments</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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<tbody>
<tr>
<td></td>
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### 7. USING PHONE + PAY PHONE

<table>
<thead>
<tr>
<th>Knows own phone number</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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<table>
<thead>
<tr>
<th>Dials numbers</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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<td></td>
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<table>
<thead>
<tr>
<th>Calls people</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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</table>

<table>
<thead>
<tr>
<th>Talks on phone</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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</table>

<table>
<thead>
<tr>
<th>Uses phone list of important numbers</th>
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<th>No</th>
<th>Update</th>
<th>Comments</th>
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<tr>
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<table>
<thead>
<tr>
<th>Knows emergency procedure</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Uses directory assistance</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
</tr>
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<tbody>
<tr>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Uses phone directory</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Uses operator</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>
### 8. SUPPORT SYSTEMS

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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<tbody>
<tr>
<td>❑</td>
<td>❑</td>
<td></td>
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<tr>
<td>❑</td>
<td>❑</td>
<td></td>
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<tr>
<td>❑</td>
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<tr>
<td>❑</td>
<td>❑</td>
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<td></td>
</tr>
</tbody>
</table>

### 9. HOUSEHOLD

**EMERGENCIES/SECURITY**

- Knows who to contact in an emergency ❑ ❑
- Knows what to do in an emergency ❑ ❑
- Knows what to do in case of a house fire ❑ ❑
- Knows how to use fire extinguisher ❑ ❑
- Knows what to do in earthquake ❑ ❑
- Responds on how to handle prank/obscene phone calls ❑ ❑
- Responds to unwanted visitors ❑ ❑
- Home/apartment security ❑ ❑

### 10. COMMUNITY SAFETY

- Knows what to do if lost ❑ ❑
- Knows what to do if purse/wallet lost ❑ ❑
- Knows response if mugging or other crime occurs ❑ ❑
- Mugging prevention ❑ ❑
- Knows what to do in response to a con artist ❑ ❑
### 11. STREET SAFETY

<table>
<thead>
<tr>
<th>Task</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Follows vehicle laws/safety</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follows street safety</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
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</table>

### 12. KITCHEN/DINING ROOM CLEANING

<table>
<thead>
<tr>
<th>Task</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sweeps floor</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mops floor</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Washes dishes/pots &amp; pans</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Puts dishes away</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wipes counters</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wipes stove top</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wipes spills</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleanses sink</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does on regular basis</td>
<td>☐</td>
<td>☐</td>
<td></td>
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</tbody>
</table>

### 13. BATHROOM CLEANING/UPKEEP

<table>
<thead>
<tr>
<th>Task</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cleans tub/shower</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleans sink</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleans toilet</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleans mirror</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unclogs sink/toilet</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stops overflowing toilet</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does on a regular basis</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Washes rug/towels</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses correct cleansers</td>
<td>☐</td>
<td>☐</td>
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## 14. CLOTHING/LINEN

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dresses/Undresses</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Wears appropriate to weather</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Wears appropriate to occasion</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clothes that fit</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wears clothes that are neat/clean</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Washes clothes/linens</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sorts dirty clothes/linens</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Stores clean clothes</td>
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<tr>
<td>Changes linens</td>
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## 15. BODY CARE

<table>
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<tr>
<th>Item</th>
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<th>No</th>
<th>Update</th>
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</thead>
<tbody>
<tr>
<td>Showers/bathes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Washes hands</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trims fingernails</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trims toenails</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Shaves</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses deodorant</td>
<td></td>
<td></td>
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<tr>
<td>Uses feminine hygiene</td>
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## 16. HAIR CARE

<table>
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<tr>
<th>Item</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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</thead>
<tbody>
<tr>
<td>Brushes/combs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shampoos hair</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Cuts/trims hair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cuts/trims mustache/beard</td>
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## 17. TEETH CARE

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
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</thead>
<tbody>
<tr>
<td>Brushes/flosses teeth</td>
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### 18. EMERGENCY MEDICAL CARE

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<th>Yes</th>
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<th>Update</th>
<th>Comments</th>
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</thead>
<tbody>
<tr>
<td>Gets emergency help when needed</td>
<td>✗</td>
<td>✗</td>
<td></td>
<td></td>
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<tr>
<td>Carries Medi-Cal card/insurance</td>
<td>✗</td>
<td>✗</td>
<td></td>
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<tr>
<td>Name of doctor</td>
<td>✗</td>
<td>✗</td>
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<td></td>
</tr>
<tr>
<td>Cares for minor injuries</td>
<td>✗</td>
<td>✗</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cares for oneself when sick</td>
<td>✗</td>
<td>✗</td>
<td></td>
<td></td>
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<tr>
<td>Obtains medication as needed</td>
<td>✗</td>
<td>✗</td>
<td></td>
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</tr>
<tr>
<td>Knows doses of prescription meds</td>
<td>✗</td>
<td>✗</td>
<td></td>
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<tr>
<td>Knows over-counter, common meds</td>
<td>✗</td>
<td>✗</td>
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<tr>
<td>Takes medication daily</td>
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<td>✗</td>
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<tr>
<td>Wears Medic Alert tag</td>
<td>✗</td>
<td>✗</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knows dangers of substance abuse</td>
<td>✗</td>
<td>✗</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoids substance abuse</td>
<td>✗</td>
<td>✗</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 19. SEXUAL HEALTH AND SAFETY

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knows information/sexual health</td>
<td>✗</td>
<td>✗</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knows information on pregnancy and birthing</td>
<td>✗</td>
<td>✗</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses birth control</td>
<td>✗</td>
<td>✗</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knows laws on sexual activity</td>
<td>✗</td>
<td>✗</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 20. SOCIAL RELATIONSHIPS

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communicates effectively with others</td>
<td>✗</td>
<td>✗</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Develops/maintains friendships</td>
<td>✗</td>
<td>✗</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Develops personal/social skills</td>
<td>✗</td>
<td>✗</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inappropriate interaction with strangers</td>
<td>✗</td>
<td>✗</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Part Two, p. 11
## 21. Essential Cooking

<table>
<thead>
<tr>
<th>Utensils/Appliances</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uses stove</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses oven</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses microwave</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses toaster oven</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses knife and cutting board</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses timer</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## 22. Meal Preparation/Planning

<table>
<thead>
<tr>
<th>Preparation/Planning</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plans meals</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follows simple instructions</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Performs basic cooking skills</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Performs basic food preparation</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disposes of grease</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Washes hands</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stores food and leftovers</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thaws meat</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recognizes spoiled food</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## 23. Self-Advocacy

<table>
<thead>
<tr>
<th>Self-Advocacy</th>
<th>Yes</th>
<th>No</th>
<th>Update</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communicates for self</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is tactful when expressing self</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is aware of their rights</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attends people first</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knows protocol when lodging complaints</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Part Two, p. 12
TRACE

Personal Assistance

NEEDS ASSESSMENT*

CONTENTS

1.0 LIFTING AND TRANSFERRING
2.0 BATHROOM
3.0 GROOMING
4.0 MEALS
5.0 COMMUNICATION
6.0 TRANSPORTATION AND MOBILITY
7.0 EMERGENCY PROCEDURES
8.0 MEDICATIONS
9.0 HOUSEHOLD RESPONSIBILITIES
10.0 PERSONAL NEEDS
11.0 INTERPERSONAL RELATIONSHIPS

* Adapted with permission from Becoming Independent. Revisions were made with the assistance of Anita Cotton, Occupational Therapist, Regional Center of the Easy Bay.

Note to Facilitators: A number of these questions are both personal and intrusive. For that reason, please be respectful and ask only those questions you must ask in order to help someone get support the way they want it.
### 1.0 LIFTING AND TRANSFERRING

(CHECK APPROPRIATE BOX—YES OR NO)

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>Do you need to be lifted and or transferred as part of your care.</td>
<td>Y</td>
</tr>
<tr>
<td></td>
<td>Explain:</td>
<td></td>
</tr>
<tr>
<td>1.2</td>
<td>Do you use or need any special adaptive equipment to transfer.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Explain:</td>
<td></td>
</tr>
<tr>
<td>1.3</td>
<td>How do you like to be lifted and transferred?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Explain:</td>
<td></td>
</tr>
<tr>
<td>1.4</td>
<td>Are you able to instruct an assistant how to lift/transfer you?</td>
<td></td>
</tr>
<tr>
<td>1.5</td>
<td>Do you have use of your arms and/or legs?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Explain:</td>
<td></td>
</tr>
<tr>
<td>1.6</td>
<td>Do you grab, pull, or resist when transferring?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Explain:</td>
<td></td>
</tr>
<tr>
<td>1.7</td>
<td>Are you able to control grabbing, pulling and resisting?</td>
<td></td>
</tr>
<tr>
<td>1.8</td>
<td>Can you sit or stand by yourself?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Explain:</td>
<td></td>
</tr>
<tr>
<td>1.9</td>
<td>Should any precautions be used when being lifted or transferred?</td>
<td></td>
</tr>
<tr>
<td>1.10</td>
<td>How do you get into bed?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Explain:</td>
<td></td>
</tr>
</tbody>
</table>

Part Two, p. 14
Getting to Know You: Planning for Services in Supported Living

(CHECK APPROPRIATE BOX—YES OR NO)

1.11 When in bed, what position are you most comfortable in? ☐ ☐

1.12 How do you lift and/or transfer onto the toilet? ☐ ☐
   Explain:

2.0 BATH ROOM

2.0 Universal Infection Control Procedures

2.1 Do you know the basic universal precautions? ☐ ☐

2.2 Do you know how to prevent the spreading of germs? ☐ ☐
   Explain:

2.3 Do you wash your hands on a regular basis? ☐ ☐

2.4 Do you require intimate personal care from an assistant? ☐ ☐
   Explain:

2.5 Do you have or need supplies for personal care such as gloves? ☐ ☐
   Explain:

2.6 How are those supplies paid for? ☐ ☐
   Explain:

2.7 How do you communicate the need to use the bathroom? ☐ ☐
   Explain:
2.0 BATHROOM
(CHECK APPROPRIATE BOX—YES OR NO)

2.8 Describe what assistance you require when you use the bathroom? Describe:

2.9 What supplies, if any, do you use for bowel and bladder care? Explain:

2.10 Do you use or need any adaptive equipment to use the bathroom? Explain:

2.11 Do you have a schedule for when you generally use the bathroom? Explain:

2.12 Do you take any medications to help with bowel/bladder routines? Explain:

2.13 Are you able to use a public bathroom? Explain:

3.0 GROOMING

3.1 Are you able to test water temperature accurately?

3.2 Can you bathe independently? Explain:

Part Two, p. 16
(CHECK APPROPRIATE BOX—YES OR NO)

3.3  Do you use adaptive equipment such as lifts, belts or commodes?

Explain:

3.4  Do you need help entering or exiting tub?

Explain:

3.5  Do you have a bathing schedule?

Explain:

3.6  Do you use special hair care products?

Explain

3.7  What safety precautions are needed when using electric appliances in the bathroom?

Explain:

3.8  Do you need help combing or brushing your hair?

3.9  Do you cut your own nails?

3.10  Can you give your personal assistant instructions on how to do cut your nails?

3.11  Do you have a podiatrist? If yes, list:

<table>
<thead>
<tr>
<th>Name</th>
<th>Phone</th>
<th>Duties</th>
</tr>
</thead>
</table>

3.12  Do you have problems with your feet?

Explain:

Part Two, p. 17
3.0 GROOMING
(CHECK APPROPRIATE BOX—YES OR NO)

3.13 Do you have orthodic devices?  
Explain:

3.14 Do you shave independently?  
Explain:

3.15 Do you have any allergies to shaving cremes or lotions?  
Explain:

3.16 Do you brush your teeth independently?  
Explain:

3.17 Do you wear dentures?

3.18 Do you swallow or clench your teeth involuntarily?  
Explain:

3.19 Do you have a habit of biting hard when something is in your mouth?

3.20 Do you ever choke? What would cause you to choke?  
Explain:

3.21 Have you ever had sores on your bottom or body that come from your bed or your wheelchair?  
Explain:

Part Two, p. 18
3.0 GROOMING
(CHECK APPROPRIATE BOX—YES OR NO)

3.22 Do you take medications or have a condition, such as diabetes, that might delay the healing process?

☐ ☐

Explain:

3.23 Are there ways that you feel more comfortable?

☐ ☐

Explain:

3.24 Are there times when your muscles feel looser than other times?

☐ ☐

Explain:

3.25 Do you need help to get dressed?

☐ ☐

Explain:

4.0 MEALS

4.1 Do you prefer to eat or avoid any particular foods?

☐ ☐

Explain:

4.2 Do you have a doctor’s order in place for a modified diet or eating techniques?

☐ ☐

Explain:

4.3 Do you have any food allergies?

☐ ☐

Explain:
4.0 MEALS
(CHECK APPROPRIATE BOX—YES OR NO)

4.4 Are you able to help with meal preparations?
Explain:

4.5 Can you eat independently?

4.6 Do you have any difficulty swallowing or chewing?
Explain:

4.7 Are there ways you like to be seated when you eat?
Explain:

4.8 Are there special set-ups or utensils that help you feed yourself?
Explain:

5.0 COMMUNICATION

5.1 Is it hard for you to ask people to help you?
Explain:

5.2 Do you have difficulty accepting help?
Explain:

5.3 Do you have a videotape that demonstrates your daily routines?
6.0 TRANSPORTATION AND MOBILITY
(CHECK APPROPRIATE BOX—YES OR NO)

6.1 Do you need or use a wheelchair? Y or N

6.2 Do you use a power or manual chair or both?
   Explain:

6.3 Do you know from where and whom you got your wheelchair?
   Who? Phone #?

6.4 How do you get your wheelchair fixed?
   Explain:

6.5 Who pays for the repairs for the wheelchair?
   Explain:

6.6 Do you have another chair if something happens to yours?

6.7 Who cleans your wheelchair and how often should that happen?
   Explain:

6.8 How do you get around the community?
   Explain:

6.9 Do you own your own vehicle?
   Explain: Insurance:
   If yes, who pays for repairs?
### 6.0 TRANSPORTATION AND MOBILITY

*(CHECK APPROPRIATE BOX—YES OR NO)*

<table>
<thead>
<tr>
<th>Question</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.11 Do you use public transportation by yourself?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explain:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.12 Can you go out in a regular car?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explain:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.13 Do you feel comfortable on your own in the community?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explain:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.14 Have you ever had an accident in your chair in the community?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explain:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.17 What would you do if your wheelchair broke down when you were out alone?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explain:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.18 Do you use community recreational facilities and resources?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>What</td>
<td>How Often</td>
<td>How I get there</td>
</tr>
</tbody>
</table>

*Part Two, p. 22*
7.0 EMERGENCY PROCEDURES
(CHECK APPROPRIATE BOX—YES OR NO)

7.1 Do you have or need a 24-hour emergency response system?

☐ ☐

7.2 If so, what are/will be its components, including family?

Who       Phone       Order of response

☐ ☐ ☐

7.3 How do you call for help?
Explain:

☐ ☐

7.4 Do you use any special way to call for help?

☐ ☐

7.5 Are you able to use a phone, TDD, Lifeline or?

☐ ☐

7.6 Would you be able to get out of your house if you were alone in an emergency?

☐ ☐

7.7 Where do you keep emergency medical information?
Explain:

☐ ☐

7.8 Are there activities, such as eating, that may put you at risk?
Explain:

☐ ☐

7.9 Will your Personal Assistant be required and trained to administer emergency care?

☐ ☐

7.10 Are there any other medical conditions you have that may require emergency care?
Explain:

☐ ☐
8.0 MEDICATIONS
(CHECK APPROPRIATE BOX—YES OR NO)

8.1 Do you take medications?
  What  When  What for  Pres by  Phone

8.2 Where do you purchase your medications?
  Pharmacy  Address  Phone

8.3 Are your medications delivered or picked up at pharmacy?

8.4 Do you reorder your own medications?

8.5 Are your medications packaged in a way that helps you keep track?

8.6 Do you administer your medications independently?
  Explain:

8.7 Do you keep a record of medications?

8.8 Do you use methods other than pills to take medications?
  Explain:

Part Two, p. 24
8.0 Medications

(Check appropriate box—Yes or No)

8.9 Can you give yourself shots if you have to take medicine that way? □ □

8.10 Where do you keep your medications? □ □
Explain:

8.11 Who do you want to be able to get to your medications? □ □
Name:

8.12 What happens if you don’t take your medications? □ □
Explain:

8.13 Do you have a way to get rid of the medicines you are finished with? □ □
Explain:

8.14 Do you know what to do if you take too much medication or have an allergic reaction? □ □
Explain:


9.0 HOUSEHOLD RESPONSIBILITIES
(CHECK APPROPRIATE BOX—YES OR NO)

Are you able to do housekeeping chores by yourself?

9.1 Kitchen?
Explain:

9.2 Bathroom?
Explain:

9.3 Bedroom?
Explain:

9.4 Living Room?
Explain:

9.5 Laundry Room?
Explain:

9.6 Yard?
Explain:

9.7 What is your experience managing people who do this work for you?

9.8 How would you let your attendants know what you wanted them to do?

9.9 Do you own or are you able to get household furnishings or adaptive equipment that you need?
List and explain:

Part Two, p. 26
### 10.0 PERSONAL NEEDS
(CHECK APPROPRIATE BOX—YES OR NO)

<table>
<thead>
<tr>
<th>Question</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.1 Do you like to spend time alone at home?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explain:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.2 Have you ever hired your own Personal Assistant?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.3 Do you have or need funding to hire Personal Assistants?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.4 Have you been evaluated by any agencies, such as IHSS, to determine your attendant needs?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agency</td>
<td>Contact</td>
<td>Phone</td>
</tr>
<tr>
<td>10.5 Do you have or need to make adaptations, such as door openers, to living spaces in order for you to live independently?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What</td>
<td>How &amp; Where purchased</td>
<td>Who maintains</td>
</tr>
<tr>
<td>10.6 If your living space need adaptations who will pay for them?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.7 Do you have or need space for a canine companion or other pet?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explain:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.8 What are some qualities you like in a Personal Assistant?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explain:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.9 What are some qualities you would not like in a Personal Assistant?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explain:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Part Two, p. 27**
11.0 INTERPERSONAL
(CHECK APPROPRIATE BOX—YES OR NO)

11.1 If you have problems with someone, a roommate or assistant, for example, how do you usually resolve them?
   Explain:

11.2 Do you put things in writing or keep a record of agreements?
   Explain:

11.3 When and where do you like privacy?
   Explain:

11.4 Have you had to fire a Personal Assistant? If yes, how did you do it?
   Explain:

11.5 Can your assistants have friends or family visit or stay with them?
   Explain:

11.6 Who pays, how often, and how much do you pay your assistants?
   Payer  When  Rate

11.7 Have you had experience completing timecards for your Personal Assistants?
   Explain:

Part Two, p. 28
Medical Information Checklist

Date of last physical exam? ______________  What did you find out?

Was your blood pressure taken? Y N  If so, what is it?

Do you have, or have you had any serious illness, disease, or have you been hospitalized? Y N  If so, please describe:

Do you have, or have you ever had the following? (Please circle and describe under remarks)

A. rheumatic fever  Y N  R. respiratory disease  Y N
B. inflammatory rheumatism  Y N  S. psychiatric treatment  Y N
C. scarlet fever  Y N  T. any x-rays for growths  Y N
C. hepatitis, jaundice  Y N  U. asthma  Y N
E. liver disease  Y N  V. peptic ulcer  Y N
F. tuberculosis  Y N  W. allergies (rash) to:
G. high/low blood pressure  Y N  1. penicillin  Y N
H. venereal disease  Y N  2. other antibiotics  Y N
I. heart disease or stroke  Y N  3. iodine  Y N
J. heart murmur  Y N  4. codeine  Y N
K. angina pectoris  Y N  5. local anesthetic  Y N
L. pacemaker or parts  Y N  (as in novacaine)
M. hyperthyroidism  Y N  6. aspirin  Y N
N. epilepsy / convulsions  Y N  7. other  Y N
O. blood disease/as enemia  Y N
P. abnormal bleeding  Y N  X. eye disease (glaucoma)  Y N
Q. diabetes/sugar disease  Y N  Y. contact lenses  Y N
Z. aids virus  Y N

Are you taking any medications, drugs, or pills, or have you experienced an unusual reaction to any drug such as, but not limited to, the following? Please describe under remarks:

Anticoagulants (blood thinners)
as Warfarin or Coumarin  Y N
Steroids (cortisone)  Y N
Tranquilizers or sleeping pills  Y N

Digitalis or Nitroglycerin  Y N
Insulin  Y N
Other  Y N

Have you experienced any unfavorable reactions to previous dental treatment? Y N
Do you have any disease, condition or problem not listed that we should know about? Y N

Remarks:

SIGNATURE _____________________________________ DATE _______________

Please make sure that you tell us about any changes in the above information when we review it.

REVIEWED THIS DATE _____________ SIGNATURE _______________________________

REVIEWED THIS DATE _____________ SIGNATURE _______________________________

Part Two, p. 29
Listen to Me Communicate

This communication plan is designed to support people who do not use words to talk, or who have difficulty communicating in typical ways. This section is also very useful for supporting people who communicate with their behavior.

The heading **what is happening** describes the circumstances. The headings **and (person’s name) does** describes what the person does in terms that are clear to a reader who has not seen it and would still recognize it. For people where it is something hard to describe (e.g., a facial expression), a picture or even a video recording may be preferred. The heading **we think it means** describes the meaning that people think is present. It is not uncommon for there to be more than one meaning for a single behavior. Where this is the case, all of the meanings should be listed. The heading **and we should** describes what those who provide support are to do in response to what the person is saying with their behavior. The responses under this heading give a careful reviewer a great deal of insight into how the person is perceived and supported.

It’s easiest to complete the communication worksheet by starting from the two inside columns first (**. . . . does, we think it means**) and then working out to the two outside columns (**what is happening, and we should**).
<table>
<thead>
<tr>
<th>What is happening</th>
<th>__________ does</th>
<th>We think it means</th>
<th>And we should</th>
</tr>
</thead>
<tbody>
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Your Pattern of Support When You Live In Your Own Home

Based on everything learned about the person’s best week days and best weekend days, and their preferred routines and rituals, what would a pattern of support look like? When would the person be alone? When would paid support be present? What things would paid support be helping the person with or doing for the person? When would the person’s natural supports be present? Remember that everyone’s days are unpredictable and that supported living services strive to be flexible and offer support if and when it is needed. This schedule is only a best guess at when supports are needed.
<table>
<thead>
<tr>
<th>Sunday</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 AM</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>11</td>
<td>12 PM</td>
</tr>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
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<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
Getting to Know You
Planning for Services in Supported Living
Part Three: Summing It All Up

This workbook belongs to:

Connections for Information and Resources on Community Living (CIRCL)

1999
Getting to Know You: Planning for Services in Supported Living

Part Three: Summing It All Up

compiled for

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by

Claudia Bolton (NorthStar Services) and Bill Allen (Allen, Shea & Associates)

1999
Summing It All Up is a place to pull together all of the information you have gathered and organize it into a plan for support. The Plan includes the following headings:

- The People who Contributed to this Plan
- Great Things about You
- What is important to the person prioritized into two or three categories:
  1st priority - Non-negotiables
  2nd priority - Strong Preferences
  3rd priority - Highly Desirables

This section prioritizes and lists what is important to the person. It should reflect only what is important to the person, not what is important to any other people in the person’s life. What has been learned about the person, not what people are guessing about. What is important to the person is divided by headings that prioritize how important things are.

- Things I Want to Learn to Do
- Things We Need to Know or Do to Help the Person Get What is Important
- Other Notes, Comments, Recommendations and Things that are Unresolved

Part Three, p. 1
The People who Contributed to this Plan:

<table>
<thead>
<tr>
<th>Name:</th>
<th>Relationship to the Focus Person:</th>
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<tbody>
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<td>12.</td>
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</tbody>
</table>

Original Date of Plan: _____________________________

Revisions Made: _____________________________
What is Most Important?

Now, please help us prioritize the important things you told us about the people in your life, the things you like to do, your best and worst days and your rituals and routines. Be very detailed if you need assistance to have or do the things that are important to you. Prioritize these things that are important to you into three categories:

**Non-negotiables** - things you must do or have/must not do or have.

**Strong Preferences** - things that are important or very important to you.

**Highly Desireables** - things you like/dislike or things you’d like to try.
NON-NEGOTIABLES - THE THINGS THAT THIS INDIVIDUAL MUST HAVE, DO, AND BE:

In relationships with others

In things to do, things to have
In health, safety

In positive rituals
STRONG PREFERENCES - NEEDS OF ________________
HIGHLY DESIRABLES - WANTS AND ENJOYS
OF ________________
Things I Want to Learn to Do

Are there things you want to learn to do? The supported living services agency can teach you to do more for yourself if this is what you would like to do. The Daily Living Skills Assessment can be used to see what you already know how to do and the Personal Assistance Needs Assessment can be used to see your physical care and personal assistant/attendant management skills. The things you would like to learn can be listed here.
Things I Want to Learn to Do
Things We Need to Know or Do to Help the Person Get What is Important

What do others need to know or do in order for the person to get what is important. Develop this section by looking at each thing listed as important to the person and ask yourself if there is anything that support people need to know or do in order for the person to have what is important.

What do others need to know or do so that the person has more good days and fewer bad days.

Include support the person needs or things we need to know or do about the person’s “negative reputation”. We all have one! Are there things that make the person upset that we need to know about? Are there concerns of relatives, friends and others who know and care about the person?

Be very detailed when the person needs physical assistance to have the routines and rituals that are important to them.

Include assistance the person will need to move toward their dreams and hopes for the future.
Things We Need to Know or Do to Help the Person Stay Healthy and Safe

To Help the Person Stay Healthy:
Gather and record the information here when there are significant health issues. Describe what people need to know or do to help the person stay healthy. Information from the Daily Living Skills Assessment or the Personal Assistance Assessment would go here for people who need support to monitor and take medication.

To Help the Person Stay Safe:
Describe what people need to know or do to help the person stay safe. Information from the Daily Living Skills Assessment or the Personal Assistance Assessment would be recorded here for people who need support to be safe.

This is also where we can describe things to know or do to support someone who has mental health issues.

If the supported living services will include emergency response services or on-call services describe what the person needs here.
Other Things We Need to Know and Do to Support Health and Safety?
Other Notes, Comments, Recommendations and Things that are Unresolved
Getting to Know You
Planning for Services in Supported Living
References for Getting to Know You


Supported Living Services Training Toolbox

Part Four:
Tools and Applications

Connections for Information and Resources on Community Living (CIRCL)

April, 2001